Address to the National Press Club

By

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Members of the National Press Club, friends and distinguished guests.

I want to begin by acknowledging the traditional owners of the land on which we are gathered today, the Ngunnawal people, and pay my respects to their Elders, past and present.

What does it mean to be an Australian with a disability in 2009?

What is life like in the Lucky Country, in this land of the 'fair go,' if you are a son or daughter of this sunburnt country?

One answer we might expext would be….. a citizen with the same rights as everyone else …

… but if you have a physical, psychiatric or intellectual disability?

What is life **<u>really</u>** like?

Many Australians would say: It's better … isn't it?

The bad old days are gone … aren't they?

The horror and abuse that went on in institutions … that's all gone now hasn't it?

The poverty, the discrimination, the exclusion, the fear and hatred – that's all ancient history … isn't it?

Women and men of the National Press Club, I would love to be able to say, yes, that **is** all ancient history.

But I can't.

I'm here to tell you, that despite this nation enjoying the longest economic boom in its history, very little has changed for most Australians with a disability.

They are still discriminated against.

They are still abused.

They are still isolated.

They are still living in poverty.

They are still treated with fear and loathing in their own country.

And if you don't believe me, let me tell you a story.

A young man with Down Syndrome goes to a café with a group of his friends.

The café is in a public park.

The young man becomes separated from his group.

Lost, he walks around the park looking for his friends.

He comes to a playground.

And there are some families at the playground.

And, as this young man has younger siblings, he tries to talk to the children.

But one of the dads screams at him to get away from the kids.

Now the young man is scared.

He tries to ask some of the other adults at the playground for help.

So what do these parents do to help this young man with an intellectual disability who is lost, alone and scared?

They all scream at him, too.

No one helps him.

He is shunned.

He is driven away.

They want nothing to do with him.

Because he is disabled, they assume he is a threat.

They want him out of ***their*** park.

Women and men, this is a true story – and it's not ancient history.

It happened a few weeks ago in a suburban park in Melbourne.

That's my city, where I come from.

Melbourne – a city that's supposed to be one of the most livable cities in the world.

But livable for whom?

Not that young man.

One study found that people with a psychiatric or intellectual disability will have a negative social experience within fifteen minutes of leaving their home.

Australia is not a livable country for people with a disability.

I could tell you so many stories.

Stories from every corner of Australia.

Like the ones about children who are not welcome at childcare centres and kindergartens – because they have a disability.

Like the ones about children expelled from school – because they have a disability.

Or the one about a young man who lost his promotion because he was unable to organise new support services in another state within six months of winning a new job.

Or the ones about the young people living in group homes, forced to go to bed every night at 5pm because the staff say so, unable to help themselves to food from the locked fridge, unable to go out for a walk through the locked doors.

Or the one about a young man who was assaulted by a fellow resident in his group home, but who continued to live under the same roof as his abuser because there was nowhere for <u>either of them</u> to go.

Or the ones about the people who'll sleep in their wheelchairs tonight because there's no one around to help them get into bed.

Or the ones about the families who become so desperate they abandon their children in respite care or in hospital because they can no longer care for them at home.

There are so many stories to tell – each with its own heartbreaking punchline.

And you will find them in this report **– Shut Out**.

Shut Out is a unique document.

It is unique because the Rudd Government established a nationwide consultation asking people with disabilities and their families two important questions:

- What is your life like now?

- What would you like your life to be like?

No Australian government had ever asked people with disabilities those questions before.

The response was overwhelming.

More than 760 individuals and organisations made written submissions.

More than two and a half thousand people attended public consultations across the country.

I saw the submissions.

I chaired the public consultations around Australia and heard from the people.

I am not new to the disability sector – I have been around a while and seen and heard a great deal.

But nothing could have prepared me for the size and the scope of the human suffering.

What I saw and what I heard was profoundly shocking – and utterly shameful.

Here we are – in one of the wealthiest countries in the world – yet I heard that most Australians with disabilities and families struggle to access the very necessities of life.

I heard that people with disabilities are unable to access housing, employment, education, health care, recreation, sport, arts – the very things most people in the community take for granted.

