Managing care integration during the implementation of large-scale reforms: the case of the Australian National Disability Insurance Scheme
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Managing care integration during the implementation of large-scale reforms: the case of the Australian National Disability Insurance Scheme

Introduction

Disability policy is an area that has become increasingly internationalized, not least through commitments such as the 2007 UN Convention on the Rights of Persons with Disabilities (CRPD), which sets out a powerful desire to support people with disabilities to live active and meaningful lives in the context of their communities. Changes to disability policy have also occurred in the face of fiscal and social pressures in OECD countries. Broadly, OECD countries are moving away from collective social provision in key areas, which drove the development of post-war welfare states in Europe and other western states. In place of these traditional welfare states, we are seeing the emergence of markets and ‘self-directed care’ (Gadsby 2013). Here, individuals are placed in control of their own service needs. The theme of self-directed care is evidence in the reforms of health and welfare systems in industrialised countries, including the National Health Service (Williams and Dickinson 2016, Van Berkel 2009) and unemployment assistance in Germany, Denmark and the Netherlands (Giaimo and Manow 1999, Knuth 2014).

Under these market approaches, citizens are given money directly by government and must negotiate their use of services as one would in any other market place – sourcing, understanding and choosing services that best meet their needs from a range of private and not-for-profit providers. Australia is the latest nation to follow the personalization/self directed care trend, embarking on significant reform of care services through the National Disability Insurance Scheme (NDIS). One of the key components of the NDIS is self-directed care, based on the idea that giving people with disabilities control of a budget which they use to purchase services allows them to tailor care to meet their specific needs. The argument goes that these processes can empower individuals and their families by expanding their choice and control over services and more fully integrate individuals into societal life, restoring people’s rights as citizens (Oliver and Sapey 2006).

It has long been recognized that the quality of disability services in Australia and outcomes for people with disabilities are poor, particularly when compared to other developed nations. A study from the OECD found that Australians ranked lowest in terms of quality of life for disabled people (OECD 2009). Other data sources echo these trends, illustrating that Australians with disabilities have low levels of income and labour force participation (Milner et al. 2014), experience social exclusion (Mithen et al. 2015) and significant levels of violence (Kmjacki et al. 2016). The evidence suggests that these challenges have become worse over time and that inequalities persist (Kavanagh et al. 2013).

Australian disability services have often been underfunded, inflexible and built around the needs of the system, rather than those of the individual (National People with Disabilities and Carer Council 2009). Disability services have traditionally been the responsibility of state and territory governments and different models have been...
developed across the eight jurisdictions (Fisher et al. 2010). The funding and organizing picture for disability services has remained complex with splits between state and territory and federal responsibilities and the existence of insurance-based funding of disability services and disability services funded privately as a result of public liability claims. One of the implications of this system is that individuals who acquire a disability through no fault of their own at work or in a road traffic accident may be entitled to greater levels of service provision through the relevant insurer than someone who is born with a disability. Following a report from the Australian Productivity Commission (2011) into the organisation and funding of disability services it was announced that a NDIS would be developed and the federal government committed to provide $22 billion to roll this scheme out across the country in order to improve disability services and the life chances of people with disabilities. The NDIS is administered by the National Disability Insurance Agency (NDIA).

Australian disability services have historically been block-funded and the NDIS will bring it closer to much of Western Europe and North America where some variant of individualised funding is available (Purcal et al, 2014, p.89). What the experience of these international schemes tells us is that the boundaries between disability services and other mainstream services is perhaps not as neat or distinct as the architects of these schemes either understand, or aspire, for them to be.

As the NDIS begins to build on the initial demonstrator sites and now roles out across the country, there are inevitable questions about where the limits of the scheme lie. As we will demonstrate in more detail in the following sections, there are challenges at the ‘boundaries’ of the scheme. For example, how to separate what are disability needs from those associated with health, education and broader views of welfare that still operate under more traditional welfare state models. In this paper we explore early perceptions relating to the degree to which the NDIS finds that the drivers and needs of other service areas are ‘encroaching’ on those of the scheme. We find there are already significant tensions evident within the scheme. This suggests a need to clarify boundaries around the services that sit within the scheme, the workforce that supports it, and also the logics inherent to the scheme.

