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TRANSCRIPT
OF PROCEEDINGS

PRODUCTIVITY COMMISSION

INQUIRY INTO DISABILITY DISCRIMINATION ACT

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

TRANSCRIPT OF PROCEEDINGS

AT PERTH ON MONDAY, 30 JUNE 2003, AT 9.34 AM

Continued from 20/6/03 in Canberra

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

On 5 February this year the government asked the commission to review the DDA and the Disability Discrimination Regulations 1996. The terms of reference for the inquiry ask us to examine the social impacts of the DDA on people with disabilities and on the community as a whole. Among other things the commission is required to assess the costs and benefits of the DDA and its effectiveness in achieving its objectives. We've already talked informally to a range of organisations and individuals with an interest in these issues, including here in Perth, and submissions have been coming into the inquiry following the release of the issues paper in March. We're grateful for the valuable contributions and opinions that we've heard from people during these informal discussions.

The purpose of this hearing today is to provide an opportunity for interested parties to discuss the submissions and their views on the public record. We've already held hearings in Darwin, Brisbane, Hobart and Canberra, and following the hearings in Perth today and tomorrow we'll be holding hearings in the remaining Australian capital cities. We will then prepare a draft report for public comment, which we will release in October this year, and there will be another round of hearings after interested parties have had time to look at the draft report.

We like to conduct all hearings in a reasonably informal manner, but I remind participants that a full transcript is being taken. For this reason and to assist people using the hearing loop, comments from the floor cannot be taken because they won't be heard by the microphones. If anyone in the audience does want to speak, I will be allowing some time at the end of the proceedings today for you to do so. If you think you'd like to take up the opportunity, please identify yourself to a commission staff member before the end of the day.

Participants are not required to take an oath but are required under the Productivity Commission Act to be truthful in their remarks. Participants are welcome to comment on the issues raised in other submissions. The transcript will be available on the commission's web site in Word format following the hearings. I now invite our first participant of the morning, Mr Brian O'Hart, to appear. I'd like you, if you wouldn't mind, to repeat your name and the capacity in which you're appearing for the transcript.

MR O'HART: Brian O'Hart, appearing as a parent.

MRS OWENS: Can we call you Brian?

MR O'HART: Certainly.

MRS OWENS: Thank you. You can call us Helen and Cate. Thank you very much for coming and thank you for your submission, and you also provided us with some additional material last night, which we're very grateful for. I'm very impressed with the way you've been following our inquiry and reading all the submissions and some of the transcript. So I thank you for that, because I think you've probably got some very valuable insights you can give us perhaps on other people's work as well as your insights on your own situation. Now, Brian, you're going to now give us a short presentation with some slides.

MR O'HART: Yes, thank you, Helen. The theme of my submission is basically summed up in the first paragraph from the Carers Association, the Queensland branch. It's the impact that the DDA legislation, state and government, can have on intellectually handicapped people and their guardians or parents. As the statement reads:

> In measuring the effectiveness of the DDA, consideration needs to be given to the impact that it has not only on the outcomes of people with disability but also on the carers, associates of people with a disability. Disability and discrimination against people with disability impacts not only on the person with a disability but also either directly or indirectly on their carers. As a consequence, it would be appropriate also to examine the carer's participation rates in employment, welfare, income, educational attainment and so on.

So fundamentally that is the theme of my presentation today from the point of a father of a 37-year-old intellectually handicapped daughter. From that stage I will now move on. After three years of communicating with state government ministers of the difficulties that we were having, I decided to make a brief summary or resume and present it to Senator Allison, who was the federal minister for justice, and as a result of that submission to Senator Ellison, that was the essence of my submission that I passed on to the Productivity Commission. This is the covering to that letter that was passed on to the Productivity Commission:

> Please find attached a brief resume as presented to Senator Chris Ellison, minister for justice and customs, of the difficulties we have or are experiencing in caring for our 36-year-old intellectually handicapped daughter. Embodied in this resume and our experience is discrimination

> against the intellectually or the legally disabled and their parents or guardians. On reading this resume, the discrimination is obvious by state and Commonwealth governments. One fundamental question: why should intellectually or legally disabled pensioners and their guardians be victimised above conditions set for normal pensioners?

That's what I wish to develop. From a historical perspective I'd like to give a brief outline of my daughter's problem. She is a twin and had a problem at birth. Her medical condition is cerebral palsy resulting in right-sided spasticity, temporal lobe epilepsy and intellectual impairment. Just to clarify the impact that that has had on her, for many, many years she used to have fits and they used to be called atonic fits, atonic seizures. Slightly different from an epileptic fit, she would veer to the right, slowly lose her consciousness and at times would be out for up to eight hours. She'd go through violent episodes and later on, about five or six years later, to relieve the tension in her body, my wife used to have to inject her with paraldehyde to release the muscles.

The cerebral palsy has left her with the intellectual impairment. She has slight spasticity on one side, which affects her walking and her gait, and she tends to drag one leg, which is sometimes pretty hard on shoes. The allowances that she was granted were the handicapped child's allowance in 75, the disability pension in 82. As you can see, I'm her father and her mother is nearing on 62 years of age. I have just turned 65. Those two ages are very important in the ramifications when it comes to eligibility for pension in our situation.

As I've pointed out here, Lisa is legally disabled. In 88, for Lisa's benefit and my wife's benefit and no doubt my benefit, we looked out for quite a while to buy a duplex so that she could live independently and develop skills and this we did. At the time we paid 83,000 for this very small duplex in Wembley. Lisa being with her problems and being legally disabled, we approached lawyers and they recommended to us at the time the best way to protect her from exploitation at any way down the track, or manipulation, was to leave the property to her for life estate, and that is what we did.

Now, life estate means that when my wife and I part the scene, no-one can sell that property on her. It is hers for the rest of her life. So that was the surety that we built in to give her independence and a place to live. Since about 91, Lisa has lived in that property and at times she has lived with either one or two other intellectually disabled people. They've either come from cerebral palsy, DSC or Catholic Care for the Intellectually Handicapped. At times she's been on her own, and when she has been on her own, my wife and I would on alternate nights go down to her residence and sleep there so she had company, and the method or the object behind that was not to break her routine.

So far the cost to my wife and I of providing the premises has been approximately 198,000. At the time when we took the loan, our interest rate was 18 per cent. So you can see that that was quite a problem for us. In 91, we decided to knock out the wall of one bedroom, put on another room and an en suite so that if two girls were there, they had separate bathrooms, because children or young adults with intellectual problems have behavioural problems, they have spatial problems, and many other problems that we could spend a lot of time with, but I won't. So that was the intent of that action.

Two years ago we built a little granny flat at the back, and that cost 36,000 to build the granny flat. The idea behind this was that there were some behavioural problems within the two girls and on occasions three girls, so that we would give them room to move around so that their behavioural problems could be distanced from one another, and that is what we did in 91.

Right through the last four years, the thing that troubled my mind was here we have a family looking after their legally disabled daughter and paying rates and taxes that are not available to pensioners, are not available to people in those circumstances but are available to disabled pensioners who are not legally disabled, and also normal pensioners. From those figures there, you can see what we currently have to pay. The local government council rates is 1048, water rates 772 and land tax 713. I have discussed these in much correspondence with the Minister for Disability, Sheila McHale, the treasurer, Deputy Premier Derek Ripper. It would be fair to say that the Minister for Disabilities is empathetic with the problem, but as to now, there's been no movement, and later on I would like to go through a few of the acts and to point out how the acts mitigate against parents in our situation in trying to carry out section 51 of the Disabilities and Administration Act.

The essence of the problem is that in 88 when we bought the property with the best intentions in the world for our daughter, no-one mentioned to us to put it in a trust, and that is the essence of the problem. If we had have incurred the cost of putting it in a trust, which I don't think should be inflicted on people in situations like us, I'm certain there are many ways around this problem and I have suggested many to the deputy premier and also to the minister of disabilities and the commissioners in the State Revenue Department. But I haven't had any response to any alterations to legislation.

To place the property in a trust would have cost approximately 29,000 at the moment, and actually it will cost more than that, I have found recently. I requested that the state government, if we had to do that, waive stamp duty, because the stamp duty has already been paid on the initial purchase of the property back in 88. Documentation can be shown that it was for that purpose. My letters to the banks et cetera in 88 indicate what the purpose of the premises was being purchased for. So we'd have no difficulty in proving what the intent of the purchase of the property was for. Capital gains tax I have taken up with Senator Ellison. Senator Ellison has been most responsive. He has written to Senator Vanstone. He has received a response. The response did not address the issue, so he is re-writing back to Senator Vanstone on that score.

Now, the major impact for us is this, when that was written, I was 64. I am now 65. My wife is just on the verge of being 62. As the property is held in our name, we hold an asset not valued at 250,000, as indicated there, but last week I got three evaluations from real estate proprietors in Wembley, and the lowest valuation of the property now is $350,000, and the ramifications of that for my wife and I in getting the pension are quite huge. So in my summary to this submission to Senator Ellison, that's the way I saw the outcome of the years of caring. After 36 years of caring, nurturing and protecting our legally disabled daughter, and endeavouring to remain independent and not to be a burden on the state, the obvious conclusion that one reaches from the foregoing scenario is that parents in these circumstances are rewarded by not being rewarded rebates, concessions on property in which their adult disabled child resides, being denied the aged pension, part or full, because they have provided at great expense accommodation for the disabled child, and to me - and I think any fair minded person's eyes - that is an injustice.

A fortnight ago, I decided to get a hold of the act, the Guardian and Administration Act, and I thumbed through it and I looked at section 51, and I reflected on it and said to myself, "As parents, as guardians, what could we have done better for our daughter under that act?" There is the act there:

To be an advocate for the person -

and we've done that for 37 years, in no mean fashion -

> in such a way as to encourage the represented person to live in the general community and participate as much as possible in the life of the community.

The community that we've built up around our daughter, everyone knows her. She has held a job part-time for 19 years at a nursing home, the Kimberly Nursing Home in West Leederville, and her contribution to that nursing home, and more importantly their contribution to her social skills, development and her mental state, have been absolutely incredible, and they have tolerated a huge amount, I can assure you of that:

In such a way as to encourage the represented person to become capable

> of caring for himself and of making reasonable judgments in respect to matters relating to his person.

That we've done at all times:

> In such a way as to protect the represented person from neglect, abuse or exploitation.

We did that, on legal advice. It may not have been perfect for this day and age, but at the time in 88, it was the best we had:

> In consultation with the represented person, taking into account, as far as possible, the wishes of that person as expressed in whatever manner, or as gathered from the person's previous actions -

That we've done -

> in a manner that is least restrictive of the rights while consistent with the proper protection of the represented person.

We've tried at all times to give her independence, to remove ourselves from the scene, and that's why we bought the property in the position it is. It is halfway between our home and her work, five kilometres either way. Our daughter, with all her handicaps, can walk down to public transport, she can get on a bus and she can go to work, and she goes to work at six to 6.30 every morning, rain, hail or shine, and she finishes work at 1.40, and it's all scheduled in with bus times, and the hospital is terrific in relation to this, negotiate at all times in terms of transport and conditions. Sometimes they ring us, they're a little concerned because she'll get there early in the middle of winter, she'll be sitting on the outside fence at 6.15 in the morning waiting for 6.30, rain, hail or shine. Now, that's dedication:

> In such a way as to maintain any support of relationships the represented person has.

We've built a fabric around her, the banks, the hairdressers, the delicatessens, the grocery shops, the doctors, they all know her. For instance, just to give you one little idea, when she goes into the bank she goes into a bank to withdraw money with a slip that I designed, which has her concessional card number on it, all the details, you won't get another withdrawal slip like it. It's immediately identified. It has the signature of the social worker who comes in twice a week for about two hours; they work out a budget; my daughter fills it out and then the social worker just checks it. Because I can assure you, from experience, one zero in the wrong place makes a difference between $100 and a thousand and the experiences I can tell you, having over the last 10, 11 years, 10 or 11 intellectually handicapped people residing with my daughter, it's an education in itself.

The last point there, "In such a way as to maintain the represented person's familiar cultural, linguistic and religious environment." That we've done. With our daughter, when we bought the place - one of the reasons we bought it was that the agency, which is a religious agency, was approximately 250 metres away from where we bought the premises and they used to have little outings and little religious ceremonies and my daughter used to go, and we used to go, about once a month, because there was a special event for intellectually handicapped people. So that was one of the factors that influenced us and it was great and unfortunately the religious agency then shifted out to Kensington.

In my very detailed communication and correspondence to the minister for disabilities, the deputy premier and treasurer, I could take a lot of extracts of things that I have pointed out to them, but this is an extract that I extracted from a letter written to Mr Ripper on 8 August 2002. These were my clear objectives, and my wife's - and in this process don't let me for one moment overlook my wife:

> To provide a permanent, secure premises for my daughter's life in reasonable proximity to her place of limited part-time employment, medical and dental services, chemists and grocery shopping. To create an environment where two or three people with intellectual disability could live and provide support and assistance to each other.

That is paramount when you get people in these situations. They have epileptic fits. They have medical problems. They need someone around them to trigger alarms. They need someone to act on their behalf. They all have skills and if you can blend their skills collectively together you've got a little community that will operate and survive. That's what I have worked with these people all the time. They have lots of problems and it's always been my policy, if there's any problem that I can solve, I will solve the problem, because they've still got plenty without the ones that we can solve.

> Create a reasonable social environment for the occupants, lessening the strain and loneliness that many others in similar circumstances experience.

Many of these people are very lonely. I have seen so many of them. I've been associated for 25 years with groups and up to 30 intellectually handicapped people. I was chairperson of Uniting Care Commission Group, Crossroads and we used to provide respite and recreation for up to 120 frail, aged and intellectually handicapped people and I've seen them and I have a great insight into their problems. I have seen it in the premises - my daughter has lived with, when they're on their own. It can be quite devastating.

Some of them have neurological problems, some have spatial problems and simple little measures that you can take. If there's a dispute - there's only one clothesline - it's quite easy to put up a second clothesline. If a girl has a spatial problem because of a neurological problem and they have trouble sliding shower doors, you take the doors off, you put up a rail and you put up a curtain. There are problems that can be solved and that is what we have worked on, to help them with the problems they can't solve, so you lessen the problems that can be resolved through psychologists, social workers and just general humanitarian principles. The last point I have there is:

> To ensure that more than one person was in residence at a particular time in case the occupant required medical assistance.

I would now like to have a look at some of the acts. These acts were framed 10, 12 years ago; society changes and this is an aspect I've taken up with the commissioners. As society changes you have to have a look at legislation and the commissioners and state revenue, they have to act by the acts and they're not in a position to change them and one of the commissioners advised me to take up the problems with the deputy premier and this is what I've done. They're the conditions under which people are granted counsel, exemptions or reductions or rebates and also water rates. The one condition that I'm very concerned about is the one that I've highlighted there. You will get your rebates, one, if the premises is held by a pensioner in the pensioner's name. Now, most pensioners who are physically disabled can make their own intellectual judgments and an intellectually handicapped person or legally disabled person can't. So there is a discrimination there. If you look at 29(1)(c):

> Being of ill-health, frailty or other cause dependent for care on others, occupies the land under the terms of a deed or a trust -

and once again, they're the key words, "trust or deed" -

> which was in the opinion of the administrative authority entered into to safeguard the interests of the person.

What they're saying is that a trust or a deed or a deed of arrangement are the only way that they would look at giving rebates and concessions. I take another approach, that our approach - well, legal advice, at the time, for leaving that property to our daughter for life estate, and they do have a copy of my will, because it's provided - should be adequate for those concessions. As I've pointed out, the cost now of transferring the property to a trust would cost us in the vicinity of 29,000 and that is fairly accurate. It's not spot on, but it's fairly accurate, it's been passed by an accountant. This is land tax exemption:

> To qualify for this exemption such beneficiaries must (a) have a disability as defined in section 3 of the Disability Service Act 1993 and have been independently assessed by an appropriate assessor as requiring full-time care; (b) be mentally incapacitated; or (c) be an orphan who is a minor.

I often wonder why they put in "full-time care", when you're trying to make these people - or lead them to independence - very, very restrictive. "Mentally incapacitated" isn't an intellectually handicapped person mentally incapacitated. Why do you have to have a trust or a deed over them? That's restrictive practice as far as I'm concerned. But then you go down and you look at what areas get land tax exemption:

> A property for primary production; a retirement village; a mining tenement; properties for educational purposes, for religious purposes; non-profit societies; clubs and associations.

Yet we cannot extend that to properties which intellectually handicapped people live in, under their guardians, unless it's in a trust or a deed. That clearly shows how legislation can be changed in no time. This is in relation to rebates and concessions for senior card and Commonwealth senior shareholders. You only have to look at local government rates. Pensioners, that is, intellectually-endowed pensioners, who have the opportunity to buy their own premises or be responsible for their own premises, get up to a 50 per cent rebate.

On 1 July 2001 an amendment was made that gave senior cardholders and Commonwealth senior health cardholders rebates up to 50 per cent. So it's not hard to change legislation. It's very opportune when it's politically driven. The intellectually handicapped do not have a voice. Their parents are living from day to day, coping from day to day, that they can't address these issues and no-one's addressing them for them, or very few groups are. So you can look down there and you can see how legislation can be changed very, very rapidly for political reasons, and I think humanitarian reasons often should be ahead of political reasons.

This is a cutting from the Sunday Times earlier this year and I was most impressed with it because Senator Vanstone was trying to press on the New South Wales state government that if a family was having another child and they were going, say, from two children to three and they only had a three-bedroom house or thereabouts, that she was trying to get the New South Wales government to exempt the family that wanted to upgrade their house from stamp duty in the process. So it indicates that when things are politically driven, things can be done or suggested. It was interesting to note that in that same article that in WA we had the lowest gambling taxes - which is terrific - but the average home buyer pays $5524 stamp duty, which is the highest in the country, and as you know, stamp duty in WA rises as from tomorrow. So that is a further burden, an impost, on anyone transferring properties.

This is the situation my wife and I find ourselves in. We bought the property in 98 for 83,000. The allowable assets for a married couple at that time was 127,000. So a variation in the threshold for the assets was 44,000. So at that time if we were of pension age we would have been able to get the pension - no restrictions from holding that property, as long as we didn't have other assets exceeding 44,000 and then you'd be into the tapering off of the pension.

As I've already explained, in 91 we made this minor extension and basically it was a community effort. My daughter-in-law's people are in the trade and their associates, and they gave very freely to build a small extension which cost 10,000 because they knew what we were doing it for, and as I explained, a couple of years ago we built this little granny flat at the back to give them room. The three valuations of the property taken last week - 350,000. That is the escalation of prices that we are all participating in at the moment. So we do have a huge problem because on that scenario with the threshold at 206,500 in assets held without cars or anything else, we exceed that by 144,000. I must also let you know that I have copies of all of these for anyone who wants them after.

Here we have the current scale, Centrelink's current scale for eligibility for the pension. The impact here is very significant because under Centrelink's gifting rules, even if we did put it into a trust, they have a five year scenario which came in as from 1 July last year, that those assets are treated as yours for five years apart from 10,000 in the first year and 30,000 over the next four years. So quite effectively this would rule us ineligible for the pension. It's as simple as that.

MS McKENZIE: For five years from - - -

MR O'HART: Yes, if it's put in - - -

MS McKENZIE: After the gift, yes.

MR O'HART: If it's put into a trust.

MS McKENZIE: Yes.

MR O'HART: Yes, it is 10,000 in the first year and then 30,000 for the remaining four years. So it is treated as your asset for that time. That is if it's placed in a trust. I have spoken to many groups about this problem. I have run into many parents who have walked down the same path as I have. I have been to meetings where lawyers have been at the meetings. I've asked the appropriate questions in relation to this and after the meetings people have come up to me and said, "Thank heavens you were here." On one occasion, October last year, three people came up. One said, "I have just bought a premises, a unit for my intellectually handicapped person." In that audience were 50 parents who are addressing the same problem. Two others came up to me and said, "I'm glad you are here because you have just saved us a huge expense."

I am coming across people by the day that are moving to independent accommodation and are unaware of the ramifications of what they have done, and this has been pointed out to our deputy premier and Sheila McHale in correspondence. In correspondence approximately six months ago I made it clear to our ministers: one, if they weren't going to assist, help or change legislation, at least they had the moral obligation to let guardians and parents of intellectually handicapped people know of the consequences and ramifications if they went down this track. Nowhere have I seen any move in that regard. If I take 400,000 off this scale, I just want to show you what it does: 350,000 for the property and 50,000 if we had a car and just a bit of furniture and what have you. That's effectively what it would do. A person not in that situation would be entitled to - a married couple - a fortnightly pension rate of $740.80. If we're in that situation our dividend - now, this is after we'd transferred it - would be $160, $80 each a fortnight. So the ramifications of that are huge.

Finally, I've made a little summary here of my perception, which can be challenged, and I've presented it this way and I've taken a little bit of legislative licence, if you like to put it that way, to make a point. I've put them into two categories. Independent pensioners: these are aged pensioners, pensioners who can make their own decisions, that are not intellectually impaired. How are they treated in comparison to the legally disabled or the intellectually impaired people? The aged and disabled pensioners: concessions for rebates, council and water rates, all concessions are granted. Intellectually or legally disabled pensioners, nil, unless placed into a trust, and look at the incurred cost. In our case, approximately 29,000 unless the person is occupying the place as a life tenant or life estate after the parents have departed the scene.

Council rates, they're granted the 50 per cent rebate, and as I've shown you recently, the amending legislation took place 12 months or so ago for senior Commonwealth cardholders. We have to pay full council rates, full water rates, and I've also referred to the Rates and Charges (Rebates and Deferments) Act of 92. A pensioner occupying their own place: land tax, nil. In our situation, no concessions, $713 payable, and I've already gone through the list of exemptions. Surely there's a place for the intellectually handicapped. With the age pension there are no barriers - the impact the age pension has in our situation when the property is held in that manner. If it's placed in a trust after you're 60 years of age, it has a huge impact.

The gifting rules come into place, and a word of warning to a lot of parents who think they're covered in trusts, a lot of them are not, because in a trust it has to meet two rules: Centrelink's rules, and they are the control and the source tests, and they're quite rigid. If they don't pass those tests, the source test, from where the money came from, and who's controlling it, they're ruled ineligible. You do have unwittingly, unknowingly, people out there now who do have trusts, and when they come to retirement, they possibly can have a lot of problems.

So people in our situation, you have the erosion of the pension part or full, married couple asset tests are there. When you're 65 to 70, somewhere down the track someone is going to disappear from the scene. If you lose a partner, just think of the agony and the anguish that's imposed on that one person when they've gone through this scenario for 40-odd years and their assets, limits, are half of what they were. They have no choice or very little choice but to sell up, shift in with their daughter, or whatever, or take out a reverse mortgage to get you through, and I also indicate here today that in our daughter's property where she lives we do still have a mortgage on it that has to be met.

So the consequences and the ramifications are quite severe, and I have placed a few footnotes on this summary asking a few serious questions. Why is it that seniors and Commonwealth cardholders that have a taxable income of $79,990 receive the above rebates, concessions, but those in category 2 per my schedule are denied. Someone would have to do a lot of talking to convince me that that is not an injustice. Why are land tax concessions not granted to those people in category 2 when you have an array of exemptions? Why is it that the Commonwealth can consider granting stamp duty rebates to families who wish to upgrade their housing situation because they're expecting another baby? That was an entertained thought of theirs.

Finally, my wife, who is a bit of a literary buff, after caring for our daughter for all those years and what we've been through and our problems, and luckily we've had a lot of skill and whatnot in handling these, and we've got three other wonderful children, she thought she's put it in verse. We have problems, but I know that out there in society you have people with far greater problems than we have, far greater. If you have them in a position where you can assist and support them, you can make very significant gains in their development, because I look at my daughter as a 15-year miracle, because the neurologists who have treated her have asked us how have we done it. But in the process of building her up and supporting her, it's like a fabric. All these little tenuous threads that you slowly build up, you've got to hold and maintain. Cut a couple of those and it unravels rapidly, and it's as simple as that. So there's the poem that my wife put out, and I think it's fairly applicable and apt.

MRS OWENS: Would you like to read it for the transcript's benefit?

MR O'HART: I'd love to.

MRS OWENS: Thanks.

MR O'HART: A Leaf in the Wind.

> The unscrupulous wind teases and twirls, the leaf lifts, laughing, ready to play. But the wind is capricious and fickle. It drops the leaf to the rain-soaked earth, shrieking in cruel delight, twirling away to frolic and jest. Instead in the wetness, the leaf lies captive, unable to rise, unable to fly in this unpredictable world. No skills to survive without support, no matter how tenuous. Will it sink and drown unnoticed? Will circumstance cause it to float against the edge there to wait, trapped in isolation? Will the sun's heat release its shackles, drying it, brittle as parchment, unimportant and unobserved, to lie until crushed neath a careless foot, its fragile structure ground into the earth, back to the dust of the universe? Its fragments may rise again, blown by the capricious wind, no longer joyous but inconsequential.

