



**TRANSCRIPT  
OF PROCEEDINGS**

**SPARK AND CANNON**

Telephone:

Adelaide	(08) 8212 3699
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**PRODUCTIVITY COMMISSION**

**DRAFT REPORT ON THE DISABILITY DISCRIMINATION ACT**

**MRS H.J. OWENS, Presiding Commissioner  
MS C. MCKENZIE, Associate Commissioner**

**TRANSCRIPT OF PROCEEDINGS**

**AT MELBOURNE ON THURSDAY, 29 JANUARY 2004, AT 12.06 PM**

**Continued from 19/8/03**

**MRS OWENS:** For the benefit of the public transcript, I would like to announce the commencement of the draft report hearings for the Productivity Commission's inquiry into the Disability Discrimination Act. The purposes of the hearings is to discuss the commission's draft report with participants who have made submissions to the commission, and provide them with the opportunity to place their views on the public record. We shall take these into account in preparing our final report to the government. Today's hearings comprise a series of telephone links with various participants. These will be followed by hearings in Canberra, Hobart, Sydney, Melbourne and Brisbane.

Thank you for taking our call, and what I'm going to do, Mr Deighton, is just start off our hearings for today with a little bit of an introduction and then hand over to you for some discussions. So if you don't mind for a minute, I'll just go through the introduction.

**MR DEIGHTON:** Yes.

**MRS OWENS:** My name is Helen Owens, and I'm the presiding commissioner for the Productivity Commission's inquiry into the Disability Discrimination Act, and I'm joined by my associate commissioner for the inquiry Cate McKenzie. Cate's here with me.

**MS McKENZIE:** I'm Cate. I'm sitting next to Helen. Can you hear me, Ray?

**MR DEIGHTON:** I can hear you.

**MRS OWENS:** Yes, and what we're doing, we're calling today to allow you to participate in the public hearings for the inquiry and to give you an opportunity to speak about your submission. So I'd like to thank you very much for making your submission and showing an interest in the inquiry.

**MR DEIGHTON:** Yes.

**MRS OWENS:** As part of our public hearings, our discussion today is being recorded and a transcript will be made available to the public on our web site. A copy will be forwarded to you to check that it's been transcribed accurately.

**MR DEIGHTON:** Yes.

**MRS OWENS:** Nevertheless, we like to make these hearings as informal as we can, but I'd like to point out to you that although you're not required to take an oath under the Productivity Commission Act, you are required to be truthful in your remarks.

**MR DEIGHTON:** Yes.

**MRS OWENS:** Now, we've read your submission and in a minute we'll invite you to make any introductory remarks that you might want to make. After that we'll ask you some questions about your submission, but we're equally happy to clarify any questions you might have about our process here. So what I'd like you to do now is just repeat your name and then just tell us in what capacity you're talking to us today. Are you talking to us in your own right or as part of a group? Can you just repeat your name.

**MR DEIGHTON:** Ray Deighton of unit 3/22 Meldon Way, Dianella, 6059.

**MRS OWENS:** Thank you, and are you appearing in your own right?

**MR DEIGHTON:** Yes.

**MRS OWENS:** As an individual.

**MR DEIGHTON:** Yes. I have acted from ASHWA, but, you know, that's what I'm appealing for, see.

**MRS OWENS:** Okay. Is there anything you'd like to tell us about - to start off our discussion or would you be happy to just take a few questions? Is there any major points you'd like to make to us about your submission or about your own circumstances?

**MR DEIGHTON:** I can't talk much about it because it's such a big story; over 35 years with the firm, see.

**MRS OWENS:** Yes.

**MR DEIGHTON:** This is where I become multiple chemical sensitivity. I've been back to the AAT 14 times.

**MS McKENZIE:** My goodness.

**MR DEIGHTON:** Yes, and this is where it's - they're discriminating against me, see, and everything, and they're bringing doctors in and all this, you know, against me.

**MS McKENZIE:** So who did you make your complaint to, which body?

**MR DEIGHTON:** The AAT - the Administration Appeals Tribunal - - -

**MS McKENZIE:** Before, when you first started, who did you complain to in the first place?

**MR DEIGHTON:** Who was that?

**MS McKENZIE:** Who did you complain to? Before you got to the AAT - - -

**MR DEIGHTON:** Yes.

**MS McKENZIE:** - - - who did you complain to in the first place?

**MR DEIGHTON:** The firm I was working for.

**MS McKENZIE:** Okay.

**MR DEIGHTON:** I'm not supposed to use the firm's name.

**MS McKENZIE:** No, that's okay, and after that you went to the AAT.

**MR DEIGHTON:** AAT, yes, the Administration Appeals Tribunal, and I've been there 14 times. It's all over compensation cases sort of thing. The MCS come into it, and I'm a member of ACTA - that's the Australian Chemical Trauma Alliance. They're based in Sydney, and also a member of ASHWA. That's the firms and that's where I get a fair bit of my information. Now, my history of the workplace, I could send you that because I've had a six-letter page of my work life with this certain firm.

**MRS OWENS:** At this stage we've had a lot of submissions from people with multiple chemical sensitivity. We've built up quite a lot of knowledge about the problems you face.

**MR DEIGHTON:** Yes.

**MRS OWENS:** And in our draft report, what we thought we would do to make the coverage of the Disability Discrimination Act clearer was to make a recommendation - a draft recommendation - which brings in cases like your own into the definition of "disability". I don't know whether you've seen our draft report.

**MR DEIGHTON:** No. I don't think I have, no.

**MRS OWENS:** But we've asked for comment about a possible change to the definition which may interest you to - just to make it much clearer that the act would

cover what we've called medically recognised symptoms where a cause has not been medically identified or diagnosed, and in the report we give examples such as conditions for people with multiple chemical sensitivity. So we thought that we could make the act much clearer if that was spelt out. Do you think that's a good idea.

**MR DEIGHTON:** Yes. Great.

**MRS OWENS:** Yes?

**MR DEIGHTON:** Yes.

**MRS OWENS:** So that's one of the things we've done because - - -

**MR DEIGHTON:** Looking into, yes.

**MRS OWENS:** Because we did hear from a lot of people, as I said, earlier on in our process about the problems that you face, and we thought that that might be something you might find worthwhile.

**MR DEIGHTON:** Yes. I have just wrote a letter to the attorney-general in Canberra and asking him to - what do they call it? Interview - - -

**MS McKENZIE:** Intervene, maybe; intervene.

**MR DEIGHTON:** Intervene, yes, into my case, see, and I haven't heard nothing back from him yet. But then if I don't hear back from him, I'm going to the governor-general.

**MS McKENZIE:** If I understand what you're saying correctly, you don't think that there's enough - there's not enough allowance made or understanding of people with multiple chemical sensitivity.

**MR DEIGHTON:** That's right, yes. They don't - the doctors won't even listen to you or whatever you say, you know. Even though I was exposed for 15 years on a certain job and exposed to this toxic chemical all those 15 years or over 35 years that I worked with this firm, and it's outrageous. I've had open-heart surgery, three bypasses. I've got cancer of the prostate. I've got acne all on my skin. I've had skin cancers removed. I've all these and they just don't think nothing of them. They're just common things, they say, but, oh, it's - - -

**MS McKENZIE:** But you think that they're linked; they're all linked to this - - -

**MR DEIGHTON:** They're all linked, yes. Definitely. See, there's the Agent Orange - now, I was in a party in Manjimup and we sprayed Agent Orange over the foliage in Manjimup under the telephone lines, and they're not, you know, taking any notice of you. They're reckon you're all bulldust.

**MS McKENZIE:** One of the things you talk about in your submission is to try and do some things to fix up the complaint system under the Disability Discrimination Act.

**MR DEIGHTON:** Yes.

**MS McKENZIE:** And one of the things you talk about is this question of costs - you know, court costs, if you win.

**MR DEIGHTON:** Yes, that is a must. The AAT - see, there's no costs in that to go to it because it's federally, see, and this is where - they make a decision on you and then they allow you to go to another court, and I've had three solicitors, two have been suspended and one has committed suicide.

**MS McKENZIE:** Goodness.

**MR DEIGHTON:** This is where - the solicitor who is acting for me now, he's suspended for over 12 months and I can't get back into the court because I haven't got the expertise to back - you know, to make out for a pro bono lawyer, see. That's where it's all hard for me and I'm not getting anywhere and I'm wondering where to look. I just rang yesterday to Slater and Gordon. They're a firm that - but they won't even look at me because it's federal and they handle - - -

**MS McKENZIE:** State.

**MR DEIGHTON:** - - - state mainly. All of them over here handle state things and they don't want to handle anything federally, and that's what you're up against.

**MRS OWENS:** Have you ever tried to make a complaint through the Human Rights and Equal Opportunity Commission?

**MR DEIGHTON:** Yes. I've got letters and everything back from them and they reckon they won't look into it, see, because they reckon there's no scientific link in MCS to, you know - I can't explain.

**MS McKENZIE:** You see, in a way this goes back to the sort of thing we were suggesting in our report where you've got clear symptoms that a doctor can recognise, but - - -

**MR DEIGHTON:** Yes.

**MS McKENZIE:** - - - they're not quite sure what the cause is.

**MR DEIGHTON:** Yes, because there was one professor over here that wrote a report on me. It's in my decision of 2002. He wrote that I was an alcoholic and all my symptoms were caused through alcohol. Well, alcohol is still a chemical, isn't it? Memory loss and all that comes into it, and I've had x-rays and I've been through the mill.

**MS McKENZIE:** It sounds like it. Did you ever go to conciliation when you made the complaint to HREOC.

**MR DEIGHTON:** Yes. Who's HREOC?

**MS McKENZIE:** HREOC is the Commonwealth body that administers the Disability Discrimination Act. They're the ones - when you send your complaint, that's the body that you send it to.

**MR DEIGHTON:** Yes. HREOC.

**MS McKENZIE:** Human Rights and Equal Opportunity Commission is their long name.

**MR DEIGHTON:** Yes. No, I didn't know. I don't know anything about them.

**MS McKENZIE:** Okay.

**MRS OWENS:** But your submissions made a number of important points about just the barriers of trying to make complaints, and our report, we've tried to think about ways to address those barriers like the issue of costs that's raised in your submission, and we've made a recommendation that the Human Rights and Equal Opportunity Commission Act should be amended to incorporate some grounds for not awarding costs. So we're interested to see whether people think that that's a good idea. So we've tried to address that issue that you've raised.

**MR DEIGHTON:** Yes. Now, there was another thing I wanted to raise. The Permanent People's Tribunal; that is national, see, and I've got about an eight-page - there's 35 sections of it, and that would be interesting for you to look at because Dr Goble, he's an active member, he put it on the Internet. So it's on the Internet. So all them recommendations, they're - do you understand what I mean?

**MS McKENZIE:** So this tribunal, is it one that ACTA is recommending?

**MR DEIGHTON:** It's from Bhopal, India, all them places that have been, you know, exposed to these chemical spills and all that, see. They've made - ACTA was involved in the submissions to the tribunal about what should happen, and is where I reckon this new Disability Discrimination Act should combine with that act. If you want the - I'd have to send it to you anyway.

**MS McKENZIE:** But it would be on the ACTA web site, would it?

**MR DEIGHTON:** Yes, under Goble.

**MS McKENZIE:** Okay.

**MR DEIGHTON:** Yes, Dr Goble. He's from Kangaroo Island in South Australia and he has written a report for me. But I was through the Administrative Appeals Tribunal on this certain case of multiple chemical sensitivity and cancer and - now I'm gone, see.

**MS McKENZIE:** No, that's okay.

**MR DEIGHTON:** When I start explaining things I wander. I can't explain it. I've got brain damage anyway.

**MS McKENZIE:** Can I ask you, when you appeared before the AAT you had a lawyer to help you, did you, when - - -

**MR DEIGHTON:** Yes, sometimes I did and sometimes I didn't, see, yes. There was a lawyer with me at the time, yes.

**MS McKENZIE:** When you appeared by yourself did you find that hard? Did you find it quite difficult?

**MR DEIGHTON:** God, yes. Yes, but see, they put my case on the Internet and if you're want to look it up I've got the web site on the bottom of the decisions.

**MRS OWENS:** Did you get legal assistance when you had the lawyer?

**MR DEIGHTON:** Yes, I had legal assistance.

**MRS OWENS:** Did you have problems getting assistance with - - -

**MR DEIGHTON:** Yes, I was knocked back hundreds of times.



**MRS OWENS:** So who did you go to in the end? Did you go to a Legal Aid service?

**MR DEIGHTON:** Yes. I was interviewed by Legal Aid and they refused me the last time I wanted legal aid because I had 6000 in the bank and that's - well, I stated to them that that was my wife and myself's burial money, and then they says, "Oh, you'll just have to use that." But if you want the web site number of my case - do you want that?

**MS McKENZIE:** It was an AAT decision?

**MR DEIGHTON:** Yes.

**MRS OWENS:** We'll be able to look for that.

**MS McKENZIE:** So they have a site. They have a web site. We know that one.

**MR DEIGHTON:** Yes.

**MS McKENZIE:** Where they set out their cases.

**MR DEIGHTON:** I'm on that.

**MS McKENZIE:** Okay, so it's on that one.

**MR DEIGHTON:** My case is on it. Do you want me to send you any information?

**MS McKENZIE:** If we've got the web site address for that case that might tell us enough, I think, if it's all on the web site.

**MR DEIGHTON:** Yes, but there's only 40 pages of it. But there was a three-day hearing and Auscript was going to cost me over 3000, you know, for my lawyer, but I can't afford that. Under this Permanent People's Tribunal I should be able to get that free of costs and everything, see, and they won't let you in and the AAT is only a kangaroo court anyway, what I can see of it. Come to think of it now there's a lot of this - there's big protests over here now and the waste sites and everything, and the exposures of people being within a certain distance from these waste products, you know, sites and the protesters yesterday were thrown out of court. They didn't fine them even. So dioxin is the main thing everybody has to look at in multiple chemical sensitivity. If they create dioxins, well, then you're as good as gone. It's a cancer seat.

**MS McKENZIE:** Is there anything else that you want to tell us? See, we've read your submission and now you've told us about some of the web sites. Is there anything else you would like to raise that's related to your submission?

**MR DEIGHTON:** Well, the costs, you know, of going to the courts and everything like that.

**MS McKENZIE:** See, what we've said in our report - but remember our report is only about the Disability Discrimination Act. We've said that it would be good to have some guidelines, some criteria, so that, you know, if a complainant goes to court and loses there wouldn't necessarily be costs ordered against the complainant, against the person that goes to court.

**MR DEIGHTON:** That's right, yes. It should be that way too. See, these firms are getting away with it.

**MRS OWENS:** We've had a lot of submissions to us about the issue of costs and costs as a barrier. So it's a very important issue.

**MR DEIGHTON:** Some of the lawyers that I've went to see, they want money up-front and this is where you - well, I haven't got it. I'm on the pension and that's how it is. But I can't even get back into the AAT again now because there's another case come up in the paper, the West Australian. It was poisoned sawmill land, a health danger, and that was down at Pemberton and I was involved in that too. I used to go in and inspect this timber that was pressurised with PCP and PCP is one of the most dangerous. Now, the union in 1984, when I was working, they banned dacriazode and the management brought it back free of one component out of 10,000 and made us use it again, and that one component was PCP, pentachlorophenol, and there you're up against that, see. So then it was finally banned for life I think. It's banned in Asia and all that now, but you can still buy it over the counter in Western Australia, yes. So I don't know where the ban comes in.