In making this case, our paper is structured as follows. In the next section we briefly review the international literature to examine the patterns regarding individual funding of disability services and their relationship to mainstream services. We then move on to outline the methodology adopted for the study and the key findings according to four major themes relating to debates surrounding what is in and out of the NDIS, how local area coordination will function and workforce boundaries. Ultimately what we find in this research is a lack of clarity in terms of the boundaries of this scheme and how it should work with a range of different providers to achieve seamless, consumer-directed care. We conclude that more work is needed to clarify the boundaries of the scheme and how it will interface with different care functions.
The limits of care funding

In reforming the funding of disability services there is a crucial but vexed question about where the limits of specialist disability services lie, and how to manage the boundaries between them and mainstream services. In respect to the English context, Glasby (2007) notes that the organization of health and care services is based on the assumption that it is possible to ‘distinguish between people who are sick and have needs met by the NHS and people who have social care needs and fall under the remit of local authority services’ (pg. 66). The reality is that those with complex illness or chronic disability will likely require services from a wide range of different government agencies and it may not be readily apparent whether these ought to be classified as ‘health’ or ‘social care’ needs. Indeed, Glasby (2006) noted a decade ago that in England direct payments (cash equivalents in lieu of directly provided services) have been used to buy a combination of social and health care. This is despite the fact that these should be used for social care and not health services, as outlined in the 1996 legislation. Hence, ‘direct payment recipients do indeed use their funds to purchase some forms of health care’ (pg. 1).

In a context of ever more constrained public funding, people with disabilities may seek to buy products or services that could be viewed as sitting within either a health or social care context. To some extent the distinction between these categories may make very little difference to the individual seeking support (aside from a need to undertake means-testing associated with the latter). Indeed, the case has been made more broadly that personalization should be rolled out to health care. This was piloted in England between 2009 and 2012 for those eligible for continuing healthcare, finding these mechanisms cost effective and supported a wider roll-out (Forder et al. 2012).

The English experience of spending care funds on non-care services is not confined to this setting. In the USA studies of the West Virginian Medicaid Aged and Disabled Waiver program (Inoue et al. 2014) and Florida Self-Directed Care program for individuals with severe and persistent mental illness (Spaulding-Givens and Lacasse 2015) found that individuals purchased a wide variety of goods and services, but many of these items related to unmet need and poverty. These care budgets were used to subsidise living expenses as many individuals were existing in a state of poverty as a result of few employment opportunities and socio-economic disadvantage relating to their disability. Given levels of socio-economic disadvantaged for those living with disabilities noted above, it is perhaps unsurprising that individuals might use any additional funds that they have a reasonable degree of flexibility over to purchase items that might help alleviate the more imminent challenges they face and which may not align neatly with the mechanisms used to organise traditional welfare services.

That personal health budgets were viewed positively in their evaluation, particularly in terms of those with the greatest level of need (Forder et al. 2012), was of note given that previous experience in piloting individual budgets demonstrated that integrating funding streams was a struggle. Individual budgets were designed to
reduce fragmentation and multiple assessments by combining funding streams. Yet, in their study of individual budget pilot schemes in England, Moran et al (2011) report that despite aspirations to integrate broader funding streams, this was largely unsuccessful in practice. These authors identify multiple different barriers to integration including concerns over legislation, accountability, market management and potential demand increase. Further to these more structural issues was a concern that services might experience financial ‘buck-passing’ from one agency to another, or that resources from one stream might be used to prop up others.

Glendinning et al (2011) report that individual budget pilots brought signs of the ‘re-emergence of the ‘boundary’ disputes that had characterised health-social care relationships prior to the major collaborative policy imperatives from 1997 onwards’ and that this was seen to be ‘incompatible with the holistic person-focused principles underpinning personalisation’ (pg. 160). This experience demonstrates a whole series of issues at play when seeking to integrate multiple government funding streams across health and social care.