That's how my wife aptly put it to verse.

MRS OWENS: Thank you very much for that presentation. I don't know whether you would like to just to stay where you are or whether you want to - - -

MR O'HART: No, I'll be fine.

MRS OWENS: That took us probably an hour but I think we've got a bit of time because I think there are a few very important issues that you have raised, and I have to say that I think your daughter is extremely fortunate to have and your wife as parents.

MS McKENZIE: And extremely fortunate in the way that you've decided to deal with the matter, in looking for independence and the way you've set up a home and a society and made sure that she'll be able to live even if you're not around.

MR O'HART: Yes. I would respond to that by saying that within a family in this situation there are tremendous pressures, at times almost unbearable, and it's to give time and space to all parties, to give opportunity, stimulus and motivation to the one with the difficulties, to maintain people's sanity, and to give them opportunity. That's fundamentally what it's all about. They are the threads by which we've built it. Deny people in these situations those opportunities, you will see very, very little progress. As I said, I look at my daughter as a 15-year miracle, from where she has come as a 22-year-old to where she is today. Anyone would be proud of her.

MS McKENZIE: Can I ask how - you've talked about what I might perhaps term the inequities of this whole situation. How do you think that it could be remedied?

MR O'HART: In this narrow situation I presented today, by governments taking notice and legislating so that parents and guardians are given encouragement and incentive and don't impose things above what you would impose in normal situations. Sometimes I think what we are doing is victimising the victims. Government can play a huge role.

MS McKENZIE: Because really it seems to me that one of the situations you're raising is that while those with a physical disability but with intellectual capacity, the legal capacity to hold land, can get certain concessions because they're land-holders and qualify according to the other criteria, receive, you know, disability pensions - or whatever the criteria are. That's not the case with people with an intellectual disability which is so severe that they are unable, legally, to hold - they haven't the legal capacity to purchase or sell or do any of the other things. Is that fair to - - -

MR O'HART: That is correct; that is perfectly correct. Unless they have the capacity to hold the premises legally, you run into these difficulties unless you put it into a trust, and then you ask yourself why should people in that situation have to be put in the place of having the added burden of the financial constraints of putting it into a trust. That in itself is discriminatory.

MRS OWENS: Did you ever think of making a complaint either here in Western Australia or through the Human Rights and Equal Opportunity Commission, or was that going to just add further to your own burdens in terms of dealing with these issues?

MR O'HART: I have been under tremendous strain, (1) with my daughter and (2) handling this situation. But as the commission here knows from evidence I've given them, I've worked and assisted many groups and organisations. I thought it only fair and proper that we go through due process. The due process is the various departments, up through the commissioners, and up through the authorities above them, which is at government levels. I have done that.

MRS OWENS: And you've exhausted those avenues at this stage?

MR O'HART: I have exhausted them, although I must state that in WA we have had what we call an accommodation blueprint steering committee set up. Its report was delivered to the minister for disabilities on 7 March. I made submissions to that report. I know that there has been an input from the deputy premier after my letters to him and also to the minister for disabilities. That report will be released on 8 July, and I'm waiting with bated breath to see what's in it because I think there will be some minor changes that will assist people in our situation, and I say "minor". They are recommendations. They'll have to go through government process, so I don't know what will transpire there.

MS McKENZIE: You've talked a bit about the Administration Act - I don't know whether it's called the Guardianship and Administration Act in Western Australia.

MR O'HART: Yes, that's correct.

MS McKENZIE: I know that there's still a difficulty as far as transfer is concerned, but have you considered whether it would be possible to have an administrator appointed - you may be already your daughter's administrator, I don't know - and then organise a transfer into your daughter's name through the administrator? That act, as I understand it, allows an administrator to act where a person hasn't got the legal capacity to. That's the core objective of that act. You would still have your capital gains tax and your stamp duty problems perhaps, but it may be that that might be a way with less dangers than going the trust way.

MR O'HART: I'm a little unsure if that can be done. My understanding is that it has to be in a trust to get the concessions.

MS McKENZIE: All I can do is just suggest that you might perhaps look at that as another alternative.

MR O'HART: Yes. I'll certainly explore it. I'll explore anything that's put in front of me.

MRS OWENS: I was going to ask you: what you've done I think has been very interesting and you have mentioned that you have spoken to other parents who have been making similar arrangements for their own children. It does raise a very interesting point about the role of parents in the ongoing care of their children, and what you're really doing is replacing government in some way and saving government money, and I think you talked about incentives before but maybe we should be thinking of ways to encourage more parents to be doing this, particularly in the context where we have a shortage of community residential units and so on as we've seen increasing de-institutionalisation.

We, as you know, are looking at the Disability Discrimination Act and issues relating to that act, and then we've also heard a number of different stories, different from yours. It's not clear to what extent they fit into our terms of reference, but we are nevertheless going to raise a number of these issues with government and say, "By the way, as well as these issues that we've looked at directly relating to our terms of reference, there are these issues that you need to think about," and I think you have raised a very interesting point.

MR O'HART: Thank you.

MS McKENZIE: The only problem, I suppose, about an expectation that somehow parents will step in where government does not is that it may be at the huge impoverishment of the parents, and at a time when, as they get older, they're least able to cope with that because they're not working any longer.

MR O'HART: If the encouragement and incentive is not there, you are going to get in time a huge divide. The divide will be an expectation that the government will provide all the assistance and unless you're a very, very wealthy parent there will be no in-between. I do know of a number of very wealthy parents with intellectually handicapped offspring who are looking solely to the state to support them.

MRS OWENS: I think it's a matter of having incentives in place so that parents can choose the most appropriate route for their own child, and for some parents it may be to do what you're doing, for others, it may be that there are other approaches that they would prefer, and I don't know whether there's any right or wrong way of doing it. I think it's a matter of providing the choices for parents and I think what you've done is, as I said, admirable. I think your daughter is extremely fortunate. I was wondering about the parents of the other people that have been residing with her and whether those parents also have as much input into their own children's - they're not children but their offspring's lives as you have.

MR O'HART: As you're aware, I've got to be very careful here. I don't want to reflect on any other parents or their offspring, because they are all different, they're all unique, and they all have their problems. It would be very unwise and foolish of me at this stage to reflect on them, but what I have seen is very, very disheartening, and what parents will go to or are driven to out of circumstance.

MRS OWENS: I suppose everybody has their own personal stresses and strains to deal with.

MR O'HART: Yes.

MRS OWENS: It was such a clear presentation and it was a very complete presentation. We will take on board what you've told us. It's a real catch-22 situation. I don't know whether that's the appropriate way of thinking of it, but you're in such a difficult situation.

MR O'HART: I'd like to thank the commissioners for providing me with the time and the opportunity to make this submission, because I think it's very important that one of your goals was to advise the community, and in the process you are doing this by making the hearings public and, two, making the transcripts readily available on the web site. So I thank you very sincerely for your attention.

MS McKENZIE: Thank you very much, Mr O'Hart.

MRS OWENS: Thank you very much. We'll now break for morning tea and we'll resume at 11 o'clock.

MRS OWENS: We'll now resume. The next participant this morning is Rosalie Leaney. Could you please repeat your name and the capacity in which you're appearing, for the transcript.

MS LEANEY: My name is Rosalie Leaney and I come with - on my own initiative as a person with a need. I want to present my need.

MRS OWENS: Okay. Would you like to do so. Thank you for coming and I hope the hotel was accessible for you.

MS LEANEY: Very, very accessible, thank you.

MRS OWENS: Good, because we try very hard to choose accessible venues. You have got a few things written down you wanted to talk to us about.

MS LEANEY: I've got a few things written down because - yes, and thanks for the opportunity, even though I find it hard to do anything publicly. Yes, I would mainly just like to underscore my written submission and say again that I come from a personal need and I've tried to make a difference, but I feel that it's almost too much for me to get through to people where I've had problems. I simply ask for equity in accessing commercial buildings, because it's not there in most areas. Even in relatively new sites I often cannot move from the road level to the footpath. I mean, that's really one of the main things I'm just asking for today, is that I can get off the parking lot onto the footpath and then that I can move along the footpath, because that's what it's there for and very often you can't move along the footpath in the areas that I'm speaking about.

Access is not provided for wheelchairs and some kerbs are impassable. Their movement along the footpath is frequently blocked by opening-out doors, bollards that some shops jump up onto the footpath that almost meet those opened-out doors, then they have tables and chairs and shops merchandise littered all along the footpath. The access I need has improved in residential areas and it's all right in cities usually, and usually in large shopping centres, but it is barely considered in the infrastructure of a large number of commercial areas that I've tried to use recently. Because of my being wheelchair dependent, we've had to do a lot of renovating of our home recently and the shops that I've been trying to get into that sell tiles and paint, carpet, plumbing, lighting, furniture, they're not within big shopping areas. They seem to be along highways and invariably I get there and I can't get up on the footpath and it's become a huge frustration for my husband and myself.

Dialogue with these shop-owners and the shires seem to be with little effect and this is when I feel greatly discriminated against. It's imperative that legislation be implemented for mandatory easy access for all at the local, state and national level into buildings and using the infrastructure before they’re built, that is, in the planning stage. Then after they’re trading, I think they need checking as well. Basically every shop door needs a ramp or a scooped-out curb in front of it.

Summarising some of the correspondence that I’ve received from shires regarding access to these shops, they seem to say to me that the carparks and the footpaths that I’m mainly concerned about for access are all on private land and the owners can build it as they like and set out the merchandise as they wish, because it’s on private land. Surely, in their shire-accepted plan, they present the buildings and the infrastructure as for commercial public use and as such it should be built for all people to use, that is equity, non-discriminatory. I submit then if retailers are there to serve the general public they are at present prejudiced towards disabled people.

MRS OWENS: Thank you very much. That was so well said. I really thought your submission was terrific, all those letters that you’ve been writing. You’ve obviously decided you were going to keep going with this issue, wherever you could.

MS LEANEY: Yes, and I’m finding it extremely hard. I don’t like being an agitator and I don’t ask for absolute total political correctness, but I do ask for fairness. I do think that if you pull up in a carpark, there’s an ACROD spot there for you, but you can’t even get over the kerb and I don’t understand why in the planning process it’s not there - everywhere.

MS McKENZIE: I don’t understand this "private land" thing either.

MS LEANEY: Well, this is what the shires are saying, "This is private land and they can have it as they like." But surely when you build a house the shire had to pass your plan and if the shops put in a plan saying, "This is for commercial use," well they’re inviting all the public to come, and if all the public can come, why can’t I? I mean, only two weeks ago I was out with my daughter and wanted to get into Tony Saddler’s and there was a huge - - -

MS McKENZIE: Sorry, we’re from Melbourne, you have to explain.

MRS OWENS: We’re foreigners.

MS LEANEY: It’s a furniture shop and all sorts of nice things that I wanted to look at and another shop next to it I wanted to go into. There’s no way I could get up the kerb. A truck driver stopped and said, "Can I help you? I won’t be long." And I said, "But where will you be when I come out." So I asked my daughter to go and ask the lady for a ramp, knowing they probably didn’t have one and she came out wringing her hands and said, "Well, we don’t have a ramp." So I said, "Well, how do I come into your shop then?" I don’t think it’s fair, and this is everywhere.

MS McKENZIE: Was this Tony Saddler's, was it actually in a shopping centre, like a strip shopping centre?

MS LEANEY: It was out there where, you know, you buy doors and - it was amongst furniture shops and it sort of - - -

MS McKENZIE: So it wasn't just a stand-alone shop, in the middle of nowhere, it was with other shops.

MS LEANEY: No. I've got a book here, full of photographs. My husband took them in a very short space of time of blatant mattresses out on the footpath, carpets, tables and chairs for morning tea and you can't get past. I did mention in my written submission about this shop that opened out two wide doors across almost the width of the footpath and had them wedged open and their bollards were jumped up on the footpath almost to the door. There's no way you could get past, you know, unless you can step off the footpath and then back again.

MRS OWENS: But even that's not convenient for a lot of people either. If you're elderly, getting up and down off a footpath is not something you might necessarily want to do and also it might not be safe.

MS McKENZIE: And a pram, if you've got kids in a pram, that's almost impossible. You don't want to take them onto the road.

MRS OWENS: That's right.

MS LEANEY: So I spoke to the manager - I don't find it easy, you know, to chase these people, every shop you want to go into, but I asked the manager, "How can you do this?" and he said, "Well, where are you coming from?" I said, "I'm coming from a person who needs to travel along the footpath." And he said, "Well, where are you going with this?" and I said, "Well, I'll have to speak to the shire." I said, "I think probably what you're doing is illegal, but I don't know for sure." And he said, "Well, what do you expect me to do?" and I said, "Well, maybe the doors could open in or slide," and he said, "I'm telling you that will never happen." That's not fair.

MRS OWENS: And the shire just basically says that that's private land and they can't do anything about it. I find it really extraordinary that footpaths can be private land. There may be some cases where they are, but I would have thought either they are not or they've got controls over them. For public use, it's land that's being used by the public.

MS McKENZIE: Surely councils have controls over these and can govern what goes onto them by local law or by-laws.

MS LEANEY: That's the letter that I got from - - -

MRS OWENS: Thank you.

MS LEANEY: - - - the shire concerned and they - I just felt very put off all the time and I just feel as though I'm on the verge of giving up trying to get into anywhere.

MRS OWENS: For Kate's benefit I'll just read you what's on the letter - and it will be good for the transcript - it just says:

> Mrs Leaney, Disability Access, Your correspondence dated 7 April 2003 regarding the disability access to the above named site is acknowledged.

And that was 433 Scarborough Beach Road:

> The city is responsible for ensuring the design and construction of the structure is in compliance with the building code requirements, however, the behaviour of tenants in this instance is a matter that must be addressed through the building management. Should you require any further information please contact the city on 9345 8555 during normal office hours and ask for Clinton Boddy.

Okay. I think we might contact Mr Boddy, because I think that that's just buck-passing. I think that's an inappropriate response to your concern.

MS LEANEY: I tried to get on to him and he was on the - - -

MRS OWENS: I think that it doesn't sound right to me and I don't think they can just wash their hands of that issue.

MS McKENZIE: Of a commercial shopping area. They must have powers to deal with that matter.

MS LEANEY: Well, surely a footpath should be viable, you know, you should move along it. I didn't even want to go in that shop, I wanted to get to one beyond.

MRS OWENS: But we're not here, obviously, to address every problem that people have got, but what we might do in this case is just ask them if they'd like to put in a submission to our inquiry, explaining their processes and exactly why that is the response they gave to you and I cannot understand the logic behind it and maybe there is something that escapes me, so we will bring it to their attention and ask them for a submission.

MS McKENZIE: And if in fact they have no control over that area, why it is that that’s the case. I simply - that part I just don’t understand.

MRS OWENS: If they don’t, somebody must and they should have been referring you on. I was going to ask you if you’ve ever considered putting in a formal complaint on these issues to your local anti-discrimination commission or the Human Rights and Equal Opportunity Commission.

MS LEANEY: I’ve been on the verge of it. But is it the minister for local government, is he the one that I should write to?

MRS OWENS: There’s various options, I think, in each state, but each state has an anti-discrimination commission and an act and we’re reviewing the Commonwealth act which is the Disability Discrimination Act and these sorts of issues could be raised in that context, if you would care to follow it through, and we’re really quite interested when we talk to people to find out whether they know about these acts and it doesn’t appear that you do until - you’ve come today so you’re now aware that there is a Commonwealth act. So you don’t know about the local Western Australia commission?

MS LEANEY: I don’t know much about it, no.

MRS OWENS: Had you heard about the Disability Discrimination Act before you came today, before you wrote your submission?

MS LEANEY: Not in any depth, you know, I just saw the advertisement and the People With Disabilities magazine, that’s where I wanted - because I’ve been frustrated for so long trying to get into all these shops, I mean, all the local ones near where I live, you know, for years I’ve been saying, "I wish you had something at the kerb so I can get up, you know, in an electric wheelchair." I mean, if I’m with a female friend, they can’t get me up.

MRS OWENS: It would be too heavy.

MS LEANEY: Yes. I mean, fortunately in one instance, there’s so much dirt and weeds in the gutter at the moment in one spot that worries me a lot, that’s forming a ramp for me, but do I have to wait for that?

MRS OWENS: Probably the storms yesterday washed them away anyway.

MS McKENZIE: And otherwise there's no ramp or the gutters are not passable, was that the other problem?

MS LEANEY: It's so many areas where the kerbs are just impassible, they're so high and I can't see that it would be so complicated to just take a bit of the kerb out and cement it lower.

MS McKENZIE: And it's not that you want one in front of very shop in the sense that if you can get up - if there are a few along a footpath and the footpath is not impeded with all sorts of goods and doors and - - -

MS LEANEY: Yes, that's right. That's two things really. As long as the footpath is okay I can get along it. But this book is full of photographs where you see carpets and - rolls of carpet and mattresses and everything all the way along the footpaths, you can't get along them, because they're not very wide anyway and they're - you can't get off a little bit.

MRS OWENS: This book that you've got with the photos, that's your own copies of the photos - - -

MS LEANEY: Yes.

MRS OWENS: - - - but we might have a look at them later. Unfortunately we can't show photos on the transcript which is a great shame.

MS LEANEY: No.

MRS OWENS: But I think I'd be really interested to have a look.

MS LEANEY: I mean, they're just - - -

MRS OWENS: I was going to ask you about one of your letters that you wrote to the Midland Redevelopment Authority.

MS LEANEY: Yes.

MRS OWENS: I have to say they're all very polite letters and I don't know if I'd be so polite at this stage in the process. But you talk about - I'll just quote. You say:

> I'm very pleased to see your consideration of heritage buildings, especially the old Woodland Junction school site and railway workshops.

MS LEANEY: Yes.

MRS OWENS: And so you go on. I'm not quite sure what was decided, what their consideration of heritage buildings was.

MS LEANEY: Just because that's an issue with me, that - I'm just trying to be very nice before I say that I want them to consider wheelchair access. I can't see anywhere - there's three books of their guidelines for the redevelopment of quite a large town in Western Australia here, and I can't see anything anywhere that mentions access for wheelchairs or - so I just thought if I got in at the ground level and wrote to them, maybe they will. But I didn't even get an answer, and acknowledgment of getting the letter.

MS McKENZIE: They didn't even acknowledge the letter, let alone answer it?

MS LEANEY: No.

MS McKENZIE: Because otherwise it means that you can't go into those heritage buildings at all.

MS LEANEY: Probably not, no. But I accept there are places that I can't go, but I don't accept there are other places that are there, new places that are built there for the public to come to buy, you know, to do shopping, things that I need. I just get so frustrated by a big kerb that might as well be 12-foot tall - - -

MS McKENZIE: So you would accept that this very old building - see it as quite difficult to put in access.

MS LEANEY: Yes. I accept that it is, but I really appreciate it when some do.

MRS OWENS: I'm just looking at your photos. I'm just looking at the one of Toyworld on the Great Eastern Highway.

MS LEANEY: Isn't that disgraceful?

MRS OWENS: I have to say, Cate, the whole of the footpath is covered with bikes and toys and everything. I mean, there is no way anybody can walk along it. I don't think anybody walking in there with a pram, and you would assume there would be quite a few people would go to Toyworld with pushers and prams.

MS LEANEY: Yes.

MRS OWENS: I don't know why anybody shops there, and you can quote me when you go and talk to them again.

MS LEANEY: I've got a lot of young - well, I know a lot of parents with disabled children in wheelchairs and they say they would love to go in there, but there's no way. You can't - there's even a bollard in the gutter where, you know - - -

MRS OWENS: Yes, I can see the bollard.

MS LEANEY: - - - a lying down one that you could not even lift a wheelchair over, then the kerb.

MRS OWENS: I hope there's another toy shop you can go somewhere else that's not even in the Toyworld chain.

MS McKENZIE: And impeded pavements like that for visually impaired people are also very difficult.

MS LEANEY: Yes.

MRS OWENS: These are incredibly good photos. They're very clear, Cate, and all of them show - well, show total lack of access. Most of them - a lot of them are too narrow for anything to get along. I don't even know why they'd bother putting a footpath there.

MS LEANEY: Yes. No, it's just some protection for the shop, I suppose.

MS McKENZIE: And high gutters.

MRS OWENS: Yes, high gutters, and then they're using the footpath really as an extension of the shop.

MS LEANEY: Yes, they are.

MRS OWENS: I presume they don't pay money to anybody to use that, although some of these footpaths you'd say would be on private land, so they just assume it's their property.

MS LEANEY: This is what they're telling me. They're private land so they can do what they like with it. But it's not safe, is it? Let's get down to safety. I want to get off that road level as quickly and safely as anyone else.

MS McKENZIE: But how does any member of the public, given the Toyworld shop, how does any member of the public get in? It would be quite difficult, I would have thought.

MS LEANEY: They would have to step over a bollard and step up the kerb and go straight in the door.

MS McKENZIE: Weave their way through the - - -

MRS OWENS: You've said in your little note with this photo:

> I know several children in chairs who would have wanted access to this shop.

MS LEANEY: Yes, I do; next-door neighbour for one and a couple of other people I know.

MRS OWENS: Those poor kids can't get into a toy shop.

MS LEANEY: No, or their grandparents or parents can't either, with them, you know.

MRS OWENS: We've got - in Swanshire - Midland Nissan. They've managed to park one of their four-wheel drives right over the footpath so nobody can get past - totally over the footpath. How they're allowed to do that, I don't know. I'm sure they're not. We've now got - there's a photo of tables and chairs all over the footpath and shopping trolleys in Midland Gate in Swanshire. Yes, these are incredibly depressing photos, I have to say.

MS LEANEY: Yes, and I could get books and books full of those, you know, very easy - they're everywhere.

MRS OWENS: You've got a picture of the disabled carparking spot in Midland Gate, Swanshire.

MS LEANEY: Yes, brilliant, and that's really a good design, isn't it? They've got beautiful scooped-out kerb, because I pressed the manager for one for a long time, and everyone who shops there goes through with their trolleys and their prams and they just love it.

MS McKENZIE: So in other words, what you've done - first it's really good that there was an agreement to do what you asked, and second what you've done is it has benefited many different kinds of people.

MS LEANEY: Exactly.

MS McKENZIE: Not just you.

MS LEANEY: Yes. I feel that they - it's a simple request and it's surely a fairly simple remedy. But how are these people made to be - I can't sort of address it all the time. I'm getting a bit worn out.

MS McKENZIE: Would you like - one of the things that's been raised in many of the submissions made to us is that where there's a class of people affected or where, you know, people just don't want to go through the whole process of making a complaint under disability discrimination legislation, it ought to be possible for either the Human Rights Commission or some other organisation to, you know, pick up the complaints and do it rather than the individual having to go through all that trouble. Would you think that would be a reasonable idea?

MS LEANEY: Sorry, what - - -

MS McKENZIE: What's being proposed in a number of the submissions is that organisations have the power to make a complaint rather than force the individual to have to actually make - - -

MS LEANEY: Yes, be an advocate for - yes. Yes, we are associated with people with disabilities who are an advocacy people. So you're suggesting I take some of these complaints to them.

MS McKENZIE: It may be worth talking to them about that.

MS LEANEY: Yes.

MS McKENZIE: But also - - -

MRS OWENS: Well, it's just also the idea of whether you think it would be a good idea. At the moment under the act individuals are really required to initiate the complaint and what we're really asking is would it be a good idea, to take the pressure off you as an individual, if it's an issue that's going to affect a number of individuals, it might be preferable to allow an advocacy group or some other organisation to do it on your behalf.

MS LEANEY: Yes. Yes, that would be good, really good. So what's the - how do you do that?

MRS OWENS: We might recommend that.

MS McKENZIE: We can recommend it, look at open-ending it when we make our report.

MRS OWENS: One of the other issues that people have raised is that they think that the act that we're reviewing, if anything, is more effective for people with physical disabilities than other people with disabilities that aren't quite so obvious, so people with mental health conditions, or intellectual disabilities. You don't know much about the act, but do you think that - does that make sense to you? Do you think that you've probably, if anything, had more response to your concerns than maybe other people with other sorts of disabilities?

MS LEANEY: I don't know that I've had very favourable - - -

MRS OWENS: Given what you've said in your submission, I - - -

MS LEANEY: I feel as though I get battered from one to the other. Shire to Main Roads to private: the owner, the builder, the - you know, it just - and I can't deal with it. I can't. It's too much. It's becoming too much.

