

Right to an Ordinary Life

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Thank you Ken Baker from National Disability Services for that introduction.

I'd like to acknowledge the traditional owners of the land where we meet, the Ngunnawal people, and pay respect to elders past and present.

I also acknowledge the Minister Anastacia Palaszczuk, the new Queensland Minister for Disability Services and Multicultural Affairs, who has been in the job for less than a week.

I also acknowledge Dr Jeff Harmer, the head of the Department of Families, Housing, community Services and Indigenous Affairs, other FaHCSIA representatives and the National Disability Services.

Last month my parliamentary duties were expanded and I've become involved in the repair and reconstruction of the towns devastated by the bushfires of February 7th.

We all know what a horrific day that was, and what it eventually meant, and what it told of Australian capacity for doing and giving; the ceaseless hours, working through days of fear, grief, fatigue, flames, smoke and appalling devastation; the respect and care for the people we love and care for, - live and work with. It's that unique spirit and ethos historians have written about us for more than a century, but its real meaning is only properly seen and felt on the ground.

Today, I want to talk of another group of Australians: Australians with the same ilk of courage, spirit and ethos, whose circumstances are vastly different from most, whose days and nights are a mighty struggle to achieve a capacity and independence that others of us have never once wondered about and always presumed to be available; Australians who speak clearly and strongly to themselves - or they simply wouldn't survive - but whose voices are rarely heard by the broader many who live in their midst and otherwise occupy this nation.

I'm talking of a silent, aching, struggle, ever infused by love, affecting millions of lives, which falls mostly under the radar.

It happens daily, quietly and inexorably, and 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 its most fundamental infringement of human rights and dignity.

I'm talking of young men and women with lifelong disabilities living in aged care homes. Living with people in their later years, nearing the end of their lives, people they are unable to connect with and share experiences with all because they have no other choices available to them.

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

Couples who've had too little sleep for too long, whose marriages collapse from the physical and emotional stress of constantly caring for a child with a disability.

I speak of people with a disability who are able and are keen to work but they can't because some amongst us are not prepared to see the value of their contribution; rather, we are worried about what they might cost us.

I'm talking of wonderful parents who love without question, people who prevail not simply endure.

I am talking of the quest by people with disability, their families and supported by professional carers, to live ordinary lives.

There are good things the Rudd Government, led by Senior Minister Jenny Macklin, is doing in disability. We've put together an agreement with the States that will add \$5.3 billion to disability funding.

We're beginning, at last, the slow work of untangling the bureaucratic crazy maze that parents go through when they seek help for their children.

We are developing a National Disability Strategy and a workforce strategy aimed at getting people with disabilities jobs.

We have rolled out 250 new places in Australian Disability Enterprises creating employment opportunities for people with more severe disabilities.

I have chaired regular meetings with Australia's top employers to obtain a commitment to improving employment of people with disability.

We have paid 720,000 DSP recipients and 120,000 Carer Payment recipients an extra \$1400 if they are single, and \$1050 if partnered.

Also 440,000 Carer Allowance recipients received an additional \$1000.

And we've made it easier for people on the Disability Pension to look for work without being punished for daring to try to get a job.

With changes from 1 July, we shall be providing Carer Payment to an extra 19,000 carers of children with disability.

We're establishing six Autism specific Early Learning and Care Centres across Australia, and have to date provided early intervention funding to over 1000 children through our Helping Children with Autism package.

We've ratified the United Nations Convention on the Rights of Persons with Disability - one of the first Western Countries to do so.

We've tabled the draft Disability Standards for Access to Premises. Once finalised, they will provide a greater certainty for people with disability as well as industry, and will cover new publicly accessible buildings and those that are being significantly upgraded.

We've expanded the delivery of individual advocacy services and improved service coverage.

But I'm not here just to praise the Rudd Government.

What I want to emphasise is where we go from here and how huge a task it is we have before us.

And I want to say it's a task that can't be solved, by funding alone.

Because it involves a change in the way we look at things; an honest appraisal of ourselves, a fresh approach to how we treat others, a deeper understanding of what it is to be part of humanity. It involves what T.S. Eliot called 'visions and re-visions'.

It's not dissimilar as the one earlier reformers faced, when they started to say in public meetings that anyone can sit anywhere on the bus, that anyone can use the washroom, that anyone can vote, whatever the colour of their skin.

But first some numbers, to show the enormity of what we're dealing with.

