TRANSCRIPT
OF PROCEEDINGS

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PRODUCTIVITY COMMISSION

INQUIRY INTO THE DISABILITY DISCRIMINATION ACT

MRS H. OWENS, Presiding Commissioner

TRANSCRIPT OF PROCEEDINGS

AT MELBOURNE ON TUESDAY, 19 AUGUST 2003, AT 2 PM

Continued from 25/7/03

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 calling you, Betty, to allow you to participate in our public hearings for the inquiry and to talk about your submissions. We've already held quite a number of hearings in all Australian capital cities over the last couple of months and my associate commissioner, Cate McKenzie, can't be with us today. So on behalf of both of us I'd like to thank you for making your submissions available and I for showing an interest in our inquiry. So thank you for that.

As I mentioned to you before we started, this is a public hearing. We treat it as a public hearing and so our discussion today will be recorded and a transcript will be made available to the public on our web site. A copy will be forwarded to you to check to make sure it's been accurately transcribed and, as I said, if there's something in that that worries you, you just need to let us know. What I have to do, we've got a number of phone hearings this afternoon so we're going to need to stick fairly closely to our timetable. I've got the next one starting at a quarter to 3. So we'll see how we go. I'd also like to point out to you that you're not required to take an oath under the Productivity Commission Act but you're expected to be truthful in your remarks. I just have to say that.

I've read both your submissions and I would just like to know, do you want to make any introductory comments before I ask you some questions? How would you like to run it?

MS MOORE: I'd like to say as an introduction why I'm participating in this is that in my own personal experience and that of local government - I'm an elected councillor - it's become very aware to me that disability discrimination is very much to the fore at all levels of our society. I have tried to do my best in whatever way I could to eliminate some of the things which make life harder for the disabled communities, but it is sometimes very, very difficult to bring about change within the systems.

MRS OWENS: This act that we're reviewing has been in place since 1992. Do you think things have got better out there in your community, or don't you see much change?

MS MOORE: In some things, yes, there has been an improvement. Other things, I think it has actually gone backwards and the act has brought to the surface a lot of animosity by various elements that really don't want to recognise the fact that disabled people are in the community and have got a right to actually be actively seen, much less heard, in the community.

MRS OWENS: Where do you think it's going backwards? Can you give us any examples?

MS MOORE: It brings out a lot of animosities because these people, because it doesn't reach them personally, feel it has no right of recognition or existence. This is happening time and time again, and I feel it's more often with males of all age groups. The fact that they are fit, physically well, et cetera, they're busy with their own careers, sporting activities: anything to do with illness or disability is not part of their world or scene, so why should they acknowledge it?

MRS OWENS: It's an interesting perspective because disability can happen to anybody at any time. There was a young man last week in Wodonga who'd had an injury on the football ground and had acquired brain injury. So it can happen through playing sport, it can happen through car accidents, it can happen in people's families. So you do wonder, don't you, about these - - -

MS MOORE: I find it very difficult to accept this point of view. Perhaps it's because of my career path. I was 27 years as a diagnostic radiographer training in Macquarie Street in Sydney and then a stint at Repatriation Concorde and then up here in the bush, and I find that the bush and the male individuality and isolation of their lives, particularly when they're on farms all the time, is that they don't brush shoulders with the other side of society that I certainly did as a radiographer, but also the fact that they are isolated.

They don't travel anywhere very much to go to work, they're not rubbing shoulders on public transport, where you actually see people. They're used to having a vehicle at their fingertips all the time, so they get in the car and go. They've got no thought for somebody that perhaps can't own a car, don't have a car, no public transport, how they get around and the sheer physical effort for some of our disabled people to actually get to the shops and the CBD to attend to the necessities of life, just the basic necessities of life without any social activities. This is not part of their world and, what's more, they won't put their foot through the door into it to even allow opening up of the subject.

MRS OWENS: You've had a long stint as a councillor. You're still on the council?

MS MOORE: Yes. I was first elected in 1987. That was the first four-year term in local government. Then I was unlucky 13th out of 12 at the next, 1991 election, and I came back in in 95 and I'm still there.

MRS OWENS: Persevering away.

MS MOORE: Yes.

MRS OWENS: I suppose there's an issue then with the attitudes of people that you work with on the council and how difficult it might be to get your fellow councillors to address some of these issues?

MS MOORE: Absolute hostility. It's incredible what they throw at you in debate and say - I've had to listen to this rhetoric for years now - they're just a minority. We're here to do with the majority of the population, particularly when it comes to - we spent $3 million upgrading our CBD, but trying to get pedestrian crossings in has been an absolute nightmare.

MRS OWENS: Have they done it?

MS MOORE: Well, it's been virtually a test case. We're now waiting for the publication of the outcome of the case that went to court that was supported by PIAC to give a technically blind person - he filed a test case because he went through HREO and that failed and PIAC supported him with an individual case.

MRS OWENS: That's still in the court, is it?

MS MOORE: It's gone through the process, and at this stage the decision has been made but the finalisation of the paperwork has not quite been completed, therefore there's been no public announcement of the outcome.

MRS OWENS: We can keep our eyes open for that to see what happens.

MS MOORE: Yes.

MRS OWENS: Is that the only complaint that you've known about or been involved with indirectly in your time on the council?

MS MOORE: There's my own case. I'm chemically traumatised through 27 years with the darkroom chemicals and I've had less than a fair go in many instances of events attached to council. I live in isolation. I'm 12 kilometres out in a patch of scrub out of town because town pollution is too much for me if I'm in there 24 hours a day. So I have a lot of living restrictions but, whilst I try and keep that as a low point of discussion, there are times when I must voice that I do have these problems, like trying to get an alternative method to using a whiteboard when we need it in meetings because the ink and the erasures send me into a life-threatening asthma attack within 30 seconds.

To get an alternative method actually made available has been horrendous, but they're now coming round to it, the same way as smoke-free zones - whilst local government is smoke-free, when we go out to various places, et cetera, I can't enter into a smoke-ridden atmosphere, and the other thing that affects is volatile aromatics, which is all of the aftershave lotions, perfumes and whatnot. So I have to be very careful and walk around people who wear such things. So that can isolate me again and on some social occasions it's been quite a problem.

MRS OWENS: We've actually met a number of people like yourself through this inquiry with multiple chemical sensitivity, and the next person we're talking to is from Queensland, Dorothy Bowes. She's from the Allergy Sensitivity and Environmental Health Association to talk about these issues as well.

MS MOORE: Yes, it's an unrecognised form of disability. We actually really should be classified as traumatised brains. All chemical victims have brain damage that can be picked up on SPECT scans, and there is no methodology acceptable in any system that will actually accept chemical trauma and ongoing chronic fatigue syndrome. This is actually in conjunction - if you've copped one of the viruses, in particular the Epstein-Barr virus, also Ross River fever, glandular fever - EBV is the precursor of glandular fever - you very rarely ever get over chronic fatigue. What makes us worse is the fact that if we are exposed to a substance that we're allergic to, this will immediately trigger another bout of chronic fatigue and we are totally and utterly debilitated.

Through the olfactory nerve process I've got less than 30 seconds to react and actually virtually flee the scene because I cannot stay there, because it brings on a tremendous - I'd imagine it would be classed as a cytotoxic headache. It's absolutely immediate. It feels as though there is a knife stabbing through my brain. Eneuresis is instant and an asthma attack is instant. The chronic fatigue lets me down in that if there's nothing to sit on I will melt to the floor, regardless of location or position where I am - totally out of control. Multiple chemical sensitisation following chemical trauma is just not on the disability program at all, and it really should be because there is a growing number of people, particularly in rural areas, the spin-off from it. Lack of diagnosis is absolutely to the fore, particularly with a lot of our rural men and our farm chemicals. There's a little bit enlightenment than there was back in the 70s and whatnot.

Unfortunately the established medical system will not recognise some of the now-established medical tests which can be done to diagnose chemical trauma.

MRS OWENS: Some have argued to us that there should direct recognition in the definition of disability in the act itself. Others have made very similar points to you and have talked about their own symptoms, which in some cases are very, very similar.

MS MOORE: Yes.

MRS OWENS: And said that maybe it needs to be clarified in the act, and we're just having a look at that issue right now.

MS MOORE: If you want to find a very particular well-referenced person, contact Prof John Pollock who's a research microbiologist toxicologist.

MRS OWENS: Where's he?

MS MOORE: He is now retired but he worked out of Sydney University.

MRS OWENS: Thank you for that.

MS MOORE: I can look out his address and relay it to you later on.

MRS OWENS: That would be very helpful, thank you. Coming back to - you mentioned that there had been an upgrade of the CBD. Was that in Inverell?

MS MOORE: Yes.

MRS OWENS: Was there an effort made at that time to ensure that all the gutters and so on and the buildings were all accessible for people with wheelchairs?

MS MOORE: Yes. I was chairman of the Council's Disabled Access Committee at that point of time. They've since disbanded that access committee for reasons best known to the majority of the councillors.

MRS OWENS: Maybe you achieved everything you needed to achieve.

MS MOORE: No, no, still far going. On some things our engineer's approach was marvellous. If a shop had an entrance step of about four inches he actually adjusted the height of the footpath for the space of the doorway. So our main street on the building side sort of undulates but it's level at the gutter. It's imperceptible but it allows - like, some doorways he could do this to and others he couldn't. But that gave far greater access into the buildings than has ever been known, so that was a plus.

MRS OWENS: Yes.

MS MOORE: Finally got right through most of the main - through the CBD a very great number of wheelchair crossings which are the proper crossings and not the old-fashioned, just the narrow, steep pram ramps that were, you know, first put in donkeys' years ago. So that has been an improvement, so that our wheelchair people can get around a little more easily. The other thing is, I've been insistent on the inclusion of disabled toilets everywhere. If we do anything, well, it's now automatic. They will put disabled toilets in and sometimes in our parks they will put a full disabled toilet in rather than the old standard narrow his and hers, which means that anybody can use them and they've usually got change tables for mums looking after babies.

Also, as I pointed out, they need a table because if somebody has got a colostomy and they need to change their bag it's not right and proper that they put their new, fresh gear on the floor of a dirty public toilet, no matter how clean that toilet is kept. So that has been a plus. So yes, and I had, well, quite a public debate and support by our chair people at that time. They put in nice, square, brick bollards on all the corners and they all look very lovely, but if you're sitting in a wheelchair you're hidden behind them. So I finally got them to take the top off some of them, so people in a chair could actually be visible, and that has been corrected.

MRS OWENS: So there has been some degree of responsiveness to the things that you thought were important when you were a member or chairing the Disabled Access Committee.

MS MOORE: Yes.

MRS OWENS: And that was a response through the local government, I presume.

MS MOORE: Yes, through our own council. The other thing is, I've had virtually a stand-up war with the New South Wales state and the federal electoral processes, trying to get disabled access into our various polling booths right around the shire, and what really upsets me there is the fact that we've offered them other alternative polling booths which were completely wheelchair accessible and they will not budge, and even although the electoral commission does not have the responsibility of any capital outlay to make the hired leased premises disabled access, that they're still insisting - insist on using places where you can't get wheelchairs in, even although there's alternative sites available.

MRS OWENS: What's the reason that they've given you for that? To me it sounds - - -

MS MOORE: I don't know.

MRS OWENS: Have they got a lease on these other buildings?

MS MOORE: No, they only rent them for the - - -

MRS OWENS: For the duration.

MS MOORE: Yes, for the duration.

MRS OWENS: Has anybody - - -

MS MOORE: I won over the federal. The regional federal returning officer, he was good and he actually - he was a new fellow and he actually did an on-site inspection of everyone in our shire and he said, "Look, this is ridiculous. You've got that location there that's fully accessible. From now on, that is the federal site." But I haven't had the same reciprocation with the states.

MRS OWENS: This is the New South Wales Electoral Office?

MS MOORE: New South Wales Electoral Office.

MRS OWENS: Has anybody thought about putting in a formal complaint, either under the New South Wales Anti-Discrimination Act or - - -

MS MOORE: I don't know how far and through the system there has been. I've mentioned it in various places, but we've actually taken them head-on for the last election and it was our MLC Rick Collis, council, myself leading the bandwagon there, various people and organisations, and I think I might have solved the problem for Inverell but I don't know about anywhere else. But the attitude, you know, the attitude is appalling because from one election to the other they still had all my previous complaints registered and in the file from the previous election.

MRS OWENS: Yes, and then they just decided they couldn't be bothered? I mean, is it just ignorance or laziness, or - - -

MS MOORE: Well, what they do, they hire a new regional electoral officer for the election. Now, that person probably and most definitely hasn't got any training in disabled access. They've got no idea of occupational health and safety requirements for their own staff and they have no recognition of risk factors or duty of care.

MRS OWENS: I'm just wondering if this is an issue elsewhere in New South Wales.