MS McKENZIE: What did Main Roads say? They also weren't very helpful?

MS LEANEY: Well, that it's a shire thing, or it's a private - you know, they just - - -

MS McKENZIE: All just shifting responsibility.

MS LEANEY: Yes, just shift responsibility continually.

MRS OWENS: No, we were just talking to people last week in regional Victoria and they were saying some people do benefit more from these sorts of acts than others, and if you've got a physical disability it's more obvious, so that people's attitudes to people with physical disability are better.

MS LEANEY: Yes, I know what you're saying. I think that's probably right. I'm not sure.

MS McKENZIE: Do you think community attitudes have changed, or - - -

MS LEANEY: I'm sure they're changing, especially as children in wheelchairs go to mainstream schools more and I think education at school for the children to accept and to consider their needs - I think that is going to be very helpful, and I think attitudes have changed a lot. As with personalities, you know, we're all different, and I think some people have a huge chip on their shoulder when you do ask for any consideration that's different.

MS McKENZIE: So it depends on the individual.

MS LEANEY: Yes. I think it does, and I think - so you've got to put up with a lot of stuff.

MS McKENZIE: Well, you don't have to - - -

MS LEANEY: My doctor keeps saying, "Why can't I get your blood pressure down?" and my husband thinks he knows, you know. I just find it too difficult to keep on at it, and I keep saying I'm going to leave this alone, but then I try and go somewhere else and I can't, so it's on again. I thank you for the opportunity to put in a submission. I think that's wonderful.

MS McKENZIE: And one good thing about it is not only is your submission on the web site, but what we've all said today will also be.

MS LEANEY: Right.

MS McKENZIE: So that way the public will start to become aware of these problems as well.

MS LEANEY: Do you think something will be done about it? It's not just an exercise?

MRS OWENS: Well, we hope so.

MS McKENZIE: We hope so.

MS LEANEY: I hope, you know, as I said - as Paul Holliday said many years ago - it's not just a paper exercise; that something concrete will come out of it.

MRS OWENS: We hope so. What we do is we put in a - well, we do a draft report, which we'll be doing in October, and then we get more feedback from people about what we've got in the draft report, and we'll be raising a lot of these issues that people like yourself have raised. We put in a final report and then the government has to respond within 25 sitting days. The report has to be released and there has to be a government response. So if we put up recommendations and the government doesn't agree with them, they've got to explain why. So we work in an independent way. So what we can hope is that - the fact that we've given this inquiry to look at this act I think is an indication that the government is interested in looking at a number of these issues.

MS LEANEY: Yes, and the extension of time I think is becoming of great interest to a lot more people who didn't know about it.

MRS OWENS: Yes, people are finding out about it gradually, and we say to people we take submissions right through the inquiry and there are some very, very interesting issues being raised along the way. Some of the issues we're starting to hear - your issues - we're starting to hear that all over the country.

MS LEANEY: I'm sure you would.

MRS OWENS: There are still issues related to physical access.

MS McKENZIE: But the different perspectives - they're always different and different matters are raised, so people should never think that because it's been raised by one person they shouldn't mention it, because the perspective will always be different.

MS LEANEY: Yes, okay, well, thank you very much.

MS McKENZIE: Thank you very much. It's a pleasure, and that's the first time we've seen such a, you know, a great set of pictures to actually underscore what you're saying.

MS LEANEY: I've got a toilet book too, if you want to see that one day.

MS McKENZIE: Actually, just before we finished, you did raise some very interesting things about toilets, and I never thought about disabled toilets, but now I go and have a look at them and your idea about having the other side with the arm that comes down, because people don't necessarily - - -

MS LEANEY: They're all different, yes.

MS McKENZIE: - - - they're usually on the left or something, and I thought it was excellent, because a lot of the disabled toilets are really - well, if there is one in the first place - I don't think that they're up to scratch.

MS LEANEY: No, the first photograph I took was the National Library in Canberra. That is brilliant, with two huge ropes, one either side of the pedestal - very interesting.

MRS OWENS: And does it work?

MS LEANEY: And more useable than you would think.

MS McKENZIE: Yes, isn't that interesting? That's quite an innovative - - -

MRS OWENS: Good, thank you.

MS LEANEY: Thanks very much.

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

MRS OWENS: The next participant this morning is Agnes Misztal. I may have the pronunciation wrong. I apologise if I do.

MS MISZTAL: That's fine.

MRS OWENS: Would you like to give your name and the capacity in which you're appearing for the transcript?

MS McKENZIE: Yes. My name is Agnes Misztal and I am appearing as an individual.

MRS OWENS: Thank you, and thanks for coming. We've got your submission and we've tried very hard to make the environment as conducive as possible for your condition, so I hope that it all works out well for us. Thank you for the submission. I see you've got a lot of points written over there that you might want to run through with us. Would you like to make a few points to start us off?

MS MISZTAL: Yes. Thank you for the opportunity. At the outset I'd like to acknowledge the staff at the hotel who contacted Dr Peter Dingle at Murdoch University and who, acting on his advice, took some very necessary steps to accommodate me and my health needs at this inquiry.

Secondly, I must say that I sometimes have difficulty expressing myself or remembering things or finding the right word, and that may happen today. I am a person with a disability. I suffer from the medical condition known as multiple chemical sensitivity, MCS abbreviated, also known as being allergic to the 20th, now 21st, century. MCS has symptoms which are very similar to allergies and asthma. On exposure to chemicals my symptoms have included rashes, breathing difficulties and collapse, which are very common - rashes, allergies, breathing difficulties, both allergies and asthma, collapse - both conditions as well.

Over the last five years I have needed medical emergency treatment many times. I've had at least a dozen admissions to emergency, seven by ambulance. One of the worst symptoms I have during these exposures is what amounts to a virtual body shutdown. I can't speak and I can't move a muscle. I seem to be completely paralysed. The treatment I should be given is oxygen, and how this works is that my threshold for toxic chemicals is now much reduced compared to the regular person. I can no longer tolerate what I used to be able to tolerate, and this is an important point, I feel: that I did not always have this condition. It developed as a result of a chemical spill for which I was never ever treated. The point about this that follows is that this condition can actually happen, then, to anyone.

MRS OWENS: Were you in the workplace at the time?

MS MISZTAL: Yes. Women, men and children are all affected. It's not something that just affects women and not men; it affects everyone.

MS McKENZIE: Or people of a particular age. It's anyone.

MS MISZTAL: Or people of a particular age either, no, that's exactly right. Everyone - men, women, children, all ages, all sexes, all income groups - is affected. The problem, or one of the issues here, though is that visible disabilities get attention but disabilities that are not visible, such as mine, don't. But if someone has a weak heart or weak lungs and has difficulty getting about on their legs and they need an ACROD sticker on their car, for instance, you can't see just from that person's appearance that they have a weak heart or weak lungs. It's the same issue with MCS.

A person who may need a wheelchair has a physical disability, and if ramps and lifts are not provided then that discrimination is very obvious, even though it may only be one person who suffers who is in a wheelchair. But a person who is severely MCS and who cannot tolerate the level of pollutants and toxins in public buildings and places, including parks and reserves - very often nothing is done about it. Many people have no concept or understanding of the chemical barrier which is just as real to an MCS sufferer who is severely affected as it is to someone who is confined to a wheelchair and needs ramps and lifts.

Every so often we hear from the media about people with various disabilities who claim discrimination based on whatever they want to access or information they want or whatever and cannot because of their disability. The matter is referred to the Human Rights and Equal Opportunities Commission and, if it's not settled there, is even referred on to the Federal Magistrates Court. There have been plenty of examples in the paper over the last number of years. In one of these articles which I found as I was preparing to do this submission I came across this paragraph relating to a person who had settled her case out of court eventually, but she had had to refer it on to the Federal Magistrates Court:

> The disability legislation obliges all people who construct buildings to ensure they are accessible for all.

I think this is the theme of my speech: that public buildings should be accessible to all, regardless of their disability, but people who are severely MCS cannot access many public places, public buildings. These include buildings such as hospitals, libraries, courtrooms, shopping centres, government offices, picture theatres even, public toilets - all these places. One of the reasons why not much has been done about this so far at this stage is that MCS is not officially recognised in Australia. That's one of the first points I've put on my submission lodged for this inquiry.

MRS OWENS: Can I interrupt there. When you say not recognised - - -

MS MISZTAL: Officially.

MRS OWENS: Officially. Is that through the Department of Health and Aging or - - -

MS MISZTAL: Yes, I think it's - I'm primarily dealing with the health aspects of the whole problem, so yes.

MRS OWENS: I don't know whether there's any list anywhere of conditions that are recognised and others that aren't.

MS MISZTAL: I haven't actually researched this but someone else has, and there's what's known as the international classification of diseases, which does provide a list. But, as I say, my knowledge on this is very limited because I haven't actually looked at it myself.

MRS OWENS: So you're talking about the ICD9 or - - -

MS MISZTAL: ICD, yes - 10, yes.

MRS OWENS: - - - ICD10 and so on.

MS MISZTAL: Yes. So Germany has recently recognised MCS in its ICD10, and many states in America recognise MCS and the Canadian parliament has come straight out and specifically recognised MCS, but in Australia we don't have official recognition, which is not to say, however, that there is no doctor in Australia who knows anything about MCS. There are of course doctors, but the vast majority are either not trained or they just don't recognise the condition as a medical condition.

MS McKENZIE: Can I ask you one question? I don't want to mess up the train of your submission, but you talked about - that a lot of public buildings, libraries and so on, weren't accessible, and presumably it's the same with public transport also, like trains.

MS MISZTAL: Yes, that's exactly the issue. It does cover public trains and buses as well. I have actually had to get off a bus once when someone got on reeking of perfume and I just couldn't tolerate the level in the bus.

MRS OWENS: What about the diesel fumes?

MS MISZTAL: That's also very bad. If I go into the city, I then spend at least however many days recovering after that.

MRS OWENS: And trains?

MS MISZTAL: Trains are bad because they're enclosed, and of course if they're full of people and if everyone is wearing fabric-softened clothing, it can be a bit of a problem. If it's not too many people that hasn't been recently cleaned with some chemical stuff, it's okay, though. One can manage. One does get a little bit affected but it doesn't necessarily lead to collapse.

MRS OWENS: Can I ask you, is there a group? Have you formed a group?

MS MISZTAL: There is a Chemical Sensitivity Self-Help Group of WA, yes, and there are a number of MCS supports in Australia, of which I do belong to at least two. I also belong to a US support group, which is the reason I know that in America they're way more advanced on all of this than here.

MRS OWENS: Have these groups here tried to say get the condition acknowledged in the ICD code?

MS MISZTAL: Many, many, many times, many years. I have only just got into this fairly recently because, as I said, my condition developed in 96 and I didn't know why I was getting so ill. It took one year, including collapsing twice in one day, being picked up on ambulance on each occasion and sent to emergency - and still the doctors didn't work out why I had collapsed - before over a year later I finally got referred to a doctor. When I told her where I had collapsed, all the different places, she said, "You've become chemically sensitive," and she explained what the condition was, and that suddenly explained why I had collapsed at the bus station, why I had collapsed at a chemist's, why I had collapsed at a place that had been refurbished probably two or three years beforehand, why I had collapsed after I'd been going to government offices. That explained it then. Until then I didn't see the common thread.

MRS OWENS: At least somebody did at some stage.

MS MISZTAL: Yes, eventually, but it took a very long time and I became extremely ill, very weak. In fact, when I went to see this doctor, whereas now I can actually have to access the public transport, even though I have to make allowances for how long I estimate it might take me to get there if I had to get off a bus and catch another bus, in those days I was actually having to take a taxi to get to this doctor because I otherwise had to take two buses to get to her and I was just too weak to get on public transport.

MRS OWENS: But even in taxis, if they're run either with petrol or gas, you've still got an issue, a problem.

MS MISZTAL: Yes. One of the issues here is where the taxi drivers have that fragrance, and if they have that on I just tell them to switch it off, that I can't handle it, and I think every single one of them has actually.

MRS OWENS: Yes, it's foul, that smell.

MS MISZTAL: Yes.

MS McKENZIE: You said that things are better in the US.

MS MISZTAL: Well, at least it's recognised by quite a few states in the US, yes.

MRS OWENS: Sorry, can we go back - - -

MS McKENZIE: That was a serious interruption.

MS MISZTAL: That's all right.

MRS OWENS: Had you finished what you - - -

MS MISZTAL: No. Were there any further questions?

MRS OWENS: No, we'll just keep going.

MS McKENZIE: We'll just ask them as you go along, I think might be the best way, but none for now.

MS MISZTAL: All right. So, as I said, it is recognised in a number of places overseas. Nova Scotia, for instance - Halifax in Nova Scotia to be more precise - a few years ago actually went all out and made all public buildings, which includes courts, municipal offices and mass transit buses, fragrance-free. I actually also have reference to a Scottish court case where a husband wanted to murder his wife by putting shampoo on the door handles, knowing she was severely allergic to this and many other common substances. When the matter went to court, the court made certain that no-one was wearing fragranced products so that the attempted victim there would not suffer anaphylaxis and possibly die. So the condition is recognised, as I say, in other places but not officially - which is not to say, however, that there aren't doctors who do know about it and have had the training, and the correct training. But there is a great deal of polarisation in the medical profession on this condition.

MRS OWENS: There probably needs to be education of the community at large.

MS MISZTAL: Yes.

MRS OWENS: One of the submissions that we'll be talking to this afternoon - we'll be talking to the Disability Coalition, which is People with Disabilities WA and Ethnic Disability Advocacy Centre, and in their submission they've said that there's a need for a focus on education on these sorts of conditions more generally, but the more invisible conditions.

MS MISZTAL: Yes, and that also includes the medical profession and associated professionals. Since I started researching this issue I have spoken to a number of people who were in the health professional field. At least two of them were previous nurses and both of them have told me, "When I started nursing it was a rule that you could not wear perfume and your fingers had to be so clean. There were conditions and all that." Now, why and where did it suddenly become okay for nurses to wear perfume in hospital?

MRS OWENS: At the same time they're allowed to start wearing plain clothes.

MS MISZTAL: Yes, well. Another reason why there's a difficulty with MCS is that in the last 50 or more years, perhaps even 100, the chemical industry has had an enormous influence on what and how it's produced in our society. This includes everything from building materials, glues, paints, plastics, pesticides, perfumes and so on and so forth. Their influence has just exploded in the world. It's conservatively estimated that we probably have 60,000 at least new synthetic chemicals in our environment which were not around in the 19th century certainly and possibly in the first few decades of the 20th century, and probably no more than 5 to 10 per cent of these have actually been tested for human health and safety. So we've got all these very dangerous chemicals floating around, mixing with each other, and it's this which we MCS sufferers are reacting to.

Because I have collapsed so many times now and needed medical treatment, the doctor who diagnosed my condition arranged for me to wear a St John's Ambulance issued Medic Alert bracelet. My Medic Alert bracelet does say "multiple chemical sensitivities" on it and it also has "contact COMS immediately" for the reason that if there is any doubt as to what I am suffering, the ambulance officers and the doctors at emergency are to contact the St John Ambulance database. They've got my identifying number on the bracelet as well. If there's any doubt, okay, get the information of the database as to what to give. What to give is - despite what I might be presenting with, you give oxygen.

Now, what has happened instead though is I have been seriously affected by chemicals, including symptoms of staggering, loss of balance, lack of coordination, clear chemical poisoning symptoms, and one of the ambulance officers who attended said, "No, I’m not looking at your medical bracelet. No, there’s no need for me to do anything there. I know what you’re suffering from." I was not given oxygen as I should have been.

On another occasion after I had been in a "too toxic for me" environment, I needed medical treatment and the doctor at emergency said this time, "No, I don’t need to look at your medical bracelet." Basically the same thing, "I know what’s wrong with you. No, you’re not going to get oxygen." But I desperately did need oxygen. Now, how discriminatory is that, that they don’t consult my medical bracelet, where they are obliged to consult people’s medical bracelets. That is one of their basic rules. I’ve actually spoken to an ambulance officer who said, "One of the first things ambulance officers are trained to do is to look for a medical bracelet." The medical bracelet is designed to speak for when you can’t, and as I said, in my worst collapses, I cannot speak and I cannot move a muscle, but I do wear my medical bracelet, and it is clearly visible.

MRS OWENS: Were you tempted to make a complaint, either to the ambulance service - - -

MS MISZTAL: I did.

MRS OWENS: The hospital or the Anti-Discrimination Commission?

MS MISZTAL: I did only make it to the ambulance service as far as the ambulance officer was concerned, and to the hospital as far as the hospital, although I did pursue one other complaint to the Office of Health Review. But while one gets these letters which say, "The matter has been looked into. We trust it will never happen again," what happens to that? The next time I go in, other things happen. So I’m put into a toxic environment, stuff like that.

MS McKENZIE: So they did, both organisations did reply to the complaints and say that they would try to make sure it didn’t happen again?

MS MISZTAL: Yes, but the ambulance situation, I’ve already had that twice now. Once before I got the medical bracelet, one of the ambulance officers completely got me wrong, and I lodged a complaint about that. Then I had the medical bracelet, so the ambulance officer had no excuse, but he still flatly refused to look. So I’ve now had two situations where I’ve been completely misdiagnosed by ambulance officers, and I have been many, many, many times misdiagnosed by the doctors in emergency. Although for a long time, because I - as I said, I didn't know why I was collapsing. I was collapsing and going into emergency and they were coming up with any number of reasons why I had collapsed and why I was coming up with rashes, but none of them were actual reasons.

MRS OWENS: But it really does come back to training.

MS MISZTAL: Yes, training.

MRS OWENS: Training by ambulance officers, training of the medical profession and the nursing staff.

MS MISZTAL: Yes, and also the community, because I keep stressing this can happen to anyone and something that does - yes, when people say, "Well, chemicals don't affect me," well, you know, they are lucky at this stage.

MRS OWENS: Yes.

MS MISZTAL: At page 9 of the information kit provided, there's an example that:

> A lack of support services such as funding for a particular therapy or device such as the wheelchair which may prevent access to employment or education, effectively discriminates against a person with that disability.

I have actually written to the hospital and asked for a chemical-free room and had my request denied.

MRS OWENS: On what grounds?

MS MISZTAL: On the grounds that there weren't enough people to warrant it.

MRS OWENS: So they don't have chemical-free rooms available?

MS MISZTAL: They don't, no.

MRS OWENS: As a matter of course.

MS MISZTAL: Yes.

MRS OWENS: A chemical-free room, what would that entail, just to give us an idea?

MS MISZTAL: Actually I have got a - this comes later into my submission which I lodged - but I have got two protocols in America, one which is from the Mercy Medical Centre from California, and it's on the Internet, approved for publication, the sort of matters which are needed. There is nothing that would constitute a hardship in here.

MRS OWENS: Would it involve things like having airconditioning that's not recycled airconditioning, recycled air, the same.

MS MISZTAL: I'll mention this one here, the Louisville Jewish Hospital, as a true leader in the medical field:

> Some of the steps to accommodate environmentally sensitive health problems include being placed in a room where there's no carpets; special hypo-allergenic linens to be used; cotton masks available for clients being transported within the hospital; portable oxygen available for transport; gowns available at the door for caregivers, as needed; scented personal care products not to be worn in the presence of clients; cleaning procedures to take the client's sensitivities into account.

Nothing at all that constitutes a hardship, and the Mercy Medical Centre guidelines are very much the same there, more detailed, but they are very similar.

MS McKENZIE: But primarily they address the same sort of things.

MS MISZTAL: Yes, exactly. Non-latex surgical gloves, non-latex powder free exam gloves and such like, porcelain oxygen mask.

MRS OWENS: I suppose you could have chemically free rooms in hospitals, but then you've still got the issue if you needed, say, surgery, of whatever happens once you get into the operating theatre, which is going to be another sort of environment again - - -

MS MISZTAL: Yes.

MRS OWENS: Where they may not be able to make all those allowances because of the way they set up the operating theatre.

MS MISZTAL: Yes, I - - -

MRS OWENS: So that's a real concern for you if you ever needed major surgery.

MS MISZTAL: Yes, it is.

MRS OWENS: Or even minor surgery.

MS MISZTAL: Yes, it is, in particular the issue of sedatives and anaesthetics is a major concern for MCS sufferers because we do not need the standard dose, and yet when I inquired from an official about titration that it starts off at perhaps 10 per cent of a standard dose and only works up till - whereas they might start off at 75 per cent and think that's it, whereas that would probably kill us. They just said, "No, we'll give you a standard dose." So I actually had a few years ago a particular procedure where I elected to go without sedation because I could not afford to risk dying.

MS McKENZIE: But so much of this seems to be education. It's not just community education. There seems to be a huge need for education among medics and paramedics.

MS MISZTAL: Yes, yes, that's right. In respect of as MCS is a condition where people who are acute react to very low doses of toxic chemicals, I know as an example of two schools here in Perth who have one or two students each who are severely allergic to peanuts. Both of those schools have banned peanut products on school grounds because the students can suffer anaphylaxis. It can be done, and a few years ago on Today Tonight here in Perth, I remember they did a story about - it could have been an Australian airline - that some people suffered anaphylaxis just through smelling a few seats in front of them eating peanuts. Peanuts now have been completely banned on airlines. So the analogy is that it can be done for - to ban substances which are known to be harmful.

Turning over to the next part of my topic which is how discrimination could be eliminated, I've put forward that it could be done by surveys, interviews, focus group discussions with people with disabilities, but in this particular case, people with particular disabilities. So if you wanted to find out, well, "How can we best meet your needs," the best person obviously always knows what they need; ask them. Ask the people with disabilities, "What do you need to be able to safely access public buildings?" - which keeping in mind disability legislation requires those who construct public buildings to be accessible to all. That includes us MCS sufferers.

The problem with MCS is that many people may not know about ads for surveys, interviews and focus group discussions because they cannot handle newsprint, or they may be in remote areas because they are so acutely, exquisitely chemically sensitive, they may be in the mountains or in the forest or living in a tent somewhere and have no human contact. They may also be sensitive to electro-magnetic radiation, in which case they cannot use phones, and so there is no way of communicating as one would.

MS McKENZIE: How does one get to those people in this case? Is that a very hard decision for focus groups?

MS MISZTAL: Yes, it is, but one suggestion would be that if a person is living in a mountain because that person is so exquisitely chemically sensitive, that person may still nevertheless have contact with someone that they used to know in their past. Letters may be exchanged from time to time, and the person who is not so chemically sensitive may contact the other person and ask, "Do you have any ideas," when you're having this sort of thing on. "Do you want to contribute?"

MRS OWENS: So writing a letter would be quite possible?

MS MISZTAL: Yes. The only problem, of course, is that in these remote areas, you wouldn't get a letter the next day. You'd have to expect a delay in the post.

MS McKENZIE: And you're assuming that they're part of some network that ongoing - - -

MS MISZTAL: Or at least that they're in touch, yes, or at least that they're in touch with someone who knows the issues, yes.

MRS OWENS: What about email? You talk about you can't use phones, does email - would using a computer - - -

MS MISZTAL: A person who is electromagnetically sensitive will not able to use computers at all.

MRS OWENS: But, I mean, you're not actually putting the phone to your ear, but it still is a problem with the signal - - -

MS MISZTAL: It still is a problem, because it's the radiation coming off the computer screens.

MRS OWENS: Okay, so that still is a problem.

MS MISZTAL: Yes. Another way of dealing with discrimination could be with how media stories present people with disabilities, and I've mentioned here this includes how the heading to the article reads, and the photographs, because a lot of people don't bother reading the entire article. They just look at the heading, the photograph, that's it, "I've got a definite idea of what it's all about."

MRS OWENS: True.

MS MISZTAL: They could get a very misleading impression if they just looked at the heading and the photograph. The information kit also states that "the Disability Discrimination Act requires a complaint", but the reality is that there have just been so many cases, as I said, when I looked at the newspapers to see what I could use for the submission, of people who had a legitimate complaint of discrimination. They have referred that to the relevant authority to accommodate. So they've made the complaint, and the authority has just said no, and so the matter has had to go further, ie to court. Now, perhaps with some issues the person themselves could handle it on their own, but invariably one does need legal representation, and legal representation costs, and the other thing about legal representation is if you were to only be able to afford one lawyer and the authority decides, "No, I'm going to fight this, I don't care. Yes, the person can think they've got a legitimate discrimination complaint here, but we're going to get three, including a QC." Three against one is a bit difficult.

MS McKENZIE: Have you got any understanding of how difficult it is in Perth or in Western Australia to get that sort of legal representation if it was needed?

