

Transcript

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Item: **ADDRESS BY DR RHONDA GALBALLY AO, CHAIR - NATIONAL PEOPLE WITH DISABILITIES AND CARER COUNCIL, SPEAKING ON "SHUT OUT - LIFE FOR AUSTRALIANS WITH A DISABILITY & THEIR FAMILIES" REPORT LAUNCH**

INTERVIEWEES: RHONDA GALBALLY, NATIONAL PEOPLE WITH DISABILITIES AND THEIR CARERS COUNCIL

| Demographics: | Male 16+ | Female 16+ | All people | ABs | GBs |
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KEN RANDALL: Ladies and gentlemen, welcome to the National Press Club and today's National Australia Bank address. It's a great pleasure today to welcome Dr Rhonda Galbally, chair, as you've just heard, of the National People with Disabilities and Carer Council.

Dr Galbally is an exceptional leader and organiser who's applied those talents over a span of some 25 years to help and in many cases create a wide range of non profit community organisations.

She's made a huge contribution to Australian and international social development through her work in building social infrastructure. Today, she'll discuss the report Shut Out: Life for Australians with a Disability and their Families [sic].



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This report that was completed, recently, by the National People with Disabilities and Carer Council, and it's the first to provide, really, a comprehensive picture of what it's like to live in contemporary Australia for people with disabilities and their families. It's not a pretty picture, but I'll leave it to her to spell out the details. Please welcome Rhonda Galbally.

[Applause]

RHONDA GALBALLY: Thank you, Mr Chairman. Members of the National Press Club, friends - and you're all 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're a son or daughter of this sunburnt country?

One answer we might expect would be a citizen with the same rights as everyone else. But if you have a physical, sensory, psychiatric, or intellectual disability, what is life really 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, and 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's syndrome goes to a café with a group of his friends. The café's in a public park. The young man becomes separated from his group. Lost, he walks around the park looking for his friends and he comes to a playground, and there are some families in 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. And now the young man is scared, and he tries to ask some of the adults at the playground for help.



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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, and 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, and 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, and that's my city where I come from - Melbourne, a city that's supposed to be one of the most liveable cities in the world, but liveable for whom?

Not that young man.

One study found that people with a psychiatric or intellectual disability will have a negative social experience within 15 minutes of leaving their home.

Australia is not a liveable country for people with a disability, and I could tell you so many stories - 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 the 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 5 pm because the staff say so, unable to help themselves to food from the locked fridges, 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 either of them to go. Or the ones about the people who will sleep in their wheelchairs tonight because there's no-one around to help to get them to 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 - and each with its own heartbreaking punch line. And you will find them in this report, Shut Out. And Shut Out is a unique document, it's unique because the Rudd Government established a nation-wide consultation, asking people with disabilities and their families two important questions: what is your life like now? And what would you like your life to be like? And no Australian Government had ever asked people with disabilities and their families those questions before.

And the response was overwhelming.



More than 760 individuals and organisations made written submissions, and more than 2500 people attended public consultations right across the country. I saw the submissions, and I chaired the public consultations around Australia, and I heard from the people. And I'm not new to the disability sector. I've 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 denied access to housing, to employment, to education, to healthcare, to employment, to education, to healthcare, to recreation, to sports, to arts, to the very things most people in the community take for granted.

I heard that they are denied access to childcare, to kindergartens, to schools, to shopping centres, to 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 institutionalisation 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's 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 on to say I believe it is the last frontier of practical civil rights in this country. And he is right. This is a frontier that's 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. Earlier 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.

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. And all the research points to the same conclusion. Child



development starts from day one. Emphasis on the early years therefore has a huge payoff, both for 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 the best possible start in life were being stymied. Stymied by long waiting lists and very limited availability. Early intervention is more like barely intervention. And make no mistake, this short-sighted approach is not just hurting those children, it's hurting our nation. We're paying for this false economy through lost potential, lost productivity, and a lifetime dependence on governments' support.

If you don't believe me, let me tell you about two brothers. Both have a diagnosis of Autistic Spectrum Disorder. And despite their common diagnosis these brothers are now travelling very different paths. When the older brother was diagnosed his parent's 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 early on 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 extensive therapy.



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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.

