<t>'Any one of us could be among that number': Comparing the Policy Narratives for Individualized Disability Funding in Australia and England </t>

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<ha>Abstract</ha>

<ind>In this article we compare the introduction of individualized budget policies for people with disabilities in Australia and England. Data is drawn from semi-structured interviews undertaken in Australia with politicians, policymakers, providers, disability rights groups and care planners, along with analysis of policy documents. This data is compared to the authors' earlier research from England on the personalization narrative. We argue that the National Disability Insurance Scheme (NDIS) currently being introduced in Australia deploys an insurance storyline, emphasizing risk-pooling and the minimizing of future liabilities. This contrasts with the dominant storyline in England in which attention has focused on the right to choice and control for a minority of the population. This difference can be explained by the different financial context: the NDIS needed to build public and political support for a large increase in funding for disability services, whereas in England the reforms have been designed as cost-neutral. Tensions in the English narrative have been about the extent to which personalization reforms empower the individual as a consumer, with purchasing power, or as a citizen with democratic rights. Australia's approach can be characterized as a form of social investment, evoking tensions between the citizenship of people with disabilities now and the future worker-citizen.</ind>

<ha>Keywords</ha>

Disability; Personalization; Personal budgets; Social investment; Narrative; Comparative social policy

<ha>Introduction</ha>

Julia Gillard was Australian Prime Minister in 2013 when the National Disability Insurance Scheme (NDIS) became law, and the first part of the title of this article is taken from her autobiography (Gillard 2015). In it she sets out the principles that underpin the introduction of the NDIS, which provides no-fault insurance for all people with permanent and profound disabilities in Australia for

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the first time. The NDIS incorporates an individualized budget allocation to people assessed as being eligible for government-funded disability support, replacing a patchwork of state-by-state entitlements. This shift has been accompanied by a large-scale increase in funding, as well as a huge increase in the political profile given to services for disabled people, and has been broadly celebrated by disability rights organizations. Piloting of the NDIS was undertaken in several sites across Australia from 2014, and the full national rollout began in July 2016. This shift to person-centred services for people with disabilities, based on the principles of individualized funding, follows similar reforms in other countries (Izuhara 2003; Grit and de Bont 2010; Glasby and Dickinson 2009; Alakeson 2010).

This article compares how far the Australian policy narrative for the NDIS was similar to or different from the personalization narrative in English care services. The NDIS is a major new policy initiative, and as the first article that considers the NDIS from a comparative perspective, we make an original contribution to better understanding its origins and framing. The NDIS is at an early stage of implementation, and it is not yet clear what its individual and system-level outcomes will be. However a focus on narrative provides insight into the discursive framing that shapes the implementation context. The article draws from interviews undertaken in Australia with politicians, policymakers, people using services, providers, disability rights groups and care planners, and compares them to existing research about the narrative of personalization in England (Needham 2011). The focus of the article is on people with a disability rather than frail older people. Whereas both groups are eligible for personal budgets in the UK under a unified adult social care system, in Australia elder care is not part of the NDIS.

The first part of the article discusses the move to individualized funding in the two countries. Following a discussion of research methods, the article then goes on to present data from interviews and policy document analysis undertaken in Australia. The analysis draws attention to two core storylines in the narrative, which together affirm the population-wide insurance-based principles of the NDIS reform, and stand in contrast to the storylines used in the English case. The first is the ‘all in it together’ storyline expressed by Gillard, based on disability as a shared risk, best approached through risk-pooling. The second is a focus on minimizing future liabilities, as a way of making the financial case for the large-scale investment underpinning the NDIS. These storylines contrast with the dominant storylines in England in which attention focuses more on the right to choice and control now for a (relatively segregated) minority of the population. We argue that the differences of policy narrative can be explained in two ways: first, that the NDIS was developed as a major new funding

initiative requiring public support that had to emphasize its potential benefits for the whole population. In this way it is more analogous to the postwar Beveridge reforms of the welfare state than it is to England's personalization agenda for social care. Second, the Australian narrative draws on investment approaches, in which current spending draws a return on investment in the future. This construction of the person with disabilities in actuarial terms focuses attention on minimizing the future liabilities of the worker-citizen and risks occluding the lived experience of people with disabilities now.

