Can the National Disability Insurance Scheme work for mental health?

Theresa M Williams1,2 and Geoffrey P Smith1,2

Introduction

In 2010, the Productivity Commission was requested by the Australian Government to undertake an inquiry into a national disability long-term care and support scheme. In its report, it recommended the introduction of the National Disability Insurance Scheme (NDIS) (Productivity Commission, 2011). The impetus for the inquiry came from active lobbying by the specialist disability sector for a nationally based insurance system. The aim was to provide people and their families with greater choice and control over the services they receive in keeping with the sector’s values of person-centred, self-directed and individualized services that promote independence, community inclusion and participation.

In investigating the feasibility of establishing the NDIS, the Productivity Commission, after ‘some debate’ (Fels, 2012) recommended that persons with significant and enduring psychiatric disability be included in the scheme. However, the NDIS has been fundamentally shaped by, and largely reflects the world view of, the specialist disability sector and does not fully ‘resonate’ with the mental health sector. For example, the requirement for ‘permanent’ impairment or disability does not sit comfortably with the ‘recovery’ paradigm. Indeed, many people with recurrent or persistent mental health problems would not view themselves as being ‘disabled’.

The introduction of the NDIS in March 2013 potentially offers substantial benefits for people with a psychiatric disability, but also raises a number of challenges. After providing a brief overview of the essential features of the NDIS, we review the findings from similar programs operating overseas to try to identify what Australia can do to ensure that the scheme delivers tangible benefits for people with psychiatric disability.

What is the National Disability Insurance Scheme (NDIS)?

All Australians under the age of 65 who acquire a permanent (or likely to be permanent) disability, including people with a psychiatric disability, that substantially reduces their functional capacity will be eligible for funding of support services based on their individual needs. The scheme will, however, only fund disability supports where they are not part of another service system’s ‘universal service obligation’, such as health, education or housing (Council of Australian Governments, 2013).

An ‘early intervention’ eligibility criterion was included that was intended to provide people accepted into the NDIS, termed participants, with access to supports designed to minimize or reduce functional impairment, reduce the need for future supports, or improve the sustainability of informal supports.

Once eligibility is determined, the National Disability Insurance Agency (NDIA), which administers the scheme, will work with each participant to develop an individual plan based on each person’s goals and aspirations. That plan will specify the amount of funding, the supports to be purchased and who is responsible for managing the plan. Individuals can receive funds directly from the NDIA to enable them to self-manage the purchase of their own supports or, alternatively, funds may be managed by the NDIA or an approved third party (Australian Government, 2013). Although the Commonwealth, States and Territories have agreed that funding from their existing mental health programs will be included in the NDIS funding pool, the details have yet to be determined.

Starting from 1 July 2013, the scheme is being progressively rolled out through a series of trial sites with full implementation set for 2019/20. The first four sites to be launched were the Hunter area of New South

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Wales (0–64 years old), the Barwon region of Victoria (0–64 years old), South Australia (0–14 years old) and Tasmania (15–24 years old). Further sites will be progressively launched in the Australian Capital Territory, the Northern Territory and Western Australia commencing in 2014.

The concerns of the mental health sector
While the NDIS has been broadly welcomed by the mental health sector, there are a number of concerns about how it will operate in practice for people with a psychiatric disability (Mental Health Council of Australia, 2013). Significant concerns raised include:

- whether there has been a gross underestimation of people with psychosocial disability eligible for the scheme;
- whether the scheme has the flexibility to respond to the fluctuating disability support needs of people with a mental illness of an episodic nature;
- whether access to early intervention psychosocial support will prove problematic given the challenge in predicting ‘permanent’ impairment;
- the degree of readiness of the workforce and service providers for this fundamental change in the way that services are to be delivered;
- how States and Territories will respond to the support needs of the many people who are not eligible for, or choose not to access, the scheme;
- the difficulty in defining the boundaries between services that are the responsibility of the health system or the NDIS.

An international perspective
There has been a progressive shift commencing in the early 1990s in the way that long-term care is being provided for people with disabilities in a number of countries, including the USA, England, Scotland, France, Germany, Belgium, Austria and the Netherlands. This change, variously labelled — but for simplicity referred to in this paper as ‘self-directed support’ — is designed to empower consumers by placing control of resources directly into their hands so they can choose the services that best suit their needs (Alakeson, 2010b; Da Roit and Le Bihan, 2009).

While the various national schemes differ, they all provide consumers with the opportunity to have greater control over an identified ‘individual budget’. In some countries, such as The Netherlands, the choice is limited to either a cash budget paid directly to the individual or access to traditional services. England and Scotland, on the other hand, have expanded the range of options from direct cash payments to include a variety of third party budget-holding arrangements (Williams, 2012). England has built on its experience of personal budgets in social care and introduced ‘personal health budgets’ for people with long-term health conditions using National Health Service (NHS) funds (Alakeson, 2010a).