And now we come to school. And 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



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completed Year 12 compared to people without disabilities. And as a result they are far less likely to 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 those children. There are still special schools in this country that do not even offer a secondary curriculum. That's how low our expectations. There are still many schools in this country that fail to provide students with communication devices that they need to successfully complete their schooling. That's how low our 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 would put holes in her clothes. That's how low that teachers 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.



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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 and write, 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 from all around the world and Australia that children with disabilities do best when they are educated in mainstream settings with their non-disabled peers. That's the evidence.

A more individualised approach and a more innovative pedagogy begins by looking at where kids are at, and where they need in - what they need in order to learn. And such an approach of course benefits every single child in the classroom. So inclusion is good for kids with disabilities, and good for kids without. So why is it then that we are so unwilling to give it a go? Why is it then that parents in many states are told - still told that special schools are best? We lack will, but do we also lack skill? Is the real truth that many teachers feel that 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, 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. And this short-sighted approach not only delivers a miserable poor quality of life, but ironically it costs more because it creates a lifetime of dependence on governments. And because the system is so highly rationed, the responsibility for filling the gaps falls on families. And it is these families who are struggling with high rates of physical, emotional, and financial stress.

During the consultations, ageing parents spoke movingly of earlier on, sharing and supporting their



then young adults 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 disability and their families. And unfortunately things are only going to get worse.

For example, in the - just the area of disability services alone current spending already exceeds \$6 billion a year and the Rudd Government recently committed to a real increase in funding for disability services of three per cent per annum above and beyond CPI over the next five years. And 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 five per cent per annum and if this growth continues, the current spend on disability will need to double in the next 14 years.



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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 lifetime that keeps people on a drip-feed 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 the population growth as a whole.

And 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 has 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 we need 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 and most importantly, it would provide this early on in order to maximise potential, facilitate independence and insure planned transitions over the life course.

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

And the scheme would provide assistance to all people with a disability no matter how they become disabled. And it will put an end to the current inequities that see people receiving different levels of support depending on how the 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 life-long 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.

The 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.

And support for the scheme goes far beyond the disability sector. The ACTU supports 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 announced its support.

Media across the country have picked up the issue. It's the right time with the Rudd Government 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 led to Shut Out and now for 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 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 the strategy to ensure that public transport, buildings, public and private housing, parks, footpaths, playgrounds, swimming pools, schools and community facilities, that they all become accessible and inclusive.

We need this strategy to ensure that education in every state is reformed so the children with disabilities have a future. We need a national disability strategy to ensure that 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 every 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 can't work in isolation. Real, lasting change will only be achieved in partnership with community. This means the business community, non-government organisations, local grassroots communities and very 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 that country. And that includes people with a disability and their families.

So I would like to ask you to do something for me; to take a copy of Shut Out with you today or to download it from the website and read it and get others to read it too. And when you read this report you'll find that many of the people you are reading



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about are not so 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 that 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?

[Applause]

KEN RANDALL:

Thank you very much Dr Galbally. As usual we have a period of questions from our media members today, starting with Suzanna Dunkley.

QUESTION:

Hi, Dr Galbally. Oh is that on? I'm Suzanna Dunkley from Australian Associated Press. I have a couple of questions for you regarding working for people with disabilities.

The report highlights just some of the difficulties that people with disabilities face getting into the workforce. And I understand that in some countries like Germany they have schemes in place where employers are required to have a certain percentage of their workforce with disabilities. I'm wondering is that a scheme you'd like to see in Australia, and could this be extended into the classrooms, into mainstream schooling perhaps.

My second...

KEN RANDALL: Let's deal with them one by one.

QUESTION: Okay. Yep.

RHONDA GALBALLY: Look I think the question of targets is a really good one and I'm personally very interested in them because I think it does set a benchmark. One of the arguments against targets is that many people with disabilities in workplaces don't want to be identified as having a disability. And that's okay, if they don't want to be identified then so be it. But still to have a target is a good idea. And you know I'd love to start with Government. With State and Federal public service, I mean I have to give a bouquet to South Australia because they've done very well in state public service in recruiting and retaining people with disabilities, and they have a particular way of doing that. And if they can do it, so can every state and so can the Commonwealth to set an example.

But then, you know, I do think targets are worth thinking about.

Another idea would be for procurement. You know there's massive contracts going out to businesses for procurement for Government services in buildings and capital works. It would be great to have this in procurement documents too as targets. That would be very valuable.