The Transition to Individualized Funding

In the UK, the Community Care (Direct Payments) Act 1996 marked a significant milestone for disability campaigners who had been agitating for many years for a change in the law to make it possible for disabled people to control their care monies. Early take-up of direct payments was low and predominantly included people with physical disabilities (Glasby and Littlechild 2016). People with learning disabilities have increasingly come to take up the budgets, with added impetus from the more conducive policy climate of the broader personalization agenda since 2007, formalized in law as the Care Act 2014 (Glasby and Littlechild 2016). In part this is because of the development of alternative funding arrangements such as managed personal budgets (where people can be involved in spending choices, but the money remains with the local authority) and individual service funds where monies can be held by a third party. Levels of take up of personal budgets stand at 88 per cent of people with disabilities aged under 65, with 42 per cent of these taking the money as a direct payment (NAO 2016).

In Australia, disability services have been predominantly block-funded (Purcal *et al.* 2014: 89). A high profile report into the viability of the proposed NDIS by the Australian Government Productivity Commission (AGPC) (2011) concluded that, 'the current disability support system is underfunded, unfair, fragmented, and inefficient. It gives people with a disability little choice, no certainty of access to appropriate supports and little scope to participate in the community' (AGPC 2011: 3). Indeed, a few years prior to the Productivity Commission's report a study by the Organisation for Economic Co-operation and Development (OECD) found that Australia was the worst performer of all 27 nations in terms of poverty levels for people with disability (OECD 2009). Australia's 'wage earners' welfare state left people with a disability 'vulnerable to poverty, reliant on meagre, fragmentary welfare services or more often on private charity' (Deeming 2013: 670).

The Productivity Commission report set out a new approach to funding care services, signalling a major new federal commitment to fund and oversee disability services, which had previously been

held at the state government level. As well as greater investment in early intervention and community-based support for people with low support needs, individualized packages of funding would be available for people with higher support needs. As Purcal *et al.* (2014) point out, prior to this there had been some limited state schemes to allow individualized funding: what was new about the NDIS was the funded federal commitment to make such access available across the country (AGPC 2011). Also new was the high-profile political will behind it, which survived the change of government from Labour to Liberal-dominated coalition in 2014 with little change. The federal government committed to provide AU\$22 billion to roll the scheme out across the country, funded in part through an increase in the Medicare levy (a tax paid by Australian residents for access to the public health system, currently approximately 2 per cent of taxable income).

It can be argued that a shared personalization narrative is emerging, across countries, which is that disability services should be person-centred, offering choice and control through individualized funding (Glasby and Dickinson 2009; Foster *et al.* 2012; Power 2014). Approaching personalization as a narrative draws attention to its role as a story about how services can and should change (and are changing) that itself draws on a range of storylines (sub-narratives) to assure its plausibility and authenticity (Needham 2011). As is well-rehearsed in existing writings on personalization, individualized funding has in part become so widely popular because it knits together two dominant policy trends in advanced democracies: neo-liberal public sector reform that seeks to strip power away from large government bureaucracies and human rights discourses that aim to maximize the scope for self-actualization amongst people who have been denied full citizenship in the past (Rummery 2006; Purcal *et al.* 2014: 89; Glasby and Littlechild 2016).

The tensions between these two strands has surfaced in the UK in debates over the degree to which person-centredness and individualized funding aim to develop consumer rights or citizen rights (Scourfield 2007; Ferguson 2007; Power 2014). Consumer rights are typically conceived as being concerned with affording people with disabilities the right to make individual choices within a free market. This is arguably a version of 'shallow' personalization as defined by Leadbeater (2004). People with disabilities are able to purchase services, which allow for modest customization and adaption to their needs, but without a transformation of the power balance between individuals with disabilities, communities and the state. Citizen rights – associated with 'deep' personalization (Leadbeater 2004) – are also concerned within individual freedom, but in this case in relation to democratic values and inclusion in society. They go beyond customizing services to giving people with disabilities a greater role and greater responsibilities in designing solutions (Rummery 2006).

Leadbeater (2004) argues that most public service systems are able to accommodate greater consumer rights through some minor work to existing systems, but to achieve citizen rights involves more than just a change to practices of service delivery – it requires a shift in power so that design and control of services becomes bottom-up rather than top-down.

In a recent study, Christensen and Pilling (2014) use the distinction between consumer and citizen rights to compare the introduction of personalization policies in two different ‘welfare regimes’ (Esping-Andersen 1990): England and Norway. Drawing primarily on national policy documents, they conclude that there are substantial differences between the versions of personalization in the two jurisdictions and that this has implications for the ability of individuals to express consumer and/or citizen rights. They identify a discourse of democracy and citizen rights around individualized care funding in Norway, compared to a consumer-oriented market model in England (Christensen and Pilling 2014: 493). They suggest that this difference maps onto the social democratic versus the liberal welfare regime.