I heard that they are denied access to childcare, kindergartens, schools, shopping centres, participation in community groups.

I heard that their lives are a constant struggle.

I heard that they are isolated and alone.

I heard that they are … **Shut Out**.

Thankfully most of the large institutions that once housed people with a disability are now closed. That's when we thought that the awful abuses from institutionalization would cease.

But where people with disabilities were once **shut in**, now they find themselves **shut out**.

Socially, culturally and economically excluded.

Ignored, invisible and silent.

Like that young man with Down Syndrome in the park, many Australians with a disability have been driven from the public domain.

When Bill Shorten – the Parliamentary Secretary for Disabilities – addressed this forum in April, he said:

> "I make no apologies for seeing disability as an issue … of basic civil rights."

He went onto say …

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

And he is right – this is a frontier that has been completely forgotten.

Forgotten by our own country.

Rather than attempt to cover the entire frontier in one go, I want to take this opportunity to focus your attention on three critical areas – early intervention, education and disability services.

I could just as easily talk about another three areas – such as employment, housing and the built environment.

But, for today, I will contain myself to discuss areas where a new strategy for disability in Australia would drive much needed reform.

Let's begin at birth.

A lot has been said recently about how critical the first years of a child's life are.

About how an investment in the early years can have a massive impact on the future prospects of a child.

All the research points to the same conclusion: child development starts from day one.

Emphasis on the early years therefore has a huge payoff for both the individual and the community.

Early intervention is therefore absolutely essential for kids with a disability if they are ever to reach their full potential.

But during the public consultations parents told us that their attempts to give their child with a disability the best possible start in life were being stymied.

Stymied by long waiting lists and limited availability.

Early intervention is more like ‘barely intervention’.

And make no mistake: this short-sighted approach is not just hurting those <u>children</u> – it is hurting our <u>nation.</u>

We are paying for this false economy through lost potential, lost productivity and a lifetime dependence on government support.

If you don’t believe me, let me tell you about two brothers.

Both have a diagnosis of Autistic Spectrum Disorder.

Despite their common diagnosis, these brothers are now travelling very different paths.

When the older brother was diagnosed, his parents struggled to find early intervention services and support.

He received ‘barely’ intervention – and is now seriously disabled and attends a special school.

By the time the younger brother was diagnosed with the same disability, his parents knew from experience what had to be done.

They would not settle for ‘barely’ intervention.

Instead, they sourced and paid themselves for daily intervention.

It came at a high personal cost, but they were determined.

And unlike many other families – they had the financial capacity to buy for their son what should be available to all children with disabilities.

The younger brother now attends his local primary school – and is doing very well.

What is the moral of this story?

What can we learn?

What we should learn is that investing in the early development of a child with a disability makes an enormous difference.

That early intervention should not be considered an optional luxury – it is absolutely essential.

Essential if children with a disability are ever to reach their full potential.

Now we come to school.

There is no way we can measure the full economic and social cost of failing to provide a child with an appropriate education.

Yet that is what is happening every day in this country to children with disabilities.

Children with a disability lag behind on a whole range of indicators, yet little progress has been made in closing the gap.

Education for children with a disability has no aspirations, no goals … and no hope.

It is still possible for a child with a disability in this country to leave school without being taught to read or write.

So it is not surprising that despite the fact that more students with a disability attend school than ever before, students with a disability are still significantly less likely to complete Year 12.

In fact, only half as many people with disabilities have completed Year 12, compared to people without a disability.

And as a result they are far less likely go on to higher education or further training.

Again, only half as many people with a disability have completed a diploma or higher qualification, compared to people without a disability.

These statistics are outrageous – but where is the outrage?

Why is it that we lack the will to close this gap?

I believe our lack of will reflects our low expectations.

We accept the differences in outcomes because somewhere, deep down, we don't really believe kids with disabilities have potential.

We have no aspirations, no goals and no hope for these children.

There are still special schools in this country that do not even <u>offer</u> a secondary curriculum – that's how low expectations are.

There are still schools in this country that fail to provide students with the communication devices they need to successfully complete their schooling – that’s how low expectations are.

How self fulfilling is that?