I'd like to add the non-government sector too because I know many are here today that I actually



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don't think there's enough employment in non-government organisations of people with disabilities either, and I think that's a real pity.

KEN RANDALL: Suzanna.

QUESTION: My second question was to do with rising unemployment and the global financial crisis. I'm just wondering if you've heard anecdotally on the road how this has affected workers with disabilities. Have they been the first to lose their jobs?

RHONDA GALBALLY: Yes we have heard on the road that it's been much tougher. And, you know, this is despite all the - again the research and the evidence that people with disabilities are wonderful workers; loyal, hardworking, extremely productive. So again it's about mythology and discrimination. And I think that's part of the story that that has to be tackled too.

KEN RANDALL: Next question's from Mark Metherill.

QUESTION: Mark Metherill from the *Sydney Morning Herald* and *The Age*, doctor. Can you tell me how much do you estimate a national scheme would cost? And are you hopeful that the Government will make the promise of such a scheme part of their election pledge for the next election?

RHONDA GALBALLY: There's a high level org... committee that has been set up by the Government called the Disability Investment Group, and they're about to report, I've



heard. And they've crunched some numbers about cost that will be released, I would imagine, before the end of the year.

But we really do need a feasibility study for such a major initiative. There wouldn't be anything - I mean, Medicare and national superannuation would be the two parallel where they had major feasibility studies before they were launched.

But the answer to your question really overall is that I don't believe we can afford not to do something because the numbers really are disastrous. And the beauty of an insurance model is that you load up the early end. You load up the end that really gets people back into life. So you load up early intervention, you load up equipment, home modification, education, retraining, everything you need to do to get people to live a life.

And that's why it's such a great model and, in the longer run, is the economically sensible way to go.

But there will have to be a feasibility study. And so - you know, that would be great if that was in there as a pre-election initiative. That would be great. And I'm hoping that will be underway pre-election.

I think there's an appetite. I think it's the right time. I think all the stars are aligning. We've got a government really interested in genuine social reform. We've got an incredibly activist



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parliamentary secretary, an extremely good minister, good Cabinet. And I think it's the right time, really.

KEN RANDALL: Thank you. Question from Jon Millard.

QUESTION: Thank you Ken. Jon Millard, ArtSound FM.

Dr Galbally, some things, physically for the disabled, physically disabled have improved over the years. We have more ramps and what have you. And even the National Press Club here has been dragged kicking and screaming into the latter part of the twentieth century and installed a lift.

[Laughter]

But many things that we need - that disabled people need are very, very expensive, as you well know, we both know, whereas you can go to the hospital - public hospital - for a life saving operation or to get a limb splinted or something like that. If you want a wheelchair or orthotic device you pay commercial rates, even in a public hospital and sometimes regardless of a person's income. You and I might be able to afford it but many people can't, and it affects their quality of life.

Do you see this as an anomaly in our system and are you bringing this to the attention of the parliamentary secretary to the minister?

RHONDA GALBALLY: Look, I think it's a really important question and it's interesting that you raise the issue of the life saving operation which would cost hundreds of thousands often. And you compare that with a wheelchair where there are children in Australia who by the time they get their wheelchair they've outgrown them because the waiting list for aids and appliances is so long.

And, I mean, this just doesn't make sense because the equipment - you know, from a wheelchair to communication devices when people can't speak, or especially children when they're learning, that you just need. And so if you don't have the equipment you can't get an education or you can't get to work. Or if your wheelchair - what did I hear on the road? I heard that one young woman, her wheelchair breaks down - it's so old, an electric wheelchair - once a fortnight and she has to take a day off from work waiting for someone to come and fix it.

This is lunacy. This is just madness. And this is - it's nobody being bad. It's a system that's rationed where it's short-term. And that's why to get a whole reverse of the system, that you do get in social insurance models, where you want everybody back to school and to work and retrained because then they'll get work or then they'll get out into the community and live productive and full lives. And then of course, you know, their health and wellbeing is better. I mean, there's a lot of evidence that if you're in the community participating, your health and wellbeing is much better.



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So there are savings everywhere.

KEN RANDALL:

Dr Galbally, let me ask you a couple of questions.

The first one is, from what you've said today, obviously there's a major lack of appreciation of the scale of this issue in the community. Some of the stories you were telling would probably shock people but if they thought about it, probably not surprise them all that much because they've lived with it for so long.