In focusing on Australia and the UK we encounter two states that have usually been seen as belonging to the same ‘liberal’ welfare regime (Ferragina and Seeleib-Kaiser 2011) – although the classic Esping-Andersen (1990) three worlds typology was challenged by Castles and Mitchell (1993), who suggested Australia belonged to a fourth ‘radical’ category of welfare capitalism. This radical category – which Castles and Mitchell suggest also contained the UK until 1980 – takes account of the use of labour relations to increase equality. Whilst acknowledging the different labour relations practices in Australia and the UK, we argue that these constitute similar welfare regimes (unlike the Norway/England comparison), and that attention to the narrative framings of care policies can uncover differences within regime types as well as between them. We separate out the broad narrative of personalization or person-centred care – shared across many developed countries – from the distinctive storylines (sub-narratives) that explain and justify that narrative within particular settings. In doing so we offer an original contribution to better understanding why NDIS took its current form and which strands of the narrative will be in tension as full national implementation begins.

<ha>Understanding Individualized Funding Schemes through a Narrative Approach </ha>

Approaching policy as narrative and storylines is to draw on the work of interpretive policy theorists such as Hajer (1993, 2005), Yanow (e.g. 1996) and Wagenaar (2011). The starting point for interpretive policy studies is that they focus on ‘meanings that shape actions and institutions, and the ways in which they do so’ (Bevir and Rhodes 2004: 130). Implicit in this statement is the idea that meaning is crucial in the study of policy and not simply in terms of the sentiments that different actors

might hold in relation to particular issues. Meaning shapes everything that we do and has proved to be particularly important in studying the implementation of policy where there may be multiple understandings of policies and policy language (Yanow 1996). By providing an understanding of the different possible meanings of personalized care funding we can better understand the dynamic tensions inherent in the system as actors seek to make a reality of a broad set of policy intentions.

In his influential work on environmental policy change, Hajer argues for the transformative role of storylines that 'suggest unity in the bewildering variety of separate discursive component parts of a problem ...' (Hajer 2005: 56). Once expressed and endorsed, storylines provide a point of reference, a heuristic, so that people need to make reference only to the storyline not to the complex bundle of arguments that underpin it, and make sense of new information and ideas by fitting them into the storyline (Fischer 2003: 124). Beyond their roots in domains such as the environment and planning, Hajer, Fischer and others have argued for the relevance of these ideas across public policy (Fischer 2003; Hajer and Wagenaar 2003; Yanow and Schwartz-Shea 2015).

Differences in the framing and design of person-centred approaches are what we call the storylines that fall beneath the broad personalization narrative. We compare the emergence of the NDIS in Australia with personal budgets in England, comparing the underlying storylines that prompted and legitimized change in the two countries, and how those stories impact on how policy is implemented. Empirical work in the UK was conducted by Needham 2011 for a prior study, drawing on national policy document analysis and semi-structured interviews with 80 people involved in different aspects of the social care system (policymakers, service managers, providers and users). A fuller discussion of the methods and evidence is available in Needham (2011). This prior study focused on identifying the storylines that had built support for personalization, leading to its adoption as a central approach to the reform of adult social care services. Five storylines were identified: personalization works; it saves money; it recognizes that people are experts on their own lives; it reflects how people live their lives rather than service jurisdictions; and it is applicable beyond social care, as other services can be made person-centred. The first of these – personalization works – is activated through vignettes of how people have used personal budgets to improve their lives. The second, on saving money, assumes that supply will better match demand as individuals make their own care choices, reducing waste within the system. The third is a rights-based appeal, affirming the inherent rights of people with disabilities to have choice and control, and not to cede power to professionals and institutions as in the past. The fourth storyline rejects segregated, service-led approaches to disability and argues for inclusive

support through which people can get ‘a life not a service’ (In Control 2015). The fifth storyline explains the scope for individualized funding to provide benefits in a wider range of public services. What is significant in these storylines is that they all assume a group of people with disabilities who are currently excluded from mainstream society (and should have better access). Only storyline five is about the relevance of the policy for the broader citizenry, and here the claim relates to the ability to harness the benefits of individualized budgets in non-disability services. Across the five storylines, aspects of citizenship and consumerism are intertwined – there is an emphasis on customized services as well as rights and inclusion – suggesting that the policy is aimed at a hybrid citizen-consumer (Clarke *et al.* 2007).