MS MOORE: And if I can just add, most of them are all schoolteachers, either former or current or part-time schoolteachers that take leave of absence to look after the election.

MRS OWENS: But it comes back to what's happening in the central electoral office in Sydney, I presume.

MS MOORE: That's right. There's no leadership coming from there.

MRS OWENS: No, and they need to have some guidelines, I would presume, to make sure that all the sites are accessible. Under the Commonwealth Disability Discrimination Act there is a clause relating to a quality before the law.

MS MOORE: That's right.

MRS OWENS: Which is meant to cover this instance. It's one of the objects of the act. So it's an important issue you've raised.

MS MOORE: I find right through, in any avenue that I touch, guidelines often only bring in confusion and opens the door to litigation. I think I've mentioned that in my report. The definitions are left open to - well, you often don't even get any definitions that you can work by and it's worded in such a fact, "Well, guidelines are not compulsory" and that is taken that they can be interpreted in a looser fashion and become ineffective. I've got great trepidation with working with guidelines.

MRS OWENS: Would you prefer to have guidelines than nothing at all?

MS MOORE: No, there needs to be something. But I really do think that the legislators or the writers of such regulations need to go back and reappraise guidelines.

MRS OWENS: Under the act that we're reviewing there is provision for disability standards in a number of areas and there has already been standards developed for public transport, and they're fairly close with access to public premises standards and education standards. Do you think that that will be an improvement if there's standards instead of guidelines?

MS MOORE: I've only dealt with one lot of standards and that came as a spin-off to the activities of - how can I word this? When I was the delegate out to North-East New England Community Options I became aware that standards were the operational textbook, if you like, for people who were actually working hands-on with people with disabilities and supplying them with services. Now again, I found that again they were somewhat iffy. The interpretation problem, or circumstance probably, was such that they actually provide a loophole, that there doesn't seem an obligation to actually follow them.

MRS OWENS: There's an enforceability problem, is there?

MS MOORE: Yes, it's the enforceability of them and as again I brought in with the circumstances of Community Options, the feds provide the money out to be processed through the state system. Well, the state bureaucrat officers say when it comes to interpret, "Oh, that's got nothing to do with us. We only handle the money." So I feel that the documentation needs to be smartened up from the federal scene on the conditions that they bestow when they hand over money for specific functions and there's too many loopholes amongst too many - like the feds, the state and then the hands-on people that's actually supposed to be monitoring and then using the standards. There's too many escape routes, if you like. Everybody passes the buck and the person at the end of the line that's receiving the services, they are the ones that are disadvantaged yet again, and again they are basically voiceless.

MRS OWENS: So is the solution to make the standards stronger and enforceable or is it to do something else?

MS MOORE: The standards have got to be enforceable. The guidelines have got to be enforceable. And again, the establishment documentation coming from the feds needs to definitely have to have a review clause in it, because this is where that particular organisation fell off the rails and disintegrated very badly. The thing is that again the feds gave the establishment documentation but they didn't set down the rules for the wind-up ending of that process. The other thing that needs to be clarified is that that federal money was put out to local government at that period of time because local government was probably the only body with trust accounting facility to keep an eye on the money and audit the books, which was fair enough. Now, there's a vast difference between auspicing and playing just a audit role than what there is to day-to-day management.

MRS OWENS: Yes.

MS MOORE: And I think that needs to be clarified, and also the fact that when the money was passed over under that circumstances and the set-up provision that there was going to be a community management committee for the day-to-day operations, now, what the problem was there, it worked very well for many years. Well, then the government changed and brought in service providers. Well, those people were sometimes part of the community organisations around the management table, but they don't know anything about the obligations under the Local Government Act about declaration of pecuniary interest, and then we had the government bodies, the state government bodies HACC and Home Care, et cetera. Again, because of service provision coming in, they were wearing two hats with pecuniary interest and everybody still had a vote.

MRS OWENS: Yes, yes.

MS MOORE: Well, I think you've got to bring commercial law fundamentals in here, and the other thing is that a lot of community meetings, there's nobody in there capable of running a meeting, and the other thing, when the wind-up was, whilst each council had its delegate onto that committee, well, a lot of councils don't have the wherewithal to send a delegate all the time, so they deputise another person in the community, usually one of the HACC or Home Care, because after all, it's women's business, isn't it, you know. So the women who really don't have any understanding of local government obligations go in and they become the council delegate. But if you're going to wind up a formal contract, that formal process should not be taken as a show of hands at a meeting. It should be passed back to the member councils to formally resolve at a council meeting that they no longer want that organisation to exist, and that's what didn't happen.

MRS OWENS: Okay. Can I just ask you about something else? Under the act that we're reviewing, there is provision for organisations to have disability action plans. Has your council got a disability action plan?

MS MOORE: Believe it or not, yes, but not until after the commencement of the last litigation.

MRS OWENS: Does it look like a worthwhile plan? We're getting a bit of feedback that some plans are very good and some local governments have done a very good job with setting targets and, you know, putting a lot of material into their action plan and working to it, and others it's just really paper compliance. I'm just interested in what your local council is doing. When did you do it?

MS MOORE: As I say, only after the litigation started on the case that I mentioned.

MRS OWENS: But when did that start? Was it last year or - - -

MS MOORE: It's probably been going about 18 months, 18 months, two years. Ours is what we - we try and have all of these plans that we've got to do as living documents so that they can be revised and amended, and with our other documents we try and do them once in an elected term. So once every four years there's a review process in those living documents of our various other plans. Now, I suppose that gives us a book on the shelf that we can refer to. Other councils are very much tokenism. I know that from around our neighbours.

MRS OWENS: Does it help you with your fellow councillors when you do want to raise issues relating to disability, to do with disability.

MS MOORE: Well, I've become very cautious and very diplomatic as to what I've been voicing since this case has been progressing, because the animosity has been great within the council and sometimes I can work more effectively if I raise the matter directly with staff and they can see that, yes, the matter needs to be attended to and it might get attended at staff level rather than go through a full council process. They've finally realised that tobacco in the work scene is a no-no, and I've been working on that for many years, and smoke-free premises are a plus. It's hard going. It's very hard going.

MRS OWENS: But at least you have got an action plan - - -

MS MOORE: Yes, we have got an action plan, but they did away with the access committee four years ago, and I felt that was particularly bad because the disability action plan was actually the first one ever legislated to be brought into existence, and that was something like, what, nine years ago.

MRS OWENS: So if you don't have an access committee, who's responsible for monitoring what happens to the action plan? Is it just the council officers themselves?

MS MOORE: Well, when we did our committees four years ago, and they've remained unchanged, they made another councillor the liaison officer with the disabled community, but the only thing is he's 86 years old himself now and they certainly didn't give me that role because I'm active and vocal, if the occasion arises. So again there hasn't been much true representation and the aged councillor would not be quoting the access plan. Let's face it, he's passed it.

MRS OWENS: Can I ask you about planning approval?

MS MOORE: Planning approvals?

MRS OWENS: Yes, how is your council coping with planning approvals when you've got the twin demands of the DDA and the building code of Australia?

MS MOORE: They've finally brought in a code to comply. See, for years, again, part of the bureaucratic system, we could not get an approved Australian standards for disabled access. That was in a state of review for many years, and that was part of our trouble, because every time the access committee would try and get a plan in place, our internal bureaucrats would say, "But, look, this code operating and that code operating. It's in review but the minister hasn't decided what the final thing is going to be," and that was another hot potato.

MRS OWENS: But things have - - -

MS MOORE: Settled down now.

MRS OWENS: Have settled down now.

MS MOORE: Yes.

MRS OWENS: Do you find that your inspectors of new buildings and so on, do they tend to comply with the standards.

MS MOORE: Well, this is one - yes, they're finally starting to realise. The hardest problem is to sometimes to bring reality into architects and builders in the town, and again I'll cite the development of a new premises for the local credit union, and they put in - they complied, the builder complied with a disabled toilet, but then one person in the community that has a lot of dealings with people in the community that's disabled, she took a fold-up wheelchair in and she said, "Well, I'll test the toilet." This was before the place opened, and the only way that she could manoeuvre a collapsible wheelchair within the toilet was to take the door off the hinges to the main compartment.

MRS OWENS: Great, everybody's going to have time to do that.

MS MOORE: You see, so that brought forth - once I received that knowledge, well, I certainly raised it in council and said, "Well, our staff have got an obligation to look at these things and check things out."

MRS OWENS: Yes.

MS MOORE: Well, that's been more effective and they're gradually coming to the fore and doing things, but it's been long and hard.

MRS OWENS: It sounds like it. Can I just ask you - we'll have to finish in a minute - but the other interesting area we find particularly in rural areas is the issue of transport, access to public transport and the use of disabled taxis. What's the situation like there in Inverell?

MS MOORE: Our public transport system is pathetic. We currently have no airline, but then wheelchairs can't get into the planes anyway. We have one CountryLink bus that goes west 40-odd miles, 60-odd k's to Warialda and then down to Tamworth. Now, that is the only - oh, and there's another CountryLink service which goes from Moree through Inverell and across to Glen Innes, which is another 60 k's to the east.

MRS OWENS: You haven't got anything going into Armidale. Is that right?

MS MOORE: No, we need it desperately, and I think I mentioned my 26-page submission, and the state government will not give us a CountryLink public transport system where we can use concession fares across to Armidale, and you must realise that a lot of our medical services have been wound down here at Inverell and we are forced to go to Armidale. We are forced to go to Tamworth. I personally a month ago was referred to Toowoomba for treatment, and now IPTAS has knocked back my claim for travel.

MRS OWENS: Is that the patient transport?

MS MOORE: Yes, yes, it's incredible, and yet our - - -

MRS OWENS: What's the reason for that?

MS MOORE: Because there was supposedly another specialist doing the same thing at Tamworth, but I was not advised of that. I didn't know he existed. My doctor sent me up to Toowoomba in good faith and now I can't claim.

MRS OWENS: How much did that cost you, out of interest?

MS MOORE: Well, several hundred dollars, you know, and it's just lost.

MRS OWENS: Yes.

MS MOORE: I do have to go back for another treatment. Now, I find it interesting, and I'll raise this with you because you are a federal body, our Australian federal constitution, two clauses states, "There shall be free movement of people across the border," and the other clause says, "There is free trade between the states," and I'd like to know why New England Area Health Service in policing or managing the IPTAS travel allowances funding refuses to pay us if we go over the Queensland border, and our shire joins the Queensland border. So a lot of our people go to Toowoomba because it's actually closer than anywhere else, and our Federal Constitution has two clauses covering those two issues and yet New England Health refuses to acknowledge that in their process and management of IPTAS.

MRS OWENS: Yes, it's getting a little bit beyond this inquiry, but it's a really interesting issue, particularly with the shortage of doctors in many rural - - -

MS MOORE: It's crucial. Now, on the 13th of this month, we lost our government medical officer, GP. He's retired and pulled out of the works. Now, he was the only doctor in town that was bulk billing.

MRS OWENS: Yes.

MS MOORE: And we've got a population of 16,000 plus in this shire and we service basically 60 kilometres or more around us in overlapping neighbouring shires, because they come to us. We are a service town.

MRS OWENS: Okay.

MS MOORE: And no public transport. When it comes to disabled taxis, we have one in the town, and that's it.

MRS OWENS: Yes, and that taxi, does it take people to other towns or is it too expensive?

MS MOORE: No, because its town workload is such - but he's a private operator, naturally, and he's got all of his regular day-to-day bookings and there's no way he can go out of town.

MRS OWENS: So if somebody had to go to Armidale for a doctor's appointment, how do they get there?

MS MOORE: Either drive yourself, get a relative or a friend to drive you, or try and get into the HACC system, try and get into the Community Transport Scheme system.

MRS OWENS: You're probably okay if you're a veteran because the - - -

MS MOORE: The DVA fellows - any DVA is well looked after.

MRS OWENS: Yes.

MS MOORE: But see, with taxis, an ordinary taxi - we're under rural taxi fares here. Now, I'm 12 kilometres from town - rural taxi fares. I pay both journeys in and out of town, just to get to town. So when I come home again, I've got to pay a double fare again, and you can't claim. Unless you've got a medical reason, you cannot - like a medical visit - you cannot claim taxi fare concessions. So again, if you've disabled but you've got to travel for the necessities of life, you're up for double fares. My vehicle is a 1985 year old model and believe me, I'm not the only one that's driving old cars because the other problem is with our rural people, what happens when they get past passing their driver's test? There is no public transport.

MRS OWENS: We're hearing this story across the country too, I have to tell you, Betty.

MS MOORE: Yes, you will.

MRS OWENS: I'm going to have to finish now because we've got to get on to our next participant. But I'd just like to explain to you what happens. Is there anything else that you wanted to raise before I close off?

MS MOORE: No, but - - -

MRS OWENS: I've think I've covered the questions I wanted to ask you because you did give you us a lot of information in your submissions.

