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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 CANBERRA ON FRIDAY, 20 JUNE 2003, AT 9.14 AM

Continued from 19/6/03

MRS OWENS: Good morning, and welcome to the public hearings for the Productivity Commission inquiry into the Disability Discrimination Act 1992, which we'll refer to as the DDA. My name is Helen Owens and on my left is my associate commissioner, Cate McKenzie. We'll be having three breaks today: a morning tea break at about 10.30 for half an hour, a lunch break around 12.30, and an afternoon tea break at about 3 o'clock. We'll try to finish the proceedings at around 4.30 to 5 o'clock at the latest. We'll need to stick fairly closely to this timetable. You're welcome to take a break and re-enter at any time.

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 your own organisation, and submissions have been coming into the inquiry following the release of the issues paper in March.

The purpose of this hearing is to provide an opportunity for interested parties to discuss their submissions and their views on the public record. We've already held hearings in Brisbane, Darwin and Hobart and yesterday in Canberra. Following the hearing today, there will be further hearings in other 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 an other round of hearings after interested parties have had time to look at the draft report.

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

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. I'd like to emphasise that the Productivity Commission is a research body; cannot deal with individual complaints. There are other avenues to resolve such grievances. To be most useful to us, comments should be directed towards the lessons learnt and policy implications of your experiences. The transcript will be available on the commission's web site in Word format. I now invite the Mental Health Council of

Australia to appear, and I'd like you each to give your names and your position with the council for the transcript.

MS HINKLEY: I am Carmen Hinkley. I'm a senior policy officer at the council.

DR GROOM: My name is Dr Grace Groom. I'm the CEO with the Mental Health Council of Australia.

PROF HICKIE: Professor Ian Hickie. I'm a board member of the Mental Health Council of Australia.

MRS OWENS: Thank you, and thanks for appearing. Also I'd like to just take this opportunity to really thank you for the very very comprehensive submission that you've given us. I think I can talk for Cate as well. It's a terrific submission and it's a very rich submission, full of very very useful information for us. So thank you.

MS McKENZIE: It also deals very comprehensively with a matter that's touched on in many of the other submissions but not dealt with globally in the way that you have.

MRS OWENS: And I'd like to thank you for tabling Out of Hospital, Out of Mind, as well. I'm going to hand over to you because we're going to have a slide show.

MS McKENZIE: I have read the PowerPoint summaries, if you like, so it will be helpful for the transcript as well.

MRS OWENS: And I've already said that we might interrupt from time to time, if that's not too distracting for you.

DR GROOM: No, that's fine. Ian is going to give most of the presentation. He's a very verbal person so I'm sure you'll get plenty of descriptions.

PROF HICKIE: I might say we appreciated the opportunity to present, because we feel the issues here, in terms of the way in which the Disability Discrimination Act is used or is not currently used to influence key areas of government policy and social development is a major issue for us. We very much welcome the role of the Productivity Commission in reviewing the act, particularly with regard to psychiatric disability. The aim of our presentation really is to highlight the extent of psychiatric disability, its cost to the community, and contrast that with a degree of lack of community understanding and, as a consequence of that, often lack of understanding at a government level and a policy level when thinking about issues related to health and disability in more general terms. So the council has prepared a very detailed submission to highlight those factors, so that in future recommendations to government in policy development and particularly in the legislative environment, these issues may be given greater precedence - certainly greater prominence than they have in the past.

In terms of the nature of the presentation, I'd like to say a little bit about the Mental Health Council of Australia and its role, as it is a relatively new organisation. I'd like to spend a fair amount of the time talking about really the global burden of disease and the ways in which we now have a metric for looking at the relative impact of different disorders, and the ways really that many of the common psychiatric illnesses for the first time have been given prominence relative to other health disorders, although they're not given prominence in terms of health spending, considerations in health legislation and in many other sectors - in the social security sector, in insurance, in the welfare sector. They don't receive the degree of prominence that would be suggested by the actual burden of disease.

The sort of adjustments that might be considered for people with psychiatric disability: to encourage their greater participation in the workforce and in other social organisations - an issue we'd like to spend some time at, and then provide some specific examples of areas where we think discrimination, either directly or indirectly, has been a major issue, and some of the ways in which that may be tackled.

The Mental Health Council of Australia was established in 1997 by the Commonwealth Minister for Health and Aged Care as the independent peak national representative body on mental health issues of non-government organisation. The constituency consists of consumers, carers, special needs groups, private mental health service providers, non-government organisations, Aboriginal and Torres Strait Islander groups, critical service providers and state and territory based peak bodies, so it's a mix, really of consumer, carer, organisational and private health service providers and professional groups. It makes it a large body but it also makes it truly representative at a national level of all of those groups coming together.

It was established under the Australian National Mental Health Strategy, which finishes in 2003 10 years of actually having a national mental health strategy, and it was one of the important developments during that strategy to actually have a peak body to make important policy recommendations to the federal minister independently of the federal department and independently of the AHMAC, Australian Health Ministers Advisory Council, representative groups. In that role it frequently makes submissions to government about key issues that affect the lives of people who are affected by psychiatric illness.

It has 41 organisations and unfortunately they are all listed here, and I won't list them all, but it gives an idea of the range and extent of those organisations. It includes the royal colleges of various medical groups, the Australian Psychological Society, social workers, et cetera, the peak groups of consumers, the Australian Mental Health Consumer network, peak carer agencies, and then a whole range of other factors like the Rotary Health Research Fund, GROW, Sane Australia, just to name a few. This is a very wide and broad organisation, and it has taken a while to bring all those organisations into a functional unit. Collectively, however, it represents over 500,000 individuals who are participants in one or other of those organisations.

I'd like to spend a little bit of time talking about the global burden of disease study. As you may be aware, the issue for most market economies of what exactly health costs and which disorders cost most is an important issue. Health statistics have tended traditionally to be dominated by simply mortality statistics and therefore putting high emphasis on things like heart disease and cancer in the developed world, and things like infectious diseases, particularly infantile infectious diseases in the developing world.

In trying to improve really an understanding of the way in which health impacts on societies, the Global Burden of Disease Studies and projects were developed by the World Health Organisation, the World Bank and Harvard University to try and develop a metric that covered both disability and death on an ongoing basis, and the metric that comes out of that is a statistic known as the disability adjusted life year. Basically it's a single measure to allow comparison of the burden of disease across different groups and measure essentially the lost years of productive life.

The international standard is actually a Japanese person. As good as you can get is to be Japanese and live healthily into your 80s. Interestingly, Australians were second and now we're third on that list of long life expectancy, and therefore you can lose a year of life either due to premature death, but every life year lived with disability is also counted in the same way. So the most disabling disorders in fact to have are disorders where you develop them when you are young and then live many years with disability, and they then cost a society the most on an ongoing basis.

When you take that notion forward, and from a market economy point of view therefore it reflects whether you're going to work and how much you're going to cost in terms of welfare and other supports, what came out of that set of studies was a surprise to most people in health policy and planning, and the extent to which psychiatric disability figured in the very high levels of disability. You have to make some judgments which were made by clinicians, by consumers, by carers, by other independent people, by people off the street, as to what was the relative disability of one disorder versus another.

For example, the disability associated with depression is equated with that associated with blindness or paraplegia. The disability of active psychosis in schizophrenia was associated with quadriplegia. That may sound dramatic, but in terms of actually the person's capacity to get out of their own house, to work, to socially interact - these were judgments made by, as I say, independent clinicians, by consumers, carers and by members of society more broadly, in terms of trying to work out how disabling each set of disorders was. Adjustments are then made by how common those disorders are in a society, and their relative responsiveness to treatments.

When this was first worked out internationally in the early 1990s, to most people's surprise, unipolar major depression appeared as number 4, and shown at that stage worldwide were lower respiratory infections as number 1, diarrhoeal diseases as number 2, perinatal conditions as number 3, and then actually unipolar major depression actually being higher than ischaemic heart disease.

The World Bank also tried to make projections as to what would happen over the subsequent 30 years, projecting forward the relative costs. Because of increasing control of those infectious disease in developing countries and a shift therefore in their disease burden as many of those countries develop, what we expect to see by the year 2020 is globally that ischaemic heart disease will be the leading cause of death and disability, but that actually major depression would be second by 2020. Again, most health planning has just not really taken account of the extent to which a common psychiatric illness would figure so prominently in this tabled ranking sets of disease internationally.

In fact not shown here - this work has been repeated in Australia by the Australian Institute of Health and Welfare in the mid-1990s, and at that stage unipolar major depression finished third on the table and again is projected to go to number 2. The projections about increasing the situation have to do with ageing in the population, so ischaemic heart disease will continue, but other things at the moment in Australia like lung disease and stroke will actually fall due to better public health measures and better interventions. Our relative lack of public health measures and the provision of treatments to many people with common psychiatric disorder will result in them actually increasing up the table.

But, in addition to that, our failure to deal with many of the social barriers that contribute to disability in those issues - the difficulty that people have in employment, the difficulty that people face in other social barriers - is built into those statistics. If those people were able to participate more, then their relative disability would be lower on an ongoing basis.

MS McKENZIE: And the measures would reflect that?

PROF HICKIE: The measures would reflect that because the measures in terms of the disability adjustments that are made are built around assumptions about capacity to work, capacity to access things like welfare payments, capacity to access insurance, so that disability for these illnesses, particularly when you live a long time with the illness, are based around notions of participation in addition to the degree of disability that you will have, the difficulty of getting - - -

MS McKENZIE: It's a question of how productively you live. In other words, if you live with the illness but you're productive it's not going to count as a lost year.

PROF HICKIE: That's right. A good example at the moment would be if you're trying to work out the disability associated with paraplegia or quadriplegia in different societies, that will depend on the extent to which those societies have actually made a physical adjustment in the workplace or in society or in public transport, to allow people to participate. There's been very little sense of adjustment to take account of the nature of the disability that people with psychiatric illnesses actually have, their degree of lack of participation in the workforce, in education, in social structures, and also their lack of degree of access to services and treatments which may reduce their disability, so the two: there's a lack of medical provision to support them to reduce the disability directly, and then a lack of dealing with social attitudes and social barriers to participation. Both have contributed to the notion of setting the current metric for the degree of disability.

MS McKENZIE: So actually it's not really just the degree of disability you're measuring; it's the degree of accommodation of the disability that's built into this measure.

PROF HICKIE: That's right. The global burden of disease study is not a one-off study. It's an ongoing process. It's important to say that organisations like the World Bank are into this sort of statistic to try and work out lending policies to developing countries, and want to see the return on investment in human terms. So they see it in terms of what structures are in place in various countries, be they health services or adjustments for disability that will allow those people to be productive economically in a society, versus actually being a large economic cost, particularly a caring cost in those societies.

The metric will change. The relative weighting of any particular illness changes relative to the extent to which a country provides services to treat the actual disorder, the extent to which they have public health policies to prevent the disorder, or they make adjustments in social policy to increase the participation of people with those disorders.

MS McKENZIE: Doesn't that make the measure difficult in the sense that when you look at it you can't disentangle the extent to which the country provides services or adjustments to cope with that particular kind of disability and the incidence of the disability among the population of that country?

PROF HICKIE: What it has meant is that there's a global process, which is the sort of international process to try and work out across the world what is the current situation, and there has been within that movement a separation of what happens in the developed world versus the developing world. It also means within each country it's important to repeat the exercise and try and make the same adjustments within a country relative to that country's health service or relative to that country's social services or their attitudes to certain illnesses.

MRS OWENS: Is that what the AIHW is doing?

PROF HICKIE: That's what AIHW is - - -

MRS OWENS: That's where you got the third ranking.

PROF HICKIE: You need to also adjust for prevalence in each country. So the prevalence of different diseases is different in each country.

DR GROOM: I think it's also fair to say - and we'll come to it later - that when the AIHW conducted the Australian study, that was done with a high degree of scepticism with respect to the results of the global burden of disease study, and our epidemiologists in Australia didn't believe that depression could, for example, be the second leg in cause of disease burden worldwide by 2020. In fact, what they found - which I will talk about shortly - is that depression is already the leading cause of non-fatal disease burden in Australia. That was quite an extraordinary finding. Cate is absolutely right: it is going to vary from country to country.

MS McKENZIE: Also because the measure puts together with the extent to which a country accommodates that disability and the incidence of that disability in the country.

PROF HICKIE: There's obviously more evidence in each country about the simple epidemiology. In fact, we're lucky in Australia that also in the national mental health strategy concurrently we had an Australian National Mental Health Survey, so we actually did count the community rate of psychiatric disorder through the Australian Bureau of Statistics in 1997 and in 98. We've had a current actual testing of how common is the disorder, but working out the degree of disability does take account of what the social situation is so that the degree of disability these days associated, for example, with paraplegia is less than would have been the case if you had tried to do the same thing.

It does mean the metric, therefore, changes over time, or can change over time, as it appropriately should; also with better treatments. So if a treatment comes into place or a prevention comes into place - the classic example in medicine would probably be polio; something suddenly disappears or is preventable or it's treatable - then its degree of disability changes.

MS McKENZIE: I can understand how treatment is measured and weighted in this overall measure, but how are accommodations or adjustments weighted? What assumptions are made about what is a good accommodation, what is a reasonable accommodation, what is an effective accommodation, what is not accommodation?

PROF HICKIE: It's fair to say that this process of thinking about disability rather than - medicine has been dominated by thinking about death. The process of thinking about disability, which is much more relevant to economic costs long term, has started to force people to think about exactly these sorts of issues. In thinking about disability, it's fair to say most of the thinking has also been about prevalence and about relative treatment effectiveness and the movement there is actually measuring days of productive working life lost relative to the treatment provided; not simply whether you're less symptomatic but what's your chance of getting back to work as a consequence of the treatment?

It's part of a movement, but I guess as this process develops there's an increasing interest in then not just traditional epidemiology but what is the situation from country to country. Is it fair to say in Australia that the disability due to depression is equal to the disability due to blindness or paraplegia? In different countries you may come to different conclusions about those metrics. As Grace was saying, in fact, there's a great deal of scepticism that the global study and the World Bank may have overestimated the degree of disability and loss associated with psychiatric disorders in various settings. In fact, many people in the area - myself included - think they may have underestimated; in fact they may have underestimated the degree of both lack of services, contribution to other disease and social barriers that people actually face.

It remains an ongoing issue about determining in each country at any particular point of time when you try and bring the epidemiology together with the sort of notion of barriers. It relies on a consensus judgment.

MS McKENZIE: In a way, this measure - not entirely - has got some element to it that actually measures discrimination in a way.

PROF HICKIE: Yes.

MS McKENZIE: Is it fair to say that?

PROF HICKIE: Yes, because it is pinned around lack of provision of health services, which we would see, for example, as the most basic discrimination. We have an area of health, of very high disease burden, of very low health expenditure, very low priority. We would see that as intrinsic discrimination, because - - -

DR GROOM: In fact, how we've described it in our report, Cate, that we've recently produced, is as a human rights abuse; not in an overt way that used to occur in the large institutions but abuse through neglect, which is essentially discrimination in another way, isn't it?

MS McKENZIE: I guess through omission, yes.

PROF HICKIE: The previous argument would have been sort of, "Well, due to ignorance, we didn't know it was such a big problem," or "There was a lack of effective treatment, so there was nothing we could do about it." We would say with this situation that neither of those is true. We have very good data in Australia about the size of the problem and the extent of the problem, and increasing data about the social barriers. We also have moderately effective treatments, and we have moderately reasonable preventative strategies at this stage, although many of those are not as clear-cut.

At this stage we'd say it's not an issue of ignorance, it's a historically inbuilt discrimination against providing these sets of services; that the situation exists where they were low cost, low services provided, and have been left that way. It's been very difficult to change the health mix to take account of what we now know and that, therefore, the most basic discrimination is a lack of access to services that would otherwise reduce disability and would otherwise increase participation.

The second level is that many of the barriers that exist in things like insurance, employment, et cetera, are based on historic notions of an untreatable illness, with great social difficulties when, in fact, they no longer apply. We'll come to the example of the insurance industry shortly, where historic notions, out-of-date data, out-of-date concepts, are used to drive current policy, but then they reinforce social exclusion.

MRS OWENS: Just before we get onto that, it's interesting that cancer doesn't rank anywhere in the top 10. There would be people out there who would put that up there with ischaemic heart disease.

PROF HICKIE: If you ask people in Australia - and we've done this through beyondlue - "What is the most important illness, health problem in Australia?" they say, "Cancer." They say cancer, heart disease and then alcohol and drug abuse, or in our most recent study they say cancer, heart disease, obesity and drug and alcohol abuse. They do not mention mental health or depression or any of the common psychiatric disorders, which tells you something about the wider society. It tends not to see mental health as health, but see cancer.

The thing about cancer is, in fact, if you look at the age distribution of cancer and the years lost and then lived with cancer, they're quite different. The burden of cancer mainly applies to people in their older years and in the later stages of their life and for many of the cancers you have a much lower rate of people living many years with disability. We are also, according to Rob Burton from the Anti-Cancer Council of Australia, probably the world's leading provider of cancer services. Right across our public and private system there's probably no better place you can go in the world to be treated for cancer. We also have some of the best preventative programs in cancer in the world. So the fearfulness surrounding cancer - - -

MRS OWENS: That would be reflected in the measure, I would think.

PROF HICKIE: That's reflected in the measures.

MS McKENZIE: The strange thing about the measure is that the way it measures death is that if you die very quickly there are hardly any lost years due to - - -

PROF HICKIE: It depends on the age at which you die. If you die at age 20, compared to a Japanese man, that's 60 years. So you die at age 20 and the average is 80, that's 60 years of lost productivity. It does allow for premature death.

MS McKENZIE: Okay.

DR GROOM: But the difference is that it used to be that we only measured death, not death and disability, and that's where the disability-adjusted life year - metric, as Ian calls it - came in, and was so important.

PROF HICKIE: The classic example would be here, if you died at 20 from a road accident, then that's 60 years lost of productive life. If you develop schizophrenia at age 20 and you never work again, your expectancy is still to live to age 60. That's 60 years of lost life. That 60 years of living with disability is just as important as the 60 years lost through death through premature road accident. This is again where cancer becomes important.

We don't show them in slides here, but there are a number of charts that are produced which break up the total disability into death versus disability. Heart disease and cancer, most of their DALY cost is through premature death. It's not through years lived with disability; it is through people dying prematurely. But many of the people who die are in their 50s, 60s, 70s, so the years lost are 10, 20, 30, et cetera. Most of the psychiatric disorders have their onset in the teenage and early adult years. Many of those people are never treated. In our national mental health survey, only 38 per cent of people with disorders presented for treatment in the last year. Of those, 75 per cent are treated by general practitioners. For example, only one in six people with depression receives an effective treatment.

What we have is a large number of people residing in the community not presenting for treatment or not having access to treatment. When they do present to treatment, having essentially primary care based treatment and low rates of recovery, less because the treatments are not effective but much more because the treatments are not delivered in an effective way to large portions of the population.

MRS OWENS: That raises another issue about the measures, because these are self-reported, aren't they, if you're talking about, for example, Australia and the ABS surveys?

PROF HICKIE: Yes.

MRS OWENS: So it's people having to self-report.

PROF HICKIE: Yes.

MRS OWENS: There may be an understatement of, say, unipolar depression; people don't actually declare that.

PROF HICKIE: That's right.

MRS OWENS: This might be the tip of the iceberg.

PROF HICKIE: It's important to say that the thresholds used here are the international thresholds based, in fact, on clinical practice. You have to get to a sort of level, you have to be reporting in the community at a level which would be treated and recognised in a clinical setting.

MRS OWENS: If they're not getting to the doctor in the first place, as you just said - some people are just not going to report to a GP or even get specialist treatment - - -

PROF HICKIE: That's an important point you're raising, because many people believe there's overreporting going on, but in fact people are not in a hurry to declare that they have a psychiatric disorder and they're not in a hurry to declare their disability associated with that - why they're not actually working.

MRS OWENS: Whereas if you're talking about chronic obstructive pulmonary disease, that is a more objective measure because those people will ultimately get into the system at some stage. It's more likely that that's going to be measurable.

PROF HICKIE: It's important to say, for different sets of disorders, that's true. The thing about cancer, for example, is that most people will get into the system, although it's highly variable at the time they get into the system - for example, patients with schizophrenia with cancer present very late and die very quickly. The contrast in Australia is with women with breast cancer, who are the group with cancer that get into treatment most early. Men with lung cancer, for example, come in late.

There are other areas, like arthritis, which has just become a national health priority, which is a bit similar to depression, where people actually live with considerable disability, don't rush to actually get effective treatments; often when they get there don't get effective treatments; often told by their doctor they're too young to have arthritis or they're old so they've got arthritis. So what? Often it's a disability that isn't managed effectively, even when it presents in situations where many people reside.

One of the important things about health surveys is that health surveys are conducted at a community level as effectively as they can be, rather than simply just within a general practice setting or within a health specialist-type setting where you see distortions, and particularly in Australia you see distortions related to where you live, you see distortions related to socioeconomic access, you see distortions related to disadvantaged communities - for example, the Aboriginal and Torres Strait Islander communities.

MRS OWENS: We'd better move on, I think, because otherwise we won't get through them all.

DR GROOM: We could go on about this for a very long. It's so interesting.

MRS OWENS: Yes, it is.

PROF HICKIE: Having said we have a statistic where you put them together, the DALY movement does allow you to separate out just straight disability from death, so if you care just about disability - some people care just about death, the cancer and heart doctors tend to focus on the death statistics; those who like things like psychiatric disorder, falls, alcohol use, arthritis, we tend to focus on the life, the years with a disability. In the 1990 statistics, five out of the 10 leading causes of disability were psychiatric disorders - unipolar depression, alcohol use, bipolar disorder, schizophrenia, and obsessive compulsive disorder.

If you look at disease burden by selected illness categories, basically if you took all cardiovascular conditions and put them all together, basically that was 18.6 per cent of the total; all mental illnesses, including suicide, put in together, then mental illness was second, with 15.4 per cent of the total burden of disease category. This is really important because, when we come to health expenditure and health set of issues, the fact that we figure so highly across the board is just not reflected anywhere in health policy or in many of the social factors that are important to us.

We chose to highlight in some ways the issues related to depression because it highlights the issue really around a common mental disorder. Now, if you have got a disabling condition - the other thing that matters in market economies is, how common is that, and a lifetime expectancy with depression is basically that one in five people will have a depressive episode at some stage during their life, typically of early onset, so typically associated with anxiety in teenage years and typically onset in its early years.

The depression then contributes to other diseases. It contributes to suicide. It contributes to alcohol use. It contributes to cardiovascular death. There's a wide set of implications on an ongoing basis. Again this has really forced health and welfare planners to think about, "Well, what does that mean in terms of disability effect?" I want to really raise that kind of issue because, when we talk about disabilities, it's fairly obvious to most people the way in which blindness or paraplegia actually contributes to disability - the way in which people are not able to carry on with their particular functions as a consequence of that.

This whole movement has forced people to describe the ways in which these disorders actually contribute to disability and then what might need to be adjusted - the way in which disorders like depression interfere with cognitive function, interfere with memory, interfering with concentration; the way they interfere with social function in people's capacity to actually interact with each other on an ongoing basis; the way they impact on emotional regulation; the extent to which people's mood is actually controlled or not in certain sorts of situations; therefore not only what needs to be done at an illness level about those sorts of things, but in what ways the social environment could adjust to take account of some of that ongoing disability in an ongoing way.

In the submission we have just highlighted the extent to which depression is a good example of a very common disorder, which has those cognitive and emotional elements and social elements on an ongoing basis, but is not appreciated by the wider society; in fact we had comments by the assistant treasurer last year in her statements in relation to a review of insurance, saying that people with anxiety and depression should just get over it and get back to work, as if they had a volition involved - these deficits they suffered were volitional. To us it is like saying people with paraplegia should hop out of their wheelchairs and get on with it.

I mean, what would obviously be insulting in a wider environment can be said in an ongoing way. We had a major figure in the AMA use similar sort of language in a context of a political debate last year around people with anxiety and depression, so it's not uncommon for people in very high office - in the medical profession, in the legal profession, in the parliamentary - to make comments to say, "Look, I understand that people with schizophrenia or people in psychiatric hospitals - who are at a much lower prevalence - have some very disturbed social functioning, but many of these other people have their disability under volition. They're choosing not to participate in some way. They don't really require intervention. They don't require medical or psychological support. They could sort it out by themselves on an ongoing basis," which reflects the extent to which the illnesses are not understood, but also the way in which they contribute to disability is not understood and believed to be under voluntary control.

DR GROOM: I think a good example of that is that there was a national report released yesterday by the Australian Institute of something or other - they are not a mental health group, but they were looking at the unpublished data from the ABS report into mental health and they put out a press release, which was titled something like - what was it?

PROF HICKIE: Drugged to the Eyeballs.

DR GROOM: Drugged to the Eyeballs and Happy, and they were saying that remarkable but unpublished fact out of the ABS data was that something like 20 per cent of Australians are either taking antidepressants, abusing alcohol or taking other illicit drugs to get through the day and, essentially, what they were doing was lumping in the antidepressant, the legitimate treatment for depression with illicit and other substances and really putting a message out there that people who are taking antidepressants are somehow just taking - - -

MS McKENZIE: Substance abusers.

PROF HICKIE: Substance abusers, yes.

DR GROOM: That's right, yes, and it's not seen in the same way that someone who has, for example, diabetes needs to take insulin on a daily basis or someone with some other disorder needs to take the appropriate medication. Again it's that trivialising of the disorder and saying that people should just get over it and they're only taking these drugs because they want to.

MRS OWENS: What you say is really interesting in terms of our inquiry because society's view could then reflect in how they deal with people with mental illnesses and lead into situations where there could be discrimination.

DR GROOM: Most definitely, yes.

PROF HICKIE: We see it absolutely in employment and insurance; an expectation for example that, to be well, you'll stop your antidepressants; in a sense, that you would stop your substance abuse in order to be a greater - the participation would in fact depend upon ending your treatment so that - - -

MS McKENZIE: If you've got cancer, it would be, "Well, you stop your chemotherapy."

PROF HICKIE: Yes, yes, or to a diabetic who's functioning, "Stop your insulin and come to work," so "When you have stopped your insulin you can come back to work." We see it very commonly, and you see this right across the board. I mean, the aviation industry is a classic worldwide: no pilot can fly on antidepressants, so they prefer to have depressed pilots who treat themselves with alcohol, flying. That's okay.

MS McKENZIE: They're not allowed to drink for 24 hours or whatever it is before they fly.

PROF HICKIE: We know from international studies about alcohol abuse and in fact about depression rates amongst pilots, et cetera, and we see very commonly sets of expectations, where the belief system is that there is not an illness here; that either in terms of medications that you use or participation in the medical system there is a voluntary choice on your behalf and therefore one which you should obviously make a choice to not use legitimate services.