This work made a significant contribution to theorizing personalization, through separating out the different storylines within it, and rejecting the simplistic binary of citizen versus consumer. In the rest of the article we look at how the storylines that are emerging in Australia compare to these English storylines. We highlight contrasts in who the policy is designed for (people with existing disabilities versus the whole population), the temporal scope of the transformation (now versus the future) and the framing of the individual (citizen-consumer versus future worker-citizen).

Methods

The storylines of the NDIS in Australia were assembled from analysis of policy documents and semi-structured interviews. The combination of policy documents and interviews helped to develop a fuller picture of the reforms than would be possible through each source alone. Federal policy documents relating to the NDIS, along with sources such as the memoirs of politicians with a known involvement in the development of the NDIS, were used as the basis for developing an initial understanding and timeline for the NDIS reforms. These documents were also used to identify the emergent storylines that justified and explained the policy. They were further drawn on to identify federal and state politicians, bureaucrats and disability campaigners with a role in the development of the NDIS who were contacted by email and asked for an interview. A snowballing approach was then used to identify interviewees who had been involved in the development of the NDIS policy or were working on translating the policy into a new approach in the pilot sites. A total of 23 people were interviewed, all during 2015. As shown in table 1, this included disability campaigners, support planners and advocates, training providers, service providers and their representative organization, federal and state bureaucrats and federal politicians. It was a purposive sample, aiming to interview a range of key stakeholders who played a role in the development of the NDIS, or in disability services more broadly. Several of these were people with a disability. Individuals were selected either because

they were named individuals who had been associated with the NDIS, or because they play a particular role in an organization or institution that had a high profile role in the NDIS. Although the sample is small, it is a cross-section of key stakeholders at an early/important stage in the implementation of such a fundamental policy, offering a broader range of perspectives than are evident in other writings about NDIS to date. We reached saturation point in the two dominant storylines of the NDIS that were being articulated, affirming the validity of the analysis presented below (Morse 2002).

[Insert table 1 here]

Ethical approval for the project was provided by the University of Melbourne's Research Ethics Committee (HREC no 1545005.1). Participants were given an information sheet in advance of taking part, and notified that they could ask to withdraw from the research at any time. Interviews were either face-to-face or by telephone, based on interviewee preference. The interviews were semi-structured with open-ended questions, asking interviewees about their own involvement with the NDIS, what had triggered the reform, and what the experience of early implementation was showing to date. Interviews were audio-recorded with the participants' consent, on the understanding that quotes would be anonymized. Quotes used below are given identifier codes rather than names.

The policy documents and interview transcripts were analyzed to draw out emerging storylines around the introduction of the NDIS. We used inductive coding to develop themes and sub-themes through the extraction of salient, recurring or significant claims within the policy documents and interview transcripts (Attride-Stirling 2001). For example 'insurance' was a theme that emerged strongly from the policy documents and interviews, and we developed sub-themes to understand what people meant when they talked about the insurance aspects of the scheme. Coding was undertaken by extracting relevant sentences and paragraphs from the documents and assembling themed tables of coded text in Microsoft Word. The coding was done by one of the authors and then checked by the other author in order to enhance validity and reliability. Our approach to data analysis was both inductive and iterative (Feldman *et al.* 2004). As with Hazenberg and Hall (2014), we did not 'test' any pre-determined set of hypotheses or choose a model *a priori*, but instead used the data to identify the storylines. A final phase of coding identified quotes for inclusion in written outputs on the basis that they were indicative of one of the two storylines.

<ha>The Australian Storylines</ha>

England and Australia are both devolving some financial control for disability services to the individual, expressed in a dominant policy narrative of person-centredness. However, the policy

storylines underpinning this broad narrative have been very different in the two countries. In England, as set out above, the key focus of its personalization reforms has been more choice and control for individuals with existing disabilities on the basis that people should have that as a right, and that choice will lead to better, more efficient provision of support (Glasby and Littlechild 2016). In Australia, personalized funding has been explained and justified through a narrative of insurance, expressed as two storylines: first, risk of disability is something that all Australians share, and risk-pooling is the best way to respond to that risk; second, early intervention and strong actuarial involvement will secure the financial future of individualized funding. These are summarized in table 2. We consider them in more detail in the sections that follow.