People with disability can be classified as having profound, severe, moderate or mild core activity limitation.

The disabilities we classify as profound or serious are many, but include Cerebral Palsy, Down Syndrome, Fragile X Syndrome, Autism Spectrum Disorders, Deafness, Blindness and pronounced intellectual disability.

In Australia there are approximately 1,145,000 people with either a profound or serious disability - that's about the population of Adelaide.

Such a disability affects about 1 in 24 children aged up to 14 years.

Over 50% of the 319,900 children with disability have profound or severe core activity limitation.

And then there are the carers.

In 2003, approximately 2.5 million people reported providing informal care to a person because of disability or old age. This is the population of Adelaide, plus Perth.

500,000 were the primary carer of a person with a disability. This is the population of Tasmania.

Primary carers are likely to be in the poorest two fifths of all households and 55% receive income support as their main source of cash income.

Most primary carers (71%) are women.

People with mental illness experience even higher rates of unemployment and lower rates of labour force participation than those with sensory, speech and physical disability.¹

Poverty rates of people with disability have been growing, and today more than 30 per cent of households with a person with disability live on less than half the median income.

And yet they pay the highest price for the basics of living, for the basics of an ordinary life.

Economists believe the impact of disability amounts to around 30% of household income.

It is not an exaggeration to say that 2 million Australians are affected every day by disability.

This is about the same as the number of Australians who belong to a trade union. And they're much less well organised.

Because I'm speaking from experience when I say: I just wish they were as well organised as the

union movement. I really do.

When I left the union movement and came to the disability portfolio in 2007 I was, like most Australians, not aware of the entrenched discrimination.

In my previous life I had stood up for workers who had been injured at work, but I didn't yet understand the scale of the problem in Australia, or how hard it was for people so injured, so traumatised, so sidelined, so internally exiled to get the help they need.

I shared the same "out of sight, out of mind" attitude of too many other people.

I was, you might say, colour-blind. I didn't see the intricate variety of life that I, as a union leader, and a Member of Parliament, was necessarily involved in as a functioning part of a democracy.

That attitude - and the passive discrimination that comes with it - is one of the main reasons why people with disability are often defined by their disability, and not by their unique humanness.

Why a whole and natural life is withheld from them, or seems impossibly hard to reach.

It is why they are still not fully participating in what Australia has to offer.

Impairments are a fact of life. They arrive at birth through life's genetic lottery, they take hold of us in a car ride or a swim in the surf that goes devastatingly wrong, they slowly permeate us as we grow old.

In a sense, impairments are not what disable people. What disables people is society's attitudes towards the impairment. An unrevised vision of the different.

An unwillingness or inability to contemplate the different, to imagine its challenges and possibilities, and to recognise what is similar and humanly familiar.

Australians with disability face a prejudice which is entrenched, systemic and subtle, though still at times overt and openly abhorrent.

They face it every day, and it shapes their experiences and responses and how they travel through the world and life.

To the difficulty they have in walking, seeing or speaking is added the treatment that they receive - the averted eye, the turned back, the over-polite response in cadences suiting, a kindergarten child, be it on a bus, in a workplace, a job interview, in a shop or at school.

I have spoken to mothers with two disabled children who have been approached by strangers in shopping centres and asked outright, 'Why did you have a second child?'

The following quote came up through our consultations on the National Disability Strategy.

'A bugbear of everyone who loves someone who is disabled is that they are labelled according to their disability or weakness. So my son is known as 'speech-impaired'; that is his label. Which is like telling someone who is totally beautiful but has big feet that they are 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?'

Here's another from someone who became disabled as an adult.

'My experience changed the day I went out the first time with a visible impairment. I was twenty-

eight-years-old and went to a large community event I had attended annually for several years. A woman rushed up to me and spoke to me in a tone of voice that one might use speaking to a very young child. I wondered why no-one else had ever done that in all the years I'd come as an able-bodied person. Surely it was wonderful that all of us had come?'

Most of us believe that our jobs define us, and so of course do the physically impaired. 13 percent of them have university degrees but this often doesn't help. 63 percent of the blind or visually impaired find it goes against them when they're looking for jobs. Those with a mental illness usually decide not to tell their employer.

Many found, as one said, they had to undergo 'well-meaning but restrictive measures under the guise of duty of care. No longer being allowed to drive a work vehicle 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, rather than as a person with a disability. Believe me, they are very different feelings.'