MS MOORE: Yes, I think we've covered it through. I did a short list and I think we've pretty well covered everything and you've got the backup of what I've put in writing there. But I would like to say thank you for the opportunity of participating, and if I can help in supplying any other information at any stage or time or place, well, I'm happy to do so because there is very much a crucial need for things to be looked at again and on an ongoing basis and particularly with brain trauma and physical trauma from chemical injury.

MRS OWENS: Yes, thank you, and that's the person we're talking to next - is going to be raising some of these issues with us again.

MS MOORE: I was actually a foundation member of the Australia Chemical Trauma Alliance, ACTA some years ago and I've been very much in touch with the top clinical ecologists particularly from my own survival and also from an education, public knowledge point of view.

MRS OWENS: I'll just let you know what we're doing now. We'll be writing a draft report which we'll be releasing in October and we'll send you a copy of that draft report.

MS MOORE: Thank you.

MRS OWENS: We'll be doing another round of hearings later in the year and early next year and then we're expected to present our final report to government by 30 April next year, and what we'll do in the meantime is send you the transcript from today so can have a look over. So thank you very much, Betty, for talking to me and your submission. Your comments have been very, very useful, so thank you.

MS MOORE: That's all right, I've been happy to do it.

MRS OWENS: Hello, Dorothy, my name is Helen Owens and I'm the presiding commissioner for the Productivity Commission's inquiry into the Disability Discrimination Act. I'm calling you today to allow you to participate in the public hearings for the inquiry and to talk about your submission. We've already held a lot of hearings around Australia over June and July and we're just now doing some telephone hearings today. My associate commissioner, Cate McKenzie, can't be with us today but on behalf of us both I'd like to thank you or making your submissions available to us and showing an interest in the inquiry and being available today to talk to us.

As part of our public hearings, our discussion today is being recorded. I hope that was made clear to you. There will be a transcript made available to the public on the web site and a copy will be forwarded to you to check that it's been accurately transcribed. You'll get that in the not-too-distant future. We'll have to stick fairly closely to the time because, as I mentioned earlier, we've got other telephone hearings scheduled this afternoon, later. I'd like to point out to you that you're not required to take an oath for these hearings under the Productivity Commission Act but you are required to be truthful in your remarks.

I've read your first submission and I've had a pretty quick glance at the second one that came in late yesterday.

MS BOWES: The case histories were fairly important in that because - - -

MRS OWENS: Yes, okay. What we might do in a minute is if you want to raise some issues from either submission and particularly from that second one, we could do that now, and then I've just got a few questions I'd like to ask, because both of them were very clear. As you're probably aware, we've talked to quite a few people now with multiple chemical sensitivity, including Agnes in Perth a few weeks ago, and we're building up quite an important picture.

MS BOWES: That's why I sent you that supplementary material. Two of those articles are very important because the chemical companies got together with other allied industries and they have endeavoured to put this problem into the psychiatric basket to save products and to save paying out on compensation claims. That's clear in two of the articles I sent you. Quite often we have people who have been sensitised in the workplace and these cases are very often settled out of court so that there are no precedents established. That makes it much more difficult for anybody trying to have redress at law and compensation for the damage that's been done to their lives.

You must realise here the same companies produce pesticides, industrial chemicals, domestic chemicals, chemicals for building homes and furnishings, personal care products, food additives, and I think there's a bit of a conflict of interest there. It's like the issue of making of money over the health and safety of the population, and I felt it important to identify that because we're finding it very hard to move forward with the issue of recognition, and probably the big stumbling block is that the companies, who have got much more money than we have, have gotten in there and done a spin on the problem. It's sort of holding us back and it makes life very difficult.

MRS OWENS: You mentioned in one of your submissions - in the first one I think it was - multiple chemical sensitivity being recognised in the Americans with Disabilities Act. I presume you've got very active companies in the United States as well. Are people in your situation facing similar problems there or is the recognition such that people acknowledge that you're not talking about a psychiatric disability but a disability that has other ramifications?

MS BOWES: People are all at varying stages. With the Americans with Disabilities Act as I remember that - and it's very large - they look at this issue on a case-by-case basis. But certainly as far as disability services are concerned in the USA, I have a web site and it's like 37 pages of links and I can't possibly investigate them all. But I indicated it was dealt with under the Arizona technical assistance program as a disability. It's been recognised in the US in the housing area and various hospitals have protocols in place to deal - - -

MRS OWENS: So it's really on a case-by-case basis. It's not a - - -

MS BOWES: As with the Americans with Disabilities Act, yes. In Canada they have moved much further forward than anybody else. They've established a hospital just for this problem and it's run by the Canadian Health Department and the local medical association in Halifax in Nova Scotia. There is legislation in the US in place for chemical sensitivity but in the main people are still sort of muddling along, trying to find their way into services, although they seem to have a much broader service base in the US than we do here.

MRS OWENS: But does the Americans with Disabilities Act try and incorporate a definition into its act? We're interested in that - - -

MS BOWES: No. We've been looking at a model for "disability" even, because I asked the local disability services did they actually have a model of "disability"; what model did they use. I wanted to see for myself where this fitted, because various people are at various stages of impairment but some people are totally disabled. So we've been trying to find a model and we realise we need an integrated model. We need something that is a medical model, a disability model and a social model, so we need an integrated approach to the problem and we need an integrated model for it. We're looking at that and we're trying to build one up, but the problem is that in this group, like all the others, we're all people with the problem and we've got no funding and it makes it very difficult for us to move forward.

I was looking at the United Nations international charter on disability rights, and in their standard rules they say that states should recognise the right of organisations of persons with disabilities to represent persons with disabilities at national, regional and local levels and states should also recognise the advisory role of these organisations in decision-making on disability. It goes on talk about funding for disabilities, communicating with them, consulting with them, and that we should have representation on the national coordinating committee or similar bodies.

MRS OWENS: Does your organisation have any representation on any national bodies?

MS BOWES: No, we find that the government tends to gravitate to peak bodies and this is where most of the funding goes as well. Those peak bodies, while they progress the issue of advocacy generally, they may progress another issue, and that will be whatever it suits them to address. We fall into the unmet need area and it's very hard for us to propel anything forward for lack of funding, for lack of workers, and indeed most of the funding is given to bigger groups because we don't have offices and volunteers and large numbers of paid workers. The latest lot of funding seems to be cutting us out of even things like stationery and administrative costs, so it's just getting harder and harder, which is not the way it's supposed to be in regard to the international charter on disability rights.

We're disadvantaged in a lot of areas, and one of the things I did want to raise here today which is pretty important is the complaint system and anti-disability discrimination. Having been through part of that process here in the last few years, it's my experience that these are legal processes and proceedings and that justice is only for those who can afford the required level of legal representation. Basically we went in and we had Queensland Health on the other side of the table - - -

MRS OWENS: This was the complaint through the Queensland system or - - -

MS BOWES: Yes, that's the one. They had three barristers and we had one blind solicitor from the welfare rights organisation and they just trounced all over us. We really should have come out there winning that because we had enough data to support what we were saying, but we lost it because they came in with three barristers from the Crown Law Department. I thought that was pretty bad because, hey, we pay taxes to support the Crown Law Department and they shouldn't be using these people against us in what should be a fair process.

MRS OWENS: So it was a complaint against a state government body, was it?

MS BOWES: I think it was Queensland Health, the Royal Brisbane Hospital, the Redcliffe Hospital and the Caboolture Hospital. I can't remember whether Queensland Health was actually represented up there or not, but the three hospitals were.

MRS OWENS: So it got as far as, what, conciliation but then just stopped?

MS BOWES: We did two conciliations, yes, and she settled because of the way the solicitor conciliated. I think that his thing was that nobody should come out being at fault; there should be a negotiated settlement. They both signed an agreement which was quite unsatisfactory to us, although the Royal Brisbane made an operating theatre available to do a very important piece of surgery on this chemically-sensitive person's lip. They were supposed to develop protocols for people with chemical sensitivity in the hospital and she was supposed to have people at the three hospitals to talk to if she was having problems in the hospital system. In fact, the Royal has developed draft protocols - I may have sent you a copy of those - but they've not come out of the draft in over 12 months, and the people who are supposed to look after this lass in the hospital system have moved on. So in effect the negotiated agreement is virtually null and void because the people have moved on.

So I'm not sure what her standing is there, but it just didn't really work satisfactorily and I think it would have worked much better had we had proper legal representation.

MRS OWENS: But there's a couple of interesting issues you've raised there. One is that issue of imbalance in legal representation, and we're hearing that in the context of the people making complaints under the Disability Discrimination Act as well. The other is what happens as a result of the conciliation. You can come to a conciliated agreement, albeit maybe not that satisfactory, but even then it's very hard to enforce that agreement after the event.

MS BOWES: That's what I'm finding.

MRS OWENS: But there's two issues, yes.

MS BOWES: That's what I'm finding, yes.

MRS OWENS: So do you think there's a way out of this?

MS BOWES: Yes.

MRS OWENS: How would you address the problem of imbalance in legal representation?

MS BOWES: Well, to start off with I think there should be either an ombudsman or a consumer advocate, an independent consumer advocate. That person would need to know the law and, you know, disease, disability, whatever. That person should help people to build their complaint and to help them present that complaint so there's a more equitable access to the complaint system. I think that - - -

MRS OWENS: It's still hard, isn't it, for that person. I mean there are advocates out there already but it's still a - if that person had a legal person in the office they're still going to be up against - if there's another complaint against the state government, you know, they - against the QCs and the big guns. Does that really solve the problem?

MS BOWES: Well, I think that what needs to happen is that everybody has equal representation, like maybe barristers are appointed for both sides, and only one, of equivalent standing. That might work but my experience in the complaints system with a whole variety of things is that people's complaints don't get heard properly because the average person doesn't know enough about the legal system or the health system or the disability system or what's going on even to make a proper complaint so the complaints are not worked up properly. I think this is bad for the system because a rigorous complaint system is an excellent quality assurance mechanism. You know, that's the sort of thing that we should have in place.

Often you find people with disabilities, well, they're really too disabled, too unwell to be dealing with such a system even. You know, I've got somebody thinking about going to anti-discrimination and she can't leave her house because she's so chemically sensitive she could die. I'm wondering, "Well, how are we going to achieve this, you know?" It will probably fall back on me to try and work it all out. So, you know, that's why I think that we need an advocate here for the consumer to make sure complaints are properly and adequately worked out - worked up, you know, so we can get the best possible outcome from the commission.

MRS OWENS: Is there not an office of the public advocate in Queensland that you could use?

MS BOWES: Well, there are various advocates and services here but I don't know about public advocate, I've not heard of that one. I'll have a look but you know, unless we get that level of representation for the consumer up there it's always going to be a lopsided process.

MRS OWENS: There usually is an office - I think there would be one. But we have heard, you know, there are other advocacy groups in each state as well. But the problem we're finding in relation to these other groups - often staffed by volunteers or very, you know, small groups - is the lack of adequate resourcing.

MS BOWES: Well, funding would be really good. I mean there's another issue here too. I've talked about funding; not having funding to repair equipment, you know, computers and copiers and not having funding for basic stuff like phone bills and stationery and cartridges for the photocopier and the printers - they tend to be cutting that out on us.

MRS OWENS: Who are you getting your funding from now?

MS BOWES: Well, we've really basically only got one source here and that's the gambling machine community fund in Queensland. We've applied for funding from Disability on several occasions and they have not even acknowledged the proposal let alone let us know whether we've got the money or not; and obviously we haven't. But I think there should be more effort here, under equalisation of access, to seek out and give us a little bit more funding so we can get in there and run our equipment, because we've got no paid people and we're all sick.

We need, urgently, to be able to do some surveys, you know, to find out what is the level of disability here, how many people and what sort of - what their major problems are. We just don't have any funding to do it. We have half-hearted grabs at it with just a little bit of money around but the surveys are not enough for a representative sample and, you know, it's really hard for us, given that we've got industry saying we're not there. It's hard for us to make progress.

MRS OWENS: Just coming back to this complaint that we were talking about before and the imbalance with the legal - - -

MS BOWES: Yes.

MRS OWENS: On the - you know, with the solicitors on both sides. Did you get involved or your organisation get involved in that complaint process?

MS BOWES: Well, I did all the research for it.

MRS OWENS: Just in your own time?

MS BOWES: Yes, and with no money. I was actually allowed to sit in on the hearings although the opposition tried to boot me out on the second conference but because I had done all the work on the further and better particulars they really didn't have a case and the commissioner hearing the conciliation decided I could stay. But we had a law student in as well who - well, we tried to get her in and the health people wouldn't allow her in the room. So I mean we couldn't even have our advocates in there. So I mean that was another really bad thing. I really didn't think this was a fair process at all. I have to tell you I'm - yes, I came out shaking my head and I'm thinking, "Well" - you know it wasn't fair, it wasn't equitable and we didn't have any proper legal representation. So I don't see that there was any justice done there at all.

