

Transcript

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 Item: **SPEECH ABOUT DISABILITY.**

Demographics:	Male 16+	Female 16+	All people	ABs	GBs
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BILL SHORTEN: Perhaps my electorate would be easier to pronounce if you put the letters U, P on the end of it, Maribyrnong-up. I wish to begin in fact by acknowledging the traditional owners of the land on which we are meeting today, and I would like to pay my respects to their elders past and present and to any of you here.

I would also like to acknowledge that this is Terriann White, Susan Takao, Helen Errington and Graham Edwards [indistinct] a fantastic person, sits on the National People with Disabilities and Carer Council, and of course has been a former state and federal Member of Parliament, some who I supervised [indistinct]. I was thinking about tonight's talk, which probably comes as a relief to you.

[Laughter]

Sort of a joke.

I was thinking about that line that Peter Finch immortalised in *Newsfront* [sic]. He said I'm as mad



as hell but I'm not going to take it anymore. And really, I'm amazed that I don't get that and that I didn't get that 10 times today in the various schools I'm in. The treatment of people with impairment in Australia is a disgrace.

When the topic that I was going to give was read out, I thought I'd written myself a little mental memo, always check four months later upon the topic you said you'd speak on. But I did intend to really go towards this issue of what's wrong with disability, in my opinion, and what should be done. And of course that importantly encapsulates much of the relationship of a National Disability Strategy and our new commitment to the United Nations Convention.

But I think it is important that I now establish to you my hypothesis on what's wrong, on what needs to be done. I want to go through what I think are some of the statistical truths. Then I want to also talk about - and I think it's appropriate - talk about disability compared to the treatment of Indigenous Australians.

I would like to talk about a report which we launched yesterday, speak about consultations by the National Ministerial Council on Disability and Carers, which Graham belongs to. I would like to talk to you about the reality that people say, as opposed to just the numbers.



I would like to talk about then the Human Rights Convention and the Disability Discrimination Act. Then I would like to talk to you a little bit about the economics of disability. Then I would like to talk to you, in conclusion, about what needs to be done.

I think that the numbers will show the enormity of what we're dealing with, to establish my hypothesis that disability had been - and the treatment of people with impairment, is a national disgrace. when you look at the size, the remarkable size of what is all too often an invisible problem.

If you were to consider some of the disabilities which we classify as profound or serious, and there are many, but amongst them cerebral palsy, Down syndrome, autism spectrum disorders, deafness, blindness and pronounced intellectual disability, amongst others, there would be at least 1.3 million Australians who have a profound or severe disability.

One in 12 Australian children have a disability. That's leaning towards about eight plus per cent of all our children under 14 years of age, or indeed about 317,900 children with an impairment which could contribute to a developmental delay. Around half of these children have a severe or profound limitation, such as [indistinct] which will shape their life.



Another number is that half a million Australians are primary carers of a person with a disability. That's the population of Tasmania. In 2009, it is not an exaggeration to say that nearly four million Australians - one in six, one in five Australians - are affected every day by some form of impairment.

People with disabilities, and indeed mental illnesses, have much lower labour force participation rates than people without. You are far more likely to be unemployed in our great nation if you have a disability. You are far more likely in our great nation to be poor if you have a disability, and it's growing.

Indeed, more than 30 per cent of households with a person with a disability live on less than half the median income. Economists believe that the impact of disability amounts to around 30 per cent of household income.

In my role, which is referred to as helping the federal contribution into the bushfire reconstruction, I saw firsthand the remarkable generosity of many Australians, and perhaps many of you in this room - the remarkable generosity of Australians when confronted with an acute and sudden crisis. Although I then have to contrast, and it hasn't been lost upon me, the approach to the long term and chronic disadvantage of people with disability. And you wouldn't be here listening to this talk if you weren't already aware of this.



You know what I'm talking about. It's the silent, aching struggle, ever-infused though by love, affecting these millions of lives which I've referred to, which fall beneath the radar of Australian public opinion.

This is happening daily, quietly and inexorably. And it has been going on for too many years, to count or know; it is invisible, or at least so accepted and entrenched in our society that we fail to see that at it's most fundamental it is an infringement of human rights and dignity.