In Shut Out you will read of a young woman with a hearing impairment whose teacher refused to wear a microphone in class, because she said it “put holes in her clothes”.

That’s how low that teacher’s expectations were.

The student failed science that year.

The next year, though, she had a teacher who was willing to wear a microphone.

And she topped the class.

That’s how high our expectations should be.

Then there’s the story of a young 16 year old woman with an intellectual disability who wept with frustration and shame because she could not read or write.

She had the ability to learn to read.

But her school had not taught her to read or write a word – that’s how low their expectations were.

Our low expectations also reflect a lack of understanding of the benefits of inclusion.

I believe that we don’t work hard enough to keep kids with disabilities in mainstream schools because somewhere, deep down, we don’t believe it’s worth it.

Yet nothing could be further from the truth.

There is now strong evidence that children with disabilities do best when they are educated in mainstream settings with their non disabled peers.

There is also strong evidence to demonstrate that children without disabilities also benefit from a more inclusive approach to education.

A more individualised approach and a more innovative pedagogy which begins by looking at where kids are at and what they need in order to learn. Such an approach benefits every single child in the classroom.

So inclusion is good for kids with disabilities and good for kids without.

Why is it, then, that we are so unwilling to give it a go? Why is it then that parents are still told that special schools are best?

We lack will but di we also lack skill?

Is the real truth that many teachers feel they are not well equipped to meet the full range of situations that confronts them in the classroom?

Frankly, I believe kids with disabilities are just the canaries in the mine.

They are alerting us to the multitude of ways we are failing to address the learning needs of all children.

But perhaps the harshest criticism during the consultations for Shut Out was reserved for the disability service system.

Disability services are intended to provide people with the assistance and equipment they require to participate fully in daily and community life.

And tragically, more than half the contributors to Shut Out said services acted as a *barrier* rather than an *aid* to their full participation in the community.

The service system was characterised as irretrievably broken and broke, chronically under-funded and under-resourced, struggling against a vast tide of unmet need.

People said more time was spent rationing services than delivering them.

The focus is on minimising costs in the short term rather than maximising outcomes in the long term.

This short-sighted approach not only delivers a miserably poor quality of life, but ironically costs more because it creates a lifetime of dependence on government.

And because the system is so highly rationed the responsibility for filling the gaps falls on families.

It is these families who are struggling with high rates of physical, emotional and financial stress.

Ageing parents spoke movingly of earlier on sharing and supporting their then young adult's dream to move out of the family home into a home of their own.

But the dire lack of suitable accommodation and lack of adequate support put an end to that dream.

Now both children and parents are old and stuck in desperate situations.

It is these aged parents who are in the tragic position of hoping that their children die before them.

Shut Out graphically demonstrates the ways in which all systems are failing people with a disability and their families.

And unfortunately things are only going to get worse.

For example, just in the area of disability services alone, current spending already exceeds $6 billion a year.

The Rudd Government recently committed to a real increase in funding for disability services of 3 per cent per annum – above and beyond CPI – over the next five years.

After so many years of neglect, the government is to be congratulated for this unprecedented increase in spending.

But it’s not enough.

The problem is that growth in demand is anticipated to exceed 5 per cent per annum.

And if this growth continues, the current spend on disability services will need to double in the next 14 years.

This would mean that funding for schools, kindergartens, roads, trains – all of it – would have to be redirected to disability services.

And that would be for a system that keeps people on a drip feed of a lifetime of misery.

Projections show that over the next 70 years the growth in the group of people with a severe disability will be between two and three times population growth as a whole.

At the same time the number of unpaid carers is expected to decline markedly.

So it is no exaggeration to say that we are at a crossroads.

Now is the time to plan and act.

The situation confronting us is remarkably similar to that which confronted Australia in the 1980s.

Then it was projected that the number of people relying on the aged pension threatened to overwhelm the tax system.

Recognition of that problem led to the introduction of compulsory superannuation – a safety net that Australians now take for granted.

The consultations for Shut Out threw up an idea that had been around the traps for a little while – the idea of a **no fault National Disability Insurance Scheme.**

Australia-wide people see that we clearly cannot continue the way we are going.