[Insert table 2 here]

<hb>Storyline 1: Insurance as risk-pooling </hb>

A distinctive feature of the Australian approach has been its inclusivity. As the Productivity Commission report puts it, ‘In one sense, the NDIS is for all Australians, since it would provide insurance against the costs of support in the event that they, or a family member, acquire a significant disability’ (AGPC 2011: 10). The Every Australian Counts campaign that advocated for the new funding scheme was a broad-based movement that harnessed public support for the NDIS through media campaigns and targeting of key politicians to make a public commitment to the proposed new system (Steketee 2013). The campaign’s title was expressive of its key message: that people with disabilities should be treated as full citizens, a message that resonates with the English narrative. However, the Australian approach drew on something else: an appeal to universality and risk assurance, which was not evident in the English case. As Darcy (2015) puts it:

<ex>Australian taxpayers are investing heavily in the potential of people with disability ... They are also investing in their own peace of mind. If they or their family members ever have a disability, they will not have to endure the indignity that many people with disability have to go through every day of their life to try and have the essentials they need to live the life they want.</ex>

This notion of ‘peace of mind’ was a sub-theme, under the broader storyline of risk-pooling. One of the interviewees involved in the Every Australian Counts campaign (and now a planner supporting people with individual packages) expressed how the campaign framed its appeal in terms of everyone needing to have the reassurance that disability support was available:

<qu>‘The Every Australian Counts campaign did a really good job of explaining to ordinary Australians that disability can affect anybody at any time. Ordinary

Australians started to realise this isn't about those folks over there, this is about me. I could have a disability myself or have a grandchild born with a disability or fall off a ladder tomorrow cleaning out the gutters. Every Australian started to realise disability was something they needed to think about.' (Support planner, #17) </qu>

There was here then a commitment to the NDIS as having a relevance for broader populations who are 'at risk', even if not using services themselves currently.

Another sub-theme within this storyline related to equity and the need to ensure that people who were born with disabilities had access to services in a way that was comparable with acquired injuries. The model for the NDIS is drawn from existing no-fault motor insurance and workplace compensation schemes in Australia – and similar schemes in New Zealand – and a sense that the absence of similar cover for people with disabilities acquired in other ways was unfair (AGPC 2011; Foster *et al.* 2012). Under the existing system those born with a disability were not eligible for support for many services, while those who acquired injury through work or a motor accident would be, illustrating a clear equity issue. During the 1980s, the Deputy Prime Minister and Disability Minister, Brian Howe, first articulated the need to develop an insurance-based disability scheme to bring disability support into line with accident compensation and 'shake off an approach to disability which has about it a whiff of charity' (Howe and Burbadge 2005: 3). This same strand is articulated by Prime Minister Julia Gillard, who led the government that introduced the NDIS:

<ex>The case in essence was a simple one. Someone who acquired a disability through a motor vehicle or at work would be covered by one of the state-based public insurance schemes. That person would have options and choices about their care. The insurance scheme would meet the costs of all necessary reasonable support. People in these schemes would not be told things like, *The only time someone can come to assist you to shower and dress is late in the afternoon, a couple of times a week. Or, Sorry, but there is no more funding and you have missed out on the care you need.* Yet people born with a disability or who acquired it during their life in circumstances where there was no insurer, frequently heard such disheartening words. (Gillard 2015: 416, original emphasis)</ex>

In the interviews, a senior bureaucrat involved in the development of the NDIS told us, '*Brian [Howe] said to me stop thinking about this as a welfare model and start thinking about it as risk and insurance. That took me on a journey where I started to explore insurance approaches to supporting people with a disability*' (Federal bureaucrat, #15). A number of interviewees talked of the New

Zealand insurance-based scheme run by the Accident Compensation Corporation as the inspiration for the NDIS.

<hb>Storyline 2: *Insurance as a way to minimize future liabilities* </hb>

The second storyline of insurance that was drawn on in constructing a narrative for the NDIS focused on its commitment to minimizing future liabilities. As Baker explains (2012: 5):

<ex>The [Productivity] Commission also listed potential efficiency gains – for example, every 1 per cent increase in productivity in the disability sector could lower the scheme’s costs by \$130 million. Further benefits could come through reduced bed blocking in public hospitals; fewer people with an intellectual or psychiatric disability in prisons; and increased economic participation by people with disability, particularly those receiving the Disability Support Pension (DSP). The combination of these benefits would give the NDIS a net *economic* cost (not budgetary) of \$1.6 billion and would only have to produce a gain of \$3,800 per participant to meet a cost-benefit test. </ex>

In achieving this goal, insurance-based schemes were compared favourably with what interviewees framed as existing ‘welfare’-based approaches, meaning a scheme without actuarial underwriting, because of an assumption that the latter are too crisis-oriented:

<ex>[W]hen faced with budget constraints, systems have little choice but to give priority to families in crisis. This displaces funds for early intervention and respite programs, increasing further the number of families falling into crisis, and leading to an on going causal relationship between shortages and crises. (AGPC 2011: 5) </ex>

This recurrent rejection of welfare was one of the sub-themes of this storyline. Welfare systems were assumed to perform poorly on investment in recovery, compared to insurance-based schemes. As one interviewee put it, *‘I looked at the way in which accident compensation schemes get people back to work and have a focus on recovery and opportunity, which are not so characteristic of the welfare scheme models’* (Federal bureaucrat, #15).

The insurance model was also assumed by this interviewee to deliver much better long-term financial management, when compared to a welfare-based system:

<ex>*‘But because it is an insurance scheme we are trying to minimize the cost of supporting someone over their lifetime. That means that we are trying to make investment decisions that maximize life outcomes in terms of independence and participation. That is fundamentally different to welfare schemes where you often get*

caught up in the immediacy of annual funding targets and inevitably make decisions which are suboptimal in the long-term.' (Federal bureaucrat, #15)

This theme of distancing the NDIS from a discredited welfare approach is echoed in the National Disability Insurance Agency's (NDIA) Strategic Plan, 'There is therefore a much closer alignment of interests between people with a disability, their families and carers and the NDIS, compared with the previous welfare-based approach to disability support services' (NDIA 2013: 10).

Actuaries were to play a key role in ensuring that NDIS achieved its goal of minimizing liabilities, emphasizing the importance of data analysis as one of the sub-themes of this storyline (Foster *et al.* 2012). As one interviewee said:

'We are gathering more data than anywhere in the world. So the population and time series data – our ability to undertake really good research and test it across databases is second to none ... we are constantly looking at the forecasts and the actual results – why are we getting a higher number of people with a particular condition in the scheme than we would have expected or a lower number, why are the costs higher or lower, why are the outcomes better or worse for a particular cohort with a particular service. So the actuarial approach will drive effectiveness and efficiency over time.' (Federal bureaucrat, #15)

The prominent role given to actuaries led to tensions in the appointment of the NDIA Board between those with an experience of insurance schemes and those with a background in disability services or a personal experience of disability. Whereas the board initially favoured people with disability experience, the then Social Security Minister Mitch Fryfield (2013–15) pushed for a shake-up of the board to bring in insurance experts instead. Justifying these changes, Fryfield said, 'As we move to the next stage of implementation of the NDIS – the transition to full scheme – the NDIA will require a Board with a highly specialized skill set to effectively manage a rapid increase in participants, from 30,000 to 460,000 over three years, and administer a \$22 billion insurance-based scheme' (Smerdon 2015).

One of the key principles of the NDIS is early intervention, another sub-theme of this storyline. Only around 10 per cent of people with disabilities – those with permanent and profound disabilities – will be able to access individual support packages. Other people will be directed into lower-level preventive services in the community, as part of the Information, Linkages and Capacity-Building strand of NDIS (NDIA 2015). As one bureaucrat put it, *'To understand the NDIS you need to understand that key point – early intervention becomes a logical investment, it introduces long-term*

benefits' (Federal bureaucrat, #15). The interviewee goes on, *'If someone has equipment that gives them greater mobility and can participate socially and economically or reduces the number of carers you need because it is self-operated or operated by one person rather than two, the payback on that is just enormous'* (Federal bureaucrat, #15). According to another senior bureaucrat, *'What government was looking for was insurance and what they meant by that was a system that rigorously managed costs, a system that knew how to get the benefits of early intervention'* (Federal bureaucrat, #23).

Not all interviewees were positive about the prominence given to cost-savings. One interviewee expressed her frustration with the continued focus on the economic gains of the scheme, *'The actuarial model shouldn't just be about the economic viability, it should be about the amazing difference you can make in people's lives if you get in there early'* (Support planner, #17). As Darcy (2015) put it, *'the NDIS is not just an 'insurance scheme' requiring knowledge of the insurance business. Rather, the NDIS is a social policy reform including the National Disability Strategy that, at its heart, requires an understanding of the lived experience of people with disability'*.