**MRS OWENS:** Mr Deighton, it sounds like you have been battling a number of issues on your own which have obvious implications probably over a large number of your fellow workers. So I wonder whether it will become like the asbestosis cases.

**MR DEIGHTON:** Yes. Well, this is where it should be. See, I was involved with asbestosis too, see. I've got shortness of breath now even.

**MS McKENZIE:** Yes, I can hear.

**MR DEIGHTON:** I'm breathing, breathing heavy - - -

**MS McKENZIE:** We understand.

**MR DEIGHTON:** Yes. It's getting me stressed out to hell. I've been fighting for 14 years or 16 years now.

**MRS OWENS:** The main thing is to look after yourself and don't let the fight make you worse.

**MR DEIGHTON:** I'm not letting them get away with it because there's other workers that have died and they've been - no compensation or the widows haven't been compensated. I know a fellow just 12 months ago, he committed suicide and he was on the same job that I was on.

**MRS OWENS:** Did you go onto workers compensation?

**MR DEIGHTON:** Yes, it's unreal.

**MRS OWENS:** Thank you. We have taken up a lot of your time and I'm very grateful to you.

**MR DEIGHTON:** No, I've got plenty of time.

**MS McKENZIE:** What you have told us is very helpful. Thank you very much.

**MRS OWENS:** Yes, thank you. We'll close off in a minute, but I'd like to just explain to you, Mr Deighton, what happens next. We'll be carrying on these hearings through until March and then we're going to redraft our report and submit it to the government by the end of April and then it's going to be up to the government to release the report and to respond to it. Now, as a participant in our inquiry we'll be sending you a copy of the final report when it has been released. So I'd just like to express my appreciation to you for talking to us today and sharing your own experiences as well. It has been very useful for us, so thank you.

**MR DEIGHTON:** Now, I'll just point out something else. Dr Donohue in New South Wales, now he came over to this wasteland in Brookdale and inspected, examined these people for, you know, exposure to the chemicals that were in the Brookdale waste site and now the Medical Board said he's not a registered doctor in Western Australia so he cannot make a report out for these - that's what you're up against.

**MS McKENZIE:** It sounds like you've had a lot of difficulties in trying to move

this matter along.

**MR DEIGHTON:** Yes.

**MS McKENZIE:** But thanks very much, Ray.

**MR DEIGHTON:** All right then.

**MS McKENZIE:** For making your extra submission to us. That's very helpful for us.

**MR DEIGHTON:** Good.

**MRS OWENS:** Thank you, Ray. We'll hang up now.

**MR DEIGHTON:** Yes, right then.

**MRS OWENS:** It was very good talking to you, thank you.

**MR DEIGHTON:** Thank you.

**MRS OWENS:** Now, we'll resume at 1.30 with our next participant, Mr Wayne Nevinson.

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**MRS OWENS:** I'm Helen Owens and I'm the presiding commissioner on the Productivity Commission's inquiry into the Disability Discrimination Act, and I've got with me today my associate commissioner Cate McKenzie who's here with me.

**MS McKENZIE:** Yes. This is me.

**MRS OWENS:** What we're doing today is just calling you to allow you to participate in our public hearings for the inquiry and give you an opportunity to speak about your submission.

**MR NEVINSON:** Yes.

**MRS OWENS:** So I'd like to thank you very much for making the submission. It was earlier on in our process, back in June, and just showing an interest in our inquiry. As part of our public hearings today, our discussion is being recorded and we're taking a transcript which will be made available to the public on our web site, and a copy will be forwarded to you to check that it has accurately been transcribed. Nevertheless we like to run these hearings as informally as we can. So just think of this as being an informal chat if you can. But having said that, I'd like to point out that you're not required to take an oath under the Productivity Commission Act, but you're required to be truthful in your remarks.

Cate and I have read your submission and we'll ask you in a minute if you'd like to make any introductory remarks.

**MS McKENZIE:** Wayne, can I first ask you, can you hear us clearly?

**MR NEVINSON:** Yes, thank you.

**MS McKENZIE:** You can. Not a problem.

**MRS OWENS:** Good.

**MR NEVINSON:** The difficulty is I've got a hearing complaint as well as sight.

**MRS OWENS:** Okay. But you can hear us.

**MR NEVINSON:** I can hear you, yes.

**MS McKENZIE:** No worries. Good.

**MRS OWENS:** Great. Okay, but we might ask you to just clarify parts of your submissions in a minute, but we're also equally happy for you to ask us any questions

you might like about our inquiry process. Would you like to just clarify for us at this point in what capacity you're talking to us today. Are you appearing as an individual?

**MR NEVINSON:** You see, I represent many peer groups. I'm disabled myself, but I'm appearing today as an educated individual, a personal statement.

**MRS OWENS:** Good. Thank you. That makes that clear. I was just wondering whether you would like to make any comments about your submission to us that you put in in June or is there anything that you'd like to highlight for us. We've got one or two questions we'd like to ask you, but is there anything in particular you'd like to talk to us about?

**MR NEVINSON:** On the one hand it might be better if you ask me the questions, and then I can make submission at the end. Is that allowed for?

**MRS OWENS:** Yes, that's great.

**MS McKENZIE:** Not a problem.

**MRS OWENS:** Whatever suits you.

**MR NEVINSON:** Thank you.

**MRS OWENS:** One of the points that you made in your submission was that you said that you thought one of the biggest mistakes in the DDA is the keyhole unjustifiable hardship. You saw that as a bit of I think a let-out clause.

**MR NEVINSON:** If I may carry on now.

**MRS OWENS:** Yes.

**MS McKENZIE:** Yes, go for it.

**MR NEVINSON:** I carry on a bit, so don't get upset with me. The unjustifiable hardship clause under the act was the biggest and easiest get out of jail quick card ever put in an act. Unjustifiable hardship as of the next sitting in parliament should be scrubbed immediately. It should be done away with. They've had time - the employer has had time, the public has had time to accept why it's written in the DDA. It's a get out of jail quick card and it should not be there - I feel anyway. Time has elapsed and now it is time to get on with the show.

**MRS OWENS:** I suppose it's been put in there to provide some balance in the act,

and you can think of some situations where - - -

**MR NEVINSON:** It is needed, yes.

**MRS OWENS:** - - - if you didn't have it, it could cause some real problems, say for example for a small business that it is required to make some sort of adjustment for a person with a disability and doesn't have the money to do so and would just possibly go out of business. Would that - - -

**MR NEVINSON:** No, under the Tax Act, you can be claimed anyway. A businessman - I used to work for sales tax, used to work sales tax prosecutions. Now a business can put in a monthly return to say they've spent this amount of money, and it will be refunded by the Australian Taxation Office.

**MS McKENZIE:** So, like, they get a tax deduction or can they actually get a refund before they have to put in their yearly tax return?

**MR NEVINSON:** No. Under the old Sales Tax Act legislation, sales tax had been done away with, but it still exists under the GST more or less. It's got a different name, but it's still the same act, different name change. If you've got to do something to your business that is allowable under the Tax Act for improvements to your business, it is claimable per month, per - what, every three months I think it is now. That is my understanding.

**MS McKENZIE:** Okay.

**MR NEVINSON:** It should be done away with. That's all I can honestly and - they've had - how long is it now? 2001, 2002 - they've had nearly two years to get it up to date.

**MS McKENZIE:** So really your feeling about unjustifiable hardship is that the act has been around for quite a long time now.

**MR NEVINSON:** Yes.

**MS McKENZIE:** And employers really should have been thinking about what to do from the beginning.

**MR NEVINSON:** Yes. Well, of course. The law - you see, it is an offence not to obey the law, right?

**MS McKENZIE:** Yes.

**MR NEVINSON:** The law has been there, but there's always been that get out of jail quick card, the unjustifiable hardship. That is where I stand on the matter, and I'm sure I speak on behalf of many, many disabled people in the community.

**MRS OWENS:** What about other areas apart from employment? Do you think there should be no unjustifiable hardship, say, for clubs or schools or - - -

**MR NEVINSON:** Clubs are a business the same as any club. It makes no difference I do not feel. A club has got just as much right to get that allowable deduction on their tax returns as a business. It's irrelevant.

**MS McKENZIE:** Can I ask you some things about the complaints process.

**MR NEVINSON:** Yes, madam.

**MS McKENZIE:** Do you want to talk a bit about what you think about the current complaints process.

**MR NEVINSON:** At the moment, HREOC has got no real power. HREOC have got no options. HREOC are a worthless base as far as I'm concerned because they've got no real power. I'm sorry if you're employed by that body or come under that act, but HREOC, the Human Rights and Equal Opportunity Commission, which I've made hundreds of submissions to, have got no real power. There's too much of wanting to be fair to both parties, not obeying the law. There's laws of the land which you've got to obey and they're not being obeyed.

**MRS OWENS:** But they're set up to act as a conciliator which - - -

**MR NEVINSON:** Yes.

**MRS OWENS:** - - - really means having to be fair to both parties.

**MR NEVINSON:** Yes, all right. Maybe I understood wrong.

**MRS OWENS:** To be fair.

**MR NEVINSON:** I can see the way forward, but there's too many stones in the way now.

**MS McKENZIE:** What about this idea where if the conciliation isn't successful, then the next step, if you want to take the next step, is to take your complaint to the court. What do you think about that?



**MR NEVINSON:** It's costly. You see, the trouble with the act as far as I'm concerned - I live in rural New South Wales now. I used to live in Melbourne and I used to live in Sydney. In the metropolitan area it's different. It's a local call, you travel round, they can talk to you, but in the bush, distance creates costs, and costs create problems, if you see what I mean.

**MRS OWENS:** We've had a lot of participants talking to us about the barriers relating to costs, and it is a big issue, but you've got a perspective from living in a rural area which I think is also another barrier that we have been hearing about. Have you actually tried to use the system? You said that you'd put submissions to HREOC. Have you actually tried to put in a complaint?

**MR NEVINSON:** Yes. You see, my problem is I'm not financial. I'm not making any apologies for that; I'm not really financial. So the problem at the moment is you've got to get legal aid which creates some problems. You're not talking to two parties - one party, you're talking to two which makes it very un-cost effective, and I'm an ex-publican myself, but I want to see fairness, justice and the Australian way, not as is being done now by employers, and some employers, managers, I can honestly say - I can't talk about myself now because I said I wouldn't. My employment, I was TPI down at the Australian Taxation Office in 99. I could tell you something about that, but I've signed a document to say I won't, so I can't.

**MRS OWENS:** No. That's fair enough.

**MS McKENZIE:** No. That's fine. Without telling us about your own experience, is it your general feeling that there is discrimination in employment; that - - -

**MR NEVINSON:** There is minor - it starts out minor, and then once you get minor discrimination, after a time it becomes big discrimination, if you can see what I mean.

**MRS OWENS:** In our draft report we've raised this issue of discrimination in the workplace and said that out of all the areas covered by the act, it's probably the area that's still creating the greatest problems.

**MR NEVINSON:** Yes.

**MRS OWENS:** The issue is then at what level are those problems; whether it's getting into the job in the first place or is it the treatment of people with disabilities once they're in the job or what happens at the other end of the process and other aspects like getting access to training and promotion. From your perspective - you don't have to go into your personal details - where do you think the problems lie? Is it at all those levels or is there a greater problem - - -

**MR NEVINSON:** I'm sorry for cutting you off.

**MRS OWENS:** No, no problem.

**MR NEVINSON:** Even within government - and I worked for the federal government. Even within government there is discrimination; minor discrimination which you do not - if you want to get on, you do not complain.

**MS McKENZIE:** Do you reckon that's more in trying to get a job with the government or once you get a job with the government or that they - or being put out of your job with the government? Which is the most effective area?

**MR NEVINSON:** I think it's right across the board with government. You see, discrimination will go on for years. No matter what we do, no matter what I say, whatever you say, discrimination will happen. You see, laws are made to break and people break the law all the time, and they think that because you're a disabled person, it's not as bad. You see what I'm saying?

**MS McKENZIE:** When you talk about minor discrimination, do you think that people don't complain about the minor discrimination because they're worried about their jobs. Is that why or is it just because it's not - they don't think it's serious enough at that time?

**MR NEVINSON:** Can you repeat the question?

**MS McKENZIE:** Yes.

**MR NEVINSON:** I've got to think about this.

**MS McKENZIE:** No.

**MR NEVINSON:** When you say the question again - tomorrow is in me mind.

**MS McKENZIE:** No, no worries. What I was asking was do you think people don't complain about this minor discrimination in employment because they're worried about their jobs? They're worried that if they complain, they might lose their job or is there some other reason? Maybe they just think it's not serious enough to complain about.

**MR NEVINSON:** Some of what you say is true. Lack of promotion - you're always scared about promotion. It's the Australian way where everyone wants to be paid more than what they're getting at the moment, right?

**MRS OWENS:** Yes.

**MS McKENZIE:** True.

**MRS OWENS:** Absolutely.

**MR NEVINSON:** Am I speaking sense or not?

**MRS OWENS:** Yes.

**MR NEVINSON:** Everyone wants to be paid more than what they're getting paid at the present moment. So you don't complain.

**MRS OWENS:** So people get scared that they won't get a promotion or more money.

**MR NEVINSON:** It's economic. It's downright economic. That's what I reckon anyway; financial economics.

**MRS OWENS:** Do you think it's up to the federal government - having been an employee in the Tax Office, do you think it's up to the federal government to set an example for other employers out there; be beyond reproach in this area?

**MR NEVINSON:** You see, I'm a member of the Labor Party, right? I'm an ex-member of the Liberal Party. I understand more about the political system than what anyone would surmise. If there's votes in it, parties will go for it. If there's no votes in it, the parties won't go for it. It's the way it works. It's the way the Australian system works and the way the American system works, the way the English system works. It's just the way it is. It can't be changed. We'll have to go to the - - -

**MRS OWENS:** Yes.

**MR NEVINSON:** I'm sorry for being so pedantic, but that is my belief. You see, Jeff Kennett, when he was a member of the Liberal Party, shocked my idea of the Liberal values. I was in Melbourne in Victoria and he shocked me to death. I was a member of Burwood, Young Liberal, and I'll never be a member of the Liberal Party again.

**MRS OWENS:** So we've put a suggestion into our draft report that perhaps employers should be required under the act to have a positive duty to make adjustments or to consider what they would do for people with disabilities. I don't

know if you've managed to look at our draft report.

**MR NEVINSON:** I've read the draft twice and I've skimmed through it about four times.

**MS McKENZIE:** That's really good to see. So this duty we've suggested people might think about, what we've suggested is that employers might up-front have to try to identify the barriers in their businesses to employing people with disabilities, and then when someone comes to your door, then you would have to take reasonable steps to remove those barriers. But you could if you want to do it earlier than that; you could fit it into your business plan and do it earlier than that. What do you think about our suggestion?

**MR NEVINSON:** It's got some - can you repeat - summarise it again.

**MS McKENZIE:** Yes, sure.

**MR NEVINSON:** I'm sorry.

**MS McKENZIE:** No problem. So the first part of it is, as an employer you've got to identify what barriers in your business might exist to employing people with disabilities, and then if someone comes to your door with a disability, you've got to take reasonable steps to remove those barriers.