MS MISZTAL: No, not for other people. I've had a situation where I was discriminated against myself. That was a court case where I had to appear as the principal witness for the police, and in that case I was very willing to appear but I wasn't going to die being in the courts, and when I spoke to the police officer about my health problem, and he understood it, but he said, "Well, the system is not geared up for you. You can just appear," and I said, "But you understand what I'm getting at? If I go in there, I could die, potentially, but at the very least, I would become very ill." He said, "Well, that's it. If you don't appear, we will seek a bench warrant for your arrest." Now, that completely threw me, because I was their principal witness. I was willing to appear, but I wasn't prepared to put my health at risk.

So I referred that to the disability discrimination unit of Sussex Street Law Centre and the lawyer of the time wrote a letter to the police prosecution unit saying basically what I had said, and alternative arrangements were made. However, that was one instance where I've had a favourable outcome and I don't know what it would be like if I would have to actually secure the services from private means, and I don't know how other people have gone.

MRS OWENS: I understand with that particular law centre that there have been resource issues there, financial - I don't know how well-funded they are.

MS MISZTAL: I have no idea.

MRS OWENS: Mm'hm. That is an issue that we're looking at, this whole issue of resourcing of legal - - -

MS MISZTAL: I gathered they only have one lawyer there though.

MRS OWENS: Yes.

MS MISZTAL: Which makes it very difficult if you suddenly get - what's the word - you know, too many complaints all in the one hit.

MS McKENZIE: What was the alternative that they used for you?

MS MISZTAL: I was going to give evidence by videolink. However what happened was, where the video was actually situated, the environment was too toxic for me so that that ended up being no good anyway.

MS McKENZIE: Mm.

MS MISZTAL: However, fortunately I only had to stay there for a few moments and the matter was finally resolved by other means. So I didn't end up giving evidence.

MS McKENZIE: All right. So you didn't have to give - in the end you didn't have to give the evidence.

MS MISZTAL: No, I didn't, no. I turn now to the matter of action plans as a way of dealing with the matter of disability discrimination. I looked at one provided by my counsel but the matters that it covers don't even begin to address the issues covered by MCS, and I also understand that although the preparation of action plans by organisations - well, I understand that the preparation of action plans by organisations is voluntary and they are not necessarily legally enforceable. However, on the plus side they do bring to the organisation's attention a problem that a person with a particular disability has. So perhaps something could be done on the action plans that if a person with what seems to be a unique disability suddenly appears in an organisation, people don't panic, but that there are action plans already set in place and one just goes to those plans and sets the necessary steps in motion.

I have brought along a mask. It's very difficult to get around in polluted areas and I used to actually wear this mask all the time when I went into the city. This one has actually become quite saturated. You could try it and see what it's actually like to even just sit and wear a mask. Although it can prevent pollutants from getting into your system, it also prevents a lot of oxygen. This is a completely new mask. The difference is huge. I checked one this morning.

MS McKENZIE: It's a better one?

MS MISZTAL: It's new, completely new. It hasn't been used yet.

MS McKENZIE: Okay.

MS MISZTAL: Because, see, masks get saturated.

MS McKENZIE: Yes.

MRS OWEN: Are they made out of cotton? What is it? Is it a natural fibre?

MS MISZTAL: I'm not really sure. Yes, I think it is but I'm not really sure. I did, as I say, used to wear it but I had quite a few unpleasant experiences, and this was before September 11. I'd actually, amongst my experiences, actually been threatened with violence. A bloke came up to me and wanted to bash me.

MRS McKENZIE: Why, because you were wearing the mask?

MS MISZTAL: Because I was wearing the mask. I'd been harassed on the train as to why the hell was I wearing a mask, and I had actually been treated as a leper when I went into an office and the person - I needed to get my change - and the person was very careful not to put it anywhere near where she might come in contact with me.

MS McKENZIE: She thought you had something that made you wear them.

MS MISZTAL: Yes.

MRS OWEN: I wonder if people would be more understanding about masks post the SARS.

MS MISZTAL: Yes, that's one thing which I have thought of that - whereas I was treated not very well when I wore a mask, when I saw all the photographs of people wearing masks around, nobody thought that was weird. That was treated as a normal precaution but, you know, people like me who are chemically sensitive - and there are others who are even more sensitive than me and they wear more elaborate masks - for some reason that's supposed to be not understandable. Incidentally, I have actually purchased masks which have respirators and I found that - the respirator is the one where there's cylinders - I wasn't able to tolerate the plastics out of which they were made.

I have referred to the need for chemical-free environments, and as people will appreciate, these environments are very difficult to find. Supermarkets, petrol stations, hospital and public buildings are all threats to the MCS sufferer. One further approach to dealing with this whole issue is a need for individuals with organisational responsibilities, such as building owners or managers, employers and health care providers, to understand it's unacceptable to deny assistance to individuals with MCS and that reasonable accommodation should be provided. There is a need for better understanding of what MCS is and how its symptoms can be eliminated with health care providers, building owners - which I keep stressing - the disability legislation, employers and the public.

So basically what I want to stress, as the final point I guess, is that may I put forward a plea of understanding that as a result of this inquiry, when the commissioner's report is prepared, it include a very strong recommendation for practical measures to be implemented as soon as possible to provide health and other support services to assist MCS sufferers to lead a better quality of life. In 1998 the CSIRO found that polluted air in homes and offices cost the nation $12 billion in sickness and lost productivity. Our society cannot continue to pollute the air we breathe, the water we drink, the soil from which we obtain our food, and think that the cumulative effect of all of this pollution will not ultimately affect us all. I don't have the figures with me at the moment but I seem to recall that it's been found that the vast majority of cancers, for instance - I think it's actually about 80 per cent - are environmentally caused.

We cannot therefore continue to pollute our environment and think or trust to luck that this will not affect us humans and the rest of the inhabitants of our planet - the animals and the plants - and the issues of global warming and greenhouse effect ultimately. But if buildings and public places are made safe and accessible to the most severe of MCS sufferers then everyone benefits. Thank you. Is there any further questions?

MS McKENZIE: I think we've asked them as you went along, which is the best way to do it.

MRS OWENS: And I think you finished on a very positive note. I mean - well, it's a note that we should - - -

MS McKENZIE: It's a very strong recommendation.

MRS OWENS: It's a strong warning to all of us and we'll certainly take your issues on board. Again, like many people we've spoken to through these hearings, you've raised some really incredibly important issues and for a group in the community that I think a lot of people are just not aware that these conditions exist and I think there's a huge education that needs to occur so people do raise their awareness and hopefully then things will improve in the future.

MS McKENZIE: And it's really important that you and Stella have come to a public hearing like this where what you say can go into a transcript and go onto our web site for people to read.

MS MISZTAL: Thank you.

MRS OWENS: So thank you.

MS MISZTAL: I wish to say though that you see me today as a person who can actually today attend this hearing. Whether I am affected in a couple of hours time, yes, we do not know but there are other people who could not even attend, with any measure of support, because they are so acutely, acutely, acutely chemically sensitive.

MRS OWENS: We really appreciate you coming.

MS MISZTAL: Thank you.

MS McKENZIE: And I hope this won't be too much of a toll but we are really appreciative that you've come.

MS MISZTAL: Thank you.

MRS OWENS: You might like to sit there and listen to Stella. Can you manage that? Would you be able to - - -

MS MISZTAL: Yes, I should be able to.

MRS McKENZIE: But if you feel that you need to leave then that's also fine.

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

MRS OWENS: Okay. The next participant is Stella Hondros. Could you please give your name and the capacity in which you are appearing and I understand you will also representing the self-help group, so you can explain that.

MS HONDROS: Okay. My name is Stella Hondros. I'm here representing myself and also the Multiple Chemical Sensitivities Self-Help Group, of whom - Miss Janet Forster is running. My - do you want me to - - -

MRS OWENS: Yes, whatever you want to raise.

MS HONDROS: I started to have chemical exposures from the age of about 12 that I recognise. We live in South Guildford and the shire council used to spray Lybacid on our home fruit trees, at home, because of the fruit fly baiting scheme. They would come every couple of weeks and spray and of course we lived on those trees, we ate from those trees. We were poor, we didn't - we had to get the fruit off the trees, so we were in constant exposure to that. Then we had the fumigation from the airport, or so we told that that's what the smell was, it was like a heavy, figgy smell and it would waft across regularly and of course we used to get severe headaches and nosebleeds and of course my brother, George, who is in the back row, also had the severe headaches and nosebleeds as well. So that's where the chemical exposures that I can remember started.

And as time went on I started to get definite rapid heartbeats, like in the early 80s, and that progressed into tachycardias. I don't know what exactly brought that on, but it could have been an exposure to antibiotics, because what I'd had is a dental problem which ended up as a Ludwig's angina and I needed to have intravenous antibiotics and I think that the doctors at the time gave me so much that I was hallucinating as a result of and what - I think that just absolutely drained my system and then of course I couldn't deal with the rest of the chemicals that were in the areas as well.

I think too that councils - I didn't know until last November that councils sprayed regularly with pesticides and of course what was happening is that the doctors were giving me some pretty horrific drugs to control the tachycardia, because I was getting tachycardia because of exposures to chemicals, but what was happening was that doctors are giving me more toxins to deal with the toxins. So of course I'm going to get very sick. In the end I was having such horrific side effects, I was virtually bedridden and what happened in the end is that I went back to the cardiologists and said, "Look, I can't take these. It's messed up my thyroid, it's just broken down my whole body." I was like a vegetable. And he says, "I'll send you to a thyroid specialist," who then put me on Thyroxin, another medication that I couldn't deal with.

So in the end I was so bad I had a list of symptoms that go down that whole page, page 3, that I've given you and trying to live with symptoms like that is impossible. I was a dying person. I had no choice but to go and see - I did a lot of - well, I tried to do reading, Jack took me to the library and I got an armful of books and I'd read two lines and fall asleep. I really struggled through that and Jack helped me as well and we worked out that it was toxicity and I went to an alternative health-care professional and asked him to help me to wean off all the medications, all the chemicals, everything, whatever, you know, because I was taking things like Amiodarone, Lanoxin, Flecanide - Flecanide, by the way, says on it, "To be taken for short-term only. Can cause sudden death." Now, my cardiologist had put me on that as a permanent medication. I couldn't go up the stairs to go to my bedroom. I was so ill from this - Tambocor, Thyroxin, blood thinners, all sorts of things.

So you can see why I had all these symptoms. In the end I felt a lot better. I started to heal a little bit, but what happened is, I realise that three or four times - or maybe twice, three times a year, over the last 20 years, I'd be getting these definite tachycardia attacks and I'd end up going to hospital. In November last year I - in June 2002, sorry, I went to Charles Gairdner Hospital in a state of tachycardia, which has irregular and fast heartbeat, and I was given Amiodarone intravenously to correct the condition. Now, what happened, as soon as that was in my veins, within a couple of minutes or not even that I had cardiac arrest, my heart stopped totally. As a result, then they had to flood the - I don't know what - the cannulars with saline and water me down as it were and they managed to get the heart going again, but in the meantime I woke up with a massive, massive headache and obviously I have come out of it with some brain damage, so that my whole body was like I was in rigor mortis.

So from then on the doctors - they realised then that I was chemically sensitive, so they realised that if this happened again they're not going to give me Amiodarone. If I had died from this pesticide exposure, because it was a pesticide exposure, as you'll find out, my death certificate would have said that I did from heart failure. Likewise, the spray man who was reported to die of an aneurism, they wouldn't have said "by weakening of the blood vessels by chemical exposure", they would have said, "by an aneurism" that he died. Hence, the statistics are not reflective of the real facts.

As it turned out, in November 2002, the lady next door was doing a garden for the neighbour and I said to her, "Please, I'm sensitive to chemicals. Do not use any pesticides because it may bring on this cardiac condition." So, she said, "All right, don't worry." I said, "My husband will come out and he'll take out all the weeds from the driveway" - because it is a shared driveway - "and please don't do it." So I went back into my house. She, in the meantime, she didn't spray the chemical, she poured it between the cracks on the driveway. So when I went to my sewing room, which is like two floors up but directly - the driveway down in front, I opened the window to get some fresh air and to do some sewing there and within minutes I’d collapsed and I was back in hospital with a tachycardia attack.

Within less than two weeks, less than two weeks from that, Jack said to me, "Look, you’ve been so ill I’ll try and get you out or take you for a walk to the park. We’ll go for a walk, we’ll come back and then I’ll take you out to dinner." This was on a Friday afternoon. Well, I never made it back. I just never made it back. I collapsed on the grass. Within two weeks I’d had another attack. However, a relative had seen the council trucks spraying only a few hours before, but because this person was very busy she didn’t have a chance to get to me and ring me and say, "Look, this is happening," and of course I had no idea that councils spray. I rang the Cambridge Council and I asked them for the spray dates of when they spray verges, parks, gardens, whatever and they gave me the dates for the last two years and they corresponded to my tachycardia attacks.

MS McKENZIE: And that’s the way you found out what - - -

MS HONDROS: Yes.

MRS OWENS: What were they spraying - were they spraying weeds?

MS HONDROS: Roundup - they were spraying supposed weeds on our verges, they do this twice a year. They do it in autumn and they do it in spring. There are no weeds on our garden. Each one of us has our lawns mowed and our edges done. There is no need for council to come and spray the drive - why spray on the road, there is nothing there. It is for cosmetic or preventative reasons, you know, I just can’t see the logic of what they’re doing.

MRS OWENS: But the other thing that amazes me is you’d had so many hospital admissions and collapses during that time, and yet the doctors treated you only for whatever symptoms happened to show, but no-one seems to have realised - - -

MS HONDROS: Misdiagnosis, what Agnes was saying is so true. The misdiagnosis led the doctors to giving me some pretty horrific, horrific drugs that leave you disabled for life and as a result I wasn’t able to protect myself. I keep going back to hospital. It’s like - I don’t want to be cynical, but like it’s perpetuating the business, as it were. Anyway, I shouldn’t be saying that. Sorry.

MRS OWENS: I don’t think the commission can offer any official comment on that.

MS HONDROS: No, that’s okay, I don’t want - that’s okay.

MRS OWENS: No, no.

MS HONDROS: They were spraying 1 per cent Roundup. When you buy weedkiller, Zero weedkiller, it is .7 per cent solution. The council were spraying a 1 per cent solution and I have been saying to them, "Please stop," since November last year. They have ignored me. The Health Department doesn't want to know about it. It's the "too hard basket". I complained to the minister, Mr Bob Kuchera. He then put me back to the Health Department. The Health Department are saying, "Well, you know, we're taking our time because we really want to have a look at your case very well" - and so it goes on.

MS McKENZIE: Have you tried making a discrimination complaint, in either Western Australia or to HREOC?

MS HONDROS: You know, it's difficult to know where I should turn to. I have complained to so many bodies it's not funny and everyone says - you know, it's just all too hard.

MRS OWENS: Did you know about the Western Australian Anti-Discrimination Commission or about the Human Rights and Equal Opportunity Commission? Do you know about those - - -

MS HONDROS: I didn't until Agnes had the courtesy to ring me about - what was it, a week and a half ago, Agnes. Because what had happened is, when I had the November attack and - let me, I'll keep going through this story, because what will happen, it will unfold, as we go. I had another attack. This time I find that Bold Park has been spraying 2 per cent Agral all over a 50 hectare property which is a kilometre away from my home and there was a drift from there that put me back into hospital.

MS McKENZIE: Can I ask - I'm not from Western Australia, but is Bold Park a big park in area?

MS HONDROS: Yes.

MRS OWENS: And is that somewhere that's in Perth?

MS HONDROS: Yes, Bold Park is - how can I say, it's near Floreat.

MR HONDROS: It's very close to the coastline and the prevailing winds in Perth are westerlies.

MRS OWENS: It's close to the coastline and they're spraying to get rid of undergrowth, for safety reasons.

MS HONDROS: Or certain weeds, yes, certain weeds and of course I'm downwind so of course I keep getting this thing and I did speak to them this morning and ask them how they have been progressing in their response to my complaint and they inform me that they will be spraying intermittently over the next nine months. So, you know, unless I pack up my bags and leave home I can't see a solution.

MRS OWENS: Have they explained why they're spraying in that area?

MS HONDROS: Yes. What happened, there was a bushfire there and unwanted weeds grew up, this is a couple of years ago that a bushfire - and they want to get rid of the unwanted weeds so that the bush can, so-called, regenerate, but with the sort of thing that they are spraying in that park, nothing is going to regenerate, not to mention that there are ant plagues because they've killed all the little lizards and everything else that eats the ants. So the ants being underground are the only things that have survived.

MRS OWENS: So it's upsetting the ecology.

MS HONDROS: Absolutely.

MR KALLIDIS: Can I interrupt a moment?

MRS OWENS: No, I'm sorry, you can't speak from the floor, because the - if you'd like to come up and give your name.

MR KALLIDIS: No, I just wanted to mention something on that issue - - -

MRS OWENS: Would you like to come up?

MS HONDROS: Come up here, George.

MRS OWENS: And just give your name and then you can talk too. That's easy.

MR KALLIDIS: I just wanted to help out.

MRS OWENS: Okay. Just give your name for the transcript and the capacity you're appearing.

MS HONDROS: It's my brother.

MRS OWENS: Yes, Stella's brother.

MR KALLIDIS: My name is George Kallidis, Stella's brother, and just to explain what was happening there at Bold Park. Basically the situation is that where you've got Winter growth, Winter weeds, they've got surface roots only and in spraying them with Roundup you're supposedly killing the plants with those surface roots only. Now, the native bush has got deeper root systems and therefore should not be affected. But that's not always the case. So those sprayings are there to kill off the plants that - the Winter grass that comes in and invades the bush area. That's the reason the council go in and spray.

MS HONDROS: Okay. Well, they've got a lot of explaining to do to me.

MRS OWENS: Stay there, because you might like to help out if somebody asks another question.

MS HONDROS: Now, after the Bold Park incident, which was about a month ago, my council then advised me - I've told them that Bold Park is a kilometre away, I said I need an exclusion zone of more than that, because you're going to be spraying - they sprayed a couple of weeks or a month ago. So they only gave me 300 metres and they also gave me only 24 hours' notice. So within 24 hours I've got to put my dog in a home, pack up my bags and just get out of here. So we drove down to Mandurah which is an hour south of Perth to get away from it. Mandurah Council said that they weren't spraying that week, so I stayed there for a week. I rang back to Cambridge Council, they said they were still spraying because of the weather so they were going to take two weeks to complete the job now. So Mandurah Council said, "We're spraying this week," so I thought, well, we've got to go again. So here we are like gipsies - - -

MRS OWENS: Like nomads.

MS HONDROS: Yes. Get in the car, now we've got to close off all the windows and everything so that no outside air comes because now I'm going to drive through farmland. I had to go - I had nowhere else to go but the very south coast where I'd heard someone at Peaceful Bay was living there with the same condition and that they had managed to get all the spraying out of that area so I might have a safe haven for a few weeks. So we got down there and I was sick for two weeks after getting there, overcoming the exposures that I'd had all the way along down to there. I was there - well, I was gone for about three and a half weeks altogether. I came back home and I'm not the full quid, as it were. Every time I feel sick, I can't sleep at night. I have all these health problems. My lungs feel like they've burnt out. I'm just not really coping. I have - like, I'm hot and then I'm really cold, and it's nothing to do with hormonal or anything like that. It's just that my body no longer controls its temperature any more.

I have all sorts of disabilities that I think I've mentioned to you. I've been very sick for the last five years or more. I need assistance to do my housework. I don't drive a car, I can't hold a job. I cannot do things like vacuuming because if you bend over my heart feels very uncomfortable. I can't sleep on my left side. I mean, you know, I'm just always having to sleep this side because my heart feels sore. Sleep is laboured, disturbed and never refreshing. I don't know if you have the same problem, Agnes, but, yes. I have a loss of executive function; in other words, I start a task and I can't finish it. I'll forget a pot on the stove and get caught up doing something else. I'm not quite there. I can't tell - sometimes I get confused left and right, and simple things like that.

When there's a discussion I have to really strain to understand what's happening because a lot of the time it's like a fog between me and the outside world, between my brain. It's like I can't think. There's not a clarity that I used to have. Also I suffer anxiety, confusion and sometimes when - I don't know if it's the chemicals in the air or I'm downwind of something, I go around the house stupefied. Like, I'll wander but it's aimless and I don't know what I'm doing. I don't know why I'm sitting there. For example, when I got back from the country I had to write a letter to Bold Park Authority and we had been out to get our vegetables - remember, Jack? On the way home we passed a spray truck, and I was all right for the first hour or so and Jack said to me, "Are you going to be all right?" and I said, "Yes, I'm all right," so he left me at home while he went out to go and do some other jobs. We'd just come back after being away for nearly a month.

I sat at the computer for five hours, I wrote four lines and I kept reading them over and over saying, "This doesn't sound right, Stella, there's something wrong with it," and I did that for five hours. I was not compos to say, "Break, you're not understanding," and it was only then that I realised, after about five hours, and Jack came home and I had to like, you know - "What's going on?" sort of thing. I come down and then I have to have bicarb of soda and some other things that we've worked out that help us to neutralise the acidity of the toxins and once we get that into us we can get some sort of PH balance back into our system to come back to it. So you can see I spend a lot of time wasted.

For my husband he's had to forsake his career in order to look after me. His life is constantly on edge because when I collapse with this heart problem there is no sound. I can't call out. I can't be left for any period of time. Economically it's been disastrous. We're living on our savings. It's cost us thousands of dollars in both conventional and alternative medical bills.

MS McKENZIE: And you can't get a disability pension and he couldn't get any carer’s allowance?

MS HONDROS: Well, I think we could be just over the threshold or something.

MS McKENZIE: Because of assets?

MS HONDROS: Yes. I mean, we’ve worked a lifetime to accumulate some sort of comfort in the latter part of our lives and now it’s being squandered on this problem. As for our children, they’re also living on edge. Like, Maria is always ringing home saying, "Are you all right, mum? Are you all right?" you know. My immune system is totally broken down through years of toxic exposures. I’m suffering multiple chemical sensitivity, compliments of the spraying habits of government departments. By government departments I mean by town of Cambridge, Bold Park Authority, the Ag Department, whoever else sprays. I don’t know who sprays.

When I complained to town of Cambridge they demanded that I put in a report from my specialist physician, specifically explaining my condition. So they put that in writing for me and the Health Department also demanded that. When I provided them with this medical bill - this medical certificate - I had to jump a queue for two years to get to see a specialist as an emergency and I also had to pay $200. I got $45 back from Medicare and I’m out of pocket $155. The council refused to pay me, they have ignored my - although I put in a bill. Why do I need to prove my medical condition before they stop spraying me? I have a right not to have my biological space violated. I have had years and years of spraying without knowing it, from councils, and now I’ve ended up like this.

Town of Cambridge also continued with the bullying. They sent my letter of complaint to Monsanto who probably replied with a wad of information saying that it was impossible for me to have this problem and that I should look elsewhere for the causes of my complaint. Their product was comparable to baby shampoo and dish detergent. I will not be bullied and how dare town of Cambridge or anyone else intimidate a sick person, pitting me against a multinational, because they think they’re going to bring in the heavyweights and bully us around just to cover their tracks. Well, it’s not going to happen.

The Health Department is slow to act or ignoring me in spite of my requests. These second list of symptoms are the ones that I now suffer generally, amongst other things, now that I’m not taking any medication. The fact that I don’t need to take medication between sprays proves that. I’m okay, it’s only the sprays that do it to me. I’ll be very quick with the rest because I’m mindful of time and I do apologise for having kept you.

MRS OWENS: You don’t have to apologise to us. It’s not a problem.

MS HONDROS: Okay, thank you. There are a lot of problems that I think we need to be recognised. The misdiagnosis is a problem. Most of this chronic fatigue fibromyalgia in my view appears to be from chronic pesticide exposures and I don't think I'm the only one suffering from this chronic exposure. We avoid going to doctors - as Agnes pointed out - because of the chemicals in surgeries. Doctors only offer pharmaceutical solutions. We're blamed on psychological reasons. We're insulted, we're ridiculed. And, yes, I do get really depressed. In fact when I found out about a year ago I was actually feeling really quite suicidal. At night I'd often not be able to sleep and I'd get up and stand at the top of the stairs and think, "Should I, shouldn't I? What am I going to do with myself? I can't take this pain any more. I just want it to end. I want these to finish. I don't want it to go on."

Doctors either ignore it or they're unaware of the magnitude of the chemical spraying by government departments. They're unaware of the problems that we have. In the spring they blame things on hay fever and prescribe antihistamines. In the autumn when the council sprays we're blamed on the flu, so they give us antibiotics. Let me tell you the town of Cambridge sprayed 35,000 litres of chemical in a tiny little space that we are. We're a very small town and on top of that we have Bold Park Authority - it's nearly, say, a quarter of our space in our thing would be the park - and they have also sprayed and they haven't told me the quantity that they're spraying. That's only one of many chemicals that they use.