Such comments highlight a tension between the insurance approach and a rights-based approach to disability, inspired by a vision of equal citizenship and informed by a lived experience of disability. The contrast between insurance and rights was another sub-theme of this storyline. Although rights were mentioned by interviewees, they appeared to be secondary to the insurance focus. As one senior bureaucrat put it, *'It came together quite nicely with the human rights model, because to invest in individuals and monitor their costs you had to have individualized funding. So insurance was about the cost containment side and the efficiency side'* (Federal bureaucrat, #23). In other words, the human rights aspect was a side-benefit of the insurance approach, not the core focus of the reforms. One of the former Federal ministers we spoke to, when asked about the rationale for individualizing the funding, said:

<qu>'Looking back now I can see what a significant change it is but it wasn't a huge part of either the intellectual argument or the campaign or the debate internally to get the money ... I know the end result is individualized thinking but that came more out of thinking what is going to be good for you over your life, rather than [the] history in the UK of individualized funding being the core thing.' (Federal politician, #2)*</qu>*

The lack of attention to the human rights element in the system design was a concern to interviewees working in the disability sector. As one put it, *'At the heart we have a real disconnect. There is a need*

for the insurance approach to have much more of a human rights framework' (Training provider, #10).

Individual Budgets as Social Investment

The Australian commitment to insurance (not 'welfare') through risk-pooling and early intervention as a cost-recovery approach, locates the NDIS within a set of policy storylines that differ from those that accompanied the implementation of personal budgets in England. The Every Australian Counts campaign needed to assure mass support for the NDIS to legitimate the fiscal commitments that the reform entailed. In this way it may be that the NDIS is more analogous to a foundational shift such as the 1942 Beveridge Report in the UK, and the subsequent establishment of the postwar welfare state. Beveridge, like the NDIS, was translated into a welfare programme in part through a popular campaign in which there was a shared appeal to everyone on a common insurance basis (Cole 1942). As Beresford puts it, 'Beveridge's plans for social renewal captured people's imagination. It can be difficult now to appreciate the resonance his 300-page report had' (Beresford 2016: 710). Like the NDIS, the 1942 Beveridge Report emphasized the importance of protecting people from risks that all may face and against which they should be insured.

The focus on early intervention as a way of minimizing future liabilities suggests that the Australian approach can be located within the social investment approach that was evident in other welfare reforms under the 2007–13 Labor Government (Smyth and Deeming 2016) and persisted under the Liberal Government (McClure Report 2015). The emergence of a social investment state has been observed in many developed welfare systems (Giddens 1998; Morel *et al.* 2012), although it has taken divergent forms (Deeming and Smyth 2015; Smyth and Deeming 2016). The language of investment features heavily in the Productivity Commission's report on NDIS (AGPC 2011), and the design of the system encompasses the features that Lister identifies as core to a social investment approach, including: investment in human and social capital; a focus on the future; an attempt to adapt individuals to the knowledge economy in order to enhance global competitiveness; an integration of economic and social policy (Lister 2003).

The location of the NDIS within a social investment approach places it in a different standing vis-à-vis the individual than in the English case. In the UK, activation policies to bring more people into the workplace have been a key part of the Department for Work and Pensions (DWP) agenda for two decades, and have included a more recent focus on people with disabilities (Garthwaite 2011; Grover and Piggott 2013). However, those DWP initiatives have been kept discursively separate from the Department of Health-led policy of person-centred care and personal budgets (Needham 2016). In

relation to personalization, it is debates about whether the reforms privilege the citizen or the consumer that have been most prevalent, as set out earlier. The tension in social investment approaches is different, taking on a temporal distinction between the current and future citizen (Lister 2003, 2004; Newman and McKee 2005). As Lister puts it, 'It is the future worker-citizen more than democratic-citizen who is the prime asset of the social-investment state' (Lister 2003: 433). Social investment approaches have also been criticized for being less inclusive than the social protection policies that they have replaced (Deeming and Smyth 2015: 314). When entitlement for support is premised on satisfying actuarial thresholds about future liabilities, there is a risk that those who cannot pay-back as future citizen-workers struggle to make a legitimate claim to the state for their support (Deeming and Smyth 2015: 314).

Lister, writing about social investment approaches targeted at children, welcomes the additional, targeted funding that social investment approaches offer, but is wary about the ways in which potential future gains slide attention away from contemporary inequalities. She warns:

<ex>the future orientation and discourses of the social investment state encourage not just the elision of demands for equality in the here-and-now, but also, paradoxically, the partial disappearance of childhood and of the child *qua* child, including the child as a rights-bearer (under the UN Convention on the Rights of the Child). (Lister 2003: 433)</ex>

In a parallel way, it can be argued that the actuarial approach of the NDIS potentially shifts attention away from the lived experience of people with disabilities now, and from the intrinsic defence of disability rights that are embodied in the UN Convention on the Rights of Persons with Disabilities.