To get effective political action, you've surely got to change that. How would you go about a program of cultural change to get a greater realistic awareness of the implications of disability?

RHONDA GALBALLY:

I think that's a big question. And the easy solution that in all - much of my work in health promotion and other areas, shows doesn't work in a lasting way, would be quite expensive advertising campaigns.

But the thing that does work is people being out there, being school mates, you know, being in kinders, being in childcare centres where parents are together, being in jobs. So being out there is number one.

And, you know, I hear - I heard all around Australia but I hear every day, about junior sporting groups - this is groups of little kids having fun, having a bit



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of a play and a game - refusing to allow children with disabilities to play because they might not win the game. Well, I mean, that's got to stop. And there can be mechanism to not allow the funding to go to parent bodies if there's any junior sporting group excluding children with disabilities. In fact, you could have a requirement that they include them. Community houses and neighbourhood houses running segregated courses because you have a disability. I mean, all that has to stop because all that stops attitudes changing.

But I hate to end my answer to that question on a very sad note. But what happens if we don't change attitudes, it's really tragic. And there was a case just this year in Frankston in Melbourne of a young man with psychiatric illness, where young men tried to set him alight. And he was living independently, living a good life, independently in the community. And now he's living in a nursing home, like he'll never live in the community again; he was very severely burned. And these young men - that's what community attitudes are about and that's why we've got to do things that are more profound than ad campaigns.

KEN RANDALL:

The other thing that struck me forcibly about your speech was the - as I said, the breadth of the issue and the lack of recognition of the scale of it.

How do you think, in public policy terms, this issue should be placed? Bill Shorten is doing a good job but, you know, we've got ageing linked with health.



We've got disability linked with families and community services. Do we have enough people with the breadth of knowledge of the scale of the whole thing to establish a separate standalone policy department?

RHONDA GALBALLY: Well, to me, the issue isn't whether you set up a separate standalone policy area. I know some people in the community think that's very important. But I'm much more interested in getting things done, and I personally think that having it in a department that's got a large budget is very important.

[Laughter]

I think having it in a department where we've got a parliamentary secretary who, for the first time - probably since Don Grimes, who some of you who are as old as me will remember Senator Grimes - but certainly Bill Shorten is out there telling it as it is in a way that I personally find incredibly encouraging; to have someone really prepared to stand up and say, right across Australia it's not - it's bad, it's got to stop, you know, something has got to happen. And then, with the minister, Jenny Macklin, with a national disability strategy that will, I'm hoping, be a very sophisticated strategy with the states and not just in family and community service ministries. But I'm hoping for a council on Australian government process in education, in every - in health, in every area that relates to disability. That's what I believe will happen.



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And so this is very exciting. I mean, I know this sounds a little bit like jargon, talking about COAG and Australian Government with the states, but that's when things really get done. And I think that we're in the right - that's what's going to happen and that's what matters.

And I'm afraid to say we have seen standalone units like - and even, you know, with proud names that really haven't achieved much. So they can be symbolically great but I'm not interested in symbolism, I'm interested in outcomes. We've got to get change.

KEN RANDALL: So, really, what you say there, I suggest, is that standalone ones become competitive with others; it's better to integrate it into every portfolio.

RHONDA GALBALLY: Well, you know, unless the standalone one has a very sizeable budget and has massive influence, massive influence.

KEN RANDALL: Next question is from Peter Phillips.

QUESTION: [Coughs] Dr Galbally, Peter Phillips - excuse me - one of the directors of the National Press Club.

Thank you very much for your address. I'll certainly read *Shut Out* and will urge upon others that they do so.



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But to my question, Jon Millard has a bit of a habit in this forum of stealing questions which I was about to ask. But...

[Laughter]

... with the deftness and the agility that only directors of the National Press Club can manage, I'll hasten forward and go to the issue of access, disabled access. The National Press Club isn't the only institution in the country which in recent times has improved its capacity and its offering in that area. It seems to me that across all levels of government in Australia, over the last couple of decades in particular - local government, state and territory government, national government - there's been an improved mandating of the provision of services for disabled access. But, clearly, it isn't anywhere near enough yet.

I haven't yet read *Shut Out* but what are the specifics that you, here now, can recommend that governments should look to first for great - further great improvement in physical access for people with disabilities?

