CHANGING THE DRIVER

National Disability Insurance Scheme

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JUSTICE ACTION

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1. Introduction

In an open market economy, individuals determine and satisfy their needs when they have the power to do so. However, in the case of disabled individuals, others make decisions about what services are available and who can receive them. This reversal of power has resulted in inefficiency and injustice in the industry. Fortunately, change is occurring. Self-directed funding systems in the United States and United Kingdom have proven enormously successful, as demonstrated in benefits such as faster recovery for individuals with disabilities and more efficient use of resources.

Self-directed funding has been shown to be three times more effective than traditional funding systems, begging the question as to why this approach has been delayed in Australia. Justice Action exposed the problem previously through the critical analysis of the 'OUR PICK Report'. That Report presented the dishonesty of the Australian Health industry and proposed the empowerment of mental health patients and prisoners and to choose the services they receive.[1]

The issue has received increased attention in recent years from other Australian agencies. The Australian Productivity Commission's August 2011 report declared that the provision of services to people with a disability is 'unfair and inefficient',[2] and proposed the National Disability Insurance Scheme (NDIS) as a solution. The NDIS aims to provide individuals with greater control over their own service packages and providers in line with the rationale of Self-directed funding. Scheduled for launch in July 2013, it is currently a federal and state government priority and has received overwhelmingly positive support from the Australian community.

This paper explores the issues surrounding the implementation of a Self-directed funding model in Australia. It will describe the Australian Productivity Commission's proposed NDIS in detail and examine issues of exclusion and power relations present within the current system. In particular focus on the Housing and Accommodation Support Initiative (HASI), concluding that the power to select and distribute services to consumers is held mostly by the service providers themselves. The federal government has proposed an extra annual expenditure of $8 billion, but has failed to indicate how that will be generated. This is a way of enticing service providers to participate in the NDIS, drawing attention away from the reversal of power between the service providers and the disabled consumers, which could potentially create resistance and block the implementation of the scheme. However, without a clear funding base, the NDIS is at risk of becoming an unrealistic political stunt that fails to reach the consumers who need it most. It has thus become a political 'hot potato', forcing Opposition leader Tony Abbott to declare himself "Dr Yes when it comes to the National Disability Insurance Scheme".[3]

This analysis follows the 'OUR PICK Report', condemning the use of the disabled and mentally ill as political pawns. Moreover, this paper demands the immediate implementation of the Self-directed funding scheme outlined in the Productivity Commission's report, using the money already available to them through existing funding systems such as HASI, in order to place the disabled person in control of the money allocated for their own benefit.

[1] Justice Action, *OUR PICK Report* (July 2010) 1-2.
Note: Please see the full report online <http://justiceaction.org.au/cms/images/stories/Our_Pick_Report.pdf>.
[2] Mental Health Coordinating Council 2011, *Self-directed Funding and the Community Managed Mental Health Sector: Opportunities and Challenges* (November 2011) 2.
[3] Phillip Coorey, 'Hockey weakens Abbott's commitment to the disabled', *Sydney Morning Herald*, 17 May 2012.

2. Definition of Relevant Terms

2.1 Self-directed Funding

According to the Mental Health Coordinating Council (MHCC) the term 'Self–directed funding' refers to cash payments that directly paid to an individual with a disability. The fund enables them to 'purchase the services of their choice within parameters set by a responsible authority'.[4]

Self-directed care models are comprised of the following components:

- Individual assessment – a professional together with the patient undertakes an assessment of the person's legal and health needs.
- Personal budget – the patient is informed of the amount of money that will be allocated to their needs.
- Choice in the way their personal budget can be managed.[5]

2.2 Person Centred Approach (PCA)

The term 'Person Centred Approach' (PCA) has been adopted by the State MP for the Ageing and Disability Services, Andrew Constance, and the State MP for the Family and Community Services, Pru Goward. PCAs place the disabled individual at the centre of the decision-making process when it comes to the support and services they use. PCAs were created as a response to the manner in which society traditionally perceived and treated individuals with disabilities, providing them with rigid, inflexible support and services. Often, this resulted in individuals becoming simultaneously more dependent on their service providers and feeling disempowered and devalued within society. PCAs reject this inequitable approach and aim to provide strong support for individuals with disabilities while at the same time allowing them greater control over their lives and futures.