The national evaluation of the self-directed support pilots in England (Glendinning et al., 2008) found a significantly higher quality of life amongst mental health consumers in the pilots than those in control groups. Similarly, in a recent survey (National Development Team for Inclusion, 2013a) of people with mental health problems in England with a self-directed support budget, participants reported improved/much improved: physical health (63%), mental well-being (71%), independence (71%), control over life (64%) and getting the support needed (66%). Furthermore, self-directed support has not resulted in any increase in cost and, in some cases, has actually reduced it (Glassby and Littlechild, 2009; Glendinning et al., 2008; Tyson et al., 2010).

Despite these promising findings, there has been a low uptake of self-directed support by mental health consumers in Scotland and England. In Scotland, the uptake has been just 2% of self-directed support packages (Ridley et al., 2012) and in England only 9% of eligible adults with a mental health issue received self-directed support funding compared with 41% of eligible adults with a learning disability (Royal College of Psychiatrists, 2013). The response of the Scottish government has been to fund a number of practical capacity-building initiatives specifically designed for the mental health sector, involving consumers and carers as active partners, to tackle this problem.

It appears that one of the key factors influencing the low uptake in both England and Scotland has been the lack of familiarity with the concept and practice of self-directed support amongst both mental health professionals and consumers and carers. This is significant given that most people’s route to support has been through clinical mental health services (National Development Team for Inclusion, 2013b).

A pilot program in Stockport (Greater Manchester, UK) for people with psychiatric disability, designed and implemented as a partnership between NHS mental health services and the local authority, demonstrated that the problem of low uptake could largely be overcome by tailoring the program to the specific population and engaging with the clinical teams. The evaluation noted, however, the difficulty encountered in engaging with young people from the early intervention program who were ‘... often at a stage where they wanted to keep official interaction with mental health teams to a minimum, and still felt they had their health under control’ (Eost-Telling, 2010). Table 1 highlights the key lessons learned from the international experience.

Making the NDIS work for mental health
Recognizing that mental health poses some special challenges, the
Commonwealth Government funded the Mental Health Council of Australia for 1 year to June 2014 to assist in building the capacity of the sector. This project is aimed at determining the supports consumers, carers and service providers will need to better engage with the NDIS. While this is a promising start, it does not adequately take into account the complexity and magnitude of the challenges faced by mental health in the roll-out of this program.

The trial sites, on the other hand, provide a unique opportunity for a structured approach to identifying problems and testing innovative solutions. Evidence from sites in England and Scotland suggests that capacity-building initiatives for mental health need to be sector specific and be:

- based on local partnership at each site between all key stakeholders, including consumer and carer organizations, clinical mental health services and NGOs;
- funded over an extended period to encourage sustained effort, recognizing that complex system change takes time;
- able to trial innovative solutions based upon an approach of ‘learning by doing’.

The establishment of a mental health ‘learning network’ across participating trial sites would support the sharing of ideas and provide a national voice for the sector to influence and shape the design of the scheme. The importance of hearing the voices of clinicians, consumers, families and NGOs from the launch sites, who can speak from experience, cannot be overstated.

### Table 1. Lessons for Australia from the international experience in implementing self-directed support in mental health.

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<th>Facilitating recovery</th>
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<td>Self-directed support has the potential to bring about powerful changes that support recovery in the lives of people with mental illness.</td>
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<th>Tailoring the program</th>
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<td>‘One size does not fit all’ and the program must be appropriate for, and responsive to, the needs of people with mental illness. Consumer and carer involvement in this process is vital.</td>
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<th>Enhancing access</th>
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<td>The uptake of self-directed support is enhanced by an active partnership between mental health and social care.</td>
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<th>Engaging clinicians</th>
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<td>The major pathway to self-directed support for people with mental illness is through mental health services and clinician support is critical for promoting access.</td>
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<th>Building capacity</th>
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<td>Self-directed support represents a fundamental change in the way that services are delivered for both government and non-government mental health services and their workforce.</td>
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<th>Maintaining effort</th>
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<td>The mental health system needs to maintain its capacity to meet the support needs of people who are not eligible for, or choose not to access, self-directed support.</td>
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<th>Intervening early</th>
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<td>Young people with early psychosis have been difficult to engage in social care/disability support programs.</td>
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### Conclusions

Experience, particularly from trials in the UK, provides us with two important messages: first, that self-directed support has the potential for being a powerful tool for personal recovery, and second, that mental health services are the major pathway for consumers into disability support. It is critical, therefore, that mental health clinicians and their professional bodies are engaged in, and have a good understanding of, the NDIS and of the principles and practice of self-directed support. A sustained program of capacity building, specifically designed for the mental health sector, is required to ensure that people with psychiatric disability do not miss out on getting the support that they need.

### Keywords

Mental health, national disability insurance scheme, self-directed support

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