I have mentioned the ABS study. It is important to say that we do have good data in Australia about the prevalence of mental disorder, but also the utilisation statistics, and this does reflect the wider issues. We would highlight the fact that 62 per cent of people do not present for care has much to do with what we would call mental health literacy or illiteracy: the little that people understand about the issues, but also their fears and worries about what happens if you declare you have an illness, so research done with the people who don't present really highlights the extent to which they don't present; not because they do not know that they are unwell - many of those people are not attending work; for example, people with depression typically don't go to work three to four days per month. It's not that they're not working. It's not that they don't understand that, but they fear the system. They fear the disclosure. "If I go and I get a diagnosis I've got one that means I have to tell my family, my employer, potentially any insurance - that I have actually got a psychiatric illness," whereas if you are just sitting at home and you're not treated, you've got one but you don't have one.

MRS OWENS: So there is a concern about stigma.

PROF HICKIE: The stigma is the overwhelming concern, so the common phrase that we hear is, "It's bad to have the illness, but it's twice as bad to live in a society that is totally intolerant of that illness and it blames you for having that illness on an ongoing basis." Of course, that increases the burden more broadly because the increase on carers then is that much of the service is actually provided by family on an ongoing basis - in our de-institutionalised system of expectation that family will provide care - but those carers themselves are living in a situation in which they, too, face the same sense of social attitudes on an ongoing basis.

MS McKENZIE: So stigma really has two disastrous effects: one is the direct effect where there is some kind of discrimination because you are viewed in a particular way because of your depressive illness, but the other is because it makes you afraid to disclose that illness, which therefore makes you not go for treatment.

DR GROOM: That's right.

PROF HICKIE: Yes, and this varies across the disorders. It is estimated that approximately 80 per cent of people with schizophrenia, for example, are in treatment on an ongoing basis or have been in treatment in recent year, but that figure, for example, around depression is down around 40-50 per cent and for anxiety disorders is down around 30 per cent; that in fact that is exactly what happens. The fear of disclosure and the fear of actually finally attracting a label exposes you then to the stigma. It also exposes you to people's belief systems about the treatments.

In our situation many people believe the treatments - particularly the medical treatments - to be worse than the illness, so that the common portrayal of antidepressants as addictive, as mind-altering, as leading to people becoming homicidal, et cetera, or to people just being drugged, to people with schizophrenia. We talk about the look that they develop when they're on medication and then people recognise that in the street, so the look of being drugged - they prefer actually not to be treated than to actually have to deal with people in a situation in which they will be identified through the treatment on an ongoing basis. So the stigma operates at many levels to prevent effective treatment, presentation for treatment, the provision of treatment, and then participation if you are on the treatment on an ongoing basis, which leads into really the issue for us around reasonable adjustment and unjustifiable hardship.

Clearly, to make advances in this particular area there are issues which I have highlighted. We feel there are very fundamental issues which we have highlighted in the Out of Hospital, Out of Mind resources about the inequity and the distribution of resources in simple health planning and simple health policy which, despite 10 years of a national mental health strategy, spending on mental disorders is no further increased than it was 10 years ago. There is no greater section of the health pie devoted to these disorders. In Australia approximate 7 per cent of health spending is actually devoted to mental disorders when we account for at least 30 per cent of the disability burden of health disorders.

MS McKENZIE: 7 per cent?

PROF HICKIE: 7 per cent of spending. There's a lot of discussion internationally about how you measure that, but that figure is stable in Australia. The way we measure it in Australia is stable and it hasn't shifted, so despite having a national policy, which has many good elements, there is a lack of investment by governments in really taking the issue forward. International comparison figures in OECD countries suggest that - figures of 10 to 14 per cent, 10 to 15 per cent are comparable figures in OECD countries in terms of mental health expenditure.

MS McKENZIE: But if the figure remains around about the same in other countries then still there is a disastrous underexpenditure on mental illness, even in those countries.

PROF HICKIE: Yes. In those countries under-spend relative to what could be done. In Australia, for historical and other reasons - and, as we have highlighted in our report, what we feel is really a failure of state governments over the last 10 years to invest. There is another factor which comes into play in health spending fundamentally. Most expenditure in health is in hospitals, emergencies, acute procedures. The more your area becomes less hospitalised and, in some ways, less intensely medical, the new health spending goes into new drugs, new hospitals, new procedures, new technologies, which are very expensive; in fact the only significant growth areas in mental health expenditures have been in new pharmaceuticals in the area and increasing Commonwealth spending - two-thirds of the increase in Commonwealth spending in the last 10 years has been in support under the PBS for new pharmaceuticals.

I'm not suggesting that that is a bad thing - that's a good thing - but that's where our only growth is, but relative to cardiovascular disease and cancer and hospital technologies, we are largely a de-institutionalised treatment service. We are a community based service and so it is probably not surprising that, although we have high need, we have a disadvantaged group, a stigmatised group, and we're no longer really within the hospital system. We're in the community based system of care and, we would suggest, largely neglected, largely ignored, within that; hence the title of our report, Out of Hospital, Out of Mind.

We used to have change in the mental health system by royal commission - by royal commission into a hospital - when it was so bad that somebody had to do things. For most of the people living in the community there is no royal commission into Fitzroy or Liverpool or any other place in which you have a high density of people with mental illness without adequate community support. Important to us is what could be done. Much of the work - my own work with beyondblue - and much of the public health work at the moment is about changing attitudes.

What we need to see happen in families, in schools, in communities, in workplaces, is to actually take account of this degree of disease burden, the needs of people with these various sets of disorders. They can't just be lumped simply as "mentally ill" either. There are many different disorders with quite a variable degree of cognitive and emotional handicaps that arise out of those disorders. We need to advance with the community understanding. We need in fact daily schedules in many situations - work arrangements, school arrangements, opportunities in training and education to take account of the specific nature of the disabilities that people present and the specific nature of their social and occupational characteristics.

MRS OWENS: When we think about other areas where reasonable adjustment is expected, they are more tangible.

PROF HICKIE: That's right.

MRS OWENS: You changing the daily schedules is a fairly tangible thing - where there is a will you can do that - but changing attitudes and community understanding - it's a more intangible thing that you need to think about: how do you do that? There is a bigger challenge, isn't there, that requires education?

DR GROOM: There is a bigger challenge, but I also think that there is a bigger challenge in changing daily work schedules, as well, particularly if you look at, for example, the employment sector. It's much easier for an employer to put in a ramp or to put in different sized doors or handles at different levels than it is to accommodate for someone with psychiatric disability. I think that is one of the key questions that we have around the DDA: how is the level of psychiatric disability determined and by whom and is that determination inclusive of mental health problems, as well as mental illnesses, because there are some important distinctions there. I can't remember who it was who said it to me - I don't know whether it was you or someone else was telling me of a story of someone recently who was diagnosed with quite severe depression.

She went along to talk to her employer about how she could be accommodated in the workplace. He said to her, "Well, you know, of course we want to accommodate you in the workplace. Just tell me which days over the next couple of months you will need off." How on earth was she going to do that? I think both in terms of the recent welfare reforms and issues like that, the whole episodic nature of mental illness is simply not taken into account, and it's as though you do have to go in and say, "I need a ramp," or "I need the door handle adjusted." If employees can't see or physically adjust the environment, they find it very difficult to go beyond that. I think for us that's where a real difficulty comes in with the DDA. How is it applied in those situations? It's far less clear, I think.

PROF HICKIE: I think also, as Grace alluded to, the notion that fixed disability versus a disability that varies is very problematic. The people we're talking about can be highly impaired at certain points in their illness and therefore require flexibility in work arrangements at a certain period of time, but are highly likely to recover to certain degrees. You may have certain degrees then of residual disability in certain areas, but it's a variable situation, which is obviously very challenging in employment or in education to take account of, but it's the nature of the illness.

What we find is that many people say they can only cope - the employer or the institution can only cope with fixed disability - "You have to tell me exactly what the disability is now and forever and I'll make adjustment, otherwise there can be no adjustment. Otherwise you can't continue in employment," or "Otherwise you can't continue in this educational course, unless you can predict a fixed level of disability." In a sense I think it arises out of some of the notions of fixed physical disability and sort of physical adjustment to that, rather than fundamental - what we are talking about are more social adjustments, they're more adjustments by group, by flexibility in attitude than they are literal physical changes in a building.

MRS OWENS: Have you any experience with different employment situations? Do government departments, as employers, do it better than say the private sector? Or can't you make that assessment?

PROF HICKIE: We see much more variability by employer, than by government versus non-government, or private versus public. Really the key issue is often attitudes of key line managers in a situation.

MRS OWENS: Would that reflect their own experience maybe with family or friends that have been in this situation?

DR GROOM: Most definitely. I think our experience has been that particularly if you're dealing with members of parliament, that they often only get it when they've had a direct family experience with mental illness. Outside of that, their understanding, their mental health literacy, their compassing, their willingness to engage in discussions about mental health is really very limited. There is an unknown factor, there is a fear factor, there is a stigma factor.

A classic example for me recently was that I attended a mental health and ageing workshop run by two very prominent sections of the Commonwealth Department of Health and Ageing, and they were looking at that important intersection between mental health and aged care, so particularly dementia. It just struck me as extraordinary that we spent about four hours of that workshop with people still using language like "the severely behaviourally disturbed" rather than talking about people who have behavioural disorders as a symptom of their illness. Again, it was this blaming factor. It was saying that these old people who are difficult to manage, are difficult to manage because they're bad people - that was the inference; not because they've got these symptoms of their disorder.

Someone even had the gall - a senior person in the department - to get up and give a presentation about a really innovative project that was implemented, which was essentially about chemical restraint. It was about using the antipsychotics to modify the behaviour of the people who were living in care with dementia. The results showed how once the patients were chemically restrained, the morale of the staff improved and staff retention improved. There was nothing in there about patient outcomes or better care for the - - -

MS McKENZIE: What about the patients?

DR GROOM: Exactly. That's what I stood up and said. I just couldn't stand it any longer. I said, "You know, for someone who has got two parents with advanced dementia, one who has behavioural problems, I find this whole workshop highly offensive." I don't think government departments do it any better, Helen. In fact, the greatest stigma we found, too, in our review of mental health care is often coming from the medical workforce, the providers of care, not just the public. You find it across the board.

PROF HICKIE: But it's important to say the reason for that is that often they deal with the most disturbed and also see the most treatment of resistance, so they tend to adopt the view - it's like seeing all the worst cancers. It's like working in palliative care. If you see that, you adopt a view of cancer as a terribly overwhelming illness that ends in death very quickly.

MS McKENZIE: But it's interesting we don't apply the same attitude these days, at least, to physical disability. We certainly don't tell, for example, people in wheelchairs that "It's your fault you're in a wheelchair. We're not going to make a ramp for you because of that."

DR GROOM: No, we've made some progress.

PROF HICKIE: But it is progress. If you went back some generations it just wasn't thought about that society should have to make adjustment. That's the issue we feel we're stuck with, with mental disorders. We're stuck with a situation where their legitimacy as illness is challenged continuously, therefore the blaming of people is seen as important. Or it is their fault or their family's fault in some way or other, and they should make the adjustment rather than there being any wider social adjustment.

DR GROOM: Another important issue - and Ian's been dealing closely with this as chair of a group set under the National Health Priority Action Council - is the comorbidity of mental health disorders with chronic physical disorders or high levels of disability, so what about the person who has recently become a paraplegic and the workplace has accommodated them with the ramp and with the different doors, et cetera - but what accommodation are they making for their mental health or their mental status? Because often those people do experience a reasonable degree of depression or adjustment to their current physical situation and, again, it's the area that goes without attention. That's what we're finding with the other chronic disease areas, such as cancer and cardiovascular disease. Often there is a comorbid mental health problem as well that's either not being treated or not being accommodated in workplaces.

PROF HICKIE: I think in terms of changing social and particularly employment attitudes, is that - Helen, to answer your earlier question - the really good employers are those who have done it. For whatever reason they did it in the first place, be it family need or they were in a situation where they were in danger of losing an employee they really valued and they understood, they stuck with the situation, made allowances and they've had the person return to productive life. So the person is valued for their contribution in the past and recognition in the future that they have - as a physical disability area. They have unique characteristics. They're not defined by their illness.

They've made contribution in other ways, so the employer takes account of that, makes more flexible work arrangements during the time of illness, promotes the person having the illness effectively managed to minimise the impact on the workplace, and then have found those people to be incredibly productive employees. There are employers who preferentially employ people with psychiatric disability and report that they are very reliable people; they are very involved and that many of their attitudes are challenged and in fact found to be inaccurate by simply having those people in employment. So it's very similar to the physical disability area. Once you have people who have ramps, and you have adjustments, that people with disability are actually participating on a day-to-day basis, then they are valued.

While they continue to be excluded they are seen as a burden on an ongoing basis.

MS McKENZIE: They're invisible in that sense.

PROF HICKIE: Yes, so they are actively participating. I think many of the things in employment have been covert around, "We can't accommodate you."

MRS OWENS: I think you made a very important point about being defined by your illness. I think that works both ways. It's the employer not defining the person by their illness, but it's the persons themselves also not defining themselves and giving up because of their illness. I think it goes two ways. We mustn't forget that.

MS McKENZIE: I think that may be partly true and certainly that's trying to ask people who have a mental illness to try to adopt a positive attitude, but that doesn't somehow relieve an employer from the liability not to discriminate against them. An employer can't say, "Well, you didn't do enough for yourself so that somehow excuses what I've done to you." That cannot be so.

DR GROOM: It becomes particularly complex with mental health problems because at what point do you say the person hasn't done enough for themselves because of their will? Or hasn't done enough because they simply haven't been able to, because they've been too unwell to take that next step. That's where some of the complexity comes in. It's very difficult to make that judgment.

MS McKENZIE: Applying for a moment what you've been saying to the DDA, is it fair to say then that as far as the objectives which concern eliminating discrimination and the other objective which concerns recognition of the rights of people with disabilities - in other words, attitudinal change - there is a long way to go.

DR GROOM: I think there is a long way to go, but what we're going to do, Cate, is give two very specific examples of direct discrimination where the DDA was useful as a stick to try and influence behaviour, and then an example of indirect discrimination through legislation, where the DDA is absolutely useless, because it can't be used to modify the behaviour of governments. So if we can just talk about those two.

PROF HICKIE: The direct example we've been involved in is there have been issues related to access of people with psychiatric disability, psychiatric illness, to insurance for many years. It was an issue the insurance industry didn't want to deal with it, and simply said there were a number of individual cases that may have occurred, but in reality the Mental Health Council and certainly beyondblue over the last two years had really been collecting cases. Cases had been reported to the

Human Rights Commission. The typical defence of the insurance industry was to say that its discrimination. At the time of the application the underwriting was based on actuarial data, therefore it was entitled to exemption under the relevant act - and really, to take up the situation.

We've taken this up particularly with IFSA, the Investment and Financial Services Association as the peak industry group that deals particularly with life insurance and income insurance, which in terms of social access are two of the major areas, particularly income protection, and their sets of products. Basically much of the work in this area had been simply to exclude anyone who declared mental illness of any sort; to lump mental illness all together and to perpetuate a community notion that it's an illness with very high risk of death, disability, hospitalisation, independent of treatment and independent of which disorder you had. So that most of the practice reported to us both at the application time and at the claims time was - at the application time to reject the application, and at the claims time to challenge the legitimacy of the illness on an ongoing basis, so a source of much difficulty.

The Mental Health Council and beyondblue in association with many of the peak medical and other organisations that are relevant have been working for two years to achieve a memorandum or understanding. We did actually sign and show on here - is everyone holding a copy of an MOU being signed by the Australian Psychological Society, the Australian Division of General Practice, the AMA, the Mental Health Council, College of GPs, beyondblue, the College of Psychiatrists, and the guy on the end is the CEO of IFSA, the insurance industry.

All those people are working together around a new matrix for dealing with how underwriting would occur - what was the actual matrix for determining degrees of risk associated with different disorders based on new data - on Australian data where there is Australian data, but certainly recent data rather than other data - how communication could occur back to people about their claims, how communication could occur back to doctors, how claims could be managed in a way that would reflect a more modern understanding of the nature of mental illness and its treatments and, importantly, to take up the issue that treatment in fact reduces risk and doesn't increase risk; so the notion of getting off your treatment to get insurance as distinct from actually accessing treatment.

From an insurance point of view what you want is people with treated hypertension in your insurance group, not people with untreated hypertension; you want people with treated asthma or diabetes, not untreated illness - whereas all the previous practices encourage in fact either exclusion or lack of appropriate treatment on an ongoing basis. That has taken, as I say, a lot of negotiation and it certainly as Grace was alluding to, I think, it's been important that the Human Rights and Equal Opportunity Commission was threatening to have a national inquiry. It was an important part of keeping the insurance association at the table. Also, clearly the extent to which the Mental Health Council and beyondblue were prepared to engage in public debate about the sensitive issues; to seek to embarrass the insurance industry was an important part of that well, but the threat of using the Disability Discrimination Act and having a public inquiry or taking action.

The insurance industry had always said, "No-one will ever succeed with a claim under the act," but we had a number of people who were willing to take that risk and certainly to try and run a case related to the act on the basis of increasing evidence, increasing number of cases and practices in the area. It was an important area in which use of the act, or use of threat of the act - to say it more appropriately - was an important part of continuing the negotiations on an ongoing basis. Now, as far as we understand, that's a world first for the insurance industry, to actually sign an MOU in relation to mental health and develop a code of practice to actually reduce some of the degree of exclusion that has occurred around these sets of disorders.

The second example that Grace is alluding to is a very disappointing one where governments are involved. It's seeking to deal with the current issues around insurance liability. The Victorian government has recently introduced the Wrongs and Limitation of Actions Act, and they're set to define and limit degrees of impairment that may be claimed. They've set a threshold for physical injury at 5 per cent, but immediately set a threshold for psychiatric injury at 10 per cent - that in some way you had to have twice as much psychiatric disability as physical disability to somehow reach some threshold for impairment.

MS McKENZIE: You can't aggregate them. That was the other thing you were saying.

DR GROOM: No, that's right. You can't aggregate them.

PROF HICKIE: No, you can't aggregate them.

DR GROOM: There is an argument that has been put to us that the rating scales are different. Clearly they are; it's a different rating scale for psychiatric impairment as opposed to physical impairment. But at the same time, if you burrow down into this legislation, it does appear to be high discriminatory.

PROF HICKIE: The implication of that is that psychiatric disability in some way is more nebulous and may be more questionable and may be more an issue of motivation or something, so you set a higher threshold to rule out. We would have no problem if the threshold were set at the same level for both physical and psychiatric disability, if a threshold is the appropriate way to go, and that's an argument in itself.

MS McKENZIE: You could understand them setting a different threshold, as Grace has said, if the rating scales were so different. So that, for example, there was - I don't know quite how to put it - an easier rating scale, if I can say that, for mental health problems where, if you were rated as 5 per cent in fact the illness would be extremely mild, whereas the physical disability scale looks at more severe physical disabilities, so 5 per cent on their scale means a more severe disability; in other words, you're trying to equate them. But that, I gather, is not what has been - - -

PROF HICKIE: That's not what has really been at work, no. If the notion of disability were being applied equally across the two areas - - -

MS McKENZIE: Yes.

PROF HICKIE: But really that's not what happened here - a notion really perpetuated that you should have a higher threshold for psychiatric disability because it's kind of more nebulous really. You know, physical disability could be determined at a much finer grain level. The two things are a nonsense.

MRS OWENS: Did you get consulted on this bill before it went through?

DR GROOM: No.

MRS OWENS: I presume it was passed in the autumn session. It says August - autumn.

DR GROOM: No. Where does it say "August"?

PROF HICKIE: (indistinct) passed August. It's actually June.

DR GROOM: No, it was just passed a couple of weeks ago.

MRS OWENS: That means autumn session.

PROF HICKIE: Autumn session, yes. It was in June, yes.

MRS OWENS: You didn't get consulted on this bill at any stage?

DR GROOM: I see. Right.

PROF HICKIE: No.

DR GROOM: No. The only time we got consulted was actually by people who were particularly concerned about it, and it had already been through the Lower

House and just had to go through the Upper House. We weren't consulted by government; we weren't consulted by anyone who wanted to get this legislation through. It was only those parties who had become aware of it at the eleventh hour and were trying to stop it.

PROF HICKIE: The other thing to say is that it's probably the precursor of a series of state acts around the same issues, so there are already in New South Wales similar sorts of issues in changes in insurance law, et cetera.

DR GROOM: It's also a medical indemnity issue. That's why it's so complex.

MS McKENZIE: It's your understanding that there's no conflict between the DDA and that legislation?

DR GROOM: No conflict. Our understanding is that the DDA does not apply to government legislation. Is that not true?

MS McKENZIE: It's something I'd like to hear more submissions on, let me put it that way. It's just that I called to mind - and it's not under the DDA and certainly the acts are different - the cases concerning fertility services, where the Victorian law at the time that only permitted a married couple to access those services was ultimately struck down because of the operation of the Sex Discrimination Act.

DR GROOM: Right.

MS McKENZIE: There were various proposals that the Commonwealth had to alter that result. My recollection is that a change was made to that act because of that. But whether anyone has ever considered that the DDA might have a similar effect, I don't know. The laws are somewhat different, as I say.

DR GROOM: Certainly that's what we've been told, Cate, when we made inquiries through the Human Rights Commission.

MRS OWENS: Who told you? HREOC told you that?

DR GROOM: Yes.

MS McKENZIE: It's something I might ask them.

MRS OWENS: I think we might check on that.

DR GROOM: We'd appreciate that, because it just seems extraordinary to us that it doesn't apply to government legislation.

MS McKENZIE: The way the matter arose in relation to the Sex Discrimination Act, it's perhaps true that it doesn't apply quite to the legislation, but where the Commonwealth act picked it up was when it came to someone refusing to provide a fertility service and, similarly, I'm wondering whether there may be trouble when an insurer refuses to provide this kind of insurance.

PROF HICKIE: Clearly the Commonwealth has a responsibility in any health services, so the Commonwealth would be drawn into the sort of issues that you're talking about. I'm not sure necessarily that the Commonwealth would be drawn into these issues. This is going to happen in each state. Our concern is that the danger of this model will be replicated across each state jurisdiction in terms of dealing with insurance issues.

DR GROOM: All the medical indemnity issues have to be sorted by the end of the financial year. That's my understanding. I think this stuff is going on in other states simultaneously, and we just cannot find out about it. I know what you're saying, Cate, about someone not providing a service, but I don't quite see how something could come up in the future where someone can have some sort of justice under this legislation that's just been established, because it's about setting up a framework for how we assess whether or not someone can make a claim for compensation under the act.

MS McKENZIE: It may be so legislation related that one can't even categorise who's providing the service. Perhaps you're right.

PROF HICKIE: Yes.

DR GROOM: Yes. That's what I think.

MS McKENZIE: It's something we'll ask the commission.

DR GROOM: If you can explore that further for us, we would be grateful.

PROF HICKIE: I think also the sequence of injury is the thing that upsets us here - the notion that you have a physical injury; that's it. It is just the physical injury and that's the nature of the injury. The subsequent development of a psychiatric disorder, which is a common pathway with physical injury, is a risk factor to psychiatric disorder. To therefore exclude that again just reinforces the notion that it's rubbery, that it's not legitimate, in some ways simply being added on to rort a system, which has been much of the sort of legend in this kind of area, as distinct from the extent to which that does in all physical health areas. Quite outside the compensation area, it's known to be one of the major contributions to disability. As Grace alluded to, earlier, much of my work with the Commonwealth is about the extent to which depression in association with stroke or heart disease contributes to people's lack of capacity to return to work. It's accepted as totally legitimate in all those other areas - that unless you deal with concurrent psychiatric disturbance, the person will be more disabled.

DR GROOM: For example, if a child was badly molested by a dog and ended up with significant facial injuries, under the legislation, providing they're rated at higher than a 6 per cent physical impairment with those scars, then they can make a claim. But if they had 4 per cent physical impairment - and it's very hard actually to get to 5 per cent. I saw a surgeon putting up some examples of what is considered to be significant scarring, but if that child had, as a consequence of having that physical injury to his or her face, then suffered severe depression with the way that they looked and had to get through life, that doesn't count under this legislation.

MS McKENZIE: Can I ask one more question. It's not quite to do with this topic but it's one we've just spoken about a little before. It was one question I forgot to ask at the time and that is, it's this distinction between a diagnosed or recognised mental illness or condition and mental health problems. You express a concern in your submission that the DDA in its definition of "disability" may not cover mental health problems, and really that relates to a submission quite early in the piece in hearings that we did where the question was raised about where should the line be drawn between what might be regarded as, for example, anxiety which is common to us all and anxiety which is beyond that which is common to us all.

PROF HICKIE: We draw lines in medicine all the time. We all have blood pressure, and we all at some point draw a line to what we call hypertension. The international classification of disease is that which imparts risk to illness on an ongoing basis, and to disability and has consequences. We have across the whole of the international classification of diseases the same thing for mental disorders. What has happened with common forms of anxiety and depression is often they'd be excluded because mental illness is being selectively used for only some of the mental disorders - schizophrenia, manic depressive illness, et cetera.

There is an internationally agreed system - whether it's the ICDX of the World Health Organisation or the DSM system of the basically North American systems, there are internationally agreed cut-offs. It doesn't matter that there may be a continuous liability underpinning that. We all experience anxiety. We all experience sadness, which I would argue is quite different to depression in fact. But anxiety is probably a better example. We can all be anxious, but there is a degree of persistence of anxiety, severity of anxiety, that results in impairment and increases your risk to disability and to other illnesses as a consequence.

MS McKENZIE: How would you distinguish? I know you've talked about a definition of mental health problems, but how would you seek to include that in the definition of "disability" in the DDA to make it clear that that's picked up?

DR GROOM: I think it's more about raising it as an issue, Cate - quite seriously - because what Ian has been saying is that there are cut-off points and there are levels of disability with anxiety that move from being a mental health problem to a mental illness. I think one of the problems is the lack of clarity, for example, in the DDA and in other legislation and in the attitudes of the broader community, because that's where we have the blurring; where someone, for example, with severe depression or severe anxiety might still be considered as just having a transient problem that's going to resolve itself. I think it's more about putting the question there that there is a need for greater clarity around how do we make an assessment whether or not someone is considered under the act for their degree of disability.

PROF HICKIE: I think the other way around is that all the mental disorders, as internationally agreed and classified, need to be included as illnesses, and that doesn't happen currently (indistinct) experience with insurance and other areas, even when our work is with things like the AMA and a number of other things, who clearly often don't want the anxiety or depressive disorders to be defined as illnesses; still would prefer to perpetuate a very restrictive notion kind of illness. I think at the bare minimum, it's the internationally accepted mental disorders to be recognised under any act, and they do include those forms of anxiety and depression that have illness characteristics. It doesn't matter that the line is being drawn across something that has a more continuous distribution. It has a predictive - - -

DR GROOM: Cate's point, I think, is around problems not disorders, and that's what we've said in our submission.

PROF HICKIE: The trouble is, as you move across a whole range of health and welfare situations, you'll see language used differently, and mental illness has certain sets of meanings which is often a more restrictive notion than mental disorders. At times the contribution of anxiety and depression that may not be at the level of illness of itself may still contribute to disability. It's in a situation which you actually have - it's not unusual, where you have a combination of illnesses. People rarely have one thing. A person may not have a stand-alone depressive disorder but they may have depressive symptoms in the context of something like stroke or heart disease that actually contributes to their disability. That would typically be talked about in another setting as a mental health problem. On its own it's not a stand-alone disorder, so I think we need to take account of that as well. It's often relevant in a particular situation even if it be (indistinct)

MRS OWENS: While we're talking about this issue, one of the things we're grappling with this is the definition of "disability" in the DDA. Some have argued that the definition should be expanded to more specifically talk about behaviour characteristics - learning difficulties or behaviour. Should that sort of expansion take place? Do you also think about the behaviour as a result of the mental disorder?