There is nowhere to go where pesticides are not sprayed. Country people are even worse off. Hospitals are not equipped to deal with us in the trauma situation. We don't go to hospitals because of the perfumes. It's like a Myer perfume department when you go in there. I've had them actually stand behind the curtain to see if I'm going to smell them and then when I say, "Please go away," they go away giggling, and I'm saying that is so immature and downright dangerous for a patient who is already at their chemical threshold.

Cleaning staff use the chemicals. The food is inedible for us in a hospital; it's got to be organic. We need oxygen as a matter of routine. Sticky plasters - and I have previously asked Charles Gairdner Hospital to please have some on hand for my condition. Every time I go in there, "Sorry, Ms Hondros, we can't wait to find them now because we need to urgently get this monitor on you." So I end up with having all these dots over me and I end up like I've got crop circles - marks all over me.

We need to be separate from other patients. There are no institutions which can take people like us; for example, old people's homes. Like, if I get old, where am I going to go to? I can't visit my mother-in-law in an old people's home because of the chemicals, so that's going to be a problem for us. There are, like, physiotherapy facilities, ambulance rides, so we suffer at home and we're just isolated in our sickness. I warned the Health Department and town of Cambridge about the state of the river as a result of pesticides washing into it. I think the bloom that we've had is the result - what happens, you see, the pesticides sit on the side of the road, on the verges and so on, and when the first rains come they all wash into the river, taking with them all the chemicals. So then the fish start to die. I warned of this. What happens is that the normal algae in the river die from the pesticides.

Only the toughest, most toxic algae then survive and then because there's a vacuum they create a bloom. So at the moment no-one is even considering pesticides as a problem for the river, and might I add, pesticides from government departments, because if a private institution sprayed so many chemicals they would be taken to a court of law, as they were when - I think at the racetrack, Belmont racetrack they had a spill and they were taken to a court of law. That was Swan and Canning River. The sprays rehydrate after the first winter rains and this is what happened to me when we had a steamy, hot day it rained and this stuff started to evaporate again so I ended up in hospital again.

50 per cent of our children here in Perth - I don't know about the rest of Australia - suffer from asthma. One in five suffer from chronic asthma. This is the Australian Bureau of Census and Statistics figures. If nothing else please consider the children and the unborns. All people will eventually be in the same MCS category if pesticide spraying continues. It's like if I start filling my glass, that's how we all are. We're like a glass. If you keep filling it, filling it, you don't have a problem till the water reaches the rim, and when it spills over you end up like Agnes, like me, like Janet, like 80 other people in our chemical group who have nowhere to go and wander around like gipsies all around the countryside trying to find a clean place.

The cost to the medical and health system has blown out. It is deceptive what the cost is because it's not diagnosed. Chemicals must not be used for cosmetic and preventative reasons. It is our birthright to live in an unadulterated environment. It is right not to be sold pesticides so freely under the deception that they are safe and convenient to use. All other avenues of solutions need to be explored and pesticides left as a last resort. Might I say that when pesticides are tested, they are tested on strong men. The levels set are at industrial levels, because industrial levels are higher than for normal because industry does not want to pay compensation easily.

There are women, because of oestrogen, for some reason seem to be more sensitive and also children and unborns are more susceptible. Also when testing is done on such chemicals as Roundup, they test to see how much glyphosate is about but what happens is that glyphosate breaks down into more toxic chemicals and it's in a different form once it starts to break down, so it's not tested properly. For example, I believe that glyphosate is made up of polyacrylamide molecules. Now these are unstable. When they break down they form acrylamide molecules which are then a highly toxic nerve substance. I think this is the problem.

We also have the sick buildings - and I won't go into that, I think you've dealt with it enough there. Teachers need to learn and recognise symptoms of chemical poisoning. Supermarket, shops et cetera public toilets - we all need carers. Most people with MCS do not realise that they have it until it's too late and then they're permanently damaged. Up to 20 per cent of the population are affected by allergies - this is according to Dr Peter Dingle - and it may be up as high as 50 per cent but most of them don't know what's causing their allergy.

Headwest has classified MCS patients as having acquired brain injury, and we do need a taskforce - we've got to stop spraying. Our government has failed in its duty of care to people like us. It is not okay to spray. I don't abuse my body with smoking, alcohol or in any other way so why is someone else abusing me. If passive smoking is recognised as a proven health hazard, then what's different about government bodies dealing with pesticides. It's the same thing. We're not directly in contact with the pesticides, we're indirectly in contact with the pesticides and it is affecting us. I want the abuse to stop.

In summary - and I'll be very quick there - we need recognition. We also need legal representation because - I don't like taking people to court but it appears that these people, the only thing that they recognise is when it hits their bottom line. They don't think of people, there is no emotion, they are cold, they are heartless, and that's the way I feel that I've been treated. Unless you hit them with the language that they understand which is dollars and cents and bottom lines, they don't care.

MRS OWENS: Or unless it happens to somebody in their own family.

MS HONDROS: In their own family, yes. Someone needs to take on the responsibility. Now, pesticide companies say that Roundup is touted as being the least toxic thing. In fact on the document that Monsanto sent me which is that big wad of paper in that bag, it says that Roundup is a very low acute toxicity. By Webster's Dictionary, "acute" is "felt or perceived or experienced intensely, powerfully, characterised by sharpness or severity". It goes on to say, "most commonly indicates intensification", so you can see they're saying it's acute. However, in their zeal to use these products, government departments don't say, "It's of very low acute toxicity." They say, "It's a very low toxicity."

So the "acute" is lost somewhere in the story, and here they are pushing the wrong thing. It's a case of semantics. They're misrepresenting the product and I think they've got to take responsibility because what happened is the town of

Cambridge sent a letter, after my complaints, to all of the residents and they told them that these sprays are of very low toxicity. They didn't say "very low acute toxicity", so people are misrepresented with this. So now with their exemption forms, people are not being told the truth.

We need to implement immediate procedures. I personally need an urgent situation where someone can assist me to put me somewhere where I'm not going to be sprayed. I could walk out of this room today and not be seen tomorrow. What is happening is Bold Park is spraying continuously for nine months now. I have nowhere to go. I cannot just leave my home. Our daughter is getting married in eight weeks. I cannot leave my home, and where do I go to? If I do leave, where do I go to? Would they like me to go to the moon or another planet, or even that they're seeking to fire rockets to go and adulterate it as well. So that is the urgent need and I wanted to ask you two ladies if anything could be done urgently - urgently like yesterday - to find us somewhere where we can go, because I cannot - my home is not a safe haven any more. Sorry, is there any other questions?

MRS OWENS: Thank you for that. I don't know what the solution is. We will be taking your submission on board.

MS McKENZIE: We can certainly make sure that your council gets a copy of the transcript and submission.

MRS OWENS: I'd like to hear from the council. We'll ask the council - - -

MS McKENZIE: Yes, we'll ask them to make a submission to us.

MS HONDROS: That would be very nice.

MS McKENZIE: But at least that will make them start to - we would hope, begin to think about the problem more carefully than they seem to have thought up to date.

MRS OWENS: You've obviously done a lot of research in the area and I was wondering, have you looked at any initiatives that have taken place internationally? When we were talking earlier to Agnes, she talked about some of the hospitals in the United States with these guidelines and making adjustments. Is there anything that you could point us to which is a good example of how these things should be done?

MS HONDROS: Well, because of the situation I personally haven't done any study internationally. What I have done though is provided you with a reference list. I did manage to get from someone some download of stuff from the Net about pesticides and some of the problems they are causing. But I haven't got any information on how other people are dealing with it. I think one of the things is that you've got to look at the real cost of using pesticides in the community. The real cost is the cost of the pesticide, plus the hospitalisation costs. If you don't look at the real costs then you're not getting an accurate bottom line, as it were. You see, it might be saving the council money but it's costing the government millions.

MRS OWENS: You need to look at the broad costs but I suppose if we got a submission from the Cambridge Council, they would say, "You'd need to balance that with potential benefits," whatever they be. It's up to them to tell us what they think the benefits are.

MS HONDROS: They've said the benefit that they're getting is that - well, they won the Tidy Town award because it all looks nice and neat. It stops the grass from growing into the road and supposedly destroying the road - the kerb of the roads. I don't know, that's the only reason they're using.

MRS OWENS: It's not to keep snakes down or prevent fires?

MS HONDROS: No, nothing like that.

MRS OWENS: Stop fire hazards?

MS HONDROS: No, no, they claim that some of the - for the drivers that it keeps the footpaths clear so that the drivers can see around corners and this and that.

MR KALLIDIS: I think in actual fact it's a cost saving for them because if they don't spray then they're compelled to go and mow verges. In some situations the owners don't bother to mow their own verges and you see grass growing in the wintertime up to a metre high. So if they don't mow - it will cost them more to mow than to spray. My experience has been in the building industry over 20 yeas now and I might make a contribution here and just say there's a compulsion from shires, before you pick up your building licence, to nominate the method of termite control for your building. In most cases, builders nominate Dursban as the chemical that they're going to spray to control termites on their site.

The spraying of that chemical happens whilst the concreters are on site. The concreters will dig the trenches, the plumber will be there and sometimes the electrician will be there where conduits need to be laid under the concrete slab. The pest controller will turn up at about 10 o'clock in the morning - they start at 6.00. Three hours later everything is sort of dug up and prepared. The pipes are in. The pest controller will come in and spray the site.

MS McKENZIE: With everyone there?

MR KALLIDIS: With everyone there, walking around over the top of the site. I've been a building supervisor for many years and I know exactly what goes on. Everybody is on site, the spray person comes in, sprays his chemical and stands aside. Now, he's wearing a mask, gloves, boots et cetera, he's protected. The other guys on site - and there might be half a dozen or more people on site - aren't protected. But he sprays, he walks off, the grano workers then walk onto the site and cover that sand pad with a polythene plastic sheeting and they do that as quickly as possible, simply to contain the smells because the chemical Dursban has - well, it's still in vapour form and it's coming off the pad. They finish, the concrete slab goes in, the building is near completion and prior to any paving going down around the perimeters of the house, the pest controller in theory is supposed to come back, dig a small trench around the building and flood that trench with chemicals.

Now, my concern is not only for the guys who are on site but for the adjoining neighbours, especially considering the infill development that we've got here in Perth, there's so many new structures, new buildings going on in built-up suburban areas. Neighbours are not advised, kids are walking up and down the street. This chemical has been sprayed and they're telling us it's fine to use but I know - I mean, just breathing the chemical in, it's such a heavy smell, breathing that chemical in, there's got to be something wrong here, it's not safe. You've got to work off site. But the guys put up with it simply because they're there to do a task, they're all working on subcontract. If they don't work and do the job quickly they're not going to get paid for the time they sit around whilst that vapour blows away.

MRS OWENS: I presume some of these chemicals though would be regulated.

MR KALLIDIS: In what way?

MRS OWENS: Somebody must be checking chemical use to determine whether they're safe near humans. Would the Therapeutic Goods Administration - I'm not quite sure who it would be - - -

MR KALLIDIS: Obviously they're unsafe because the operator who's spraying the chemical is told that he has to wear a mask, he has to wear gloves, he has to wear protective gear, and then all the other guys on site don't have this. So he's spraying, he's got his protective gear, but nobody else does. So there's got to be some harm coming from these chemicals otherwise the operator wouldn't be told that he has to be wearing all this protective gear.

MRS HONDROS: George, I think the operator is not operating according to the specifications. I think you'll find that that's what's happening.

MR KALLIDIS: Well, he's a paid a wage to go onto site and spray, you know, this site and the next one.

MRS HONDROS: He just wants to finish, same as the spray truck that comes around our suburbs. They say, "We only spray where it's necessary," but they don't, because I tell you what, it's very difficult switching that little pump on and off and on and off as they go down the street. It's easier for them to just let it run as they go down the street, just blanket cover the whole road, and then that way, grass is not going to come back again and they won't be called back again to do something that may not have been totally covered.

MR KALLIDIS: In the past, I mean, we know the effects of dealdrin and other things that we now have banned, but in the past, buildings, houses, had core holes drilled at the bottom edge - every fourth brick one course from the bottom and the cavity of the wall was flooded with chemical. That's illegal now because there were so many times where there was single-leaf walls and operators would go in not knowing that there wasn't a double-leaf wall and they'd drill through the first leaf into a bedroom and pump chemical in it.

MRS OWENS: Into the bedroom?

MR KALLIDIS: Yes, and that's why it's now banned. But those older homes - I mean, I'm talking about 20, 25-year-old homes, that still have those holes - quite often you'll see an operator who goes back to treat a site and he goes and finds these little holes and puts his chemical into them, getting that chemical into the cavity. I don't think the metropolitan area of Perth necessarily needs to be treated - every site doesn't need to be treated for possible infestation of termites, especially in the inner suburban areas. In the outer suburbs, in ex-pine plantations in Winthrop for example, that was a pine plantation which was developed, and there were a lot of termites in that area. Maybe shires could say, "Okay, we've got a specific site here which has got a problem and we'll demand that everybody does it so that" - you know. But in built-up areas where the chances that there are termites is minimal, why demand a builder to have chemicals sprayed on his site?

MRS HONDROS: Termites also don't like soil that's been disturbed, so it's a pointless exercise as far as I'm concerned.

MR KALLIDIS: And the only - and most homes these days don't have material that is edible by termites. Even the roof framing is steel in a lot of homes.

MRS OWENS: So it's probably unnecessary.

MR KALLIDIS: It's unnecessary, but it - - -

MRS HONDROS: Sometimes.

MRS OWENS: But you're saying in these areas where there are pine plantations or near pine plantations it may be needed, but then you could have warnings and give people adequate warning and so on when it's going to happen.

MR KALLIDIS: Yes. They should be - yes, neighbours should be advised prior to spraying and maybe there should be a two-hour or maybe one day timeframe where the sprayer can come on-site and that spray will dissipate before the workers go on site.

MRS HONDROS: Notification is always a problem. Our council advertises in the local rag. Well, the first thing is chemical sensitive people don't read the local newspaper because of the smells. So we don't get to know about it, and who's going to look through X number of publications to see what the council is doing? You wouldn't do that. If I have something to tell the council, I tell it directly to them and they should do the same to us, and unless you have - Janet wanted to ask a question here. Janet, if you - okay. It says:

> A submission on the recognition of MCS was put to the National Centre for Classification in Health in February 2002. This is under consideration which must be accepted by doctors' committees referred to by specialist physicians. It then goes before a political committee, I was told originally, but it seems not to be necessary. MCS is listed by the World Health Organisation as an environmental chemical disease, which asthma, chronic fatigue syndrome, fibromyalgia and multiple chemical sensitivities is part of that. We are asking for it to be recognised here in Australia in line with the World Health Organisation. The decision will come in July 2004. Meanwhile, we are severely at risk to further injury and collapse; death from mismanagement. Public health offices are happy with submission.

MRS OWENS: Okay, well, that's very useful.

MS McKENZIE: Okay, thank you. That's very helpful.

MRS HONDROS: Any other questions?

MRS OWENS: No, I think we're fine.

MRS HONDROS: Okay.

MR KALLIDIS: I think education is very important. I was at Charlie Gairdner

Hospital three weeks ago, just to give you an example, to visit a friend of mine who had a triple bypass. He was on the third floor. So we go in there, come out of the lifts, and what’s happening - this is at about 7 o’clock in the evening - and there are four painters there sitting on crates. They had all their drop sheets down on the floor, and they were painting the foyer or the landing on the third floor.

MRS OWENS: Near the patients.

MRS HONDROS: Yes.

MR KALLIDIS: Yes, the patients were down the corridor, and I stepped out of the lift and there they were painting with paints that were not odourless. There are paints you can buy today which are odourless, or low odour anyway.

MRS OWENS: They’re probably more expensive.

MR KALLIDIS: They are a little bit more expensive. yes.

MRS HONDROS: But worth it.

MR KALLIDIS: And they’re - - -

MRS OWENS: No, I’m saying, yes, if they’re painting the hospital, they’ll probably just go for whatever they can get.

MR KALLIDIS: You’d think in a hospital situation which is a closed environment, you know, you can’t open windows in the hospital, you can’t let it breathe and let it dry out quickly - - -

MRS OWENS: And a patient can’t just get up off the bed and wander off and say, "No, I don’t like the paint fumes."

MS McKENZIE: No, that’s right, you have no choice.

MRS HONDROS: No. Yes, this is why I can’t go to a hospital, why Agnes can’t go, why Janet can’t go. Any last comments, Janet?

MRS OWENS: Okay, well, thank you very much.

MRS HONDROS: Thank you, thank you everybody.

(Lunchtime adjournment)

MRS OWENS: The next participant this afternoon is the Association for the Blind of Western Australia. Could you each give your name and your position with the association, for the transcript.

MS CLARK: My name is Marija Clark. I work as the advocacy officer with the Association for the Blind.

MRS OWENS: Thank you.

MS SOLOSY: I'm Carol Solosy, manager of Library Information and Research Services.

MR GRIBBLE: And I'm David Gribble, the manager, Technology, Training and Employment Services.

MRS OWENS: Good, thank you, and thanks for coming, and I'm sorry we started a little late but hopefully we'll make up some time now. I'd like to, on behalf of Cate too, thank you for your submission and you've raised quite a number of interesting issues in there and we thought you were happy for us to just start to chat to you about each of those - - -

MS SOLOSY: By all means, yes

MS McKENZIE: Do you want to say anything first or are you happy for us to just start chatting?

MS SOLOSY: No, I think we agreed, Cate, that anything that we really wanted to say that we felt was important, we'd put into our submission, and so we're really just happy to address any particular questions you might have for us now.

MRS OWENS: It was a very good submission and I thought you covered just the right sort of issues.

MS SOLOSY: Thank you.

MRS OWENS: And I know that you were a little bit worried about coming - - -

MS SOLOSY: Mm.

MRS OWENS: And I hope that we're able to set your mind at rest. It's a very easy-going process.

MS SOLOSY: Yes, you're both very friendly and I can see that now.

MS McKENZIE We're not going to scare everyone away. We want encourage people to come.

MRS OWENS: Yes, and I think you've got a set of the sorts of questions that we would like to ask you.

MS SOLOSY: Yes, thank you. That was helpful.

MRS OWENS: So maybe we'll just run - - -

MS SOLOSY: Launch into it.

MRS OWENS: - - - through some of those. I don't want to give you any surprises. I mean, an important issue you did raise was the issue of insurance and people with vision impairments being treated differently, and I think a number of participants are raising this issue of insurance.

MS SOLOSY: Okay.

MRS OWENS: Not just for people with vision impairments but generally people with disabilities.

MS SOLOSY: Yes, it's a hot topic, isn't it?

MRS OWENS: And it's a hot topic, and so I think what we're trying to do is get to the bottom of it. How big a problem is it now? Has the industry addressed some of the key concerns? Are these concerns still there? So the question that we were really going to ask you was, you know, how common is it now for people with vision impairments to be treated differently or has the situation improved over time?

MS CLARK: I thought I might start with attempting to answer the question about, is the problem of discrimination in insurance common? I don't have any statistical-type data to offer.

MS McKENZIE: Have you got - any kind of stats is fine. I mean, there are many cases where there's not stats.

MS CLARK: Great, but I understand that it certainly is a problem, to the extent that I'm aware of one Western Australian specialist employment service - they're a competitive employment-training placement agency - that receives Federal government funding through the disability programs at the Federal Department of Family and Community Services in Perth, that they were looking at earlier in the year lodging a complaint, I believe under the Disability Discrimination Act, against an employer's insurer because they had a job seeker, a candidate, who was offered a position by an employer but it was in fact the insurer that was the barrier, and I'm not sure where that's gone and where that's at, at the moment. But that to me does certainly indicate it is a big enough problem for an agency to be considering - - -

MS McKENZIE: Mm, because with unemployment insurance of course it makes it very difficult for the employer to include that person because all the rest of the workforce are covered by it.

MS CLARK: Yes, and apparently, from what I understand, the employer didn't have an issue at all. The sticking point was the insurance company. So if I can refer you to that employment service, that they could probably give you more details about that.

MRS OWENS: That would be good if you can give us some details about that service. You can do it either on the record or we could talk to you later about it.

MS CLARK: Certainly, yes.

MRS OWENS: But do you know whether the complaint was going to be under the Disability Discrimination Act or under the Equal Opportunity Act, the Western Australian act?

MS CLARK: From my understanding it was under the DDA but I could stand corrected. I wasn't involved in the - - -

MRS OWENS: Maybe we could get onto that agency and talk to them about it. That would be very useful.

MS McKENZIE: Ask them if they'd like to make a short submission perhaps.

MS CLARK: But certainly the case that I had mentioned in our submission that I was personally involved with, I certainly did have a - that was supporting a young man, a gentleman, who was highly educated, he had a couple of university degrees, very employable, and he wanted an immediate job, which he was offered by a Western Australian government department. It was in a call centre. They were keen to offer him the job and again the sticking point there was the employer had said to him, "Look, we'd like you to start on Monday, however don't turn up on Monday if you do not have a certificate from AGP stating that this job won't unduly affect your health, type thing."

MS McKENZIE: And there was no other health problem that - - -

MS CLARK: No, and the job was quite unrelated from what I could gather. It was a call centre job. We were both a bit astounded about that request. Like, no other employee was required to provide such a certificate. The young man, the gentleman, was also relatively new to the state, so he didn't have a regular GP and he felt as though, you know - rather disempowered, I would imagine, in terms of he would say to me, "Gee, I don't have a GP that could comment on this, and they really wouldn't know." But essentially it was a matter of, "Well, do you want the job or do you not want the job?" When I spoke to the employer it was very much a matter of, "Well, our insurance company insists on this and if he doesn't come up with the piece of paper, he doesn't turn up" - blatant as that. So that is quite discriminatory.

MS McKENZIE: Goodness.

MRS OWENS: So they were using the insurer as their excuse for asking for the medical certificate.

MS CLARK: That's right.

MS McKENZIE: Did you believe that it was the insurer who was in fact asking for the certificate or was it the employer?

MS CLARK: Yes, Cate, I didn't have the opportunity to sort of investigate that to that extent. The young gentleman had just gone to AGP and was fortunate enough that he could get the piece of paper. He even had to pay personally for the GP's consultation fee because he didn't have a Medicare card yet. So you can imagine the hoops and the barriers there but to answer your question, Cate, I can't - all I can tell you is, that is what the supervisor was adamant to me was the policy. He was employed just from luck.

MRS OWENS: And I presume that certificate was requiring the doctor to certify that that person was capable of doing that type of work, presumably.

MS CLARK: He was actually to certify that the type of work he was doing won't impact on his vision impairment, which was a genetic issue. It wasn't a function of injury or anything like that.

MRS OWENS: I've just finished completing another study for the Commonwealth government on GP red tape and I've spoken to many, many GPs about filling in such certificates, and the general consensus was a degree of discomfort about making assessments about people's ability to do the job, whatever the job is, because of lack of knowledge about what's going on the workplace, and doctors say, "We're very happy to provide advice about a person's medical condition," but taking it one step further to saying they are or they're not capable of doing a job is asking them to probably extend beyond where they should - - -

MS CLARK: Applying it to their functional ability, which, yes, is probably - yes, most GPs might not be able - and the client himself didn't feel as though - it was so depowering for him literally. He sort of felt, "Well, I'm compelled to do this but it makes no sense. I have no control over this."

MRS OWENS: It's not a great way to start a job, is it?

MS McKENZIE: No.

MS CLARK: No, but for the record, he did start the job and he went very quickly from part-time to full-time. He must have made an impression.

MS McKENZIE: When he went from part-time to full-time they didn't ask him for another medical certificate, did they, in case - - -

MS CLARK: Not to my knowledge.

MS McKENZIE: Which really is the point, isn't it?

MR GRIBBLE: And this is a scenario where the employer actually was keen to have him start work. So I would hazard a guess that it really was a requirement from their insurer or they perceived it to be one, which may be a different thing.

MRS OWENS: Regardless, it's a matter of making certain assumptions about what you need to be able to do a job and - - -

MS CLARK: And I guess, Helen, for me that really showed - the Disability Discrimination Act, certainly it's highly useful in terms of access to employment, and this I guess is one issue that we could see that might limit the good work or intentions of the DDA that could be improved upon to help achieve the desired outcomes of the disability discrimination in terms of equitable employment opportunities.

MRS OWENS: What about other sorts of insurance? Has anything else come to your attention?

MS CLARK: Yes, sure.