You know who I'm talking about. I'm talking about the young men and women, for instance, with lifelong impairments, who live in aged care homes; living with people in their later years, nearing the end of their lives, people that are unable to connect with and share experiences with, but all because they have no other choices available to them.

You know who I'm speaking about when you speak about ageing parents and carers looking after an adult child as long as they can, forever haunted by the thought of what will happen to their son or daughter when they die or when they're no longer able to give them the constant attention and support they need.

Why is it that in our country, our rich and great country, our wealthy and generous country, that we cannot look these parents in the eye and assure them



that their child will have a safe and secure home after their dying

You know who I'm talking about when we talk about couples that have too little sleep for too long, whose marriages collapse from the physical and emotional stress of constantly caring for a child with a disability, with little support and much isolation. I'm sure you know what I'm talking about when we talk about people with a disability who are able and keen to work with us but can't because some amongst us are not prepared to see the value of the person's contribution, rather they are worried about what it might cost us.

You know I'm talking about wonderful parents who love without question, people who are determined to prevail, not simply endure. I'm sure you know what I'm talking about when we think about a quest for people with impairment, their families supported by professional carers to live ordinary lives.

These are the numbers and these are the people and you understand this. You do so I think by your self selection to even be here. But it's interesting, when you come to the University of Western Australia and I think about Sir Ron Wilson and I think about the stolen generation. Ronald Wilson who despite the advice of someone in my department who is not here with us tonight, thought I'd check that. It'd be remarkable if he was, it'd be lovely but as you know he's a great activist for civil rights in this country of ours and in 1997 when it came to the release of the



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report about the stolen generations, Sir Ronald Wilson looked beyond the statistics and he went to the human reality of what happened.

He gave voice to people and put face and stories to an issue that had been invariably ignored by too many. That reform was a landmark in the process of reconciliation in this country and helped to celebrate the journey to 12 February last year. But it was a landmark in the process of reconciliation in this country because it opened the eyes of the Australian community to the past and the present.

I'm not going to compare between the struggle of different equity groups and the disadvantage they suffer, and we all know about the treatment of our Indigenous Australians. But I would like to put to you tonight a view which says that people with a disability, people with an impairment, are in fact eternal exiles in our own country, not from what they do and not through the efforts of many. But if in this nation of ours, you're more likely to be in jail, more likely to be unemployed, more likely to have public housing, more likely to be on income support, less likely to complete tertiary education, less likely to have adequate secondary education, less likely to receive valuable early intervention, you are not an equal citizen in our country.

The process of being pushed to the margins has been forgotten about. It is in fact I would suggest to you a similar process of not being involved in the decisions which determine their futures. I think the



outcomes in Australia for people with disabilities are similar to other greatly marginalised groups; poorer, worse health, less education, less likely to have a life expectancy that other Australians take for granted. And in the case in particular of people with intellectual disability, you're more likely to be in prison.

Aboriginal rights in Australia have come a long way, but there is a recognition that we need to close the gap. There's an understanding of the problems but not the solutions. Where I feel people with impairment miss out is I do not believe there is automatically the same awareness if you don't have a lived experience of disability. Australians are a generous people; there is an absence of malice in our national character which is remarkable as reflected by our history, but there is equally an ignorance of the living experience of people with impairment which needs to be challenged.

We as a nation are too ready to accept that somehow the problems are insoluble, that there can never be enough money. Somehow it is accepted that it is all too hard to fund the basic needs of people with impairment. Yesterday, the government released the Shut Out Report(*) which is a summary of the consultation process for our national disability strategy which we hope to release next year.

When the Rudd Government was elected, we established the National People with Disability and



Carer Council because we wanted to genuinely consult people with disability, not dictate or ignore. They oversaw a consultation involving 2500 people attending forums and focus groups, with 750 plus putting in written submissions.

This document is an honest look at the problems faced by people with disability. It does not make for comfortable reading, nor should it. It shows us that too many people with impairment remain shut out, unable to access jobs, education or even buildings. I believe the report is not a plea for special treatment or special rights. Over and over again, it is simply a call for the right to be ordinary.