To do so would be both socially and financially irresponsible – even scandalous.

We need a safety net for individuals and a safety net for the country.

A National Disability Insurance Scheme would be such a safety net.

There are many misconceptions in the community about such a scheme.

But in reality the concept is very simple.

A National Disability Insurance Scheme would provide funding for early intervention, essential care, support, therapy, aids and equipment, home modifications and training.

Most importantly, it would provide this early on in order to maximise potential, facilitate independence and ensure planned transitions over the life course.

The scheme would, in short, provide people with what they need, when they need it to ensure they reach their full potential.

And the scheme would provide assistance to all people with a disability no matter how they become disabled.

It will put an end to the current inequities that see people receiving different levels of support depending on how their disability is acquired.

It shouldn’t matter whether you are born with a disability, acquire one through a car accident or develop one through a serious illness.

Everyone should be able to get what they need when they need it in order to lead as full a life as possible.

This is clearly a socially responsible idea.

But what people don’t understand is that it is also an economically responsible idea.

The social insurance model, with its focus on the assessment of the lifelong needs of the individual, provides an incentive to reduce overall costs.

Such a scheme will have an inbuilt incentive to maximise independence.

Such a scheme will have an inbuilt incentive to maximise opportunities for participation and productivity.

And because participation and productivity would be maximised, there would be savings not only in the disability service system but in health, income security and other programs.

This idea is uniting the disability sector.

For the first time in this country, Carers Australia, the Australian Federation of Disability Organisations and National Disability Services have formed an Alliance to campaign for a National Disability Insurance Scheme.

People are mobilising.

The list of organisations pledging their support grows every day.

There is a genuine sense of excitement that after so many years of struggle we might just be on the cusp of real life changing reform.

But support for the scheme goes far beyond the usual suspects.

The ACTU support the scheme.

The AMA, who are here with us today, have also come out in support of the scheme.

And I’m delighted to tell you that the Pharmacy Guild just this morning has also announced its support.

Media across the country have picked up the issue.

It is the right time. The Rudd Government is interested in genuine and lasting social reform. And credit must go of course to Parliamentary Secretary Bill Shorten and Minister Jenny Macklin for raising the profile of disability issues and for undertaking the government consultation process which lead to Shut Out.

And now to major reform through the National Disability Strategy.

The issues raised in Shut Out will not be ignored. The voices in Shut Out will not go unheard.

The National Disability Strategy that will ensure the full participation of people with a disability in the life of our nation.

We need this strategy to put an end to the daily discrimination experienced by people with a disability – in jobs, in life.

We need this strategy to ensure that public transport, buildings, public and private housing, parks, footpaths, playgrounds, swimming pools, schools and community facilities all become accessible and inclusive.

We need this strategy to ensure that education in every State is reformed so that children with disabilities have a future.

We need a National Disability Strategy to ensure disability becomes the responsibility of every government department.

For far too long disability has been seen as the domain of welfare. It is seen as one department's problem. And while it remains contained in this welfare silo, very little progress will be made.

Disability is in fact the responsibility of every minister in every portfolio across every level of government.

It's the responsibility of every Premier of every state. It's the responsibility of every Mayor and CEO in every municipality across the country.

Disability must be on everyone's agenda.

I've focused today on what governments could and should do.

But governments cannot work in isolation.

Real, lasting change will only be achieved in partnership with the community.

This means the business community, non government organisations, local grass roots communities – and, importantly, the media.

Much work needs to be done before Australia is a truly inclusive nation.

An inclusive nation is one that celebrates and embraces diversity – and disability is core to diversity.

An inclusive nation ensures that every citizen has the opportunity to fully participate in the social, cultural, civic and economic life of the country.

So I would like to ask you to do something for me.

Take a copy of Shut Out with you today.

Read it.

Get others to read it too.

When you read this report you will find that many of the people you are reading about are not that different from you.

They have the same hopes.

They have the same needs.

They have the same rights.

They live in your cities, in your suburbs and in your towns.

But they are shut out of the life you take for granted.

Read about your fellow Australians and ask yourself – how would you feel if the person who was shut out was you?