MRS OWENS: We're not reviewing the Queensland processes but we are trying to learn from - you know, what are the good - and what are the strengths and weaknesses of the different approaches so that we can at least try and improve what's happening with the federal act, the Commonwealth act. So it's interesting - these issues, as I've said before, of imbalance in legal advice and resourcing and so on I think are important issues. We're getting quite a consistent argument being put to us on those issues.

MS BOWES: And another area that I really want to raise is the legislation.

MRS OWENS: Yes.

MS BOWES: I'm going through the Disability Discrimination Act and I can see this is aimed at service providers. That's my feeling about it, that it's - they're aimed at service providers. Then I've been looking at various other pieces of legislation because, you know, I've sat on various boards and committees over the years. All the legislation has been reviewed over a period of time and there has been an overall weakening in legislation. It has sort of gone to an economic model. I find that most of these things are aimed at business and it certainly looks that way with the Disability Discrimination Act that it's aimed at the service providers. It doesn't seem to have any social conscience in there, you know, there are social issues apart from economic issues. I think there's a bit of imbalance is what I'm trying to say. I'm not a legal person.

MRS OWENS: No, it does have fairly important objects to eliminate discrimination and ensure equality before the law and one relating to changing attitudes which I think very much as having an important social dimension.

MS BOWES: Well, I agree - - -

MRS OWENS: That's what the act is meant to be there doing.

MS BOWES: I agree but like most of the legislation I think there's too much focus on economic stuff and not enough on social issues. I guess that's a bit of an odd statement because it really is about social - - -

MRS OWENS: Nobody else has made that comment to us.

MS BOWES: Sorry?

MRS OWENS: Nobody has actually made that comment to us. I suppose there is - are you referring to having clauses in there relating to - be able to show unjustifiable hardships for not making adjustments?

MS BOWES: No. No, there were whole areas I didn't understand what it meant. I asked a university lecturer and she said, "Well, you wouldn't, because that's more aimed at someone like Endeavour Foundation who is providing services, they would know what it means." I thought, "Oh well, you know, maybe it's going on with this minimal standards legislation that's everywhere else like in pesticides, industrial chemicals and stuff like that" - minimal standards stuff moving towards industry self-regulation and the economic model, you know. The economic model of being self-supporting. It just sort of seems to me that well, you know, it's not - it's moving away from the social model that we have been accustomed to and maybe it has moved away a bit too much. I find that generally in a lot of legislation. Certainly there were parts of the Disability Discrimination Act that I certainly did not understand.

MRS OWENS: I think some of those examples you're giving like minimum standards, they're actually meant to be pinning service providers down to ensuring that they do certain things to provide certainty out there. You know, I think they've been - those clauses have been put in for positive reasons rather than negative reasons.

MS BOWES: Well, it was - yes.

MRS OWENS: But you said in your submission, the first submission, that you thought that the DDA - the act was a good piece of legislation but not effective in all areas.

MS BOWES: Yes.

MRS OWENS: I was wondering in terms of areas where you don't think it's effective have you got any examples? Are you saying that it's not effective in terms of the standard setting or - - -

MS BOWES: No. I've sort of got these all marked out in issues of unmet needs. The new and emerging - recognition of new and emerging diseases is a big problem along with equalisation of access, especially for people with MCS. The other thing I've marked down here was the complaints, equalisation of opportunity and funding. Those were the key things that I had marked out here.

MRS OWENS: Okay, well, coming into new and emerging diseases, what do you think we need to think about there? Do you think the definition of disability in the act could - do you think it added - properly covers illnesses such as multiple chemical sensitivity?

MS BOWES: Well, it certainly fits in there.

MRS OWENS: Yes.

MS BOWES: With qualification, in some cases it's just impairment and it's not permanent sort of thing. But as we don't treat the thing or we don't avoid the things that are causing the problems it gets very much worse. It can go to total disability where people are struggling to get out of bed even and certainly can't take part in a normal life. Some of them have to have carers. We get to full disability but it reasonably covers, yes.

MRS OWENS: It's a very very broad definition in the act but others have also said to us that maybe the coverage needs to be clarified in these sorts of areas and chronic fatigue syndrome has also been raised as another area where maybe it does need some clarification but it is a very - as it's written at the moment it talks about, you know, having conditions from the past and in the future and it covers - as far as I can see it covers just about everything that you can imagine.

MS BOWES: The thing that - - -

MRS OWENS: But some are concerned that it doesn't.

MS BOWES: - - - surprised me was that I couldn't find a disability act. I can find a Disability Service Act, a Disability Discrimination Act but I can't find a Disability Act. Does such a thing exist or have I just not been - - -

MRS OWENS: Well, we're reviewing a Disability Discrimination Act.

MS BOWES: Yes.

MRS OWENS: But it is about - it does have a human rights - - -

MS BOWES: Yes, the HREOC.

MRS OWENS: Yes, it has got - but it has - it focuses on appropriate human rights for people with disability. It talks about equality before the law, for example, and improving people's attitudes towards people with disabilities. So it probably does go beyond just thinking narrowly about discrimination. Do you think it should have a broader focus than it has got at the moment? Is there more it could be doing?

MS BOWES: Well, I'm not a legal person, as I said, and I'm - you know, I have to read this several times and think about it and then wonder, "Have I got the right meaning for it?" So I guess that it's perhaps not overly clear for a lay person. So maybe that's something that needs to be looked at.

MRS OWENS: There are - the Human Rights and Equal Opportunity Commission does have on its web site - - -

MS BOWES: Yes.

MRS OWENS: - - - guidelines and advisory notes.

MS BOWES: I saw that.

MRS OWENS: And frequently asked questions.

MS BOWES: Yes.

MRS OWENS: But I mean at the end of the day it is a piece of legislation.

MS BOWES: Yes, I know.

MRS OWENS: Sometimes legislation is hard to wade through.

MS BOWES: Well, it is, and I guess it is hard to wade through. That's another reason why it's hard for me, when I'm looking at minimal standards legislation and we're moving into privatisation and I'm looking at the social issues that are cropping up as a result of that and I'm thinking it's lopsided, so that we need more social stuff written in here to balance off the economic model stuff. But I've got the act up in front of me on the screen at the moment; I downloaded the whole act.

MRS OWENS: Good on you.

MS BOWES: I'm actually looking at it at the moment. We haven't got much longer to go, have we?

MRS OWENS: No, we've almost - we'll have to wind up in a minute.

MS BOWES: I just - what I would like to see come out of these hearings and I'm hoping I've given you the right amount of information, you know, to contribute to what I'm asking for, is that I'd actually like an inquiry into MCS to recognise the problem so that we can be ensured equalisation of access, because you know you've got people who are extremely ill and they've got a very high level of need, they're on the lowest income, they can't access hospitals, refuges, crisis accommodation, disability aids, you know, and one of the reasons is that we can't get recognition of the problem either at medical level of any other level for that matter. There's a bit of push - we're pushing with federal health at the moment and we've got some people there who are saying, "Yeah, yeah, yeah, yeah," but we need to do a lot more pushing. So I really would like to see some sort of an inquiry here - - -

MRS OWENS: Mm'hm.

MS BOWES: - - - that will maybe help pursue the issues so that people with disabilities are actually going to be able to access - have that equalisation of access, because a lot of them can't work and I've just this afternoon had a call from a lady who can't send her kids to school because they're very chemically sensitive and the school is such a very toxic place.

The other recommendation is funding for small groups and this is going into the unmet need area, so that they can better establish and be able to operate and do that initial amount of work that's required like the numbers with the problem, the type of disability need to support and identify the support needs. If we could just get some simple funding, you know, maybe tied to indicators like I just mentioned, those basic stats, so we've got some idea what's going on and we can maybe pursue it into the system a bit faster. That ties into consultation, you know, we're not being picked up in the consultation process or we're too sick to do it, which is another problem.

So I'd actually like to see something happen there so that the unmet-needs people can be brought into the system, because the peak groups don't take them out - bring them in and the last inquiry they had into unmet needs simply focused on aging carers of disabled family members and it did nothing to bring in groups like chronic fatigue or chemical sensitivity, which in fact can be the same problem and it ties up with kids with autism, Aspbergers, attention deficit as well, it can be very much part of that too and I'd like to see that consumer advocacy and better legal support.

Those would be my recommendations here for something coming out of the act and I don't know how to say that I think we've gone too much into privatisation and the economic model and we need to balance it off a bit more with social stuff.

MRS OWENS: We're trying very much in this inquiry to have a balanced approach and look at the human rights issues and look at the economic issues, because we have a terms of reference which requires us to look at the economic issues as well as looking at the effectiveness of the act and achieving its objectives, so we'll try very hard to bring those values to bear and I'll have to close off now, Dorothy, because we've got our next participant we have to contact.

MS BOWES: But if you need any more material or you think you want to pursue something a bit further with me, just let me know and I'll make myself available and I'll see if I can talk to some of our academic people and see if they've got anything to contribute.

MRS OWENS: We've certainly had very, very good participation from people with multiple chemical sensitivity and from people in some of those other areas you've talked about, so we're very, very appreciative of that.

MS BOWES: We're really at crisis-point, you know, with the lack of access in basic things like housing, respite, crisis accommodation and that lass on the case history whose father has been snatched by the adult guardian, he's been put in a nursing home and it's very distressing. They've got him doped to the eyeballs and he just cries all the time, he just wants to go home and they're doing him more damage in there and this happened just because nurses would not leave the perfume off when they come. They have no humanity, you know, it's just - it's an issue that really needs to be brought forward, but I realise you'd had enough of - you've probably heard that all over the country and I tried to focus on issues of advocacy, you know, over-arching issues.

MRS OWENS: No, I think the issues you've covered are very important ones and you've given us a different perspective; you've raised some - you know, there's been a consistent argument that you have raised, but you've also given us some perspectives on other issues, which I think is very useful.

MS BOWES: I always try to take an unbiased approach to things - - -

MRS OWENS: Yes.

MS BOWES: - - - and I've been looking at this for a very long time and although I don't have qualifications in law or things, you know, I'm sort of a very deep thinker and I hope I've been able to make some kind of decent contribution.

MRS OWENS: You certainly have, so thank you. As I've said, we'll have to wind up now because we've got to get on to our next participant, but we'll give you a copy of the transcript when it's completed and just to let you know where we go from here, we'll be writing a draft report for public comment and that will be released in

October and we'll send you a copy of that draft report.

MS BOWES: Is there somewhere I can work here? Is there some area that I need to fill in a bit more here?

MRS OWENS: No. I think we've got plenty of material at this stage, but what you could do is have a look at our draft report and if there are gaps in that that you think that we need to fill, then maybe later on in the process you could maybe let us know, we could have another talk later, because we'll be running another round of hearings later in the year and early next year and then we'll be finalising the report in April, by April 30th, so that's where we're going, so there will be other opportunities later on.

MS BOWES: I'll see if I can get one of the academics I know to look at this too.

MRS OWENS: Okay. Thank you for that and thank you for talking to me today.

MS BOWES: I'm very pleased, thank you.

MRS OWENS: It's been very, very useful, so we'll hang up now and thanks for your time, Dorothy.

MS BOWES: And thank you for talking to me, I appreciate the opportunity.

MRS OWENS: And I hope you stay well.

MS BOWES: I'll try.

MRS OWENS: Yes. Bye.

MS BOWES: Bye.

MRS OWENS: Hello, Sheila and Robin.

MS KING: Good afternoon, Helen.

MR KING: Hello.

MRS OWENS: And I'm sorry we're just running a little bit behind time.

MS KING: That's all right.

MRS OWENS: But we've been doing other phone hearings this afternoon as well and once we get on the phone it's actually quite hard to get off the phone.

MS KING: Well, we've most likely all got so much to tell you that we really want to get in as much as we can.

MRS OWENS: I just have to say we got a fantastic submission from you.

MS KING: Thank you.

MRS OWENS: You've covered a whole lot of areas from our issues paper and we're very grateful for that. I know a lot of thought went into your submission. But what I'm going to do just to start us off is, I'm just going to going through just a little thing I have to read out onto the transcript and which is just a formality I'll go through. Then what I'll do is, we'll come back to talking about some of the issues. So if you can bear with me for a minute.

MS KING: Yes.

MRS OWENS: My name is Helen Owens and I'm the presiding commissioner on the Productivity Commission's inquiry into the Disability Discrimination Act and I'm calling you today to allow you to participate in the public hearings for the inquiry and to talk about your submission. We've already held hearings in all capital cities over the last couple of months. My associate commissioner, Cate McKenzie, can't be with us today but on behalf of us both I'd like to thank you for making your submission available and showing interest in this 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, and a copy will be forwarded to you to check that it has accurately been transcribed.