**MR NEVINSON:** But, you see, I've been working on the New South Wales Adaptable Housing Bill - well, I haven't been working on it; I've been advising on it, because I can't do nothing; I'm not a politician. If everything keeps going the way it's going, we're going to get down the track 20 years - the year 2010, 2011, and it's not going to change a bloody bit unless we say across the board, "You've had time to enforce the law, make sure you uphold the law. Now there's going to be a blanket ban, a blanket right across" - it's got to be enforced by HREOC or the police or somebody that it is so. That's what I believe. I'm sorry if I'm being silly, but that is what I believe.

**MS McKENZIE:** Yes. You think it should happen now, not in 20 years' time.

**MR NEVINSON:** In 1979 when - I think that was when the act first came out, wasn't it?

**MS McKENZIE:** 92.

**MR NEVINSON:** 92?

**MS McKENZIE:** Yes.

**MR NEVINSON:** I don't know, but it's one of the acts - 92. Was it 92?

**MS McKENZIE:** Yes, 92 was - - -

**MRS OWENS:** That was the Commonwealth act.

**MS McKENZIE:** - - - the Commonwealth one. There are some earlier state ones though.

**MR NEVINSON:** Yes. Well, 92 - 11 years or near 11 - 10 years say. The act was supposed to be - under the act you always give - there's always an amount of time given to people to get - comply with it and get used to it and then it's enforced, right?

**MRS OWENS:** Yes.

**MR NEVINSON:** That time is just about due, isn't it?

**MS McKENZIE:** You reckon two years is enough?

**MR NEVINSON:** Of course. If you haven't changed your idea and ideals now, you never darn will. I'm sorry for swearing. You never will. If you never change now, you never will. I don't mean to be hard on the employers, I don't mean to be hard on business. I'm a fair man and I'll always speak my mind, and that is what I feel.

**MRS OWENS:** So to enforce the act, have you got any ideas about that's HREOC's role for example or - - -

**MR NEVINSON:** HREOC has got no real powers.

**MRS OWENS:** But we could - - -

**MS McKENZIE:** We could give them some.

**MRS OWENS:** We could recommend greater powers.

**MS McKENZIE:** We could suggest that they be given some powers.

**MRS OWENS:** Because we're reviewing the act and we could make recommendations about what HREOC should be able to do. In fact we have got a few things in our report already, but also we talk about resources for HREOC as well

and perhaps the need for greater resourcing of HREOC.

**MR NEVINSON:** Yes, but before - I would agree that HREOC should have more powers. That is what I will say pedantically. With all sincerity, I don't lie. I believe HREOC should have more powers. There's been too much scope goes under the unjustifiable hardship. Blanket ban that, give more power to HREOC and once HREOC have got the power, the police have got the power to do - it's written under the act.

**MS McKENZIE:** You said a couple of times that police should have some powers. At the moment under the act, it's unlawful and you can make a complaint about it, but it's not generally an offence, like a crime, to discriminate. Do you think it should be an offence; a criminal offence.

**MR NEVINSON:** Yes. I don't know how long you've been a commissioner or anything or an associate commissioner, but once it's written in that little piece of paper called the bill which becomes an act and it's law, then a policeman can enforce if he wants to. Do you know that? Under the Jurisdictions Act.

**MS McKENZIE:** That's true with normal laws; you know, the normal crimes like parking offences and traffic offences and theft and all those other offences, that's true. The police can enforce them, but this discrimination act is different. It's basically - the only people who can really enforce that is HREOC and you can only do it through a complaint. The police really - - -

**MR NEVINSON:** Yes. That's what I'm saying. It's too weak. It's like saying, "If you do that again, I'll give you a smack." They do it again, smack. There's no real powers under the act.

**MS McKENZIE:** No teeth.

**MR NEVINSON:** By HREOC or anyone. It's a whitewash. It's a vote-grabbing whitewash. I do not mean to be pedantic or silly or anything, but that is my belief and I'm going to say what I believe. I'm looking at a picture of Mark Latham now.

**MRS OWENS:** I was just going to say if HREOC was given more teeth, the teeth could be used in different ways, and one way would be to provide HREOC with some ways of enforcing conciliated agreements. So at that level there could be something we could be doing. We've suggested some possible options in our draft report and asked for comment on those, but have you got any other suggestions? Are you suggesting that HREOC could be more proactive and - - -

**MR NEVINSON:** Instead of reactive.

**MRS OWENS:** Right, and - sorry, you - - -

**MR NEVINSON:** More proactive instead of reactive.

**MRS OWENS:** I mean, HREOC at the moment can undertake inquiries, and we've suggested that - we've put in a suggestion that they could initiate complaints and that could be right from the word go or possibly initiate complaints to go to court. So we have got some suggestions of HREOC doing more than they're doing now which would make them more proactive. Would that satisfy you?

**MR NEVINSON:** But you see the problem is lodgment of complaint, I believe - I've faced this problem myself - that lodgment of complaint has got to be in written form. That should be done - should be taken verbal, and then they send you the complaint - you've made the verbal complaint, they send you a typed statement of what you've said, and you put your monogram on it or your tentative monogram and send it back to HREOC. That is the official complaint. It should be verbal as well as - it should be ascertained in writing after the verbal complaint on a 1800 number.

**MS McKENZIE:** You see, in some states the Equal Opportunity Commissions will do that. They will help to write out your complaint and get you to sign it. But HREOC does not do that. Is that right?

**MR NEVINSON:** That's right. That is my belief. That is what I believe to be true. Don't challenge me into court for telling lies, but that is what I believe.

**MRS OWENS:** Okay. Well, we'll take your comments on board, and I was just wondering, is there any other issues that you raised in your submission? You did talk about the problems in rural areas, and we touched on that earlier. Do you want to say anything else about the particular problems in country areas while we've got you there?

**MR NEVINSON:** Yes. Thank you - is that Helen again, is it?

**MRS OWENS:** Yes, it's Helen.

**MR NEVINSON:** Sorry, Helen. I hope I've been calling you the right names I'm sorry.

**MS McKENZIE:** No, it doesn't matter. That's all right.

**MR NEVINSON:** You see, if I might just add one thing, distance is a killer. Now, with distance becomes costs. The costs of - you see, me, myself, I - I am in a

wheelchair. I'm a disabled person. I cannot get to the post box. I cannot do anything. I'm useless. I've got a computer which I got through TRD for the disabled which I used a fair bit, but still the system creates costs and there should be a 1800 number to HREOC. I've asked for this to happen and it's not happened so far. They used to have a 1800 number but they've done away with it or 1300. This story that you can't use a 1800 number on a mobile phone is not found to be true; somebody's a liar.

**MS McKENZIE:** Can I just ask, HREOC doesn't have an 1800 number, it has a 1300 number. Is that right or - - -

**MR NEVINSON:** Yes, the 1300 number.

**MS McKENZIE:** And 1300 numbers - - -

**MR NEVINSON:** 45 cents.

**MS McKENZIE:** So they cost you for the call 45 cents.

**MR NEVINSON:** It costs you 60 cents via public phones, and your rent for the phone call from your own phone.

**MS McKENZIE:** But an 1800 number doesn't cost you so much.

**MR NEVINSON:** Doesn't cost you a brass razoo.

**MRS OWENS:** We'll have a look at that one, Wayne.

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

**MR NEVINSON:** I hope I've made some sense.

**MRS OWENS:** You have.

**MS McKENZIE:** You've made lots of sense.

**MRS OWENS:** So thank you very much.

**MR NEVINSON:** Hang on, if I might indulge a bit further.

**MRS OWENS:** Yes.

**MS McKENZIE:** Sure.



**MR NEVINSON:** I'm talking to you from Melbourne, aren't I?

**MRS OWENS:** Yes. We're in Melbourne.

**MR NEVINSON:** Yes, that's right. You see, if I could - I don't know whether I should submit this to you or who I should submit it to, but I will anyway. The PPS - prescribed - the PBS - - -

**MRS OWENS:** Pharmaceutical Benefits Scheme?

**MR NEVINSON:** Yes.

**MRS OWENS:** Yes.

**MR NEVINSON:** I had a bit of workings in - I don't know if I should admit that, but I did. I had a little bit to do with that coming into legislation. I believe that it is too high, it's - pensions should be 75 per cent for every average weekly male income. We've got - for the first time in history, we've got 24 bidding apparently, but I suppose it will be about 33 by now because it has not been reduced, in GST fraud. For the first time we've had the money to enforce the acts for the disabled to make it fair for everybody, and what's John Howard going to do? Give it back in tax refunds. It's ridiculous. For the first time, even though it was done through fraud, we've got moneys to enforce the acts, we're going to give it back. It's not the government's money. It's obtained through fraud under GST fraud I call it. Are you there, Helen?

**MRS OWENS:** Yes.

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

**MRS OWENS:** We're just puzzling over what you're talking about. I think you were initially talking about the DSP - the disability support pension - and I can't quite pick up where you're going now. It's just - I think it's going beyond our terms of reference.

**MR NEVINSON:** That's what I thought.

**MS McKENZIE:** I think it's not sort of a Disability Discrimination Act issue; it's probably a broader issue which - - -

**MR NEVINSON:** I'm sorry.

**MS McKENZIE:** No, don't worry. Don't be sorry. It's a bit beyond us to be able

to make any recommendations or suggestions about this one.

**MR NEVINSON:** But you will take my ideals on notice, won't you?

**MRS OWENS:** Yes, we are. We will.

**MS McKENZIE:** We will. We will.

**MR NEVINSON:** Thank you. I'm sorry for bothering you.

**MS McKENZIE:** No.

**MRS OWENS:** You're not bothering us. We've probably held you up long enough, but I'd like to thank you very much for talking to us today. We'll close off shortly because we have our next participant waiting to talk to, but I'll just explain to you what happens next. We finish these hearings in March and then we'll be redrafting our report and submitting it to the government by the end of April, and then it will be up to the government to release the report and respond to it, and as a participant in the inquiry, you'll be sent a copy of the final report when it has been released.

**MR NEVINSON:** Yes.

**MRS OWENS:** I'd like to just thank you, Wayne, very much for talking to us today.

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

**MRS OWENS:** I think your submission and comments have been very useful to us.

**MR NEVINSON:** I hope I don't speak a lot of innuendo or crap.

**MS McKENZIE:** No.

**MRS OWENS:** No.

**MS McKENZIE:** Not a problem.

**MRS OWENS:** You've done very well.

**MR NEVINSON:** Thank you very much. As I said, I'm TPI anyway. I can't do anything now.

**MRS OWENS:** You've talked to us on the phone and we're very grateful for that.

**MR NEVINSON:** Thank you, Helen.

**MRS OWENS:** Okay.

**MS McKENZIE:** Thanks a lot.

**MRS OWENS:** Thank you. We'll hang up now. Bye.

**MR NEVINSON:** Thanks, Helen. Bye.

**MS McKENZIE:** Bye.

**MRS OWENS:** Catriona Gunn, can we call you Cath?

**DR GUNN:** Yes.

**MRS OWENS:** I'll just say some things you probably know already. My name is Helen Owens and I'm the presiding commissioner for the Productivity Commission's inquiry into the Disability Discrimination Act, and I'm joined by my associate commissioner for the inquiry, Cate McKenzie, who's here. We're calling you today to allow you to participate yet again in our public hearings for the inquiry and to give you an opportunity to speak to your submission. I'd like to thank you for making another submission to us and I'd also like to take this opportunity, Cath, to thank you for sending those statistics last week that you sent us. As part of our public hearings our discussion today is being recorded and a transcript will be made available to the public on our web site. A copy will be forwarded to you to check that it is accurately being transcribed. Nevertheless, we like to make these hearings as informal as possible and just assume that we are being informal, just like we were when we saw you in Adelaide.

I'd like to point out to you that, although you're not required to take an oath under the Productivity Commission Act, you are required to be truthful in your remarks. We've read your submissions, the earlier one as well, and we'll shortly invite you to make any introductory remarks you might want to make. After that we'll ask you some questions about your submission, but we're equally happy to clarify questions about our inquiry process. Can I just ask you in which capacity you're appearing today. You're appearing on behalf of the Communication Project Group?

**DR GUNN:** That's correct.

**MRS OWENS:** As part of the group?

**DR GUNN:** Yes.

**MS McKENZIE:** Cath, you can hear as, can you?

**DR GUNN:** I can hear both of you. I can recognise your voices.

**MRS OWENS:** It's good to talk to you again after all these months. I'm very grateful that you've taken the opportunity to talk to us and I'm sorry we're not there to see you in person like we did last time.

**MS McKENZIE:** Cath, can I just also ask you, without interrupting Helen - I didn't mean to interrupt her - you don't mind us mentioning the statistics to you? They

were of great interest to us and - - -

**DR GUNN:** No, I don't mind in the slightest. In fact, there's a slight revision from the first lot of statistics that I sent you. David gave me a bit more information after that. I might just send it to you in an email, because it's probably easier to have it there in front of you than me try and read it out to you, I think.

**MS McKENZIE:** Does it alter some percentage radically, can I ask?

**DR GUNN:** No, it doesn't alter it radically. It's just that there was some information I didn't realise he'd given me when I started to work out what the percentages were. But it doesn't make a lot of difference to the overall result.

**MRS OWENS:** I think the results are extremely interesting and they give some general impressions which I think are interesting. You can correct me if I'm wrong, but I will give you my impressions, the messages I got out of them. One of the impressions I got was one of some isolation on the part of some of these people and dependency on their family members and/or carers. Another question I had in my mind was the impact of the limitations that people face in terms of getting information in terms of their understanding of their rights under the DDA or understanding how to use the Disability Discrimination Act or to contact HREOC. I'm just wondering how we use this material in terms of thinking through whether there is indeed some sort of role for the Disability Discrimination Act or for HREOC in terms of dealing with the problems that your figures and your material are I think indicating.

**MS McKENZIE:** Can I perhaps just add a couple of comments to those impressions as well and say that one of the other things I took out of those stats was that relatively few of the groups had daily access or unrestricted access to computers or the net. Relatively few of those groups had daily access to a newspaper and, even if they did, read only material of a very limited nature and by far the greater access was had by these people to television and radio, and as far as radio is concerned, commercial and talk-back programs.

**DR GUNN:** Yes, I think that would probably be a very fair summary. Certainly I think one of the problems where newspapers are concerned is that on the whole - it's certainly not true of every individual - people with disabilities tend to have a lower level of education, and because of that they tend to read less. If you look at their use of libraries, the use of a personal library card is much lower, although interestingly, for the second group rather than the first it's about twice as high.

**MRS OWENS:** Is that because they've got a carer to get them there?

**DR GUNN:** That's possibly part of it. I'm also wondering whether it's because they are physically able to do less.

**MRS OWENS:** So they want the distraction of using the library material?

**DR GUNN:** Yes.

**MRS OWENS:** There are probably a few things going on there to explain it, yes.

**DR GUNN:** Yes. There's more than one thing to go on to explain the use of it, but both groups are tending to borrow the audiovisual material rather than the printed matter.

**MS McKENZIE:** Can I ask, there's something in one of your earlier submissions which said that some of the groups excluded people who were blind or at least profoundly deaf, but did these groups includes those - - -

**DR GUNN:** No, they don't. No, this is the same group that we were talking about before. So there are no people in this group who are either severely visually or hearing impaired. There were people in the group who needed large print and there were people in the group who were hearing impaired but not so profoundly impaired that they had to use sign language.

**MS McKENZIE:** The other thing that I took from the stats was that they may well show a need - as far as the groups that you're looking at are concerned - to communicate with those groups not just by the Internet - that if for example HREOC is wanting to get educative information to these groups about the DDA or how to complain, that information would perhaps be better targeted if it were sent by radio or television and even on a particular set of stations.

