

**Speech Outline of
The Hon Bill Shorten MP, Parliamentary Secretary For Disabilities and
Children's Services**

Community Visitor Annual Meeting
Wednesday 30 June, 11.00am to 12.00pm

I am a union man and I believe that advocacy is important.
I believe that people who are pushed to the margins of our society need their champions.

The work you do to promote the rights of people with disability, with mental illness, or in institutions, and to protect them from the exploitation that is too often the lot of the powerless, is vital.

You are volunteers who devote your time to making the case that people with disability should be treated as equal citizens, not as a burden or a nuisance, or somehow less than human. Your work slowly changes attitudes across the community and changes them for the better.

It is your dedication which supports services and actions that promote the rights of people with disabilities, while protecting them from exploitation and abuse. You are fighting for the civil rights of people with disability who have been left out.

I commend you on your commitment and ask that you keep up the good work because I know a lot of people are counting on you.

Like many other organisations that work with vulnerable Australians, you rely on volunteers. I suspect that you feel a lack of money and time to do the work that is required, and a feeling that there is more need out there than you can address. I believe that feeling is widespread across groups that deal with disability.

Disability/ Productivity Commission Inquiry into NDIS

Disability has been a 2nd-order issue politically for too long.
It has been seen as important but never as urgent, or urgent enough for a radical change in the way we do things.

I think there is a consensus that we can not keep going the way we are. We cannot continue putting blood, sweat and tears into systems that are inadequate today and will be overwhelmed tomorrow.

This is why the Federal Government has asked the Productivity Commission to investigate the possibility of a disability insurance scheme.

I believe such a scheme is the best way to deliver a better deal to people with disabilities and their carers.

The best way to move away from a situation where support is rationed, where early intervention is limited and where there is a terrible uncertainty about the future for too many.

There are 2 million people with disability and carers who currently do not have a united voice.

I believe the disability sector needs to unite behind the idea of an NDIS¹ if we are to achieve anything. I'm talking about uniting behind reforms that are achievable and will make a difference to those two million involuntary internal exiles.

If this is it, now is the time for the disability community to adopt it as a cause — and campaign for it.

I'm not saying that to abrogate the Government's responsibilities. I am a believer in Government, and a passionate supporter of what this Government is doing in disability. The point I am driving at is this:

I do not believe Government can provide the whole solution. The challenge is too great for Government alone.

We need to enlist corporate support.

We need to raise public awareness and understanding.

We need all hands to the wheel.

We can get further faster if we educate and enlist the support of the general public and business community.

I think we are on the verge of a transformational change in the way we deal with disability. We are that close.

But we will require a strong and united, ebullient, strategic and well-funded campaign to make it a reality. A campaign like no other the sector has seen.

We need to make the moral, economic and political arguments for an insurance scheme.

We need to be unified.

We need to be organised. And we need to be motivated.

Many of the details of the scheme are yet to be worked out. There will be complexities, arguments about scope and definition and how best to structure it, and how best to administer it. But let's not be diverted or delayed from our goal.

Our goal is transformational change.

The kind of change that will put Australians with a disability on a secure footing, and deliver gains that cannot be wound back. Some people say this is a once-in-a-generation opportunity for social and economic reform.

I don't.

We can't afford to think the chance to implement a National Disability Insurance

¹ National Disability Insurance Scheme

Scheme will come around again in a generation if we miss this chance.

We need the sector to be vocal and united, to be loud and proud, to be organised and to be political, to be consistent and persistent.

When Governments hear a babble of voices from any sector, advocating competing or conflicting demands it is easy for all of those demands to be ignored. When Governments are repeatedly confronted with the same message, the same demands, the same visual evidence, the same cries of the heart – they have to listen. When a sector is fragmented, disorganised or riven by turf-wars, it will end up fighting over a shrinking power, rather than a power.

My time in the union movement as an organiser taught me that 95% of a successful campaign consists of uniting people behind a common set of demands.

Success is overwhelmingly preparation of the base, not contact with decision makers.

Success is overwhelmingly an understanding by the base of the demands.

Success is the creation of an overwhelming inevitability.

As leaders of this sector, I look to you to play the role of an organiser and unite those with an interest in disability behind a common theme.

Generally speaking, the Australian people are not malicious about disability. A vague sympathy is felt, but there is no empathy. Australians in general don't understand the magnitude of the crisis, nor the level of pain and sorrow.

Not yet.

But they can and they must understand.

We need to turn that sympathy into empathy.

We need to make Australians understand that what is happening to people with a disability could happen to them.

If we can do that, we create the overwhelming inevitability necessary to succeed. That's why we need to keep driving home the point that an NDIS will deliver huge benefits for people with disability and should not, in the long-term, lead to an increase in taxes or government budgets. It is the Productivity Commission's job to crunch the numbers, and to work out what can be afforded and how, but it is clear to me that we are already spending a lot of money on disability.

