

Building a social movement for disability reform: insuring the National Disability Insurance Scheme

A submission to the Productivity Commission Inquiry into the National Disability Insurance Scheme (NDIS) Costs

The Able Movement, March 2017

Mark Bagshaw, Miguel Carrasco and Martin Stewart-Weeks

Our submission

The NDIS, and the generational shift it heralds in administrative arrangements for the support of those who have or acquire catastrophic disability, will not be successful in the end without a larger shift in the beliefs and attitudes of all Australians about the capacity for the vast majority of people with disabilities to enjoy full and equal participation in work, learning and the community.

That simple aim - **equal participation of people with disability in every aspect of Australian life** - should be the unequivocal ambition of all disability reform in Australia.

As well as investing in the extraordinary, but long overdue policy and administrative changes for disability insurance in this country, we should also be investing in a sustained program of social movement building that gradually but fundamentally shifts beliefs and attitudes across the Australian community.

Without investing too in that larger project to shift minds, hearts and behaviour when it comes to the way ordinary people think about, and engage with people with disabilities, the risk is that the NDIS will hit the target, but miss the point.

The administrative, financial and program changes are a necessary, but not sufficient investment in the outcomes we are trying to achieve as this quote from the Disability Discrimination Commissioner, from page 5 of the PC Issues Paper, makes clear:

*"The NDIS is a major social reform in Australia. ... The NDIS is about ensuring people with disability can get out and about in the community — it's about getting them to work, to school and to cafes and restaurants so they can catch up with family and friends. It's about getting people with disability being able to be part of the workforce, getting an education and spending money on food and drinks — in other words, being part of the economic, social and cultural fabric of our lives. It isn't just making life equitable for people with disability. It's also making it possible for them to participate in every-day life with their families."*¹

¹ McEwin, A. 2016, 'NDIS is having a powerful impact', Brisbane Times, 4 October, <http://www.brisbanetimes.com.au/comment/ndis-is-having-a-powerful-impact-2016-1004-grudp9.html>

Introduction and context

This submission has been prepared by The Able Movement (www.theablemovement.com.au) to the Productivity Commission inquiry into the costs of the National Disability Insurance Scheme (NDIS).

The Commission's inquiry is a "review of NDIS costs and is designed to inform the final design of the full scheme."

Our submission is indirectly about the costs of the NDIS and whether this expenditure will be effective in achieving the expected outcomes for people with disability without social change. It invites the Commission to consider the relationship between the costs and operation of the NDIS itself and the surrounding culture and beliefs in the Australian community about disability and people with disabilities.

We think an investment in the ambitious, but necessary task of shifting minds, hearts and attitudes creates an environment of support, engagement and solidarity which will translate into the capacity for better and more efficient administration of the NDIS itself.

We also think that investing in changing the surrounding culture in which NDIS operates is also a vital insurance for the NDIS itself to play its full part in helping to achieve transformative ambitions for people with disabilities.

Empowerment, Community Engagement and the delivery of NDIS Outcomes

Our premise is simple: the NDIS will deliver the best possible social and economic participation outcomes at the lowest cost and greatest efficiency when people with disability take ownership of their own support, and when communities actively engage in the process.

Shifting individual's mindsets

As the many people with disability who have been managing their own disability support for decades around the world have demonstrated, when people develop the skills and confidence they need to take control of their own lives, their perspective on the amount and type of support they need changes. Dependency is a mindset as much as it is a practical issue – one that often becomes a self-fulfilling prophecy.

And not only is a person with a dependent mindset likely to seek higher levels of support than he or she may need, it is also less likely that the person will embrace the opportunities for greater community involvement, education and employment that the greatly improved support system represented by the NDIS offers. Disempowered people don't find jobs.

We are certainly not advocating for a reduction of the level of support and funding provided for people with disability under the NDIS. As the Productivity Commission stated in its landmark report into Disability Care and Support in 2011, the level of funding and the mechanisms for delivering disability support in Australia has been woefully inadequate, one effect of which has been that people with disability have often not even entertained thoughts of gaining education or employment because they have struggled to gain the basic support they need simply to survive. We support the increase in funding for disability supports under the NDIS, provided that the expected outcomes are indeed achieved.

Community engagement – a key to success

The Australian community have embraced the NDIS, and the level of support it maintains across government and community is testament to the quintessential Australian culture of “support for the underdog”, and to the tenacity of the disability movement in Australia who worked so hard to bring the parlous state of disability support to the attention of the Australian people.