MRS OWENS: Life insurance or income protection insurance.

MS CLARK: Interestingly, if I can offer - I don't have a case example to share in terms of life insurance, income protection insurance, but certainly we were aware that locating adequate insurance coverage for some adaptive technology, some equipment that one might need to carry around with them that is highly portable and certainly expensive, can be very difficult to locate because they tend to be, I understand, highly portable and very expensive. So that has been an issue that I'm aware of some of our consumers have had difficulty locating that. I'm told that larger companies like, for instance, Toshiba who sell laptops, these days are able to expand their service and offer insurance to cover the new laptops as well - an insurance policy. However, smaller companies that create adaptive technologies, like Pulsestarter, are a much smaller company and don't have similar programs. So that has been an issue.

MS McKENZIE: And they come at a price. That's the other thing.

MS CLARK: Generally in regards to accessing information about any type of insurance policy, what it covers and so forth, the DDA gives the individual who is blind or vision-impaired a right to have that information available in an accessible format. So the DDA is very important in terms of trying to access for an individual information about insurance policies and information. However, again I'm aware that there's the Community Law Service in Western Australia called Sussex Street. They have a disability discrimination unit. I understand that they have received a number of complaints regarding the accessibility of information provided by professional services, be it accountants or lawyers or financial advisers, that sort of thing. So you come along to seek professional advice from such a person and you're a fee-paying client and you're getting the information in a format that's accessible to you - have been a problem.

MS McKENZIE: You've raised the accessibility issue as well in relation to textbooks in education. Do you want to talk a bit about that?

MS SOLOSY: Yes, certainly. I mean, that is quite a significant problem for tertiary students who have a visual impairment who get accepted into their courses but then have such enormous difficulty in obtaining reading materials and textbooks in a format that they can access. I mean, our organisation does provide a service whereby we will reproduce textbooks and reading materials into Braille or audio format for the students. But, of course, there's always the difficulty of actually being able to receive your information in time. It's one thing to get it in an accessible format, but you have to have it in a timely manner so that you're not disadvantaged, so that you can read your material in time to meet all of your study deadlines.

What we discovered or what we were experiencing is that with technological changes, more students are able to access their reading materials in electronic format, which is a good thing, because it speeds up access, but that in itself raises other problems. The reluctance of publishers to make their texts available in electronic format, the way in which they format their texts can often make it difficult for students to access them because, you know, they're formatting for publishing purposes rather than for somebody to read in an electronic form, so that's difficult. Overcoming copyright hurdles - yes, they're the biggest issues really. David and Marija, if you want to jump in and add anything - but, yes, I mean, that's an ongoing problem and it's been a problem for a long time. It's still a problem.

You're probably aware that the Human Rights and Equal Opportunity Commission did have a forum on the accessibility of tertiary texts for students with a visual impairment, and they had a forum and arising from that forum were some recommendations where there's a lot more concerted effort now in bringing people together, and appropriate bodies together to try and thrash out some of these issues. Really what you need are publishers who will be very willing to make their textbooks accessible in electronic format, but in an accessible electronic format, and some sort of a central repository would be the best solution.

MS McKENZIE: How far has that initiative got? I mean, the forum has occurred.

MS SOLOSY: Yes, that's right. Yes, well, I'm not sure. Obviously probably they would know better than me, but I'm not aware that there's been a lot of positive outcome at this stage.

MS CLARK: You might be aware that there was, not too long ago, an act passed in the United States saying that all textbooks used in compulsory curriculum had to be made available in electronic format for this very reason.

MR GRIBBLE: I'm not sure that it's actually reached legislation stage. It's certainly a draft bill for the US.

MS McKENZIE: So it's a proposal at the minute.

MR GRIBBLE: Yes. They went through a process very similar in that they had a forum which involved both the disability community and the publishing industry to look at how they could thrash out a standard for electronic publishing and a legal deposit system that meant that when a book was published an electronic version of it was automatically put into a format that would allow it to be used for somebody in an accessible way, and deposited with another legal entity in a matter of course. That was accepted by the industry. I should point out this is the educational publishing sector, not the publishing sector - - -

MS McKENZIE: Not the general publishing.

MR GRIBBLE: And from that was then drafted a bill which has gone forward to the US government for consideration, as I understand it. But if that passes they will be a long step down the way of actually providing timely access to materials for students, and much further, I might say, down the path than Australia is until we go down that same direction.

MS McKENZIE: And the proposal is there'd be some central database where - yes.

MR GRIBBLE: Yes. I think the National Library, the US National Library was considered to be the central repository for those.

MS McKENZIE: And presumably then, as far as accessing, there would be - I don't know whether it would be generally accessible to any student irrespective of whether they had a disability that needed availability in that format. But you can see the publishers' argument which is if anyone can do this we're never going to sell any books.

MS CLARK: Yes, that's right.

MR GRIBBLE: That's right, and I think there was still the generic restriction of copyright around that, similar to the copyright laws we have here, that it was only accessible for certain purposes by people with disabilities. So what it does mean though that is when the book is published, that electronic copy is available, which means that if a student is using it as a text, it's immediately available for them at the beginning of the year or the semester as opposed to three months into the semester when it can be Brailled, or three months into the semester once the publisher has finally agreed to give up an electronic version of it.

MS CLARK: And we wonder, you know, it is that the students, particularly when they further their education after compulsory schooling, they attempt to tackle a university course and we wonder why it is that they're on a backward foot.

MRS OWENS: So this bill in the US is only going to cover compulsory courses, so it will only be primary and secondary, or will it cover some tertiary education as well?

MR GRIBBLE: Initially it is K-12, but my understanding is that's phase one, and then it will be extended to the post-secondary educational publishing sector as well.

MRS OWENS: Some of our kids here might benefit from some of that US material, but a lot of the material I presume that we use in our Australian schools is Australian-based material. So we still need to do something here as well.

MS CLARK: Yes, most definitely.

MR GRIBBLE: And the other restriction of course is that's a piece of US legislation which may have no impact off-shore. So they may not be prepared to give you an electronic copy if you live in Australia.

MRS OWENS: Yes, that's true. It's probably a worthwhile bill to watch the progress and see what happens with that one. Sorry, I was going to say, who's going to be expected to bear the cost? Will that be the publishers themselves or how do they fund it?

MS McKENZIE: Or does the Library of Congress help to produce the electronic copy? In other words, actually, does it bear some of the cost?

MR GRIBBLE: The electronic copy is produced anyway because of course publishers all publish electronically initially at least. So it's a question of - my understanding of it was it that it was about that coming up with an agreeable standard that they could all work with, and they've got a standard now for how the file should look. It was really a question of them then using that as their base for going on to print publication. So there's no additional cost in theory incurred by the publisher at all. The cost would be in the warehousing and maintenance of those electronic legal deposit copies.

MS McKENZIE: But that would be borne by Library of - - -

MR GRIBBLE: And again I understood the government would pick that up under the Library of Congress budget.

MS SOLOSY: You've got a standard mark-up language, then that overcomes so many barriers. Because you might assume that because it's in electronic format it's going to be accessible, but it has to be the right electronic format.

MS McKENZIE: But once they've done that basic work to develop the standards and so on and then it's done - - -

MS SOLOSY: That's right.

MS McKENZIE: - - -with some updating as required, but - - -

MS CLARK: And certainly the West Australian TAFE colleges and universities do their best to obtain alternate formats for their students who require that, but do find that they're limited when they have a publisher umming and ahing or taking months to decide. So it would make a huge difference in terms about - - -

MR GRIBBLE: It's also an issue where a book may not be a current edition and the publisher wipes routinely its electronic publication files. They don't hang onto them necessarily. So again a legal deposit system would get around that because there would always be a copy.

MS CLARK: Preserved, yes.

MS McKENZIE: What about the related topic of adaptive technology? Do you want to say something about that because you talked about it in your submission?

MR GRIBBLE: Okay, yes, I'll talk about it. Adaptive technology really is having an enormous impact on people who are blind and vision impaired and in some respects is opening a lot of doors for people to be able to access things that they've never been able to access, and at the same time highlighting a number of areas where there are barriers to access. They've never been apparent before because the technology has never been able to provide that access. An example is obviously the Internet, which has been an enormous boon for people who are blind and vision impaired because suddenly you have material that, given the right set of accessible technologies, access technologies, can be available, readily available without any need for translating or transcribing or any third party to intervene in the process of accessing information.

So the Internet is a valuable tool but only on a couple of premises; one, that the person has the technology to access it - and there we're talking about technologies that take textual information and put them either into a magnified form or into a spoken word synthesised speech form or present them as Braille, one of those technologies. But at the same time, those information sources are only as accessible as they way they've been constructed by the person who's actually put them on the Internet. So we spend a lot of time and energy in terms of advocacy with organisations that publish their information sources onto the Internet and as web pages in trying to get across to them the need to meet basic access standards as proposed by the World Wide Web Consortium for how they design those pages.

The technologies themselves, those assistive technologies, are pretty useless unless a web page or web information source has been designed to meet a certain set of minimum standards. So that's an example, I guess, of where the technology has made a whole new area of information accessible. But at the same time it's highlighting the barriers that are created in the generic information providers area through not considering the broad spectrum of people who will access those information sources when they're created.

MRS OWENS: Will this create an opportunity for more children with vision impairments to go into the general education system rather than be in special schools? Will it lead to more integration?

MS CLARK: We actually don't have any segregated schools.

MRS OWENS: There'd be hardly any special schools left, I would have thought.

MS CLARK: No.

MR GRIBBLE: Western Australia, there aren't special schools as such. There are special education units attached to mainstream schools. They're primarily for students with multiple disabilities who couldn't function in a mainstream classroom without high levels of support. So vision impaired children are fully integrated into the K-12 system. Western Australia has an education department district support unit called the Vision Impairment Service, and they operate a program I'm sure which is very similar to the other states of visiting teachers who work directly with the students in the classroom on a regular basis to provide them with those additional skills around techniques and abilities that are related to their vision loss rather than to the curriculum directly. So it's things like Braille instruction and technology and keyboarding skills and those sorts of essential skill sets.

MRS OWENS: Are there enough of those sort of people in the system?

MR GRIBBLE: Never. No, I mean, you would say no in that the amount of time any VT can spend with an individual child is fairly limited. They might see them once a week.

MS SOLOSY: Maybe even less in the country.

MR GRIBBLE: Or less if they are - yes. Obviously Western Australia is a huge state and I think they have, at last count, probably 15 to 20 visiting teachers who have to cover 600 plus children throughout the system throughout every school in the state.

MS McKENZIE: So the amount of time they can spend has got to be relatively small.

MR GRIBBLE: Yes. So they really focus on the core skill set and they, I think, would say themselves that there is a lot of room where they could do a lot more with the child and expand a lot more on the essential skill set for a child, but they don't have the time or the resources to do that.

MS McKENZIE: So does that really mean that a lot of the day to day problems that might arise are really left to the classroom teacher and maybe the student with the basic skills to try and sort out between themselves.

MS SOLOSY: Yes, that's exactly how it is.

MR GRIBBLE: Yes, and that can lead to disadvantage in the school system for the child, particularly if you have a teacher who is really - finds it difficult to address the needs of a single individual child in a class of 30 or 35, particularly where those needs might be quite different. We find the same issues in post-secondary, I might add. It's not just in the K12 system; it's being able to say, "How do I adapt my curriculum or my teaching methods to address the learning needs of this child?" - and some teachers are better at that than others. Some are better at looking for help, for people who might be able to give them some ideas. As an organisation we have regular contact both with the visiting teachers and vision impairment service and with lecturers and disability officers in the post-secondary system to try and give them that expertise in terms of, "These are the strategies you might use."

MS McKENZIE: One of the matters that have been raised in numbers of the submissions that have been made to us is there's a question about specialist training for teachers. There seems to be a feeling in some of the submissions, not all, that there could be a bit more and that teachers would be helped by having a bit more specialist training in the areas of disability.

MS CLARK: Absolutely, and I feel as though then there's more ownership by the teacher to feel a larger sense of responsibility, "This student is in my classroom or my lecture theatre," and then I have to consider how I will make my information that I'm teaching accessible to that student. Yes, encouraging the push for mainstreaming, if I can call it accessibility ideas through the mainstream, if that makes sense, is so important. I think of Microsoft company in the United States, who have an arm now that is devoted to research and development in considering how do they make their products consider people with disabilities perhaps. I strongly believe that that initiative is an enormous initiative because they're such a huge company and the potentials there are huge. I would understand that that initiative comes from the anti-disability discrimination legislation in the United States, so the spin-offs are potentially - - -

MS McKENZIE: Vast.

MS CLARK: - - - great, yes.

MR GRIBBLE: One area that we probably did want to highlight, I think - it's later on but we may as well talk about it now in the context of what Marija is talking about there - is the fact that the Disability Discrimination Act is a great piece of legislation but it's not a piece of legislation that is very proactive in that it's a reactive piece of legislation. It requires an individual to feel that they have been discriminated against and then pursue it. To our mind - and this is the example that Marija is using with the American system - the Discrimination Act would have more impact on society if it was regulated through a set of standards across various sectors.

Now, in the US the example of that is section 598 of the Rehabilitation Act, which effectively says that the US federal government will not purchase anything unless it can be demonstrated to be accessible. Since that was introduced that's had enormous ramifications for all companies that want to sell to government and in fact government themselves, but what it's brought home to them is the need to be accessible, to make sure that equipment and resources that are being purchased - and services - are all accessible.

MS McKENZIE: Is that only to vision-impaired people or to people with disabilities generally?

MR GRIBBLE: No, it's to people with disabilities generally.

MS SOLOSY: It's IT related.

MR GRIBBLE: Principally, yes. But what it means is that the awareness is now being raised. You see examples of the fact that the primary driver for people to make services and information and products accessible is government regulation. There are not too many organisations out there who are looking around to do things for groups of people without some sort of driver to make them do that, and certainly regulation by government seems to be a driver. An example of that is in the environmental area where the principle cause for organisations to practise environmentally aware products and production processes is still government regulation. It's not the consumer market; it's about the fact that government requires them to. So in the area of the disability legislation we feel that having a set of standards that organisations need to live to in terms of regulation would probably have a much greater impact and be proactive in the sense that organisations would be thinking, "How do we meet this?" as opposed to thinking off the back foot of, "I hope I don't get anyone suing me under the DDA."

MRS OWENS: There of course are mechanisms in place to develop standards and there's already been a transport standard put in place, but we've heard from others that the transport standard is there more for people with physical disabilities and it's not necessarily embracing some of the - - -

MS McKENZIE: Hearing impairments, for example.

MR GRIBBLE: And of course you have the education standards that are being reviewed at the moment, the proposed ones.

MS McKENZIE: But do you think it's that kind of standard that you'd be looking for, or are you looking for something different?

MR GRIBBLE: One idea we've suggested - did anyone talk about this one, disability service plan?

MS SOLOSY: Yes. I mean, a great example here in Western Australia, which I'm sure you're both aware of, is the disability service plan that such agencies - local government agencies, state government authorities and organisations - have to prepare and submit. That's a very positive way of making sure that all organisations are mindful of their requirements. We think that that's the sort of thing that could be explored to be extended because it is so positive and it does require everybody connected with an organisation to make it such a systematic way and a systemic way of making sure that those things are embedded into the way an organisation thinks and works. So if you're not necessarily going to go down the track of exploring standards, that's just another way of doing it.

MS McKENZIE: So you're looking at accessible practices throughout an organisation.

MS SOLOSY: Yes, that's right.

MR GRIBBLE: So a logical extension would be to Commonwealth agencies as opposed to state-based agencies to have a disability service plan.

MS McKENZIE: Because in Western Australia it's state government agencies and local government, isn't it?

MS SOLOSY: That's right. That's - - -

MS McKENZIE: So that's compulsory?

MS SOLOSY: It is compulsory.

MR GRIBBLE: And they are reviewed every five years.

MS McKENZIE: Who reviews it? Do the organisations have to review it or is there a monitor?

MS SOLOSY: It's lodged with the Disability Services Commission.

MS McKENZIE: And they're the monitor?

MR GRIBBLE: They're the monitor, yes. They're a statutory authority, so they monitor all the disability service plans for state government agencies.

MS McKENZIE: You would want them to be introduced into the Commonwealth sphere, so then that would apply to Commonwealth government and its agencies.

MR GRIBBLE: Yes.

MS McKENZIE: And anyone else, like private sector?

MR GRIBBLE: It would be more difficult, obviously, in the private sector. You might take a very slow and careful approach to the private sector because one of the obvious questions is: how do you police something like that? The last thing you really want is government trying to police the private sector in terms of those. But one idea that we thought was perhaps - where you've got private sector industries that are in receipt of government funding, they're already in a contractual obligation with the government to get those funds. There is nothing to stop government building in a requirement for them to practise accessible employment processes, for example.

MRS OWENS: Why not the others?

MR GRIBBLE: Ideally, yes, you would say that all private organisations over a certain size where you could demonstrate that it wasn't going to cause them undue hardship should have a disability service plan in place, but the realities are we felt it would probably be very difficult to police that.

MS McKENZIE: Just because the - - -

MR GRIBBLE: Well, who would monitor it?

MS McKENZIE: Yes, the monitoring is an enormous task.

MS CLARK: Unless you make it like a voluntary - a little bit like the various quality assurances that are about and then perhaps some organisations can choose to have that status of having a disability service plan as well, and that's a very positive thing.

MS McKENZIE: That's like an incentive, isn't it?

MR GRIBBLE: Yes, and you could weight it. I mean, if people are tendering for government purchase contracts, there could be a weighting on, "Do you have a disability services plan?"

MS CLARK: And the sorts of mandatory outcomes that the state disability service plans require is for the organisations to look at how they are going to adapt their existing service to meet the needs of people with disabilities and how they're going to ensure that their buildings and facilities are accessible and inclusive, and certainly how they're going to ensure that the information that they provide is accessible and inclusive. It also ensures that - has the organisation considered how they're going to ensure that their staff and employees have awareness and information and knowledge? So you have a bit of in-service training, which is so important for people's attitudes, I think.

MS McKENZIE: So it address behaviour and attitude all together.

MS CLARK: And, lastly, it has the organisation look at what opportunities they're going to create to include people with different disabilities in their decision-making process. So they're the five-step mandatory outcomes that the state disability services plans require of state and local government organisations. In addition to that we would consider what would be extremely effective and desirable is if you could add a sixth outcome that relates to employment, not only employment outcomes but certainly employment recruitment processes and practices and consider, "Are they discriminatory in any way?" So for the DDA to really have an impact in reducing discrimination in our community based on disability, that would probably be one of the most effective ways to make it occur. We know that government needs to maintain that longer-term goal and vision because of the benefits to the country and to the community.

MRS OWENS: Marija, have you got any examples of benefits that have arisen from the Western Australian disability service plan? Are there some examples out there of some good things that have - - -

MS SOLOSY: Our current one has worked really well.

MS CLARK: Yes, fantastic. The states - they're now called departments of planning and infrastructure, which is our state government department of transport - have got a huge disability service plan, and that has the department not only continually review and consider how they are performing, so there's that continuous improvement element, but in terms of improving access, absolutely. The trains I think in this state have improved immensely in terms that now they have the voice output. There has been a lot of effort into considering buses and trains, how accessible they are from a physical and sensory point of view.

We know as an organisation that a lot of the taxi services in this state can be problematic sometimes for passengers who have a guide dog, and in the last review of what was then the Department of Transport's action plan it was the perfect opportunity for us to raise that with the department and say, "Look, this is an ongoing concern - it hasn't gone away - where cab drivers wrongly don't allow a passenger into the taxi because they have a guide dog." A lot of cab drivers, it being a transit industry or what, don't quite understand that they can't not accept. So it's a real concern if you're out there somewhere with a guide dog on your own and you've got to get home or somewhere and there's a driver refusing to take you. It's a real safety concern. So the action plan - that's what comes to mind as an example.

MS McKENZIE: And that's been a success story?

MS CLARK: If I can explain a little bit further. Because that's essentially breaking the law, breaking the Discrimination Act if that occurs - but unfortunately what was happening was the individual taxi companies, should they receive a complaint from a passenger about this issue, as with any other issues that is a breaking-the-law type issue, not only a customer service complaint, were required to report this to the government department, the Department of Transport then, and we didn't actually pick up that that wasn't occurring until we were asked to sort of be involved with the review of the department's action plan and we didn't actually pick up that that wasn't occurring until we were asked to sort of be involved with the review of the department's action plan, and so it was quite an enormous opportunity to sort of say, "Hang on, this is happening," and they were, like, "We're not aware," is it, you know.

MR GRIBBLE: I guess one of the best parts of that disability service plan process is that the agencies are required to consult with the community about are we meeting our disability service plan standards, and it is an opportunity for an organisation such as ours to have some input.

MS CLARK: Yes.

MR GRIBBLE: Which wouldn't normally occur.

MRS OWENS: So they are consulting.

MS SOLOSY: Definitely, and not just with agencies but also individuals, and not a lot of local government councils, for example, have got disability access groups, committees where they're having membership from people in their local government authority with a disability to give input, so real grass roots local people providing input to their local councils, which is terrific.

MR GRIBBLE: And concrete examples of outcomes from that process. A lot of libraries now have adapted technologies in the library that have been something that that disability awareness group, that group has recommended and the council has then followed through. So there's concrete outcomes.

MRS OWENS: We had a lady that came to see us this morning in a wheelchair, and she and her husband brought along a number of photos, and she was talking about access to footpaths and access to shops and to be able to go along footpaths unhindered, but quite a lot of those photos showed, you know, fairly interesting examples of footpaths which were totally blocked where it would be very, very difficult for somebody that was sight impaired to make their way along those footpaths.

MS McKENZIE: Tables, chairs, merchandise, open doors that open out into the - - -

MRS OWENS: I'm just wondering about these compulsory disability service plans that local government is meant - if they're meant to have one, why aren't those plans bringing in these sorts of issues? Why aren't they covered, or if they are covered, is anybody policing it?

MS SOLOSY: Well, I mean, obviously it's a long, slow process, and I guess, you know, for local government authorities, especially those that are very large, that's a heck of a lot that they've got to get across. I can give you an example, just talking about going along footpaths and how safe are the footpaths for people with a vision impairment, our organisation developed some guidelines on safe alfresco dining facilities. So we produce guidelines on how to arrange your furniture on the footpath to make it easier for vision-impaired people to walk down the street, and we sent those out to every local government authority and I know some of those have picked up on those and have actually contacted us and asked for clarification and will refer to them when they're going to be giving permission for premises to have alfresco dining facilities. So I think it's - I mean, obviously you can come up with examples of bad access or no access. I just think it's a question of just keep on trying, keep consulting, advising, promoting, encouraging, supporting and even rewarding, and just pick up the hard work.

MS CLARK: Carol, I suppose the role of the disability service plan certainly puts it on the agenda for the council - - -

MR GRIBBLE: Yes, and the fact that there is a disability service plan that they have to live up to and that there is an external body in the Disability Services Commission which is actually monitoring those, gives people an opportunity to say, "Look, these areas of your local electorate don't meet the requirements of your disability service plan," and somewhere to go with that. Whereas if that level wasn't in there, it's really where do you go to progress that issue?

MS CLARK: It shouldn't then transcend the staff that might be in office at that point in time.

MS SOLOSY: I mean, we're certainly consulted a lot by Main Roads WA, and we give a lot of advice to Main Roads about the placement of tactile ground surface indicators and when they're doing works, new developments or upgrading traffic light intersections and asking for our advice and help, so, you know, it is happening. I guess it's just not happening as quickly as we might like.

MS McKENZIE: What's the division of responsibility between Main Roads and the council for things like - - -

MS SOLOSY: Well, there is a division of responsibility and I'm not across that to be able to tell you, Kate, but I think that's possibly one of the problems.

MS McKENZIE: That may be - that's what I'm thinking - there may be a real confusion.

MS SOLOSY: Yes, yes, that's right.

MRS OWENS: I was going to say some things could be falling through the crack. That's probably not the right term, but you know what I mean?

MS McKENZIE: I've expressed it politely, you've expressed it directly. I think there's a bit of a - - -

MRS OWENS: I was going to ask whether your members are aware of the Disability Discrimination Act or the Equal Opportunity Act in Victoria, whether any of your members - sorry, in WA. Why do I - we haven't even done Melbourne yet. It's just when we got talking to people in other states, the feedback we're getting is that a lot of people aren't aware of either act, and it they are, it tends to be the local act, just because of the local presence, and I'm just wondering whether your own members are aware and if so have they tried to use it? Have there been any complaints? Have they tried to use either act?