Access to public buildings or transport always was, and continues to be a major issue.

Their access to public or government buildings matters less, because they spend so little time in them, than their access to shops and cafes and restaurants.

The people I speak of are real. They don't ask for a ramp to the top of Mt Kosciuszko but they do expect to be able to get into the local public library, the local community centre.

They are in fact the last of the invisible, marginalised groups whose suffering is overlooked by the broader community.

They are more likely to be in prison.

This issue is of huge concern to me. Susan Hayes of the University of Sydney found that 20 percent of people in the prisons of New South Wales, that's eighteen hundred prisoners, had an IQ below 70, which represents a serious intellectual disability, compared with 1 to 2 percent of the general population.

And what I want to know is, what are we doing wrong that is turning them to crime.

What are we doing wrong as a society to let so many people with an intellectual disability to end up in and out of the prison system?

Is it to do with their developing anti-social and aggressive behaviour, because of the way we treat them? Maybe.

Is it to do with the accommodation we put them in, which makes it hard for them to live without dignity and self-respect? Maybe.

Is it to do with our not allowing them to enter the general workforce? Absolutely, I'd say.

I've been thinking about all this, and I've come to some conclusions, and I make no apologies for seeing disability as an issue, not of resource allocation, but of basic civil rights.

I believe it is the last frontier of practical civil rights in this country.

And after two and a half centuries, we may reach that frontier.

Rights remain theoretical especially for people with severe disabilities and their carers, without

adequate access to robust and specialist service systems.

To take a simple example: if someone was told they could not get on a bus, train or taxi because of their sex, or their old age, or the colour of their skin, there would be an outcry.

If someone is unable to get on a bus because their wheelchair won't fit - we make no comment, we turn a blind eye.

The range of accessible public buses is around 25% to 70% - depending on where you live. Again the availability of timetable and surrounding infrastructure also varies greatly. NSW has around 700 accessible buses out of nearly 1800.

It's easy enough to rationalise in those circumstances, to find reasons why it's too hard, or too expensive for that person to be allowed on the bus.

And it's somehow also too hard to ask the question: How would I feel if that was me? If that was my mother or father or my child?

Some of you may think the person in the wheelchair should demand their rights, that it's up to them. They've got it, they own it, they should deal with it, I'm busy.

I think it's up to us, to all of us, to say: "This bus isn't moving until we're all on board."

The Disability Discrimination Act came into effect in 1992, in Paul Keating's day.

Only 18 years ago. 90 years after women were first allowed the vote in this country. Only 18 years ago.

And daily the cases come in, and the Australian Human Rights Commission deal with them:

...the woman refused a job as a telemarketer because she was blind in one eye;

...the man in a wheelchair told that he could not board a return flight from Thailand on an Australian airline that left him stranded there;

...blind people told they couldn't bring seeing-eye dogs into a clean, protected place.

All of these people who till 1992 had to fend for themselves, to push alone against the unmoving barriers of ignorance and prejudice, and all of us who don't want to know, the things we half-know, and will not think on.

Compare that with the racial and sex discrimination acts signed into law in 1975 and 1984 respectively - thirty-three years ago, and twenty-four years ago.

Today this prejudice, this enduring prejudice, occupies a huge proportion of complaints received under discrimination acts.

For instance, under Victoria's Equal Opportunity Act, more than 700 complaints are made per year on grounds of disability.

That is more than in any other category.

It is more than complaints about sex, race, religion, sexual orientation and political activity combined.

In the Australian Human Rights Commission, half of the 998 of the total 2077 complaints that were

made last year were on disability grounds.² Yet these complaints seldom get media coverage.

It happens in the workplace most of all.

People with disability want to work.

And less than 10 per cent of people on the Disability Support Pension are in any form of paid work. And this is not acceptable.

What about how you only hear media of DSP when someone is roting?

It is not acceptable either that only HALF of the people with a disability can find work, when so many want work.

Humankind is a challenge-seeking animal. We all know that.

A good many companies get this.

They understand that people with disabilities, stay longer and are less likely to be injured at work.

And they're telling me this. They get it.

But, there are also attitudes that are blinkered, like mine a year and a half ago, and no doubt, many, many others.

The Rudd Government lately, with the support of the Opposition, a happy rarity these days, altered the Act to add in clauses to do with catering for people with disabilities, and how to take steps that were not 'unreasonable' to better accommodate them and serve them in the workplace.