The three core aspects of PCAs are:

- Person centred planning: personalised and directed by the individual, where possible, with support if needed.
- Personalised funding: allocation of resources for support based on consumers' individual needs, identified through the planning process.
- Personalised service delivery: delivery involving a combination of formal and informal, public and privately provided services, which are coordinated to provide the best outcomes for an individual.[6]

3. Justification for a New Approach and Funding Model

The Australian Productivity Commission (The Commission)[7] has recommended that the Australian Government implement a new funding program which allows 'greater consumer choice and control' by enabling individuals to choose their own service providers.[8] The Commission describes the current funding system in Australia for individuals with disabilities as:

> "…under-funded, 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

[4] Mental Health Coordinating Council 2011, *Self-directed Funding and the Community Managed Mental Health Sector: Opportunities and Challenges* (November 2011) 8.
[5] Ibid 8-9.
[6] Mental Health Coordinating Council 2011, *Self-directed Funding and the Community Managed Mental Health Sector: Opportunities and Challenges* (November 2011) 8-9.
[7] Referred to as The Commission for the purposes of this report.
[8] Mental Health Coordinating Council 2011, *Self-directed Funding and the Community Managed Mental Health Sector: Opportunities and Challenges* (November 2011) 8.

community…(it is) a system marked by invisible deprivation and lost opportunities."[9]

In NSW, individuals with disabilities, their families and carers have expressed the need for greater choice and control over the support and services they currently have. These individuals have provided personal accounts of how inflexible the support and service limit their ability to conduct their everyday lives.

Patient or consumer centered care is increasingly being recognised as a dimension of high quality health care in its own right. There is strong evidence that a patient centered focus can lead to improvements in health care quality. At the same time, it also increases safety, is cost effective and provides the satisfaction for the individuals with disabilities, their families and health care staff. This approach responds to the preferences, needs and values of patients and consumers.

The key components of PCAs involve the core patients, consumers, carers and families. These include:

- Treating the core group with dignity and respect.
- Encouraging and supporting participation in decision making.
- Communicating and sharing information.
- Fostering collaborations between the core group and health professionals in program and policy development, as well as health service design, delivery and evaluation.[10]

Self-directed funding enables individuals with disabilities to become more independent. This funding approach empowers individuals with disabilities to take control of their own lives, thereby encouraging social inclusion.

4. Development of the National Disability Insurance Scheme (NDIS)

In mid February 2010, Senator Nick Sherry from the Labor Government asked The Commission to begin an inquiry into the feasibility of a NDIS, fulfilling an election promise from 2007. The inquiry, which began in April of the same year and concluded on the 31st of July 2011 focused on the adoption and form of the NDIS.[11] This inquiry coincided with the release of the Justice Action's 'Our Pick Report' in July of 2010, which highlighted the significance of the empowerment on mental health patients.

At the end of the inquiry period, The Commission released the 'Productivity Commission's Disability Care and Support Inquiry Report' in August 2011. The report recommended the Federal Government take over the funding of disability care support in Australia under a NDIS. The Commission suggested that a NDIS be established 'to provide all Australians with insurance for the costs of support if they or a family member acquire a disability', similar to Medicare.[12]

The proposed NDIS would transform the way services are currently funded, ensuring individuals with disabilities, their families, and supporters would all have appropriate support, care, therapy, and equipment.[13] The proposed NDIS would also fund a range of long-term disability support that is currently provided by specialists. These services include the following:

- Personal care
- Community access

[9] Ibid 2.
[10] Mental Health Coordinating Council 2011, *Self-directed Funding and the Community Managed Mental Health Sector: Opportunities and Challenges* (November 2011) 2.
[11] Mental Health Coordinating Council, *Self-directed Funding Discussion Paper* (October 2011) 14.
[12] Ibid.
[13] Every Australian Counts, *The Need for NDIS* <http://everyaustraliancounts.com.au/about/the_need_/> at 23 January 2012.

- Respite
- Specialist accommodation support
- Domestic assistance and guide dogs
- Therapies

The proposed NDIS is also flexible as it provides networking opportunities between the communities, individuals with disabilities and organisations. This would allow consumers such as patients, their families and supporters to receive the best quality services.[14]

The Productivity Commission proposed the NDIS would allow individuals with disabilities or their carers acting on their behalf to exercise consumer choice. The scheme would provide individuals with the power to choose their own service providers and change to new providers if they are dissatisfied. The Commission also recommended that individuals under this scheme should have the option of choosing to fund a support package over another. This would allow individuals to personalise the type of services they receive to meet their own needs.