I keep using the word about impairment. I believe that impairment is a fact of life. You can acquire it at birth through a chromosomal twist of fate, you can acquire it in a blink of an eye on any of our many thousands of kilometres of roads. It can happen to you at work, [indistinct] it happens with the onset of ageing. I believe practically what disables people is not their impairment. Practically what disables people is barriers which our society puts in the path of people with impairment to be able to enjoy full participation.

I think it's the community's attitudes that need to change all too often. The inability of the general community to adjust, to tolerate, to adapt to the fact that some of us come in different sizes, shapes and packages. The Shut Out Report does not pretend that everything is fine, it recognises injustices and



slights faced by people with disability every day. It does show, and this is the report's view, that the stories of hope and achievement are outnumbered by those in frustration and anguish.

In politics, there is no premium on bad news. The premium is on the good news, the announcables, the releases, the positive stories, but I believe in disability if we're to move to the positive, taking nothing away from the many accomplishments of many people over many years and decades, we have to promote and recognise the bad news.

I'd like to share some of the submissions to the report: 39 per cent of the submissions to the report specifically mention discrimination, violation of rights of disability. I've got some summaries which I think say it better than any politician can. And the summaries of the lack of respect and understanding that people feel, people making the submissions feel, is entrenched in the everyday practice of our society.

It's written: first of all, disability is subject to multiple and aggravated forms of human rights violations including as bleak as in most basic survival rate of needs. These human rights violations do not occur in far off places, the black and white of legislation policies, or the resources needed to meet their basic needs. They occur every day in every region of every state and territory in Australia. Virtually every Australian with a disability encounters human rights violations at



some point in their lives, and very many experience it every day of their lives.

In 2009, in one of the most enlightened and wealthiest nations in the world, it is possible for persons with disability to die of starvation in specialist disability services to have life-sustaining medical treatments denied, or withdrawn in health services; to be raped or assaulted without any reasonable prospect of these crimes being detected, investigated or prosecuted by the legal system, and to have their children removed by child protection authorities on a prejudiced assumption that disability simply equates with incompetent parenting.

Other submissions focus on the lack of community understanding, the fear of disability, and the needless barriers that this raises: I definitely made the correct decision when diagnosed about five years to limit the people and work colleagues who knew of my situation to a small number. Once the full extent of my situation became public to work managers and the HR, the barriers [indistinct]. This took the form of well-meaning but restrictive measures under the guise of duty of care.

Freedom of movement included no longer being allowed to drive a work vehicle, which meant the loss of a portion of my independence, even though there were no restrictions on my driving outside of work. The psychological impact was that for the first time I started to feel like a disabled person



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rather than a person with a disability. Believe me, they are two very different feelings.

And another: I remember my year eight science teacher said she couldn't wear my microphone because it put holes on her clothes. I couldn't do anything about it; she was the teacher and I was the student. I failed year eight science. But it had nothing to do with my ability, because in year nine science I had a teacher who wore the microphone, and I topped the class.

And one of a parent, one from a parent: the bugbear of everyone who loves someone who is disabled is that they're labelled according to their disability or weakness. So my son is known as speech-impaired; that's his label, which is like telling someone who is totally beautiful but has big feet that they're primarily identified as having big feet, and the fact that they happen also to be beautiful is lost. Can we focus a bit more on addressing the strengths, so that John Smith, the disabled boy, can become John Smith the brilliant rocket scientist.

This report also highlights the desperation of ageing parents, haunted by the thought of what will happen to their children when they're no longer able to provide a high level of care. And this is a sadly recurring theme in the submissions.

Here's the view of one submitter: governments rely on most parents never being able to bring



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themselves to abandon their children. Deep parental love and a sense of duty are being heavily exploited solely in order to save money, which in a country as wealthy as Australia is profoundly shocking. But even the most devoted and self-sacrificing of parents can't keep on caring if they're dead.

The Shut Out Report shows that the prejudice faced by people with disability is entrenched, systemic and subtle. It's experienced by people with disability every day and it shapes all their interactions and experience with the wider world.

