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In all its unfitness: the publics' framings of the NDIS

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Abstract

Disability is intensely personal. It affects your bodily senses and functions and your thinking; it leaves its traces in self concept and social identity. It produces pain and shame as well as desire and achievement. It opens doors to new life-giving meaning and/or to stumbling down the stairs of self-abnegation. And if it is not your impairment but the journey of one you love, its personal impact is just as intense. Different but no less transforming. This paper explores the recently announced National Disability Insurance Scheme and some of the challenges around disability in society.



“where the facts are most obscure, where precedents are lacking, where novelty and confusion pervade everything, the public in all its unfitness is compelled to make its most important decisions. The hardest problems are those which institutions cannot handle. These are public problems”. John Dewey 1927

“A dark secret thought that haunts a growing number of legislators and administrators is that no one seems to have control over the system of delivering social services, no matter how specific the regulations or how specific the regulations”. James McDermott 1980

Disability is intensely personal. It affects your bodily senses and functions and your thinking; it leaves its traces in self concept and social identity. It produces pain and shame as well as desire and achievement. It opens doors to new life-giving meaning and/or to stumbling down the stairs of self-abnegation. And if it is not your impairment but the journey of one you love, its personal impact is just as intense. Different but no less transforming.

Of course, disability is also social, at times astonishingly so. Yes maybe more than the ‘social’ that is lives generally. Mainly because dependency renders it so; our bodies and ways of being are so clearly bound to others. For those of us with fewer needs for daily assistance, collective discomfort with the odd, the challenging, and the disordered, un-ordered or over-ordered draws us into awkward social spaces beyond our choosing. Disability defies order and yet (and perhaps therefore) is the terrain of a long-term and sustained power struggle in the attempt to put things in order. Or to bring people with spectacular impairments to order. It is this key element that renders disability what John Dewey calls a ‘public problem’ (1927).

A ‘public’ forms in two ways. A significant group of people are troubled by the appearance, behaviour and life conditions of another group. They form to put things in order via an appeal to state intervention. Not necessarily a lack of care or a concern for justice. We are talking solutions here. Let’s for sake of simplicity call it ‘the welfare voice’. The voice says we need paid others to do the bulk of the work of caring. Comprised of disparate forces, this public also acts to reduce the social discomfort brought by contact with disabled people. But another disparate public forms because state-sponsored intervention into the lives of tidied-up people is judged to be undesirable and dysfunctional. Let’s call it ‘the community voice’. This solution says that, even with welfare provision, the responsibility for including disabled people remains firmly within civil society...it is not the job of others paid for by the state. Dewey’s idealist and non-elitist view is summed up in the words of Melvin Rogers, that the public viewed thus is not a rigid state determined category but ‘an emergent property among individuals fighting to give direction to their lives...’(2012,3)

There is an implied linearity here – a problem is expressed, a public forms, a policy is developed. At times it is an intense process but still an observable process with a measurable outcome. Yet a survey of the history of state intervention into the lives of disabled people in the West reveals



anything but linearity. I will explore this as a policy and institutional palimpsest (see Debra Park and John Radford, 1999, 73). Palimpsest refers to the multiple inscriptions on parchment made from papyrus. The parchment was cleansed of its script and re-inscribed. Overtime however, the earlier inscriptions become discernible. These re-emergent ancient scripts are known as the *scriptio inferior*. In disability policy we can discern the *scriptio inferior* of exclusion – the expulsive forces expressed through the contemporary welfare voice – asserting itself through each succession in policy.

In Australia this complex struggle over meaning and power remains as intense as it has been since the early 1800s and although the NDIS, as policy and program, aims to settle it for the next generation this power struggle will not be settled. Unless and only when services move to the background of the lives of those who must rely on them the struggle will continue. This struggle, in my view, is a desirable outcome. A policy landscape free of conflict will signal that an enduring settlement is likely to have cemented exclusion so firmly that those shut out are rendered truly mute. It means the hopes of disabled people are still alive and being voiced.