**DR GUNN:** Yes, I think that's true. I think that if you wanted to get information out, even quite specific information out to that target group you would need to put it on commercial television, commercial radio, and things like - well, in this state it's 5RPH, the radio for the print handicapped, those sort of stations. You would possibly also need to put it into places like the library where as I said - and I mean there's 40 per cent of the second group who actually use the libraries and they were using them on quite a regular basis.

All the local libraries in this state for instance carry information pamphlets. If something like the DDA is going to be effective - obviously I mean if people have got to know about it - so I think, yes, you're having to look at where people are getting their information from. They're not getting it from newspapers although interestingly again people who come from families where languages other than

English are spoken tend to have - although they don't always use it - a greater access to a paper which is not written in English. The thing I can't answer about that is whether or not that's true for the overall population. I haven't found any figures on that yet.

**MS McKENZIE:** So you're not looking comparatively if you like at the rest of the population; you're looking at the particular problems of this group or of these groups.

**DR GUNN:** Yes, I do know that the use of a library card is certainly much lower for group 1 than it is for the overall population because I mean the use of library cards is well over 50 per cent for the rest of the population.

**MRS OWENS:** I suppose you could turn the issue around the other way and say: is the lack of access for the first group to the library facilities and Internet facilities for both groups a result of some sort of discrimination that's occurring, or is it just a reflection of the people's conditions? It's really interesting to start thinking about why these things happen. Have you got any sense of that? You could talk about discrimination in terms of access to the library because physically people can't get to it in the first group - there's physical barriers - or in the case of the Internet there may not be opportunities presented to people because they don't end up in the education system or whatever where they might get access to the Internet.

**MS McKENZIE:** Or they can't afford it.

**DR GUNN:** Yes, I was going to say that the most common reason that I was given for not having to the computer and the Internet was the expense. In the first group that's 58 per cent and in the second it's nearly 76 per cent.

**MRS OWENS:** That could just be then an affordability issue which is not necessarily reflecting some discrimination elsewhere in the system. It could just be that they can't afford it, but then their income levels may be lower because of something that's happened in terms of not getting education, not getting into jobs, and so on. So it could be a sort of an indirect impact.

**DR GUNN:** Yes, and the other thing of course for group 2 in particular is that very often there's an added expense because of the disability, because they need special equipment in order to access the computer. I mean it is now possible to get a program - possibly you have one, Cate, that will read your email to you.

**MS McKENZIE:** I do, yes.

**DR GUNN:** I understand that it's fairly expensive.

**MS McKENZIE:** There are different grades of them if you like. Some are simpler than others. But you're right, they are not cheap.

**DR GUNN:** Yes, that's it and I think possibly because the income levels that people with disability tend to be very much lower overall, then they don't have the money to access that sort of thing because their other expenses are that much higher. But I mean that was true. One of the reasons for not reading a newspaper, I was told, was because it was too expensive to buy one. People said to me, "Well, yes, I would if it wasn't so expensive." One or two people mentioned that they actually looked at them when they went to the library. It impacts on their social life as well because when we got down to the "Belongs to a club or organisation", for instance, I mean you get the same sort of pattern. People don't belong because it's expensive and it's expensive to get there.

**MS McKENZIE:** Those stats show a considerable degree of isolation, particularly the quite large stat for people who have little or no communication with neighbours, friends, or community groups.

**DR GUNN:** Yes, and I found some of the people who have moved from residential institutions into community homes or group homes in the community, they were saying to me that they felt more isolated. I mean they didn't always put it in these terms but they felt more isolated in the community home than they had felt in the residential institution because they saw a limited group of people, and they didn't get out, and they didn't have the activities that they'd once had in the institution.

**MS McKENZIE:** Should communication needs as such be added to the definition of "disability"? I mean at the moment communication needs would in some cases at least be covered within the definition of disability if they stemmed directly from the disability. But obviously there are many which might stem for other reasons - and some, for example, might stem from your first language not being English.

**DR GUNN:** Yes, except that I wonder whether or not the problem of not having English as a first language is actually as great as some of the other problems. I found that people who came from groups in the community where English was not their first language, particularly if they were perhaps from cultures where family traditions are very strong like the Greeks or the Vietnamese or the Italians for instance - I mean, I'm sort of thinking of individual people we talk to here. Very often they had a wider group of social contacts and they were more involved in social activities than people who came from, say, an Anglo-Saxon background. So I'm not sure that it's a language other than English which is the problem. I think that quite possibly there are an entirely different set of factors which makes up - or tends to make a person isolated in the community.



**MRS OWENS:** I suppose the issue that we're grappling with is your suggestion, on the last page of your most recent submission, about - you said you're not certain about whether our suggested amendments would cover the concerns with respect to communication difficulties, which are most often associated with some other difficulty and I suppose it's a similar sort of issue that we've been grappling with in relation to behaviour. So I'm not quite sure what the answer is. Do you want to expand on that. Do you think there is a way that the definition could be adapted. Have you got any suggestions about how we could do that, or would you like to take that on notice to think about it?

**DR GUNN:** I think I'd better think about that. I mean, it is clearly very, very difficult to draft it into legislation. I'll make myself a note there. I think it's probably important that we look at some sort of recognition in the act. Whether or not we can include it in the definition I don't know, but if we can include some sort of recognition in the act so that people are made aware of it. I think there's a tendency to think of communication problems as people with a visual impairment not being able to read, people with a hearing impairment not being able to carry on a "normal", in inverted commas, conversation and they forget the huge range of other problems, you know, the intellectually disabled person's difficulty perhaps in understanding something that's said to them or somebody with Asberger's syndrome having inappropriate comments in conversation. People don't look on those as being communication problems. So I'm not sure, I really don't know how you could include it but I do think it's worth thinking about.

**MS McKENZIE:** What I'm thinking for the minute is perhaps we're really trying to make it clear that where that particular difficulty is related to the disability then it's proper to regard it as a characteristic of the disability. Maybe that's what we're looking at, rather than the communication difficulty being a disability in itself, but where it is related to a disability, because after all that's what the DDA deals with. Where it is related to a disability then it should properly be regarded as a characteristic of the disability.

**MRS OWENS:** We have got in our suggested change to the definition three clarification points, one of which is about genetic abnormalities and conditions. But we have got one that says "behaviour that is a symptom or manifestation of a disability". So you could say behaviour or communication problems that are symptoms or manifestations of a disability or something like that.

**MS McKENZIE:** Yes.

**MRS OWENS:** We'll have a think about it anyway. We'll ponder this idea.

**MS McKENZIE:** It occurs to me that that might be really at the core of what might

be needed.

**DR GUNN:** Yes. I think Helen's suggestion is probably very sensible, behaviour and/or - yes.

**MRS OWENS:** And/or, something like that.

**MS McKENZIE:** Yes, communication problems.

**DR GUNN:** Yes.

**MRS OWENS:** We'll see whether that works for us, or at least we'll think about your other suggestion about including recognition somewhere in the act, because I think you have raised an extremely important issue there and it's a particular issue that I think we'll need to acknowledge when we are discussing this other issue about how HREOC promotes community understanding and recognition and how people can use the HREOC processes in terms of making complaints and so on. So we need to think about it. There's various areas where we need to address this issue and so we will ponder this. But if you have any ideas about it, just feel free to share them with us.

**DR GUNN:** I certainly will. I'm not backward about coming forward, you know.

**MS McKENZIE:** No, but it's another excellent submission and a really helpful set of stats. Can I just raise another issue that you covered in your submission and that was, you supported our recommendation which suggested there should be an inquiry by the attorney-general into access to justice, and again it's another issue where - and I thought it was useful that you said that you supported that idea. I think you said that many people with disabilities do not understand what's required of them in law. Have you got any suggestions there about how that problem could be addressed?

**DR GUNN:** There is slowly I understand, Helen, a campaign to put everything into what they call plain English. That does help. I don't know that their plain English would always be my plain English, but nevertheless I think that is a start: making documents and so on - simplifying the language in them is one start. I think one of the other things it might require is a greater training on the part of people who work in the court system to understand just what the difficulties are. It doesn't justify people with disabilities. I think that giving greater training just to court officers would probably also help people from non-English speaking backgrounds, older people, people whose education is less and so on.

I mean, as you well know, the courts are designed and targeted at people who are sort of middle income, you know, well educated, well able to understand what's going on,

highly articulate themselves, and that the people who go in who are, you know, sort of working class background, perhaps only sort of an average level of secondary education, possibly not even reading and writing terribly well because they've just lost the skills because they don't use them - I mean, they go into court over something minor and come away with a bigger fine or a longer jail sentence or something, sometimes when a middle-class person would just have walked out with a slap on the wrist because they can argue back.

That's one possibility but of course that's assuming that the problem gets as far as that. I think possibly we need mechanisms - and I don't know how we would work it - to get people to try and sort out situations before they actually reach that point, more sort of conciliation services and so on, so that if somebody bumps into somebody else's car for instance in a carpark and there's a bit of an altercation you can go to some sort of conciliation service to sort it out, rather than end up having the thing go to court. I mean, it can happen and it's a waste of court time which is terribly expensive.

I imagine it would be much simpler to provide, say, two or three officers, the court officers even, in each state who worked on some sort of conciliation basis than, you know, a sort of a magistrate and the recorded proceedings and all the paperwork and so on that goes with it. Again it's something that I just sort of threw out for you because I'm conscious of the fact that people from the northern and the southern suburbs of South Australia for instance, some of those people get themselves into financial difficulties when there was no real need for it because they didn't understand the document that they were signing, or they thought somebody else had greater rights than they actually had. They believe it's their fault when they don't understand what their rights at law are. In the courts if you have a disability and you don't understand all of those things on top of all of that and your expenses are that much higher, then you can get yourself into a real financial mess.

**MS McKENZIE:** In Victoria there's an organisation called the Dispute Settlement Centre where the courts or certainly the Magistrates' Court has a practice with small claims, suggesting that people go to that centre before bringing their claim to the court and a lot of disputes are informally resolved that way.

**DR GUNN:** There's a Small Claims Court here and I think probably most states have got - in fact I don't think any of the states haven't got a Small Claims Court. But very often things get to the Small Claims Court when they shouldn't.

**MS McKENZIE:** Yes. No, it should be before you actually walk in the door of the court, that one, I agree.

**DR GUNN:** It would be very interesting to see an inquiry into the justice system to

see just what happens.

**MRS OWENS:** So you'll have to get involved in that one too, Cath.

**MS McKENZIE:** There's no rest.

**DR GUNN:** No rest for the wicked.

**MRS OWENS:** Can I just come back to your notes you sent us on the statistics. I don't want to go into the content of that again, but I found that information quite valuable and I was wondering if you would be prepared to let us use it as a form of a supplementary submission or an attachment to your original - - -

**MS McKENZIE:** Attachment to your original one perhaps.

**DR GUNN:** Yes. I mean, my only concern was that it's easy to take statistics out of context. I was just being cautious because I didn't sort of want you to feel that we were abusing the statistics in any way.

**MS McKENZIE:** But I'm happy if you want to put qualifiers on - you know, to prevent misinterpretation of the stats. That's no problem.

**MRS OWENS:** We mightn't actually use any of the actual figures. I mean, the other issue is also that we've got these data and we don't really know how they compare with the general population. But to me, I think that they - you know, it was sufficiently low to indicate an interesting story. But have a think about it and if you change your mind you can let us know about that.

**DR GUNN:** Yes. Well, what I was going to try and do was try and find some figures to find out for instance how many people in the general population get a newspaper. I mean, I know it's much higher than that. But it's a matter of being able to sort those statistics out and find places where I can find them.

**MRS OWENS:** Yes.

**DR GUNN:** If I can, and I mean, the statistics start to be much more meaningful.

**MRS OWENS:** Yes, it gives some context to it, you know.

**DR GUNN:** That was my concern. I mean, they're sort of stand alone at the moment. They're not in context and they probably need to be in context. But I mean, if you want to use them go ahead and use them. But I think perhaps it probably needs to - if you do use them it needs to be with a qualifier that, "This is

just a group in the population and we don't know what the figures for the general population are."

**MRS OWENS:** We can always check that with you if we are going to use some of the material. But it does lead to a set of interesting observations and questions which I think are worth making.

**MS McKENZIE:** Particularly as to how education for people with disabilities, at least in those groups - about the DDA, how it should be targeted.

**DR GUNN:** Yes. I mean, if we can find a way of making people more aware, which is perhaps cheaper than a mail-out from the Department of Social Security and perhaps more effective. I mean, people will say that's one of the interesting things now. The Department of Social Security does send out an occasional newsletter and one of the questions we ask - I didn't put any of the statistics in and I can't remember them off the top of my head. We asked people whether they actually read that and the answer was largely no, I mean for a variety of reasons. Some people said they couldn't read but a lot of people thought it wasn't relevant and some people were saying they didn't understand the language which was used. So, I mean, there's not much point in an extensive mail-out if they're not going to read it.

**MRS OWENS:** Indeed. Well, I think I've covered what I wanted to cover with you. I'll just see what Cate - - -

**MS McKENZIE:** I've raised all of my questions as we've been going along. It's been really excellent.

**MRS OWENS:** Cath, have you got anything else you want to raise with us? Is there something we've missed?

**DR GUNN:** I don't think so, Helen. I think perhaps we've - I think probably we've covered it, because we've raised - yes, I think we've probably raised all the issues that I've marked off here on the papers.

**MRS OWENS:** Okay. Well, thank you.

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

**MRS OWENS:** We'll close in a minute, but I'll just explain what happens next. When these hearings finish in March, we then redraft the report and submit it to the government by the end of April, and then it's up to the government to release the report and to respond to it. As a participant in the inquiry, we'll be sending you a copy of the final report when it has been released. So thanks very much for

talking to us again today, and your submission and comments have been very, very useful to us and got us thinking in another direction. So thank you very much.

**MS McKENZIE:** Thanks. Thank you, Cath.

**DR GUNN:** Thank you very much too. Good luck.

**MS McKENZIE:** Hi, Dorothy. Cate again. Thank you very much. It's been quite a few months since we've chatted with you, and we're very pleased to do so again.

**MRS OWENS:** I'll just go through a little introductory bit that I have to do and then we'll come back to your submission in a minute. My name is Helen Owens and I'm the presiding commissioner for the Productivity Commission's inquiry into the Disability Discrimination Act, and I'm joined by the associate commissioner for the inquiry, Cate McKenzie. We're calling today to allow you to participate in the public hearings for the inquiry and to give you an opportunity to speak about your submissions. So we'd like to thank you very much for the submission and showing an interest once again in the inquiry.

As part of our public hearings, our discussion today is being recorded and a transcript will be made available to the public on our web site. A copy will be forwarded to you to check that it has accurately been transcribed. Nevertheless, we like to make these hearings as informal as we can. But I'll point out to you that although you're not required to take an oath under the Productivity Commission Act, you are required to be truthful in your remarks. We've read your most recent submission, as we have the earlier ones.

**MS McKENZIE:** And the others also, yes.

**MS BOWES:** Here we go again.

**MRS OWENS:** We shortly invite you to make any introductory remarks that you may wish to, and after that, we'll ask you a few questions about your submission, but we're equally happy to clarify any questions you might have about our inquiry process. What I'd like you to do now is just clarify for us in what capacity you're appearing today, whether you're appearing on behalf of the - I think it's called the Allergy, Sensitivity and Environmental Health Association.

