



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

Speech by Alan Johnson

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

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In the late 1930’s and during the Spanish Civil War the well know Irish playwright Samuel Beckett was asked to make a contribution to the idea of republicanism. His response was one word printed on a card UPTHEREPUBLIC.

Less than 20 years after Irish independence a leading Irish intellectual was thoroughly disillusioned by the notion of republicanism.

Irish journalist Fintan O’Toole in his 2010 book titled ‘Enough is Enough: How to Build a New Republic’ offers some suggestions as to why Irish people are so disillusioned with the idea of republicanism. He suggests that in part this disillusionment is due to the fact the Irish Republic is mythical and has been almost since independence.

Amongst his justifications for this claim O’Toole offers the example of parents of disabled children trying to get an appropriate education for their children. He says that at this time (in the 1990s) the political elite and those responsible for running the State saw ‘the state apparatus as an entity in itself, with interests of its own that are not necessarily the same as the public interest’. During the court cases taken by the parents of disabled children he says ‘the state sought to establish once and for all that citizens have only such rights as the state is willing to grant them.’ He goes on ‘This notion is based on the profound belief that the state is an entity up there, above and beyond the people, with a life and will of its own’.

And so it is in New Zealand and perhaps even worse so. We continue to cling to the notion of the state as the Crown and much of the present Government’s reference to itself and its actions uses this label. The corollary and it is explicitly spelt out in article 3 of the English version of the Treaty of Waitangi, is that we are subjects. As subjects we are the subject of and subjected to the actions of

the state – sorry Crown. We are not participants and partners – we have our place and that is to obey a higher authority.

There is perhaps in play today a good test of this idea that our political elite see the state apparatus as a separate entity. We have already seen the reluctance of various Justice Ministers to accept liability for the apparent wrongful imprisonment of David Bain. A Canadian jurist who was commissioned to offer independent advice on the matter of compensation has said that the Government is shopping around for the advice it wants. Somehow the interests of the Crown are different from those of citizens who have been wrongly imprisoned – instead of offering an apology and just compensation the Crown denies culpability.

The test today is around how Teina Pora will be treated. This clearly is a case of a significant miscarriage of justice and it will be interesting to see what the Crown's stance will be. Will we see a comprehensive acceptance of fault, an unreserved apology and a just and immediate offer of compensation? Will we see those individuals within the Police who have clearly framed Mr Pora held to account or will the Commissioner of Police also laud them as having 'integrity beyond reproach' as he did for bent cop Bruce Hutton? Will we see an acknowledgement of the inherent racism of our criminal justice system and a complete review of it? Or, will we see haggling over the compensation amount, minimising of the harm done and trivialising of Mr Pora all in the name of looking after the public interest? As if somehow the public does not have an interest in a just justice system.

As we know an injustice done to one is an injustice done to all and this lesson is especially compelling when the injustice is to our most vulnerable citizens. The most vulnerable of course have the least ability to defend themselves and so rely most heavily on us having an inherently just justice system to protect them.

This is especially so for disabled children who must be amongst the most vulnerable in any society. This report by CPAG highlights I believe some of the nature of this vulnerability and the indifference of the state or Crown to addressing it. The obvious parsimony with which the Crown approaches the question of financial support for families with disabled children and the indifference it shows toward the educational rights of these children suggests that those working in Government see themselves as somehow protecting the public interest from any claims which these children and their families may have. These children and their families are somehow separate – the proverbial lepers, to be kept apart and ignored if at all possible. The claims if acceded to will create expectations of yet more to come, it will build dependency and a belief that these people have rights. Such dangerous ideas need to be guarded against by the stringent denial of any fundamental obligation on behalf of the State.

A have a close friend with a severely disabled son. He is my oldest friend and aside from sister he is the living person I have known longest in my life. We lived next door to each since we were three years old, grew up as friends and are now beginning to grow old as friends.. My mate left Auckland about eight years old and now lives with his wife and two sons in Wellington. I catch up with him whenever I can.

About four years ago we met up and as you do you talk about the three F's – football, fishing and family. My mate told me about the problems he and his wife were having with his son who are that stage had grown into a large young man who occasionally got violent toward his Mum who looks after him at home. The answer offered by doctors was medication and the side effects of which were fits and personality changes. My friend and his wife had to balance the risk of their son injuring his mother and giving him drugs which endangered his health and to some extent robbed him of his dignity,

In a rare moment of intimacy between us my friends asked me “how long am I going to have to put up with this crap?”

Counselling and emotional honesty are not my strong points but even I appreciated that this was not a time for platitudes, empty assurances, a pat on the hand and a cup of tea (or beer as the beverage in question was at this time) I looked my friend in the eye and said ‘mate you know it is for the rest of your life’.

As so it is with the parents of all disabled children. By some genetic misfortune, medical misadventure or accident, their children have few if any prospects of leading independent lives. The burden of responsibility of these parents to their children is in many cases a life sentence. A burden which is underserved and surely a burden which should be shared by the wider society.

But it would be quite wrong to frame the lives and needs of disabled children and adults with disabilities as a burden – either on their families or the whole of society.

This was the only time my friend had complained to me about his life in the 18 years of his son’s life. Most of the time when we met he talked dispassionately about his son’s problems but quite passionately about his character and achievements.