PROF HICKIE: Yes. I think there's a strong need to expand the language, because people do not understand the disability. In other areas of physical health they think they intrinsically see it, understand it, understand that a person with paraplegia is going to have trouble getting on a bus. It's apparent. In this area there is a need to describe the way in which depression gives rise to cognitive disability and that affects memory, concentration (indistinct) and that is then defined as the way in which the disability is acting then, or ways in which that can be dealt with may have to do with flexibility of work time.

It may be totally unreasonable to expect that person to work eight hours continuously each day, or to attend to a computer screen for four hours continuously. Similarly with their social behaviour; there are certain psychiatric disorders that will impair a person's ability to be in a large group, or to be in a certain kind of office situation, or to be - as is mentioned in the submissions here - certain sorts of closed buildings or closed environments where it is not easy to exit; the behavioural difficulty is described.

There are certain sorts of emotional regulation problems typically: people with head injuries or with some emotional disturbances who are easily upset, they are easily aroused, they easily become irritable in certain situations which are different. It's a predictable characteristic of their behaviour, for which there are social adjustments.

MS McKENZIE: Yes, or attention deficit disorder.

PROF HICKIE: Attention deficit, learning difficulties. We talk about these disorders in illness terms, without actually describing well the behavioural characteristics and the way in which those characteristics are then problematic in important social environments like workplaces or schools or educational courses, et cetera. Unfortunately the professions in the area tend to take that for granted. We see it all the time so we see how it operates, whereas the wider community doesn't - wouldn't.

MRS OWENS: But an employer or schools may not.

PROF HICKIE: No.

MRS OWENS: So it's a matter of: how do you make this as clear as possible?

PROF HICKIE: Yes.

MRS OWENS: We are looking at an act at the moment. How do you make this really clear?

MS McKENZIE: There are drafting ways to do that, but the first is to accept that it should be there.

PROF HICKIE: Yes. There are accepted domains in describing behaviour - in social behaviour, in cognition, in interpersonal behaviour - that are accepted. The accepted descriptors are the things we actually use in our criteria, sort of making the diagnosis. These are the sort of domains that we discuss: the person has this impairment in emotionality, and this impairment in cognition, this impairment in social behaviour. That adds up to a diagnosis of X. So in fact our diagnostic systems have the domains described.

MRS OWENS: Are they described in the international classifications?

PROF HICKIE: Yes. In fact, in terms of working out our disability ratings, we would try and find weights. How much you would weight the cognitive disability, how much you'd weight the social disability, how much you'd weight the interpersonal disability, et cetera. There are models for that and there is a lot of work going on through WHO and others to try and further refine those disability ratings and the domains. It is the subject of very active research, particularly in the cognitive area, which I think is most important to employment.

Some of the social and interpersonal things are obvious. If someone screams or if they react or they can't be with other people, other people tend to see that. Things like concentration impairment and difficulties with memory are not so easily seen. A person may come to work but actually not do very much. That may be not actually understood as to what is the contributing factor to that. A lot of work at the moment is with information processing in many of these disorders and better tests of that, better understanding of the neuropsychology of disorders.

Just to take up one episode of what we call indirect discrimination is really through our Medicare system and potential changes in our Medicare system. Many people with a psychiatric disability are concession card holders or pensioners or of low socioeconomic status. There is a strong gradient between socioeconomic status and the prevalence of psychiatric disorder. It's higher in lower socioeconomic groups. That's partly because people with a disorder lose employment and go down the socioeconomic scale. It also has to do with life circumstances and opportunities and supports contributing to higher rates of particularly anxiety, depression and substance abuse in lower socioeconomic groups.

As a consequence those people, in terms of access to primary health care - their health care for both medical and psychological disorders - have been highly reliant on bulk-billing practices. Many of our changes that we have recently supported in service reform - particularly an initiative known as Better Outcomes in Mental Health in Australia - tied to better primary care management of a psychiatric disorder and then access to psychologists for the first time and other non-medical mental health professionals, relies on getting to a GP in the first place. As the rates of bulk-billing actually fall, then access for those people actually declines. As we see a shift in practices towards more psychiatric services being provided, in services in which people pay up-front, then we get a preferential shift in the provision of those psychiatric services to people who are paying, to higher socioeconomic groups, to those who actually - as a group - have less need than the others.

We also have good research showing that the amount of time spent by a GP has strong effects on the quality of services provided. We know that the more patients a GP sees per day, the lower the quality of mental health service provided. As the pressure on bulk-billing practices increases, consultation times go down in those practices. So as a consequence of a change in other medical factors going on, it's highly likely - and we already have evidence - that people with a psychiatric disability are actually significantly disadvantaged in terms of both the quality and quantity of services they are provided. It was never the intention, I think, of any of the initiatives that have taken place but a highly likely outcome.

MRS OWENS: The government has recently announced a policy change in relation to this. I don't know whether you want to comment on that.

PROF HICKIE: Yes.

DR GROOM: The Medicare changes?

MRS OWENS: The Medicare changes which are going to directly impact on those people that have healthcare cards, but what you're saying is that some of these people may not necessarily have healthcare cards and so they're not going to be picked up in - - -

PROF HICKIE: It's not just healthcare cards, it's socioeconomic status.

MRS OWENS: That's right, yes.

PROF HICKIE: And also the proposed government changes are really strongly tied to geography, so the real incremental increases - if you look at the scales - are around where you live. The people who will be worst off in the situation are those in the lower socioeconomic status living in the urban areas and outer urban areas of our large cities. While there is proposed significant compensation to the doctor to maintain bulk-billing practices in rural and regional areas there is very little proposed for the outer urban areas. That's in fact where our highest density of people with mental health problems and mental disorders - frank mental disorders - reside. While we'd accept there is some proposed partial compensation it's probably only likely to have a benefit in rural and regional areas.

And, even then, it won't necessarily deal with the issue because even within those practices the number of patients seen per week by those doctors, the business of those practices, will still have a strong impact on the quality of services provided, and then access - not just to the services they provide, but access then to the specialist services that have been initiated under other situations - and access to particularly the additional treatments provided by GPs, so that specially trained GPs - there are additional services they can provide but they're already tied potentially with co-payment systems and with the GP being able to charge increasing amounts for those services.

Major changes in the health system, while well-intentioned - we've been lucky to have a health system that has had relatively good access for people with mental health problems, but many of our reforms in this area are tied to a notion of ready access. If that ready access changes or gets worse, or changes the characteristics of practice, either the quality of services and/or the quantity of services provided may decline. We think there is already evidence of that from the work that's already been done. That's the current situation.

MRS OWENS: Given the time, we might go straight to issues, I think.

PROF HICKIE: The issues that the council has identified as high, from its issues, is a general lack of awareness in the Disability Discrimination Act - I think, as we were saying in this area, and the extent to which it may apply; the processes around the act; the beefing up of the importance of the act - that an act does exist and that it sets these sorts of parameters, but seems to have little impact at times on employers, on governments at times and legislation framework, et cetera.

DR GROOM: I think one of the things we've seen, too, and Helen would be aware of this, is the high emotional cost for an individual, of actually making a complaint and going through the complaints process and staying with it. I know that when Helen and the other commissioners first came to visit us at the council, there was a case where a young woman had recently lost her job. She was employed by one of the large pharmaceutical companies and she had lost her job on the basis of having a manic depressive disorder. We talked with her about that, because she'd contacted the council for help.

She wanted to do something. She wanted some sense of justice. We asked her if she would be willing to share her story. She really wanted to, but she couldn't. Eventually she just had to withdraw because of the emotional trauma that she had experienced through her sacking, and then to have to stick with a process that was actually going to take a long time and bring it all back in the public domain, was just too much for her to deal with. That is a common experience, I would expect, for people who need to use the DDA. I know that there is no way of making that easy for people.

MRS OWENS: There might be ways of making it easier. Some people have been suggesting to us that other organisations be able to initiate a complaint on behalf of people.

DR GROOM: Yes.

MRS OWENS: Or that HREOC itself could initiate the complaint.

MS McKENZIE: Or that more use be made of public inquiry mechanisms, if it's a systemic problem.

PROF HICKIE: Yes.

MRS OWENS: Public what, Cate?

MS McKENZIE: Inquiry mechanism.

MRS OWENS: Yes. By HREOC. Because I think the particular groups you're talking about are the particularly vulnerable people - - -

DR GROOM: That's right.

MRS OWENS: - - - where it's going to be extremely difficult for them to make a complaint.

DR GROOM: Yes.

MRS OWENS: Because it could just aggravate the condition.

DR GROOM: That's right, yes.

PROF HICKIE: Exactly. I think we should open the insurance situation. We had many, many complaints but very few people have had the resources or have been able to face the emotional issues of being constantly challenged about the nature of their problem and the effect that may well have on their illness course, if they take on such an issue. I think, for us in this area, it's a really important issue about potential alternatives, to just taking an individual action.

DR GROOM: And that's why it's so easy for the broader society to discriminate against people with mental illness, because by and large they withdraw and there is not a strong resistance. The advocacy for mental health consumers is building, but it's still nowhere near what it has been, for example, for people with AIDS or other physical disabilities.

MRS OWENS: Just coming back to this idea of organisations such as yours, or others in your long list being able to initiate a complaint on behalf of individuals, you would support that idea.

PROF HICKIE: I'd strongly support the council. The council is the peak advisory body through the federal health minister on issues affecting the lives of people with psychiatric illness. So it represents all those other 41 organisations around. Its raison d'etre is exactly these sorts of issues.

MRS OWENS: Good.

PROF HICKIE: As the peak national body.

MRS OWENS: Can I just go back one step because we are running out of time and I don't want to let this one go. The memorandum of understanding that you came to with IFSA, how is that working?

DR GROOM: We are actually going to meet with the CEO of IFSA as soon as we leave here. It's slow and it's painful and it's a difficult process. We need to say that because it would be wrong of us to give the impression that it's all rosy and it's all going to be fantastic. But there is a constant checking on our behalf to ensure that the insurance industry stays true to the intent of the MOU and shows a genuineness in their commitment to it.

We recently had an example where part of the MOU was to revise the guidance notes, so the best practice notes, if you like, are around making a claim and purchasing an insurance product. We got those guidance notes to a certain stage and our understanding under the MOU was that they would come back to the mental health sector stakeholders for final endorsement before they were publicly released. Now, that doesn't look like that has happened. In fact, I received some communication yesterday to suggest that those forms in fact have gone out to the insurance industry and they're now saying that their interpretation was that they would put them out, play with them, use them, have some experience, and then come back and we'd modify them and tweak around the edges and put them back out again. That was never our understanding. In a sense they are pushing the envelope a little bit and trying to just keep on doing what they've always done.

PROF HICKIE: I think we feel clearly if there was a tougher legislative environment, if the external issues were tougher on them, the progress would be quicker.

MRS OWENS: Do you think insurance should be excluded under the DDA?

DR GROOM: No. Why should it be?

MRS OWENS: It is at the moment.

PROF HICKIE: There are two issues.

DR GROOM: But why should it be? That's what I was saying about the Victorian legislation, about the public liability insurance. Why should that be excluded? It just makes it too easy then to discriminate against the most vulnerable groups in our society, because government perceives them to be potentially a risk of high cost - which is no different to what the insurance industry has said to us in their argument; that this a high-risk category of people.

Well, why are they high risk? They are high risk because they are not getting appropriate treatments, because we have failed to provide the sort of care that people need, or to make the reasonable adjustments that should be made. So our argument has always been with the insurance industry that if these adjustments are made, if people are encouraged to get care, if that care is easily accessible people will get better; you know they're not all going to stay unwell and all be a high risk but, for some bizarre reason that I simply don't understand, our governments are allowed to behave in that way and other sectors are not. I don't get it, quite frankly.

PROF HICKIE: I think in a sense the insurance thing has been too easy. You simply say you're excluded if you can produce actuarial data. In fact that is a very complex argument and one we are working through with the daily groups of insurance industry at the moment - that what is the actuarial data? You know, what data are they basing that on? And in fact data is changing in a world where treatments change and illnesses change. It's quite complex but it's a very easy out.

MRS OWENS: It's hard to build up actuarial data if you haven't actually been insuring those people in the first place. That's why I say it is excluded in this particular case - people with mental illnesses - because they have not got the actuarial data.

MS McKENZIE: But see, if they don't have the actuarial - the only exclusion is if - - -

PROF HICKIE: If they have the actuarial data.

MS McKENZIE: - - - they have got the actuarial data. That's right.

DR GROOM: If they don't have the actuarial data they are covered.

MRS OWENS: But they are still excluded - - -

MS McKENZIE: Yes, but the reasonable grounds have to be other reasonable grounds and presumably - - -

PROF HICKIE: I think on the actuarial data they have never been challenged. One of the things we got him to do was challenging their data; in fact, I think they would have a very rubbery case if they tried to actually say they had the actuarial data. They're operating on very old data, which wouldn't stand up - - -

MRS OWENS: They often are operating on data that is international - - -

DR GROOM: That's right, yes.

MRS OWENS: - - - which may not be relevant to - - -

DR GROOM: To the Australian population.

MRS OWENS: - - - the Australian population.

MS McKENZIE: And one also wonders how they weight the individual considerations because obviously one individual may vary greatly from another.

PROF HICKIE: Insufficiently. In our area there is just a global, "No. You're all high risk. Out you go," so that has also been an issue with us and the MOU is to actually define and agree to matrices that better define individual risk rather than some global thing. We think it has basically been too easy. The bottom line is the exclusion criteria has been too easy - to just sort of say, "We're happy to claim the exclusion. If anyone can get it together to challenge us, we'll resist," and I think that is what Grace is saying - is seems to have been too easy therefore to just simply not cooperate.

MRS OWENS: Yes, okay. Was that your last slide you were going to put on?

PROF HICKIE: Yes.

MRS OWENS: I think we have run a bit over time. Sorry to hold you up.

MS McKENZIE: We did warn you that we would interrupt. There are many issues - - -

MRS OWENS: Just before we close I was going to say that it might be worth your while having a look at the ISA submission to us and, if you have got any feedback, we would appreciate it.

DR GROOM: How do we access that?

MRS OWENS: It's on our web site, but we can make sure you get it.

DR GROOM: All right.

MRS OWENS: The other is that one of your - you have got member organisations that deal with indigenous issues.

PROF HICKIE: Yes.

MRS OWENS: If you have got any information that you can provide on that at some stage we would also be grateful.

DR GROOM: All right.

MRS OWENS: Thank you for that.

DR GROOM: Thank you for your time.

MRS OWENS: As we have said, it was a most comprehensive and very interesting submission - both the oral one and the written one.

DR GROOM: Thank you.

PROF HICKIE: Thank you.

MRS OWENS: We will now break and resume, I think, at 11 o'clock.

MRS OWENS: We will now resume. The next participant this morning is Alexa McLaughlin. Would you like to repeat your name and the capacity in which you're appearing here today.

MS McLAUGHLIN: My name is Alexa McLaughlin. I'm coming as an individual.

MRS OWENS: Thank you very much for coming and thank you for the points you've just given us, which we can refer to as we go through. I just want to make it clear - and I made this point at the beginning of the proceedings today - that the Productivity Commission is a research body and we cannot deal with individual complaints, and I think we discussed that outside the room. It would be very useful if your comments could be directed towards the policy lessons learnt from your experiences. With that proviso, we invite you to talk about the points that you wish to make and then we can ask you some questions. Thank you.

MS McLAUGHLIN: Thank you. I've made some speaking points here. The first one relates to the act in which I've just made essentially my take on what other people have made submissions about, so they're not detailed ones. That's on the act and the way it operates generally. I've got some specific comments to make subsequently around things like the definition of "disability". Perhaps I could just quickly go through these general points about the act and if you have things that you'd like me to expand on, will you perhaps interrupt me.

MRS OWENS: Sure.

MS McLAUGHLIN: Because I'm not proposing to do more than one line that says, "I like this, I don't like that." The first one is that I certainly support retaining the complaints process. It's my understanding that, without a complaints process and penalty provisions, it's very hard to shift community opinion. I've been watching that process through questions around sex discrimination and whatever for nearly 30 years. I'd like to see the act expanded to cover voluntary working employment. I support there being a better definition of "reasonable adjustment" and a proposal for there to be a duty to make reasonable adjustment. I support there being standards for all areas, not just those that are currently covered as possibles, and especially I'd like to see employment standards developed and in place.

MRS OWENS: What about guidelines instead of standards? Do you think standards have got more clout?

MS McLAUGHLIN: I don't have a view about that. My sense is that the dilemma is that people don't know and whether you provide them information in the form of guidelines or standards is going to make a huge difference. However, if they can just turn around and say, "Well, standards aren't law," and ignore them, then they're not useful enough. So it's about having something that recalcitrant employers, for example, are going to grapple with.

MRS OWENS: I suppose standards provide greater certainty, but some have argued to us that the problem with standards is that they can be a bit inflexible.

MS McLAUGHLIN: Yes.

MRS OWENS: And become out of date very quickly.

MS McLAUGHLIN: And I understand that. I understand the issues around things like accessible transport and the huge time frames and huge costs involved, and I can see why some inflexible rules around that could be difficult. But I'm also concerned that things don't happen, so you want something that will force people to look hard.

MRS OWENS: Have the transport standards helped you in any way?

MS McLAUGHLIN: It's not an issue for me. I can't use public transport for lots of reasons, substantially because of chemical sensitivities. I used to use trains in Melbourne, but you sit in a carriage full of people who have been smoking or are wearing perfume or whatever, and I'd get to work a mess. Of course, public transport is more difficult in Canberra; there's less of it. I have tried with my scooter to access buses and, while I think that the accessible buses for chairs do the job, I've got a scooter that's longer and I have to say I felt frightened backing in. I actually was afraid of falling over or whatever, so I didn't repeat the exercise.

MRS OWENS: You tried it once.

MS McLAUGHLIN: And I tried it in the context of a training day. I was much the youngest participant in this wheelchair scooter training day, but they actually had brought an accessible bus to the site where we were having our thing. We had an hour or two with the bus driver to help us, so there was no pressure. It wasn't like there's a whole bus full of passengers and people waiting to get in being inconvenienced. There was time to try and fiddle.

MS McKENZIE: It was a proper training session.

MS McLAUGHLIN: It was a proper training session and a wonderful opportunity to test out the - - -

MRS OWENS: It sounds like a good idea having the training day.

MS McLAUGHLIN: It was excellent.

MRS OWENS: Was that organised by the bus company?

MS McLAUGHLIN: COTA.

MRS OWENS: Pardon?

MS McLAUGHLIN: No, it was organised by COTA, which is the Council on the Ageing.

MRS OWENS: That's really good.

MS McLAUGHLIN: The training itself was fine. I think that the perception is that poor old people are going to not be able to manage their scooters and it was like, "Oh, gosh, we'd better have rules and we'd better have strictures in place to protect the poor old dears." I'm being a bit facetious. I didn't feel like it was an empowering exercise and to me it was about, "Poor old dears might be too frightened to get out on their scooter if they heard these stories, and let's have training that will make them do it right and have the courage to try." So there's a question around how you approach some of those questions and, of course, being a younger, more active person, I sat there concerned about those things.

MRS OWENS: Thank you.

MS McLAUGHLIN: I certainly support monitored compulsory action plans, having been involved in affirmative action plans in the past. I think they do focus people's minds nicely and, if they're monitored, then they're accountable for them.

Ms McKENZIE: Both as to content and implementation?

MS McLAUGHLIN: Yes. I think the drafting of them makes people think about things they hadn't and, if they're monitored, then they do implement, or at least they can be held to account if they don't.

MRS OWENS: Who does the monitoring?

MS McLAUGHLIN: That's a really interesting question. I read a number of submissions that talked about HREOC doing it. I don't mind, as long as it's done properly. I don't mean that that has to be a huge expensive exercise where every plan is monitored every year. I'm not suggesting anything as expensive as that, but if you have spot checks and you collect them, then that's going to create an impression that you had better be careful about what you do, to employers.

MRS OWENS: You're talking about employers in both the public and private sectors?

MS McLAUGHLIN: Yes.

MS McKENZIE: So random checks?

MS McLAUGHLIN: Yes. That may make it financially more feasible but still have a strong impact on employers.

MS McKENZIE: Random, without notice, checks to have.

MS McLAUGHLIN: Very nice, yes.

MRS OWENS: If you talk about the private sector, what about very small businesses? Would you expect that of a small business like a shop?

MS McLAUGHLIN: No, not a very small business; not because I don't think they need to do it, but just because of the burden it creates in terms of all the compliance costs that they're already trying to deal with.

MS McKENZIE: Where should we draw the line? How small do you think?

MS McLAUGHLIN: I don't have a view. I've seen things where they talk about 10, five, in different contexts. But I don't have a view.

MRS OWENS: It's a matter of being sensible about it.

MS McLAUGHLIN: Yes.

MRS OWENS: We were talking yesterday to one of the groups that appeared about the dangers of a compulsory action plan or even voluntary plan - that there could be just a paper compliance.

MS McLAUGHLIN: Yes.

MRS OWENS: They'd put it in the bare minimum, and that's where you think the monitoring of both the content and implementation - need to do both.

MS McLAUGHLIN: Yes. In Jocelynne Scutt's discussion with you, she was talking about the difficulties of private conciliations - the outcomes of those remaining private. I'm very concerned about that, too, in seeing that a whole lot of important decisions are going unreported and therefore not having an impact on the wider community. I support conciliation activity remaining private, but I would support outcomes being made public.

MRS OWENS: But not necessarily naming the complainant and the respondent?

MS McLAUGHLIN: Don't know about that. I think there's a time for large companies who are involved in those things being named. I haven't thought that through, but certainly enough information so that it can have an impact on other employers and on the community, knowing what they're entitled to.

MS McKENZIE: You can imagine a scenario where - it may be hypothetical, it may happen, I don't know - to take some company, whether it's a service provider or an employer, who discriminated against a number of employees who, for example, in the same way all bring complaints at different times, individual complaints, and the plan that the employer adopts is to conciliate those complaints in the commission. In other words, a pattern of discrimination is continuing against different people - - -

MS McLAUGHLIN: And nobody knows.

MS McKENZIE: - - - and no-one will know.

MS McLAUGHLIN: Yes. That's why I'm not saying you should be keeping the identities of the employers necessarily private.

MS McKENZIE: Yes. I'm wondering whether there should be some limitations on when the name should be made public. For example, perhaps that should only occur where some systemic solution is adopted so that everybody should know about that or where there is a continuing pattern and a number of complaints have come in at the time which show a continuing pattern. I don't know whether it's right in every case to publish the names and the outcome of conciliation. That may not be what the parties want - either of them.

MS McLAUGHLIN: Yes, especially if there were a continuing employment relationship, for example, and essentially that was what I tried to convey. I'm not saying announce all details of all of them all the time, but just some of them some of the time, in some of those terms you just talked about. I don't support industry self-regulation. I see that not working in a lot of other areas. I think that would be a disaster here. I think it would be really good if there can be some systemic - whether they're initiated by HREOC or whatever - to deal with bigger issues like airlines and accessibility and stuff, or handling difficulties of people who have chemical sensitivities, rather than simply individual complaints.

MRS OWENS: If there were to be a more systemic approach which would complement the complaints process, which you're also supporting - - -

MS McLAUGHLIN: Yes.

MRS OWENS: - - - I suppose there's the issue of how that's done and one mechanism is for HREOC to conduct more inquiries.

MS McLAUGHLIN: Public hearings, yes.

MRS OWENS: And another approach is for HREOC to initiate complaints. You've probably seen that idea floated in some of those submissions you've read and in the transcript.

MS McLAUGHLIN: Yes.

MRS OWENS: Have you got any views about which systemic approach you think would work best?

MS McLAUGHLIN: I actually think both of them could work. The public hearing is a good one for flushing out all sorts of things that aren't as formal as a complaint but can offer you an opportunity to make an input, like I'm doing today. The other one you were describing essentially was HREOC - - -

MRS OWENS: Initiating.

MS McLAUGHLIN: - - - initiating a complaint.

MRS OWENS: Or other organisations initiating complaints, say, on behalf of individuals who may find it difficult.

MS McLAUGHLIN: I think so, because no matter how capable you are and even how capable the representation you may have, it's still a huge thing to take on one of these complaints.

MRS OWENS: Did you personally find it difficult when you brought your complaint.

MS McLAUGHLIN: Hugely. Mine was an employment complaint and it reflects events which actually started to occur prior to the implementation of the act in 93 and went on for several years after that. My first prong was to follow those issues through as workers compensation issues and seeking rehabilitation in order to return to the workplace. Only when all of those avenues failed did I - I had also made a disability discrimination claim very early in the piece with the hope of sort of alerting them to the fact that the issues went beyond just occupational health and safety. It had no impact at all. Never, at any stage, did they ever contemplate really that there was as disability discrimination issue involved. So the actual hearing process in fact didn't start until the late 90s, because all of these other opportunities were going along concurrently.

MS McKENZIE: Do you want to finish what you want to say about the act first - - -

MS McLAUGHLIN: Yes, I'm happy to do that.

MS McKENZIE: - - - and then say something about that process, so that we can look at what suggestions we might make, or what you might want to make to us for future improvements.

MS McLAUGHLIN: Yes.

MRS OWENS: We may come back to that, but while we're talking about systemic approaches if HREOC was to initiate complaints or have more inquiries - there is a resource issue but there is also an issue of how they prioritise that. There are a lot of very interesting issues out there. We're hearing a lot of those during this hearing process. How would they prioritise?

MS McLAUGHLIN: One of those submissions I read was the Victorian Disability Discrimination Legal Service submission which listed its criteria. I found those interesting; it was sort of like winnable. My memory is not good enough to give it to you completely, but my vague recollection is that it was about being winnable, about having a capacity to impact on a lot of people - if it was successful, having an incapacity, and if it was failed it wasn't going to make things worse. They were the sort of criteria they were using. I didn't really see - I don't remember seeing anything that seemed to be prioritising on the merits of the case, and so, for example, I don't remember - and I could be faulty about this - the most disadvantaged people, or disadvantaged situations being at the top of the list or that I would have thought - - -

MRS OWENS: That you should be one that was affected, you know - - -

MS McLAUGHLIN: Yes. One of the things I'm really conscious of is that people with chemical sensitivities are currently not being accommodated and have no other options, other than being accommodated to enable them to participate. So I would think that that was a really important issue to go forward in such a case. It is much better done as a group activity. Mind you, you might want to wait until a bit more of the medical people have got together some good evidence relating to it. If you were going to have to decide, you know, this has got to be winnable, you wouldn't want to maybe run the risk that you could get knocked off on those sort of technical grounds. But if, in fact, the medical evidence was already sitting there, then I would think that that is - because that affects a lot of people.

MRS OWENS: Okay, thank you for that.