Now, we'll need to stick reasonably closely to the time. I think we told you it would be about half an hour because we've got our next participant scheduled for 4 o'clock, but we might go a little bit over to give us enough time. I'd like to point out that you're not required to take an oath, but under the Productivity Commission Act you are required to be truthful in your remarks. I've read your submission and I'm just wondering would you like to make any introductory remarks about your submission. I've got a few questions I'd like to ask. We don't have to necessarily cover the same material as in your submission because we've got it in writing, but we use this as an opportunity really just to clarify points and so on. So is there anything you would like to say in introduction or would you be happy just to take some questions?

MS KING: I just felt - this is Sheila here.

MRS OWENS: Yes, Sheila.

MS KING: That we did a rather large submission because we have been doing this advocacy work now for four years and we sort of come up a stumbling block when we come to the section that if we go to a tribunal or a conciliation agreement there doesn't seem to be anything to enforce what's said or signed off on, and we have two ADCQ things at the moment but we're stuck because everybody tells us the next step is the Supreme Court and we as a small not-for-profit voluntary organisation, we can't afford to go to the Supreme Court. So that's why our submission, we've been interested in this productivity thing. Even though it's through HREOC we feel that there are sort of parallel lines with the ADCQ ones that we've come up against.

MRS OWENS: Yes. It's interesting because we're not directly reviewing the different states' legislation and the processes. But what we are doing is, we are learning from what happens at the state level and trying to find are there better ways of doing things or are there problems at the state level we have to make sure doesn't creep into the Commonwealth process. So it is interesting and you raised one important point then, which was there's nothing to necessarily enforce an agreement or a conciliated agreement, and we're hearing that sort of story about the result of conciliation at the Commonwealth level as well, with the Disability Discrimination Act.

MR KING: This is Robin speaking.

MRS OWENS: Yes, Rob.

MR KING: This is one of the main stumbling blocks we've had. The ADCQ, we've got two matters pending there. Both of them have not been adhered to. But nobody seems to know the protocol to initiate enforcement and then they said of course we've then got to go to the Supreme Court, which makes it a bit arduous but it's not an easy thing putting a claim in, because we've also had a representative claim through our little organisation, through HREOC, and we're now waiting on the decision from the judge.

There is no way, or no definitive way, we can say, "You have wronged us," other than have to go up and be an aggrieved person and demonstrate your disability and in one case there were some quite personal issues involved. The witnesses with - in wheelchairs had to go - the court was closed and they had to openly discuss some very personal bodily functions and this is quite arduous for somebody with disabilities in the first place. They tend to be a little bit timid.

MRS OWENS: Can I just go back one step. You said you've got a little organisation, an advocacy organisation.

MR KING: Yes.

MRS OWENS: On whose behalf are you advocating?

MS KING: We're a volunteer community group and we were established in 1999. We were incorporated. We were established to ensure equitable and dignified access to all premises, facilities, whether they're private practice in the built or natural environment, and this came about because Hervey Bay where we live has got a 16-kilometre esplanade and 32 accesses to the beach but not one access for disabled people, and that's how we formed a little group to fight the council to make them do this.

[in –confidence text removed]

MR KING: I'm also an access consultant registered with the ACAA. I'm an associate member and we actually deal with primarily BCA compliant premises and highlight non-BCA compliant areas, and where necessary put in a complaint to the Building Service Authority.

MS KING: So if you would like to question us, Helen, that might cut a lot of ground away, and waste of time.

MRS OWENS: I'm just interested in that because I didn't understand that from your submission, that you had this other interesting background. I picked up that you had been involved in complaints because you said you had been involved in mobility complaints, but I didn't quite understand the background to that, so that's useful.

[in confidence text removed]

MR KING: One other area - and I think you highlighted that we had asked that any financial hardship figures actually sworn be used in any further court case. You questioned that, but in this particular case, whilst we were negotiating and they were pleading financial hardship they were negotiating the purchase of a $40 million resort on the other side of the island.

MS KING: Which after being granted unjustifiable hardship they announced the following week they had purchased.

MRS OWENS: I thought that was a really interesting little story, that, and that was another very important point that you made, was that if the other side, respondent, has some cost figures relating to unjustifiable hardship I think you said that it's very hard to - - -

MR KING: They should be sworn.

MRS OWENS: Yes, very hard to challenge them.

[in confidence text removed]

MRS OWENS: So you're quite happy under an act like the Disability Discrimination Act to have an unjustifiable hardship defence?

MR KING: Yes, I think that's a necessary section of the act. But I think it's got to be reviewed as to how it is presented in any conciliation case.

MS KING: I think the accounts that - this is Sheila speaking. I believe that any accounts that are presented for unjustifiable hardship should be audited by an auditor who is neutral, because any auditor can make figures that the other side want them to say.

MR KING: I think creative accounting really is the enemy of the act.

MRS OWENS: Can we quote you on that?

MR KING: Yes, you can.

MRS OWENS: Well, we're going to anyway. I like what you've put.

[in confidence text removed]

MRS OWENS: As I said at the outset, we'll give you the transcript and if there's anything that you'd like to say that you don't want us to quote on, we could just block that out.

MS KING: We're just saying this for your benefit, but you understand.

MR KING: I think you can find that there's a frustration coming from - - -

MRS OWENS: This is being taped, you see.

MS KING: Yes.

MRS OWENS: And we usually put our transcripts on our web site. But before we do so, we'll give it to you. If it is a case that has been where there was a confidentiality clause or there's a case pending, I think you just need to draw that to our attention and we won't put the details into the transcript. I think the important thing is just getting the points that you're raising.

MS KING: Helen, can you tell me, if a conciliation or tribunal agreement is signed and broken because it's not kept, how long does the confidentiality clause live on? Because we have confidentiality but these people have not done anything for two years. How long does it last, the confidentiality? The contract is broken.

MRS OWENS: I suppose you've got the right to go back to the Queensland - what is it, the Anti-Discrimination Commission?

MR KING: Yes.

MRS OWENS: And say what's happening. But I suppose that it leaves you with only the - - -

MS KING: To be in court.

MRS OWENS: The prospect of putting in a complaint or going to the court.

MR KING: Yes. I think if we put another complaint in, Helen, there's a feeling of, "Oh, well, it's only more of the same."

MRS OWENS: Yes.

MR KING: The QADC registrar will not give advice. She said quite openly, "I am not able to give you legal advice. All I can do is advise you on the procedures necessary." Now, this I believe is quite correct.

MRS OWENS: We've heard this story, as I said, in relation to the operation of the Disability Discrimination Act as well and one idea that people have had is that those sort of agreements should be registered with the court.

MR KING: Yes, most definitely.

MS KING: Yes, we've said that.

MR KING: And I think I mentioned that in my submission.

MS KING: I believe there should be a penalty for not adhering to them without just cause. I believe in the Small Claims Court in Queensland, this in fact does happen. So you know, the system is in place.

MS KING: Do you have any specific questions you want to put to us for Helen?

MRS OWENS: Yes, I've got a few.

MS KING: Okay.

MRS OWENS: So how about we just go through them.

MS KING: Yes.

MRS OWENS: One of them was about the nature of the complaints that you were talking about in your submission and I think we've - you've covered that really quite well, but have you at any stage ever been to court.

MR KING: Yes.

MS KING: Yes, we've been to - - -

MR KING: We've recently finished a - - -

MS KING: A representative claim.

MR KING: Under HREOC under Judge Bremer.

MS KING: No, make it straight, Michael Baumann.

MR KING: Baumann, sorry.

MRS OWENS: So that was in the magistrates' service?

MS KING: It was heard three days in Hervey Bay and two days and a summing up in Brisbane.

MRS OWENS: Which issue was that one?

MS KING: Well, that was - now, Hervey Bay council have built blocks of unisex toilets and put the basins outside. So they've built a block of two with one basin outside in the middle and our court case was around that people with catheters, colostomy bags, myself with a brace that comes up to my thigh and gets wet, have no means of cleaning ourselves if there's no basin inside.

MRS OWENS: What was the - - -

MS KING: There's no decision yet, we're waiting for it.

MRS OWENS: How did you - that went right through to the court?

MS KING: Yes.

MR KING: Yes.

MRS OWENS: How did you fund that?

MS KING: Well, we got - - -

MR KING: It was very arduous and you feel a bit shell shocked.

MS KING: No, QPILCH that recommended a pro bono lawyer and we had Dan O'Gorman as our pro bono QC.

MRS OWENS: So you got a QC. Did you feel that at any stage it was going to - was it intimidating, the thought of going through a legal process in going to the Federal Magistrates' Service?

MS KING: The paperwork that we ourselves had to do for the solicitor was absolutely mind boggling. There were heaps and heaps and heaps and things like we would get an email a half past 4 in the evening and they want us to have ***[in confidence text removed]*** affidavits, notarised and back in the post by the morning. I mean almost impossible things to do bearing in mind that we're not near the Brisbane Court, we're five hours away from it. So we found - and at the same time going back to the basics, we tied together three items. The other item was that the council on the foreshore have ***[in confidence text removed]*** round tables. They're in like, half moons around an inner circle and no wheelchair can reach the table. Every one of them is inaccessible to a person in a wheelchair, that was one. The third part of that claim was a community hall that had been built with an outside entertainment area, but only access to it is on grass which is very difficult for manual people to push their wheelchairs and people like me who are ambulant - ex-polio - to walk on grass and we ask for some sort of path of travel.

MRS OWENS: I suppose all of these are part of this one claim?

MS KING: Yes, yes.

MR KING: This was a representative claim.

MRS OWENS: This was to the - a claim against the council?

MR KING: Yes.

MS KING: Yes, all three.

MRS OWENS: It's interesting that it's got to that point that the council was not responsive to your concerns?

MR KING: Having gone through the conciliation from the ADCQ and a conciliation through HREOC, I believe the ones with ADCQ, we came away feeling that we'd had a very fair hearing. The ones with HREOC, I felt was very biased towards the council. For instance, the situation at the community hall was investigated by the building services authority. Because that had happened and it was only an investigation and they made recommendations, we were given the opportunity to make a formal complaint or ask them to investigate and we chose the latter. Having said that, the conciliator said, "I believe this had been suitably addressed by the Building Services Authority," and yet later on in other areas we weren't allowed to quote BCA compliance. Now, the BCA of course is administered by the Building Services Authority. So on one hand she said, "No you can't discuss that because it has been dealt with by them, yet you cannot bring up any parallel legislation that you felt was applicable.

MS KING: Also at the HREOC conciliation, the conciliator kept on telling the council, "Don't worry about that, you can claim unjustifiable hardship if it goes to court."

MRS OWENS: Okay.

MS KING: She told them that at least five times and that's why they didn't conciliate.

MRS OWENS: Yes.

MS KING: It was wrong I'm sure, that she told them that.

MRS OWENS: I think in your submission you mentioned that there should be some sort of guidelines for conciliators?

MR KING: Yes - - -

MS KING: Yes.

MR KING: - - - and they should not give any advice whatsoever.

MRS OWENS: So the guidelines should really be a protocol of what they should and shouldn't be able to do.

MS KING: Yes.

MR KING: Yes, in fact really they should have a training course with the ADCQ conciliators. We've had two of those and they were very, very fair. In fact if you bordered on any personal request for guidance, they said, "We are not allowed to give this, but we are here to conciliate two parties and that's it.

MS KING: But the HREOC lady, she would not allow us to put in any question, but as I say, she constantly told the council when they said, "That's expensive," she said that could be claimed as unjustifiable hardship when it goes to court - when it goes to court and she didn't tell them "if", "when". So she was more or less urging them not to conciliate and now it has gone right up to court.

MR KING: You see, this same council conciliated under the ADCQ, but they went all the way with the HREOC claim.

MS KING: But even then, their conciliations with the ADCQ as I've just said, have come to nothing because they haven't met them.

MR KING: You see, this is also I think why the disability standard on access to premises is so important. We have in fact quoted the access to premises guidelines issued by HREOC and the first reply you get back is, "That has no force in law" end of conversation.

MRS OWENS: Yes.

MR KING: It quotes 1428.2 which really is in bulk 1428.1 with a few extras. Most of the clauses in 1428.2 refer to total compliance with 1428.1. We haven't got this definitive landmark like we have say in the access to public transport standard - DDA standard that's just come out.

MS KING: Also, just to show exactly what happened on the one for the beach access is that we - ADCQ. I telephoned our CEO about a week before they were due to go up and I said, "You know, this conciliation has the force of law" and he said, "So sue me."

MRS OWENS: Right, yes.

MS KING: So that's the sort of thing. What do we - you know, we're only a small little group with about $200 between us. How do you answer such a person? Anyway, your questions?

MRS OWENS: No, I'm finding this really fascinating.

MS KING: Good, we find it heart rendering.

MR KING: Well, I think you could put it down to stories from the coal face.

MRS OWENS: Yes, indeed. In terms of the building environment up there, what proportion is accessible at the moment.