As we have outlined in this brief account, experience of individual funding systems from a range of jurisdictions demonstrates that individuals do not necessarily recognise the need to spend allocated funds according to particular functions. Further, the evidence base suggests that boundaries between these functions exist for governments more than service users. Although we may administratively deem a product or service as a ‘health need’, consumers may not label this accordingly and simply identify this as a pressing need. As a result, they often choose to spend these on issues that they determine are of greatest importance to their life. In terms of addressing these issues, simply having a desire to integrate funding streams does not mean that this will happen. The legislative and accountability context combined with a tendency of some professionals to closely guard the boundaries of their service and guard against the encroachment of other needs means that there is often a complex relationship between funding for care services and those earmarked for other ‘needs’. In this paper we will explore the early experience of the NDIS to identify the types of discussions and issues raised in terms of the relationship between care funding and those of other mainstream services. Before setting out our findings we provide an overview of the method used in the research.

Method

This paper draws on data from a longitudinal study of the implementation of the NDIS. The study has human ethics approval from the University of New South Wales (UNSW Grant number G160892). The study aims to investigate implementation with a particular focus on how governance structures enable and/or constrain policy learning and change (necessary for the successful implementation of complex reforms). An initial set of semi-structured interviews (N=26) was conducted with key policymakers in the national government charged with the design and implementation of the NDIS. These participants form the team who have carriage of the NDIS at the federal level. All interviews were carried out in 2016. Interviews were recorded and transcribed verbatim. Themes covered in the interviews...
included: decisions regarding the governance structure of the NDIS, implementation challenges relating to the development of the scheme, NDIS markets, individual care packages, integration with other government services and challenges associated with national roll out. This paper focus on how the NDIS will relate to ‘mainstream’ services in the early stages of full national roll out.

Data was analysed using a thematic approach (Blaikie 2010). ‘Like’ data were grouped together to form categories and subcategories. These categories were developed into more substantive themes, by linking and drawing connections between initial categories and hypothesising about consequences and likely explanations for the appearance of certain phenomena (Strauss 1987). This was done through discussion between the team. In the refining of themes, selective coding was carried out, whereby transcripts were revisited with the explicit intent of finding further linkages and connections between the central issue being explored and other themes.

In this paper we have extracted themes relevant to issues of boundary-work and where the outer limits of the various facets of the NDIS lie. We now move on to set out these findings in more detail.

**Findings**

Our interviews revealed a series of different dilemmas and tensions relating to the boundaries between the NDIS and other service domains. We explore a few of the key points of debate here, before moving on to consider the implications of these for the scheme.

**Who is in or out of the NDIS?**

The NDIS accounts for around 20% of people in Australia with a disability, meaning only those with significant and lifelong disabilities are eligible for this scheme (Australian Government Productivity Commission 2011). Those who do not qualify receive services through mainstream health services. Our interviews found concern amongst stakeholders in terms of who would cater to the 80% of people with disabilities who are not eligible. As one interviewee described, “The high level story about the NDIS is almost inarguable; people with severe and chronic conditions have been underfunded and suffered from a disjointed and fragmented service system for years. ...The issue I’m most focused on ... is what about those people with mild to moderate conditions? They’re not going to get into the NDIS. Is there going to be support for them, or are we saying, “Your answer is clinical and it’s only clinical”. [Participant 6]

Some interviewees expressed concern that with the creation of the NDIS there would be inevitable attempts from mainstream services not to cater to the 80% of people with disabilities who are ineligible for the scheme. Given that substantial amount of money being invested in disability services ($22 billion) there are concerns that those in mainstream services might assume that the NDIS should be
doing particular things, but the reality is that it only focuses on those with the greatest disabilities (Bonyhady 2014, National Disability Insurance Scheme 2014). One interviewee described this as follows: “the NDIS rollout – the implementation in the NDIS is brilliant, but of the four million odd people with disability in Australia, not a huge proportion of them will actually get a funded plan from the NDIS. And for many people with disability... it’s the mainstream service systems that they interact with every day, the health system, education, transport, criminal justice, all of that. And the risk is if there’s not kind of constant reminders and pressure maintained on those systems they’ll tend to think that the NDIS will just take care of everything in disability land...there’s an unintended consequence that we want to try and guard against...the NDIS is the biggest game in town, so it gets all of the media attention”. [Participant 10].