However, while that level of support is almost unprecedented in our country, it remains largely “passive” in the sense that the Australian people, having agreed to support the NDIS, now mostly expect others – primarily the Government and the disability sector– to deliver.

We believe the community needs to be more engaged in the ongoing delivery of the NDIS and in the delivery of the other key reforms that will be required to provide a level playing field for people with disability, described succinctly in the National Disability Strategy. Unless the community actively welcomes people with disability into all aspects of society, the risk remains that the NDIS, while undoubtedly significantly improving the daily lives of people with disability, will fall short of its promise to transform their lives through significantly increased participation in the community.

The Able Movement: purpose, progress and possibilities

As an emerging movement of people and communities anxious to shift mindsets and change beliefs, we have some beliefs of our own:

- People with disability are the largest untapped human resource in Australia
- People with disability are more capable of participating at all levels of society than most believe – including many people with disability themselves
- Thousands are already participating economically and socially, including those with the most severe disabilities of every type
- It's not ok that 45% of people with a disability in Australia are living below the poverty line
- It is not OK that people with a disability are 40% less likely to participate in the workforce and education
- It is not OK that a person with disability can't choose where she or he lives.

This is a quick summary of our progress so far and of some of the possibilities that now lie ahead.

A group of us, led by Mark Bagshaw and with the support of The Boston Consulting Group, have been developing a concept to **grow a social movement to tackle attitudes and beliefs across in the Australian community towards disability** and the potential of people with disabilities for a full engagement with work, community and learning.

We think the massive reforms of the NDIS will be much stronger and more extensive if they draw from, and help to reinforce, some big shifts in attitudes and beliefs across the Australian community. The two things are should feed off, and into, each other.



Big structural and institutional change (the NDIS) needs the protection and energy of a similarly ambitious and scaled social movement that shifts the architecture of belief about disability in the first place.

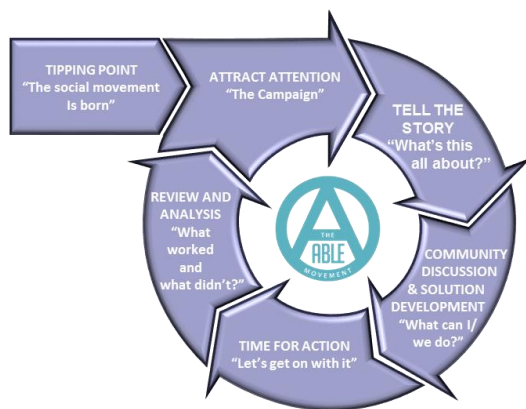
In that sense, the social movement becomes an insurance for the NDIS and its sustained impact and effectiveness.

We've made some **real progress**.

- We raised \$50,000 on the crowdfunding site startsomegood.com.
- We have an active website - <http://www.theablemovement.com.au/>
- We have a strategy and business plan, created in partnership with a pro-bono team from The Boston Consulting Group, it is ambitious yet achievable.
- We have a range of projects on the go, including some terrific new work, called the Shoreline project, which is showcasing new initiatives to help people with disabilities embrace the full experience of Australia's astonishing shoreline and beach cultures. <http://www.theablemovement.com.au/the-shoreline-project/>.

This is how we have characterised some of the dimensions and potential of harnessing a social movement strategy in the wider ambition for deep, sustained shifts in disability policy and impact.

Social movements are born when individuals and communities either become incensed at things they believe are wrong, or excited with the possibilities for change – and sometimes both.



And while social movements are organic and, over time, evolve into entities that even those closest to their genesis can't necessarily predict, they do tend to change and go through several stages.

It starts with simple awareness that a problem or opportunity exists, and moves through a learning stage where communities come to understand the nature of the problem or opportunity to a solutions development stage during which communities determine what they can do to fix the problem.

Finally, there has to be, an action stage where they come together to do what

needs to be done. Critically those involved in the process needs to then lookback across the whole cycle to understand what worked and what didn't, feeding back into the next cycle of change.

The Able Movement remains rightly obsessed with storytelling at the heart of this social movement approach to shifting culture and assumptions about people with disabilities.

That ambition is at the heart of our contribution to the big game – and the long game – of changing our “hearts and minds” about what we think people with disabilities are capable of and how we, all of us, can welcome them more practically and energetically to engage in life and learning.

We're not the only ones, of course, trying to use the stories of real people with disabilities to open up the perceptions and mindset of the wider community. But we're keen to play our part in the long, deep effort that Australia has to make now to turn this brilliant moment of potential growth in our approach to disability – think NDIS especially – into a lasting shift in the game.