MS SOLOSY: I'm not actually too sure how many of them would know about the Commonwealth act, but certainly in our newsletter we definitely have promoted from time to time the local act, state act, and also the fact that organisations, state and local government organisations have to have disability service plans and encouraging our own consumers to make use of those plans, to ask to see the plans, and if they have a problem to go to the agency or the local government authority concerned, and also we've encouraged them to join access committees. So we try to sort of make them aware of that.

MS McKENZIE: Do you have a problem with the fact that - I'll just take the WA act for a minute - but like the DDA, the WA act is complaints driven. To actually begin a process under that act, you have to make a complaint.

MS CLARK: Yes. I wanted to add, if I can, the fact that - - -

MS McKENZIE: Sure.

MS CLARK: The fact that certainly in my, I guess, you know, work with individuals, I find that although some people might have very basic, I suppose, some understanding that there's right or wrong and "surely people can't discriminate against me because of my disability understanding", I find that I - I can't say all the time, but in many instances - I'm in the position of saying, you know, explaining a little bit about - specifically it's the Disability Discrimination Act, the Federal act. Most of the clients that I work with tend to be either students in further education, or prospective students, or job seekers mainly, and I find that I'm inevitably in the position of saying, okay, look, answering their questions and in doing so trying to explain some of the act, as I understand it - obviously not giving legal advice, but sort of - and I find that so essential, so important, because people want to know, they need to know.

If they are a prospective student applying to a university and, you know, "How am I going to survive in the university? How am I going to get all my text books?" - and inevitably I start explaining the act and structure of the uni, and the same in employment, you know. So it is certainly required, certainly a benefit to inform people, have them empowered with that information, and then they can a bit more confidently and self-assured, sort of, understand what their rights are and what they can ask for. A lot of people are shy just saying things.

MS McKENZIE: Yes, "We feel we'd like this," without realising that actually it's their right.

MS CLARK: Yes, and I think that that's the main aim, from my experience so far, is putting people at ease a little bit, reassuring them that, you know, they can take the step to attempt a course and there are going to be some supports there and help them realise their career dream or whatever that might be.

MR GRIBBLE: Getting back to your other question though, Kate, it is a reactive process, and we've had several people who have got to the point of wanting to put in a DDA complaint but have not actually gone through with it for one reason or another.

MS CLARK: Yes.

MS McKENZIE: Do you know why?

MR GRIBBLE: One of them, at least, is because it was resolved with the organisation, okay?

MS McKENZIE: Yes, so the threat was - - -

MR GRIBBLE: Yes, the threat was - - -

MS McKENZIE: Some people have said that that the DDA is really good to have around as a threat.

MS CLARK: Absolutely, yes.

MR GRIBBLE: It's a good awareness raiser. I mean, the organisations we talk to about, for example, making their web content accessible, are all aware of the Maguire v SOCOG decision where Maguire was awarded 20,000 by HREOC for the failure of SOCOG to make their web site accessible. So those sorts of landmark decisions really have an impact on the community in that it's an awareness raiser of, yes, there are minimum standards, and at the end of the day, for most organisations, it comes back to risk management. So for them to be saying, "We're exposing ourselves to a risk here, potentially, in terms of bad publicity," et cetera, that does have an impact on their internal processes.

MS CLARK: I think employers look for that, you know, how much are we required to do under legislation, and if it says we must, we will, but otherwise if it says we don't need to, well, we won't spend the money.

MRS OWENS: But why would you suggest that they go the DDA route rather than the WA route?

MS CLARK: Well, I wouldn't be suggesting that at all. I'd be referring them for legal advice from the Sussex Street Community Law Centre, and then the solicitor will provide that advice and - - -

MS McKENZIE: But you would be telling them there was discrimination legislation around.

MS CLARK: Yes, my way is very much a sort of, you know, explain to me, yes, it certainly does sound like - - -

MR GRIBBLE: It would very much depend on who the complaint was involving as to whether it was a federal or a state jurisdiction, and that would determine - - -

MS CLARK: I suppose another person I'm thinking of who - sometimes one individual sort of has come across or has experienced a quite overt discrimination. It's all about their own self-healing as well, and so to be able to rectify the situation, perhaps work out what it is that they need - it may be an apology, it may be - and often people have a secondary issue of, "I never want anyone else to have to go through the same issue again," and so a lot of people want the situation sorted out. They don't necessarily want to go down the long path of a legal complaint.

MS McKENZIE: They would rather have it sorted out as soon as possible.

MS CLARK: Indeed, yes.

MS McKENZIE: But you said in your submission that you wanted the DDA to remain separate legislation, but of course in WA the Equal Opportunity Act is on the disabilities list. It covers lots of different grounds. What do you see is the real strength of keeping DDA separate?

MS CLARK: Disability discrimination issues we wanted to be acknowledged in its own right. We're a bit concerned, I think, of the idea of rolling it into blanket discrimination with other complaints, be it gender discrimination or race or - because I think that disability-related discrimination issues are a huge and detailed, convoluted issue in itself, and it needs to be, I think, respected as that.

MS SOLOSY: Have its own profile.

MS CLARK: Yes.

MRS OWENS: But you have an omnibus act in Western Australia where everything is rolled in, and some accept that - - -

MS CLARK: Equal Opportunity Commission.

MRS OWENS: You may have an issue related to an ethnic person who is disabled, so it brings it together.

MS CLARK: Yes.

MRS OWENS: But I don't think you necessarily have to have it rolled into one act to be able to do that satisfactorily.

MS CLARK: Yes, I think certainly being able to tease out the issues, and certainly individuals are a package of all sorts of different things.

MR GRIBBLE: One of the potential disadvantages, I guess, of having a separate act is how it relates to other acts of government. Now, an example of that might be where a person with a guide dog is legally entitled to enter premises with that guide dog under the DDA. However, a conflicting piece of legislation at a stage level might mean that they can't do that, and an example would be the state Zoo Act which says that no dogs are allowed into the zoo. However, the DDA says that they should be allowed access to the zoo. Now, that's not being tested in any court, but I am aware that the zoo has, in their eyes quite rightly, quoted that piece of legislation and is precluding people taking their guide dogs into the zoo.

MS CLARK: But they at the same time have a disability services plan and will - - -

MS SOLOSY: Make accommodation.

MS CLARK: Absolutely, yes.

MR GRIBBLE: So they're trying to get around it, but what I guess I'm pointing to there is the fact that there is a potential conflict between various pieces of legislation, and that hasn't been resolved and won't be resolved until you've got a test case where somebody actually went through the process of taking it further

MS McKENZIE: That's an interesting question actually.

MRS OWENS: I'm not a lawyer, but I wonder would the DDA override the state legislation.

MS McKENZIE: If it can really be said to be inconsistent it might and that might well be the case. I mean, it could well be said that the zoo was providing a service. Again you've got that funny question, if there's a specific thing in their legislation which says you can't come in with a guide dog, you may have to wait till they actually refuse entry and then that might be picked up by the.

MS CLARK: But I think you can't lose sight of the spirit of the DDA and that's what's the important thing, is to ensure that no-one, based on their disability, is treated less favourably or discriminated against because of that disability and keeping track of that purpose is so important. You know, if the zoo sort of turned around and said, "No, no-one with a dog can ever enter and we're not going to accommodate your needs," that's quite different. But the point is certainly there and I think we've certainly seen that with the Immigration Act as well, that we talked about in our submission.

MRS OWENS: That was interesting case. What's happened with that computer programmer.

MR GRIBBLE: He was ultimately refused entry. A number of blindness agencies round Australia advocated on his behalf, including ours, but without a result at the end of the day. We've got another example of the Immigration Act as in conflict with the DDA.

MS CLARK: Yes. I also worked with a gentleman who had been in Australia for a year or two, he couldn't return to his country of origin and therefore, you know, had applied for his wife and two school-age children to migrate as well, obviously to join him here and maintain that family integrity and of course one of their children had vision impairment and didn't pass the medical exam. So based on that the entire family's application was refused, which of course left the father quite distraught, which you'd understand. So again a number of organisations advocated on the gentleman's behalf and argued that the initial diagnosis of the child was in fact not correct. From what I remember the medical report said that the child was blind and made awful assumptions about, "This child will cost the country millions of" - whatever it was - "thousands of millions of dollars in supported schooling and supported employment," which you had to laugh at, because particularly when you looked at the child's vision loss, it was very minor, it was not severe at all. But the assumption was crazy anyway. And I believe that's where it was challenged, the decision was challenged, was the assumption, not that the child's support needs were in fact not that high anyway and that was a success story to the family's delight, but it certainly did take a lot of challenge and lot of, I think, heartache for a very long time.

MR GRIBBLE: I guess our position on the Immigration Act would be that where somebody is applying to immigrate - emigrate - into Australia, to Australia and they have a disability, an additional set of criteria are placed on them that aren't placed on any other applicant in that the government is looking at what sort of a burden are they going to be on the social security system and we feel probably doing that with an incomplete or poor understanding of the issues involved in the first place.

MS CLARK: Considering we don't have - - -

MR GRIBBLE: The programmer, for example, had employment lined up in Australia, was a professional with multiple degrees, would never have been a burden on the social security system perhaps until his old age, but the immediate assumption seems to be in the immigration process is that that's going to be the case - the person is going to come in and go straight onto a disability pension.

MRS OWENS: The assumption is that there's going to be costs involved and they're not looking at the potential benefits to the Australian society of having these people.

MS CLARK: And the assumptions were so ill-informed, I think, about - it's certainly out point, in this state we don't have special schooling and we don't - you know the assumption that this young child would need supported employment - - -

MS McKENZIE: That's just ridiculous.

MS CLARK: Exactly.

MRS OWENS: And with the computer programmer, obviously, coming into a job where they were going to - they must have been a valuable person to be offered the job.

MR GRIBBLE: And I mean, it's an industry that Australia's - in great demand for people in those areas.

MRS OWENS: One of the matters we sometimes raise is, there's an objective video which has to do with promoting the recognition of the fundamental rights of disabled people, the same as the rest of the community and so we do sometimes ask a number of questions about, what effect on people's attitudes do you think the videos have? Do you think people's attitudes have changed since it was passed? Or do you think that's really got more to do with, you know, changes in society, with perhaps the growth in mainstream education for vision-impaired people so that people begin to understand better.

MR GRIBBLE: That's a hard question.

MRS OWENS: I'm asking you this because we're going to have a little trouble in answering it as well. We need help.

MS CLARK: We're actually considering that we sort of felt as though - we hope it has been changed. We felt as though there perhaps has been some change in certain sectors than perhaps others. Like dominant with the government sector, seems to have - a lot of government agencies have proactive employment outcome programs and recognise the value of having a diverse workforce.

MS SOLOSY: But quite what's driven that change is hard to determine, isn't it?

MRS OWENS: It's a real problem, I think.

MR GRIBBLE: I think like all legislation it's probably had most impact in areas that have been directly affected by it, so industries where they would come into contact with disability issues on a regular basis would obviously be aware of it. Areas where government has regulated that there is a requirement for a set of standards that relate to disability are obviously impacted by it, so I guess it's horses for courses in that areas that don't generally have any disability-related issues won't have any disability-related awareness either, regardless of whether the DDA exists or not. I guess from our perspective as an organisation what it means is that we're aware of the standards and we can pass that information on to our client group and do our best to promote the fact that such a set of legislation exists and you're not making up a solution or advocating with nothing to back you up on an ongoing basis.

MRS OWENS: So it provides that support that - - -

MS CLARK: Indeed.

MR GRIBBLE: So I think most of the disability sector would agree that it's an essential set of criteria to work from as an advocate on behalf of people with disabilities.

MRS OWENS: But then there's the broader question of how do you get to the rest of the community to change attitudes. You can talk to your own constituents and make them aware of their rights, but it's a matter of continuing to educate the community and that's one of the roles of the Human Rights and Equal Opportunity Commission, but they've got very limited resources with which to do this.

MS CLARK: I suppose what occurs to me, too, is that - I think there has been a change or there is - and I think the DDA does help with this change in attitude from like a welfare, kind of charity idea or attitude to a more human rights, "Look, people are people and people are different in many different ways and it just so happens that some people have some degree of disability and they shouldn't be treated - it's quite - in fact it's unlawful to treat them less favourably," and I think that says a lot, you know, to have that enacted.

MR GRIBBLE: And part of that is promotion of positive images. The Western Australia government ran a series of advertisements a while back, a number of years back, showing the person behind the disability, demonstrating that they were just people like everybody else and they had quite a high impact in the community in terms of awareness-raising.

MRS OWENS: Have there been more of that sort of advertisements or - I don't know how effective they are, but do people remember those advertisements? Did people comment about them?

MR GRIBBLE: They tend to because they're different to the other forms of advertising they're exposed to and this was a particularly effective campaign in that was well done and it demonstrated that people who had a disability just were involved in the same activities as everybody else, so from my experience, just anecdotally, I know that people I talk to have certainly been aware of that campaign and have remembered it. Then it's other things, other high-profile events such as that Maguire v SOCOG decision, which I think stick in people's minds and again are a proactive, positive model in that it shows immediately that, "Wow, this guy is blind and uses the Internet," which is a way you can't get - you can tell people that endlessly but the fact that he does it is more meaningful in terms of getting that awareness across.

MS CLARK: When you have people in positions of note, you know, in employment and perhaps managerial and - be a commissioner or - I think that has a lot to do with attitudes as well.

MS SOLOSY: And also even on television, you know, in drama programs when you have a character with a disability and is fully functioning and capable and holding down a position of employment or being a contributing member of society within just a local drama show, that gets the message across to a lot of people without them even really realising that they're taking on that message.

MRS OWENS: Can I ask you, have you got - we've had some submissions that have talked about the distinction between direct and indirect discrimination and some technical problems with that. Do you have anything to say about that?   Should it be made simpler or - if you haven't thought about it don't worry about it. I'm asking you all about our various headaches, the headache questions.

MS CLARK: I think it's a really important question. So, sorry, you were asking - - -

MRS OWENS: I was asking do you have any comment to make about direct and indirect discrimination and the difficulties that have arisen around the definitions and their distinction between the two and - - -

MS CLARK: Yes. I mean, if your legislation didn't cover indirect discrimination it would be a bit pointless, I think, and surprisingly, although clear, direct, obvious discrimination based on disability still occurs. Amazingly. You know, indirect obviously is not as easy to pick up, but it is there and it's so important to acknowledge that it's unlawful to have indirect and the first example that came to mind was the recruitment practices, you know; I see that a lot. A lot of employers might create a job description and a selection criteria to go with that and it might be an administrative job, yes, office and administration officer and essential criteria, great, all the usual ones that you'd expect to see there about office skills and team work and so forth, but then they'd have the beautiful essential criteria of driver's licence and you think, "Oh, surely not." We know that's not appropriate and that's where I'd like to see some more education in the human resource-type schools, courses, degrees and that's where I come from, part of the inclusive recruitment practices and that's just systemic, that's all around. To me that's clearly indirect discrimination.

MRS OWENS: Yes.

MR GRIBBLE: But much more insidious and much more difficult to deal with in that the organisation is not setting out to deliberately discriminate against somebody which makes it then commensurably harder for the individual who is discriminated against to demonstrate that they are being discriminated against. It's a much more onerous process for them to follow through that DDA complaints process and I think we're - - -

MS CLARK: It's really not an individual, direct discrimination, it's more of a systemic - - -

MRS OWENS: It's serious for an individual but it's even more serious - - -

MR GRIBBLE: It certainly is and nine times out of 10 it's resolved if they point out to the organisation that they are being discriminated against. Most organisations, to give them their due, will say, "We didn't realise that," and they will resolve the problem. I guess why is the DDA is important is for that one in 10 organisations that doesn't want to resolve the problem, that indirect discrimination then becomes direct discrimination and there is somewhere to take it beyond that.

MS CLARK: Certainly from an awareness point of view it would give us the backing really, the legitimacy to - or anyone to run an awareness campaign or a course pointing that out and then the legitimacy is there in the DDA under indirect discrimination.

MRS OWENS: I've certainly finished my questions and I think we've probably asked you more questions than we warned you we were going to ask.

MS McKENZIE: Except that it's hard to - I mean, things you said just automatically raise in my mind other questions. I'm really sorry for asking them but I would have felt very sorry not to ask.

MRS OWENS: I think you handled them all very well. I was just wondering whether you've got anything else you wanted to raise with us?

MR GRIBBLE: I was just looking through your list of questions and I think we've covered most of them.

MS CLARK: I think we have.

MRS OWENS: We've followed them in one way or the other.

MS McKENZIE: As one thing followed from the another.

MS CLARK: I certainly don't have anything I wish to add. On behalf of the association I guess I want to thank you for the opportunity to come and discuss our submission.

MS McKENZIE: I want to thank you for your submission and for the enormous help that you've given to today as well. You've answered a lot of questions from us.

MS CLARK: I hope it will be helpful to the inquiry.

MRS OWENS: Thank you for coming.

MS McKENZIE: Thank you.

MRS OWENS: We will now break until 3.30.

MRS OWENS: Okay. We'll now resume. The next participant this afternoon is the Disability Coalition. Welcome and thank you for coming, the three of you. Would you like to give your names and your position with the coalition or with your respective organisations for the transcript.

MS CASEY: I'm Debra Casey from People with Disabilities WA.

MS McMAUGH: Luba McMaugh, and I'm an advocate with the Ethnic Disability Advocacy Centre in Subiaco.

MS JASINSKI: I'm Sophie Jasinski and I'm the vice-president of the Ethnic Disability Advocacy Centre.

MRS OWENS: Good, thank you, and thank you for the submission from the coalition. Perhaps - I think it was Debra said before we started that you'd outlined which organisations were involved in putting this together.

MS CASEY: Yes, there are a number of organisations from Western Australia that form the Disability Coalition - People with Disabilities WA, the Council of Disability Services Commission Funded Agencies, ACROD WA, the Ethnic Disability Advocacy Centre, the Developmental Disability Council, Carers WA, the Western Australia Association for Mental Health, Committed About Securing Accommodation, and the Ministerial Advisory Council for Disability Services. They were the organisations involved in making this submission.

MRS OWENS: I think it's admirable that you can get so many organisations to sit down and agree on a submission.

MS CASEY: Yes, agree on all these different views.

MRS OWENS: Luba, I think you also wanted to make a few comments.

MS McMAUGH: Yes, I'd just like to thank the Productivity Commission for the opportunity of coming along today, and just refer to one of your terms of reference in terms of the review of the DDA which is 2.A. The rationale for the passage of the Disability Discrimination Act was:

> A vision of a fairer Australia where people with disabilities are regarded as equals, with the same rights as all other citizens, with resource to systems that redress any infringements of their rights, where difference is accepted and where public instrumentalities, communities and individuals act to ensure that society accommodates such difference.

Well, I guess kind of 10 years on we still have a little way to go but the passage of the act itself has been a very positive thing. I'm specifically here - I'd like to give some background about non-English speakers directly. That is sort of EDAC's brief. We're here to represent people from a non-English-speaking background specifically. I know that the word these days that is used is CALD - culturally and linguistically diverse - and that is very inclusive and it includes English-speaking people. But migrants and refugees with a disability are the reason that EDAC was formed in 1985, so we sort of try to assist them in relation to the rights that are included in that rationale that I just read out. I don't want to take all the attention here, actually, but will I just give a little bit of statistical background?

MRS OWENS: Sure.

MS McMAUGH: I think that will give you a context.

> Western Australia has the highest proportion of people born overseas of any state or territory, according to the most recent ABS figures and the WA Office of Multicultural Interests in their 2001 population census. The total population is 1.2 million and 27 per cent of Western Australians are overseas born compared with 22 per cent nationally. WA is very highly urbanised and approximately 72 per cent of all people live in and around the capital city.

So we're very much concentrated.

> The main countries of birth of residents in WA are the UK, New Zealand and Italy, followed by Malaysia, South Africa, India, Netherlands, Vietnam and Germany.

The most recent refugees, including refugees from the former Yugoslavia, Iraq, Iran and Somalia, are represented amongst EDAC's clients. They are not included in those statistics that I just read out to you. If I could make a brief reference to the atlas of the Australian people, which I think is a pretty brilliant document, that the last one was produced in 1996. It indicated that in WA approximately 6 per cent of non-English-speaking background populations speak no English. Italian is the most common language other than English, spoken in the home, 4.7 per cent; followed by Cantonese from China, 2.5 per cent; followed by Vietnamese.

Of interest in the same report is that 21 per cent of those speaking Italian had problems with English; 43 per cent of the Chinese-speaking people, and 42 per cent of the Vietnamese-speaking population. So we have successive migrations and as the population ages, in particular, sometimes there is a regression in language, so that does affect people accessing services. Perhaps if I just hand over to you and I'll go back into some more statistics at a later date.

MS CASEY: Right. When Luba and I were talking the other day, one of the things that we looked at was some of the training which could be attached to strengthen the DDA and some of the more positive focusing. I think the biggest factor I've found when working with external organisations to encourage people to fulfil their responsibilities under the act is actually to give them some education and training. It often swings people around into a much more positive frame of mind. That was one of the things we concentrated on when we were talking last week.

Then when you're looking at the effect on competition that has a positive flow-on effect because people are much more understanding of why they need to do things and then they're much more likely to do them without resorting to unjustifiable hardship exemptions and thinking there's going to be a negative impact on their competitiveness within the market. So that was one of the issues that I thought was important to raise.

MRS OWENS: It's a very, very important issue, and in your submission at various places have talked about what you want the training to do. We raised your submission actually this morning with one of the other participants where you said that you wanted people to know more about their obligations or rights under the DDA, that flexible approach is to including people with disabilities, the advantages of including people with disabilities. You talked about the competitive advantages; the proactive measures to prevent discrimination, and you referred also to increasing people's knowledge about invisible disabilities. We were talking this morning to people with multiple chemical sensitivities which are one of those invisible disabilities that people either aren't aware of or if they are aware of them, they're not really aware of the consequences of those disabilities.

So I think education is an important issue. We find as we go around that people often are not aware of the act at all. They're not aware of the Human Rights and Equal Opportunity Commission, so they don't know that there's a complaints process that they may avail themselves of. So there's quite a challenge still ahead. Who should be doing the education?

MS CASEY: I think it can probably be done by a range of groups. I used community law centres to do some education on the DDA when I worked in local government to give that education to planners and people working in local government so they had more of an understanding of how the act related to their work and I found that the flow-on effect of that was that they had a much more positive approach to consumers with a disability because they had more of an understanding of how their work and the different legislation interrelated.

PWD - People with Disabilities - also did a training session with the Equal Opportunity Commission, and Sussex Street Community Law Centre recently, which was looking at the DDA and also the Equal Opportunity Act in Western Australia. That was also a very positive session, giving people that work in the area more knowledge about different aspects of each act and how they can use those within their work.

MS McKENZIE: So that was given to people who actually work in that area, not - - -

MS CASEY: As it turned out it predominantly was people that work in the area but it was also open to people with disabilities and I think one of the strengths of the program that we put together was that it would be relevant and understandable to people that didn't work in the disability sector as well, so it could be expanded into other areas, so if you're looking at a customer-focused approach to give that training to people that work in local government or people that work in the services industries so they can use that in their jobs as well.

MS McMAUGH: Could I just add there that we've also been in touch with the new solicitor - the Disability Discrimination Unit - and the education officer, and sometime in September or so we will work out a program to target some of the ethnic communities because I think consumers have very little knowledge about the provisions of this legislation. The National Ethnic Disability Advocacy submission, that was one of the submissions to the Productivity Commission, they made a number of recommendations which we endorse from EDAC. Certainly that issue of education was a large one. They have actually asked I think for additional resources for the Human Rights Commission to do some more work with ethnic communities. They're also working on the disability standards on some sort of uniformity in disability standards in relation to people from a non-English-speaking background.

Could I just raise maybe at this point the exemptions, because we were talking about unjustifiable hardship and exemptions. Two in particular that affect people from non-English-speaking backgrounds are the Migration Act and the Social Security Act, in relation to pensions and allowances and there are ongoing discriminatory effects of those blanket exemptions, and section 52 of the Migration Act in particular which has had the effect that people with a disability are often ineligible to emigrate to Australia because of their disability. As noted in NEDA's submission - page 15, I've just made a point there - it is not uncommon for immigrant families to leave behind a relative with a disability. In fact we have one example at the moment that Sophie might just want to talk about that was referred to us.

MRS OWENS: Thank you, Sophie.

MS JASINSKI: One such example has recently been referred to EDAC - which is Ethnic Disability Advocacy Centre. A mother from a Middle Eastern country who has been in Australia for 20 years was forced to leave behind a son with a learning and a psychiatric disability due to migration provisions under - as Luba mentioned - S52. The son was cared for in their country of origin by his grandmother until she died approximately 18 months ago. The son who speaks no English is now approximately 40 years of age, sponsored by his mother under the last living relation category. However, he has been in the country less than two years, he is not entitled to a Centrelink benefit in his own right.