Unlike the English scheme, the NDIS is only available for those aged under 65. For another interviewee this raised concerns that we will find gaps in terms of age and eligibility for different schemes. “We don’t have a good grasp on...the interface between aged care and NDIS. So as people progressively age over 65 in the scheme and start developing frailty as opposed to disability...where does the NDIS stop and where does the aged care system come in? What does that interface look like and we’re not going to know that for 10/20 years when you start getting around the fluctuation of the scheme?” [Participant 18]. Similarly, “we didn’t do exactly what the P[roductivity] C[ommission] said, we did something similar but not exactly. There are policy differences, particularly aging in the scheme over 65 they need to face with aged care and we have much tighter financial controls on the [implementation] agency than they would otherwise have preferred” [Participant 18]

What became rapidly apparent in interviews is there is a point of contention in terms of what should be classified as mainstream services and what should sit within the NDIS. The boundaries between different services lack clarity at present, rendering it difficult to conceptualise the start and end of different services. “What can your own informal supports and family do to help you with your – address your goals. Then, what does the local community do for you? Then, what does the mainstream do for you? And then what do you need by way of additional funding and supports?” At one level they are all markets of supports, they are all ways of getting your assistance and the funded supports are only component of that, the [Local Area Coordinators] might [use] the person’s informal supports. They might work with strengthening and building and just connecting together the community supports for somebody. Again, they can problem shoot around mainstream service provision”. [Participant 13]

The line between the NDIS and mainstream services in the context of mental health was seen as particularly problematic. Mental health was brought into the NDIS in 2015, but differs significantly from other types of disability covered by the scheme. For example, people often experience episodic disability associated with mental illness and are also far less likely to identify as having a ‘disability’ and therefore be reluctant to access the NDIS. One interviewee described this in the following terms;
“Mental health being in the NDIS... it is a strange bedfellow. There’s a lot of people with mental illness who don’t acknowledge there is any condition that they have. There’s others who see it solely as a health issue.” [Participant 6]. And another expressed concern that “The language in the disability [insurance scheme] criteria, what is it, severe and permanent or likely to be ... That doesn’t sort of capture that episodical, the fluctuating sort of nature of mental illness”. [Participant 7]

Some individuals may be eligible for the NDIS, but as the individual drives this, it may mean that some do not apply for support from the scheme. One interviewee described this in the following terms: “You may as an individual not even acknowledge that you have a mental illness, but you’re eligible for the program which is around people with mental illness. NDIS is absolutely driven by client choice into the program and so that presupposes a level of cognitive capacity and decision making that people with mental illness have, but that’s not all the time. So it’s a much more complicated task from an NDIS eligibility testing and so on point of view” [Participant 7]

Many individuals with mental health issues will not meet the eligibility criteria of the NDIS and will therefore be required to rely on the healthcare services: “35 percent of our 170,000 clients in the disability and employment service would be because their primary barrier to work is a mental illness. A very small percentage of those will end up in the NDIS. We look at people who are on partial capacity to work or in the Job Active scheme of the Department of Employment or who present as homeless or who are affected by family violence; mental health issues run through those and a dozen more of our systems.” [Participant 7]. For those who are deemed in eligible for the NDIS this might have significant implications for the types of care that they can access. As another interviewee described, “The Victorian Government had funding for psychosocial disability... And through the psychosocial disability programs they were picking up their mental health clients. So all of their disability funding has gone to the NDIS which means that whole bucket that has gone to people with psychosocial disability, some of whom may not be eligible for the NDIS, it does present a bit of a challenge”. [Participant 6]

Some interviewees described having experienced the dilemmas that these systems create already: “we had a program in New South Wales where people could apply for money and they would have a window replaced or their washing machine repaired, which really wasn’t in the scope of the scheme. And in another state, we had dog food being funded and medicines being funded. And so there's a very clear rule around mainstream systems and what's reasonable. So if you have a dog, you normally buy good dog food, but also there's a PBS system for your medicines, so you should use the PBS system for medicine” [Participant 22]. Others pointed to areas such as the provision of teacher assistants in classrooms, arguing that this should be considered a traditional mainstream service but increasingly it is being expected that the NDIS should be responsible for covering these costs.