Perhaps this is part of Dewey's 'unfitness' – an unwillingness to see things settled and to maintain vision and expectations.

Between exclusion and liberation

The fate of disabled people has at times variously received attention from the state and the church; and organisations such as charity and welfare bodies. Most notable are four main policy shifts as I see it. We start with our colonial period, leading through to the beginning of the 20th century.

From outdoor relief to indoor relief...

The shift from outside relief to inside relief under the English New Poor Law of 1834 was, at its core, a renegotiated settlement of the balance of responsibility for support shifting from community and church to state. Here the doctrines of *noblesse oblige* and the moral turpitude of the poor that set the ideological framework of The Victorian Poor Laws shift only slightly in emphasis as the welfare state within industrialising capitalism takes root. The main shift lies in the locus of delivery of support provisions and in the location of recipients. *The Poor Law Reform Act* [1834] certainly maintained a powerful doctrine of categorisation between the undeserving poor (sexually incontinent, indolent and indulgent) and the deserving poor (benighted, imbecilic and impotent). The work of Park and Radford (1999), demonstrates however, that the harsh treatment, including enslavement, doled out to the idiots, imbeciles, lunatics and cripples in the Canadian hospitals and institutions throughout the second half of the 19th century, was rationalised by an appeal to sexual incontinence, unbridled reproduction of yet another generation of imbeciles, and laziness. Importantly we see first the workhouse congregation which in turn yielded to the hospitals and asylums under Lunacy and Idiocy provisions dictating custodial state protection. These facilities, known collectively as The Institutions, are in their final days throughout the West. This policy was what I call *The Great Gathering Up*. This is the



other-side perspective of the Social Hygiene Movement, in which potentially toxic, scary, unhealthy, mutating groups and individuals are removed from the streets for the common good. Later we relied on sterilisation, often still within the institution.

Australia's record here is no different, with the holding cells for the insane (a loose category for all manner of infirmities) operating within the first prison building erected at Parramatta in 1798. From there, purpose built asylums, hospitals and institutions emerged throughout the colony. Throughout the asylum era, which did not begin dispersal until the mid 1970s in Australia, these facilities were plagued with scandals as overcrowding, harsh treatment, and neglect took the lives of inmates. Reformers were inspired to reduce the overcrowding, clean up the sites, attempt training of custodial staff and build healthy work-like, farming settings. These reforms were often stifled by political maneuvering, bureaucratic indifference, lack of funds, the influence of those with vested interests in preserving high levels of authority in each facility and workers concerned about loss of employment. It may be surprising to some to note that all these forces, holding hands with an uncertain populace, are currently arrayed against the development of the NDIS as a truly socially inclusive policy and program. The resistance is not heard in public statements in clear opposition but in views such that 'this is about resource allocation, not rights protection.' (Johns, 2013)

Into old and mixed welfare...

The move for liberation from these segregated settings is foundational for the disability movement in The West. While this liberatory impulse does not emerge publically until the 1970s the intervening period is distinguished by another development. The emergence of a parent-led, diagnosis-specific charity sector, fuelled in part at least by a professional-parent alliance declaring the colonial-era institutions an unattractive solution for those born with significant impairments. This operated largely as a middle class response – richer and more stable families were able to mobilise more resources than those who were left with what seemed no option but to hand their child over to the state.

Lynn Froggett (2002,16) examining relationships within welfare settlements, postulates four successive paradigms in post-war British welfare – old welfare (from the perspective of the 21st century), mixed welfare and no welfare. She then moves into a model called 'beyond welfare', which I will examine in a later section. Froggett's work is sufficiently broad brush to be applied to Australia. In this post war period in Australia we can see old welfare operating within a social democratic political framework, privileging professionalism and maintaining high dependency among client groups.