These changes have been attacked by some in the business community as being potentially damaging to business.

Too costly. Too disruptive. Not reasonable. Not economically sound. Not economically defensible.

Unthinking prejudice wearing the fig-leaf of economic responsibility.

They say they'll cost more in workers' compensation. There's not a shred of evidence of this.

They say that modifying the workplace will cost too much - when the average cost is under 500 dollars.

How do we think people with disability feel, when they know the only thing standing between them and their dream job is a lack of empathy from their potential employer and a lousy 500 dollars?

Unemployment in Australia is expected to rise to 7 per cent, and many people will ask the question: "Why should it be a priority to get people with disability into the workforce? I need a job too."

I have two answers to this.

One is the standard sensible answer:

That in the long term we have an ageing population and once this current economic crisis has passed we will need to use the potential of all members of society in all walks of life.

The second answer is more simple:

When did basic civil rights become dependent on the state of the All Ordinaries, or the strength of the dollar against the yen?

People with disability should not be pushed to the back of the queue, the back of the bus, or out of the washroom, by the current economic crisis.

Because what we're asking isn't charity, and it doesn't involve sacrifice, and it never did. People with disability can be as productive as anyone else.

Take this example of four people looking for work: One, let's call him Leo, is deaf, the second Frank is in a wheelchair and the third Helen, is blind and the fourth, Steve, can not make himself understood.

It is likely that all four resumes would be put on the bottom of the pile by a boss or a job agency too concerned about the problems that these unhappy unfortunates might cause.

That boss would have turned down Ludwig van Beethoven, Franklin D. Roosevelt, Helen Keller and Stephen Hawking.

How many Beethovens, Roosevelts, Kellers and Hawkings are we missing out on in our nation because of this willed blindness, this inability to move beyond looking at someone's impairment to the whole person?

In the last 16 months we have made progress down this path. The new National Disability Agreement with the Australian Government, States and Territories will improve and expand services The Commonwealth will provide approximately \$5.3 billion in funding over five years to the States for specialist disability services.

This significant injection of new funds will provide for more services and to achieve reform of the disability service system over the life of the new agreement. The key elements of the reform of the disability service system are:

- Early intervention and planning to ensure that clients receive the most appropriate and timely support.
- Improved measurement of unmet demand for disability services.
- Population benchmarking of disability services.
- A national workforce strategy to address attraction and retention of the disability services workforce.
- A National quality assurance system for disability services.
- National harmonisation of aids and equipment

The reform of the disability service system should create an effective, efficient and equitable disability services system. Together these reforms will provide a responsive system of disability support that is easy to access and responds flexibly to people's changing needs.

Just last month Minister Macklin and I persuaded the State and Territory Governments to agree to a series of timelines to implement the National Disability Agreement. They have also agreed to increased transparency - providing information every six months on the progress of key elements of the Agreement, including the Disability Assistance Package, the Young People in Residential Aged Care and the \$100 million supported accommodation initiative.

So, we are moving in the right direction, but there is much to do.

About this time last year, I convened the Disability Investment Group³, or DIG, to explore

innovative funding ideas to help people with a disability and their families take greater control and plan for the future. They will shortly report to Government. Their view is that: a further major drawback of the current disability services system is that the client is not at its centre. Whilst the move to more individualised packages of care is welcome, there is little opportunity for planning over the life course with individuals which involve their families, helps them meet their aspirations and prepare for key transitions.

This echoes the experiences of thousands of parents who struggle to get assistance for their children.

And once they do get help then they find that there are a series of points, generally beginning and ending secondary education, where they are forced to start from scratch.

They feel that: at a systemic level, there is not the robust data or monitoring capacity across the current fragmented system to enable effective integrated planning and continuous re-evaluation of outcomes.

Again we recognise this and are working with the states to ensure that things begin to improve.

I understand parents in the main aren't looking for handouts, but only a lessening of the bureaucratic barriers that stop them looking after their children fully.

I understand we should look at the individual circumstances.

I understand we should look at home modifications, medical equipment, respite care for parents as *necessities*, not luxuries because they are necessities.

The DIG looked at a National Disability Insurance Scheme, an idea from the 2020 summit, and believes it is worthy of further investigation by way of feasibility study.

They also believe in reform of the state based schemes which provide lifetime care and support for the traumatically injured.