MS KING: The council are advertising that Hervey Bay are the most accessible destination for people with disabilities on the eastern seaboard. However, the accessibility doesn't go past the esplanade really. The Esplanade is accessible, but people phone me from all over and say, "I want to come to Hervey Bay. Where can I stay where I have a fully accessible room?" and I can only answer one motel which is out of the way. "Where can I go? What can I do in Hervey Bay in a wheelchair?"

[in confidence text removed]

MRS OWENS: Where you do have a unisex toilet, the basin is outside.

MS KING: Exactly.

MRS OWENS: Right.

MR KING: That's the local government - - -

MS KING: That's the public ones.

MR KING: Yes.

MS KING: But you see, we fight with restaurants saying, "You know, you're losing 19 per cent of the community because we can't come here with our friends because you have no unisex toilet or even a wheelchair accessible toilet, so we don't come and she doesn't come" and they don't seem to get it. They just call us "Youse lot".

MRS OWENS: Who is they?

MS KING: The business people of Hervey Bay.

MRS OWENS: They don't see it as a selling feature for the area?

MS KING: No, I have taken it up when the government themselves - department - have advertised that they are holding meetings in certain places in Hervey Bay and I have phoned those government things and said, "If you expect 500 people to come to that meeting, a certain percent must be in wheelchairs and that place doesn't have a wheelchair or a unisex toilet and they've had to cancel it. The regional council disability council cancelled one of their meetings, [***in confidence text removed]***

MRS OWENS: So this is why you think the standards are going to - - -

MS KING: Yes.

MRS OWENS: It will pull them up a bit.

MS KING: Yes.

MR KING: You see, at present you have got to be agreed, but under - on section 32 when the standard comes in, it is unlawful to contravene it. The definitive requirements are there, albeit they might not completely comply with one hundred per cent of what is required, but even if we can get an 80 per cent effort under the standard where you are bringing in - upgrading the BCA and bringing in an upgrading 1428.1, that's a giant leap forward.

MS KING: Just as a matter of interest, we've asked HREOC to put in a public inquiry on post boxes. Michael Small I believe is looking at that because in a wheelchair you can't reach these high boxes and in Hervey Bay the post office put a trial of low boxes in our main street and after two years took them out because they told us that the public said they didn't like them, as if we're not part of the public. So that's I'm hoping in the wind and we also will be coming to HREOC. We're doing a national survey of doctors' examination beds. People have been phoning me up who have wheelchairs or are confined to wheelchairs, saying, "I haven't had an internal examination for 20 years because my doctor can't get me onto his fixed height bed.

Now, we're doing a survey, Helen. We've done every state and the figures we are getting are absolutely disgusting. 430 beds in ACT fitted with 46 adjustable beds throughout the whole of the ACT, and so we'll be coming to HREOC and saying, "We believe this really is a public inquiry item." too big for us to take on.

MRS OWENS: With the public inquiry into post boxes, you haven't had a response on that one yet?

MR KING: No.

MS KING: Michael told me he was trying to get information from other countries first.

MR KING: The reason we found out later that they removed the post boxes, was that because they were lower, they didn't have the capacity of the large ones and they had to be emptied more often. It was a financial, procedural matter rather than the public complaining.

MRS OWENS: Is this an issue just in your area or is it - - -

MS KING: No, no.

MRS OWENS: Are these post offices - - -

[in confidence text removed]

MRS OWENS: All states, yes.

MS KING: All new boxes are really high and you can't reach them from - and I mean, Helen, while we're on it, we've got other problems right across which I'm sure you've heard about. It's payphones - in public telephones in the road. You can't reach the - and ATMs, you can't reach the money parts or the bit that you put your card in from a wheelchair. You know, it opens up a Pandora's box.

MRS OWENS: One of the suggestions that we've been getting in a number of hearings is that people think that the Human Rights and Equal Opportunity Commission should be able to initiate complaints.

MS KING: Yes.

MR KING: Most definitely.

MS KING: Most definitely. All these things that we're putting to you for public inquiry should be able to be initiated as complaints by HREOC.

MRS OWENS: What is advantage of that over an inquiry do you think?

MS KING: an inquiry takes so long to even get off the ground.

MR KING: Then it's got to go through some judicious process to make an order for it to happen. So why not cut the matter short and if HREOC believes that the matter is sufficiently important or has a big enough public interest, they can then take it up on the public's behalf.

MS KING: We've been talking about an inquiry with Michael over a year now and we really haven't got off the ground.

MRS OWENS: So it's over a year ago, yes.

MS KING: So you know, a public inquiry even you know, when we wanted to do it for one of our members, said, "We don't want to go that route, it takes too long."

MRS OWENS: Yes, I suppose just in support of HREOC on this one, they have very, very little staff.

MS KING: Under-resourced.

MRS OWENS: Yes, and that's another issue that we've been - - -

MS KING: Yes, we know that.

MR KING: This claim by the way, was actually put into the ADCQ and they bounced it back because Telecom - - -

[in confidence text removed]

MR KING: - - - Australia Post was a federal body. So that was one option and that was HREOC.

MS KING: So what more questions can we answer for you?

MRS OWENS: We've just been talking about standards, we've talked about the complaints process, I'm just going through my little checklist here.

MS KING: And unjustifiable hardship - - -

MRS OWENS: Unjustifiable hardship. What else have we got? I'm just - - -

MS KING: I'm just looking to highlight what you said about our submission in the disability - we had two items where we got a - well, one was the inaccurate unjustifiable hardship and the other one was the enforcement - - -

MR KING: Yes, I think this registering with the court is a very, very important - - -

MRS OWENS: It is important and that can happen now under Queensland law.

MS KING: No, not that I know.

MR KING: No. We've now got to go through another process. If the magistrate deems that it is an unreasonable request then he can actually toss it out and then the owner that you're - or the proprietor can actually appeal the decision in the enforcement court.

MS KING: And I really believe consideration should be given to a time limit for confidentiality if the other party does not comply fully at the time stated. I really believe - you can't go on - I mean, the problem is, for instance, if a shop has two steps and you take it to court and confidentially it's conciliated and the shop next door has two steps, you can't say, "Well, look, this one went to court and was made to do it so you should do it," you've got to start all over again, because of the confidentiality. Yet they're like problems.

MR KING: I think if one party would like to waive the confidentiality in any agreement, then there should be no confidentiality.

MRS OWENS: That probably could happen now, though, couldn't it?

MS KING: Not under - - -

MR KING: We had no choice. We were told that of course the confidentiality clause had to go in.

MRS OWENS: It was just automatic.

MR KING: It was automatic, yes. I believe Larry Laikind, in his submission, said that the confidentiality clause in fact works against any conciliation because publicity really is the best defence - it's the best offence, rather.

MRS OWENS: Although some have said that if you don't have a confidentiality clause then the respondent just doesn't even bother with conciliation and digs the heels in and - - -

MS KING: No, but I'm quite happy with the conciliation up to the time - if you sign that, "Yes, you will do this in two years," it should cut off after the two years if it hasn't been done. I don't mind the confidentiality when the time you've given to rectify it is that part of it, but when you've got now three years and we're now two years overdue, how long can we be confidential. I'd like to go to the press.

MR KING: Yes. I think that would be resolved if in fact this was registered in a court as a court document and then if they reneged on that document then it was a contempt of court. This is the procedure that's missing.

MS KING: I hope some people other than us have said the same thing, hopefully.

MRS OWENS: Coming back to this issue of people having problems accessing the complaint system, have you got any ideas for us on how you can make it more accessible? Apart from the legal representation issue.

MS KING: I think that you shouldn't have to be aggrieved. We have people who, as I say, can't go to toilets in restaurants or can't get into Centrelink or anything and they won't make any waves because (a) they're scared, "Might lose my pension; I might get this - - -" - they're really frightened of authority and it seems to me that you shouldn't have to be aggrieved, you should be able to take a complaint and say, "That firm or that restaurant hasn't got a toilet." We've been trying to get - our Centrelink, it was a new one in November two years ago and we did an audit and they have no way of a person with a vision impairment going from the door to the desks, which are way back in - vision impairment - no way of seeing that desk and we asked that a strip of luminous or highlighting carpeting be put from the door entrance to the desk where the person had to go and we were told strictly by the manager, "We're not spending any money on this."

MRS OWENS: Mm.

MS KING: And we can't take it any further because it's a federal thing. We've taken it to the minister, we've done everything we've done and Centrelink will not move. But if a vision-impaired person wants to go into Centrelink they have to ask for help.

MRS OWENS: So we talked about HREOC being able to initiate complaints. Another idea then is if it's not a person aggrieved it potentially could be another person on that person's - - -

MS KING: Behalf.

MRS OWENS: - - - behalf.

MS KING: Yes. I mean, if we could do it on another person's behalf, we have people who are bedridden who have got problems and we could take it on their behalf, but they can't get out of their bed and come to court and that and they just won't, they don't want to rock their boats.

MR KING: You see some people also have a paranoid fear of the court system. Like one of the complainants on the initial conciliation for our HREOC case was a quadriplegic and she turned around and she said, "No, no, I'm out, I'm not into courts."

MRS OWENS: There's other instances we're hearing of people that if they've got an intellectual disability where it's just totally overwhelming.

MS KING: Yes.

MR KING: That's right.

MS KING: That's right. I mean, one of the people who were on our representative claim, she was completely overwhelmed once she got into the witness box and she really was crying because she made a hash of it and she was someone with not - I wouldn't say a poor intellectual, but because she was intimidated by the whole set-up. You see. I mean people who spend a lot of time in doctors and hospitals, they're really not - they're not prepared for court type of things, where everything is so formal.

MRS OWENS: I think I'd find it intimidating, quite frankly, I mean most people do, but for some people it's even more difficult.

MS KING: Exactly. I mean, when I took my case right up to - when we had conciliation in the law courts, the registrar told - congratulated me and said there's not many people that come this far and it is because of intimidation. I mean, I'm not a person easily intimidated and I was one of the witnesses because I more or less initiated the representative claim, but some of our other people were really, really intimidated by the whole affair. They told me the next day, "I didn't sleep last night," you know, and it's really bad for someone who needs - who is disabled.

MRS OWENS: Yes. The other issue, I can't - I'm just trying to find it in your submission, but you talked about - you suggested adding examples of harassment to the Disability Discrimination Act. I'm not quite sure how you had it. What would that involve? Is that clarifying the act on harassment, or is it putting real examples into that?

MR KING: Together a "for instance" of harassment, like under the ADCQ they actually say, "Indirect discrimination is this, this and this and this; direct discrimination is this, this and this," and they give a couple of scenarios of areas where this would apply and be deemed to be harassment.

MRS OWENS: Mm. So we should look at some of the state acts and just see how they handle it.

MR KING: I think, yeah, but I think that's probably a good idea, rather than trying to reinvent the wheel, because some of the ADCQ, the Anti-Discrimination - Queensland Anti-Discrimination Act is very, very good. But of course, again, it's got its own shortfalls.

MRS OWENS: You mentioned something about section 121 - - -

MR KING: 122 she's talking about. We actually applied for a section 122 action, but - - -

MS KING: On our representative claim with HREOC.

MR KING: Which was similar to the Coffs Harbour where damages would have been awarded but they said - I believe the Coffs Harbour decision said that although the council was wrong, it did go through the procedures, unacceptable procedures, and it actually used those procedures on incorrect information, but then he did qualify that and say, "Well, on the other hand, council was well placed to verify these facts."

MS KING: What I said at our solicitor was that the council had knowingly allowed the community hall to be built with these deficiencies and I felt that that came under section 121, because the council knew they were doing it wrong, but our solicitor didn't think it was a strong enough case for that, so we have all the costs and we're not - and we're in the right and it seems to me that apparently the court doesn't give costs and even, I mean, even though we had a pro bono solicitor, we had to pay for his accommodation when he came down here and his food and it cost us a lot of money to our members to put their hands in their pockets.

MRS OWENS: How many members have you got?

MS KING: We've only got 27 and we had to dig out 600 - $1000, even though we were pro bono.

MRS OWENS: Yes. Just - I think we'll have to finish in a minute - - -

MS KING: Yeah, I'm sorry, we've gone on longer than you expected. I'm sorry.

MRS OWENS: We've notified our next participant they're on at 4.15 now; they were meant to be 4 o'clock. But I just wanted to ask you, is the - do you know whether your local council has got a disability action plan?

MS KING: No, it hasn't.

MR KING: The disability action group, they just disbanded it.

MS KING: We have been asking them and in fact I offered to put together a disability action plan for them and they said, no, they wanted it done by a consultant but they couldn't afford it and that's where it lay for the last four years.

MR KING: But Sheila and I have assisted. She's also on the advisory group for Maryborough City Council and they have in fact made an action plan and it's quite a good one and we have had an input into that, where they have actually done it similar to the Adelaide City Council's action plan where they've highlighted areas of concern, put a budget on it, put a target date and people responsible for acting on that. It really is presented very well and I believe the councillor in charge actually went to a meeting whilst commissioner - - -

MRS OWENS: Not dear old Ostrowski?