With the election of the Hawke Government in 1983 we see a shift into a mixed welfare framework which prevails in Australian states. Froggett (2002) describes this as the shift into contractualism and welfare consumerism with the state responding to clients as stakeholders. Within services, the paternalism of old welfare need not yield to the aspirations of the changed funding model. In 1984, under the guidance of Social Security Minister Don Grimes the Federal Government conducted the first ever national consultation of people with disability, families and



service providers. Known as the *Handicapped Programs Review* this consultation, which resulted in the *New Directions* report and the passage of the *Disability Services Act* [1986], established the pattern for future consultations. The *Disability Services Act* [1986] established the Disability Services Program which block-funded a new generation of disability services, aimed at transforming the charity sector services which had lost parent control and become increasingly segregated and congregated. It also aimed to put pressure on the state-run institutions and to assist those state governments which had begun the work of de-institutionalisation.

At this point, the settlement of the balance of responsibility for care takes a strong shift toward community and family based care. Over the almost three decades since this reform many people, especially those with physical impairments, (we do not know percentages) have managed to build well supported lives in the community of their choice, to gain education and employment, to build families and to contribute to community life. Many others, especially those labeled with intellectual and/or psycho-social disability, live with exclusion from family and community, material poverty, boredom, fear and rights denial. A surprising number still live in the colonial-era institutions and about 7000 young people with severe disabilities live in aged care residential settings. We have seen gathering up of people into group homes and small employment support services and community integration services that move bunches of disabled people around in buses from one segregated activity to another.

The findings of the second large scale consultation in Australia, leading to the *Shut Out Report* (2009), that the current service system is broken and broke, and that people with disability and their families are at a considerable distance from the lives of most Australians, are supported by the research literature which shows low levels of educational attainment, poor employment prospects and involvement, insecure housing, poverty and poor health. Family members and informal carers reported little contact with 'normal' community activities and settings, reduced employment opportunities, increasing care loads, and little appropriate support from most services (a smaller number were and still are doing a stellar job in supporting individuals with disability and their families). This is bolstered by anecdotal and research evidence about sustained discrimination, rights denial and violence within services. The finding of the Productivity Commission Report *Inquiry into Disability Care and Support* (2011) arrives at the same conclusions. The report goes on to lay the groundwork for the NDIS and to point disability policy firmly in the direction of personalisation (a trend seen in the preceding decade in the UK and parts of Canada).

...and back to outdoor relief

It is this story that grounded the Federal Government's initiative to develop the NDIS. Froggett (2002,16) would perhaps see this as a shift within mixed welfare, retaining elements of 'old welfare' but taking on strong elements of and aspirations to 'no welfare'. No welfare centralises market provision, based on individualism and market competition. Once again, her model does not reach into the dynamics within services, which I think, could for quite some time preserve segregated paternalism. (This is based on a perception of the welfare voice, which combines an industry perspective with a vocal parent lobby that, despite all the evidence about the



stigmatising and life-limiting aspects of congregate and segregated services, and the propensity for such services to tend to increasingly controlling relationships with dependent clients, persist in calling for the special, the separate and the labeled.)

The development of the NDIS marks a shift away from block-funding to individualised funding. This shift certainly opens up the possibility of a more market driven approach of support provision. The foundational NDIS principles of providing that which is reasonable and necessary to ensure that eligible people with disability can get the supports they need when they need them and for as long as needed such that they can pursue goals of economic and social participation, while exercising control and choice over the nature of the provision points to a strong shift away from old welfare with its reliance on a professional determination of need and related service. It signals a move away from the contractualism that has prevailed in the disability service industry since the late 1980s. No longer will the state pre-purchase services that individuals must conform to in order to gain a near-enough address of their needs.

A related output should be registered here.

The *National Disability Strategy 2010-2020*, involves all governments in a strategy clearly linked to social inclusion, aimed at ensuring people with disability can participate as equal citizens in all areas of Australian life. It lists personal support as only one of six areas for policy focus including building accessible and inclusive communities; rights protection; economic security; learning and skills and health and wellbeing. This is directly linked to the *United Nations Convention on the Rights of Persons with Disability* which the Australian Government ratified in early 2008.