MS McLAUGHLIN: Just a couple more points in my basic one. It comes out of what I'll say later about my hearing experience, but I certainly think that the act ought to provide that - if one ends up in the Federal Court or the Magistrates Court - it's making accommodation for people with disabilities, and especially - the two things that are really great disincentives to pursuing that matter are the lack of accommodation of disabilities, like the tight time frames and stuff for various stages, and the fear of costs.

The other two points that I would make are that I would support much clearer stuff in the act about how costs will be apportioned. There are some people who will say, "Look, it won't happen. You won't have costs awarded against you." But in fact the act doesn't say that and one of the cases said: look, the act doesn't say it, so I have to do it this way, and I have to say that I have not a lot of money. I wasn't willing to be bankrupted by it, so I wasn't willing to appeal. If people actually do have an asset, like a house, it must be incredibly difficult to take on this sort of thing and fear losing it.

MS McKENZIE: But you did go to court at one stage.

MS McLAUGHLIN: No, I went to the hearing - I went to a hearing. I was one of the last hearings before it changed.

MS McKENZIE: But you didn't appeal from that hearing, for the reasons you've just given.

MS McLAUGHLIN: Yes. Both of those reasons played a major part. That's my list of things about the act.

MS McKENZIE: Thank you. That's tremendous and very clear.

MRS OWENS: Very well structured, I think you'd say.

MS McLAUGHLIN: Would you like me to talk about - - -

MRS OWENS: The definition.

MS McLAUGHLIN: Yes, the definition of disability.

MRS OWENS: Just before you get into that. A minute ago you just said people with chemical sensitivities are not really accommodated.

MS McLAUGHLIN: I meant in the world, I didn't necessarily mean in the act.

MRS OWENS: Yes, in the world, but not necessarily in the act. I just wanted to clarify that.

MS McLAUGHLIN: That's a question I want to raise. I noticed that HREOC expressed some concerns about - in their submission - CFS and MCS and a couple of other conditions. It wasn't clear to me from reading that paragraph whether they were talking about whether these conditions exist, which of course is debated in the medical research world; whether they are physical conditions, physically caused conditions or whether they are psychiatrically caused conditions. How on earth do you diagnose them? How do you treat them? Even how do you accommodate them? I don't know which of all of those questions HREOC was drawing attention to.

I would say that each of them are actually important. You need to actually tease that out. My experience is that 10 years ago if I had told somebody that I had ME, CFS, or if I had told them that I had chemical sensitivities, most people would have looked at me blankly. They didn't know what I was talking about, so they'd ask and I'd tell them and the responses would vary from sympathy to empathy, to whatever. If I'm in that same conversation today a lot of people do know what they are and they think that they are psychiatric conditions, or that they're malingering or whatever and so you find maybe 50 per cent of those people who, a decade ago were open to you, are closed. That's employers, that's people in the street, that's people in community groups. There's been a huge shift and I can't really explain it.

There's certainly a huge debate in the medical world about those things I said - about physical versus psychiatric, whatever. There's been a little bit of coverage of that in the media and there's been some horrific debates around guidelines for managing these subjects, which haven't had an awful lot of coverage in the media, so I don't know what's shifted it. I couldn't look at you and say, "That person has gone on television 50 times and everybody now believes them." But all I know is - I don't know whether those people have written enough articles in the medical journals to persuade most GPs. I only deal with GPs who are reasonable, so I've only heard the stories anecdotally, and I've heard many of them about GPs who are difficult here, and everywhere else in the English-speaking world.

I don't know what it is. All I know is that 10 years ago people were open and today many people just are quite clear that you're malingering or that you are kidding yourself, or you're being silly or whatever. What they are not interested in believing is that if I say, "If I'm exposed to perfume I won't be able to think straight" - then that’s a load of nonsense. Therefore when I say, "Please don’t wear perfume," it’s just like the smoking lobby - people didn’t like having to give up smoking and now they’ve recognised that passive smoking is a problem. They still don’t like it and they’ll go and have their puff outside the building door, or whatever, but there’s now an acceptance that there shouldn’t be smoking in a workplace.

But I’ve had colleagues, who just wouldn’t even contemplate not using perfume, sitting next to me at work. They’re decent people. We’re not dealing with crazy people or whatever. So that’s a real problem. You said, "What’s it like in the community?" I’m telling you that in the community there is a huge resistance.

MS McKENZIE: I’d love to know what has happened in a decade to change perceptions.

MS McLAUGHLIN: I’m not saying there’s been a media coverage - there has been media coverage especially when we were going through the exercise around the CFS guidelines. I have to say that I feel very strongly that a lot of researchers and the people involved in this policy-making have done some pretty sloppy work. They’ve looked at one strand of research and reported it, overstated its conclusions and ignored other evidence that was placed before them. I know it was placed before them, sometimes I did, but more often I’m talking about doctors placing it in front of them and researchers and medically refereed journals and whatever, and they’ve just said, "I like this stuff, but that stuff doesn’t exist." I think that’s really sloppy science. It’s really sloppy policy-making.

I can remember a doctor who was quoted in an Australian or Age article - Saturday glossy - which said believing that you have to avoid chemicals was evidence of a psychiatric problem, or words to the effect of. It seems to me that it is possible that somebody who is believing they have a problem with a chemical could be a phobia, but if you’ve gone to a specialist who has said, "You are allergic to perfume and you should avoid it," and the patient takes the advice of that doctor, then I don’t think that’s evidence of any psychiatric problem on the part of the patient. This was a good doctor. This was a doctor who was reputed to be compassionate and helpful to this patients.

MS McKENZIE: Why is it that some allergic reactions seem to be accepted as some kind of syndrome or condition, or as a recognised thing, and others are not? I don’t think the community would dispute that people get hay fever at various degrees and that it’s the result of, in many cases, allergic reactions.

MS McLAUGHLIN: I think there are two issues: one of them is how visible - so, for example, with hay fever or eczema or anaphylactic shock or whatever, you’ve got something that everybody can see. The other thing is to do with how it happens in the body. Mostly hay fever and eczema and asthma are processed in the body through something they call IGE mediated consequences. Many of these - and the doctors will call that allergy and they really keep hold - that that word "allergy" only applies to these IGE mediated effects. Generally there is a fairly narrow range of what they think are the causes and what they think are the symptoms. But there’s a wider range of things which I might loosely use the word "allergy" to, but shouldn’t really and that’s why I used the word "sensitivity" earlier - or intolerance is another word for it. Sometimes you can find immunological effects involving complements and mast cells and I’ve just thrown out a whole lot of words I don’t completely understand.

MS McKENZIE: You’ve gone one better than I have.

MS McLAUGHLIN: But the point is that sometimes it isn’t possible to detect changes in the body to confirm that there is something going on, and secondly, it may well involve reported but not visible - what they call signs, not symptoms. If I say to you, "I can’t think straight," and I sound perfectly coherent, which I can do because I often can talk more than I can think - I mean, I can talk more clearly out of memory, than I can process new ideas. You know, people just tell me, "You’re fine." Or if I say, "I can’t remember," but I seem to be remembering some things, I haven’t probably explained that I could remember that I’d read that article and those things, but I didn’t remember the details; I tend to have a good memory for big picture stuff, but not for detail, even when I’m trying. I mean, I wasn’t trying to remember that, therefore I didn’t. I made notes of the other points I wanted to make.

So part of it is about what you can’t see. If you can’t see - if somebody just tells you they’re depressed and actually is crying with it, you might believe that they are depressed. But if somebody just quietly says, "Look, I don’t feel very happy," unless they’re actually out cutting their wrists you might not believe them either. Does that answer your question?

MS McKENZIE: Yes, that does answer my question.

MRS OWENS: Do you want to go through your points on definition of disability?

MS McLAUGHLIN: Yes, certainly.

MRS OWENS: Because you make some interesting points here.

MS McLAUGHLIN: I certainly wouldn’t want it narrowed any more. I think there are some ways that others have reported that it may well be usefully broadened. I am particularly concerned that disability caused by chronic illness shouldn’t be precluded by your definition.

MRS OWENS: Is it precluded now? It's a very, very broad definition as it stands.

MS McLAUGHLIN: I did say "may be broadened" because I don't - there's nothing that jumps out at me that says there is something wrong with it. As far as I'm concerned - I'm very concerned that things like obesity, depression, CFS and MCS should be included. I assumed they were, until I started reading submissions that seemed to think that they weren't, or that maybe it's only in certain circumstances. I certainly think all of those things should be.

MRS OWENS: Yes. I'm not a legal expert - Cate here is - - -

MS McKENZIE: It seems extremely wide to me. But certainly there are some things - the difficulty may be this word "syndrome".

MS McLAUGHLIN: Yes.

MS McKENZIE: If it hasn't got a medical category that doctors can fit this thing into, there may be a problem as to whether it's a disability.

MS McLAUGHLIN: The interesting thing with things like CFS and MCS, which are syndromes, is that the WHO classifications have put them into some medical categories. Mind you, there seems to be some retrograde action going on in England to pull them out of those categories between ICD9 and ICD10, but they're unfortunate names, and in fact there are some medical categorisations of standing which do put them into disease categories.

MRS OWENS: Are they in ICD9?

MS McLAUGHLIN: Yes. It's in G48, I think, which is neurological something or other, but then there's something else that's sort of like - the new expression is "medically unexplained symptoms". There's some psychiatrists in England real keen on this, and they're trying to put all of these things into that category, which is the new jargon for psychosomatic.

MRS OWENS: Okay.

MS McLAUGHLIN: She says sarcastically. I say sarcastically.

MRS OWENS: But it shouldn't be jargon for that.

MS McLAUGHLIN: No, of course it shouldn't. I think that's a really serious issue, and I'll allude briefly to that at the end of what I have to say. It's really how hard you look. If you want to see whether there's something formal in this, you can find it, but other people choose not to notice, but of course that covers ME. There's a dilemma with ME and CFS. ME is probably the more severe situation and there's been a huge movement to broadening the category, calling it CFS, and then finding no solutions.

MRS OWENS: What's ME?

MS McLAUGHLIN: Well, I think it was myalgic encephalomyelitis, and they argued that that in fact wasn't exactly what was going on, so then they changed the name in America in the - anyway, the body that makes these sorts of decisions in America - it might be the National Institutes of Health - and in 1988 they started calling it chronic fatigue syndrome, and then the Brits seem to have broadened it again, and it really really now picks up chronic fatigue; so it picks up anybody who's complaining of fatigue, rather than complaining of a whole range of other physical symptoms, which all went into the definition of ME.

The reason I raise this question of chronic illness - you're quite right - it looks as if it's covered - is that a few years ago I was essentially asking for my perfume accommodation , and was speaking to somebody else, who said, "Oh, no, no, we've been through this battle. We don't want the medical model. We want the social model." I haven't given you a very good jump from that first statement to the second one, but, anyway - I don't remember the details to explain the jump, but we suddenly had this conversation about medical model versus social model, and it's something I really wanted to raise with you here because I know a number of other people are doing it. I've been doing a lot of reading on this lately, and I haven't got to a final, good, one-paragraph summary of what I think is going on, but it seems to me that the medical model says, "There's something wrong with you which needs fixing. This is medical territory. We're the experts. You're the victims."

There's a group of people who don't necessarily have chronic illness who have an impairment that's relatively fixed, who say quite vehemently, "I'm not sick. Don't treat me as if I am," and I really support that - for that situation. The trouble is that those same people are saying, "So nobody with a disability should be treated as if they're sick," and that's where I really want to make a strong statement: that if you've in fact got a disability because you are sick through chronic illness, then that first lot are going to exclude you from getting accommodated, because they're so busy saying nobody should be treated as if they're sick, in terms of their disability.

So I want both. I'm really happy for those people who aren't sick not to be treated as sick, and I'm very happy that the doctors aren't the ones in charge of this whole process, because they don't have solutions to so many of the things that I encounter. I'm quite happy to work with them but I don't want to give them the power to decide what happens to me, so I really support those - and so I see why they went looking for a social model, but if you're going to say it's all about how society is doing it, if society didn't have steps, then we wouldn't have a problem. The trouble with that is - I mean, I see that. I think they've thrown out some babies with the bath water, and I think that because there's a range of people's needs - you can't meet everybody's needs at the same time because they often will be conflicting or sometimes be conflicting - and just say, "We're not going to look at the individual. We're just going to look at society" - is going to lose the individual and the individual's needs.

MS McKENZIE: I would have thought that there are really two - and perhaps it's an oversimplistic way to express it, but I would have thought there may be two strands of thought, both of which I would have thought the DDA should accommodate, and it probably does accommodate them. One is, "Don't treat me unfairly because of my disability", and the other is, Don't make assumptions about either me or my disability."

MS McLAUGHLIN: Yes, and "If I have special needs and they're easily accommodated, please do it" That's what I think is the third one, regardless of whether they're common or whatever. From what I read of the literature, most people these days are gung-ho on the social model and antagonistic to the medical model, for the reasons that I mentioned earlier. I've actually found a researcher in England who's an academic and a person with disability, who has been arguing quite vociferously that that model is not appropriate for the sorts of reasons that I've mentioned and, in addition, even for people for whom mostly it is a social question and they have fixed impairments, they do have sometimes some medical difficulties that are overlooked through this process. This guy's name is Tom Shakespeare and his argument is that we really need a new paradigm.

MS McKENZIE: Have you got the reference?

MS McLAUGHLIN: I will get it to you. I haven't at the moment. I think the paper I've been working on was written in 2002. I've been looking for some more stuff because his argument is, "Look, it's had its day. We need a new paradigm that really" - he doesn't seem to think you can just modify the social model. He actually thinks we need a new one, and on the face of it I think he's right, but nobody has done that yet, but I would be very concerned if the outcome of this process was to accept the recommendations you're getting from a number of people, to somehow or other really embrace the social model. I'm sure that taking some account of it is really important.

MRS OWENS: Is the way that the act is written now reflective of the social model or do you think it's - - -

MS McLAUGHLIN: I think it allows for both. My concern is that I know that at least - I've read that the Physical Disability Council of Australia argued very strongly that you should use the social model, and I've seen discussions of the social model in a few other places. It's not so much that I think it doesn't reflect it now, I'm just afraid if you took some advice that it might change in a way - - -

MS McKENZIE: Yes, and don't make it now and don't exclude things.

MS McLAUGHLIN: Yes, because in a way, the really interesting thing is that the people who are supporting the social model are saying that we're looking for inclusivity. Well, what I see is that that model does not include me and people like me. I don't mean that they're setting out not to include, but that is an unintended consequence of what they're saying. That's all the things I had to say about disability.

I've got a couple of brief comments about the disability discrimination climate that I didn't know quite where to fit in, so I've just put them together. The first is that as our community is moving towards over-employment and under-employment, where those who have jobs are working 60 hours a week or something, often unpaid overtime, to hang onto their jobs, especially in this town with a lot of government employment, and then there's other people who can't get work, I see that as disproportionately disadvantaging people with disabilities who can't work full-time, let alone full-time plus plus, and so what I would hope is that - I mean, I say it every time I get a chance but I think I'd like to see HREOC incorporate that in their education processes because - I mean, I have never said to somebody, "Look, you can have employee A and B and they're going to be paid to work 40 hours and they're going to do 60, but I can only work 20." I'm quite happy to be paid for the same proportion. I don't want to be advantaged compared to that person who is working full-time, but I'd like my chance at the table, so I think that's an important issue that's sort of lost. I mean, I don't like the idea that people are working such long hours and everything, anyway, but in addition to that, it's particularly difficult for people who can only work part-time for various disability issue reasons.

MRS OWENS: You can't compel employers to reduce hours of work for their employees or compel people to reduce the time that they're prepared to put in over 37 hours a week or whatever, so it's about the education.

MS McLAUGHLIN: Yes.

MRS OWENS: You think that it's a matter of HREOC getting out there and explaining what the ramifications could be, both for the people in the workforce that are working excessive hours - - -

MS McLAUGHLIN: Well, excessive hours is another question that I feel strongly about, but I'm not sure that that of itself isn't a disability discrimination question. But saying, "The only people we want in our workplace are people who can do those excessive hours," rather than recognising that two part-timers are as good as one full-timer, that's the dilemma: if the person with a disability can only do the part-time work and employers have this idea in their minds that the only useful people are the people who work 60 hours a week.

MRS OWENS: Yes.

MS McLAUGHLIN: The other point - I've got an unusual name, as you can see, and if you do a Google search on me, there's only two of us. There's an American woman who has completely different interests, and me, and so you might get 80 hits out and 40 of them are mine and 40 of them are hers, and they reflect a whole range of things - I actually don't have a web site and am not going looking for it, but there's maybe 40 hits of different things I've been involved in where that report will turn out, and for quite a long time my discrimination hearing came out about halfway down because I was on a list of cases, but for some reason, relatively recently, I now come up first. I think what's happened is that the often-embedded databases weren't being picked up by database search engines.

I don't know whether that means that the databases have changed the way they are set up by the government, or whether the search engines have changed. But I'd really rather that my hearing did not turn up as item 1, encouraging anybody who looks me up to read it, all 46 awful pages, which we'll come to in a moment. It's hard to see what the right way about this is, but I wouldn't want them to set up those databases so that they can't be found, but I think it's a pity that it's set up in such a way that it's going to be found as the highest hit, because of course your name appears every line, or so frequently that - the way search engines work is to essentially look at the proportion of times your name is mentioned.

I think there are ways in which you can code items so that they are not found, and if you've got both lists and the actual hearing case itself, and you leave the hit list, the list searchable but not the case, then that might revert it back to where it was. Anyway, I just say that if you've had a hearing that you're uncomfortable about or that you don't want to draw attention to, it's a problem.

MRS OWENS: Do you think employers do go to the Web?

MS McLAUGHLIN: I think they might. I mean, there's many people with fairly common names for whom this would not be an issue, although - because people wouldn't bother looking up people with common names, but even people with common names I think this would happen to, because of the density in which their name will appear in a hearing report, but I certainly feel that - I've been attempting to do some contract work and I think - if I'm going to do a Web search on potential employers, my guess is that potential employers are going to do a Web search on me.

MRS OWENS: Yes.

MS McLAUGHLIN: So it's not easy - about whether you ought to do it, but I'd like somebody to look at it.

MRS OWENS: Shall we - - -

MS McLAUGHLIN: Yes, talk about my employment experience. I was employed as a policy analyst with what was then the Department of Social Security, the part of that department which is now the Family and Community Services policymaking area rather than Centrelink, which is the service delivery arm. I had a relapse of chronic fatigue syndrome and my manager didn't understand it, so I tried dealing with it, and as events went on, it became more difficult and I ended up very stressed and with severe anxiety and depression out of that, and as the workplace had caused it was accepted as a workers compensation claim. And while I think the rates in which those stress-related claims continued to increase in the 90s, it was still considered a pretty serious, unacceptable issue then, so the fact that it was accepted was a pretty strong statement of the merits of my claim.

As I indicated before, I was sort of trying to identify ways to solve the problem, and many of the people who made life difficult for me actually meant well. They just didn't know what they were doing. I think there were a couple of people who were just stroppy and difficult, but that wasn't the whole story. In the middle of it I got cancer and people were fantastically supportive and I was very lucky that the surgery was undertaken early in the piece and the recovery - and I haven't had any relapse of the breast cancer since then. That's more than 10 years ago.

But the difference between people's attitudes to that and the other was really marked. With respect to the depression, I wasn't sitting around working out ways and means of ending my life. I'm a really resourceful person and if I'd got to that point, we wouldn't be having this conversation. But what was going on for me was that I felt like I was going to disintegrate, as if - these are my words, this is not a medical term - I just felt that I couldn't go on. I don't mean I wouldn't go on, I just meant that it would end. I just would disintegrate, and I was really frightened by that. So when every attempt that I had made to resolve these questions - we were going through rehabilitation assessments and I'd have rehabilitation providers who would be helpful one minute and not the next and make promises and then not deliver - I mean, it was a real saga. Nothing was working, so I resigned.

I thought, I've got to prevent disintegrating. Big mistake, big mistake. Of course it worked. Taking away that stress lifted me enough that I could think more clearly and I actually quite quickly applied and said, "Look, please overturn that resignation. It was a factor of being ill." Arguing about - and of course they stopped my workers comp immediately, saying I wasn't cooperating with my rehabilitation. It took a year to get them to overturn that. It took them about six months to not agree to my resignation being overturned. By that stage we'd got to a personality conflict. They were really clear they didn't want me and they were going to fight me tooth and nail.

MRS OWENS: Who is "they"?

MS McLAUGHLIN: They as in my employers, and I would say the workers compensation authority as well. A lot of the actions that they took were inappropriate and unhelpful but there were also on both sides some really helpful, effective people. It wasn't that I was dealing with this monolith of difficult people, but, I mean, I argue back. I knew what was right, I knew what was possible and I knew what I could do if given half a chance and so I kept hanging in. I mean, I had more strength than I think many people have and I really had a nightmare that went on for five years until I gave in on the workers compensation stuff, and then still tried to pursue the disability stuff.

So that was the background - and remember this was early in the implementation of the Disability Discrimination Act. So my guess is that right at the beginning they really didn't understand that they were discriminating or that there were reasonable accommodations, and they certainly, of course, being a government department, didn't have any arguments about undue hardship. In that process I had a lot of support from my union. I mean, there were obviously changes of organisers over that period but I had people who'd sit and take notes, who'd talk through things with me.

I contacted the Disability Discrimination Legal Service in the ACT early on and again, I have had bad experiences with lawyers in a lot of different jurisdictions, but this lawyer who worked with me over a number of years was respectful and understanding and helpful and all of those things. When it actually got close to the hearing, though - I mean one day they were going to represent me, the next day they weren't - I really lost track of exactly where they were at with it. So I went and I started the hearing process with representation and was really concerned at some of the steps that the lawyer took in the early period, and so I stopped.

I did understand what was going on in the act. I'd read widely, both materials presented in paper form by HREOC and in the latter stages by reading most of the stuff off the web site that related to it - you know, the FAQs on employment and all that sort of stuff - and really trying to grapple with the questions around direct and indirect discrimination because they were very relevant to my situation. Some things that had happened had been one or the other and they were technically really difficult to come to terms with and I certainly don't think I could do justice to them today.

I'd found when the process started there was the combined HREOC - the Human Rights office here I was able to deal with; but as time went on and the office moved back to Sydney, that became more difficult. I felt that the HREOC offices, grappling with the complexity and evolvement of the materials, were finding it all very difficult.

MS McKENZIE: Can I ask, did they have an 1800 number or 1300 number at that time? Were you aware of one?

MS McLAUGHLIN: I know they have had at some stages and I don't remember paying for phone calls being a major issue. That's not the point I was actually going to make. It's just that - we were doing it by mail substantially and latterly by email. My concern was not whether I could get to talk to somebody - in my memory I may be forgetting relevant bits about that. What I am really conscious of is that as we exchanged letters it was really clear to me that - well, it seemed to me that they hadn't understood what had been said and they didn't seem to have really pushed Centrelink, at that stage, into conciliating. So I really believed that what we needed was to get all these facts and exchanges of documents and exchanges of positions and everything else and then I wanted to have a conciliation along with everything else.

Centrelink were now handling it. I don't understand it because it really was a FACS matter, but somehow or other they dumped it onto Centrelink when the department split and Centrelink just said, "No, no, no." Centrelink wrote a whole lot of nonsense as their responses and I really am concerned - so I really like this idea, an idea, of compulsory conciliation. You can't actually compel people to be reasonable, but if you've got a compulsory conciliation process, you're more likely to get them to talk than if you don't. So I was really sorry that we had - you know, our first real dealings over this matter with the department was at a hearing. While I have raised a range of issues over a range of periods, in the end the decision of the president - I think the first decision was to reject the complaint completely and I appealed that internally.

MRS OWENS: Why was that?

MS McLAUGHLIN: I'm sorry, I didn't come prepared with that one. No, I'm sorry. I can tell you what they did agree on, to some extent. But I certainly remember that the reasons that they gave I didn't feel were valid, so I challenged those. Then they came back with a reconsideration which acknowledged some of what I did but still rejected a whole lot of other ones. Well, I have to tell you it was easier to only have to deal with one year's worth of issues, but it left all of these other issues off the agenda. So from that I take - feeling that they sort of reluctantly agreed to something because they couldn't really justify doing nothing; but I had this feeling that this was a tussle between me and HREOC, probably because it was a whole pile of paper. I have to say the department when it submitted its stuff - you know, the department has got to submit materials - it just gave a pile with no summary, no list.

MRS OWENS: No index.

MS McLAUGHLIN: No index. It was really unhelpful.

MS McKENZIE: Did HREOC not require that? You know, it's often the practice of courts and tribunals to require, if material is going to be submitted and it's very lengthy, that an index has got to be provided.

MS McLAUGHLIN: And certainly when they produced the material that they had to provide to the AAT with respect to the workers comp things, they did. It was what they provided to HREOC that was just dumped like that. I have to say that I did provide my documents with lists and everything else. So in the end I did the job that somebody else might have done.

MRS OWENS: See, even having what we've got in front of us today that you've provided, just the point form to give a bit of a roadmap through the issues in a very clear way, would have helped HREOC and the HREOC officers.

MS McLAUGHLIN: And in a sense, that's what I did in the submissions that I wrote to them at different times. I have to say it would have been - I mean, there's no text in here, so it's a nice short document, and it's why this is all you got, because to me, to write the text, it starts to get long and people seem to have this view that if it's longer than about two pages, it's too long.

MS McKENZIE: You may as well speak to it. We can then ask you our questions as we go along and so on.

MS McLAUGHLIN: It's fine today. What I was actually wanting to draw attention to is that because if I had to write a submission about a particular thing for HREOC or the AAT or Comcare or whatever, they seem to take offence at the length of it. But I think they were coherent, signposted documents. I don't know what else you can do. The thing is, if the issues were simple, I would write a simple document, and they weren't simple. The events weren't simple, and grappling with what the significance was of them - - -

MRS OWENS: You can even make a complex case easier to understand and easier to follow by having, as Cate said, an index, maybe a little summary here - - -

MS McLAUGHLIN: I did that.

MRS OWENS: - - - and little signposts saying, "Go here if you want to read that," and people could be selective and say, "Well, I'll concentrate on those bits and I'll come to that later." We do that with all our submissions. I read our submissions, and some are very long, but I really do appreciate it when I get something that I can prioritise within the submission and concentrate on that, and the people that then attach useful things - you can say, "Well, I'll go back to the attachments later, read those more carefully later."

MS McLAUGHLIN: I think I did do that, and it was so disheartening that that wasn't helpful, that that didn't get me clarity. The clarity didn't seem to be received.

MS McKENZIE: But the thing that concerns me more even about that is that you have worked as a policy officer so you're used to dealing with very large numbers of documents and being able to index and summarise them and so on. How would that be for a complainant who had no experience with dealing with large numbers of documents?

MS McLAUGHLIN: Yes, exactly. That's what I was trying to say earlier. If I ended up losing - what we haven't established and we won't establish here is the merits of the case, but I think there were merits to the case as well - then how on earth can other people do it? Because in the end, the deal that I had with DDLS was essentially that I would pull together most of the materials, and they were struggling to deal with what I was producing for them, so even they weren't really on top of the issues.