That's what social movements, in the end, are all about. Think of some of the big changes we've witnessed in the last few decades around women's rights, marriage equality, Aboriginal rights and recognition here in Australia, the environmental and sustainability debate, the civil rights struggle especially in the US sparked in the 1960s and still continuing. These are all great examples of the power of wide, networked movements of people and organisations whose shared ambition for culture shift in the pursuit of the big goals of equality, opportunity and fairness collides with bedrock attitudes and culture that impede progress and often stop change dead in its tracks.

With disability reform, led in the past couple of years by the NDIS changes, we're at the same point. Some very big changes are being wrangled to change the way we fund and support at least some people with disabilities. These are changes which are welcome, necessary and long overdue.

But the liberating potential of the NDIS, and our capacity to offer at least something similar in terms of real shifts in power and choice for all people with disabilities, will be held back, perhaps even lost altogether, if we don't at the same time change the way people – all of us – think and feel and act when it comes to people with disabilities.

And that, in the end, comes down to a question of belief.

What do we think people with disabilities can do or should be expected to do? How do we think people with disabilities set about giving their lives the same sense of purpose and hope which the rest of us get to do, pretty much as a matter of course (even if we occasionally don't always live up to our own aspirations...but that's another story)?

What do we have to do as ordinary people, as employers, as owners of shops and restaurants and other businesses, as people who run transport systems, as people who run schools and TAFES and universities, as people who put on sporting and cultural entertainment – all of us – to make it easier for people with disability to have the same chance to engage in life, work and learning as the rest of us?²

Dangerous times ahead for the NDIS

Two things have become obvious in the last few months as we've reflected on how far we've come on our original plans and, more importantly, what is happening to the NDIS itself.

One is that the NDIS is facing enormous challenges. Given the political and financial conditions under which it was launched, and given its size and ambition, that isn't so surprising. This is one of Australia's biggest ever social change projects, and it has a positively Olympic "degree of difficulty" associated with its success!

In [this piece](#) from Luke Bo'sher recently in *The Mandarin*, a number of warnings are called out:

The NDIA board is a third or fourth order priority if we really care about accountability and the input of people with disability in the NDIS. Our public debate should be about how to have genuine community input and consultation on the decisions about the NDIS that matter the most.

² Some of this material is taken from an earlier blog post <http://www.theablemovement.com.au/lifes-a-beach/>

As Luke rightly says in his piece, “Australia cannot afford the current indecision and finger pointing on a scheme that is worth 1.5% of Australia’s GDP, and that literally makes the difference between life and death for some of Australia’s most vulnerable citizens.”

We agree with him. But as well as rolling out the NDIS itself, we think Australia needs to invest in other pieces of the reform puzzle. Chief among them are the attitudes of Australians themselves about disability. Working to shift those attitudes over time will, in the end, provide the kind of emotional ‘glue’ that can help to hold the change process together and give it motivation and momentum,

The second thing we’ve realised is that, if we’re going to match the scale and ambition of the NDIS with the kind of deep, sustained and robust social movement campaign that

can amplify and entrench its change ambitions, we’re going to have to work at a much different scale than we have up to now.

Bootstrapping our start-up and early stage development is fine, and it’s been fun and rewarding. We have several hundred people volunteering their time and skills to add to the small team that has been coordinating the effort thus far.

Now we have to get bigger and stronger.



And for that, we need financial investment so we can do three things:

1. Add to the professional and full time resource base of skilled people to lead in the various elements of the Able Movement program
2. Dramatically extend the leadership we can offer to grow the social movement aspect of the program
3. And start working with local communities to put in place the activism and practical change activities we’re keen to see people take up in their suburbs and towns across the country.

We need to raise around \$2 million in start-up funding to put this venture on a viable footing. That figure reflects detailed business planning which we’ve now done to give us a solid framework of planning and analysis.

What we want to achieve with this submission: three propositions

We are asking the Commission's review to reflect these three propositions in its thinking and report back to the Government.

- 1 Ensure that the importance of cultural change and the persistent focus on shifting minds, hearts and behaviour about the disability reform process is as prominently featured in the larger debate as the policy, administrative and financial dimensions of the NDIS itself.
- 2 Support further research into the relationship between administrative and program reform and cultural and attitudinal change, including the contribution that a social movement approach might make to the larger NDIS purpose and impact
- 3 Support further consideration of direct investment by the NDIA into the work of innovative and reform-minded organisations and movements like The Able Movement, to match and amplify investment by the corporate and philanthropic communities, to enable our work to grow in scale, reach and impact.