In terms of governmental effort, resource allocation and wider community engagement, the NDIS has eclipsed the wider strategy and signals a strong pull into the service corner. Have we moved from seeing people with disability as equal citizens back to those with serviced lives? Or, are we finally after 180 years seeing the end of the destructive, exclusionary inside relief policies? Is outdoor relief the only thing we need for liberation? Is outdoor relief best expressed within a market? These are not simply rhetorical questions...they are dilemmas that must be pondered if we are to see this moment as a turning point away from the *scriptio inferior* of exclusion into a new script that is about appropriate welfare provision, rights protection, belonging and wellbeing.

My tentative conclusions are these: yes, we have distorted the public conversation about disability into a loud noise around need and services (ah, the deep pulse of old welfare); yet, we have made decisive moves into finishing the scourge of inside relief. With full implementation of the NDIS we will scale back residualism and rationing such that the competition will shift from among recipients of services and funding to among providers of supports and services. This final outcome offers the potential for something quite powerful to emerge, provided that the services offered and selected within the market place are not still living in old welfare world, carrying out the earlier intention of social hygiene. I am not so quaint to declare that private, for-profit operators cannot develop highly effective, life-expanding supports and services. Indeed, we see imagination and capacity emerging in private operators in other sectors. Yet without disabled people and their close associates taking full advantage of their new found opportunity for



solidarity (we no longer have to compete over scarce resources) we will find that the nation just ends up oppressing people more expensively. And let's face it, since the late 1700s we have invested vast sums in keeping disabled people out of the places and pathways of shared life in community. Froggett (2002) characterises this as the emerging struggle between fracture and solidarity. Allowing this thing to lead to fracture is a dangerous possibility.

Between solidarity and fracture

The possibilities for solidarity

Clearly I am interested in the possibilities for and politics of solidarity. Theorists and practitioners of social innovation, Robin Murray, Julie Caulier-Grice and Geoff Mulgan (2010) want us to look at the possibility of new and improved connections and cooperation across different parts of systems, currently in discord or at distance from each other. This might be seen as an expression of solidarity around shared purpose in public institutions seeking to navigate the pathways advocated by competing publics, so often shaped not by aspirations but by path dependency and declarations of disadvantage. I want to stretch our understanding to solidarity in two other directions.

First, the solidarity that could emerge among disabled people, their close associates and supporters and based on a shared vision of valued lives as citizens. And yes here I mean *all* disabled people can live as valued citizens, as to belong you do not have to achieve anything other than to live among us. This solidarity would emerge as attentiveness to the lives of others, a constant vigilance that ensures that those who have missed out on previous reforms (remember those still in colonial-era institutions and aged care facilities) do not miss out this time. A vigilance that ensures that exploitation of those who are needy by those who would provide does not occur. A vigilance that ensures that when the *scriptio inferior* of exclusion becomes the dominant script in policy, its erasure is swift and sure.

Next, the solidarity that can emerge in the wider society. A solidarity that is based on a moral understanding that being a citizen is an aspect of how we accept each other in all our strengths and weaknesses, our ugliness and awkwardness, our stumbling and our soaring. This is Froggett's 'beyond welfare'. A settlement built on a renewed ethic of care, of inclusion, and of justice and recognition.

By now you will be thinking that I have launched into a state that looks more like Ruskin's (1860) calls for gentleness and justice than a critique of the possibilities of welfare in our era. Unrealistic, utopian and unachievable. While I acknowledge that my heart is stirred by Ruskin's Elysian writings, it is not so. I am being tough about two things that I know from almost 40 years connected into the worlds of disability. First, as recipient of services, then as a social worker and advocate, more recently as an academic and policy advisor.