As we have sought to illustrate in this section, decisions concerning what falls within the parameters of the NDIS is far from straightforward and there are a number of
different dimensions to this debate. The first is that there are a number of individuals who received support prior to the scheme who will now miss out and have to rely on mainstream health services. Secondly, those who rely on these mainstream services may find that these attempt to pass the buck for these individuals back to the NDIS. Finally, even if you are eligible for this scheme you may not access it as you do not identify with the language of the NDIS.

Role of Local area coordinators
In addition to providing individual funding to people with disabilities, a further function of the NDIS is around local area coordination (LAC). The LAC function has a number of roles that relate to assisting NDIS participants to engage more effectively with the scheme by connecting them with service providers (both mainstream and specialty), but also assist people who are not eligible for the NDIS through capacity building and information provision. LACs will also have a role in engaging with the broader community to inform about the scheme, better understand the needs of people with disabilities and create more opportunities for people with a disability to participate socially and economically.

In the main we found a lack of clarity in terms of the LAC role and what this would actually involve. Many we spoke to were concerned about the size of this role and where the limits of this reside. In practice it is likely that the role will take on a number of different potential shapes and activities depending on the local characteristics of the area and the individuals that reside within it: “the role of LAC will change. So they’ve actually already been modified somewhat because what their role will need to be during transition will- when you read kind of what they’re meant to do, it’s already like “well that’s like superman type stuff.” ... So there will be a bit more of a juggling of what I would call the general local area coordination stuff, and assisting the claiming and bringing people in. You would hope then in three years’ time, LAC can go to that real intent much more because people will be in and actually looking at how the community supports them, how are the linkages with mainstream” [Participant 16]

One interviewee described that “part of [local area coordinator] role, and I think they’ll have a limited capacity to do this, but part of their role is the capacity building in communities. And to build up capacity in communities to provide informal supports to build the capacity of mainstream systems to work with the NDIS. So that’s a pretty big ask. So the NDIA for example needs to work with systems like the new one, the primary health network system, and that will be a great partnership. But you know, health systems are pretty complicated as they are etc. But that is their role, to try and build the capacity to have that engagement and so planners really, their role in working with a participant on their plan is to talk about participants goals and aspirations, but they need to be developing a pretty good knowledge because they’ve got to be able to draw on mainstream supports before they go to anything else that might be funded.” [Participant 16]. What this quote illustrates is somewhat of a paradox in terms of the NDIS, where mainstream supports need to be in place first, but as suggested in the section above, mainstream services are
increasingly attempting to move away from providing services to people with disabilities (seeing this as the remit of the NDIS).

If the NDIS is to operate as an insurance scheme; that is operate as a preventative scheme that focuses on appropriate disability care over the life course and works to better enable people with disabilities to integrate with society, then the LAC function is critical. However, as our research shows, the role of the LAC contains many different elements and is unclear at present.

**Strain on a limited workforce**

Much has been written concerning the workforce implications of moving towards personalized care schemes (e.g. Ungerson and Yeandle 2007) and we detected concerns over workforce issues in the Australian research too. Some interviewees expressed concerns relating to perceived gaps in the workforce. As one interviewee described, “we’re probably going to have a shortage of workers who deliver in home services and care and some of that. I mean there will be shortages of allied health, there’s shortages of allied health now. But is that where the real demand is going to grow, maybe not as - and there’s also talk that there’s shortages in that kind of complex behaviour area and end of things. But again, it’s really hard - it’s very hard to be predictive”. [Participant 2] Others described gaps not in terms of particular professional groups, but the capacity if workers: “The challenges mostly arise in workforce capacity. That goes to issues around making sure that there are enough people to provide direct services to participants and that there is this new function, particularly around local area coordination and support and planning. So making sure that there’s an adequate balance in where the workforce will be at different times, and I think it’s going to be a big challenge for the agency.” [Participant 4]