**MS BOWES:** Yes, I am.

**MRS OWENS:** Okay - the ASEHA Queensland Inc, yes. Thank you for that. So I'll just ask you, Dorothy, if you'd like to make any key points, you'd like to summarise any key points from your submission.

**MS BOWES:** Well, I've had a few interruptions up here. We've had some really bad storms in the last few days and I keep losing power, so I haven't really been able to summarise it all so far, but I think the main thing that comes out of this for me, and for a lot of other people, is the need aspect in that. You know, the DDA has actioned - it's had success in the easier things to action, like deafness and blindness, but there's a whole area of unmet need there and this is difficult, because there are

new and emerging illnesses causing disability in the community, and we have no process of picking them up to ensure that they get into service provision, because these are the people that fall through all the cracks.

So we need - and that comes through time and time again when I read through my submission, which is very verbose, that we really need some process for picking up the unmet need and dealing with this whole area of unmet need, because currently it's very unsatisfactorily dealt with, and I think it's very poorly funded. But I also would like to see the DDA better funded. The HREOC, I'd like to see them better funded to go out and educate the community about function of HREOC, the DDA. It also has raised awareness of disability discrimination in the community really well, and I think with better funding, it might actually encourage more individuals to use the processes, because there's a few problems there.

I actually sat on the management committee of a health advocacy service here in Queensland and I guess, you know, that's very strong coming through in my submission about advocacy there. But service providers don't always tell people they have a right to complain or indeed where they can make a complaint. So we can see that there's a role for more funding for HREOC to go out and do a better job of what it's clearly doing.

**MRS OWENS:** Can I just draw your attention to one of our draft recommendations in our draft report, I just want your feedback on it, but we took onboard, I think, from our discussions last time with yourself and quite a number of other people we spoke to with multiple chemical sensitivities, this whole issue of unmet need, and we've put a draft recommendation in to change the definition of "disability" in the act, and one of the changes that we've suggested is that it would include - and I'll just read it out to you - "medically recognised symptoms where a cause has not been medically identified or diagnosed", and in our discussion around that recommendation, we did talk about multiple chemical sensitivities. Does that help, do you think, that changed definition, our suggestion?

**MS BOWES:** Well, I can see that it will partly cover it, but for the most part, you know, we're just getting a huge amount of denial from health providers and government that this area is there. So it's really a very difficult one and it is essentially a syndrome which is a cluster of symptoms with no known cause.

**MS McKENZIE:** See, we thought that at least if we did that, then you get over the threshold as far as the Disability Discrimination Act itself is concerned.

**MRS OWENS:** Yes. At least you'd only be able to use that act. It mightn't solve all your other problems, but at least it means those people can, as Cate says, get over the threshold.



**MS BOWES:** Well, indeed, they're probably dealing with some of these manifestations of MCS. Asthma is a good case study of MCS because most asthmatics are very sensitive to perfumes and strong detergents, disinfectants, pesticides, and indeed recently I was out talking to a local asthma group. But they're all elderly and nobody is really getting up and doing anything about it. They're saying, "This is the problem," but nobody is really funded to get up there and do the advocacy and do the hard work. That's, you know, something that we think with the unmet need that, given that government is cutting funding left, right and centre, we think that there's a need for either an individual advocate or for groups - well, both, in fact - for groups to be funded to do this job of advocacy and lobbying that needs to be done here.

**MS McKENZIE:** And to some extent as well, apart from needing better advocacy services, it seemed to me that your submission is also really asking for better services full stop, better medical services, more responsive, more sensitive medical services and so on.

**MS BOWES:** That's right, because what usually happens is instead of saying, "I've got MCS," I say, "I'm badly fatigued," and they say, "You're depressed," and once that depression thing or psychosomatic somatisation disorder gets onto the medical records, you then cannot seriously get any healthcare. So, you know, it's just about the worst thing that could happen and all of the recent studies that are coming out indicate that if there is any depression, it's secondary to the illness. But that's another thing, which is another reason why we need funding for groups working in unmet need and groups like those that are working in the MCS area.

We're very poorly resourced in terms of people power, which means we can't go and fundraise because, you know, most of us can't even think about insurance, so we can't go out and fundraise. Nobody is well enough to do it anyway. We've got poor energy within the group. We can't afford to pay someone to do the advocacy stuff for us. But because there isn't any funding there, it impedes us in many ways, and in a way that's the worst kind. It doesn't give us any money to do research or attend conferences to upgrade knowledge base and skills, to pursue the recognition and access we need, and it doesn't allow us to do something like epidemiological studies, and these are imperative for us to get that recognition and service provision for the unmet need.

So I feel that, you know, resourcing routes that identify an area of unmet need may help in a way, but we really clearly do need some process for this to be included, picked up and included, because, you know, the government will just do an inquiry of some kind and they will bring in a heap of experts who know nothing about the area or who are diametrically opposed to it, for whatever reason. You

know, I mean, we're not getting anywhere. It's very difficult.

**MS McKENZIE:** Would you also say that when the act - not so much the act, but when things like standards for access to premises are formulated, there's perhaps not a sufficient understanding of the needs of people with MCS.

**MS BOWES:** Well, we've just been through this with the Redcliffe Hospital. The administrator up there no longer responds to my correspondence. We went in in a conciliatory manner and we just asked if they could fast-track the MCS people to get them through the system, out of the hearing officer, because they can't stand the indoor air quality, and, you know, we were just told, "Well, everybody wants first appointment," you know, and I was saying, "There's not five million of us, there's only a handful that are going to ask for this," but I really don't believe that we've actually been taken seriously there. When one lady did complain when she finally got her appointment at the dental clinic, she was just treated with retribution. She was just treated with contempt. I mean, you know, if you complain, that's what happens sometimes, and then nobody wants to take the complaint further because now she's worried that she's not going to be able to get any care.

**MS McKENZIE:** That's a point that a number of people in remote areas made to us, saying that that happens often to them where there's only one service provider, and that service provider has, they feel, discriminated against them if they complain.

**MS BOWES:** Take what you get, not what you need or what you want.

**MS McKENZIE:** Yes.

**MRS OWENS:** So is it a manifestation really of a lack of understanding in the community and among medical service providers and others about the conditions that you're dealing with?

**MS BOWES:** Well, I really don't know because it happens in other areas. I can give you an example. When I went up to the Redcliffe Hospital to talk to the respiratory group up there, the social worker took me into the next room where they have the home service provider and she introduced me to a lady there, and I was explaining about people who were perfume-sensitive, and she just really lost her cool and said, "People have to wear underarm deodorants, and they have to use strong detergents," and she said, "I can't deal with this," and she walked back to her computer, just turned her back on me. I mean, that lady really needs counselling because what's happening is that I get calls from people who are perfume-sensitive and in some of them it causes cardiac problems. Most of them it causes respiratory problems, throws them into respiratory distress, and providers just don't want to know about it. It's a too-hard area. Yet in some places, they actually have

perfume-free workplaces.

I've got a web site, it's got about 37 pages of actions to reduce perfumes in the workplace and societal structures. It's, like, 37 pages, and I need a year, I think, to investigate it to see just how widespread local authorities and educational facilities have gone to reject perfumes in their areas, in their buildings. It's becoming a big area and pesticides in the hospital is another one. It's a very difficult area because, you know, we need pest control, but you don't want to be putting stuff in there that's going to be upsetting patients either, and that's the hard part that we've got to get through, and we've got a lot of material coming in from America at the moment, from the American government, but, you know, we're not really being heard here, and we don't have the people to do the job. We don't necessarily have the skills. I mean, I just persevere.

**MRS OWENS:** Well, we in this inquiry can't address all the problems that you're having to deal with, but we can try and ensure that the act is working, the Disability Discrimination Act is working as well as possible to at least try and prevent discrimination against people with MCS.

**MS McKENZIE:** And we can also - - -

**MS BOWES:** It's not just MCS. It's other areas as well with the same kind of discrimination.

**MS McKENZIE:** We can also raise, even though it might not strictly be within the issues that we can actually address in our terms of reference, we can simply raise that these other important issues were mentioned to us in submissions, so that at least there will be a list of those very important issues which are not quite DDA-related.

**MS BOWES:** Well, I do think, you know, one of the important things here too is access to the processes of the HREOC - - -

**MS McKENZIE:** Yes.

**MS BOWES:** - - - and I spent a bit of time talking to a few colleagues on improving the complaints process, and we looked at all of those negatives and we tried to come up with some solutions to this, and that's why I went into the fact that many advocacy services only do systems advocacy and what's needed here really is individual advocacy, and we sort of thought, well, here's a role for an individual consumer advocate because most people can't really develop a complaint because they don't know the law, for starters. They don't know the health system. They may not know enough about their health problem to do the complaint properly. So the complaints don't ever get sufficiently worked up, and therefore they're not as

effective as they could be because we see the complaints system as a quality assurance mechanism.

It's like something to base improvements on, and it's some way of measuring how successful you've been. We just really think that unless the complaints are properly worked up and unless you've got somebody who's got the skills to actually work them up properly, that we're losing a lot of ground here with the DDA and we'd like to see that individual consumer advocate funded, so that people can actually get the help they need to make their complaints and to make them properly, instead of floundering the first time the barrister bullies them. You know, we've been through the process and we know how it worked out, which is badly and we'd like to see it improve. We also thought maybe that these things should be resolved at the point of service rather than going into antidiscrimination hearings. If they could be resolved where the problem is we think that might be a better way to go as well.

**MS McKENZIE:** So like an informal conciliation at that point?

**MS BOWES:** Yes, I would think so. I mean there's a lot of things about the law and rights. We've got legal rights but they're not like human rights. They're a world apart basically and the laws can favour certain groups over others. A barrister is going to win over a raw consumer. Consumers don't know the law to begin with. The legal system is complicated, it's expensive to use, and that means limited access. It's also not necessarily reliable so there's a need to find other ways to resolve issues. There are also limitations to law. It's adversarial by nature; it's geared to winning rather than achieving a resolution of dispute. So it may not be the best way to go.

Human rights are not enshrined in legislation; they're not enforceable. But enforceable legal rights aren't always an accurate reflection of our basic needs. So in some way we need benchmarks to measure the justice of our relationships and the effectiveness of our methods of resolving conflict.

**MS McKENZIE:** Did your suggestion in one of your submissions for some sort of independent panel of conciliators come out of this idea that conciliation is best done as soon as possible at the point of service?

**MS BOWES:** Yes, it did actually. We sat around, some of use who have had a bit of experience in this area and we've always talked about the independent consumer advocate that we've never been able to achieve. We really believe that unless government is very realistic about human rights and disability discrimination and people's rights generally we're not going to see that consumer advocate, that government needs to be much more serious about it. But it could well be a good function for the HREOC and to help with the DDA; the effectiveness of DDA.

**MRS OWENS:** I just wonder how this independent conciliator or panel would fit in with a HREOC conciliation process. This is a conciliation process before you get to conciliation.

**MS BOWES:** Yes, I think that probably it would be better. All the complaints should be resolved at the point of service. I really believe that's where they should be resolved. How that's resolved, I think if there was an independent consumer advocate, a hospital administrator, and the aggrieved person, it might be resolved. In that manner, I don't know, because it worries me when we have to have people appointed to committees because sometimes they haven't got a clue what it's all about. Sorry, that's my experience.

**MRS OWENS:** I think HREOC does have an initial preconciliation process where they try to get informal agreement. I think that already happens under the umbrella of HREOC.

**MS McKENZIE:** But certainly that's not at the point of service as you mentioned. That's really later after - or at least when some inquiry has been made to HREOC.

**MS BOWES:** I think what happened with the complaints that I worked up to go through, we went straight to QADC, the Queensland Antidiscrimination Commission. We went to a conciliation with them. Then we went into HREOC and we had to stop there because, you know, this is a person with no income and if she lost a case at hearing and costs were awarded against her she could lose her house. She's already not got enough money to live and provide for her disability needs so that wasn't an option. We just had to stop there.

I told her, "Don't sign that confidentiality agreement. Don't sign it." I wouldn't have signed it if I were her and I'm really diametrically opposed to the way that process was undertaken. It wasn't fair in any way, shape or form. I have a great deal of problem that as Barb always says, "Well, we might have law, we might get more, but we don't necessarily get justice," and that's a problem.

**MS McKENZIE:** You raise also, you suggest that there should be some kind of enforceability mechanism for negotiated solutions, some sort of system of penalties if the agreements get broken.

**MS BOWES:** I'm not sure how this would work but the experience here is that within the state hospital system people get moved around and those are the people that signed the agreement. So the agreement is then null and void which is why I'm talking to you about it because it's been voided. Because I was bound by that confidentiality provision but I reckon if they've breached it so can I. So I'm just talking to you about it.

**MRS OWENS:** Did you have a look in our draft submission at our discussion about this issue about enforcing agreements? We have a bit of a discussion about different ways, different approaches that could be thought about and asked for more information about what approach should be adopted. Did you get a chance to have a - - -

**MS BOWES:** I guess this is my response to that. You've got to realise I've had a migraine for three years and four months now and I don't necessarily achieve the degree of thought that I would like to achieve. Some days it's all too much and I'm a bit fuzzy so I'm really struggling but that's the best I could come up with that maybe some penalties but I really don't know. Maybe we need an inquiry into the whole area of these negotiated agreements and what happens when they're broken. It's something that needs to be further looked at.

**MRS OWENS:** We thought of some ideas like one approach we suggested was being able to register the agreements in the Federal Court was one option. We had various approaches. I won't go through them all with you now. Your view was that we should be thinking about penalties.

**MS BOWES:** That's all I could come up with, sorry.

**MRS OWENS:** But there was another issue that you just touched on before and that was relating to costs. In one of your submissions you said, "Nobody should have costs awarded against them."

**MS BOWES:** Yes.

**MRS OWENS:** In our report we've got a draft recommendation which says, "Subject to a review of the implications of other federal discrimination laws the Human Rights and Equal Opportunity Act should be amended to incorporate grounds for not awarding costs against complainants in the Federal Court and Federal Magistrates Service." So we've actually said maybe there should be some grounds that are set out for not awarding costs. We haven't gone as far as saying they shouldn't be awarded but we're saying that there should be some grounds.

**MS BOWES:** This is why I'm saying let's try to resolve these things at the point of service and let's get them out of the legal system. For all those things I rattled off before it's not really an accessible or I don't believe it's a suitable process.

**MRS OWENS:** But supposing you have to go beyond that to the legal system, I mean this could still occur. There is the issue about costs still at that point.

**MS BOWES:** I can see that some things will go beyond that to the legal system but I think it could be improved by definitely trying to resolve these things at the point of service and avoiding the legal sector as much as possible.

**MRS OWENS:** In an ideal world that's nice but there will probably still be some that filter right through and I think we're just trying to grapple with how you deal with this costs barrier which is, I think, a real barrier for some people.

**MS BOWES:** It is and it's one of the reasons why you're not seeing people using the DDA because it comes down to legal costs and they haven't got it. It's very stressful once you're having to deal with solicitors and barristers. There's a world apart between solicitors and barristers. You can talk to solicitors but you don't talk to barristers. They talk down at you. At the hearing we went to I really was just about to jump up and down and say, "Stop intimidating," but I thought I'd better not do that because it might be disrespectful. But I felt that his tactics were clearly intimidatory and the poor girl was actually told that if she proceeded with this issue that her relationship with her doctors would change.