The feeling that I have when I look back at the events of my employment and my attempts to resolve those issues is that I don't think that my employers were model employers and I don't think that they were model litigants. My guess is that they spent about $100,000 on legal costs to fight my workers compensation battle. I went to one little directions hearing about accessing a document and they had three lawyers. I suppose I should be flattered that they put such an effort into keeping me out, but I'm not. I'd like to be working. I think that there's really serious questions about the Australian public service, the federal government being a model employer, and being a model litigant. You might think that McDonalds is going to fight tooth and nail if somebody sues them, and use every dirty trick in the book to get their way, but that's not what the federal public service should be doing.

MRS OWENS: Can I ask you, while we're talking about lawyers, do you think there's a degree of unfairness in a process where a Commonwealth department can have access to the Australian Government Solicitor's office as a respondent, when the complainant has to fall back, if they can, on whoever? You used the Welfare Rights and Legal Centre.

MS McLAUGHLIN: Yes.

MRS OWENS: I don't know how easy it was to get access to support there.

MS McLAUGHLIN: I think I was lucky and I just hung in there. They could have easily said, "This is too hard. Go away."

MRS OWENS: But is there an imbalance?

MS McLAUGHLIN: I wouldn't say it's because they've got access to them. It's what the government solicitor's office does that's the problem. So it was the government solicitor's office running these cases. I had the same lawyer responsible, firstly, for the AAT matter, about the worker's comp, and then she did the Disability Discrimination Act as well. And my concern is that they just played hard ball. I think that they wanted to win and they weren't interested in what the facts were.

MS McKENZIE: And perhaps also, when you tell me about this, it looks to me very like many big commercial cases that are run this way in court.

MS McLAUGHLIN: Yes.

MS McKENZIE: And I have to say, I wonder whether that's appropriate. After all - - -

MS McLAUGHLIN: No. That's what I'm saying.

MS McKENZIE: - - -it's HREOC - the tribunal. This is the primary decision-making, it is not the third appeal to the High Court. And one has to wonder whether it's appropriate to apply so many legal resources. The other thing that worries me about that is of course if there were ever a cost question the costs that would be asked for by the respondent are the costs of all those legal resources not just some of them.

MS McLAUGHLIN: Yes, exactly. That's what I was really concerned about. It brings me on to questions around the hearing and how the court - I mean, when I ended up in the hearing the commissioner that I was working with actually was a former judge, which is very analogous to what is probably going on now in the Federal Court. In other words, there are commissioners who don't have a legal background, who might be operating in a more - we'll sit around the table talking approach. But my experience was probably closer to what happens in court, in terms of structures and language and expectations, and I have serious concerns about what happened there - and that goes on - because if the way that commissioner operated is the way the Federal Court judges are still operating, then it's still an issue, even though we've got rid of HREOC actually doing those decisions. But I've got a couple more things before we can get to that. I've been trying to do it in order.

MS McKENZIE: Yes. Sure.

MS McLAUGHLIN: With respect to the welfare rights and legal service, the support that I had - there was some physical stuff around; you know, copying or whatever, although mostly the union supported me with that, so I was very fortunate that I didn't have to cough up for that sort of expense. Most of the medical and employment reports had been prepared at other people's expense for the workers compensation matters, so I wasn't needing to go and get medical reports, particularly.

But the barrier that I found, when I was going into the hearing, was that there were a couple of their people that I would have wanted to call as witnesses and I just didn't have the money to pay witness expenses. It turned out in fact that somebody had gone to New Zealand, so it would have been even worse. But even when I thought they were local people - and you've got to pay witness expenses - it was my understanding, and it may have been wrong, but my impression was that the Welfare Rights and Legal Service were providing a lawyer and maybe an odd bit of photocopying, but there wasn't any money for reports.

Now, I think it's a real problem. If that was just the way they were operating, that's one thing, and so my beef would be with them. But if in fact that's the way they are funded, to cover legal costs but not expenses, then that makes it impossible, because in most cases you would have needed - I mean, I had one medical report ready to go - and we will come back to that. But most of it was already there and paid for by the government. But if you needed some of those expensive reports, that can put it out of the question. So I would like to see that any of this funding that occurs for legal aid, or through these Disability Discrimination legal services, should allow for some expenses.

MS McKENZIE: And the obtaining of some medical evidence, for example?

MS McLAUGHLIN: Yes.

MS McKENZIE: You said that one witness you wanted to call was in New Zealand. Sometimes - and certainly tribunals do this; many tribunals - there can be arrangements where video evidence can be taken from a place, or even telephone evidence.

MS McLAUGHLIN: I must say I didn't think of that. I must say I was struggling to keep going at all. But there's a bigger question.

MS McKENZIE: Was it offered by the - - -

MS McLAUGHLIN: No. When we got into the early hearing, and the respondents were asked who was going to appear, essentially they said, "The personnel manager, who had played a big part in all of this, full stop." The commissioner said, "Oh, no, I want to talk to A, B and C." The next morning he walked in and said, "Oh, no, that would have been totally inappropriate; end of the subject." So I went home that night thinking, he is going to tell them, he is going to compel these people to bring them, so I don't have to worry about paying. And then the next day - and the reason he gave, it just didn't - it was almost like he had had a conversation with somebody, although I know that that's inappropriate, you know. He shouldn't have had a conversation with the other side, other than in front of me. So I don't know what happened. It was just like this: click. One night he wanted it, the next morning he didn't. And so I then just kept putting one foot in front of the other to appear at that hearing.

So, not only was I not offered the opportunity of some cheaper form of access, I wasn't given the opportunity for this person to appear at all. I know it's always dangerous to have their people and ask them questions, but because I knew how involved she had been, asking her those questions would have - even if she wasn't inclined to be helpful - given me a stronger case; at least that was my perception. I mentioned earlier that I felt that the HREOC staff was finding it all too much of a struggle, and the DSS has refused to conciliate.

MRS OWENS: Just going back to the staff. You talked about the complexity of the case and the large amount of documents. Did you get a sense that perhaps there was a lack of resources generally?

MS McLAUGHLIN: And furthermore, the officer that I'm talking about is one of the most senior in the place, and is well considered. So I don't know exactly what the issue was. All I know is that the documents that that person signed didn't properly reflect the information that had been given to them, and that when I came back and said, "Oh, wait a minute," it still didn't. It felt as if it was a mixture of a resource issue and an "Oh, gosh, don't bother us." I can only raise those as possibilities. Given that I know how senior and respected the particular officer was I am in no position to say, clearly, which it was. But I think they are both possibilities and they both should be considered: the possibility that the staff are not being even-handed and the possibility that they are overworked.

MRS OWENS: We can talk to them about those issues. We've had feedback that they really do have very few resources, and that can possibly then affect the way they deal with individual cases, if they are having to do too much.

MS McLAUGHLIN: I think the AAT hearing was at the beginning of December 1997, and then I was given something like 10 days to get my final response in on the discrimination matter. There had been long delays, and I understand that that's a problem, but I felt pressured also. It was a huge thing to go through those AAT things, and then to sort of have like a week or something to pull together this final document; I don't know whether it was the appeal, I can't remember the detail. And it raises questions for me about that pressure.

MS McKENZIE: Could you not have asked for more time?

MS McLAUGHLIN: I did.

MS McKENZIE: And they said, no?

MS McLAUGHLIN: Yes. I've probably asked for more time before, and I have been given it. I'm not saying it was the first time I ever asked.

MS McKENZIE: No. But this was the final document, so there were no more opportunities to put in further documents.

MS McLAUGHLIN: No. Furthermore, I'm really convinced that that final reconsideration decision knocked out legitimate grounds. And my suggestion is that they do need more and better resourcing to handle complex situations. Of course it has got much worse since then, and there have been such dramatic budget cuts to HREOC every year since. Now, maybe we can go on to the hearing?

MS McKENZIE: Yes.

MS McLAUGHLIN: Up until now the problem has been the department, and suddenly we get into the hearing and the problem is the commissioner. One of the reasons that in the end I said to the discrimination service that I would look after my own case is that we got into a hearing in which the lawyers all got together and decided that they'd agree that I did have disabilities and that wasn't going to have to be a question; we would all just agree that I had these disabilities. And I was uncomfortable that I wasn't really part of that conversation because, of course, the lawyers talk to the lawyers and the clients aren't there. I wasn't warned. I mean, I don't cope with surprises. I've got my list of things to say to you and if you say something surprising to me I will try. But part of the cognitive difficulties that I have is that I really do need to prepare.

So I was absolutely taken aback, in that I thought the first order of business was establishing that I had disabilities and the content of them; not just whether, but what they meant. He just went across and organised this - I'm not saying he didn't ask me - and of course it was a disaster. I suppose I should be grateful that the commissioner was willing to agree that these things were all disabilities, given the things I've read since questioning each of them. But I had a psychiatrist ready to describe what the impacts were, of my disabilities, and he was willing to come and be paid later. I had pulled this together. He had written a brief report, which had been submitted, and the commissioner refused to let me present that evidence.

So, he has agreed I've got these disabilities. "He understands CFS," he says, which I suspect there is probably almost nobody in the world who could honestly have said that so categorically, as he did; and he proceeded to demonstrate that he didn't. If I said at 4.15, "Look, I'm really tired, can we please stop?" He did that. But when I said, "I'm having trouble with my memory," he would say, "Oh, you seem fine to me." I knew I was having selective issues. There were plenty of things I remembered. I have told this story so many times that I could tell bits of this story coherently, but I couldn't necessarily remember. You've asked me a couple of questions that I really couldn't remember, and so that would be proof that it didn't happen, in the way he took it. So I had this situation of a commissioner who didn't understand my condition, and he was obstructing - we were definitely having a personality conflict.

It was like he was really offended that I was unrepresented. He would repeatedly tell me that my understanding of what had happened, my perceptions about actions taken by my employers as being discriminatory as being wrong. He just kept on telling me I was wrong. He didn't say, "You haven't convinced me," which of course is a perfectly valid thing to say, he told me I was wrong. He didn't understand, really, how the APS works, not having come from that background; he was really intimidating. It was intimidating.

At the end of all of the hearings he said something about how he had operated, and I can't remember it; I'd have to find the tapes. I've got some transcripts, and tapes of the rest, and I don't remember what the explanation he gave was. But whatever it was - I mean, he didn't say at the beginning, "I'm going to take this approach," and explain it. I didn't understand it. I thought that commissioners sat there, and there was a lawyer to argue their case every minute of the day.

At the beginning I'd say, "Look, can we just have a couple of days or whatever, at a time?" He would agree to that. But at the end, when he decided there was only going to be seven more days, and they were going to be in a row, I was flabbergasted, because I can't do much more than two days in a row. So we did five days, a weekend, and two days. He said at the beginning of that, "That will be it.

You will not be allowed to have any more. You've got to finish your case in that time." And on the Thursday afternoon he decided that- I was working my way through the documents and he said, "Look, I need to know how many more of these - of all the ones that have been originally provided - you are going to talk about. I want you to give me a list before you leave tonight." 7.30 I got it to him. So by Thursday I'd had three ordinary days, plus a long day.

So we start cross-examining on all this stuff, and on Tuesday I'm just tearing my hair out trying to get it to the point where I had finished my cross-examination. At 3 o'clock he says, "Oh, it doesn't have to be finished today." By which time my mind was just fixed around how did I get it finished by - so I did close my examination at 4.00 or whatever. But then, again, once I'd slept a few days and whatever I realised that I really hadn't covered a number of things, so I wrote a submission and said, "Please, can I come back and plead those?" And he agreed to that. We came back and we had one three-hour session, or whatever, where I completed the cross-examination, and it was much more focused. The transcripts between the first lot and the second demonstrate it. I think what I did - although that wasn't the intention - was that I demonstrated that rested I am sharp, and I could do a clear, effective process. Of course all I did was prove that I didn't have a problem at any time, I think, from his point of view.

Then he argued about whether I could do a - I had no access to transcripts during the thing. I asked if I could make a tape-recording, so I could go home and listen to it at night, because I can't remember, and it was terribly hard to make notes as you were participating. The system wouldn't allow that. The system wouldn't allow me to make a copy. The only way I could get access to the tape that was being made was to pay big bikkies at the time.

MS McKENZIE: What you were just told was that if you wanted transcript you paid for it.

MS McLAUGHLIN: That's right, yes. In the end HREOC got transcripts of these cross-examinations - not the original evidence, which of course was important that I knew what I'd said - and they did give me those transcripts, so I did have some transcripts at the end of the day, but all of that made it difficult to participate as I was going along. Every now and again I would make little notes about something that I'd heard when they were talking that I didn't have the opportunity to interact on, or the next day I'd think, "Ah, that's the answer to that."

I wanted to pull it together and we never got to the point of arguing the questions around direct and indirect discrimination; like I understood that what we were doing was collecting the evidence about what had happened, and then we would have some discussion around - well, we never got to that. I said, "Can't I make a submission?" and I had a fight to get him to agree that I could make a submission, but I was struggling. I was so exhausted from this effort of these months of preparation and then these huge things - - -

MS McKENZIE: And did the respondent - - -

MS McLAUGHLIN: - - - and the respondent wanted to shut it all down. They kept on saying, "Look, she's had enough time. We don't want to bother." Sorry, was that your question?

MS McKENZIE: No. I just wanted to ask you, did the respondent also make a submission in reply to yours? Is that how it worked or - - -

MS McLAUGHLIN: I think we were supposed to make them concurrently, but I may be confused about that - that level of detail - but we both did make submissions - I can't recall the time frame - but in the end I couldn't pull that together and he said, "That's it. Finished," and I wrote and said, "Wait a minute. Give me some more time," and he said, "No," so towards the end of nineteen - I'm not sure which year, but anyway a year after this whole process started he closed it down, so then I had to wait. I rang up a year later and said, "What's happening with my report?" and it came out the next day.

I did a Freedom of Information request, trying to find out how come it had sat - what had happened with it because from various things that were said it was quite clear that from at least the beginning of the report had been written very soon after he'd closed it down because it was just after Christmas and there were ways in which - you know, the thing had been closed down about October and it was released a year later, but the wording indicated that a lot of it had been written around January.

It felt to me like somebody had said, "Wait until she asks and then we'll release it." I have no idea if that's possible. There was nothing to indicate any correspondence between HREOC in Sydney and the commissioner in Brisbane, so there was very little - I tried to find out what had happened because it really bothered me that I had waited a year and then it had come out. When I read the report it did not say I was malingering. It did not say I was crazy and it did not say I was lying. Now, with my conditions, any of those things can happen and they are really devastating if they happen, so I was blessed that that didn't happen.

What he did say was I was mistaken that these things were bad. What I feel I have is a clear mind and a commitment to participating, and that is damaging. Could have been worse, but it is still damaging, and it seems to me that his description of - the evidence that he presented was not thorough. I mean, it missed bits and misunderstood other bits, but he had presented his evidence and then he said, "And this is my conclusion" and I think he missed evidence, and I didn't see a reasoning to go from that evidence to the conclusion, and he just dismissed the whole lot.

MRS OWENS: And as you have said, you felt that you couldn't go to the appeal process because it was a court setting, because of the cost - - -

MS McLAUGHLIN: It was really clear to me as I went along that there were many, many things he had done wrong in that hearing, some of which I have mentioned to you. I don't know that I've made a note of some others, but there were a number of things which I'm sure - I mean, at one stage of the game he said, "Oh, that duty of care business, that's ridiculous," or words to that effect, which I'm pretty sure is not legally appropriate because that is, as I understand it, a legal concept that's of standing. There was a whole pile of things that he said either about me or to me or about legal questions which I'm pretty sure were wrong. Errors - I think he called it "errors of law" or something like that.

MRS OWENS: Yes.

MS McLAUGHLIN: I'm sure that I had grounds for complaining about the process and complaining about the decision. That was really clear to me when I read it, but I thought to myself I just couldn't - I can't do it in - you've got a month or something to appeal or spend time fighting about delaying it. I've struggled financially since all of this started and fought really hard not to go bankrupt. I wasn't going to let this situation jeopardise that.

MRS OWENS: Alexa, I also think that if you just kept going - I mean, I don't know what it would have done to your health - - -

MS McKENZIE: But having said that, do you still have a feeling of injustice? I mean, have you felt yourself able to move on in that case?

MS McLAUGHLIN: Absolutely. I mean, what I have done since that time was to concentrate on improving my skills around writing and doing some contracting work and continuing to do a lot of community participation, community activity, but I was really pleased when I heard about this hearing. I thought, "This is the place. I can go there and I can talk about these faults in that system and draw attention to them in the hope that it won't happen to other people," because I do think that most of the things that went wrong in that hearing would be still a problem in the Federal Court system because those same sorts of people with their same backgrounds will be running that system.

MRS OWENS: You've made a few what I think sound like very good suggestions in your list of points that you have given me.

MS McLAUGHLIN: The ones that come after?

MRS OWENS: Do you want to go through those?

MS McLAUGHLIN: Sure.

MRS OWENS: Just go through those. We'll be running out of time shortly and I want to get this on the transcript.

MS McLAUGHLIN: Absolutely, and we're nearly done, too. Jocelynne Scutt in her appearance before you talked about the need for the judiciary to have training to really understand discrimination law and, despite the fact that this guy was an experienced commissioner, to the smallest extent that the questions of direct and indirect discrimination even came up in our conversations, I had a feeling that he didn't really understand those, and so I think it is very important that they do understand discrimination law, especially in the context of a Federal Court, where there may be many jurisdictions that they are hearing matters in.

MS McKENZIE: And disability awareness issues, as well - - -

MS McLAUGHLIN: That was the next one.

MS McKENZIE: Yes.

MS McLAUGHLIN: No, it wasn't, but it should be. The next one was about employment practices. I mean, especially in this town where so many people are federal public servants, this commissioner didn't understand how that worked and so he was sort of applying some sort of private sector approach to things that really have been solved and formalised and everything else in the public sector and, in addition, there is the question of disability issues in general. I certainly thought it was appalling that he kept on saying he understood my condition but wouldn't let me talk about it, but even more importantly it seemed to me that that hearing process did not accommodate my disabilities.

I have to say that one day the court reporter arrived reeking of perfume and I reacted really strongly immediately. Fortunately I had some support people who came with me. I couldn't even deal with it, I was so distressed, and the support person went to the HREOC officer and said, "Look, we need to deal with this," and they got another court reporter, which I was really grateful for, because if that person had sat in the room, even though they were perhaps about the same distance as you and I are, it was still a small enough room that it was a problem - and it was strong. I'm pretty sure that I had raised that prior to the hearings, but of course the court reporting system is separate from the hearing, so obviously there had been a breakdown in communication, but this whole business of having long days and many days at once - - -

MRS OWENS: We understand how tiring that is - just doing this work.

MS McKENZIE: That's right.

MRS OWENS: It's exhausting.

MS McLAUGHLIN: So whatever is your need - and it is going to vary. I mean, everybody doesn't see it, thank God, but the system really ought to be the model accommodator.

MRS OWENS: Mm.

MS McLAUGHLIN: Can I just briefly mention with regard to good services and facilities: I personally have had some pretty horrific experiences around being denied medical services; you know the specialist who told me recently that I needed surgery, but not until I lost a lot of weight and kept it off, and didn't say the operation wouldn't work. He said that recovery would be difficult and it was an occupational health and safety issue for the people caring for me. Well, it's an occupational health and safety issue for people half my size, and they should have equipment to deal with that. I just felt like he wasn't trying because I was obese.

I had had previous surgery without half of these complications only a year before, so it isn't as terrible as it might be, but they were really struggling to accommodate my chemical sensitivities and they sort of said they would and they put all this stuff in place and then it all fell apart, so there is an issue right across Australia, as I understand it, from people across Australia, of having chemical sensitivities accommodated in hospitals. It is possible with a will, and it is the lack of will that is the dilemma, and so I am making representations in the ACT to try to get it done, but it seems to me that it is a disability discrimination issue. You shouldn't have to make choices between staying ill and - - -

MS McKENZIE: Yes, and having necessary surgery.

MS McLAUGHLIN: Yes, so I am really concerned about that. Finally - I don't know whether it really follows under Commonwealth programs or good services and facilities, but I'm really concerned about a lot of the choices that are made about medical research. With respect to obesity, for example, there is this absolute urban myth that you can fix obesity with more exercise and a different diet. If that works that's wonderful, but there is plenty of research that shows that it doesn't, or it doesn't work for many people, but that's all the research that's being done. That is what everybody reads.

Yesterday in the paper - or last night on the television - the consequences for people for whom it doesn't work and the way you get treated if you are obese is really horrific. I would like to see somebody spending some money on exploring the other evidence. Similarly with CFS and MCS - all the money that is going into the psychiatric stuff. I wouldn't mind a label of a psychiatric condition if they could fix me, but they don't. They have got a really low success rate of using their psychiatric interventions and there is lot of evidence that shows that their psychiatric interventions with people with severe cases - they're actually detrimental.

MRS OWENS: Yes.

MS McLAUGHLIN: Nobody is doing the research about the physical stuff. The other stuff isn't working, so we need to be doing stuff on the physical causes and possible physical treatments if we are going to stand any chance of helping people at all, and those decisions are made at the NH and MRC level, and that is a government funded program - a government program of funding. The end.

MS McKENZIE: I don't have other questions - I have asked you plenty as you were going along. It has been a really fascinating presentation and very helpful for our purposes, just as all the other submissions are, too.

MRS OWENS: I would like to thank you, too, Alexa. I hope you don't mind us calling you by your first name.

MS McLAUGHLIN: No. That's fine.

MRS OWENS: I think through these hearings we have been hearing a lot of distressing stories and I think you have just added to the distress load. I am really grateful that you were prepared to come and share it with us and I hope it hasn't been too tiring for you today. I know it must have been difficult dredging over it again and having to think it through again, so thank you for that. I think you set it out extremely well. It was a very logical, well ordered prescription, so thank you.

MS McKENZIE: And good luck with your work.

MS McLAUGHLIN: Thank you very much indeed.

MRS OWENS: We'll now break and we'll be resuming at 1.30.

MRS OWENS: The next participant this afternoon is the Australian Chamber of Commerce and Industry. Welcome and thank you for coming and forgoing your lunch to do so. Would you like to each give your name and your position in relation to ACCI for the transcript.

MR BALZARY: It's Steve Balzary. I'm the director of employment and training with the Australian Chamber of Commerce and Industry.

MR MAHONEY: Neil Mahoney. I'm an adviser in the employment and educational unit on disability strategy.

MRS OWENS: Good, thank you. I understand one of you or both of you would like to introduce your submission.

MR BALZARY: Yes, thanks. Yes, I might start off and Neil may just make a brief comment too. I guess to start off and say thanks for the opportunity to address the review. As you're aware, we're in the process of putting together our submission but I thought it was useful to at least come here and have some dialogue.

Just where ACCI is at the moment in the whole of area of disabilities: we've got an agreement through our general council and board process to actually, for the first time, develop a comprehensive approach to people with disabilities and we're doing that right now. So that's why I guess it's timely for us and that's Neil's direct responsibility within ACCI. Our view is that, starting from the broad, we have been involved in a range of disability-related issues including some award restructuring, some general employment.

I sit on a disability vocational and educational training advisory committee through the Australian National Training Authority, et cetera, so we're obviously involved in a whole range of activities but at the moment we actually haven't got a disability employment, education and training policy. We've now decided to in fact do that, which is a considerable move, so that's part of the background about why we at the moment haven't put a submission in because we're doing it at the moment.

Obviously we've got a whole range of other policies that in fact talk about the need for equal opportunity within the workplace. We've recognised that in the employment and also training areas there need to be particular strategies that are targeted towards people who have been disadvantaged in the labour market and that obviously includes people with disabilities. So we are keen as well in terms of a context from work we're doing at the moment which is really looking at the ageing of the Australian population.

The reason I raise that here is because in the end, even within 10 years, the supply of labour in this country won't meet the demand so we're actually looking at a whole range of groups that are classified generally as marginal to the labour market into about how they could increase participation in the workforce. So rather than coming from an equity and EO angle we're actually coming from a labour market arrangement angle which is, I think, an important development with the Australian Chamber of Commerce and Industry.

Getting down to some basics, and I'll just touch on a few of these and you can obviously ask me some questions in terms of some of the detail. Our view in this particular area is there is no trend towards higher levels of complaint in the area. We haven't, in terms of our discussion with members, detected any growth in that area and I know some of the statistics that have been done by HREOC and others also indicate that but that would certainly feed back and support some of the things that we've found as well. So in other words, it doesn't seem to be a particular issue when we've talked about it to employers that's it on their radar of significant concern.

Our view generally about things is that conciliation is the most effective means of resolving discrimination or other issues in the workplace and we think that should be done at the local level rather than having outside agencies and others directly involved or being involved in a mandatory way, although obviously mediation and other services are often used by employers for a range of dispute and other resolution processes. Also one of our principles is that we obviously are concerned about the impacts of legislation that place restrictions in terms of the workplace and they can be time-consuming and also costly for employers but also it may eventually have a by-product of inhibiting and increasing the risk for employers on taking people on and I think we need to be very mindful of that, not only in terms of the discussion we're having here but also in terms of insurance, workers compensation and a range of other things in terms of the workplace in terms of cost.

So to us it's more an issue of general promotion for employers in terms of the range of opportunities and about a promotional strategy for involving people with disabilities more in the workplace rather than any punitive measures or other measures but obviously we support having some process where people can actually complain if things do occur. I think as well that one of our concerns in this whole area is generally - and we've been obviously involved in the welfare of formwork and other areas - is that we recognise that there is an issue in terms of labour participation rates for people with disabilities in this country in the workplace. So therefore that is one of the reasons we're actually moving towards doing more in this area.

We know as well in terms of vocational education and training that participation of people with disabilities in fact is the only trend that's either maintaining or going backwards and that's a significant issue that we've taken up with the Australian National Training Authority, that the profile of people in terms of vocational education and training for people with disabilities is in fact fundamentally different than other participation.

So just to do a sketch, it's basically people with disabilities are usually unemployed when they take vocational training. Not only are they unemployed but they are usually doing it full-time and they're doing it totally off the job. When they complete, their employment outcome is substantially less than any other group, including indigenous people. So that is a very different scenario that I think we need to actually do something about and that's certainly some work that some of the committees I'm on with the Australian National Training Authority are doing.

In addition to that, we've been active in terms of the International Labour Organisation, ILO - I've just come back from overseas actually myself - and they're doing a whole lot of work with people with disabilities across the world and, in terms of comparative arrangements and in terms of what we do in this country, usually we're the leaders in a whole range of areas but certainly with people with disabilities our view, from the employer's view, is it's one area that we're not, which is another reason why we've decided to give a bit of effort in this area.

MS McKENZIE: Can you say how much we're not the leader? Would you say from an international perspective we are close to last, we're somewhere in the majority range of what most countries do or are we close to the forefront?

MR BALZARY: There are ratings - the usual OECD rankings on this that you could get from OECD - but my view would be that we're sort of bottom in the middle group and that's unusual for us. I mean, usually we're sort of getting towards the better groups. Now, part of that, and there's all sorts of reasons that we're looking at at the moment, is it seems to be there's an issue around - I mean, a whole lot of countries haven't got the income support arrangements that we've got so therefore there is real requirements about people participating very clearly in terms of employment and they have to in a lot of countries.

MS McKENZIE: Otherwise there is nothing that's done for them.