MS McMAUGH: So we will be meeting with that family and looking at options that are available, but that's an example of how that has specifically impacted on this particular family and others.

MS McKENZIE: If you're in the country for more than two years then you can - - -

MS JASINSKI: No, not for a disability pension. With a disability pension - this is where I think it's very wrong - you have to wait 10 years.

MS McKENZIE: If you came with a pre-existing - - -

MS JASINSKI: Of course if it happens in Australia that's a different thing but if you've got a pre-existing disability why is it 10 years? It's two years for everything else. So why are we being so discriminatory and asking disabled people, if they are lucky to enter the country, to wait for 10 years.

MRS OWENS: Can we just go back one step. He was able to come in under some special provision of what was it?

MS McMAUGH: Last living relative and there were no other means of support for him to remain in the country of origin. But now at 40 years of age he has joined the family. There are many issues involved and he's not - - -

MRS OWENS: The family is having to really support this man.

MS McMAUGH: The family has to support - the mother is now at a pensionable age, so he's not entitled to a Centrelink benefit in his own right at this point.

MS JASINSKI: Also, I don't know whether you're aware, but if say a disabled person here chooses to marry from a country of their origins - and we've got a case in EDAC - he loses his single benefits. He's put on married rate but she is not entitled to anything for the next two years, so he is $80 down straight off. Now, okay, she's not entitled, so leave the man on a single benefit until she entitled to some benefits.

MS McMAUGH: Could I give another example just while we're on the exemption. We're currently assisting a single mother with nine children from an African country. She was originally accepted as a refugee to New Zealand. Due to domestic violence and for other reasons, she was forced to leave New Zealand and has been in Western Australia for less than a year. Whilst here one son, aged 10 years, was diagnosed with Dushan muscular dystrophy, and as she's been in Australia for less than two years, she's ineligible for a Centrelink benefit. She does get family tax allowance, and equally she may have difficulty in obtaining services from the state Disability Services Commission for her son, and they're going to be fairly high-need services with Dushan muscular dystrophy. The prognosis is he may live to 15, maybe not, and will require - - -

MRS OWENS: So does this lady survive?

MS McKENZIE: How does she survive?

MS McMAUGH: Through a number of agencies and through family tax allowance, community settlement support service workers, ourselves, through a variety of agencies. She's getting by and that's all. One of the things we'll look at is maybe applying for a special benefit in her circumstances. But because any discrimination that occurs within pensions and allowances currently is allowed under the DDA and it does impact particularly people from a non-English-speaking background, as Sophie mentioned, anyone with a pre-existing disability must make for 10 years, whereas for all other benefits at least it is two years. You are a permanent resident, then you become eligible to apply for certain benefits. So that 10-year rule does create enormous hardship.

MRS OWENS: So do you think that there's something that could be done within the Disability Discrimination Act? Should it be amended to take these sorts of situations into account?

MS McMAUGH: As I understand it, the age discrimination bill that was recently debated in Commonwealth parliament has a similar exemption as for the Social Security Act but a two-year review period. So now that the DDA is 10 years old it's probably timely to have this matter reviewed, and again I think in recommendation 11 in the NEDA submission they actually raise this as an issue for a special inquiry.

MRS OWENS: I suppose we are reviewing the act now, so we can look at these issues.

MS McMAUGH: Yes.

MS McKENZIE: So the question is, what should be done about the Migration Act exemption - - -

MS McMAUGH: Yes, and the Social Security Act.

MS JASINSKI: The Social Security Act for the disability pensions and the like.

MS McMAUGH: And the pensions and allowances, yes.

MRS OWENS: We haven't as yet had submissions from Family and Community Services, as far as I'm aware, and the Department of Immigration, but because these are important aspects of the act I think we'll try and entice those departments or encourage the departments to take an interest in this inquiry, because if we were to recommend that those exemptions were dropped, for example, I think they probably would fairly quickly take an interest.

MS McMAUGH: I think so.

MRS OWENS: My colleague here said that might be one way of enticing them. But we will be looking at this issue, and these sorts of case studies I think are very valuable to us.

MS McMAUGH: I wondered as an added incentive also if there can be some tax incentives. I mean, one of the other issues - our current executive officer has a complaint with HREOC in relation to petrol stations.

MS JASINSKI: Yes, and I support her in this.

MS McMAUGH: Sophie will have a few words to say about that as well. Perhaps one of the things that could be looked at is some tax relief for some organisations to undertake some proactive and positive action in this regard, although - - -

MS JASINSKI: Provide some sort of a service even if they do it two hours a day or something, but you'll be driving past and you see petrol there at 84 and you can pull in and no-one is going to come out and help you, so forget it. Sure, all of us can make arrangements with the local stations and some home towns - I can go into mine but I can't go there during the weekend, they will assist me, but if I run out of petrol on the weekend, what do I do? I have to stay home because no-one's going to fill your car up for you.

MRS OWENS: It's quite interesting. I don't know whether this is the case in WA but in Victoria you get into some country areas and you can get driveway service, very nice driveway service.

MS McMAUGH: It's probably the same here actually.

MS JASINSKI: To justify, some of the stations here do employ a pensioner for certain days of the week but they're so far and few. Like, I mean, I live south of the river and the only one I know of is about 40 Ks north of the river that does that. So if that could be possibly done, some sort of incentive for those.

MS McMAUGH: And I think Debra has some role in this.

MS CASEY: Yes, we actually - it's something that PWD have found a lot as well, that people are having problems with driveway service, and I think there's just increasingly people are reducing the number of staff they have in service stations. So they don't actually provide a full court service any more.

MS McKENZIE: A driveway service.

MS CASEY: We've recently written to all the petrol companies to try and find out which service stations in the areas have got driveway service and also to find out what their policies are with regard to services for people with disabilities, and again part of that is an awareness-raising exercise for the petrol stations to get them thinking that this is something they need to address, and I know in other countries there's various solutions to this problem but it's something that will only get worse if it isn't addressed at this point.

MRS OWENS: So what sort of solutions in other countries?

MS CASEY: In England I think some of the petrol pumps actually have mikes on them so people can ask for them but there's also a system set up where people flash their lights, to a certain pump and flash their lights, and the person in the service station will know that that is someone needing assistance.

MS JASINSKI: But Debra, that's all very well but if there's one attendant, she's not going to leave the shop, even if you speak to here. So this is why Luba's point is very good.

MS CASEY: I agree with that but at least it's a solution that is further along the lines than we've got here. Here in Australia, people are just taking away their driveway service and there's actually nothing to replace that at this stage, apart from, like you were saying, Sophie, people are going around the state trying to find petrol stations that they can access.

MS McKENZIE: And using more petrol in the process.

MS JASINSKI: That might be the whole idea.

MRS OWENS: Another issue that we've been discussing with various people is the whole complaints process and we have heard from many people - and I think your own submission raises this issue - about the onerous nature of the complaints process and the difficulties that it can create for people if they wanted to go through this system. Now, you've got particular issues, I would imagine, with people from non-English speaking backgrounds; firstly knowing what their rights are, whether there's information in their language; and then whether they can then get legal assistance, whether they perceive it as being a very difficult process. I mean, it's hard enough, I think, for people that speak English to go through this for various reasons but there must be special issues for people where English isn't their first language or who can't speak English at all.

MS McMAUGH: There are actually. I don't know if you want to talk about this, Sophie.

MS JASINSKI: This is not so much a complaint but I am very aware of the carers, their spouses - and they're mainly in their 70s now - that the Social Security needs to see their naturalisation certificate and everything, but not a copy, they want the original and they've got to take it to the office. Now, that becomes extremely difficult for someone to leave their spouse they're caring for and the English comes in very strongly because they don't know what - surely to goodness with all the staff employed in Centrelink, that they could send someone out there to see those people and cite those documents. The aged people, they're very reluctant to post the original documents.

MRS OWENS: Indeed.

MS McKENZIE: That's a very sensible idea.

MS CASEY: We have similar problems of people needing forms filled out. There doesn't appear to be a great deal of help from Centrelink for people that are filling social security forms. If we fill them out - - -

MS JASINSKI: And, I mean, they're not forms now they've got, they're booklets.

MS McMAUGH: They're books.

MS McKENZIE: They're difficult forms and lengthy ones too.

MS JASINSKI: And if you don't speak English or English is your second - you look at it and you're not quite sure. You know, you've got yourself there, your husband there. That's been an extremely difficult thing.

MS McMAUGH: And people who are refugees often come with very little documentation and it's even more difficult for them to establish medical records, a whole series of things. I mean, we are a society that depends on the written word and are computerised. So people coming from different cultures find this incredibly different, and dealing with some of the concepts, and also if you're a relatively recent arrival making a complaint, it's not necessarily something you'd be very comfortable with because depending again on experiences in your country, authoritarian regimes. So people are very, very reluctant. I noticed also something else in NEDA's submission that they've requested that:

> A special NESB disability information strategy be devised in consultation with relevant communities regarding the provisions of the DDA.

And they also mentioned that HREOC did have, like, a small guide on the DDA in different community languages but it hasn't been reprinted. So access to information is a first step before people can access rights, and at this point there's very little information going out to ethnic communities. So again we'd be happy to work with the local DDA in terms of doing some work in this regard. But I think also the fact that HREOC, you know, can go right through to a hearing - and there are very wonderful effects, like the transport complaint means that we've got CAT buses in WA, and there are standards that are being sort of devised. But I believe they won't take effect until about 2009. So we've got a little way.

MS JASINSKI: Anyway - - -

MS McMAUGH: An effective standard, that's true. So we're getting there, and in relation to education as well. But, you know, the decisions of HREOC are not binding, so then you must explain to people, "You can get to there but then you have to go to the Federal Court, and it's almost a hearing from scratch." So trying to explain this to people from non-English-speaking backgrounds, it's not an easy process.

MS McKENZIE: And the other difficulty is, you've talked about often the fear or authority because of what has happened to them in their countries of origin. The fear of court authority might be - - -

MS McMAUGH: Yes, yes. So it's a very cumbersome process and the more proactive, you know, strategies that can be devised to ensure that that vision is achieved, the better, and I don't have all the answers definitely but can certainly work together on that.

MRS OWENS: One of the possibilities or ideas that people have been raising with us is that instead of individuals taking complaints that organisations could do it on their behalf, particularly if they found it intimidating or not necessarily wanting to be the leader on an issue and I was wondering do you have any views about that idea?

MS CASEY: I think that would quite a positive step. I think a lot of our consumers just find the day-to-day life of living with a disability or caring for someone with a disability is exhausting enough in itself without raising major complaints. So if Sophie has got to struggle to find somewhere to fill up her car with petrol she probably doesn't have the energy to then take that to a major complaint process. I met with a lady this morning who was having some problems with her accommodation and people had been out to fix things and she actually didn't feel that she had the energy to keep on telling people to come back and fix it again because they hadn't done the job properly and yet the housing manager that was talking to her said, "Well, if something is not done properly you have to tell us so that we can get it fixed."

But if you're looking after - in this instance two people with a disability, you probably don't have the energy or the inclination to go and deal with that, you'll put up and make do with minor problems which you shouldn't have to do. So if there was a different way of bringing complaints forward under the DDA I think that would be beneficial for a lot of people and it would also probably raise a lot more issues and have a lot more positive effect.

MS McMAUGH: I'm not sure if the commissioner has power self-initiation under the DDA?

MRS OWENS: Not at the moment.

MS McKENZIE: That's another question.

MRS OWENS: That's another matter that's been raised.

MS McMAUGH: Because that would certainly be another way - they get an idea nationally of patterns and trends and so therefore it seems to me the logical step to be able to initiate complaints that affect people across the board.

MRS OWENS: They can run inquiries now often run off a complaint. Do you think this would have added benefits over the current inquiry processes?

MS McMAUGH: I think both are needed in a sense because if there's redress required under a complaint our legislation is set up so that people must lodge individual complaints or representative complaints and together with an inquiry and the inquiry may raise issues but it doesn't allow for redress for individuals so perhaps the two together. I'm not sure, if the commission has self-initiation then we could move to something closer to perhaps in the US where there's like a class action which at this stage in our law isn't quite possible but it certainly could be reviewed.

MS CASEY: That would probably be beneficial for most people because I don't think - people aren't actually looking for financial redress for themselves, they're looking for access and inclusion in most cases. So if class actions of that type were able to be taken up, then I'm sure people would come forward with examples to put toward something like that, but it would take the onus off people to actually be so involved themselves.

MS McMAUGH: I think as you mentioned getting legal assistance these days is incredibly difficult, so something along those lines needs to perhaps be considered.

MRS OWENS: Another related issue is the accessibility that people have got to HREOC and, as you know, the commission is based in Sydney and I suppose you're a long, long way away from Sydney and I know they do come here, they were here a few months ago for their 10-year anniversary and - - -

MS JASINSKI: Yes, but it's not advertised enough that they're here. Though we work in the field we might know about it, but if we're talking about the average person they probably here about it after you're well and truly gone so it's not advertised enough that they will be here and they're made accessible.

MS CASEY: So maybe if HREOC were coming over here for a function like the 10-year anniversary that some days either side of that could be set aside for people to actually go and talk to someone at that time and that could then be publicised on - we have pretty good networks in WA to publicise information so it would be easy to get those opportunities taken up I think.

MRS OWENS: Another potential approach that could be implemented would be for HREOC to have an ongoing presence in WA, have a shopfront or have some connection with the local Anti-Discrimination Commission as used to occur until the mid-90s. Would that be useful?

MS CASEY: That would definitely be a positive change, I think, and it would also make it easier for people to just go and raise issues. It would be a much more low key way to talk about something and bring it up and talk through some issues rather than making a formal complaint.

MS McMAUGH: They would have a real presence her in terms of respondents, you know, like businesses so there would be a point where that presence would perhaps be a force to be reckoned with hopefully.

MS McKENZIE: Also there could be immediate negotiations. It's much harder if someone has to be flown in for that from Sydney.

MS CASEY: Someone based in WA would have more of a sense of what actually happens in the community here and what's going on and that might be a beneficial thing in negotiations with businesses and organisations, especially if you're looking at issues like competition. If you've actually got a presence in the area that you're talking about then you can talk with more knowledge about the competition in those areas so it might be good as well.

MRS OWENS: Of course you have got your own commission here, so what's the additional benefit of having a HREOC presence or at least the advertising when HREOC is here, if it's not an ongoing presence over just working through the Anti-Discrimination Commission?

MS CASEY: I think HREOC probably carries more weight and people link the DDA as the national legislation to HREOC and that's the stronger legislation for them to use.

MS McKENZIE: They regard that as a strong legislation?

MS CASEY: Yes.

MS McMAUGH: Certainly for the DDA, yes. I think the fact that the Equal Opportunity Commission here has state legislation and a number of grounds to be administering and HREOC is probably - it's not totally so but a little bit tacked on the end because they are a state body and they get limited funding.

MS McKENZIE: Like one of many.

MS McMAUGH: Yes, one of many and to have a HREOC presence would be a much more forceful - - -

MS McKENZIE: Could I ask about this whole question of reasonable adjustments and unjustifiable hardship under the DDA? I think you suggested the whole idea of having some provision in the act about reasonable adjustments would be a positive thing and probably has more positive connotations than negative. Do you want to say anything more about that?

MS CASEY: From my point of view of working with people when I was in local government obviously we had a lot of planners and builders come through who needed to make their premises accessible and people used unjustifiable hardship as a way of getting around those responsibilities.

MS McKENZIE: So just to avoid them, not just - - -

MS CASEY: Yes, and that to me is quite negative whereas if you could look at reasonable adjustment it would be a much more positive way. Because with unjustifiable hardship the idea I get is that people think it's just too hard to cope for people with disabilities, so we're just not going to, it's just really difficult for us and the image it creates straightaway is that those people are thinking that what they've got to do is a really difficult thing and it doesn't actually need to be that difficult.

MS McKENZIE: So do you think that the unjustifiable hardship defence should be abolished in favour of a reasonable adjustment requirement?

MS CASEY: I'd like to see definitely some changes and whatever happens I'd like to see some sort of time line where people who might gain some sort of exemption and had to work towards making their premises or businesses fully accessible in the future in the same way that we have disability services plans here for local government authorities which have meant that over a period of time they've had to make services and facilities accessible that that sort of plan could be extended to private businesses and individuals to make their facilities accessible. It gives people then some time within which to work so the hardship in terms of financial cost is decreased because it's spread out over time and it also indicates a willingness to do something.

MRS OWENS: So you'd make those action plans compulsory?

MS CASEY: I would, yes.

MRS OWENS: For the private sector as well as government agencies?

MS CASEY: Yes, I think they shouldn't be extended to the private sector as well as government agencies.

MS McMAUGH: And they're not at the moment.

MS CASEY: No.

MRS OWENS: What about small businesses? What about your local shop?

MS CASEY: I think ironically the small businesses and the local shops are the places that are more likely to make access improvements because if you go into your local shop and say, "I'm Joe Bloggs, I live around the corner. I want to get a pint of milk but I can't come down by myself because I need some help to get into your shop," those business people are much more likely to make their premises accessible than the big businesses who can well and truly afford to do it and for some of the smaller groups that's where the education would be more beneficial to give people an understanding of the benefits of making a premises accessible, but they're probably - - -

MS JASINSKI: That's very true.

MS CASEY: - - - the places that would do the access - - -

MS JASINSKI: I can support in this because I had a coincidence where I couldn't go in the newsagency and he himself made a ramp to make sure I could get in and that was a very small business. Like restaurants, you might be able to get into the restaurant, but you can't use the toilets so that is not accessible.

MRS OWENS: But in some instances it might be very expensive for the restaurant to put in a disabled - - -

MS JASINSKI: Yes, but as Debra said, if they were given, say, five years or something that will sort of - it's very expensive, I'm very aware of that, but just given the time so they could plan for these necessary alterations.

MS CASEY: You do go into a lot of businesses and look around and think, "Well, there is no access here but it would be really easy and really cheap to include." I was at a local cinema recently and it was the same situation, you could get into the front door, there was level access but in the toilet there was no accessible toilet. But the toilets were just built with wooden partitions so you could easily have knocked them out, taken one of the toilets out and straightaway you've got an accessible toilet. It would probably cost a few hundred dollars and the enhancement of the business would be - - -

MS McKENZIE: It's not necessarily undoable, you just have to think of it laterally about how it could be done.

MRS OWENS: Although preferably you need the disabled toilet to be a stand-alone toilet rather than be in the men's or the women's toilet because people might go in with the carer, need to go with the carer, so we're hearing that it's preferable not to put it into the men's or ladies' toilets.

MS CASEY: That's true. It's better to have one than not one at all as well.

MRS OWENS: I suppose there's a lot of areas where we're not talking about access to premises but there's access to jobs and so where there may be - I can't think of any adjustments off the top of my head for a small business, it may be very expensive.

MS CASEY: But then if those small businesses are aware of the exemptions and financial support they can get to make their businesses accessible so that people can work there, again that would be another positive spin-off. So there is a lot of help available for businesses to provide support to people with disabilities so they can take a job. Lots of small businesses probably don't know that, but they would probably be quite willing to employ people because of that smaller more friendly front whereas the larger organisations that can afford it may or may not make use of it but they're the organisations that are more likely to know about that. They're more likely to know about the exemptions and money they can apply for, but they're probably less likely to because it's more difficult for them on a kind of personal relationship level.

MRS OWENS: Some businesses might say it's risky because they've got to pay their workers compensation premiums and some people might be an added risk/ I mean, we hear all the reasons why you can't do things. I always feel like saying, "Let's think of all the reasons why you can."

MS CASEY: I think that's why I keep going back to the fact that education is so important because if you educate people then they're more able to look at the possibilities rather than the difficulties.

MRS OWENS: See it as a challenge to be met rather than something to resist.

MS CASEY: That's too hard, so I'm not going to do it, but if you know what you're dealing with then we all work around that.

MS McKENZIE: Yes, if you're actually aware of what you might have to do, for example, or what it might involve, that's going to be much better than if you're starting from a base where you know nothing about what you might have to do and therefore think it's going to be really expensive and difficult and so on.

MS McMAUGH: And there may be best practice examples, you know, in other states or wherever that can be utilised in this process as well. So there's always ways around, isn't there?

MS CASEY: There is.

MRS OWENS: If you were to have these compulsory action plans, there would be a need to monitor them in some way, enforce them, wouldn't there? Would that be a role for the HREOC? Who would look at those plans and assess whether they're good plans? What potentially could happen, if you're not careful, is that there will just be paper compliance. People will put in a plan and just not really mean to do much about it or it could be just so superficial that it doesn't mean anything. So how do you prevent that?

MS CASEY: I suppose if it was - I keep coming back to physical access, which is really bad, but if it was a building that was being renovated and there was a physical aspect to it - that action plan could actually be attached to a building licence and the local government could be flagged to review that each year. So, you know, in three years' time you have to have this, this and this, and if you don't have all these things then you'll lose your licence to continue trading, then that would be a fairly big incentive, I would think, for most people to do what they said they were going to do.

MS JASINSKI: Debra, I've been out of the field for a little while but ACROD had a great input into the planning stage for access for everything. I don't know whether it still does.

MS CASEY: I'm not sure but, I mean, ACROD as a national body would definitely be another organisation that might be able to be involved.

MRS OWENS: And should HREOC have some sort of role in looking at these plans? I mean, you're talking about thousands and thousands and thousands of plans. There's an administrative issue here and I'm just trying to think through how you would do this, how you would make this into a manageable exercise.

MS McKENZIE: Yes, should it do random audits - - -

MS CASEY: I'll get back to you in a couple of weeks on that one.

MS McKENZIE: It is a difficult question.

MS McMAUGH: Perhaps access and equity audits would be a role that HREOC could feasibly play in terms of what's happening with the plans because, yes, they can sit there, you know, have nice policies but nothing much happens.

MS CASEY: An annual reporting process would be good and then it would be a case of having somebody designated to actually go through some of those reports. Maybe just the process of knowing you've got to write an annual report on what you've done would be enough to make a lot of businesses comply.

MS McKENZIE: Yes, that's a good thought. It would still make a lot of work monitoring - looking at the reports but certainly less than doing the whole action plan in the monitoring centre.

MRS OWENS: I think we've covered all our questions. I was wondering if there's anything else that you'd like to raise with us.

MS CASEY: What is the process now after the hearings? When do you finish these and then what's the next stage in the process?

MRS OWENS: We finish these the last week in July and Melbourne's the last hearing, and then we go away and we look at all the transcripts and we continue to read the submissions that come in and we prepare a draft report and then we put that out for people to look at. You'll get a copy because you've been participating and you'll see you'll be quoted in there and then you can look at what were our findings and our recommendations, and if you feel inclined, you can pass on further comments, and then later on at the end of this year and in January-February next year we'll be carrying on another round of public hearings. You get another opportunity then.

MS McKENZIE: That's really to look at the responses that you have to the draft report and if you need to add some additional matter - - -

MS CASEY: I know that was what other people in the coalition were thinking, that they would like to get involved again at that next stage.

MRS OWENS: They're really welcome to.

MS McKENZIE: They'll have a chance.

MRS OWENS: It's a very open process and we give people ample opportunities to participate. So you may like to look at what we write and say, "No, you didn't get that right," or "There's not enough emphasis on issues relating to people from non-English speaking backgrounds." We also want to deal specifically with indigenous issues, for example. So we're just trying to get some information on indigenous disability issues at the same time, and then of course the inquiry is covering a wide range of areas which are covered in the act. So the challenge for us is to try and bring all this information together and do something worthwhile with it.

MS McMAUGH: And your recommendations, how will they be processed?

MS McKENZIE: The recommendations will be - there will be some indication of them in the draft report but really that is a draft report. So that - - -

MRS OWENS: They're draft recommendations.

MS McKENZIE: Yes, they're draft recommendations. We want to have a look at what people then say about it, how they respond to that - - -

MS McMAUGH: And that will go back to government eventually - - -

MRS OWENS: Yes, eventually the final report goes to government and then it's up to the government to make a response to the report - they have 25 sitting days to do so - and to release the report and the response. Sometimes the government will release the report with an interim response and then come back later with the final response. So it just depends on what they think about our recommendations.

MS McKENZIE: Thanks very much. Thank you very much for your submission.

MRS OWENS: Now, does anybody else want to make any comments today before we close? No? Okay, right. That concludes the day's proceedings and thank you for attending. We will be resuming tomorrow morning at, I think, 9 am on 1 July. Thank you.

AT 4.26 PM THE INQUIRY WAS ADJOURNED UNTIL
TUESDAY, 1 JULY 2003

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