The proposed scheme would be based on the no-fault Workers Compensation model, and provide support on a needs-basis for people with serious disabilities

This is a big idea. It's as big as the original idea for Medibank. It would turn our current system of providing disability services on its head. Instead of funding services for people with disabilities to find (knowing we are not funding enough), this proposed new approach would provide individualised lifetime care and support for each person from the point of diagnosis.

Individual case managers would work with individuals and their families and carers, developing customised plans of treatment, care and support, aids and equipment, transport, home modifications and so on. For the first time there would be certainty and a whole-of-life perspective for people with disabilities and their families.

It's a simple yet exciting and visionary idea. It has big implications for our society - and is a fundamental shift in the provision of services for people with disabilities. There is a lot to consider before Australia can go down this path. But I believe it is a good idea that demands serious debate and investigation to see if it could work in our nation.

Old systems are being discarded, and a new and better system is beginning to emerge, though we are not there yet. We have, as the Americans say, a 'ways to go'.

Where we should be one day, I think, is somewhere like this.

Support should begin on the day a child's condition is diagnosed - which in many cases is before birth.

One co-ordinator, and one only, would be appointed for each family, and deal with all the agencies, government and non-government, working with that family.

They would guide the family through the treatments and resources which are available.

All services would be provided with input from parents, and take into account the needs of the whole family.

It would also use a family's existing social network, which is so often an untapped reservoir of support.

For instance friends, neighbours and grand-parents could be given basic medical training about dealing with a child's disability, or taught to help the child at school.

The child would be brought into the school system as early as possible, through pre-schools and kindergartens, as well as quality child care that could cater for their specific disability.

The first five years of life are where most of our learning is done, and it is essential that a child's disability does not become a barrier to learning, and that the child falls needlessly behind his peers.

Missing out on valuable learning early in life is a missed opportunity that can never be regained.

During school there would be an emphasis on determining how the child could be as independent as possible, and eventually become part of the workforce.

It would focus on how their potential could be used and their disadvantages overcome.

When the child left school, support would continue, and that child would have a genuine choice about its future accommodation.

It would have the same freedom to leave the parental home, or to stay, that other young people have.

They would enter a world that did not judge them, fear them or pity them, but rather one where they were judged by the content of their character not by their impairment, judged by their ability, not their disability.

Public buildings, shops and vehicles would be as accessible as possible and housing would be designed with their needs in mind.

"No longer living years of quiet desperation"

Finally, the extra money that we would need to achieve all this would not be seen by society as a cost.

It would be seen as a valuable investment in creating adults who are able to work, be fulfilled and be independent.

I believe we are moving towards this human right.

Government and community organisations are already working towards it, and, as the bushfires show, Australia will be there, we'll always be there, if the *precedent* is there, if the tradition of help and service and the bureaucratic superstructure is there, to guide us towards the steps we should

take in this, as in any other emergency. The WILL is there.

I have seen the determination of people with disability to work and make the most of their lives. I have seen them leaping over hurdles, attempting marathons, attempting decathlons of social difficulty that most of us have never even had to begin to think about.

It is core to labor values of social inclusion and it has become my cause, that they should be liberated from the shackles of their genetics and their accidental circumstance, from those shafts of fate that strike down and impair the innocent and the good, so they may participate fully and without prohibition or prejudice in their own lives and this world we share, so they may - un-handcuffed, un-chained, un-forbidden - seek and enjoy the opportunities that we each regard as fundamental human rights.

In all this, it is impossible to over-emphasise the need, the primal need, that people with disability feel, and it's the need to be ordinary, to not be thought of as amusing, or pitiable, or brave, or admirable, or coping wonderfully with difficult circumstances.

Just to be one of the gang, a girl in the office, a bloke at the pub, not invisible but unremarkable, part of the normal order of things, a friend like any other, a neighbour, an average Australian, a citizen, another human being.

I thank you.

¹In 2003, their unemployment rate was 19.5% compared to 7.9% for people with sensory speech and physical disability.

The labour force participation rate for people with mental illness was 28.2% compared with 49.5% for people with sensory speech and physical disability.

The 2003 SDAC figure is just over a million people aged 15 - 64 with a disability were employed - 135,000 people aged 15 - 64 with profound or severe disability.

²998 of the total 2077 complaints

³Ian Silk, Bruce Bonyhady, Prof Allan Fels AO, Bill Moss AM, Kathy Townsend, John Walsh.