To the difficulty they have in walking or speaking or seeing, is added the treatment they suffer and the discrimination they receive when others in the community might dismiss them or ignore them, be it on a bus, in a workplace, in a job interview, in a school or in a shop.

As I've said, Australians are not malicious, but when it comes to impairment and disability, all too often unfortunately we still have a two-class society. Like all prejudice, prejudice against people with impairments is an opinion not sustained by any fact. In fact, it is born of ignorance and a lack of empathy for the experiences of others.

It can come in a form of attitudes ranging from the patronising to the hostile. People with impairments continually have to deal with systems that have never been designed with a thought for their needs.



People with impairment know the frustration of [indistinct] barriers which, in the case of many of them, could be avoided or minimised with a little time and effort.

I believe, and the Rudd Government believes, that this sits badly with our democracy. It sits badly with our culture of mateship and with our history of neighbourhood communion and kindness that some people are still treated this way.

We often hear that human rights in Australia are by and large respected, that we are the nation of the fair go. This report offers a challenge to that assumption. The report is not a challenge, however, I suggest, just to government, but to the entire community. There's a challenge here that we all need to look at what we're doing and what we need to do differently.

I do believe - and this is the dilemma in politics - that you should promote the bad news, but there's also good things happening. I believe the Rudd Government has done a lot in its first 20 months for people with disability.

We've doubled the money going to the states over the next five years. We've literally transferred billions of dollars extra in income for disability support pensioners and for carers. We did ratify the United Nations Convention on Disability Rights, and we've indeed signed onto the optional protocol



to allow enforcement mechanisms through the United Nations.

I do recognise that the problems can't simply be done by transferring payments along. Resource allocation is fundamental, and I'll speak more about that, but real improvement will also come only through a change of attitudes.

By signing the UN Convention on Disability Rights, there's a recognition in our government that the issue of disability is a practical issue of human rights. Part of the struggle that people with disability is to have people treated not as charity, but as full human beings with rights and aspirations; not as costs, but productive and social participants in our society.

Many of you would be aware that one of the key reforms in our stop-start process to change with disability in the history of our Commonwealth was the passing of the Disability Discrimination Act in 1992. It was the first piece of federal legislation that made it illegal to discriminate against people with disability.

It is amazing to think that less than 20 years ago people with disability in some parts of our Commonwealth had no legal protection against prejudice and discrimination. Since then, there have been major changes in the way in which people with disability are treated.



The Act, and complaints under it, have led to several concrete improvements: TTY being part of the Australian telephone network; better access to public transport; improved standards of access to buildings.

In the hands of activists and advocates, the threat of the DDA has been used to drive change. And our government has recently amended and strengthened the Act to ensure it remains a vital tool accessible for the rights, the Rudd fight for equal rights. I think Eleanor Roosevelt sums up human rights terribly well. As well as being a wife of a man who overcame prejudice and had to fight prejudice against people with disability, to make sure [indistinct] husband became President of the United States.

I believe that she was undoubtedly the most influential member of the UN Commission on Human Rights. She said: where, after all, do universal human rights begin? In small places, close to home. So close and so small they cannot be seen on any maps of the world, yet they are the world of the individual person, the neighbourhood he lives in, the school or college they attend, the factory, farm or office where they work. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to



home, we shall look in vain for progress in the larger world.

Now I said earlier that I wanted to talk about disability and human rights as an economic issue as well. I did say that the Rudd Government has demonstrably increased funding to the states for disability services for recipients themselves.

This was badly needed in the short term, but in the long term we need to do more than just put more resources into the same old systems. I believe that we need to look at new ways of funding the needs of people with disability.

We will hold the states to account, but further than that, we've set up a disability investment group, which is made up of some business people, men and women who have a lived experience of impairment. They will report to us soon and give us some new thinking on how we can better provide for people with disability.

Of the nation's economic wealth, 30 per cent is generated through a government activity, 70 per cent by the private sector. And we do need to enlist the resources and the wealth of the entire economy in the service of people with impairment.