In response to this, there may be some opportunities for agencies to think about sharing workforces in more creative ways than has happened in the past. As one interviewee described, “So what Commonwealth will do more broadly is I suppose look at how disability, aged care and child care sectors, where there’s potential for doing things in more joined up ways around workforce development more broadly where there might be a flow in and out of some of those and particularly we think we might see like players in more - being in the aged care space kind of, maybe move more into the disability space because aged care has also got more of a focus now on the linking funding to individuals going forward. So there’s potential things like more casualisation of the workforce or whatever or so but there will be more work than there’s ever been before. So we’re not sure how some of the - I mean, the Commonwealth’s got a role around education in the sense of sufficient allied health professionals, university sector kind of picking up those [Participant 8]”. Another described how “we’re looking at it from a regulation point of view, and talking a lot to our aged care colleagues in terms of what they do and what that might look like in the future. How you can actually grow the workforce by looking at things and talking to Job Active providers given that, as well as like some of the industrial relation stuff. So given that these are relatively low skilled work force, there are opportunities to align a lot of those things, as well as how we influence some of the education and
training opportunities across the board. So it’s how you grow the care workforce. There’s a lot of concerns also around having enough allied health, because that’s been an ongoing issue. [Participant 16]"

To date, workforce issues have received limited attention. Yet it appears that there are gaps within the current system and this has implications beyond the parameters of care services and into other associated service areas.

Discussion

It is clear from the findings reported above that there is somewhat of a lack of clarity in terms of the boundaries of the NDIS and how it will work with a range of different services in the provision of seamless and consumer-direct care. One thing to note is that it is relatively early days for this scheme in the sense that it was been trialed initially starting in 2013 either distinct geographical areas or for particular user groups in Tasmania, South Australia, Victoria and New South Wales, with the addition of trials in the Australian Capital Territory, Northern Territory and Western Australia in 2014. As of 1st July 2016 the scheme started to roll out across the whole country. The initial trials took place against a policy background that was far from clear. A review of the National Disability Insurance Agency, the organization set up to administer the NDIS, was described is as being ‘like a plane that took off before it had been fully built and is being completed while it is in the air’ (Whalan, Acton, and Harmer 2014: pg. 7).

On top of these design issues has been immense political and community pressure to begin the implementation early, and grow the scheme rapidly “the former government started a year earlier than the productivity commission said and so it’s always been a bit like building and implementing at the same time.” [Participant 16] (see also, Caneva 2015). What this means in practice is that, three years into implementation, there is much about the policy context that remains uncertain and our data was collected at a time when many individuals were struggling with what the NDIS would look like and how it would operate. As illustrated above, some we spoke to believe that the scheme will turn into a rather different model to that initially as a result but the timelines for this are very long (i.e. 10+ years).

It is concerning that the boundaries of the scheme are quite opaque. We find challenges in terms of what is seen as sitting within the NDIS and what should be in mainstream services. To this extent we have detected some of the same sorts of ‘buck-passing’ tendencies that Glendinning et al (2011) observed in their research of the English context. Where significant changes are made with an oft-reported large price tag then many will be feeling that responsibility for disability services should lie with others. It can be difficult in this setting to distinguish between what is a care need and what should sit with other mainstream services such as health or education. This is particularly the case with mental health, which was a late addition to the scheme. The episodic nature of NDIS, along with many people suffering from mental illness not identifying as having a disability, makes it in the word of interviewees “strange bed fellows”. Turning to the care workforce it is clear that
there are still important gaps here and issues that are worthy of further attention if people with disabilities are to be supported to truly achieve choice and control.

Of course we need to be careful about overstating our findings. Data collected here were from policy makers early on in the process of the development of the NDIS. Given the scope of the research we spoke to a sample of policy makers and at a particular point in time. It is likely that the understanding of the scheme will develop over time and this will likely not be the final word on this matter.

Conclusions

Overall, there is still much to be determined about how the NDIS operates and how it interfaces with a range of other allied services. The same kinds of debates that have emerged surrounding English individual funding schemes have also emerged in the Australian context, suggesting that Australian policymakers should look to England for clues on how to resolve the tensions raised in this paper. If the NDIS is truly to support individuals with disabilities to achieve choice and control, important work will need to be undertaken in order to support individuals to overcome organizational and institutional boundaries.
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