Choice and control is about the restoration of citizenship within a democracy, not a consumer identity within a market. Democracy demands a collective response, not simply an individual response. Here we have strong evidence of the benefits of the confluence of the solidarities to



which I refer. I have seen people whose lives were destined for closure and grimness find new openings, possibilities and connections of love, care and joy. I have seen policy makers 'get it' such that they release their genius and capacity for connection. I have seen families come to celebrate the life of their disabled member, not just struggle with a growing demand for care. I have seen professionals and services know how to hold hope and vision for people in the face of cynicism and barriers, such that they have supported the most commendable visions to fruition. I have seen everyday community members – neighbours, work colleagues, and fellow club-members – figure out ways that the person with disability they have come to know need never again feel the sharp sting of discrimination. So I know it can happen. And I also have a fairly clear idea of how it happens. Policies of personalisation, containing processes of pulling people into richer, safer life experiences and met with integrity, ingenuity and combined effort will contribute greatly. I think that the possibilities under the NDIS are enormous.

But I also know how easily we can slide back to meeting the agendas set by the solely welfare voice. This is the threat of re-fracturing.

The threat of re-fracturing

In my recent research I have revisited the public conversation since 2007, especially at the national level, looking at how messages are formed, elicited and framed in that interface between the politics of the disability sector and the policy making process. I am particularly interested in the moral content of the advocacy of public players and the links with, and emergence of certain messages in community engagement processes, mainly consultation processes, initiated and orchestrated by public sector policy makers. I am aware that less public lobbying processes are influential in this but I am not able to analyse the content of interactions that happen at the citizen/politician interface or the advocacy organisation/politician interface. I am however going to assume that, in the lead up to the 2007 election, with political change in the air and the freshly minted international convention, those with access to influential places and people managed to get disability onto the radar. I saw it happening then and I see it happening again. I also sat through many of these consultation events and have contributed to the analysis of submissions. Since then I have looked at a wide range of documentation from the period.

My question is this: *In all of these political processes does the formation, elicitation and framing of disability experience at core as unmet need for services also related to sorrow, grief and desperation contribute to the production of such a negative, even repugnant understanding of disability that it constitutes a threat to social inclusion?* This, a slightly more nuanced version of Carol Bacchi's analytical opener: 'what is the problem represented to be?' (2009), asks us to consider the possible impact of certain problem formulations. It is a particularly squirmy question for those of us influenced by the claim that social neglect and abuse grows in the silence, the shutting in, shutting out and shutting up of those who are not faring well in our economy. It is these people who must be heard, some would argue unmediated by the professionals, the politicians and policy makers, not only in problem formulation but in solution development. It is squirmy because we fear that we trap the person and indeed the whole collective of persons in perpetual neediness, victimhood, tragedy, dissatisfaction.



Even a brief scan of those key documents mentioned above (*Shut Out Report*(2009) and *Productivity Commission Report* (2011)) shows that the problem that is drawing most policy energy and resources across the nation is the issue of unmet or inadequately met need, largely identified as a need for formal services and supports. Alongside are some subsidiary problem formulations relating to the unmet or inadequately met needs of carers as carers; the future and sustainability of existing specialised services; the place of other services systems e.g. health, education, transport etc in meeting these needs; all underpinned by political jousting about funding and state's rights and responsibilities. Slightly to one side we see a set of concerns about other pathways to recognition: the past and present history of violence and rights denial in services and the wider community; discrimination and denial of opportunity and finally, the emergence of a disability culture focussed on pride. There is no doubt that the momentum in the public conversation lies with services as the response to need. This is a conversation about what is necessary.

Now that the legislation is in the place, the *DisabilityCare* agency is to open its doors in July 2013 in five sites and bi-lateral agreements are being negotiated to move towards full roll out in 2018, it is the time to shift this national conversation. If we don't the power of the innovation towards outdoor will be lost.

A freshly focussed national conversation

From an account that begins with what is necessary...