It's interesting when you look at some of the costs. And some people say to me, Bill, you've got a human services portfolio, a welfare portfolio. And I



say, no, I've got an economic portfolio. Let's have a look at some of the measures and the costs of disability in the way we currently do business.

I think these numbers I give you will give you an idea - a further idea, I should say, because you need little reminding - of the urgency of the situation, and the need to rethink the way we do business.

Governments currently spend nearly \$6 billion per year on care, support, equipment, et cetera, for people with a disability under the age of 65. And for the last number of years - particularly since the change at election, but certainly in the last number of years - this has been growing in real terms, that is, on top of inflation, by about 5 per cent per year.

This rate of growth will be needed for the next 10 plus years, because of the increasing need and unsustainable burden on ageing parents. Despite our efforts, and they will be ongoing and constant, and rigorous, the work of the states to improve benchmarks and accountability and identify unmet need, I do not believe that we do know how efficiently we're spending this money at this point.

Where we had 31 different aides and equipment schemes being run across Australia, 100 different parking schemes, multiple levels of regulation for the use of assistance animals and transportation around the states, know that we are inefficient.



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Furthermore, we are spending \$9 billion plus on the disability support pension each year, with too little to show in terms of these people being able to participate in work.

We have up to 50 per cent of approximately \$2 billion in growing expenditure in the prison system which goes towards issues around disability. And all of the money we're spending, much of the money, I should say, we're spending on homelessness that is spent on people with intellectual disability, psychiatric impairments or acquired brain injuries keeps on rolling.

You look at our \$100 billion health budget, an estimated eight per cent spent on people with chronic and complex conditions, many of whom have an unsupported disability. And indeed, more than 50 per cent of the total cost of catastrophic medical treatment injuries do not go to the injured person.

This is an economic debate of some massive, Leviathan proportion.

I'm aware that the University of Western Australia's School of Population Health is facilitating an 18 month collaborative study to undertake research to evaluate the costs of and the availability of care [indistinct] people in Western Australia.



Estimating the cost of care incurred by the compensable and non-compensable parties, and to provide a clear measure of accessibility of care assistance provided to non-compensable people in Western Australia. This kind of research will lead us to being able to reshape how we fund disability and move towards a system focussed on the individual.

That in the Commonwealth of Australia, 108 years after Federation, the manner and quality and quantum of care you receive depends not upon the injury you incur, but the jurisdiction and the manner in which you incur your industry, to me, is an anathema.

The idea that you can suffer a C5, C6 cervical or spinal injury of severe nature in Victoria in a motor car accident will give you a better outcome than incurring it through other forms of public liability injury in other jurisdictions is not fair, and it is not acceptable.

Indeed though, when I think about the University of Western Australia's research I am constantly perplexed by how little research is done in the field of disability.

The Toyota motor car company in Japan does not spend all its money building cars, it spends much of its budget on research and development. Yet those billions of dollars that I referred to that are spent on



disability are spent on a service system and income support with very tiny, miniscule amounts being spent on research.

We are spending billions of dollars on disability without looking at what works and how it works and whether what we're doing works.

How we're looking after people with a long-term impairment is a major public policy issue. The 2020 summit threw out a challenge to the Rudd Government. It called for a national disability insurance scheme, both for those catastrophically injured, and for those born with a disability.

As part of developing the National Disability Strategy, we will examine the implications and the potential of such schemes, I hope. An idea like the National Disability Insurance Scheme is ambitious and complex. So is Medicare. So is superannuation.

We do know the benefits of early intervention, and this government is committed to social inclusion, it's committed to early intervention. We need to ensure that we keep working - that we deliver support to [indistinct] and programs that allow people - and that we also have programs that allow people with disability to work.

The field of work is an area which is [indistinct] when it comes to disability. The disability funding system for far too long has been a stop-gap,



patchwork program providing aid when the situation reaches crisis point.

I think about the future and I wonder what we - what the future will look like for people with disability. I had the opportunity to represent the Australian Government at the Beijing Paralympics last year. Some people in the disability sector say, that's all crap, the Paralympics [indistinct]. Elite Australian athletes aren't representative of all Australians either.