MS KING: Yes, that's - and he commended the council's actions.

MS KING: And he said that the councils won't have it so easy when the new DDA comes in.

MR KING: DDA Standard.

MS KING: DDA Standard. And he agreed that councils were having it easy at the moment. So I'm sorry we've sort of waffled a bit, Helen, but - - -

MRS OWENS: You haven't.

MS KING: - - - we're really chuffed on this idea of speaking to you, because we've never had anybody that we could speak to before.

MRS OWENS: I wish I was speaking to you in person, but this is almost as good.

MS KING: It is, it is.

MRS OWENS: So I've really enjoyed it and I think it's been very, very useful for us and I liked all your examples and you have clarified a few things to me. But are there any other issues you want to raise, and if not I'll close off in a minute.

MR KING: I think we've taken enough of your time. As you say, we could go on for - - -

MS KING: Can you tell us when the results of the Productivity Commission is going to be roughly?

MRS OWENS: I was just going to tell you that.

MS KING: I see.

MRS OWENS: Apart from sending you the transcript from today, we'll be finishing the hearings after I speak to the next person this afternoon and then we'll be writing a draft report for public comment.

MS KING: Yes. Will that go on the web site?

MRS OWENS: That will go on the web site.

MS KING: Good.

MRS OWENS: We also - we'll be releasing it in October and you'll get a copy.

MS KING: Wonderful.

MR KING: Wonderful.

MRS OWENS: We send the participants a copy. Then we have another round of hearings later in the year and early next year, relating to the draft report, so if you've got any comments about the draft report you can let - - -

MS KING: Will that be asking for submissions or just comments?

MRS OWENS: You can write a submission - - -

MS KING: Okay.

MRS OWENS: - - - and you can come to hearings.

MS KING: It's very difficult to come to hearings.

MRS OWENS: No, well, you can come to hearing by talking on the phone.

MS KING: Yes, that's the best way.

MRS OWENS: So we really welcome submissions again and then we report to the government in April, the end of April next year, 30 April and then it's up to the government to release the final report.

MS KING: Good. We were a bit worried we might be a bit verbose in ours, because when I was looking on the list everybody was doing one, two and three pages and - - -

MRS OWENS: No. I thought yours was very good and you raised some very important issues for us, so I'm very grateful for that.

MS KING: Good, thank you very much for your help.

MRS OWENS: So thank you and - - -

MS KING: And your understanding.

MRS OWENS: - - - maybe we'll talk again later in the process.

MS KING: Hope so.

MR KING: Thank you.

MRS OWENS: I'll hang up now, so thank you. Bye.

MRS OWENS: Hello, Jan. It's Helen Owens.

DR HAMMILL: Hi, Helen, how are you?

MRS OWENS: I'm very sorry we're running late.

DR HAMMILL: No, that's fine.

MRS OWENS: We get people on the phone, and it's hard. You know, with telephone conversations, it's sometimes hard to just stop them.

DR HAMMILL: Yes.

MRS OWENS: We get into these interesting debates and discussions.

DR HAMMILL: That's right.

MRS OWENS: Look, I'd like to thank you for the submission you gave us, and what I'll do, I'm just going to read something to the transcript in a minute, which sounds very formal.

DR HAMMILL: Yes.

MRS OWENS: This is really pretty informal, and then I thought we could just have a bit of a chat about the issues you raise in your submission which are really, really interesting issues, all right. So if you can just bear with me for a minute - - -

DR HAMMILL: Okay.

MRS OWENS: And I'll just do this little read into the transcript and then we can get going.

DR HAMMILL: Okay.

MRS OWENS: You're not in a hurry to be anywhere else?

DR HAMMILL: No, no, not at all.

MRS OWENS: Okay. 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 calling you today to allow you to participate in the public hearing for the inquiry and to talk about your submission. We've already held hearings over the last couple of months in all Australian capital cities. My associate commissioner, Kate McKenzie, can't be with us today. In fact she's on leave in Sri Lanka, but on behalf of us both, I'd like to thank you for making a submission and showing an interest in our inquiry. As part of the public hearing, our discussion today is being recorded and a transcript will bee made available to the public on our web site. A copy will be forwarded to you to check that it has been accurately transcribed.

DR HAMMILL: Yes.

MRS OWENS: I'd like to point out that you are not required to take an oath. Under the Productivity Commission Act you are required to be truthful in your remarks.

DR HAMMILL: Right.

MRS OWENS: I read the submission that you provided for us and I was just wondering if, Jan, you'd like to make any introductory comments, or we can just launch into a bit of a discussion.

DR HAMMILL: Yes, I would like to make a point that in the last decade, researchers who are looking at neuro-development and those sort of issues, the brain research has taken quite an advanced step and we're finding out more and more about how the brain actually does operate, even more-so how birth disabilities arise from exposure to teratogens, that is agents that cause birth defects. We are very familiar with thalidomide and herbicides and things that the Vietnam Veterans were exposed to in Vietnam, but few people realise that tobacco, alcohol and the marijuana also have the same effects, and we're seeing children who are being invisible to the system because these disabilities are not recognised early and they are children who could keep up with their fellows if the right interventions were put in place as soon as they're born, okay?

MRS OWENS: Yes, thank you. When children are born that look like they're going to be potentially exposed, or have been exposed in the womb, is there any protocol in place at the moment to address the issues that they may be facing? I think your submission is implying that there is absolutely nothing.

DR HAMMILL: Absolutely nothing, that's true. Even though we know when expectant mothers go along to antenatal classes and a history is taken, you know, they may say, "Yes, I am a smoker. I am a drinker or might binge drink occasionally," and even when they tell those things to the midwife or who is running the clinic, there is no intervention. They might be advised to quit smoking, quit drinking, but there are no alarm bells ringing for when that baby's born, "Look, check that one out." As a matter of fact, we've dropped some of the measurements at birth that would have identified problems. For instance, we have dropped abdominal girth measurements for babies which could tell us whether or not a child was adequately nourished in the womb.

MRS OWENS: Is this in Queensland or - - -

DR HAMMILL: Yes, it's in Australia, right across Australia, I believe, they have stopped taking abdominal girth measurements of babies. They've also stopped taking length, because they're saying that's too traumatic to stretch a new-born baby out and measure their length, but surely in this day and age there must be other ways of measuring a baby's length. We need to know whether or not the little one is well developed for their nine months in the womb, because, you know, more and more research is coming - we're keeping more premature babies alive, but the research is showing that premature babies are at higher risk also for various developmental problems, and I think that we need to be more vigilant. We need to more vigilant from the time, or even before the mother - you know, these problems start before conception because the father also, you know, the father's use of tobacco, cross-disciplinary studies showing that father's use of tobacco is a factor in some early childhood brain tumours and leukemia, and so there are a lot of issues to do with tobacco that are not getting out to the public.

So at the time of conception, you need healthy sperm as well as a healthy ova, and then throughout the pregnancy, mothers need to have some assistance to - if they continue to smoke - at least some sort of strategies to help them cut down. The same with the alcohol, because, really, no alcohol is safe. It's better to avoid it totally during pregnancy. You know, in our communities, we're finding that young mums tend to - it's a bigger issue, they can't be blamed for it, but they tend to continue the sort of hapless life course that they're already on. They're usually - some of those children are also a product of a mother and father who smoked, drank, et cetera, et cetera, so this young mum is not the first generation that's been exposed to the teratogens. In actual fact she might be second or third generation. So any problems there could be actually magnified over the generations.

MRS OWENS: I presume that the knowledge of the impact of these teratogens is out there. Why haven't we had public health responses?

DR HAMMILL: Well, I blame the medical fraternity because for working - having come, you know, it's an elitist situation, and having come - they work within silos, you know. The medical fraternity doesn't look across disciplines to see what other disciplines are actually researching and finding out, the behavioural scientists, people in those sort of studies, you know, the forensic psychologists and forensic psychiatrists working within the prison system. The medical fraternity is not liaising, not looking at those sorts of things, and it's been a great omission and the children have suffered. The children have been the victims of this hierarchical system that totally left out people outside other disciplines, you know, the medical fraternity. Even now, that's what happens with behavioural medicine. When the conferences and things are on I look and I see and I think, no, they still don't understand what behavioural medicine is, and they look at it purely from a medical model. They're not looking at the social determinants of health. They're only looking at straight out physical, medical determinants. They really need to look, as I say, outside the silo.

MRS OWENS: But there are some subgroups within the profession, the public health professionals and the epidemiologists that I would have assumed would have cottoned on to this issue.

DR HAMMILL: Yes, I think increasingly there are more. There are more, increasingly, and there are people, you know, Prof Frank Oberklaid who works with children at the University of Melbourne and at the Royal Melbourne, and he's one of those people. He's on the Australian Research Alliance for Children and Youth, and I'm on that too, and within that group there are some people who are very forward thinking, but most of the people, the professional people who are still working out in the field that are doing the decision-making, et cetera, et cetera, like the medical schools, don't just have it, have the foetal origins of adult disease or this type of teratology on their curriculums. They're still very much based in the traditional curriculums that they've had for years and years.

MRS OWENS: Well, given the focus on the appalling indigenous health issues that are out there, I would have thought that - I'm just surprised that this issue hasn't been given more attention.

DR HAMMILL: Well, you know, I did a presentation, a seminar here at work this week and I talked about, "What does morbidity and mortality data measure?" Mortality just measures death, and I gave a case history of a recent death. It was a young man in his 20s, father of eight children from three partners, and he had a very troubled life. He'd been abused. He'd suffered right throughout his life. Plus his mum, who is a friend of mine, said that she had been drinking when she was pregnant, and depressed, and she had tried to take her life a few times and overdosed on antidepressants and whatever else she could, and, you know, now she doesn't drink or smoke and she admits that had she known, she might have been more careful. But this young man, he's just one more mortality statistic, yet in fact his father, his uncle and his brother all suicided, and that shows, you know, how mortality doesn't really tell the picture. It's just a figure on a piece of paper, on a chart, and I think that the epidemiologists really need to bring a lot more of the social factors into their quantitative data.

Another example I gave of morbidity was a woman who had been bashed by another woman and her two daughters. Now, she went to the hospital and she became a statistic, but we know that that poor woman had a very troubled life, you know, and the only time she went to the hospital was when she couldn't help it, that she had to go, but the other woman and her two daughters were in a similar situation. They certainly weren't well. They might have been perpetrators or bashers, but they were also very unwell people, but they don't become a statistic.

MRS OWENS: You've got to ask what would drive them to that sort of behaviour, and that's because of life events for them.

DR HAMMILL: Yes, and enormous mental wellness problems, and I think that's what I'm looking at. You know when I look at statistics like that, because I am a social scientist or a medical anthropologist and I actually work with people, you know, I use a participatory action and a capacity-building model and you know I am out there and I see both sides of the picture and I see two entire families or clan groups with very few people who are 100 per cent well and yet only the ones that end up quite badly hurt will become a mortality statistic, a morbidity or a mortality statistic, yes.

So they're the sorts that I think we need to be aware of, but also we need to be aware of the fact that in the womb, you know, when children are exposed to teratogens, that it ends up with their brain development being hampered. As Prof Fiona Stanley says, "Their brain becomes wired in a different way," and their thought processes - now, one little boy who came to my house last year in January, off the street, he came with some other little indigenous kids whom I was going to be taking away end of February, March, to Melbourne and he came to my house with the other children and when they went back to the community to enrol for school he stayed, because - and that was really - there was this little fellow very comfortable in my - in the spare bedroom, you know, he had everything at his touch and just a beautiful child.

MRS OWENS: Did he have a mum and dad somewhere?

DR HAMMILL: No, he didn't and then I sort of said, "Well, love, haven't you got somewhere to go," and he says, "No, no," and he was right. He was abandoned in a community hospital at three months of age, one of the nursing staff took him out and reared him and then when he was about 11 she passed away after a long illness with breast cancer and from then on his life went wrong. About the same time too his father hanged himself in another community; I was really concerned about him. I took him to child development specialist who said, "Yes, he does appear to have foetal alcohol exposure, not the full syndrome, but the exposure," which has affected his executive control.

MRS OWENS: Was this the little boy that you mentioned in your attachment?

DR HAMMILL: Yes, that's right. Do you know I haven't been able to get help for that little boy from anywhere and I've been out in the field working and he was with - in another suburb with another lady who was - but unbeknown to me he ended up back in trouble again with the law and he's just been in and out of detention centres. He gets put into detention, which is not the most ideal place for him, but then before he can really benefit from the schooling, the education system they have in there, he's put out on conditional bail again and then he re-offends because he has absolutely no impulse control and he sniffs paint, he's a chromer, so you know he lives for days on end down on the street, but he's a very respectful little fellow and there is just nowhere satisfactory to put him. Family Services - he really needs to go out in the country with a family who've got, you know, perhaps other children, animals and things like that. He's a very gentle boy, excellent with animals, but there is - no place exists like that for him, so he gets put in wherever he can convince people to take him.