The second question, which Jon Millard hasn't yet stolen, is...

KEN RANDALL:

Let's do them one at a time...

QUESTION:

... the impression...

KEN RANDALL: Let's do them one at a time, Peter.

RHONDA GALBALLY: Look, I think the question of physical access is really important. I'd like to throw in though the issue of deafness access, you know, of audio loops and all the things that are needed that should just be built in. And, you know, to say that I'm - you know, the building code and building standards improvements are very welcome but not enough. I won't go into the technical details of those. And that's great to think that this government got started with that immediately they came in, you know, because they'd be sitting around with the previous government for about five years which was really hopeless, absolutely hopeless. So that's good.

In Victoria, we're hoping that there will be a new regulation passed that makes private housing downstairs and apartments accessible. And this makes sense of course for an ageing population. I mean, in countries around the Western world it's just taken for granted. In Sweden and Scandinavia it's been in since 1975, in the UK for 10 years. But in Australia, still struggling. So we're going to have a real problem with the housing of the ageing population.

And then I come to the local level, and this is where I really appeal, please mayors and CEOs of local government do something, you know, because you can't get in to playgrounds. There are playgrounds being built, as I speak, where if you have a disability as a parent or you have a child with a



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disability, you just can't get into play. So not only are they excluding people such as the Down Syndrome man I spoke about - that's emotional exclusion that's very cruel - they're not allowing people in.. So that's disastrous and that - there's swimming pools, there's footpaths, there's recreation facilities. Local government is responsible for an enormous amount and it's extremely patchy, you know, really patchy. You get some that are great.

And, for everything I've said today by the way, you get some schools that are great, you get some local governments that are great, but the vast majority are just disastrous.

KEN RANDALL: Peter.

QUESTION: The second question was, one has an impression that there is a wider spread and a greater number of disabilities across the total population. There's an increase going on, as we speak. Is it that we are confronting the ageing population phenomenon or is it more widespread than that? Can you offer us a comment on that impression?

RHONDA GALBALLY: Look, it's - certainly the ageing population is very much a part of it.

I think this is a really crucial question because sometimes I get asked this question, and I get asked it at ethics conferences; you know, should people



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with disabilities not be born. And I'm a woman that has always supported right to choose, so I want to say that upfront, but I'm strongly of the view that people with disabilities add an enormous value to the Australian society.

But I'm strongly of the view that people with disabilities add an enormous value to the Australian society. I think it is diversity, like we hear about diversity being all sorts of things, but people with disabilities are about emotional diversity.

And they add value. They make people really be a humane, compassionate, and warm society, and empathic. And what's the point of having an Australia if it's not like that?

You know, so, I could go through lots of reproductive technology and all sorts of issues to do with why numbers are increasing, but really, I think the more important point is, this is valuable. If we want a society that's sort of somewhat about eugenics, well I don't want to be here really. I'm going to go somewhere else to live.

KEN RANDALL:

Murray Shriver(*).

QUESTION:

Dr Galbally, I'm pleased you're out here. You've [indistinct] today. My question, in your travels and the consultation around all of Australia, I just wondered whether you had any sort of significant comment or complaints about you know, the



different levels of governments, and the different levels of services, and how they differ between states. And you haven't really mentioned it in your report.

And I just thought you could make some comment whether the coordination between governments is a very difficult task, as it often is between the federal and state level. And I notice you gave South Australia a bouquet, which is very rare at this forum I might add...

RHONDA GALBALLY: About jobs.

QUESTION: About j... I wonder if anyone, in any of the state governments deserves a brickbat today?

RHONDA GALBALLY: I think this is a question about how not to win friends and influence people, and I'm going to try and sidestep it a bit. Look - to answer the question about coordination with federal and state, I think it's going very well around the service area. I think it's better than ever before. And I think a lot of credit has to go to the Federal Government and the state governments for that highly cooperative approach.

I think it's going well.

Local government's a complete - look, I don't want to speak too strongly, but it's a real basket case. You know, how do you get local government in there to do anything? You know, like, and, you know, I was



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very interested in the mayors gathering in Canberra, where I don't believe the word access for people with disabilities was mentioned; and with the money that went out for the recovery money, where I don't believe that this issue for retrofitting, you know, all the things you could have done with that money - boy, would I have loved to have spent it at local government level.