MR BALZARY: Otherwise there's nothing, so I mean you've got to look at this. In terms of any international comparison, in my view, it has to be done in context. In addition to that, a whole lot of countries are actually doing things around entrepreneurial and self-employment areas for people with disabilities rather than necessarily seeing it's only an issue for people within the workplace. There's certainly quite active strategies involving employee and employer organisations that are being undertaken in a whole range of countries as well. In addition to that, governments are very active in the area in terms of government employment now. I mean I don't know again all the statistics in terms of each of those different areas but it seems to me that we need to lift our game in a whole range of those areas.

MRS OWENS: Neil, you were going to add to that.

MR MAHONEY: Just on a couple of points really that were raised in the issues paper. They're really areas of interest for us rather than areas that we want to make definitive statements on at this point in time but one is around the incidence of complaints under the DDA. HREOC say that they've had 5 and a half thousand complaints under the DDA in its first 10 years of operation. Obviously not all of those were to do with employment and not all were successful, so we're trying to look at it in terms of I guess the severity of the issue and what's happened over time.

Now, no case of unlawful discrimination in the workplace is acceptable; however, the rate that we're seeing isn't high and when we look through the cases that HREOC report in their publications, we can't see any area where there's systematic discrimination or any kinds of repetitive types of discrimination that you could actually approach with some sort of strategy to overcome. We are aware from some of our reading as well that there's a sense that some parties feel that there's a lot of unreported discrimination; people don't think we move ahead with complaints, and that's an area that is a little bit of a concern, in that unless you've got some way of measuring the extent to which people have genuine complaints and don't come forward with them, it's very difficult to do anything about addressing it or to put in place any strategies around that kind of discrimination because it becomes the subject of innuendo and rumour. And it would be good, if that is the case, for some research analysis to be done on that so all parties can see what the problem is and do something about it.

MS McKENZIE: What about, for example, where - although a complaint is not made to HREOC or to one of the state bodies - a complaint of discrimination is raised through internal employer mechanisms?

MR MAHONEY: Again it's difficult unless we have information on how often that occurs or what are the areas in terms of recruitment practices, promotion practices, workplace modification practices, what have you. It's difficult to make a comment unless you can actually analyse what the problem is. If that is an issue it would be nice, as I said, for that to come forward with some sort of evidence base so that everyone can address the problem.

MRS OWENS: Is it difficult getting that sort of evidence though? I mean, some of the possible discrimination could be quite subtle or indirect.

MR MAHONEY: I don't think it would be impossible to conduct surveys that would give some sort of elimination of that issue.

MRS OWENS: Who do we survey? Do we survey employees? I mean, there's going to be the people that have missed out on jobs. There's the people that may be in jobs but having difficulty and then there's the employers. I mean, who do we ask?

MR MAHONEY: I can't really give you an expert answer on statistical methodology but I think all of the groups that you mention would be worthwhile surveying if that is an issue.

MS McKENZIE: Employment agencies may be of some help.

MR MAHONEY: Yes.

MR BALZARY: I think that's an important issue Neil has raised, because numbers are so small. In other areas like this it depends what it is about, whether there is a substantial complaint and what forms that complaint and whether it's taken forward and then how you measure that in terms of analysing whether in fact something is done about it. I mean, employers don't keep, and nor should they, lots of statistics in terms of where there's subtle arrangements in the workplace. It is just ridiculous red tape for the sake of doing things.

Perhaps surveys or case studies may be useful but, again, when we went out there was no - I mean, normally in these sorts of things you can find a number of cases but we didn't find any in terms of people that we could even see in terms of through membership, in terms of whether this has been an issue, because they're so small, the number of cases. So that's been a problem even from our side.

MRS OWENS: You said when you started off, Steve, that ideally any conciliation is more effective at the local level, presumably rather than letting it go as far as going to say the Human Rights and Equal Opportunity Commission under the DDA.

MR BALZARY: Yes.

MRS OWENS: There are other mechanisms, aren't there, like unfair dismissal complaints?

MR BALZARY: Yes.

MRS OWENS: Do you know if there's any information in terms of those complaints that relate to unfair dismissal on the basis of disability?

MR BALZARY: No, I don't. There's certainly some general analysis done by type or categories in terms of unfair dismissal, but that's maybe something we can do some work on and come back in our submission. I'm happy to do that.

MS McKENZIE: AIRC would presumably have some.

MR BALZARY: Sure, and the employment advocate would certainly have something, and that's probably who you could talk to.

MRS OWENS: There may be some information out there, at least on those issues.

MR BALZARY: There are general processes that any employee can actually utilise. Whether they're broken down for people in terms of discrimination and people with disabilities - it would surprise me if it is, but there may be something in the general category of discrimination in the workplace.

MS McKENZIE: I don't know whether some employment agencies might keep figures, or perhaps the government contracted organisations that help people who are on the various government supports, like Newstart and so on. There may be also some records kept there.

MR BALZARY: Well, certainly the job network providers who are doing a lot of work and specialising in areas of people with disabilities would have a good feel, and some of those people (indistinct) but they'd certainly have a good feel about that, but again it's more a question I think - I mean, my view in terms of balance is about promoting and increasing the number of people in the workplace. That's where trying to concentrate our effort.

MS McKENZIE: You mentioned in your submission that there may be some inhibitors as far as employing people with disabilities that concern you. You mentioned insurance risks and so on. Do you have any additional things to say about that?

MR BALZARY: In reality, our view is that this whole issue is not really on the radar screen for a whole lot of employers, in reality. We know that some people are actually doing things at the local area because they've been approached and they have an arrangement or an individual commitment or something like that, and that's sort of fairly located around the arrangement, but certainly in terms of putting anyone on, you've got to judge what the impact of that will be on your workplace.

The other thing we've found as well is, for example, that employers just aren't aware of the tremendous amount of schemes that the government have about workplace modification, and part of the strategy that we have is in fact to do a lot of work about promoting the range of assistance that's available to do that, but it's just not known, so that's a barrier in itself, where you've actually got people not understanding about what they're entitled to and what sort of assistance they can actually get.

MS McKENZIE: And what about the awareness of employers of the DDA? You were talking about beginning this policy of looking at the greater participation of disabled people in employment, but one of the things for us in our terms of reference is that DDA has been around for a long time and we're asked to have a look at how effective it's been, and one of the matters we look at of course is awareness. Do you have anything to say about awareness of the DDA in the last 10 years that it's been operating?

MR BALZARY: Again, because this hasn't been on the radar, most employers would not have a clue about this particular area and all the legislative and other requirements around it. Those who are involved would obviously know a lot more, so it's more about direct experience. That then breeds information, which then breeds I guess better understanding. So those who are participating in those sorts of areas would know obviously a lot more, but on the whole, generally people are aware of EO arrangements and that requirement, but they wouldn't know specifically.

MRS OWENS: As part of this comprehensive approach that you talked about at the outset, are you going to look beyond say education and training issues to these broader issues about awareness of this environment in which employers are working?

MR BALZARY: Absolutely.

MRS OWENS: Is that going to be part of it?

MR BALZARY: Definitely. We have two outcomes that we're trying to work towards at the end of this year. The first one is doing a policy which is just like a whole range of our other policies, which will cover a whole broad range of areas, which will look at employment, it will look at, as you say, education and training, it will look at workers comp, it will look at rehabilitation, et cetera, et cetera - and industrial relations in terms of the supported wage assistance program and all those sorts of things. So we'll look at all of that.

The next element is really about what we'll do about the strands we'll actually undertake, and one of those will be working, I think, with governments about a generalised promotion and strategy to employers, which will talk about not only these sorts of requirements and outcomes, but will also talk about, as I touched on before, the extensive range of support measures available to employers if they participate in these sorts of things. So getting some information out there is fine, but it needs a context, and it needs to obviously be employer friendly and all of those things, and it needs to be connected I think to the employer organisations systemically, rather than be done on an ad hoc basis which relies on individuals talking to individuals.

MRS OWENS: And it's not just about focusing on discrimination issues and the narrowly defined issues, but you're looking at the whole; putting it into a much more positive context about how we can promote understanding about employment of these people with disabilities and what does this mean in terms of workers compensation and so on.

MR BALZARY: That's right.

MRS OWENS: So it's a more positive way into it, isn't it?

MR BALZARY: You've got to do that. I gave an outline to our council just in terms of the numbers of people who were on welfare in the disability category, and I think that concerns a range of people and I think we know, just from the face of it, that the closer people are to the labour market, the increased impact that has on a whole range of things, including self-worth and self-being and all those sorts of things, and that's with a whole lot of groups, including indigenous and others. So what we've got to do is work on that, but have a strategy from an employer's point of view rather than from governments and others, so we actually own part of what we do and where we're going to go.

MR MAHONEY: Just to reinforce what we're saying, it's about having a pool of skilled labour for employers to draw on and looking at eliminating barriers across a wide range of things that might otherwise make people with disabilities uncompetitive in the workforce.

MR BALZARY: That's why I guess I used the example of vocational training. We've got in this country 1.7 million people undertaking VET, which is very workplace focused. I've got a report here I can leave with you which is on this, but basically in 2000 there were 62,000 VET students reporting a disability, and I went through all of those things in terms of how it's fundamentally different, so what we've got to do is actually do a lot of work in terms of getting a workplace component in that, which then connects it, and that's what we've got to try and do, rather than, in my view, putting people in institutions, whether they be TAFE or even in higher education. You've got to get this workplace component together.

MS McKENZIE: So that they come out with experience and it means they're much more employable.

MR BALZARY: Absolutely. So it's all about interaction between the workplace and also further education and training, which then means you're building a skill base which then means people will come out with not only a qualification but some work experience and usually, at some point, a job. And it's the same in terms of the school-to-work transition. Obviously we're very interested in terms of - vocational education and training in schools has grown. There's about 182,000 people doing that in years 11 and 12 now, which is about two-thirds of all years 11 and 12 students.

It would appear there's not a very high proportion of people with disabilities undertaking that work either. For many reasons, obviously, there's a whole range of things most people are undertaking, and even groups that are disadvantaged in the labour market - people with disabilities are not participating in, or if they are, they're doing it in quite different ways, which I think seems to be an issue about - when you're talking about skilled labour, there is serious disadvantage. So in terms of missing out on a job, one of the big requirements will be the lack of skills and work experience people have, and our view is that would be at the central core of it. It's not so much about the extent of the disability; it's more about the lack of skills and work experience.

MS McKENZIE: Can I just go back a couple of steps. We asked you some little while ago about the conciliation question and you said that you favoured internal conciliation. Some of the submissions that have been made to us say - particularly when they look at HREOC conciliation - that the outcomes of that conciliation should be made public. Some submissions say that in every case that should be so. Some say it should be limited to where the outcomes are systemic ones, or for some other compelling reason they should be made public. Have you got any views about that matter?

MR BALZARY: It depends I think in that debate about what outcome you want. If you want the resolution within the workplace to be the primary goal of what you're doing, publicising that and publicising the employer I think it is tantamount to actually doing a whole lot of negative things. If people are seeing publicity in terms of those sorts of cases with the employer mentioned, I think we have a clash of what we're trying to achieve. If I'm trying to achieve on the one hand an increase of employers taking on people with disabilities and providing opportunities for those people, and on the next hand I've got a whole lot of cases with employers being named - not that there's many of those - I don't think that's actually useful.

But to turn it round and say, "There are case studies, and the issues are these" would actually be quite useful I think in terms of some of the work we're doing, which doesn't mean to talk about anyone being named, but it actually says this is the situation, this is what happened, this is how you deal with it and this is how you can prevent it, probably more importantly.

MRS OWENS: But you could have case studies, couldn't you, without actually naming employers?

MR BALZARY: Yes. I've got no problem with case studies.

MRS OWENS: Or the individual complaint as well?

MR BALZARY: Yes, I think so.

MRS OWENS: So you could still have all the benefits of the education without necessarily jeopardising either trying to resolve the issue in the workplace or necessarily putting up barriers for future employment because, as I said at the outset, you can discriminate in fairly subtle ways. If you've got two people going for a job and one is a person with a disability and one is not, and they are fairly well balanced apart from that, you might go for the one that hasn't got the disability because you don't want to put yourself in the situation of potentially having a problem in the future or possibly having to make adjustments in the workplace which are going to cost. So one is going to actually end up costing more than the other. I don't know whether that would be a consideration in the employer's mind, but employers are not there providing a social service and they might look at the potential relative costs, or don't they?

MR BALZARY: I think you'd look at all components about bringing anyone into your workplace. That's always a consideration. And that's assuming that you have two people with exactly equal qualifications, experience, and we just talked about a whole series of issues in relation to whether that is in fact the case for the majority of people with disabilities. I'm not sure. But certainly that is also to me a lack of understanding about what sort of assistance is available, so in fact it all goes together. I guess what I'm saying is that in fact if people don't understand that, then it's more about their lack of knowledge about the assistance available, to my mind, and how to fix that, rather than say that's a real problem, in my view, in terms of discrimination.

The other thing is that it's about how to be positive, so in the case studies for me, it's not so much saying, "We found this and this was the issue." It's more about saying, "These are the things you need to think about as an employer." So it's a different way of using the case studies. Generally in other case studies you'd say, "This is what's happened, this is what the employer did," so therefore it's more a promotion about saying, "You shouldn't really do that." For this area, my preference is in fact to try and give much more information about how things can actually be avoided, and utilise those in terms of some tips for employers, so we actually do that, in terms of that positive slant that we were talking about earlier, because it's a very fine line.

It's a bit like the unfair dismissal legislation. When the unfair dismissal legislation was introduced, basically employers were very concerned in terms of taking people on. It had a massive impact, and even when those unfair dismissal arrangements were introduced, sorry, and modified over time and made a lot more employer-friendly, there were still views, because the legislation was there, that it was a real problem, and people had to be very careful about what they did, which is in fact nothing to do with what the legislation said.

MRS OWENS: A perception thing.

MR BALZARY: So recruitment and employment and perceptions of risk and I guess ongoing risk in the obligation as an employer are very important things in terms of consideration about who you bring into your workforce, and what obligation you will have in the long term in terms of that arrangement.

MRS OWENS: If employers aren't really aware of the existence of the Disability Discrimination Act, they're not going to be particularly aware of some of the clauses in the act in relation to making reasonable adjustments in the workplace, are they?

MR BALZARY: That's right. It's hard to know. If there's a direct involvement, bearing in mind there's a whole lot of support assistance out there in terms of people being referred on, so if that's there - because people will be told about it, employers will be told about that. But if they're not involved in that, I think people generally think it will be, "What have I got to do in terms of the employee?" It's hard to know whether that's clear across all employers. I'm hesitant to say, "Oh, well, that means no-one knows any of those things," because to be honest some of them seem to be eminently sensible. Some of them seem to me to be self-evident, I have to say, which any reasonable person would understand.

MS McKENZIE: But you would say that in your view there are a large number of employers out there who really don't have a detailed knowledge of the DDA.

MR BALZARY: I think that's right about a whole range of measures in a whole range of areas. A part of the issue on this is in terms of a whole series of regulations around employment practices and things like that. Employers can't know every act at state or federal level, sometimes which compete with each other, about what they do in terms of the workplace. Part of what we try and do is obviously promote that and also provide support to employers where they have difficulties, bearing in mind one of the issues about taking people on is, in fact, the wealth of workplace relations and other legislation; impacts on taking people on, letting them go, or in fact working.

MRS OWENS: One of the aspects of our terms of reference is to look at the costs and benefits associated with the act. It's being done as part of the national competition policy legislative review, part of that program. We're not just focusing on those issues, obviously, because there are other important parts of the terms of reference, looking at the effectiveness of the act in terms of meeting its objectives, but nevertheless we have been required to consider this whole issue of costs and benefits. A number of people have said, "Well, there are significant benefits to employers, for example, in employing people with disabilities, because it enriches the workplace. These are good workers, they're reliable workers; they often stay in jobs longer. They're prepared to put in, because in some cases they're very grateful to have the job."

On the other hand, potentially, there could be some costs associated with employing those workers, like making reasonable adjustment, unless the employer can prove that there is some unjustifiable hardship. I don't know whether your written submission will be addressing that issue, but it is an issue that we need to think about - whether any of your members have raised with you these cost issues or whether you have any sense that there has been acknowledgment of the benefits associated with employing these people.

MR BALZARY: Again, benefits in this area seem to be obviously those people that have actually employed people with disabilities. Therefore, you're already talking about a very limited number of people in terms of employers. Some of those things in terms of - it's part of the case studies and other things that have been worked upon - where people do stay on longer, is again known by those people that are involved but probably not in general, and anything like that I think those processes need to be included in part of what we're doing in terms of promotions.

Experience, and connection with experience, is vitally important in terms of recruitment practices and, if there are cost inhibitors - and there's increasing costs about anyone coming into the workplace, doesn't matter who it is; it's an issue. So you have to work out essentially how you can balance the change in the workplace and fitting the workplace around with some of those benefits, which may come to you or may not, depending on the workplace and what the individual does. It's a careful balance, and I think it's a real issue about what's the degree of government support in terms of areas of modification of the workplace but also about what happens with the modification if that person goes and, depending on the sorts of disabilities we're talking about, if you take on someone else with a different disability, what happens there in terms of modifying the workplace.

There are also different workplaces. We're talking about, if you're in building and construction as an industry and you're working on work sites, that may not be possible for some people with some forms of disability to undertake that work because there would be physical labour. That's all obvious.

MRS OWENS: That's obvious, yes.

MR BALZARY: But I think there is an issue about employers understanding the different groups. Quite often governments talk about people with disabilities as a homogenous group that is like one, and it's obviously not. Part of that is getting a handle on which sort of groups, in terms of certain industries, can plug in in terms of an easier and better way. So splitting up the groups, I think, is a very important thing and getting a bit of a handle on what we're talking about. That's one of the things we've started to do already, to say - and everyone has assumptions, usually through lack of knowledge. But talking to a builder who has a couple of apprentices and is prepared to take those people to work on a building site with very physical labour would say in a whole lot of these areas, "It's not really for me."

MRS OWENS: There are clauses in the act about inherent requirements for jobs, so there are going to be some areas where it's just obvious that certain people would not be able to do that job.

MR BALZARY: Of course not.

MRS OWENS: Cate is not going to be able to fly a plane, for example.

MS McKENZIE: No, nor would I.

MRS OWENS: Nor would you. But there must be some grey areas, too, where the employer would say, "No, that person couldn't possibly do that job," when if given the chance that person possibly could, with suitable adjustments in the workplace.

MR BALZARY: There's no doubt they're the cases in terms of the margins, and that's what you're obviously interested in because that's where some of the cases are. To me, though, I think there is a whole range of opportunities within industries right across the board where some people can work, so it's about people labelling people with disabilities and saying, "Well, they can't really work in this industry." The building industry has everything from people working in - I don't know why I'm using that; it's probably because I just came out of a Senate inquiry and the builders were there; I've come from Parliament House this morning.

There are occupations within that industry that are in offices, there are occupations that involve drafting; there's telephone work; there's work on building sites, et cetera. Industries have a whole range of occupations within them and there are a lot of opportunities throughout industry. It's about weaving all of that, and then one employer may actually operate - and using that industry again. They will have an office, it will be staffed; they will also have people on site, et cetera. There will be a range of skills within any employment. It's quite unusual to get just one fixed classification structure within one employer. That's very unusual.

MS McKENZIE: It has to be a holistic thing as well. If you're going to employ a person with a disability, there needs to be a structure in place so that that person's performance is monitored and also that person has similar career opportunities in that job to those that other people who are doing similar jobs would have.

MRS OWENS: It leads onto the issue of the impact on competition, which is also something we need to think about. I suppose there's local competition and there's competition internationally or globally, and to the extent that all employers in Australia are subject to the DDA, the act, and hence have possibly an equivalent sort of imposition on them in terms of what they're required to do under the act, it may not necessarily have a significant impact on competition. We haven't had anybody come and say that it has yet. That's why I'm asking you because you're an obvious group to tackle this issue with. I'm wondering whether there would be some concerns that there are requirements on Australian employers that may not be being placed on employers in other countries that we're competing with.

MR BALZARY: Competing against. That's right. It's obviously a major concern of course where there's national or state based legislation which in fact can do that. It can increase costs for employers, and this is potentially one area where there may be some cost increases. We have not heard back from anyone - bearing in mind we've only done a preliminary discussion with members so far - about people saying that this is an undue burden. Part of that is probably because again a whole range of employers are not necessarily directly impacted.

It is an area where, in terms of our structures, we are talking lots in terms of discussions that we seem to be having on this whole area. It really is about employment - you know, for employers rather than self-employment. As I alluded to earlier, a lot of the things overseas are in fact about self-employment, so the impact would be much more in this country on people that usually will be competing as part of a firm, as part of a company. If it's going to be an impact at all, it will actually impact probably on employers more than in some of the countries, particularly in our Asian neighbours.

The other issue is in terms of as it broadens, and you hope that the participation in the labour market increases. Obviously some countries we're competing with have been fairly active in this area for a number of years and actually have structures and processes in place already - in Japan and some of those other countries where they've had active disability strategies for some time. It may be, while there's initial cost as we increase participation for a period of time, a bit of a challenge for Australian business.

MS McKENZIE: So in a way, greater participation in the workforce - given the scenario of a demand for more workforce - might actually help Australia compete more effectively rather than less.

MR BALZARY: It depends. There certainly would be, I guess, a cost hump for employers potentially, but that depends on what we do, once we find out what the government assistance is and what it goes to. On the other hand, there is also the issue of markets and whether in fact people with disabilities in their own right are a market in themselves and how much companies use that as just a straight profit-cum-exploiting a particular market of individuals who want particular services, and they want particular products. Increasingly people are doing that in other areas. Obviously as the population ages in most of the developed countries, people are beginning to shift some of their focus from young people onto older people.

MRS OWENS: The baby boomers are always at the lead in terms of having changes brought in in society.

MR BALZARY: Everyone following. That's exactly right. You can see that impact there. By the time you add up the number of people with disabilities as a market in their own right across the world, that's a significant thing in its own right. I don't want to overstate that, but certainly there's some potential there for employers to actually target the market.

MRS OWENS: Have you had any feedback about recruitment agencies? Recruitment agencies have attracted quite a lot of attention, and I have to say so have employers, in terms of the people that we've spoken to. They tend to say, "Well, employment is still a difficult area in relation to discrimination." You said that there's been no major increase in complaints, but in terms of the composition of complaints, I think employment is still up there as being one of the difficult areas, and recruitment agencies have also been raised with us as attracting quite a bit of attention in terms of disability discrimination. Is that something that you've come across as an issue.

MR BALZARY: I'm not sure.

MR MAHONEY: Are you referring to mainstream employment agencies, such as those that operate under the Job Network?

MRS OWENS: Yes.

MR MAHONEY: No, I have no evidence of - - -

MRS OWENS: Maybe we'll have to talk to the agencies themselves.

MR MAHONEY: I think so, yes.

MR BALZARY: I think that's a better thing to do. They've obviously got arrangements with a certain number of employers, just like any of the Job Network agencies tend to have. Obviously, they've got their own processes and promotional strategies in place. We appeared before another Productivity Commission inquiry into the Job Network but we didn't raise people with disabilities at all, and we did a fair degree of work there. We raised issues around indigenous people but we didn't hear anything from anyone about a major issue around people with disabilities through that inquiry.

MRS OWENS: That's interesting, really, that observation.

MR BALZARY: That's right. But again it could be because of numbers, but also in terms of advocacy, and it could be in terms of those people that are actually in the labour market may be getting a job rather than not getting one. Whereas, in terms of the other area, everyone had knowledge that in fact the placement rates weren't too good.

MRS OWENS: What about standards development? Did you get involved in that? Did ACIF get involved in the development of the employment standard, the draft standard? Do you have any views on that, either on the process or on having a standard?

MR MAHONEY: It seems that there are a number of views on standards. I mean, the extent to which standards might give additional rights to people under the DDA, and the extent to which they might actually limit the play of the act, cross what are probably very subtle areas of human interactions and human relationships in the workplace at times as well. It doesn't seem, from our review of progress in the standards, that there was any compelling view that would say, "Yes, we support the standards, the development of standards."

I guess on reflection, in terms of the types of complaints and the numbers of complaints that are coming through at the moment, there's no evidence base again to say that the standards would create an improvement in that area.

MRS OWENS: What about providing employers with some certainty, in terms of their own processes - employment and recruitment processes and so on - having a standard?

MR MAHONEY: Yes.

MR BALZARY: I was just going to say, the trouble with that is there's not one recruitment/employment process. I mean, small employers do something fundamentally different than large employers. Regional employers tend to do things through networks, even putting it in terms of open vacancies. So doing a "one size fits all" recruitment or employment standard - - -

MS McKENZIE: Is too inflexible.

MR BALZARY: Is really difficult, irrespective of what area you are talking about. So if you are going to have any form of intervention like that, to my mind you are better off doing it in more the general promotion, guidance and support arrangements, and encouraging people to do that, rather than putting standards that have got some sort of legal framework backing. Because I think it's all part of that sort of saying, "Have you thought about this? This is the sort of thing you can do." And some of the arrangements now - I think the ILO have done some of that sort of work, for example, which is a bit of a guide to employers.

MRS OWENS: Yes. So preferred guidelines and something that's more flexible.

MR BALZARY: I think so.

MRS OWENS: Like the "HREOC frequently asked questions" type of approach?

MR BALZARY: Yes. I think so.

MS McKENZIE: Perhaps just informational material.

MR BALZARY: Just informational material, which is around, sort of saying, "These are the sorts of things you can think of to do. These are the sorts of processes." And you need to split that up, I think, around the difference between, again, small, medium and large; I mean, they are very very different groups with very different needs. So slotting all of that together in terms of rather than having it streamlined into dealing with, particularly, the difference between small and large, I think creates a bit of a problem in terms of reaching the market. We would have a different strategy, even in terms of what we are doing with the larger companies. They are much more sophisticated in terms of their recruitment practices than some of the small ones. The medium, they are quite different as well. Some of them have got fairly sophisticated mechanisms. It depends on what position they are actually recruiting for.

MRS OWENS: Could you have standards within standards, like substandards and that? Substandards sounds wrong, doesn't it?

MR BALZARY: Yes. I'm with you. I understand.

MRS OWENS: But standards for small companies and standards for large companies. You don't think so?

MR BALZARY: Certainly we are happy to hear submissions from people, in terms of why you'd need standards, but I just don't think there's a case at the moment for why we need standards. On the other hand, though, in terms of when you are actually developing assistance and guidelines or guides for people, and doing that in a supportive way, I think as a package of things to do, which includes again government assistance and all those sorts of things, I think it is much better and would be much better received because it doesn't talk about the things you've got to do. If you don't do that then there will be some sort of punitive mechanism. This is more about saying "Well, these are the things you should do", in a supportive environment.

MRS OWENS: I think there's also an issue with the content of the standards in this area. Others have said this to us, well, if you are developing a transport standard it's very objective, and it's all about the height of the floor of the buses, and so on. And if you are looking at access to premises standards, based on the building code, again it's the physical environment and you can envisage standards there. But when you come to employment and recruitment practices, and so on, it is more difficult.

MR BALZARY: Sure.