Australian governments already spend around \$22 billion a year in total on the disability welfare system.

- Around \$8 billion goes towards payments to community care and support providers;
- Nearly \$3 billion is for payments to family and other informal carers;
- And almost \$11 billion goes towards income support through the Disability Support Pension for more than 770,000 Australians.
- Add to that the indirect costs of disability — such as the cost of keeping people with an intellectual disability in jails, the cost to the health system of

disabilities diagnosed and treated too late, and the economic cost of making it impossible for countless Australians to participate in the workforce.

What am I driving at? The current system is not working — and is not cheap.

We need to make the case that sticking with the current system is a false economy.

We need to make the case that an insurance scheme will save money in the long-term – as will any policy that intervenes early and moves people from unemployment to work.

It is also my belief that no political party "owns" this issue, and that a big proportion of voters are genuinely undecided about who serves people with disability best.

What is needed is for the disability issues to move from the "important" basket into the "urgent" basket, from problems that we should deal with in the future to ones that must begin to be tackled now. The struggle for disability rights in this country has been a slow one.

At times it has resembled trench warfare, a series of bloody battles to push forward a few inches and secure a tenuous foothold for the next push. I think many in the disability sector believe it will always be thus, a case of slowly chipping away at established structures. But there are also periods when things can change quickly, when societies begin to question their entrenched prejudices and attitudes, and the actions of a few leaders can have a tremendous impact. When creative and dedicated minorities can remake the way we think and the way we live.

In the 1960s, the struggle for Aboriginal rights went from a battle to be counted in the census, through the right to vote, through equal wages, to the establishment of land rights within a decade.

In a time of social flux strong and united leadership persuaded the Australian public of the justice of the indigenous cause, to the point where 90 per cent of Australians voted in support of indigenous rights in the 1967 referendum.

A lot has improved for people with disability in the last generation, but it is still the case that the myths and fears the general public holds about disability are as limiting as the condition itself. It is not my intention to blame the disability sector for this situation, or to ignore the fact that Governments must do more.

I have seen the pride and energy of the disability sector and the work that you do, but I have also seen the opportunities lost through a lack of co-ordination. I have the paths not taken, the door not opened, the key not turned, into a better way of being, a better way of befriending change.

There is no way you can change an asymmetrical power relationship without pushing, without acting together and without political power.

We need to work to create a climate where disability is taken seriously as an issue, not just by the sector, but by the general public.

We need to work to change the hearts of humankind, to make them understand it is us, not them, who are bound in our lives to be in the end disabled, but some of us get there earlier, and need to be helped up the steps they have to climb.

We need to appreciate how close we are to real change.
Just as we need to understand the enormity of the task that lies ahead.

What am I telling you?

We're not there. Not yet. But we can be — soon.

Restraints

- There is something else I want to mention today which is a concern for me as Parliamentary Secretary for Disabilities.
- That is the use of chemical and other restraints on people with an intellectual disability.
- The number of young people with an intellectual disability, particularly autism, being subjected to physical or chemical constraint is far too high in Australia today.
- Victorian Senior Practitioner, Jeffrey Chan, found that in Victoria there are approximately 2,000 people in care facilities being restrained on an almost permanent basis.
- I should say that the use of restraint and seclusion is not peculiar to Victoria; it occurs in all Australian jurisdictions and in international jurisdictions.
- In fact Victoria should be congratulated for leading the way in monitoring and ensuring that standards are followed and complied with, particularly within a human rights framework.
- I believe it is a cultural problem which exists across all our jurisdictions and elsewhere it just as not been reported on with the thoroughness and openness that has happened in Victoria.
- Nevertheless, it is true that belts, body suits, solitary confinement and medication are being used to control behaviour in Victorian facilities.
- Dr Chan's report and recommendations urged a rethink about the treatment of 827 very vulnerable people he found to be living almost permanently under a heavy dose of drugs and other restraints.
- Most of these 827 had multiple disabilities, 35 per cent had autism and most were men aged between 15 and 44.
- Whilst restraint might be the right thing to do from a medical point of view and in some cases a health and safety point of view, there is no doubt in my mind that it is happening too often.
- It is a big thing to physically shackle a person, remove their independence and personality through medication, or put them into solitary confinement.
- It should only ever be considered as a last resort.
- It should not be a substitute for proper care and treatment. It should not be a solution which removes the need to address the causes of a patient.
- I do know that both New South Wales and Queensland are working on positive behavioural intervention teams Victorian Advocacy League for Individuals with Disability, has said that the level of chemical restraint in Victoria is something about which we should hang our heads in shame.
- The issue has been made a priority by the Australian Government.

We are working with the states and territories on a national mental health seclusion and restraint project. We want to establish national standards and find out the extent of this practice across jurisdictions.

We need national collection of data and national standardised definitions to inform policy and practice.

We also need groups like yours to keep reporting on the abuses of restraints and Victoria and advocating for a more balanced system.