If that's not intimidation - and it may have been just to within the letter of the law - well, I don't know what is intimidation but I was very angry, extremely angry. I could say that this is not a just and equitable process and I think what it comes down to for me is issues of access and equity. I don't think we get that through the legal system as things are currently structured.

**MRS OWENS:** I don't know, I think I have covered the questions that I had too. Have you got any other issues you wish to raise with us, Dorothy?

**MS McKENZIE:** We've asked you lots of questions as they occurred to us along the way.

**MRS OWENS:** You have given us some very detailed submissions. In an earlier submission you gave us a lot of other useful material as well.

**MS BOWES:** I think I've made some recommendations on this one.

**MRS OWENS:** You have.

**MS BOWES:** Once you get to recommendations.

**MRS OWENS:** Yes.

**MS BOWES:** I think my major thing is that the unmet need thing needs to be sorted out and also the equity and access to the DDA and I think every effort should

be made to resolve these things before things come to that. That's why I think that maybe an individual consumer advocate could really move things along. They'd be seeing all of these complaints, all the problems in services and with consumers, and they could probably do a really good job of putting together some kind of process whereby we could resolve these things at the point of service and reduce the need for antidiscrimination proceedings which are legal proceedings.

**MS McKENZIE:** They've been really helpful submissions.

**MS BOWES:** I'm sorry I couldn't come up with more solutions to those things. In terms of the DDA those are the barriers as I see them.

**MRS OWENS:** You've probably got more recommendations in your submissions than, I think, most other submissions for us to think about.

**MS BOWES:** Because I've been so ill for the last few months I was struggling to get through the document and to put it all on paper and I actually - when Delwyn rang me to organise a teleconference I was still fiddling away. I thought, "No, no, I've got to stop here. I've got to try and put it together," and then I've had all these storms and no power.

**MRS OWENS:** We're very grateful.

**MS McKENZIE:** We are really happy that you've been able to do so much; it's great.

**MRS OWENS:** I hope our report hasn't accentuated your migraine. There's a lot of reading.

**MS BOWES:** I don't know what accentuates that. It's got something to do with my eyes. A lot of it is light-triggered but the other thing is pesticides. I'm in the wetlands area here and they do a lot of mosquito stuff and every time they do a mosquito drop I just about go into shutdown and it's a while before I get up and go but that will start the headache off as well. Yes, I'm really keen to stay in this process because I'd really like to see something happen. I think the DDA actually has done some extremely good work. It just needs finetuning here and there and I would really like to see that happen.

**MS McKENZIE:** We're just really happy that people contribute to the process because that helps us obviously.

**MS BOWES:** Yes.



**MRS OWENS:** We'll close off in a minute but I'll just explain to you, Dorothy, what happens next. When we finish our hearings in March we'll then redraft the report and submit it to the government at the end of April. It's then up to the government to release the report and respond to it. As a participant in the inquiry we'll be sending you a copy of the final report when it's been released. So I'd like to thank you very much for talking to us today under fairly difficult conditions obviously. Your submission and your comments have been very useful to us so thank you.

**MS BOWES:** We're going to have another storm here soon.

**MRS OWENS:** We need a few more down here.

**MS BOWES:** It's just timely. They're very severe storms. We've never had them this severe. They're just playing havoc. We've got heaps of suburbs with no power and indeed I didn't think mine was going to go on in time today but we've made it and we're just about to have another storm; I'd say about half an hour's time. We might have no power again. But anyway, thank you for the teleconference. I really appreciate that because I really am too unwell to get downtown and appear in things so I really appreciate that.

**MRS OWENS:** It worked out very well so thank you very much.

**MRS OWENS:** Margaret, it's Helen Owens speaking.

**MS McKENZIE:** Yes, and Cate next to her.

**MS SPRINGGAY:** Hello, Cate.

**MRS OWENS:** Thank you very much for - we were just running a little bit behind time, but thank you for talking to us today. We're calling you to allow you to participate in the public hearings for the inquiry and to give you an opportunity to speak about your submission, which we'd like to thank you for, and we'd like to also thank you for showing an interest in this inquiry. Can you hear us okay?

**MS SPRINGGAY:** Yes, I can.

**MRS OWENS:** Good. As part of our public hearings, our discussion today is being recorded and a transcript will be made available to the public on our web site. A copy will be forwarded to you to check that it has been accurately transcribed. Despite all that, we like to keep these hearings as informal as possible. So just look on it as being a conversation. But I'd like to point out to you that, although you're not required to take an oath under the Productivity Commission Act, you are required to be truthful in your remarks.

**MS SPRINGGAY:** Yes.

**MRS OWENS:** Now, we've read your submission with interest and in a minute I'll invite you to make any introductory remarks that you may wish to make, and after that we'll ask you a few questions about your submission, and we're equally happy to clarify any questions about our own inquiry process. Now, what I'd like to do is clarify in what capacity you're appearing today. Are you appearing as Mental Illness Fellowship of Australia?

**MS SPRINGGAY:** Yes, I am.

**MRS OWENS:** Thank you very much for that. Are you interested in summarising your key points, or would you like us just to discuss them?

**MS SPRINGGAY:** Yes, I will summarise them, and firstly will preface my remarks by saying that we are fully aware that the Disability Discrimination Act covers a whole plethora of disabilities, including intellectual, physical, mental, and within those there's many, many subsets, within all of those. The comments that have been put into this comment on the draft report focus almost entirely to people with a mental illness, but of course have implications for people with other

disabilities. See my comments, for example, about genetic testing and my comments about the insurance sector. So while my focus is mental illness, and indeed there are some specific and unique issues relating to that group, some of my comments also cover issues for other forms of disability as well.

I think my paper really focuses on two broad areas, and that is the perhaps existing discrimination in service provision that arises in the mental health services throughout Australia, and secondly a need for improving legislative protection in some areas, and I will go into that later if you wish. Okay?

**MRS OWENS:** Yes.

**MS McKENZIE:** Please do.

**MRS OWENS:** Do you want to talk about service provision?

**MS SPRINGGAY:** Yes. As you may well also know, Australia almost 10 years ago adopted a mental health plan and mental health policy for Australia. Nevertheless, the reform in services as a consequence of those policies and national plans has been very slow and the uptake and implementation by states and territories has been less than satisfactory. So in that sense, it stands out from the rest of the disability sector where considerable reform occurred in those areas in the 70s and the 80s. The mental health sector was largely overlooked in the reforms of the 1980s, and in my opinion, still suffers as a consequence of almost being overlooked and further marginalised and stigmatised.

I think the plan and the policies that have been set out in Australia at a federal level have been implemented to a varying degree within states, and we now have a large degree of inequity, and I do think that the issue of equity across varying disability types is an issue in service provision. So, for example, the community services that were developed in the 80s for people with severe physical and intellectual disabilities resulted in the provision of housing, and that was funded by the Commonwealth. While housing is a significant need for people with mental illness, there has not been a substantive allocation of funds by the Commonwealth to enable sufficient housing to be provided, and so that's resulting in a significant level of homelessness in the community, and a significant proportion of the homeless are people with mental illness and mental disability.

The other factor that I wanted to specifically raise was the HACC Act, which was introduced in 1986, was specifically targeting the frail, aged and younger disabled, and it excluded people with a mental illness, again marginalising that group. Whether it was an oversight or whether it was deliberate, I don't know, and that's not what I'm commenting on. But it certainly resulted in a failure to develop sufficient

community services for people with a disability, and I note in the draft report that the focus of the disability legislation is on social integration and social services rather than enhancing, if you like, a medical model, and that is the very area of mental health services that has failed to develop; that is, sufficient community-based services.

Indeed, I wonder at the exclusion by HACC and whether in fact that is unlawful in itself, particularly given all of the policy changes within Australia since the HACC Act was introduced, and I think perhaps that needs to be challenged. As I said, their justification is that mental illness is a medical diagnosis, when in actual fact I think that itself needs to be challenged, because mental illness is a class of illnesses that are, if you like - if not a medical diagnosis, there are subsets that are part of the ICD9, 10 - the International Classification of Diseases or the DSM-IV, classification of psychiatric disease or disability. But in the same way as other classes of disability, like paraquads have been funded by HACC - you know, again that's a class that hasn't been excluded, but people with a mental disability have been excluded under HACC. So I think that needs to be challenged.

My second significant area that I comment on was the areas for increased legislative protection, and the first of those that was an area that in fact was an invitation within the draft report where the Productivity Commission requested further information on options for extending the scope of the harassment provisions and addressing the vilification of people with disabilities, and I think this is incredibly significant for people with a mental illness or mental disability, and that is the misrepresentation of mental illness, and thereby stigma towards those people, within the media in all its forms: print, advertising, films.

I think a way, if you like, of assisting to reduce that level of stigma - already there has been, if you like, publicity in the form of a number of guides for the media, people in the media, that have gone some way to improving the situation, but it still has a significant way to go. I think a significant way of improving it is to extend the scope of protection, including vilification, by increasing the areas of specific activity - currently there are nine within the act, but not vilification - and making it unlawful to discriminate against people with disabilities in relation to vilification.

**MRS OWENS:** Did you have any views about the clause that we mentioned in the New South Wales act, which was amended back in 1994? It says something like:

To make it unlawful to do any public act that is capable of inciting hatred, serious contempt or severe ridicule of people on the grounds that they are or presumed to - - -

and they were talking about living with HIV or AIDS. I mean, is there a potential to build on that sort of definition, or - - -

**MS SPRINGGAY:** Yes, except that it's often the misrepresentation of mental illness that is a problem. So, I mean, the New South Wales example is specific to, as you say, homosexuality and HIV/AIDS status, and there's no ambiguity in relation to what the issue is. But often with a mental illness, it's the misrepresentation of what that illness is or what that person with a mental illness will do. We've seen quite a bit of media coverage just recently in relation to release of people from prison, and you know, the fear that that engenders in the community by the media stating a diagnosis and not putting the full story, the full story being if that person is properly treated and the services are there to follow up, then the risk to the community is not great. So I don't think it answers your question, and - - -

**MRS OWENS:** So it's almost like publishing misleading comments, deliberately misleading comments.

**MS SPRINGGAY:** Yes. Yes, I think that would certainly go a long way to addressing it, because often the comments, either in advertising or media or film, are misleading. It's a misuse of information.

**MRS OWENS:** We'll have to think about exactly - if we get more feedback on our requests for information, we'll have to think about exactly how that would be addressed in the act itself. But there may be legal precedents that Cate is probably more aware of than I am.

**MS McKENZIE:** Don't worry, I know - I could rave on about several, but that would - - -

**MRS OWENS:** We'll do that later.

**MS SPRINGGAY:** Okay.

**MRS OWENS:** We'll give that some consideration. In terms of extending harassment provisions to the other areas where they're not included at the moment, you're supportive of that too?

**MS SPRINGGAY:** Yes, indeed. Now, another area that I raise in relation to legislative protection was the use of genetic information and the need for clear protection, both of the information and of the individuals to whom it relates, and there's a number of other reports. The NHMRC and the Federal Privacy Commissioner's report in the joint inquiry into the protection of human genetic information - and I've quoted from those reports, and where indeed they have

highlighted the need for better and more regulation in some areas, and, for example, the Federal Privacy Commissioner suggests that the abuse or misuse of genetic information needs to be regulated. There is clearly the potential for huge benefits for people with a number of varying disabilities, but however, the - my mind has gone blank. I'll have to go back and start again, I'm sorry.

**MRS OWENS:** No, that's fine.

**MS SPRINGGAY:** I think the Federal Privacy Commissioner is saying that the abuse or misuse of information is the issue, and we also want to protect the individual who may feel disempowered or disinclined to progress, to adopt, if you like, any advantages from genetic experiment or genetic development because they fear exposure of that information and exposure of their disability or matters relating to it.

**MS McKENZIE:** I might say just a couple of things about that. The first is that you've mentioned a couple of reports, and certainly the Australian Law Reform Commission's one is a very large and very well-researched body of information, and we will in the final report deal with it in greater depth than we have done so far.

**MS SPRINGGAY:** Yes.

**MS McKENZIE:** Some of the recommendations that are made in that report relate directly to disability and suggest that genetic status, at least where it relates to disability issues or where it might relate to possible future disabilities, should be taken into account under the Disability Discrimination Act, and obviously we'll look at that matter, but also that report deals with the privacy legislation and makes substantial recommendations about tightening that legislation to protect unauthorised disclosure of genetic information, and obviously although that's not quite so directly concerned with the DDA, that's, you know, something that we're not going to grumble about.

**MS SPRINGGAY:** No.

**MS McKENZIE:** Finally, as far as the use of genetic information is concerned, obviously it's a matter that we will consider as far as insurance questions are concerned, because there's an exemption and we've made some recommendations about what's relevant for the purposes of that exemption under the current DDA, and so we will certainly consider that again there.

**MS SPRINGGAY:** Okay. The other two that I mentioned was the employment sector and the use of health information, which currently apparently the small business exemption within the Privacy Act and it's just that if genetic information is

considered, likely to be considered health information, if not already, then that may disadvantage people with disability, and a lot of that, as you say, if we're predicting or trying to predict implications for future discovery and how that might affect people and how it might impact on legislation or the lack thereof.

**MS McKENZIE:** So is the real problem - can I ask, is one of the real problems that say you're a small business so you're not within the meaning of the Privacy Act so you're not covered by that act.

**MS SPRINGGAY:** Yes.

**MS McKENZIE:** So then you have someone with a mental illness and you've got genetic information about that person, say, or health information more generally about that person. They leave you and go to another small business and you, the first small business, then disclose that information to the second.

**MS SPRINGGAY:** Yes.

**MS McKENZIE:** Then the second uses that information without telling the potential employee to either exclude that person, or demote them, or do something else to them. Is your real concern that even if this were discriminatory it would be really hard to prove because the employee wouldn't know that information had been passed to the second employer and presumably the second employer isn't going to tell? So it may well make proof much harder.

**MS SPRINGGAY:** Perhaps one of the protections is that health information is passed between employers needs to be - you know, the individual about whom that information relates should be informed of the fact that that information is being passed on.

**MS McKENZIE:** So at least they get the chance to be able to say something to the second employer about what that information means.

**MS SPRINGGAY:** True, yes.

**MRS OWENS:** Would there be situations where an employer might use the information in a positive sense, that is to say, "We need to know about this individual because this is a job which may, in certain circumstances, be a dangerous job or whatever for certain people, or have OHS implications and so we want to find out whether that individual can perform the inherent requirements of the job and hence that information is useful for us but also protects that person as well"?

**MS SPRINGGAY:** I'm sure that there are cases where that is so.

**MRS OWENS:** I'm probably being generous but there may be good reasons for an employer to what that information.

**MS SPRINGGAY:** There may indeed be reasons. In particular industries or particular occupations it may definitely be something that is of significant import for that particular industry or occupation.

**MS McKENZIE:** But there should be no reason why a potential employee shouldn't be given a chance to address those matters.

**MS SPRINGGAY:** Indeed, and therefore participation by the individual in whatever decisions are made or an opportunity to challenge decisions should be, if you like, regulated or mandated so that they can indeed have the right to contribute to whatever the decision is or to challenge it. But, yes, I think it's quite possible that an employer could use such information positively and with benefit to the individual is that it would be of the best altruistic motive. But I don't think we can necessarily assume that will happen all the time and therefore we have to protect against misuse.