MRS OWENS: In an ideal world - and we don't have one - but if we had an ideal world, you would - you suggested you needed a protocol that would kick in as soon as these children are born.

DR HAMMILL: Yes.

MRS OWENS: What would it look like?

DR HAMMILL: It would look like - do you know the Pathways to Prevention program that Prof Ross Homel and his colleagues wrote for the Commonwealth about five years ago?

MRS OWENS: Not really.

DR HAMMILL: And the minister, the federal minister for families, Mr Anthony, he has put out the national agenda for children, which really does address all of these things. It's about putting in place structures that will support them if the mother is not being supported, to support her. Perhaps it's the nurse who needs to maintain contact with the family after the birth, you know, visiting the family until the little one goes to pre-school or wherever and trying to get all of these children into pre-school and supporting the mother in whatever - you know, and helping her become a good parent within the home. Then following these children right through school and putting in extra resources at those key transition points, especially going into high school. The Pathways to Prevention program actually spells it all out and the programs are there, there are many programs across the world like this that advocate this, but there's just - the money seems to be going into the justice systems towards - you know the criminal justice system, rather than into the human rights and justice system for the child at birth.

MRS OWENS: In Queensland do you have any maternal and child health services?

DR HAMMILL: Yes, we do. We have - right across all the communities.

MRS OWENS: Do these children get access to those services?

DR HAMMILL: Because they're still operating under the medical model, if a midwife suspects something they go along to the doctor who looks and say, "No, they're fine," sort of thing, you know what I mean - - -

MRS OWENS: Yes,

DR HAMMILL: - - - there's not the training that needs to be done within the medical schools to identify these children or to have them - you know, if a mother says, yes, she has used teratogens, you know, smoked or drank during her pregnancy, then surely that child, when they're born, deserves to be fully assessed by a tem of people such as they use for foetal alcohol syndrome. There are some very good programs in the US and Canada where children are assessed according to - just the word escapes me at present - but they're assessed by occupational therapists for their fine motor skills, physiotherapists, developmental paediatricians, you know, and a close eye is maintained on them right through their growing up years, especially that first three years which is so important.

MRS OWENS: But in the US and Canada, which kids are getting targeted for these team assessments? Is it children with particular backgrounds?

DR HAMMILL: Not particularly, but where a mother has stated to a midwife that she's smoking - you know, that's - the foetal alcohol exposure, that's one of the first criteria is maternal exposure to alcohol, that's one of the diagnostic criteria, the positive exposure to alcohol.

MRS OWENS: Do you know in Australia whether there's any similar program say for children born to Caucasian parents who are potential problems or - - -

DR HAMMILL: Yes, there is. Sue Meiers is a mother in South Australia and she set up the foetal alcohol network a number of years ago and her name is M-e-i-e-r-s - and it's the FAS Internet line and I'm just trying to think of - but it's Sue Meiers and she is a mum who set this up and then there's a doctor on the Gold Coast who is a mother also of a - I think it's a 14-year-old indigenous - adopted indigenous boy and when I said that - she's a medical doctor and so is her husband and I said to her, "Where did you get your son diagnosed," and she said, "There is nowhere this side of Seattle." Since then things are changing and I know here in Brisbane there's Dr Michael McDowell and Dr David Jones, that's the Child Development Network at Milton, they're also on the Internet, but Sue Meiers is M-e-i-e-r-s@cobweb.com.au.

MRS OWENS: Thank you for that. She set up a network to deal with any child that's got these problems.

DR HAMMILL: It's the foetal alcohol - the alcohol exposure and she actually sends around information and she'll travel to various events talking to groups and I think - I'm trying to think who else might do it. I believe there may be somebody, a friend, Lorene Hayes, was doing the indigenous foetal alcohol awareness up in Cape York, operating out of Apunipima Cape York Health Council, but I think she was telling me that there are now, there's other groups, non-indigenous groups working across the Cape and I'm thinking, is it a Dr Hazeldene? The name escapes me at present, but I know that - you know, Lorene Hayes worked with the Cherbourg Community Health Service. Their phone number is 07-41681072 and she could put you in touch, because she is really - it was her research into foetal alcohol that actually started most of this.

MRS OWENS: Can I just turn the discussion to the issue of discrimination while we've got you there, because we've reviewing the Disability Discrimination Act. Do you know whether - you deal with the Cherbourg Aboriginal Community, you spend time there, don't you?

DR HAMMILL: Yes.

MRS OWENS: Has there even been anybody from that community that has felt strongly enough about this issue to put in a complaint or would people be aware that they've got rights under a Commonwealth act?

DR HAMMILL: No, that was why I put in the submission, for the women that I work with at Junda Aboriginal Corporation. The women there - there's a women's group that operates a shelter and women's information service and family violence prevention, sexual abuse, child sexual abuse awareness organisation and they have recently spoken about these issue at an international conference on domestic violence and sexual abuse at the Gold Coast last month, so they - Grace Bond, who's the coordinator, they're very keen to get the message out there, but you know it's only that people like Lorene and myself had access to research findings to take that to them in the community and there's this breakdown between researchers who publish, you know, in their academic journals and actually getting it back to people on the ground who will make a difference.

MRS OWENS: Mm. We're sort of interested in this whole issue of discrimination and disability and we've been told that in the aboriginal community that disabilities - there's a cultural issue there in terms of what is recognised or not recognised as a disability within the community.

DR HAMMILL: I think that's, again, as the women are trying to make it in education programs that people do have a better understanding of what is a disability and you know I think the fact that certain disabilities aren't recognised relates back to the fact that it's a failure of researches to disseminate the findings. And you know the fact that so - well, this young boy I was telling you about, he's now 15, he can't read and write because he was totally missed as having a disability and he's not the only one. I could actually - he was just one that I took - I could actually identify many more. They drop out of school early, they get into trouble with the police, you know, but also they're behaviours at school, the fact that they are unable to take on board the lessons via the teaching methods that are standardised. We really need customised - a woman actually presented the other day at the conference a customised education that can be adapted to children with every type of learning need.

Also, you know, I think we've got to be very careful again with the labelling. I notice the CDC, the Community Call Diseases Centre in the US, that's their peak monitoring body for health, continues to call foetal alcohol syndrome "mental retardation" and that wouldn't go down very well at all in communities and I certainly wouldn't use it.

MRS OWENS: No. You've got to look at the underlying cause of a problem and the symptoms and then deal with those. But I think that label is not a particularly helpful one.

DR HAMMILL: No, it's not, and you won't get people then coming forward and saying, "Yes, well there might be a problem," but also it's hideously blanketing people and people aren't mentally retarded. Even the child with foetal alcohol exposure, they have disability that need to be addressed in a different way.

MRS OWENS: As you say, right from the word go.

DR HAMMILL: Yes, because as we know that with children the neuro-development years are in the womb and those first three years, they're the very vital years and if children miss out at that period they may not catch up.

MRS OWENS: Do you think the communities you have dealt with have any understanding of their rights?

DR HAMMILL: I don't think so. Now, today my community colleagues have had a problem, and just before you telephoned they rang. The community response group are going to seek training and advocacy and health rights. The health rights commissioner - last year I spoke with - and they signified their intention to do community education, so I think now the community will actually invite them up to do that training.

MRS OWENS: Yes. We're looking at the Disability Discrimination Act and we're tending to find that it works reasonably well - not perfect, but reasonably well - for certain groups in the community and not work so well for other groups in the community. You probably put into that category the indigenous people, as well as people with intellectual disabilities in other groups. You've got compounding factors with the indigenous communities as well.

DR HAMMILL: Yes, because there's the issues - okay, if you diagnosed a child with a disability, so what. Where are you going to get help for them, out in rural or remote areas? They're just not there. The facilities you need are just not there.

MRS OWENS: That's another issue we are also hearing - is just about service provision and the lack thereof of adequate services, in a whole range of areas. The inquiry is not looking directly at service provision but we will certainly be raising some of these issues and saying, "Well, this is what we are saying about the operation of the act. But by the way, if you don't have adequate services in place, that could ultimately lead to people not being treated fairly in the community, there is then discrimination."

DR HAMMILL: See, some communities - occupational therapists are unheard of, and physiotherapists might just visit occasionally. There's no-one stationed there permanently and - you know, that happens in not remote areas too. The services marginalise people further. Another thing that really marginalises people further, I find, is the funding processes. You know, for essential needs, for essential - the women were working in 44-degree heat in their office and we were actually having cases of women suffering from heat exhaustion, heat stroke. To get airconditioning for the office we were actually sent off to one of the gaming machine benefits to get funding, where you have to compete. This is what happens, you keep competing with all your friends, and it takes time. But also, there's nobody there to write the funding grant.

I mean, people who are functioning very efficiently in the communities - and there are many who are functioning very efficiently I might add, that are really quite wonderful in what they do - they are loaded down because of that efficiency. It attracts more work to them. These sort of funding applications, grant applications, are things that could be wiped off - if they need it, they need it - and just give people money, what they need to operate at a reasonable level. I think that is discrimination in itself. I find it's quite demeaning but also it marginalises people so much more.

MRS OWENS: Well, that was very useful for us. My colleague Cate McKenzie has visited a number of the communities up out of Alice Springs.

DR HAMMILL: Right.

MRS OWENS: We're hoping to go to Western Australia later in the year if we can organise a visit to Fitzroy Crossing and I think we're trying to build up a picture of what is happening among our indigenous communities and what some of the problems are. I don't think that will come as any news to you. But you've added to that rich tapestry for us, so I really do appreciate what you've given us.

DR HAMMILL: Well, thank you very much for giving me the opportunity, Helen.

MRS OWENS: Is there anything else that you want to raise with us today?

DR HAMMILL: No. I think the funding grant system is really discriminatory, and that's a process that needs urgent attention. But the children, I think, as the women were saying when they finished their presentation on the Gold Coast - they asked Australians to look at the world through the eyes of our children, and I think that's exactly what needs to happen. Nobody seems to - there's very few people seem to be looking at the world through the eyes of indigenous children. Other than Fiona Stanley and her friends, there are very few people out there that understand. Actually, I'll read it to you. Their last slides of their presentation, it said:

> Please look at the world through the eyes of our children and their families. We plead for earlier investment to enable participation in a just and equitable society, so that our children may access optimal life chances. Hear our plea so that all children will live free of violence and stigma.

That's how they finished it the other day. I could ask if they don't mind if I forwarded it to you.

MRS OWENS: I'd like that.

DR HAMMILL: Right. Helen, I have your email address, don't I? Yes.

MRS OWENS: I hope so. It should be in the material you have received.

DR HAMMILL: Okay, I’m sure Gracie won’t mind, and Lillian, because there is quite a bit about disadvantage - you know, where they see the disadvantage. But also, it’s called Junda’s Road Map for the Second Decade, it’s this next 10 years and what they need to do about teratogens and things we have just spoken about.

MRS OWENS: That will be lovely, thank you. Can I just ask you, with your PhD research - when will you be finished your PhD?

DR HAMMILL: I finished it in 1999, end of 1999, but I’m doing post-doctoral studies now into granny burnout. The grannies are saying, "We need to grow up our kids better." So the grannies know that there’s something going on with the children, and they can’t put their fingers on it. This is what I am talking about, the teratogens, because the young adults are producing more children but they’re not always capable of caring for them, so grandmothers have got quite a burden now as they are rearing grandchildren and great grandchildren.

MRS OWENS: And that’s where the burnout comes in?

DR HAMMILL: Yes, and there doesn’t seem to be any improvement in sight for them. Yes, it’s really quite debilitating.

MRS OWENS: Oh dear. Thank you very much. I’ll just close off the hearing now, but I’d like to thank you for taking this time.

DR HAMMILL: No, thank you for including me, Helen.

MRS OWENS: I’m sorry we’ve taken so much of your time this afternoon. Just to clarify where we go from here, we will be writing a draft report for public comment. That will be released in October this year, and we’ll be sending you a copy of the draft report. As I mentioned earlier, we’ll also send you a copy of the transcript for you to have a look at.

DR HAMMILL: Right.

MRS OWENS: There will be another round of hearings after people have had a chance to look at the draft report. They will be conducted over December, January - later January and February. Then we will be handing our final report to the government by 30 April next year. Thank you for talking to me today.

DR HAMMILL: It has been a pleasure.

MRS OWENS: Thank you very much for the submission, and your comments have been very, very valuable to us.

DR HAMMILL: Fine, thanks, Helen.

MRS OWENS: Thank you, bye.

AT 5.01 PM THE INQUIRY WAS ADJOURNED ACCORDINGLY

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