The future orientation of the NDIS was evident in this observation from one of our interviewees:

<qu>'This scheme will work best for babies who are being born with a disability today and people who are acquiring a disability today because they are not bringing any old baggage. They are not trying to shift from the old world to the new world. Families are struggling with how do I dream of a new life or a different life for myself because the last forty years with a disability I was told don't have any dreams because I will never achieve any of them.' (Care Coordinator, #17)</qu>

This anxiety about whether or not the NDIS will improve the experiences of existing adults with disabilities has been a theme expressed by disability organizations during the piloting phase of NDIS (Purcal *et al.* 2016). There have been concerns that people were not taking up the opportunity of greater choice and control to opt for something different than they had in the past, or indeed to be more connected into low-level community services. Several interviewees expressed concerns that

people did not have the skills or knowledge to make different choices about what to spend their packages on, *'You've really got to have advocacy skills if it is something out of the box and it is a bit different from existing services ... It is a battle most of the time'* (Service provider, #7) Another used Plato's allegory of the cave, *'Do you remember the cave when people only saw the reflection of the light? There are people who are still living in that cave, including planners, they don't know what life can be ... There are people in the community but who are locked in their own house with little idea of what they can access'* (Training provider, #11). A Citizens' Jury on the NDIS concluded, 'The plans for most participants appeared to emphasize funded supports with existing disability providers, with little evidence of participants being connected to mainstream services' (People with Disability Australia 2015: 46). There are concerns that people are being steered towards existing ('in-kind') service to avoid the double running costs of sustaining existing service contracts alongside new individualized packages, exemplified in the *My First Plan* initiative that appears to limit participants' scope for individual planning and goal-setting (Every Australian Counts 2016).

Conclusion

Person-centred approaches to care, including individualized funding, are established as key principles in the disability sectors of the UK and Australia and are seen as crucial in affording individuals with disabilities more choice and control over directing their care. Comparing the narratives of person-centred care at work in the disability reforms being implemented in both countries, we found considerable differences in terms of the storylines around the development of these policies. In this article we have argued that one of the major differences between these countries is the focus in Australia on an insurance mechanism with pooled risk that is applicable to the entire population, rather than an issue of choice and control for a small proportion of the population as we find in the English example. Whereas the English policy design has been argued to counterpoise a voucher-wielding consumer against a rights-bearing citizen, we have argued that the Australian design positions the person with a disability now against the future worker-citizen.

Our research is based on a small number of interviews, and at an early stage in the piloting of the NDIS. Now that the policy has moved to the national implementation phase, large scale evaluations are underway,¹ and will help to trace the extent to which disabled people are getting better outcomes as a result of a better-funded and more individualized approach to budgeting. However, the experience of the UK suggests that such evaluations will not close down debates about whether disability services are undergoing deep, transformative changes that enhance people's rights now. The changes within disability services are located within broader shifts in welfare regimes that are towards

the residualization of state welfare (Deeming 2016). In the case of Australia, the benefits of its social investment approach will not be evident for many years, raising questions about the commitment to transforming care services for people currently using them.

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<ha>Notes</ha>

<not>

* Catherine Needham, corresponding author.

1. For example, <http://ndisevaluation.net.au> (accessed 24 March 2017).</not>

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<t1><cap>Table 1

Interviewees </cap>

<i>Type of interviewee</i>	<i>Number</i>
Disability campaigners	2
Service planners and advocates	4
Training providers	2
Service providers and provider representative body	6
Federal politicians	2
Federal bureaucrats	4
State bureaucrats	3
Total	23

</t1>

<t2><cap>Table 2

Narrative themes within the National Disability Insurance Scheme</cap>

<i>Narrative: Disability support as insurance</i>	
Storyline 1 – Risk-pooling	Storyline 2 – Minimizing future liabilities
Sub-themes:	Sub-themes:
<i>Peace of mind</i>	<i>Rejection of welfare</i>
<i>Equity</i>	<i>Data analysis</i>
	<i>Early intervention</i>
	<i>Rights</i>

</t2>

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Table 2: Narrative Themes within NDIS

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Sub-themes: <i>Peace of mind</i> <i>Equity</i>	Sub-themes: <i>Rejection of welfare</i> <i>Data analysis</i> <i>Early Intervention</i> <i>Rights</i>

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