MRS OWENS: And even there, maybe it's simpler to think of some simple process-type markers for recruitment. But it's harder when you've actually got somebody in the workplace and are trying to develop standards about the treatment of that person, because every workplace is a bit different and the types of jobs are different, and so on.

MR BALZARY: Yes.

MRS OWENS: Do you have any comments about that?

MR BALZARY: It's basically just a different line, in terms of what we've just talked about, in fact. You've got so much diversity there, and it talks about what Neil said, in terms of it has got a lot to do with just human interaction and different classification structures and different workplaces and all those sorts of things. There are so many variables, and the standards would have to be either so broad that they don't mean anything, or so tight it would sort of be your hierarchy of standards where it would have to cover every different sort of situation that no-one would actually understand them. You'd end up with a Tax Act, heaven forbid.

MS McKENZIE: That was just a little throwaway line.

MR BALZARY: That's right. I couldn't resist it.

MR MAHONEY: Or even issues like appropriate language, and those sorts of things, which are very subtle and hard to make rules about. We feel there's probably an issue about education and problem solving, rather than introducing a standard that prescribes every situation.

MRS OWENS: I have just got one other area that I wanted to just raise with you, and that is the whole issue of affirmative action. We have got examples of some countries that have introduced affirmative action policies, requiring employers to achieve proportional representation of particular groups, and I was just wondering if ACIF has any view on such policies.

MR BALZARY: It probably won't surprise anyone that we don't support legislative or other - - -

MRS OWENS: I'm not surprised. I thought I had to ask you.

MR BALZARY: You had to ask; that's right, in terms of other requirements like that. Largely because, in terms of the examinations we've seen, we are not convinced they work, for a range of reasons. Now, by "work" I mean in terms of across the entire workforce, and whether in fact there are actually negative implications of doing this sort of arrangement or not. Obviously we are much more into the supportive, promotional arrangement rather than sort of, I guess, the creation of an arbitrary requirement where people have to take certain quotas on as a proportion of a target group's representation in the economy, or in fact their proportion overall within a workplace.

So we would be strongly of the view that that's not the way to go, in this area, particularly, given that the issues that we've talked about earlier, about skills and the way a whole range of people in terms of people with disabilities, aren't participating up to the levels of others, in terms of higher education; not so much higher education but more vocational and education training rather than the skills pathways. So it's a real issue about how people can fit in and what are their attributes and abilities, in terms of doing that. And there have been instances - and again I will use the indigenous example - where that has occurred, and in fact not only is it a legislative requirement but it's a goal, by certain companies. And that hasn't necessarily produced the best outcome for those individuals either.

MS McKENZIE: Can you explain why?

MR BALZARY: I think because again it's seen as a punitive blunt instrument in an environment that in fact is more about people being recruited on merit and how they fit into the workplace, and strategies about equipping and skilling people up to compete is much much better, in terms of a successful outcome for all, than blunt instrument; and that's the thing that would worry us about doing it. And it's the same thing. I mean, how do you apply that across small firms, large firms? What does it mean? What's the requirement and what's the real outcome?

MS McKENZIE: If in fact that's right, that it's not a helpful instrument to use to increase awareness - and we are talking for the minute about indigenous participation in the workforce - can you say that the education way, which is really the way you are advocating, and the education information encouragement way, is succeeding?

MR BALZARY: I don't actually see that it's only about employers. I have talked about the vocational and education training system needing to fundamentally reform in this area. I think the transition area, in terms of schools and the working life, needs to reform. So I guess I'm talking about if you are going to tackle this issue it's not just saying to employers, "Well, you've got to take these people on. That's the way it is." You've actually got to do a whole series of work in a whole series of systems.

And it's a whole-of-governments approach. It's not a whole-government approach, which seems to be trendy at the moment. It's about all governments actually having a strategy in this area and working cooperatively in not only education and employment and those sorts of areas, it's also about a whole range of other things to do with other forms of support, transport policies et cetera.
So I think it's a bit simplistic to sort of say, "Oh, well, if employers take people on it will all be solved." In fact I don't think that's the answer, in terms of a whole series of issues that are in this area.

MS McKENZIE: It's very difficult. One can understand perhaps that - and again, since we've been talking about groups of indigenous people - one might feel they have been waiting a very long time for these things to happen, and what you are telling me now is that there should be a whole-of-governments approach as well as education, to make this happen. But even then, at the end is there any certainty that there will be a change in employment practice?

MR BALZARY: It's a difficult thing. But there is a range of providers out there that need to be given direct financial incentives in terms of outcomes in this area, and if they don't achieve the outcomes they shouldn't get the rate of return. So you've got to actually balance the systems, in terms of providers in the system, whether they be education or employment providers or recruitment agencies we are talking about, that may receive government funding, to make sure that they in fact fulfil the obligations they've taken on themselves.

In terms of employers, obviously I still think that - certainly in terms of our straw poll - people haven't ruled out participating in this area. A lot of the lack of activity in this area is because either someone hasn't knocked on their door and said, "Are you aware that?" or it's not on their radar and they are waiting for a bit more information in terms of what the requirements are. I mean, they are the gains.

MS McKENZIE: So is what they are really telling you is that they have not had disabled people come to them and say, "Can I have employment?" Or is it that they really just haven't had anyone come to them and say, "Look, there's this legislation around that says this, this and this."

MR BALZARY: It's probably more the former than the latter, I think. It's also about what forms of assistance - and a lot of people haven't had job placement agencies knocking on the door for this particular target group. It's a bit of everything. This area to me is not just sort of saying, "Oh, well." And that's why I guess, to me, an affirmative action policy is more about saying, "Well, we've done something that's going to be a blunt instrument," so it makes governments feel good, more than located around outcomes.

MS McKENZIE: Addressing the problem properly.

MR BALZARY: That's right, and that's why we are developing a strategy, which has got a whole series of tiers to it, rather than just saying, "Look, we think it's a good idea," and we will go out and just promote it by itself. It's about knowledge, about the legislative requirements, whether they be OH and S or other requirements in the workplace, that includes DDA. It's also about the assistance that's available; it's about the benefits, in terms of the requirements, where we've got some case studies already that have been developed, and it's about facts; those that you need to use, those that are available in the labour market, because there is a lack of people and that will impact on business.

MS McKENZIE: And that will get worse. Is that what you are saying.

MR BALZARY: It will get worse. And so it will be about - in terms as little as five years from now, and this is, I guess, part of our other scheme; we are doing some work in the mature age area. But in terms of 2014 all of those children who are going to be the workers in 2014 are currently at school, and already we know that if the trends continue there's not enough kids in school to meet the demands in 2014, and that's a fact.

MRS OWENS: So the tight labour market is going to be another fairly significant factor. You can do your bit now and you think the economy itself is going to do its bit to assist - - -

MR BALZARY: There will be pressures - there will be labour shortages.

MRS OWENS: - - - the interests of the elderly people and the other what you call more marginal groups.

MR BALZARY: Yes. I mean, the labour shortage will be a major issue. Now, that's assuming settings. I mean, you have got to assume these things. I mean, we can't predict the future exactly, but certainly in terms of assuming current rates of migration - so we don't anticipate that to increase markedly - and we advocate more migration than current levels, but you're assuming that and you're assuming in terms of general arrangements for continuation for the demand for labour, but if you do that then there will be serious - - -

MRS OWENS: Labour shortage.

MR BALZARY: - - - labour shortages. Rather than skill shortages there will be labour shortages.

MRS OWENS: Although I suppose it also depends what is actually happening with technological change and productivity and so on.

MR BALZARY: It depends on that, too.

MRS OWENS: You've got to factor all those things in, so it's quite a complex scenario that you need to put up.

MR BALZARY: Yes, you're right, but irrespective - even if you factor all those in there will be a deep - the issue about that will be the extent of labour shortages rather than whether you've got one.

MRS OWENS: But these are skilled labour shortages we're talking about.

MR BALZARY: It may or may not be because it depends on your view of "skilled" - that's a debate in itself - but in terms of where some of the opportunities are, it's a question of when it's retail; it's a question of where it's business services; it depends whether it's aged care. There is a whole range of growth areas in terms of employment that do not necessarily mean they are high-tech areas, so the assumption that all the new and emerging employment areas are all ultra high technology and cutting edge is, in our view, not quite right.

MS McKENZIE: That's a really interesting submission.

MRS OWENS: Thank you for that. Will we be getting something later, Steve, as a more formal submission?

MR BALZARY: Yes.

MRS OWENS: We're obviously going to have the transcript, but it would be really good to get further information. You had some other pieces of material there that looked like they could be quite useful to us.

MR BALZARY: Yes, that's right. I might actually be able to hone down some of the - - -

MRS OWENS: Table a couple of documents. Okay.

MR BALZARY: Yes.

MRS OWENS: Thanks very much. Is there anything else, Steve or Neil, you want to say?

MR BALZARY: No, I don't think so.

MR MAHONEY: Only very shortly, and I won't raise it as a huge issue at this stage, but we skipped sort of lightly across the impact of levels of income support - people with disabilities and the interplay between that and whether or not that is an obvious incentive - for people to undertake skills acquisition at an early age or whether it is encouraging people to return to work if they acquire a disability. Early days yet, but I think that's an area we wanted to have a look at because - - -

MRS OWENS: It will be an issue.

MR MAHONEY: Yes, I think so.

MRS OWENS: Yes, that's another sort of fairly major issue. You could almost do an inquiry on that in its own right.

MR MAHONEY: That's right. Absolutely.

MRS OWENS: Thank you very much.

MS McKENZIE: Thank you very much indeed.

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

MRS OWENS: The next participant this afternoon is Action for Autism and Autism and Autism/Aspergers Advocacy Australia. Would you like to give your name and your position with the group for the transcript.

MR BUCKLEY: Certainly. My name is Robert Buckley, normally called Bob. My position is currently convener of Autism/Aspergers Advocacy Australia which is a national grassroots organisation. I'm also president of Action for Autism, incorporated here in the ACT.

MRS OWENS: We have a submission from you, which is submission number 104, in your own name as Robert Buckley - just to make that clear for the transcript. I would like to thank you for that submission on what I think is a pretty interesting topic. We have both read your submission very closely, but I understand you do want to introduce it at this point - and then we can open up for discussion.

MR BUCKLEY: Certainly. There are just a few words I'd like to say. I just wanted to point out that autism and the autism spectrum disorder does, as far as we can tell, represent a major burden in our community and I presented some evidence in my submission of people that agree with that position. In coming to the Productivity Commission I wanted to point out that autism and the autism spectrum does have some significant impacts on productivity in our community.

People with autism are actually typically very disabled. The classic autism - very few of them ever achieve independent living at all and, in fact, if we look at the burden that they represent in our health community care/disability sector, there is some evidence that these people have some of the highest needs and that the health outcomes for this group and for a larger group, which is people with developmental delay, are particularly bad; in fact some people would suggest that health outcomes for people in this group are worse than the indigenous population, which is a fairly damning indictment of where the health system is in terms of dealing with these people. Not only is it the person who has the disability that is disadvantaged, but the family is severely disadvantaged as well; for example, I had to close down my business and go into something that was less stressful once I realised the impact of my son's condition. It has an impact on siblings.

There are other carers. If you think about the cost of supporting a person - and autism is a condition that is there basically life-long - it is suggested that group homes can only accommodate two, maybe three people, which is about half the normal number of people. That basically means that people who are severely affected by autism need round-the-clock supervision on a one-to-one - and sometimes higher than that - basis. So you not only have that person not being productive, but you have another member of the community who, although their input and things is going to be counted in the national GDP and things, don't really produce anything, except the accommodation for that person and, in terms of real economic benefit, it is hard to see how that fits into most of the economic models in any case.

We are seeing a very large increase in the number of people being diagnosed with autism spectrum disorder. The traditional view, up till about 10 or 15 years ago, was that it affected about four per 10,000 of the population. Today, I can tell you - and one of the annexes to our submission shows - that the diagnosis rate for autism and autism spectrum disorders has reached about 1 per cent of the population, which makes it one of the largest disability groups and yet there is virtually no recognition of this in any government agency whatsoever, anywhere in the country.

MRS OWENS: Can I just interrupt at that point. Is this because the incidence has increased or is it because it is being recognised more as a condition?

MR BUCKLEY: We don’t know. Unfortunately research into autism is minimal - is probably the polite way to put it. The NH and MRC spends less than .03 per cent of its budget on looking at autism and yet it's the fourth highest burden of disease amongst boys. My feeling - having probably looked at more of this data than virtually anybody else in the country, which is the sort of role that parents of children with autism get assigned - is that there is certainly a much higher rate of diagnosis. We know that it was being chronically undiagnosed previously, but there are probably social reasons that are shifting where the definition is, but there could also be an underlying increase, although it's probable that we will never be able to tell because simply not enough is known.

MRS OWENS: And this is a worldwide phenomenon?

MR BUCKLEY: Yes. We are certainly seeing these increases in most other major countries and the increases are very similar to what we see here; same sorts of characteristics in the way it increases. You can actually look at subgroups and, if you look at the changes in the number of people in each of the subgroups and how that has changed over time, you see the same pattern here, and that pattern is probably indicating that a significant contribution to the increase is better diagnosis.

MRS OWENS: And I think with Aspergers disorder - I don't even know if that was on the radar screen a decade ago. I think it is something that people are becoming more aware of. There has been newspaper articles written and so on in recent years.

MR BUCKLEY: The simple facts on that one are Aspergers syndrome was included in the DSM-IV when it was published in 1994. Prior to that the diagnosis wasn't really available to practitioners because there wasn't a definition that they could work with, so you can actually set a date and say Aspergers became available as a diagnosis probably in 1994, when the books were published.

MS McKENZIE: But that doesn't necessarily mean that everyone was aware - that medical practitioners were aware - of the availability of that diagnosis?

MR BUCKLEY: There were people who were sort of tending towards that diagnosis prior to that time and since that time people have become significantly more aware, and there are factors probably pushing that as well. I mean, when the education system says to you, "You're not going to get the services unless you have a formal diagnosis," then that's going to push medical practitioners to say, "Well, if I have to give a formal diagnosis so that this person can get the support that they might have got otherwise previously, then I am going to have to give a formal diagnosis."

It's an interesting thing to think about, that these conditions are purportedly clinical diagnoses. They're on category 1 of the DSM-IV, which is the same category as other major forms of mental illness, clinical forms of mental illness - they're in that category. I am not a professional in this area, but my understanding of it is that to get a clinical diagnosis is basically saying that this is a condition that needs clinical attention, and yet we have an education system that is saying, "You can't get support in education unless you have a clinical diagnosis." That's a major conflict in terms of what the terms are supposed to mean and what sort of direction - what sort of guidance people are getting as to what the diagnosis is supposed to mean and how this system is supposed to operate, so there are some big challenges and there is a huge amount of confusion in this area. That's my view of where we are at the moment.

MRS OWENS: In terms of the Disability Discrimination Act that we're interested in, do you think that autism and Asperger's disorder are covered through the definition of "disability"?

MR BUCKLEY: I'm absolutely confident that autism is covered. I don't know whether there is a ruling - I would suspect that in most cases Aspergers would be covered.

MRS OWENS: Are there any cases, do you know, that have come to the Human Rights and Equal Opportunity Commission?

MR BUCKLEY: I am probably the wrong person to ask.

MRS OWENS: We can ask them, but that would give us some indication. I mean, my presumption would be that - - -

MR BUCKLEY: Not that I'm aware of.

MRS OWENS: - - - it's such a broad definition that they would be covered. That would be my inclination, but I wonder if there is some degree of uncertainty out there among people with these conditions, or the parents of people with these conditions.

MR BUCKLEY: Well, I can certainly say that there is a lot of uncertainty. There's a famous case at the moment that's being decided I believe in the Supreme Court or something about - New South Wales v Purvis - which has cast a massive amount of uncertainty over the area that I'm interested in. So at the Commonwealth level there's that sort of uncertainty.

At the moment as far as I'm concerned - and in fact I've been having a dialogue as you can see in annex 3 with the Human Rights and Equal Opportunity Commission - there's a lot of confusion and understanding about what is covered and what isn't covered and what it means, but what I do have to say is that the operation of the Disability Discrimination Act at the moment is that most of the people - and I've had quite a few people come to me and say, "We're interested in thinking about a case," and I have to say to them, "I think you would be very unwise to even contemplate doing one."

I think the operation of the law at the moment is so tragically uncertain that you would be - I think I had a line in there that says, "You'd be better off spending your money buying lottery tickets." The outcome is probably equally balanced in your favour, just as arbitrary - I mean, if you lose the lottery you only lose the money you put in whereas if you pursue a case into the courts under the DDA you lose everything. Virtually no parent can afford to do that while having to maintain the child with a disability. I mean, that's just an utter impossibility and that's even assuming that you could legal representation and, getting legal representation, is extremely difficult. I do, however, have to say that I have some experience of this process, not at the DDA level but at the ACT level, so I'm not just speaking as a parent here. I'm involved in a legal process at the moment.

MRS OWENS: I'm not sure what the issue is in that regard but is there anything you can say about why you chose to go the ACT route vis-a-vis the DDA route, or was it not a discrimination disability issue?

MR BUCKLEY: It's a disability discrimination issue. I guess it's more tractable in the ACT. We were advised that HREOC would probably send it back to the ACT anyway. I guess those are the main reasons for doing that.

MRS OWENS: So it's just the accessibility. You've made fairly negative comments about using the DDA in your submission and what you just said - - -

MR BUCKLEY: I am not trying to be negative about it. I'm simply trying to state what the position is.

MRS OWENS: Yes, well, your position is that you've expressed comments like, "It's like a lottery" and "It's arbitrary" and so on.

MS McKENZIE: Cost - the delays.

MRS OWENS: And the costs and delays. I presume that implies that by going through the ACT system you see that's it more accessible, potentially less costly, less of a lottery?

MR BUCKLEY: Yes - - -

MRS OWENS: This is not an inquiry into the ACT system but we're interested as to why - - -

MR BUCKLEY: No, and I would be very hesitant to make any comments about that.

MRS OWENS: We're just interested in why people go one route rather than the other.

MR BUCKLEY: I guess it's an ACT matter that we're dealing with because we're dealing with the services provided by the ACT government. Many of the services that we're dealing with in terms of my son who is still of school age - most of the services that we would be dealing with would be state-level services. Unless it's a Commonwealth issue, I don't really see why you would - and I guess the other thing is that the ACT discrimination tribunal has not been known to find costs against people, so if you are going to go into a sort of lottery process there's probably a little bit more certainty there.

MRS OWENS: Many people have mentioned similar factors in their own states and territories in other submissions also and we just wanted to round it off with an ACT - - -

MS McKENZIE: To pick up the ACT perspective.

MR BUCKLEY: Okay. I think that's a fairly general comment. I would expect it's pretty much the same in other states in regard to that, although that then leaves you in this issue of in the ACT we have this section 27 and I think there's a comment in there that there's a ruling in the ACT Administrative Appeals Tribunal that basically says that government agencies can't discriminate. That's their ruling.

MRS OWENS: This is where a service is provided for people with a disability. Is that the - - -

MR BUCKLEY: Yes, it says if there's a service that caters for somebody with a disability then there can't be possibly any discrimination in there and that's a ruling in the ACT.

MS McKENZIE: In the course of that's - - -

MR BUCKLEY: Yes, and that's been a very interesting process in the ACT, working out what's going on and what that possibly means. Where that's going to go nobody knows at this point and that one I regard as a complete and utter lottery.

MRS OWENS: You did mention in your submission a survey which showed that most people making education complaints through the DDA were not satisfied.

MR BUCKLEY: That comes from a survey that was published in association with setting the education standards by HREOC. It was a survey I believe commissioned by HREOC and it simply reported that that's where people were at with that. I found out about that after lodging a complaint about education and had I known that information beforehand I might have thought, "Well, am I to go against those odds or not?"

MRS OWENS: Do you think it's because of the time taken or the outcome or the process?

MR BUCKLEY: Yes.

MRS OWENS: I suppose we can look at the survey - - -

MR BUCKLEY: All of the above, yes. In our case the first of the matters that arose was lodged in the middle of 1997. The person who lodged that complaint is still to be cross-examined in that case.

MRS OWENS: That was with - - -

MR BUCKLEY: With the ACT.

MRS OWENS: With the DDA.

MR BUCKLEY: That's the ACT.

MRS OWENS: Sorry, that's the ACT one?

MR BUCKLEY: Discrimination. It's probably an extreme example but it's just been a very disappointing process to see going on.

MRS OWENS: And if you take too long the kids are no longer at school.

MR BUCKLEY: The outcome in our case - I mean, we were asking for early intervention. The two children involved - there's no prospect of them getting early intervention any more.

MS McKENZIE: Well, because they're past the age.

MR BUCKLEY: Yes, I mean, my son turns 12 on Sunday. We've been watching this process and engaged in it for more than half his life. In terms of these children getting answers in those kinds of areas is just intractable. It's just a nonsense.

MRS OWENS: Coming back to the DDA, you said that you didn't think that it adequately focused on promoting human rights in your submission and I was just wondering what more could be done within the DDA to provide a greater focus on that issue. What's missing?

MR BUCKLEY: If you go through the list of things that - say in there there's the convention on the rights of the child and there's a list of things that should be covered and part of that is rehabilitation and treatment. Now, health doesn't even get a mention in the DDA. It's one of the prime areas of government service, probably one of the biggest budget items, and yet it's left out of the - it's not mentioned. If you want to raise a health issue under the DDA, then you have to bring it in under the sort of general services area as if it's getting your shoes cleaned or something.

MS McKENZIE: So you think that health should have its own specific section?

MR BUCKLEY: I fail to understand why it wouldn't. It just seems very peculiar to me that we have education and a number of other areas specifically mentioned but health doesn't get covered. That's particularly relevant for this group of people because we're talking about a clinical diagnosis, and so part of what they're looking for is treatment and rehabilitation for this condition and yet the government is simply - I mean, when I write to the health minister, the health minister says, "No, that's a responsibility of the disability sector in Family and Community Services," and you go to Family and Community Services and they say, "Treatment and rehabilitation? No, no, no, that's a health issue," and that's it. You have no response to it.

MS McKENZIE: There's a gap.

MR BUCKLEY: You have systemic discrimination here. As in your white paper you said not having a service there would be discrimination but when you go to HREOC and say, "Is this discrimination?" they say, "Well, if it doesn't exist, it's not discrimination." That's not discrimination and HREOC is in complete disagreement with your view that not having an essential service would be a form of discrimination.

MS McKENZIE: It's a little more difficult than that. Under the current legislation, and it's a bit tricky but it's probably generally fair to say that under the current legislation there may be a discrimination case if you can frame the claim in terms of there being a particular service which has been refused to you or being a particular service and the terms of that service are that you don't get access to particular things. Now, it may be that in this case the claim might be frameable as the overall service is health care and the terms of that service are that it's provided in certain ways for certain disabilities and not for this particular one or not enough of this particular one. There may be a question of an indirect discrimination claim but it is a very tricky area and certainly I suspect your next submission might be that if it's tricky it should be clarified.

MR BUCKLEY: Well, that would be my suggestion, yes. I don't think it's actually that tricky. I have in the last few days received - well, I've been in communication with HREOC again and they have said, "Yes, well, it does sound like it could raise a complaint under that section of the" - now, what is it, section 24 of the Discrimination Act - that their view is you would have to prove that you are worse than anybody else. Firstly, I don't actually believe that that's what the DDA says. I don't think you would have to prove you are worse than anybody else and, secondly, if that is the case, then it seems to me that's not what the convention on the rights of the child says. So it may be that the DDA is not actually meeting the requirements of the convention on the rights of the child and, if that's the case, it's an interesting question: whose responsibility is it to monitor that to work out - but anyway I'm not sure that that's what we're really here for at the moment.

MS McKENZIE: As I said, it is actually a tricky area; the way in which it all has to do with the technical definitions of direct and indirect discrimination and the way they work may be quite tricky.

MR BUCKLEY: And finding a lawyer who could actually run that argument somewhere is even trickier.

MRS OWENS: That's our challenge - to see whether we can make things as clear as possible to reduce the amount of legal argy-bargy and debate.

MR BUCKLEY: I would really appreciate any inroads that you can make in that direction.

MS McKENZIE: I think I've asked you about all the matters that I wanted to raise.

MR BUCKLEY: The other thing that I would bring into this discussion - and this probably comes from the larger Aspergers group where there are a significant number of people who are a lot more functioning but have quite a number of difficulties in the workplace. It comes down to issues like people who by diagnosis have poor social skills really don't always get treated very well in the workplace, and we find that there are people who miss out on both education and employment opportunities or find themselves in very difficult situations because of that lack of social skills which is part of their diagnosis. There are certainly quite a number of those.

They are not always unproductive members of society. I'm a former academic and I also spent quite a significant amount of time doing industrial relations and human resource management consulting. The business I closed down was one of the top 10 consultants to the Defence Force through much of the 90s, so I spent quite a bit of time looking at workforce issues. I haven't done research into this, but certainly I would suggest that some of our design and workforce management practices are around designing the workplace for people who fit certain categories. Certainly our workplace practices at the moment go around saying, "Right, we're going to design the way this business operates, the way this institution operates. It's going to have these positions," and we go looking for people to fit into those positions.

If you do that, you find that you sort of say, "Well, what's the sort of normal people that you're going to be looking at?" and people who don't fit that description aren't really up for the job. If you do that, you find that you're reducing the amount of the potential workforce that you can actually employ, so there are some big social issues about some of our human resource and industrial relations practices about how we go about designing workplaces, designing workforces and figuring out how to fit people into those. We just heard the last submission talking about the fact that the workforce is decreasing.

When I was consulting to Defence, one of our big issues was, "Gee, there aren't many women in the Defence workforce. Why are we excluding 50 per cent or more of the potential people?" I think the same thing is happening in terms of disabilities, and particularly the biggest disability groups. Depending on your view here, intellectual disability is one of the biggest disability groups. If you go the statistical route it should be 2.28 per cent of the population; if you take the definition of "intellectual disability" to standard deviations below the mean on an IQ test, the Australian Institute of Health and Welfare says that it should be about 1.86 per cent. That's a fairly big group - that's of the whole population.

If the autism spectrum is then another 1 per cent, because they don't overlap, then you have a big chunk of the potential workforce that's really finding it very very difficult to be accommodated in a lot of the ways that our current workforce has been structured and designed. Those people are not going to be very competitive in many situations. In fact, many of them don't even have the expectation of going to tertiary education. People with intellectual disability, the ones who in my experience generally don't even think about tertiary education - it's outside their expectations - and I sort of wonder what's the purpose of tertiary education. Is tertiary education about putting a stamp on academic achievement or is it about preparing people for the workforce?

If it's about preparing people for the workforce, we ought to be thinking a lot harder about how to do that. It turns out that there is funding in that area and people are trying to put up courses and they're saying nobody comes. So there are some big gaps in terms of what's required and what could be done in this whole area. I think things need to look a lot broader across the whole way we do business in this area. We need to be thinking about whether or not competition is really the way that we ought to be going or whether we can look more at productivity issues and figure out how to make people who aren't necessarily competitive more productive. That's a big challenge, I think, but it's a different way of looking at some of the things that we do in the way that we design our industrial relations and workforce management. I think there's a lot of work could be done there if people actually wanted to do it.