The other area of legislative protection that I felt was an area was pharmacogenetics and that is the design of pharmaceutical drugs that will be effective in populations with identifiable genetic conditions. Again, we're predicting future discoveries that may well identify populations far more than is currently possible and therefore it affects the whole of the disability sector. While I'm a bit concerned that the current NHNMRC statement of ethical conduct in research involving humans doesn't require compliance from the private sector - that's in research but also the application of that research may similarly not require compliance in the private sector or even the public sector. So I think that's an area that needs to be considered in this redrafting of the legislation.

**MRS OWENS:** Yes, I think we'll have to follow that up. I'm not exactly clear on what that's all about. You're the first person who has raised that particular issue with us.

**MS McKENZIE:** So what does it do? It looks at the genetic status, if you like, of whole populations?

**MS SPRINGGAY:** For example, using mental illness there's a great deal of research happening to say that generally it's often believed, or certainly believed that certain mental illnesses have a genetic component. They're not entirely a result of genetic traits, but there's certainly a genetic component. If there can be the development of some pharmaceutical agent that can perhaps block that genetic trait and either treat or prevent or obviate the symptoms of that illness, then it's a very



commercially attractive area for the pharmaceutical industry at the moment and they're doing a lot of genetic research right across the board.

As they develop drugs that are suitable for populations that have genetic factors that are influencing their health then including such information across the board to employers, to government, et cetera, raises all sorts of potential.

**MRS OWENS:** So I'm just trying to get the leap from the development of the drugs for particular populations to that information being disseminated.

**MS SPRINGGAY:** For example, if there is a discovery of a particular medication that can because they have discovered - let's say bipolar disorder has the genetic trait that results in bipolar disorder has been discovered and it affects 10 genes or something. Then at the same time a pharmaceutical company develops a drug that can obviate those 10 genes. The drug, however, is not fully, completely available to all those people with bipolar because the costs to the Pharmaceutical Benefits Scheme would be horrendous, therefore they are making available its use through that scheme in certain situations, let's say to people under the age of 25 because they want to try and improve, if you like, the opportunities for younger people with that disorder.

However, the information that other people have bipolar disorder, it may possibly be disadvantaged if that is not available to them. I'm probably not giving a particularly good example but I think the potential for abuse of again that genetic information in relation to the population is an issue we've got to face this century, in fact probably in the next decade.

**MS McKENZIE:** So one question then is the unavailability of treatment. If there's a limited availability only of treatment that's potentially unfair. The other is - am I right - that people who can afford this expensive treatment and therefore have it are going to get treated better than those who have got the same genetic disposition but can't afford the treatment?

**MS SPRINGGAY:** I mean, that's certainly a possibility. I mean, that happens now. People will pay for something rather than stay on a waiting list for a certain procedure if they can afford it. So certainly health care is often - and certainly more so in some countries than others - but certainly the more money you have the more options you have for treatment and that certainly would apply in this instance with pharmacogenetics development.

**MRS OWENS:** I think what you've raised is a subject for a whole other inquiry; probably two inquiries.

**MS SPRINGGAY:** It's a hugely complex area. I agree, I think it is certainly something that concerns people with a mental illness and people who are affected, in other words their families. In our area, that is the Mental Illness Fellowship of Australia, of course we're directly involved in dealing with, through our state and territory members, the people in this sector. It's an area of growing concern, but growing hope at the same time and I think the hope and the possibility of so much good to come out of it - we don't want to disadvantage that but we want to protect the people from the potential misuse of any information or any material.

**MRS OWENS:** I think the interesting point probably that links back to the abuse of information in terms of pharmacogenetics is the potential for people to become involved in clinical trials using those drugs.

**MS SPRINGGAY:** Yes.

**MRS OWENS:** Then they are going to become eligible for those trials, they're going to have to go and be tested for the genetic predisposition to get into the trials. Once that test has been done then it's incumbent on those people, say at least in the context of insurance, to make that information available to the insurer because they can't deny the insurer that information. So it raises issues at least in insurance. I suppose they could decide not to provide that information though to a new employer. I don't think there's anything requiring people to divulge genetic information at this stage but that could happen.

But I suppose the real issue is with insurers. If you think about insurance there's different ways that insurers source information. One is information that comes just from a person undertaking a medical test and they have tests, a cardiogram, or whatever, or they have a genetic test. An insurer would say, "It's not particularly fair to use one source of information for particular groups and not use available information for other groups that may have just happened to have a genetic test."

**MS SPRINGGAY:** Yes, that's true.

**MRS OWENS:** Have you got any comments about that?

**MS SPRINGGAY:** Have I thought about that?

**MRS OWENS:** Yes.

**MS SPRINGGAY:** Not really.

**MRS OWENS:** It's just an interesting issue.

**MS SPRINGGAY:** But it's true. I mean this raises so many questions and has so many elements to it and to untangle those and to articulate them and then to redress or protect individuals is - I think you're right. I think it's raising the possibility of yet a further review.

**MRS OWENS:** I think the Australian Law Reform Commission has suggested some interesting possibilities and they have suggested that a human genetic commission of Australia be established and one of its responsibilities would be to review the appropriateness of certain genetic tests for use by insurers. We're thinking about that as a possibility at the moment to see whether we think that that's a possible way to go at least in the short term while these tests are so new.

**MS SPRINGGAY:** Indeed, I think that's excellent and I think - as I say, it's a particular concern because mental illness is so stigmatised. There is a significant amount of research being done in relation to genetics and mental illness so it's an area, if you like, fraught with hope and potential and benefit to the community and to the individual. But it's also fraught with the potential for abuse and misuse and particularly if it's in the hands entirely of the private sector. There's not always a good track record particularly overseas but I think that would also have an impact on Australia. I'm very glad to hear that the Australian Law Reform Commission is looking at that - - -

**MRS OWENS:** Well, they have put in a report which has yet to be released, but it's a mammoth report with a lot of good material in it, some very - we think - very good ideas, and as Cate said, we will probably try and address some of their suggestions in more detail in our final report and do it justice. We did pick up - we had a similar recommendation to the Law Reform Commission in terms of changing the definition of "disability" to make specific mention of genetic - we called them genetic abnormalities. I don't know whether you've looked at our recommendations in any detail, but we did suggest that they should be made explicit in the definition of disability.

**MS SPRINGGAY:** Yes. I think that dividing the line between, if you like, the genetically induced disability as opposed to the non-induced genetic disability is one fraught with huge difficulties because a lot of - the boundaries between those two areas is not yet very clear at all.

**MRS OWENS:** Indeed.

**MS McKENZIE:** Yes. I mean, I agree, we certainly don't want to get involved in an inquiry as to what the cause of a particular disability is, because if the disability exists, that's enough for the DDA, but the thing we're concerned about is where the

disability doesn't yet exist, and all you've got is some sort of genetic, for want of a better word, mutation or difference to - - -

**MS SPRINGGAY:** With a potential to - - -

**MS McKENZIE:** With a potential to - - -

**MS SPRINGGAY:** - - - be activated.

**MS McKENZIE:** In the future sometime perhaps create this disability, and you're discriminated against on the basis of that.

**MS SPRINGGAY:** Indeed.

**MS McKENZIE:** We want to make sure that that's covered.

**MS SPRINGGAY:** That's exactly right. That's exactly where - particularly with mental illness, for example, because there are other environmental factors, if you like - for example, somebody might - it's considered now that some of the illicit drugs, cannabis and amphetamines in particular, can, if you like, initiate schizophrenia in a person who has a vulnerability. Now, that vulnerability is thought to be genetic, but there is an external factor coming in, in this case cannabis and amphetamines, that is triggering, if you like, full-blown schizophrenia, and the data is coming out of a lot of research to, you know, support that belief or that finding. Certainly if somebody has that genetic marker or markers, then yes, the potential for discrimination because this person has the marker - well, what if it's another environmental factor?

**MS McKENZIE:** Yes.

**MS SPRINGGAY:** They don't have the cannabis and amphetamines, but what if something else was going to set it off?

**MS McKENZIE:** Yes.

**MS SPRINGGAY:** So, yes, the potential for that is huge.

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

**MRS OWENS:** Well, thank you very much. I think I've covered everything I wanted to cover.

**MS McKENZIE:** Yes, I've covered all the matters I wanted to raise too. That's been an enormously helpful discussion and really excellent submission.

**MS SPRINGGAY:** Thank you so much. Okay.

**MRS OWENS:** Thank you.

**MS SPRINGGAY:** Thank you for the opportunity.

**MRS OWENS:** Before you go, I'll just give you some idea of where we go from here. When we finish our hearings in March, we will be redrafting our report and submitting it to the government by the end of April, and then it's up to the government to release the report and to respond to it. As a participant in the inquiry, we'll be sending you a copy of the final report when it has been released. So thank you very much, Margaret, for talking to us.

**MS SPRINGGAY:** You're most welcome.

**MRS OWENS:** We really appreciated your submission and the comments you've made today. They've been very useful.

**MS SPRINGGAY:** Good. Thanks again.

**MS McKENZIE:** Thanks a lot.

**MRS OWENS:** It's Helen Owens speaking, and I'm very sorry.

**MR FILSELL:** That's okay.

**MRS OWENS:** We were running a little bit late with our last participant.

**MR FILSELL:** I was just hoping I got my call, that's all.

**MRS OWENS:** No, you got your call and here we are.

**MS McKENZIE:** I'm Cate, Jeff, sitting close to Helen.

**MRS OWENS:** What we do is we're calling you today to allow you to participate in the public hearings for the inquiry and to give you an opportunity to speak about your submission, so I'd like to thank you very much for - you've given us a few talking points, so thank you for that, and I'd like to thank you for showing an interest in the inquiry.

**MR FILSELL:** Sure.

**MRS OWENS:** As part of our public hearings, our discussion today is being recorded, and a transcript will be made available to the public on our web site. A copy will be forwarded to you to check it has accurately been transcribed. Nevertheless, I'd like to say at this point that we try and run these hearings as informally as possible. So just think of it as being a phone conversation with the two of us.

**MR FILSELL:** Yes.

**MRS OWENS:** But having said that, I'd like to point out that you are not required to take an oath under the Productivity Commission Act, but you are required to be truthful in your remarks. We've read your letter to us and I'll invite you in a minute to make any introductory comments you're like to make, and then we'll possibly open it up for some discussion and you can clarify what you want to raise with us. Could I just clarify with you, Jeff, are you appearing as an individual or are you representing a group?

**MR FILSELL:** I'm an individual at this point in time. I mean, that's the capacity under which I'm participating in this. There's no other people involved.

**MRS OWENS:** Okay. No, that's fine. We always like to clarify that in case there is some group behind you which we should be specifying in our transcript.

**MR FILSELL:** Sure.

**MRS OWENS:** Well, thank you for that. I was wondering, did you want to expand on some of the points that you've made in your submission?

**MR FILSELL:** Well, yes. It's necessary that I obviously make some comment while you're doing the call around. I unfortunately don't have that in front of me. Would it be a big task perhaps just to read it?

**MRS OWENS:** No, we can read each one and we could maybe just ask you what you want - - -

**MR FILSELL:** Yes, sure.

**MRS OWENS:** We could talk about each of the points individually.

**MR FILSELL:** Yes, sure.

**MS McKENZIE:** Might do it point by point. That might be easier, mightn't it?

**MRS OWENS:** Yes.

**MR FILSELL:** Okay.

**MRS OWENS:** It would make it easier for us too.

**MR FILSELL:** Yes, sure.

**MRS OWENS:** You list a number of areas in DDA structure that require reform, and the first one was:

Effective human rights legislation in workplaces, including and especially government, to provide avenues for victims to attain advocacy and redress re the DDA.

**MR FILSELL:** Yes.

**MRS OWENS:** So this is an employment-related point that you're making.

**MR FILSELL:** Yes, it certainly is.

**MRS OWENS:** You want to say something about advocacy? I don't know whether it's about getting more resources for advocacy.

**MR FILSELL:** Giving advocacy more teeth. At the moment, the way the advocacy is structured, the organisations are funded by government departments. So there's obviously limitations as to the level of advocacy that victims can receive.

**MRS OWENS:** In terms of money? You think there should be - - -

**MR FILSELL:** No. No, there are limitations not only in money - - -

**MRS OWENS:** But in terms of the functions they can perform.

**MR FILSELL:** Exactly. They need to be able to convince, I guess, the employer, in the case of it being a government employer, this particular incident or whatever occurred, which there is no dispute. Why hasn't there been proper recourse, why hasn't there been a proper response from the employer's side in regard to these matters? Now, I'll go into more detail shortly, but that's basically it anyway.

**MRS OWENS:** Do you want to go in - or do you want to address the response from employers under - there's another point you've made here about employers. Maybe we can discuss that under that heading.

**MR FILSELL:** Well, the big problem, I think, and I'm sure it's listed there somewhere, is that the Human Rights Commission seemed to make decisions on the evidence provided by not only the victim but the employer, and what's of deep concern is the fact that the employer is able to exert influence on the decision-makers, and of course this is extremely unreasonable for the victims.

**MS McKENZIE:** So you feel that it's not a level playing field for - - -

**MR FILSELL:** It certainly is not a level playing field. Mine was orchestrated, my particular case was orchestrated by the employer virtually from go to whoa, and I was forced to go and see a Comcare so-called independent consultant, and that independent consultant in fact attacked my deceased father for the way in which he brought me up, and various other personal attacks in regard to myself going through puberty that has nothing whatsoever to do with the injuries in the workplace.

**MRS OWENS:** So this was a workers compensation claim, was it, and you had to go - - -

**MR FILSELL:** Yes. It was also a human rights claim.

**MRS OWENS:** Okay, because there's another point you've made a bit further down in your list about:



Ensure Comcare does not ignore DDA and similar laws.

That was what you were referring to? Because that was a bit cryptic, and I was wondering what was behind that.

**MR FILSELL:** They ignored everything, not only the DDA laws. They ignored a number of known facts that had been basically acknowledged by the employer. All they were concerned about was calling their interviewee an obsessive compulsive. That was the out that they had in regard to dismissing the claim for compensation, and from what I can gather, that's the game they always play.

**MRS OWENS:** I don't think giving people labels like that is very helpful.

**MS McKENZIE:** Did you feel that HREOC just didn't treat the parties equally?

**MR FILSELL:** Absolutely not. In fact, I am aware that the employer exerted considerable influence in the decision-making of HREOC in my particular case. I'm aware of what was submitted from the employer.

**MRS OWENS:** So did your case go to conciliation?

**MR FILSELL:** No.

**MRS OWENS:** It didn't?

**MR FILSELL:** No.

**MRS OWENS:** It was - - -

**MR FILSELL:** It was shoved under the carpet from day one. Nobody wanted anything to do with it.

**MS McKENZIE:** So did they strike it out virtually? Is that what they did?

**MR FILSELL:** No, what they did is basically force - well, it was totally unbearable in the workplace. I had to take a retrenchment package in the end.

**MS McKENZIE:** Because of the time it took to process your claim or - - -

**MR FILSELL:** Well, I mean, when you go through stresses like that in the workplace and even residuals, you're not really clear in your mind as to what you should do, because you're still trying to process it and digest it all. But at the end of

the day, what actually happened was I had to go through the usual process of claiming compensation via Comcare for the injuries, and of course also - I'm not sure if I included it in there - I was also abused in the workplace and had it inferred that I'd colluded with the medical fraternity and lots of different things, which eventually of course, by the time I'd been unemployed for nearly two years, they had to admit that I was honest and that I was a man of honesty and integrity. But of course by then I was long gone, out of the workforce, dismissed. They didn't want to know about it.