Michael Ignatieff in that curious work, *The Needs of Strangers* (1984), has this to say about need:

To define what it means to be human in terms of needs is to begin, neither with best, nor the worst, but only with the body and what it lacks. It is to define what we have in common, not by what we have, but by what we are missing. A language of human needs understands human beings as being naturally insufficient, incomplete, at the mercy of nature and of each other. It is an account that begins with what is absent. (p57)

Ignatieff published in 1984 and seems only slightly affected by the post-modern mood...the capacity for individuals and groups to maintain open, fluid, non-self enclosed identities. I can be needy in the public sphere but in semi-public and private spheres I can be strong, satisfied and empowered. I can be rebellious and transgressive. For many of us living with impairments this is often the case...the capacity to shift into and maintain a positive determining self while advancing a claim for more resources for services and support.

But impairment is not delivered fairly, falling more upon those who already lack social and economic resources (despite the popular notion that it could happen to any of us any time, I think we can safely assert that the link between pre-existing disadvantage and the production of impairment is operating in Australia's disability profile). Impairments can deny the person the capacity to exercise self-regarding decision-making. The denial of these avenues to explore and develop an expanded self that acknowledges the impact of impairments and associated injustices but also speaks of a non-needy self can lead to ongoing peripherality. An advocacy around needs



alone can further contribute to this. It is further added to by carer' discourses of burden, stress and exhaustion. The more that we argue for special treatment in the name of social inclusion and based on the horribleness of life in this particular periphery, the more we run the risk of further marginalisation and stigmatisation. That is the irony of our action for change.

It would be a tragic outcome of the development of the NDIS, if in adding volume to the solely welfare voice, we distorted solidarity into more segregation and congregation, while valorising the potentially abandoning aspects of individualisation. This could happen if we allow ourselves, as a wider society, to think that the problem of disability will be solved when 'they' have more funds to get what 'they need'. In other words, 'no longer my concern'. Collective responsibility for all citizens gets turned into paying for someone else to do the hard work of being around people who cause us discomfort. This demonstrates a profound path dependency in policy, predicated on the *scriptio inferior* of exclusion.

So we have to find a way that we can think this tension through with grit such that we can influence the initial problem formulation. G. Bonoli (1998), distinguishing radical change from path dependency argue for, 'change that affects the institutional factors that have contributed to structure debates, political preferences, and policy changes in the past'.

...into an account of what is possible

Mulgan (2007) provides a simple description of social innovation as 'new ideas that work to meet pressing unmet needs and improve peoples' lives' (P.5). I want to argue here that changing initial problem formulation to a focus on an improvement in people's lives (not simply an improvement in the scope of service provision) could open the door for that more radical shift. A shift from what is necessary to what is possible. A 'voice of community' advocacy about what is right and possible, rather than about what is broken and needed, could open up pathways within a wider range of social institutions to develop the confluence necessary for successful social innovation. Here I am not simply seeing the question of 'what is possible' as a shift from problem formulation to solution proclamation. I am suggesting that problem formulation must be seen through the lens of where we want to go, not just where we find ourselves currently mired. This is nothing new in the world of thinking about social innovation. Richard Elmore's groundbreaking work on backward mapping as reversible logic in the analysis of public policy (1983) provides the mechanism for us to think this through.

Elmore addresses his thoughts to policy makers within public policy roles, here I am addressing the community voice, especially in its public phase, as I caution that an over concentration on need potentially fractures the social solidarity necessary for the effective and sustained inclusion of people with spectacular, confronting and complex impairments. Elmore, along with Dewey, reminds us that implementation is influenced mainly from the bottom up, not the other way round. So his formulation gives a valid place in implementation to those who must rely on services. While services can and must bring support with the tasks of daily living, ensuring that the person's life is protected, that they experience comfort and ease with getting through the day,



this cannot be where it stops. The services must include those things which open the door to a bigger world and a more richly lived existence. Unless this is at the forefront of our public claims we will never make the radical move into a beyond welfare settlement. Dewey's emergent property of people aiming to give direction to their lives therefore becomes prescriptive...the giving of direction, rather than sole the enunciation of complaint, becomes the powerful force that challenges the persistence, within the policy palimpsest of disability, of expulsion and dependency. When we see this emerging we will be able to declare the NDIS a truly radical innovation in Australian disability policy. Until then we remain vigilant, critical and visionary.

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