But what I did see in Beijing - and they were clearly a very small portion - was after the first five minutes you arrived there, you literally see thousands of people with impairment. Sure, they're elite athletes, but you see their trainers, their families. I saw buildings designed such as to facilitate the access and living for people with disability. What I saw was people of every possible colour and every possible appearance living and working together, and achieving remarkable things.

What I know about Paralympians - and I was speaking to a former Paralympian today, Priya Cooper - is that she, to me this personifies the possibilities of the future, she's not someone in a wheelchair. She's an elite - she's a former elite athlete, mother, she's a high achiever, who happens to have an impairment.



But in Beijing I saw what is possible, and I know that in the future, and it should be possible, and this is a very personal conviction, that when a baby is born and diagnosed at the time, or within months and early years after, with an impairment, why can't parents have a case manager who will help them navigate the shock, the waiting lists, the search for a paediatrician, the child psychologist and occupational therapists, search for early intervention programs, the search for schools.

Why can't parents have the choice between special schools or mainstream schools? Why can't a person with impairment have the ability to go to secondary school, be treated with dignity not to be bullied? Why can't someone - why can't a family be able to navigate the system of vehicle modifications, navigate the system of transition into work, to study, or day-care - depending on the nature of the impairment?

Why can't we have a future where people are able to look ageing parents in the eye and say, okay, we can source some sort of independent accommodation?

I think that future is possible, but what is required is the disability sector - in my opinion - to become more of a movement, to have a more united focus, to be able to articulate to anyone, this is what we want.



People in government will play this role, and we're currently considering the possibility of a feasibility study - because we haven't studied the numbers - to see what is necessary to fund disability to provide lifetime care. I don't think that what we're talking about is too hard. I certainly don't think it's going to happen too quickly. In politics, they teach me three or four lessons. They say, don't get people's hopes up, because then if you can't deliver it straightaway, then you're in worse trouble than if you've getting all their hopes up.

I reject that view. I think that it is possible to put forward an idea, and then encourage people to own an idea and be empowered and to educate their neighbours and their fellow citizens about the power of an idea.

I do not think the change is inevitable, but nor do I think it is impossible. I think that, if you look at the history of priorities in disability, just as if you look at the history of progress of society as a whole, we have periods of the status quo, and then we have periods of change.

In this cycle of status quo or change, it is not inevitable, but it certainly can be brought to life, and it is possible with the combination, I believe, of clear ideas and animated supporters, who are capable not of necessarily just convincing the politicians - because in my experience, most politicians, left, right, various colours, whatever, they get the importance of disability. But it is only



when the electorate demands the urgency of the issues can you see genuine change.

But I do think it is absolutely possible, in a wealthy nation, that we can fulfil the promise of equal citizenship of people with impairment by identifying what it is that is required to be done, and then insisting upon the rights that this be done, not in the voices of supplicants, but diverse and diffuse people, but in the voices of a very large assembled group, who are able to say, this is where we want to go.

I'm very pleased to be with you tonight, very pleased to be here. I think it is important, and I think that, as I said, change is not inevitable, but nor is it impossible, and I think that, even events like this, help sow a seed of an idea, which is that we are capable of funding equal citizenship for people with impairment and their families.

And it's not a matter of if, it's a matter of when, provided that we focus on what it is that we require. And I certainly don't think that there is not enough money. And I certainly think that we can make the changes, but nor should we expect for others to make the case for us.

I didn't think that disability issues could change a nation, could change a government, but I also think in order to make disability one of the biggest political issues, we need to unite. We need to be



able to get the electorate to look at buildings and ask themselves spontaneously, would a person in a wheelchair get in there?

I think that my party, the Labor Party, needs to recognise and what we stand for is we should recognise the need for improvement and recognise the need to treat what I've said as an issue of civil rights.

I think the Government's started the process of change, but I do think that we need to educate Australians of the reality of living with disability, what it is. I do think that we need to make sure people not in this room become aware of our views very quickly.

Thanks very much.

[Applause]

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ABs = Managers, administrators, professions. GBs = Grocery buyers.
