



DISABILITY RESEARCH

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DISABILITY AND SOCIAL INCLUSION: WHAT POLICY MESSAGES ARE THERE IN THE 19 STORIES?

A/Prof. Helen Dickinson

In recent years we have seen a growing amount of attention being paid to issues of disability and to social inclusion. This is a welcome addition given that it is well-evidenced that people with disability face profound marginalisation (Goggin and Newell 2005) and report poor outcomes in terms of levels of income, labour force participation, health inequalities and levels of violence (Milner et al. 2014, Kavanagh et al. 2013, Kmjacki et al. 2016, Mithen et al. 2015). Following the United Nations Convention on the Rights of Persons with Disability, we have seen high level policy commitments to improving the social inclusion of people with disability across a number of different countries. Australia is no exception here and a range of recent policy initiatives, including the establishment of the National Disability Insurance Scheme, hold aspirations for improving the social inclusion of people with disability.

In this piece I reflect on the narratives set out in the 19 Stories initiative and the systematic review by Gooding et al (2017) and consider what these tell us about policies to drive more effective social inclusion of people with disability.

Disability research has often been a rather neglected area of study and as a result we have often lacked quality evidence through which to inform policy. A study from the Institute of Medicine Committee on Disability in America (2007, 288) concluded that, despite some progress, disability research is 'still substantially underfunded'. These findings have been echoed in Australia, where an audit of disability research (Llewellyn 2014, 43) found little research examining the 'practice implications of policy innovations'. Perhaps we should not therefore be surprised that in their literature review into disability and social inclusion, Gooding et al (2017) find only nine papers that deal with the issue of how social inclusion for people with disability is implemented in policy and practice in Australia.

What the evidence review by Gooding et al (2017) illustrates are a number of policy initiatives that typically seek to address rather narrow aspects of inclusion for people with disability. To this extent they focus on, for example, changing where people live, the role of paid support, volunteering and the role of the person with disability as a consumer of services. Many of these mechanisms are found to be effective to a certain extent but will

not on their own achieve social inclusion. As Gooding et al describe, social inclusion is a complex process and it takes significant effort to find ways of translating different initiatives into everyday inclusive practice. Social inclusion is not achieved just by delivering one service or intervention in a slightly different way. A further common feature is that these initiatives typically focus on people with disability and not the broader population. To some extent this is because they seek to 'fix' people with disability and not the broader population, just as some initiatives to address gender inequities have been critiqued for their focus on 'fixing women' (Fox 2017).

From the research evidence what is clear is that turning a high level policy aspiration like social inclusion into a reality is a huge implementation challenge. As Gooding et al (2017) conclude, 'social, health and economic indicators suggest that the policy objectives of social inclusion have not yet been reached and people with disability remain largely excluded from the mainstream of society' (pg. 24). This is made all the more challenging because the broad discourse of social inclusion is driven by a number of forces. For some, social inclusion is an economic imperative and greater social inclusion of people with disability should lead to greater overall economic productivity (see, for example, Australian Government Productivity Commission 2011). For others, social inclusion is a matter of rights, be these human or civil. Of course, these are not mutually exclusive drivers and in reality there is an overlap between the two. What this does demonstrate though is that there are various and often unspoken assumptions about why we might want to drive greater social inclusion of people with disability and what this might look like. This ambiguity in meaning can make the task of achieving authentic inclusion an even greater implementation challenge.

What the narratives in the 19 Stories collection do is translate this rather amorphous notion of social inclusion into a real sense of what this actually means in terms of the day-to-day lives of individuals. Given what we know about the social inclusion challenges for many people with disability these stories are remarkable and show individuals who are highly engaged with their communities. It is clear that these individuals benefit from this engagement, but even more evident is the great impact that these individuals have on their communities through their passion, drive, professionalism and enthusiasm. But in another way they are perhaps as unremarkable as they remarkable. What I mean by this is that they are stories about people connecting through their passions, work, family, indigenous heritage and education, which is something that most of us achieve – or hope to achieve – within our lives. As Hannah tells us social inclusion is about being "with a group of people who like to do the same things as me". Dee sees this as being able to live a happy fulfilling life.

In some senses social inclusion isn't really that complicated; it's about how many of us would like to live our lives. But as we also see in the 19 Stories, all too often policies do not enhance social inclusion, but can inhibit it. Whether this is because people are forced to live in institutional settings, attend specialist day care centres or are excluded from mainstream education, some of the very policies that are set up to support people with disability can end up isolating them even further. This is not to say that some specialist services are not

important, they absolutely are for some individuals. Further, many of the important political campaigns that have advocated for greater rights and inclusion on the part of people with disability have emerged out of the disability community, who banded together to demand change. But what this does tell us is that – unsurprisingly – all people are different. We can't just come up with one policy mechanism that will improve social inclusion for all people with Down Syndrome or a visual impairment or cerebral palsy, any more than we can for all people called Frank or Farhad or Feng.

Ultimately what this project reminds us is that social inclusion is not simply an issue of ability, but is relevant to us all. People with disabilities do not want to be defined by their impairments any more than many of the rest of us wish to be defined by different facets of our identity (e.g. age, class, faith, ethnicity, sexuality). In order to improve social inclusion of people with disability we need to understand their interests, desires and drives and find ways that we can use these to connect individuals to their communities. But more than this, we also need to work to educate the broader community about disability and to break down the stigma attached to disability. A significant proportion of the population have never met or interacted with an individual with profound disability – in part because of the segregation that has been created through disability policy – and do not know how to act, what to do or what to say. Although there have been some limited improvements in recent years, people with disability are also often absent from our public life and the media in significant ways. So policy also needs to address this issue by intervening at the community-level, educating people about disability-related issues and the assets that individuals can bring to their communities. We need to see more role-modelling of this inclusion within the mainstream media and Australian public life. Finally, and importantly, such initiatives can't just be about the social inclusion of people with disability, they need to be about all of us.

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