And it's because it's just not on the agenda.

So I think local government is a real problem. And if anyone's got any ideas about how to make it work better I'd love to hear from them, you know, in a coordinated way: not where you have to go to all 800 or 790 of them, one after another, to get this issue really on agendas.

You know, I think that that's what - when I talk about the relationships between Commonwealth and state, working well in the disability service area, education, it has to work well there, with the topic of disability on that agenda. You know, disability has to be on the COAG discussions in the education area, and it has to be strongly on that agenda.

It's not just about league tables, and, you know, which schools are best in reading and writing, it's which schools are best in educating children with disabilities. That should be what's counted. That's very important.

KEN RANDALL: You in the mood to deliver brickbats today?

RHONDA GALBALLY: Um, I'm trying to avoid it. I think all states are, you know, I think there's a lot of talking going on and a lot of changing. I'm hoping a lot of improvement. There are some states that are better than others, obviously, and you know, the sad thing is is that I have to say that when people can afford it, some people will even move from one state to the other - and that's really tragic.

And when people can afford it, some people will move from one region to another when states are highly regionalised, and people certainly move from one local government authority to another - and that's really terrible to have to move to get what you should be getting.

But I have avoided that question.

KEN RANDALL: Thank you.

RHONDA GALBALLY: I'm a diplomat in my old age.

KEN RANDALL: Yeah. Let's go back to Mark Metherell.

QUESTION: Doctor, the horrifying stories [indistinct due to audio problems at press club]... sorry. The horrifying stories you've told that came up in the Shut Out report about the antagonism shown towards Australians with disability - is this



something if not peculiar to Australia, how do we compare with other nations?

Do we have a problem here in terms of accepting and embracing people with disability or less?

RHONDA GALBALLY: Look, I think that every country has a problem with accepting and embracing people with a disability because disability reminds people of the fact that they're not, that they're flawed, that every human being is flawed. You know, and I think there's some myth around of perfection - you know, that you, we hope for a perfect child, a perfect society. We hope that nobody gets old like we a... we hate ageing. We hate illness. We hate dying.

And these are all the things that people with disabilities remind people of just in being out and about.

But other societies have systemically decided that this is wrong - and they've done things, they've transformed their education systems, they've made their societies completely accessible, they've change... they've m... you know, people aren't shut out, they're welcomed in, and once people are welcomed in, then the whole society gains.

Because people's fear declines.

And I really think people are far more comfortable in their own bodies when they know they don't have



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to be this figment of the imagination, the perfect person. I think it makes everybody much more relaxed. But not when it hasn't been fixed, you know. So we act as a country as though we do hate disability - because we haven't done nearly enough about fixing it.

KEN RANDALL: Thank you. A final question today from John Millard(*).

QUESTION: [Indistinct] Ken. Dr Galbally, you've mentioned horrific stories like the kid with Down's syndrome, and the way he was treated in society. Perhaps in some ways though, the treatment of people with disabilities has improved, and [indistinct] to the other extreme, you can get people who go out of their way to be - compensate for people's disability to the point of patronisation.

How do you think that you strike that balance between disrespect, patronisation, and how - more importantly, how do you educate the public as to the appropriate attitude to people with disabilities?

RHONDA GALBALLY: I think that little children in childcare in kindergarten and school, you know - when you go to a school that's, you know, terrific mainstream school that isn't failing children, because I should have added of course that mainstream schools do fail children with disabilities - but when you go to a school that isn't, where it's, where there are children with disabilities and children without, and they're



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all just sitting together and learning together and playing together and in the schoolyard together, then, things change profoundly.

Like, that's what changes things profoundly.

And people go on to grow up. And they become friends and lovers and partners and you know, it's just ordinary. It's just ordinary life.

So that's the way to change attitudes.

I really really do think that, really transforming the early years - and of course not forgetting about the later years - it absolutely transforms society.

KEN RANDALL: Thank you very much.

[Applause]

Dr Galbally, on behalf of this very large audience here today, exceptionally large audience here, thank you very much for the past hour. I hope that your report achieves significant results, and with your club membership which you'll get today, you might be able to come back and talk to us about it. Thank you very much.

RHONDA GALBALLY: Thank you very much.

[Applause]



KEN RANDALL: That's it.

RHONDA GALBALLY: That's it, thanks very much, yeah.

* * **END** * *

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