MS McKENZIE: The only other thing I was going to ask you was about standards under the DDA. There is discussion of a draft education standard. Do you have any views about that? Have you been involved in that in any way?

MR BUCKLEY: I saw the initial draft and was appalled. I'm much more comfortable with the current draft.

MS McKENZIE: What's your view about the standard? Why did the first one appal you and the second one you feel better about?

MR BUCKLEY: The first one basically gave excuses for kicking our kids out of schools. The situation for kids with autism is that they often present with a behavioural problem, and that's a real challenge for a school. When you have a child with behavioural problems, it can be extremely disruptive and it disrupts the classroom; makes teachers unproductive and it makes other students unproductive. We can look at why that behaviour is occurring, and generally the children don't want to be challenging. It's generally a result of people simply not having the training, knowledge and experience of what needs to be done and, in many cases, being chronically underresourced.

I don't know how the education system can - there is a huge amount of pressures backwards and forwards. Under the other draft standards, what we were likely to see was schools just kicking kids out and at some stage there would have had to have been some kind of reaction to that because we just can't have kids out of schools, apart from the human rights issues and that being a form of discrimination, if there is no place for them. The practice at the moment is schools can kick kids out. They don't have to find somewhere for them to go. I think the new standard is aiming to sort of say, "Well, it's a bit more complicated than that. If you are going to kick a kid out of school, then you have to think about what's going to happen." The pressure is going to be on the education system to say, well, there needs to be somewhere that that child has some chance of getting an education.

In that sense, I think it deals with the issue more directly. Ultimately, if you kick out all the kids with challenging behaviours or who have been taught that kind of behaviour in schools, then the society is going to react, so ultimately something is going to happen and there's going to be a swing one way and a swing the other way. I guess having a standard means that the swing is not going to be as extreme. I don't think it solves the problems. I think we're still going to have some big issues around what to do with these very difficult children. The fact that most of them are not getting adequate early intervention, they're not being prepared for school effectively, and the fact that schools are chronically underresourced for coping with these children, is a big problem for the education system. That's not necessarily a problem that the education system is making.

MRS OWENS: What are your views about integration - vis-a-vis specialised education?

MR BUCKLEY: This is a really difficult issue, and it's one I face very much at a personal level because my son for the first time this year is in a special school. Last year he was out of school because there was no place for him; this year a significant effort is being made to try and create a place for him. I would rather that he not be in a special school but I've got to say that, the way resources and things are structured at the moment, that's probably the best place for him in the ACT at the moment. I would generally like to see these kids placed in integration or into a more normal setting.

MS McKENZIE: Mainstream setting.

MR BUCKLEY: The way I like to describe it is to see these kids placed in the least restrictive environment you can achieve, but I think some of them just do not have the skills to be in anything like that sort of setting, and putting them in that setting does nobody any good.

MS McKENZIE: Neither the child nor the rest of the school community.

MR BUCKLEY: Yes. The problem there is that the system is being chronically let down by the health system. You have to send kids to schools. If the school has no means of dealing with them, educating them, and lacks the resources - I mean, these kids have really chronic learning difficulties. If you have a child who does not understand any language - my son spent two years in special education and nobody realised that he didn't understand the words yes and no. It wasn't until we actually started doing some clinical interventions with him that he picked up on what yes and no meant.

If he doesn't understand yes and no - I mean, the teacher used to say, "He really loves the story of the three little pigs," and we'd sort of go, "Well, Kieran knows the numbers." He worked out the numbers up to 140 when he was three. But the idea that you could put "little" after "three", he thought that was the funniest thing in the universe - "Little doesn't come after three." That's just absolutely hilarious. If the teachers have not caught onto this, you're sort of wondering what's going on. He was in class and we were told that they were really happy. Kieran had shown assertiveness for the first time. Some other kid took a toy off him so he whacked them, and he was being rewarded for that. His sister has lived with that lesson since then. That has a massive impact on your family. Disability Victoria has a web site that says, "If your child likes the sound of breaking glass, then board up your windows and live like that." Now, what impact does that have on the productivity of the members of that family? That's not a solution, and yet that's what we get out of our disability services. That's where the thinking is at. It's a fundamental failure to understand what's going on here. Until those sorts of issues get addressed, I really don't think - education standards are just so far out from where I'm thinking.

MS McKENZIE: It's like searching for the moon.

MR BUCKLEY: Yes. Sorry for that long ramble.

MRS OWENS: No, it was a good answer to that question.

MS McKENZIE: I don't know what the question was now.

MRS OWENS: I was asking about integration versus specialist schools. That's where it started.

MR BUCKLEY: It's a big issue. One of the things I find really challenging is helping people understand the sorts of issues that we're dealing with here, because the group that I'm looking at is a group that's largely ignored and it goes from the group of people who are PhD candidates because they're sort of asocial and have this massive focus on one particular issue: are we talking about a disability in that context or not? There may be huge mental health problems attached to that, but in some respects it's an enabling thing.

There are some really interesting examples of that. One of my favourites is Stephen Hawking. Basically my understanding is that he really didn't do much until he was restricted to a wheelchair, and suddenly he became productive and a significant sort of person. One has to look at this disability issue a bit carefully at times, because sometimes there are two sides to it. But certainly for the kids who are really disabled by autism, the ones who basically need round the clock, 24-hour support - and that happens to a significant percentage of them, especially if they don't get treatment and intervention which is simply not available in this country - I shouldn't say it's not available.

If you can afford it, then you can buy it, but you can't claim any of that on Medicare, you can't get it under health insurance; you have to pay for it. There are no tax deductions - maybe you get 20 per cent tax deduction. That's what families have to deal with, and the ones who can't afford it have enormous guilt in some cases about that. You have to make this choice about how much do I give my child with autism versus the siblings; how much attention does that take, what sort of support can I get. If you've got a child who wakes up every two hours and is likely to tear your house apart then you are not going to be a very productive member of the community. It's really that simple, and yet you can't get the treatment that deals with that. The government agencies say, "It's not my problem. It's another agency's problem," and that's really all there is to it.

MRS OWENS: Thank you. That was extremely interesting.

MS McKENZIE: Thank you very much.

MRS OWENS: So thanks very much for that.

MS McKENZIE: It's a very interesting submission.

MRS OWENS: Thank you for your submission. We will now break and we will resume at 3.30.

MRS OWENS: Our next participant is the ACT Human Rights Office. Good afternoon and welcome and could you please give your name and your position with the office for the transcript.

MS FOLLETT: Yes. My name is Rosemary Follett. I'm the ACT discrimination commissioner.

MRS OWENS: Thank you, and thanks for coming. We are almost on time; we're just running a little bit late. We appreciate getting your submission written, I know, under difficult circumstances with few resources and I think it's a very useful submission to us, particularly the issues that you cover in relation to definitions and your own definitions and how they differ from the DDA. As I mentioned to you before we started, we are interested in the whole issue of the interaction between the Disability Discrimination Act and your own act and why people choose to work through one system rather than the other. So maybe I will just hand over to you, Rosemary, and if you want to just highlight some key points for us and then we can discuss them.

MS FOLLETT: Certainly, yes.

MRS OWENS: Thank you.

MS FOLLETT: I would like to open by saying that I do believe the DDA is an extremely valuable piece of legislation and I hope that this scrutiny of the legislation may lead to it being perhaps strengthened, even perhaps to being better resourced because I think that all legislation ought to be reviewed from time to time, and given that this is such an exhaustive process, this would be a good opportunity to have a look at the act and see where it might be improved for the future. For my own part I administer the ACT's anti-discrimination law which is called the Discrimination Act 1991.

Like most states and territories we have a single omnibus anti-discrimination law. We don't have specialised areas of discrimination the way the Commonwealth does. So our law includes disability discrimination which has coverage very similar to the coverage of the DDA. There are very, very few differences in the definition of what constitutes a disability and in the areas that are protected from discrimination. So I think that the two pieces of legislation to that extent are very complimentary.

It seems to me though that one major difference is the issue of the comparator which is inherent in the Commonwealth DDA which is absent from the ACT's act. We don't have a comparator. What that means is that for a person to show they have been discriminated against they really only have to show that they have suffered unfavourable treatment rather than compare their treatment to somebody else's. So any unfavourable treatment which constitutes a detriment - we use the term "detriment" - may be classed as discrimination.

MS McKENZIE: Granted in disability though - on the basis of disability.

MS FOLLETT: On the basis of one of the characteristics covered by the act, yes, including disability.

MS McKENZIE: Do you have an - and I can't remember this, I'm sorry - indirect discrimination definition?

MS FOLLETT: We do indeed and it's again very similar to the Commonwealth's of a policy or a program which doesn't appear to be discriminatory on its surface but may have a disproportionate impact on one of the groups covered by the act, yes.

MRS OWENS: In terms of your own definition where you only have to show unfavourable treatment, that's a relative concept though in some way. It's quite subjective: what is unfavourable and what is a detriment.

MS FOLLETT: Yes.

MRS OWENS: Whereas if there is a comparator at least you are comparing what has happened to that person vis-a-vis that person, so you can say that person is not getting as much as that person or being treated more poorly than that person. So there is something you can hang it off. Whereas in your case there is not. Does that cause problems in terms of interpretation?

MS FOLLETT: I don't believe it has caused problems. I think that very often there's an implied comparator in that if a person is claiming to have been treated unfavourably, almost in the back of your mind you have some notion of what might have been fair treatment or favourable treatment very often. So even notionally we do often have that concept. But I think the lack of a comparator does allow for unique circumstances where a person's situation may not readily be able to be compared to anybody else's, and in the area of disability where people have very complex disabilities or dual disabilities, where there are new areas of research and new diagnoses coming up, sometimes the absence of a comparator can be quite useful in that they really only have to show that they have been unfavourably treated because of that.

I find it a helpful way to go and I think that it can avoid some very technical arguments about what is the same treatment, what is comparable circumstances and so on, and focus on the impact of the disability on that person's services or whatever it is they are seeking.

MS McKENZIE: The other thing is to say that the notion of detriment is common throughout all the anti-discrimination legislation in Australia, so that word is one that is used all over the place.

MS FOLLETT: Yes.

MRS OWENS: Does it imply then if somebody doesn't get access to a particular service that they can bring a case? If there was a government service that was not made available to them, say, being able to get access to a school of choice or a medical service or whatever it is, would they be able to bring a case and say that they have been treated unfavourably?

MS FOLLETT: Very often they can, yes, and that has been the case in discrimination complaints made to my office where, for example, a child has been refused admission to a particular kind of class because of some kind of testing that has occurred where they've not been found to meet the criteria. That has been made the subject of discrimination complaint. Similarly with access to services; if people are refused services that can also be the subject of a discrimination complaint. I think there is a difficulty that arises when there is simply no such service and a person requires that service. I think it can be then very difficult to say that they have been refused it or denied it when in fact it doesn't exist. I think that is a real problem.

MRS OWENS: And you're not in a position to go to government and say, "You need to provide that service."

MS FOLLETT: I have done, but not in the context of a complaint, no.

MRS OWENS: Yes, but you don't really have any ability to go and dictate to government, "Thou shalt provide a particular service", because it's really up to your current chief minister and colleagues to make those sort of decisions and not you.

MS FOLLETT: That's right.

MS McKENZIE: It depends on the definition of "service". It depends whether you can say that there is some broader service you fall within and then look at it as simply some variation in the terms of the service because that clearly - anti-discrimination legislation normally covers, but if there is no broader service you can fall within then you are right, it doesn't cover the forced provision of a service that doesn't exist now.

MS FOLLETT: I think that's a real difficulty and there are ways of raising that. I mean, any of us can raise that with government. Any of us, I think, can even look at a question of dealing - I certainly can - with an issue on my own motion and in effect investigating that area completely and then reporting on it, and I have done that too.

MS McKENZIE: Should there be some broadening, do you think, of the services provisions to cover something like this in some way?

MS FOLLETT: The definition of what is a service I think could be much more helpful and I know that my own act refers to all services provided by government, but I take Mr Buckley's point that health is, of course, a service provided by government as it is by many others, but perhaps it ought to be more specifically addressed in the Discrimination Act. There are also a range of other transactions, if you like which are difficult to envisage as services; things like being detained in custody - is that a service? And other similar events in your life where you may suffer real discrimination, but I think if anybody wanted to mount a technical argument about whether or not this was strictly speaking a service then you could find yourself in some difficulty.

MS McKENZIE: There have been a number of cases concerning things made available to prisoners but they have always been fought on the basis that there are some services clearly given to prisoners, welfare services, access services, recreation services and so on, but it's not been considered on the basis of solely for their detention.

MS FOLLETT: That's right, yes.

MRS OWENS: So is there anything that we can learn in terms of the DDA from the act that you were administering - in terms of the lack of comparator, for example. Do you think that is a preferable approach to the DDA?

MS FOLLETT: I think that's a more inclusive approach that is less susceptible to a very technical argument about whether a complaint may be made or not, so I favour that approach.

MRS OWENS: And you haven't run into any problems because of that approach?

MS FOLLETT: No, not so far.

MS McKENZIE: And there hasn't been any back-sliding from that original tribunal decision which said that unfavourable treatment didn't mean a comparison?

MS FOLLETT: No, there has not. That has remained the standard in the ACT. I think one other suggestion that I might make, because it is something that seems to be becoming more common, is to put a time limit on the investigation of complaints. Under my own legislation we have a strict time limit of 60 days on investigation. It's the same as Victoria. It was in fact modelled on the Victorian legislation. I believe that is an extremely useful and disciplining feature of our legislation. It has been my experience over many years now that you can get the most salient features of any complaint within 60 days and it puts a discipline on everybody involved if, at the end of that 60 days, a decision must be made, so - - -

MS McKENZIE: Can I ask - and I am not implying it happens, but does that mean in your view that sometimes you're not able to do an adequate investigation just because of the size of the matter and, if so, then what do you do?

MS FOLLETT: Very rarely is that the case. I do believe that the benefits of the time limit outweigh the occasional case where I think to myself I wish I had more information. What I am looking for when I investigate a discrimination complaint is, first of all, does it come under our act? Are the grounds and the areas and so on relevant to our act? Is there a detriment to the person and is that detriment linked? Is there a causal relationship between what has happened and the person's disability in this case? I really believe that you can most often find out that level of information within 60 days and do so certainly to a standard that satisfies me on the balance of probabilities, and if my decision is that the matter does fall within the act; that it does appear to raise issues under our act, then we proceed to resolve it, or attempt to resolve it by conciliation. There is no time limit on that. Further information can come to light in the course of conciliation, which people may want to discuss and again resolve in the course of conciliation.

MS McKENZIE: Have there been times when - one thing that has been said in a number of submissions which has to do with HREOC conciliations, is that it would be helpful if, either in all cases or in some of the systemic cases, the outcome of the conciliation were made public; not the process but the outcome.

MS FOLLETT: I think ACCCI went not quite as far as that and said that that could be done by way of non-identifying case studies rather than names.

MS McKENZIE: But have you followed any similar practice in your jurisdiction?

MS FOLLETT: We certainly do publish case studies without identification of the parties. We do that in our annual report every year and we do it through our newsletter and in other ways because I think it is important for people, first of all, to know that these matters can be resolved, and sometimes there is a policy change or a wider impact of what is in that conciliation agreement, so it can be important for others to know about that, as well. I think that conciliated agreements could be more widely broadcast. I think it could be an extremely good way of achieving change across a broader spectrum of the community if people were to see what cases had led to what outcomes, more generally, yes.

MS McKENZIE: And you haven't received negative feedback about that practice?

MS FOLLETT: No, I haven't. Our conciliated agreements are formal documents. We draw them up as a legal agreement and our legislation has recently been changed to make those agreements in effect orders of the court.

MS McKENZIE: Similar to Victoria.

MS FOLLETT: That's right, yes, so it is quite a strong document when it is finally drawn up and signed off by all the parties. I think it represents quite an achievement on the part of the parties and I would be happy to see the outcomes more widely known.

MRS OWENS: So is that another lesson for the DDA and the HREOC processes? I mean, HREOC does publish case studies, as well.

MS FOLLETT: They do.

MRS OWENS: It's a question of do they do it frequently enough? Do they provide the right sort of information at the right time? As part of their 10-year anniversary celebrations they published quite a useful book, which I thought had a lot of very interesting case studies, but what you're saying you do is publish as you go.

MS FOLLETT: We do. We publish every year in our annual report and we do them in between times, as well. We have a document which we often include in our community education, which is a list of conciliated outcomes, just so that participants in community education can read all the very short case studies and the outcomes of quite a number of them, and people are always interested in that. Usually the easiest and most interesting part of community education is to tell people about the complaints we've received, the actual people involved and what the issues were and how it was resolved. People do want to know that. I think that they are then able to see the act more as a living and relevant piece of legislation.

MRS OWENS: The other thing you have in your act, which is different from the DDA - which may not in fact have any significant difference in terms of interpretation - is that you use the word "impairment" instead of "disability".

MS FOLLETT: Yes, we do.

MRS OWENS: Does that have any inference? I mean, Cate might be able to answer this question, too.

MS McKENZIE: The definitions are really similar.

MS FOLLETT: The definitions are extremely similar. I have recently put to our legislation program that we should drop the word "impairment" in favour of the word "disability". It has been my experience that disability is a much more well understood word and, whenever we use the word "impairment" we have to put "disability" in brackets after it anyway. Impairment also, to some people, has rather a pejorative overtone - that there is you know something wrong with you - and I think we can do without that. I think disability is the common term. It's well understood, and that's the word we should use.

MRS OWENS: In your submission I think you mentioned about the joint Commonwealth ACT human rights office that used to be in existence and which is no longer there.

MS FOLLETT: Yes.

MRS OWENS: There is no longer a formal relationship, although there is an informal relationship between yourself and HREOC.

MS FOLLETT: Yes.

MRS OWENS: We have heard in other states from people who have said what that has meant is that HREOC has become a more distant presence in Sydney and that there is then a tendency to use the local system rather than HREOC and the DDA because there is greater visibility and so forth. Do you think there is any potential to reintroduce a joint arrangement or would there be no benefit at this stage?

MS FOLLETT: I think for the ACT there would be enormous benefit. I agree with the comment made about HREOC appearing to be somewhat remote. We're probably the closest geographically to them and yet don't have a great deal to do with HREOC. I would certainly welcome a presence in this territory by HREOC. I think there is a great deal of scope for more cooperative work and we have other examples; for instance, with the ombudsman's office; we have an Commonwealth and an ACT ombudsman in the ACT - they share accommodation for one thing - but the Commonwealth ombudsman also has offices throughout Australia. What is different about HREOC? I do think it leads to remoteness. I think that we've got a great deal to learn from each other and a great deal in common.

As I have pointed out in my submission, I think the lack of the Commonwealth presence in the ACT is of particular concern because of our Commonwealth employment - I do not have jurisdiction there - and because of the major Commonwealth programs like Centrelink, Veterans Affairs - again I do not have jurisdiction. I often wonder to myself - when we get people inquiring about discrimination in those areas and I refer them to HREOC - if they have chased it up -

if they have followed it up. We certainly do our best to make sure that people have enough information and all the contacts to follow it up, but I have the definite impression - I think Mr Buckley said that people would prefer to be dealing with the local office.

MRS OWENS: Why did in this case in the ACT that joint agreement come to an end back in 96?

MS FOLLETT: I wasn't around at the time. I understand it was a funding matter - that agreement could not be reached on the cost-sharing arrangement - but I know that HREOC has pretty much withdrawn from all states and territories and, I think, maybe it was part of a strategy for them to consolidate in one area. I would welcome reopening that question.

MRS OWENS: Okay.

MS McKENZIE: You talk about the significant part played by disability complaints under your legislation. Are they rising?

MS FOLLETT: It's certainly true to say that of all the kinds of grounds covered in our omnibus legislation that disability complaints have nearly always given rise to the largest number of complaints. As to whether they're rising, I think they may be. They certainly have risen as a proportion of the number of complaints, yes, so - - -

MS McKENZIE: And of course my next question is, I wonder why?

MS FOLLETT: I don't like to think that there is a great deal more discrimination around. I think it may be a combination of factors of people knowing more about the discrimination law - simply as time has gone on - of the visibility of some of the big cases, mostly that HREOC has run, where people may become aware that they do have rights in this area and that there are mechanisms available. As I pointed out, a good proportion of the community - about 19 per cent - has a disability of some kind, so it's a large constituency we are looking at anyway.

Another factor, I think, is the number of our complaints that are made about employment and I think you might want to look at current employment patterns, current work practices, the role of the Workplace Relations Act, for instance, which means that some people don't have access to unfair dismissal laws. I believe there would be quite a range of factors that might have an impact on an increasing number of disability complaints.

MRS OWENS: I think your table A on your third page shows that - the bar chart tends to show a fairly significant rise since 97-98 to 2001-02.

MS FOLLETT: Yes, it does indeed across a rising number of complaints, but it is a rising proportion of complaints, as well.

MRS OWENS: Yes.

MS FOLLETT: I hope it does show that people are aware of the mechanisms and are prepared to use them. I haven't asked them.

MRS OWENS: I think others in the ACT would say that your office does have a high degree of visibility, and that you, as an individual, have visibility in the ACT. So there may be a combination of those sorts of factors at work.

MS McKENZIE: But also I think you raise a cost matter too, in your submission, as far as complaints are concerned, and compare them over the two acts.

MS FOLLETT: Yes. Well, ours is not a costs jurisdiction, and when people want to make a complaint or when they are responding to a complaint, to the maximum extent possible I try to ensure that they don't incur costs, either costs of representation or interpreters or whatever it is they may need to make an effective complaint or respond to that complaint. And of course for our complaints that proceed to the discrimination tribunal, again it's not generally a costs jurisdiction. Costs have never been awarded, and it would only be if a complaint were found to be not made in good faith that the question of costs would arise in the tribunal.

MRS OWENS: Now, you have a bill, I think, in place, that you mentioned at afternoon teatime, relating to the ACT Human Rights Act.

MS FOLLETT: Yes.

MRS OWENS: Is that going to overtake the other legislation or is it going to be standing to one side?

MS FOLLETT: The government at the moment is considering the Human Rights Act. It will be additional legislation, and the kinds of issues that are being considered at the moment, following a major consultative process, are whether that Human Rights Act should include social and economic rights as well as civil and political rights. So it's possible that it could have major potential for areas like the provision of health services, education, accommodation and so on. As I understand the act, in its current development it will apply only to government legislation and services; so it will be a bit like the British Human Rights Act. There is a role there for a human rights commissioner, who will, in effect, oversight the compliance of other laws and programs with the Human Rights Act. If the act goes ahead, and if it's the government's decision that it may be administered from my office, of course it will have a major impact on the way we do our work, and what work we do.

MS McKENZIE: So at the moment there's a question of whether it covers social and economic rights, but it will cover civil and political rights?

MS FOLLETT: That's my understanding, yes.

MRS OWENS: What's the timing on that?

MS FOLLETT: The consultative process is complete, and the report of that is now available. The government has accepted that report for consideration and I believe they are looking to respond to the report by September this year, with the possibility of introducing legislation, either late this year or early next year.

MRS OWENS: Some of the other state acts, they have all got slight differences. And as we've gone around and talked to your counterparts in the other states, we have heard about the strengths and weaknesses of the different acts, and some, I think, don't cover things like harassment, mental health, and others cover everything. I think, when we were in Tasmania, Jocelynne Scutt said that the Tasmanian act was set out in a very clear and non-repetitive way. And I was just wondering, in terms of your own act - I haven't, I have to admit, sat down and examined it in detail, but do you think that your act, in the way it is drafted, has got most of these areas covered, and is it clearly set out and easy to follow?

MS FOLLETT: It's not a particularly easy act to follow, I must say. I think most discrimination law is really highly technical and quite complex in many ways. I think that our act could be clearer, and it is being reviewed from that point of view now; that's one of the reasons to change "impairment" to "disability", to make it clearer. The wording is also being brought up to standard, more or less Standard English, to the extent that it can be. But I do think it's a fair comment across all of our jurisdictions, and the Commonwealth, that all of our laws could be much easier for people to understand. I think that whilst the application of the law might be technical and complex, if a person picking it up and looking through it - reading it - really isn't sure whether it covers them or not then I think we've got a problem. And it works both ways - I mean, for respondents as well. Because laws like the DDA impose rights and obligations on all of us, the clearer it is the better, frankly.

MRS OWENS: Why do we need a DDA and an ACT Act?

MS FOLLETT: I think, in practical terms, there is the jurisdictional issue. I think if HREOC were everywhere, and performing a service, then it's possible that we wouldn't. But it's a bit of a bias. I prefer to have all forms of discrimination covered in one act, and I think that people have a general idea about what discrimination means; they know when it has happened to them, and I don't think they should have to look at more than one act to find out if that's the case.

MS McKENZIE: The other point that has been made in submissions to us that is also helpful is when there are multiple claims involved you don't have to go under different acts.

MS FOLLETT: That's right. And I was just going to say that it's often the case that people wish to complain about more than one ground; disability and age; sex and disability. I saw the submission there from women with disabilities; I think they made some very good points. The omnibus legislation does allow quite readily for that. It also, I think, allows for consistency of complaint handling, no matter what kind of a complaint it is. The procedures and time lines will be the same. I think that's again an area of certainty that's appreciated by your clients, whether they are complainants or respondents.

MS McKENZIE: On the other hand, having a DDA and an ACT Act couldn't possibly lead to some confusion and uncertainty as well?

MS FOLLETT: I think it does. I believe that's the case. And I often have to explain to people that there are two acts. Sometimes people have a choice of which act they proceed under. It's not really difficult for me, in the terms and provisions of the act, because they are so very similar. It sometimes happens that people ring HREOC instead of my office, and are referred back to my office. So I'm getting them on the rebound anyway, and I know they are confused.

MS McKENZIE: Yes.

MS FOLLETT: If it turns out we then can't help them anyway, I think it reflects badly. Ideally, I guess one piece of legislation, administered equitably and with ready access, would be the best outcome, but I don't think we are anywhere near that.

MS McKENZIE: That's all the questions I was going to ask you.

MRS OWENS: It's a really good submission. I just threw that question in at the end.

MS FOLLETT: Yes. It was curly one.

MRS OWENS: Thank you very much. Was there anything else you wished to raise with us?

MS FOLLETT: The only other issue that I should have touched on is to do with standards, and the development of standards, under the DDA. I think for the moment, because my own legislation doesn't allow for standards, that I would appreciate some clarity about whether the standards do in fact override the territory level legislation. I know there's a view around that that is the case and that will remain the case. I think if there is a considerable conflict between the provisions of the standards and the provisions of the state or territory legislation, then it seems to me to be not a very good outcome if that then denies a person the right to make a complaint. So I've got concerns about that, and we are at an early stage in the development of standards, I know. But I think it's a debate that we really need to have amongst all of the agencies.

MRS OWENS: Good point.

MS McKENZIE: Thank you very much.

MS FOLLETT: Thank you very much indeed.

MRS OWENS: That concludes today's scheduled proceedings, and I was wondering if there are any others that would like to have an opportunity to talk to us. No. Okay. I thank you for attending and I will now adjourn the proceedings. We will be resuming in Perth on Monday, 30 June. Thank you.

AT 4.20 PM THE INQUIRY WAS ADJOURNED UNTIL
MONDAY, 30 JUNE 2003

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