And from what little I know of other families with disabled children or siblings there is often an immense joy for them alongside the demands and trails of having a disabled son or daughter, brother or sister. As I see it this joy comes in part from the new insights we can gain by living with a disabled person. Insights into what true success and triumph look like, and, insights into our own strength of character and our humanity. I think many and perhaps most people with disabled children or siblings would admit that they are better people for having their son or daughter or brother or sister in their lives. Perhaps they would even say that they are somehow blessed.

But it occurs to me that society does not see the lives of people with disabilities this way – in fact it is the reverse. We now live in a society dominated by celebrity culture. The activities of some quite extraordinary people as well as some quite un-extraordinary people now pass for news – a news reader becomes ‘the mother of the nation’ and murder trails are covered intensively if the grieving widow is a cute blond.

People with disabilities are the antithesis of such a culture. Their lives are seldom celebrated and they are virtually invisible – especially if they are poor. It is probably no accident then that public policies which are designed to support disabled people are at best residual and at times perhaps even negligent.

An example of such negligence has been highlighted recently by the Dyslexia Foundation around special assessment conditions for NCEA exams. Based on information requested under the Official Information Act the Foundation showed that in 2014 students attending Decile 10 schools (the wealthiest) were 17 times more likely to be granted these special assessment conditions than students from Decile 1 schools. But it gets worse. This outcome arose after the Ministry of Education had been made aware of this inequality and had pledged to address it.

Such an outcome is not the fault of students and their families and probably not even the fault of the schools concerned. It is – as the worn out old phrase goes; a systemic problem. There is my opinion a significant middle class bias to the way public policies are conceived, designed and administered. Those responsible for developing and implementing policies most often have no idea of the barriers some people face in gaining access to what must only loosely be described as entitlements under

these policies. These barriers are invisible to many of us but they are tangible and overwhelming to people without resources or networks to engage with the system or for those who lack the confidence to even try.

Such barriers assume a benign policy environment – one in which the people from the Government actually want to be helpful. This of course is a dubious assumption as the report points out. It is dubious for two reasons – administrative practice and budgets.

Many of those who work within the State apparatus have become inculcated with the idea that their job is to guard the public purse against unreasonable claims and expectations of citizens – well at least citizens who are under 65 and poor and disabled. For example it is difficult to see the advent of the so-called Regional Health Advisors who are gatekeepers of access to a Child Disability Allowance as anything but a move to limiting entitlements. It may be entirely coincidental that the introduction of such advisors in 2008 corresponds with a subsequent 19% decline in the number of allowances paid out. In my opinion those who subscribe to the coincidence theory rather than the alternative conspiracy theory need to explain how the two events are completely unrelated.

Such reductions are of course not coincidental because they fit into overall budget expectations that spending will be reduced. To be fair spending on the Child Disability Allowance peaked in the 2009/10 at almost \$102 million up from \$88 million two years previously in 2007/08. In the current year the budget for the Child Disability allowance is just under \$84 million. In inflation adjusted terms this is a decline of 24% since 2010. Over the same period spending on the Disability Allowance also dropped 14% in real terms.

We don't see proud press releases issuing forth from the Beehive announcing such cuts. We have not heard the former Minister of Social Development gushing 'that she is passionate about cutting the support which her Government is offering families with disabled children'. Instead we see sly and cynical reductions which although small in the big scheme of Government budgets end up costing our most vulnerable children and their families.

The Minister of Education last week announced a '*sea change*' in the way in which schools are embracing students with special needs. Based on a recently released ERO report Ms Parata said "*Schools have become much more welcoming places for children with special educational needs. Schools can be proud of the progress they have made,*"

How did ERO know this?. Well they asked 152 schools whether they were inclusive – it's as simple as that. Perhaps unsurprisingly over three quarters of the schools surveyed said, 'Yes Mr ERO we are being inclusive'. What other proof do you need?

Clearly we need more information and analysis than is offered by such flawed and perhaps self-serving approaches before we can claim enthusiastically that there has been a sea change in the way in which children with disabilities are being included – both in our education system and in our wider community. In my experience as a school trustee for over 15 years, some of the worst school principals have the best paper work and their poor leadership is seldom exposed by ERO whose assessment processes largely rely on ticking boxes and a degree of honesty from principals and boards.

ERO, or any other official body, has not for example asked parents of disabled children whether they have experienced difficulties in getting a meaningful and just education for their children. Such agencies have not reported on the distribution of ORS funding across schools and regions and sub-populations of students. We do not have a legal basis to establish the educational rights of children –

disabled or otherwise, so it is difficult to decide if current access and opportunities are fair and reasonable.

For CPAG these gaps are concerning and compelling. We are glad to have been involved in this study of the experiences of parents with disabled children. We are pleased that we could offer some small advocacy for the needs of disabled children and their families. We believe that we understand some of the invisibility of disabled children and as a group and as individuals we want to work with disability groups to change this.

As an organisation CPAG is committed to continuing its research around the inequities – especially the policy inequities; which disabled children and their families face. We are keen to do this in partnership with others who share our concerns.

The links between child poverty and child disability are clear and direct just as the challenges in addressing these issues are clear and direct. As Paul McCartney once famously said. '*The movement you need is on your shoulders*'. It should not be this hard to get justice for disabled children – it is simply a matter of being honest about the current state of things and agreeing as a community to - once again as Paul McCartney said '*make it better*'. We need to continue to challenge and expose the quite deceitful and deliberately misleading impression being created by the Government who would have New Zealanders believe that all is well and in fact that things are getting better. But this is not about a change of government but a change of heart and I think New Zealanders have the heart to change if only they knew the truth. This report is hopefully a contribution to exposing this truth.