**MS MCKENZIE:** Would you say, from your own experience, that to actually run a complaint to someone like HREOC while you're still employed, while you're actually still in the workplace, is particularly difficult?

**MR FILSELL:** Well, it's most uncomfortable while you're in the workplace, but when you're outside the workplace, it doesn't seem to be so much struggle for them because they can simply get the reports they want from the employer or whatever. I'm not saying they do that in all cases. They certainly did it in my case, and they couldn't wait for the time to expire to say, "Sorry, Mr Filsell, you're out of time. Your complaint is out of time now, so therefore we've gotten rid of it." They just stalled and sometimes even ignored the overtures I made to them. They were just looking for the gong to go so that they could tell me it was all out of time.

**MRS OWENS:** Who was "they"? Was that HREOC or was that - - -

**MR FILSELL:** The commissioner.

**MRS OWENS:** The commissioner of HREOC, that's right.

**MR FILSELL:** That's right, and Chris Sidoti.

**MRS OWENS:** Okay. So did you use some sort of legal service in your complaint? Did you have legal - is this what you talk about in terms of the advocate limitations?

**MR FILSELL:** I was forced to hire a lawyer, if that's what you're saying.

**MRS OWENS:** Yes, and didn't the lawyer - did the lawyer help with all this or - - -

**MR FILSELL:** The lawyer tried to do their best, but when it's like batting your head against a brick wall, you either go along with the system or you go away, and in my case, you had to go to Comcare and listen to the guy lie his head off when he did his report, or you just went away and didn't bother.

**MS McKENZIE:** Would you have had the option to go to court?

**MR FILSELL:** Well, by this time I'd spent I don't know how much on my lawyer, probably 11 or 12 thousand dollars.

**MS McKENZIE:** You couldn't afford - - -

**MR FILSELL:** No, not possible.

**MS McKENZIE:** Most people couldn't.

**MRS OWENS:** You didn't consider going to Legal Aid or - - -

**MR FILSELL:** You see, I was gonged out of Legal Aid because I had too much in the redundancy package.

**MRS OWENS:** I see.

**MR FILSELL:** They scuttled that one.

**MS McKENZIE:** As if you could use your redundancy package to fund your legal case, because that's what's supposed to fund the rest of your life.

**MR FILSELL:** That's my life savings. You don't delve into that. I mean, I had to delve into that to live. Centrelink wasn't enough to support a family. I mean, I could tell you now how much I've actually had to draw down on life savings, simply to exist and for a few sort of expenses in regard to this particular issue. I mean, you know, there is a bit of a limit, and you have to watch the financial side of it and you have to try and get a balance to it somewhere, but, I mean, as I'm sure you ladies can well imagine, this last few years has been a life of pretty unreasonable stress and so forth and trauma, and the fact that you know that you're doing the right thing and with total honesty and integrity, "I'm on your side," that counts for zilch at the end of the day.

**MRS OWENS:** But the danger is by trying to work your way through this system, it accentuates all that stress and trauma even further and makes it even more difficult for you. I'll just move on to the next point you made, because we can come back to this again if you like, but the next point you made was:

Effective legislation to prevent -

"is needed", I think you would probably put in there -

to prevent the need for victims to seek DDA redress and similar avenues.

So what have you got in mind there?

**MR FILSELL:** Well, in my case, and I doubt you'll believe this, I was denied access to OH and S in my particular case. I requested OH and S and was denied it.

**MS McKENZIE:** So you couldn't sort of access that - - -

**MR FILSELL:** No, couldn't access OH and S and in fact the whole thing had been orchestrated. By the time OH and S was in fact contacted, they had been told by the employer just exactly what position they were going to take in regard to those injuries. So OH and S have probably got more blood on their hands than anyone, in my case. OH and S have done exactly what they shouldn't be doing, and that is listening to what the employer wants them to do for expedience, and that's what happened in my particular case, and I've got names and all sorts of things.

**MRS OWENS:** What do you think, looking at - because one of the things we're trying to look at is how we can improve the process, what recommendations we can make about that so that - - -

**MR FILSELL:** It would have been handy to me eight or nine years ago.

**MRS OWENS:** At least problems like this may not happen in the future. What do you think can be done to improve the process?

**MR FILSELL:** Well, I think firstly you've got to get CPSU to give a damn, that's the first thing you've got to do, and not just disregard older people that have been members of their organisation for a long time and then just can't be bothered when it comes to the end of the day, because they know you're not going to pay any fees any more. I think that's the first thing you've got to have. You've got to have specialist people within that organisation to be there to advocate for their members. I think that's the first very necessary thing, but of course it shouldn't be necessary to do that. The various steps and so forth that people can take should be there in an orderly manner in such cases, and people shouldn't be frightened to seek medical attention when they're injured and when they're in pain. It's absolutely unbelievable that someone should have to stay at the desk in pain and take abuse from other people in the workplace.

**MRS OWENS:** I would have thought, coming back to this OHS issue, once you got into the Comcare system, it would have been incumbent on Comcare to have - - -

**MR FILSELL:** It was only incumbent on Comcare to get out of paying

compensation. That was the only thing that was incumbent on them, and they couldn't wait to make sure there was an obsessive compulsive there because at times I was very thorough in the work, and the supervisor made sure, with the other authorities, that that was the line they were going to take. They made sure that that would come across as being obsessive in the way in which the work was done, and that therefore it was very easy to put the tag "obsessive compulsive" on this claimant and dismiss the claim in regard to it being valid as a permanent injury or condition, and that's the basis on which Comcare make their heinous decisions. They don't give a damn about what someone has gone through, and the fact that it is a permanent injury or condition that's going to go to the growth of me - that's the way Comcare operates or operated. I don't know if it's improved any since. I'm not the only one that knows about it. Lots of people are aware of it.

What is concerning me is: how did this DDA aspect of it get ignored all the way down the line? Because that case went on for several years and you see the thing that I'm concerned about, ladies, is why HREOC chose to ignore those aspects of the claim. Why did they say there was no DDA applicable in my case? That's something that Alice Tay and Chris Sidoti who actually hung up on me need to answer.

**MS McKENZIE:** Did they give you reasons for making that conclusion?

**MR FILSELL:** They wrote a lot of bureaucratic double-speak in their letters as they usually do. I'm sure you've seen it all. As I said, today he actually hung up on me.

**MRS OWENS:** They, I suppose, have interpreted your particular claim under the act and said, "Is this a discrimination matter or is it another sort of matter?"

**MR FILSELL:** They simply looked for an avenue where they could get out of it because I know that they succumbed to the influence that was exerted by the employer at the time because I read the employer's report.

**MRS OWENS:** HREOC is meant to be there as an independent conciliator.

**MR FILSELL:** Aren't they all? So is Comcare.

**MRS OWENS:** But, Jeff, just going back two steps from that, did you ever feel inclined to go through the Tasmanian system rather than through HREOC, or because it was Commonwealth you couldn't?

**MR FILSELL:** HREOC was the only average.

**MRS OWENS:** So you've made a point here that you would like to make HREOC properly independent and fair. So we'll ask HREOC when we talk to them at the hearings, we'll raise this issue with them about that there has been charges that they're not properly independent and fair and see what they say.

**MR FILSELL:** They'll find a way to get out of it. They usually do. But I mean the evidence is totally overwhelming. They saw all the evidence at the time. The employer even acknowledged a number of things. Still it gave me no compensation.

**MRS OWENS:** If your charge that they're not being fair was accurate, what would you do to address that? Would you reconstitute a HREOC in some other way?

**MR FILSELL:** They should conduct a review on my case to start with and retrospective on anybody that's been duded in the same way. I mean a lot of we people out here are innocent victims that have had a miserable life since all this occurred.

**MRS OWENS:** You've also put a point about, " DDA to ensure effective advocacy regarding HREOC claims." We've talked a bit about advocacy. But your concern there is - - -

**MR FILSELL:** There should have been advocacy at the OH and S level when the injuries occurred instead of it being covered up which it was and really is unto this day. That's where the advocacy should have been, right at the very coal face, in the workplace. Why isn't that in place? Why isn't it there.

**MS McKENZIE:** That's actually something that other people have made submissions to us have said that there should be an attempt to resolve the matter properly at the very beginning at the coal face.

**MR FILSELL:** There was action and energy to do exactly the opposite. Okay, I won't go into the fact that there was - yes, there was personality problems in there. That doesn't have anything to do with it though does it really? I mean the fact is there's an injured victim.

**MRS OWENS:** It shouldn't and the employer has got a duty of care and those issues should not enter into it.

**MR FILSELL:** No, of course they shouldn't enter. They've got nothing to do with it because either a person is injured or they're not, as simple as that.

**MRS OWENS:** Indeed, and your next point is, "Ensure that Comcare does not ignore the DDA and similar laws." We've talked about Comcare. Then the last one

was, "Ensure the power structure is not geared to ignore the DDA." That's a very big one and I think one of the issues that we're interested in is: how do you get employers, and other organisations, educational institutions, and so on to actually know that the DDA is there and then to take the DDA seriously? That's a very big issue for our inquiry, is just getting people understanding that there are certain requirements under the DDA and ensuring that that act is used appropriately.

**MR FILSELL:** Why isn't OH and S given the information that's necessary to have that actually occurring in workplaces? Why did it not occur in my workplace and why didn't OH and S - well, the first thing of course you have to ask is: why was I denied OH and S referral? The second thing you have to ask is: when OH and S did eventually find out why is it that they didn't come and counsel - or whatever the word is - the victim and say, "Hey, we've found this out"?

But what in fact of course occurred was that by the time it all got there - and I'd insisted on it getting there - OH and S referral became an interrogation and the interrogation went along the lines of, "Who was the doctor that you saw? Was it the doctor that you'd seen several months ago when there had been industrial stress in the office? How long did you see the doctor for?" I was interrogated. I was interrogated in relation to the medical profession, the people that I had associated with at the clinic that I go to. It was inferred that I was lying and that I was colluding with the medical profession.

I don't think you could probably get anything more heinous than that with someone that's probably at their most vulnerable. It was the most cowardly and obscene strategy of trying to kick the victim when they're down that you could possibly imagine and that's what occurred. This is from an OH and S senior officer I have to tell you, that had been coerced into taking that stand. It was simply so that I couldn't assume any kind of leadership in that interview. It was there to put me on the back foot right from the very start. Of course I wish I'd had my time over again. I'd have done things a lot differently but of course hindsight is 20/20 vision, isn't it?

**MRS OWENS:** Yes, it is. We've run through all the points in your letter.

**MS McKENZIE:** We've asked you questions along the way as well.

**MRS OWENS:** We've asked you some questions and I just wondered is there any other issues that have arisen from our discussion that you would like to comment on further?

**MR FILSELL:** As I say, I'd like reviews of the cases that have been clearly orchestrated to be thrown out like mine, and mine. A review should be conducted immediately by the minister of the department concerned and there should be an

initiative to pay retrospective compensation for both the injuries and also the long-term unemployment and stress that followed, and unnecessary distress on the family and so forth that followed. I'm looking for a review. What I'd just say again is something that I'm sure you heard me say earlier, was that the employer eventually made a number of acknowledgments, one of which - although it may not have been mentioned - that there was disability discrimination - had actually occurred during the process.

**MRS OWENS:** So they acknowledged that to you?

**MR FILSELL:** Pretty much. I don't know if they said it in those words but they wouldn't have made a couple of small ex gratia payments had they not been in concurrence with those claims.

**MRS OWENS:** So you got a couple of payments out of them?

**MR FILSELL:** I got a couple of insulting payments from the department, yes.

**MRS OWENS:** Which you spent on your legal advice.

**MR FILSELL:** Yes, and also on day-to-day living because I was long-term unemployed. As a matter of fact of course I was unemployable for about two or three years.

**MRS OWENS:** Are you working now?

**MR FILSELL:** I do a little bit of part-time work but I don't know if I'll ever have the confidence or self-esteem back to what it used to be and that goes for daily life as well you see. As I said before, I mean enjoyment of life has been zilch for about nine years. I don't know whether that will ever really recover but I guess I can just do my best to keep as positive as possible and try and put a lot of the past into some kind of perspective. Yes, I did get something back whereas some poor so-and-sos get nothing. But it seems to highlight the disgrace that goes with employer coercing and colluding with decision-makers which I know for a fact occurred in my case.

**MS McKENZIE:** The other thing is that it's not as if you don't have a voice. Some people can't even express what has happened to them and you've at least been able to do that in submissions to us.

**MR FILSELL:** You see I've had a bit of practice at it. I mean I was humming and herring quite a bit for a while, the first 12 months to two years and it was very difficult when the conversation came to a bit of a halt as to know where to go. You kind of hope that the other person is going to lead you a bit but when it all stops the



stresses just seem to multiply because the thing is not going anywhere.

**MS McKENZIE:** The submissions you've made are really helpful as far as we're concerned.

**MR FILSELL:** I just hope they help me in fact.

**MS McKENZIE:** Yes, I hope so too.

**MRS OWENS:** Your submission and - as I said earlier - this transcript will be in the public domain. I know that HREOC is reviewing all the submissions and transcripts where they are mentioned so this discussion will come to their attention which I think from your perspective should be a useful development.

**MR FILSELL:** I think it's only going to be useful if HREOC decide to do something about it and say, "Mr Filsell, we feel that maybe there were some aspects of your case that were overlooked."

**MRS OWENS:** From our perspective we are also interested in ensuring that the act works as well as possible for everybody. So we have some broader questions to answer too.

**MR FILSELL:** I'm sure you've heard others say the same as me, that we only wish you'd perhaps done this quite a while back.

**MRS OWENS:** We have to wait until we get a reference from government but we're doing it now and it's been a challenging inquiry.

**MR FILSELL:** I'm sure it has.

**MRS OWENS:** We're hearing a lot of very interesting stories like your own.

**MR FILSELL:** I hope you can do your best for people like us because that's where the real tragedy lies and I appreciate the time that you've given me and the hearing you've given me and hopefully something of mutual value can be added.

**MRS OWENS:** We appreciate you talking to us and as I said, I'm sorry that we were running a little bit late.

**MR FILSELL:** No, that's okay.

**MRS OWENS:** But before we close off I'll just explain what happens next just so that you're aware, Jeff. When these hearings finish in March we will be redrafting

the report and submitting it to the government at the end of April. It's then up to the government to release the report and to respond to it. As a participant in the inquiry we'll be sending you a copy of the final report when it's been released. So thank you very much for talking to me today. Your submission and your comments have been very, very useful and I'm sure Cate agrees.

**MS McKENZIE:** Yes, I entirely agree. Thanks a lot.

**MRS OWENS:** We wish you good luck and I just need to say your job and your working life is not all that life is about. There are other things that make life very worthwhile.

**MR FILSELL:** I appreciate your comments and thanks again for all that.

**MS McKENZIE:** Thank you.

**MRS OWENS:** Thank you. I'll just hang up now.

**MR FILSELL:** Okay then.

**MRS OWENS:** That concludes today's scheduled proceedings and for the benefit of the public transcript, public hearings will resume next week in Canberra at the Saville Park Suites. The first session will commence at 9.30 am on 4 February. More details about the hearings in Canberra and other locations are available on the commission's web site. I'll now close the proceedings today.

**AT 4.43 PM THE INQUIRY WAS ADJOURNED UNTIL  
WEDNESDAY, 4 FEBRUARY 2004**

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