



The launch of “It shouldn’t be this hard”: children, poverty and disability.

Speech by Colleen Brown

Deaf Society, Potters Park Events Centre, 164 Balmoral Road, Balmoral,

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Thank you for inviting me to help launch the report, ‘It shouldn’t be this hard’ for the Child Poverty Action Group. Congratulations on embarking on such a difficult, complex subject matter.

Sometimes it feels as though people with disabilities and their families live in a parallel universe to the rest of New Zealand society, almost a race apart. We have a different language, different world views; many of us are cynics, above all else some of us are survivors - not all, some.

Many of you will see me as a Pakeha woman, middle class, professional. And yes I am all those things and more; but above all else I am a survivor.

In the language of disability we talk about surviving the system, the indifference, the lack of Well a heck of a lot actually, the roadblocks, the constant challenges....every single day, on every front – health, housing, education, welfare and sometimes we are fighting on all fronts – and anyone with a smidgeon of military nous will know that fighting on all fronts is impossible. Our language is the language of struggle, of battles fought; won, lost, re-litigated. Undoubtedly this is a social justice issue, a civil rights issue – a basic human rights issue.

I am a survivor of 34 years fighting, arguing, and pleading, writing, cajoling, speaking, creating solutions, explaining, and educating – all for my son Travers who is a stunning young man who is now flattening with his mates, has a better social life than my husband and I do; can just fit us into his diary when we want to visit, spends his day helping others, doing sport, having a great time with people he loves and enjoys being with; and who enjoy being with him. I could list all of Trav’s disabilities but actually that’s not who Trav is – unfortunately that’s not the way the GAME IS PLAYED. Usually the game – the policy and disability game is played using the deficit model... what a person is NOT; is administered by state employees – so the person themselves gets lost, obscured and devalued by the

deficit model language of 'cant's', 'needs', 'categories', 'disability tags' that defines them within the system.

In this room I can see a number of other survivors. We are tenacious, passionate and at times fearless. Many of us are 'lucky' – we go against the odds for many in the disability sector – we have partners, parents, extended family/whanau, children and great mates who support us. We support and help each other – if we find a solution, we share it. If we have particular skills we share them.

And so you'll be asking yourself – if she finds the system difficult what about those who aren't all those things – Pakeha, educated, able to speak to other professionals as equals, understands the system, confident.

In short, they don't survive the system. **And this report is about those people.**

Alan is right. The most vulnerable in our society are children with disabilities; but the most vulnerable are Maori and Pacifica children with disabilities.

Rod Wills the parent of Sophie – another stunning young woman living in West Auckland who happens to have a disability wrote - "It is hard to be the parents of a child that no one else would want to have. It must be even harder for our children, growing up to be the one person that no one wants to be!" (Wills 1994, pp. 252-3).

What happens to those children that no one wants to have; and the parents that no one wants to be?

The report says it all – every day people with disabilities face extraordinary barriers to any kind of inclusion – it should not be the norm!! Unfortunately when you are consistently told you don't belong; you are different in a negative way, if you are too challenging, you just don't fit – then of course you believe the messages and exclude yourself.

Len Barton – an English writer and advocate in 1992 said,

Oppression is more than a denial of access and opportunity; it is about being powerless and viewed as essentially worthless in an alien society.

I would suggest that many children with disabilities and their families fall into this category.

Now you might think I'm angry, - well yes I am very angry – ten years ago I wrote a piece in the New Zealand Herald about how people with disabilities are invisible, the forgotten people until a crisis happens, then the people of New Zealand ask in outraged tones – how can this be?

How could a father/mother kill their daughter/son, they ask? How could a child be denied entry into a school in this country – the land of opportunity and fairness, they question. Well it happens. And more frequently than we'd like to admit. People are jolted into awareness about the current issue then a new issue will engage the public attention and curiosity and again we slide into obscurity.

I wrote ten years ago – 'Rights issues are a constant for us. They don't just pop up when there is a tragedy. When this item of news has faded we will still be fighting and battling for our children. The topic of the value of our children's lives is a continual debate for us. It is life as we know it.'

Years ago former Youth Court Judge Mick Brown gave an address at the Papatoetoe Cossie Club – I went to it. He is a calm reflective person – and he pondered the thought that really – to be a mature society we have to have the hard conversations. We have to be brave enough to have the challenging discussions that we often avoid. How we treat children with disabilities and their families is one of those hard conversations. Personally I don't think this country has ever had the hard conversation.

This report raises important questions and makes strong recommendations that should be followed.

I am afraid that when I read the report – the impact was immediate – despair and outrage. Despair because these are not new issues. Many of us have been talking, lobbying, writing and working to change the statistics that are so apparent here. Outrage because we appear to be slipping even further behind from where we were and outrage that it seems that no one cares. Who is responsible? Who is seeing these trends? Is someone saying – Oh I passed the information along the line and that's my job finished – I'm not asked to analyse anything. It's not my job. Who's job is it?

Where is the plan? And importantly – who is putting their hand up to say – I'll take responsibility for this.

We need a Minister with guts or maybe a Prime Minister who has guts – to lead a comprehensive review into the lives children with disabilities lead in this country. That's the challenge. If you really cared about the children in NZ, you'd care about the MOST vulnerable. Not a day goes by when I'm not contacted by a parent or a professional about a disability related issue.

And actually ..it's not my job – but you do it because you are tired of seeing people dealt to by the system, I'm tired of seeing people who are living from crisis to crisis and I'm tired of seeing people with a sort of numb acceptance that this is their lot in life.

I've been around long enough to be very sceptical of any disability policy that is rolled out by any government. Usually it doesn't herald good news for families and children with disabilities. I call them meringue policies – you know the ones – just like a meringue – they look great on the outside but like a meringue they are hollow inside, even jammed together with a good dollop of cream can't save a meringue policy. So we are cautious about change. I don't think anyone has ever tapped me on the shoulder and said – here you go Colleen and Barry here is something for Travers to use or have as of right. We have fought for everything he has.

So where do we go from here? How do you get those recommendations implemented? One of the first things I learned about lobbying and advocacy is that first of all it's about MANY VOICES SAYING THE SAME THING and secondly - to form partnerships with other groups – it's the 1+1=3 principle. When there are only a few of you – you need to forge strong partnerships – to create lasting solutions.

Martin Sullivan a senior lecturer at the School of Social Work at Massey University says that unless passion, tenacity, and fearlessness in overcoming setbacks, has a precursor of a clear understanding of what the problem is, then all that energy will dissipate and scatter.

In other words a social movement for change must be underpinned by a clearly articulated and agreed upon analysis and strategy for change if it is to succeed. Most importantly, the analysis will give a sense of right and justice to the cause, elements so necessary in sustaining the self-belief, fearsomeness, tenacity and sheer hard work throughout the campaign. Most importantly the analysis will shape the political strategy of the campaign will give rise to a politics of struggle. By political I mean a particular course of action designed to achieve specific outcomes. That course of action is driven by a commitment to a particular ethic or set of moral principles which produces a particular point of view or position and ways of doing and being.

So this report in essence has opened up a Pandora's Box of complex and historical issues. I am challenging you – the Child Poverty Action Group to work with the disability sector – to see this through.

Your recommendations are great but in order to make sure this report does NOT end up on a shelf or a number of shelves in offices throughout the country – the challenge is to tick the recommendations off one by one.

There are people in the room and elsewhere from the disability sector who will walk with you on this journey. We will be stronger if we walk together, we know the path well and will guide you over the rough bits – but only by working together will we get the justice we deserve.

Thank you.