The Mental Health Coordinating Council has also expressed support for the NDIS and made recommendations regarding the scheme:

- Certainty of funding to provide lifetime support to individuals with disabilities, their families and carers.
- Simplicity in gaining access to disability specialists and universal services.
- Fairness in the application of eligibility criteria, assessment and support to people irrespective of where they live or their disability.
- Choice to gain control over their supports.[15]

MP Jenny Macklin has stated the NDIS ensures that any Australian with a disability will have access to the care and support they need to participate in society, regardless of their place of residence and nature of their disability.[16] Other state and territory governments have also expressed support for a NDIS:

> "Victoria is keen to be at the forefront of the implementation of an NDIS, and the Minister for Community Services Mary Wooldridge has this morning reiterated to Minister Jenny Macklin Victoria's commitment to implementing the first-stage rollout of the scheme here in Victoria."[17]

Premier of Victoria, Ted Baillieu has also specifically expressed his support for an NDIS. He quoted on one occasion:

> "We are pleased that the Productivity Commission has taken note of our overarching support for an NDIS as well as other specific suggestions such as the need to include people with significant and enduring psychiatric disabilities in the scheme and the need to urgently develop a common assessment tool."[18]

Following the release of the Commission's Report, the main political parties mirrored the state and territory governments' overwhelming support for an NDIS. It was reaffirmed in December of 2011, where an NDIS officially became part of the Labor Party Policy Platform.

[14] Australian Human Rights Commission, *Pod Rights Transcript: Episode 16 – National Disability Insurance Scheme* <http://www.humanrights.gov.au/disability_rights/index.html> at 18 January 2012.
[15] Mental Health Coordinating Council 2011, *Self-directed Funding and the Community Managed Mental Health Sector: Opportunities and Challenges* (November 2011) 8.
[16] The Hon Jenny Macklin MP, 'Working with South Australia to get NDIS ready' (Media Release, 19 December 2011).
[17] Jenny Macklin. *Department of Families, Community Services and Indigenous Affairs.* 'Media Release: Working with South Australia to get NDIS ready' <http://tinyurl.com/6vnej96>.
[18] Josh Gordon, 'Victoria presses care for disability plan', (press release, 3 February 20012).

5. Breadth of Application of the National Disability Insurance Scheme

Although the NDIS is proposed for individuals with 'disabilities', uncertainty exists in the reasons for focusing on individuals with disabilities rather than all government service recipients. The definition of 'disability' may be relevant in determining whether individuals with disabilities have an intrinsically greater entitlement to Self-directed funding than other recipients.

According to the 1980 classification from World Health Organisation (WHO), 'disability' can be described in three dimensions: impairment, disability and handicap. Based on this definition, the Commission's Report on Government Services 2002 defined disability in terms of three aspects: body impairment, activity restriction, and participation restriction. Generally speaking, people who lack mobility or communication skills or the ability to care for themselves may be defined as being disabled.

The *Disability Services Act 1993* (NSW) defines the target group for disability services as "people with a disability that is attributable to an intellectual, psychiatric, sensory, physical or like impairment or to a combination of such impairments". In this way, 'disability' is defined more by behaviour that manifests as a result of a disability, rather than the disability itself.[19]

The *Disability Discrimination Act* 1992 (Cth) (DDA) defines disability more comprehensively. In the DDA, disability refers to:

- Total or partial loss of the person's bodily or mental functions or a body part.
- The presence in the body of organisms causing or capable of causing disease or illness.
- The malfunction, malformation or disfigurement of a part of the person's body.
- A disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction.
- A disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgement or that results in disturbed behaviour.[20]

The DDA's definition also includes conditions that:

- Presently exist; or
- Previously existed but no longer exists; or
- May exist in the future; or
- It is imputed to a person.[21]

6. Exclusion from current disability support

It is crucial that the NDIS addresses the issue of scope and eligibility of funding and services provided to disabled people in order to avoid the pitfalls of the current funding system, which excludes a number of individuals or groups. As an example, this section provides an analysis of one of the major current funding systems in NSW, the Housing and Accommodation Support Initiative (HASI). HASI aims to provide people in NSW with mental illness access to stable housing, accommodation support and clinical mental health services. It functions through a partnership system between NSW Health, Housing NSW and non-government organisations (NGOs). It is a broad system that operates on approximately $53 million a year has greatly been expanded since its implementation in 2005.

[19] *Disability Services Acts 1993* (NSW) s5(1)(a).
[20] *Disability Discrimination Acts 1992* (Cth) s4.
[21] Ibid.

There are several tiers of HASI support available, loosely divided into high-level and low-level support. Successful applicants are selected from a large pool through a multi-tiered process. Potentially successful applicants are chosen by a client selection panel and interviewed by accommodation support providers such as NGOs who decide who can receive funding and how much funding they receive. The service providers therefore have complete power to select clients at their discretion, as they develop priority lists according to the relative needs assessment. Although they must establish clear assessment criteria, there is no standard regarding the processing of outcomes.

A further issue concerns the selection criteria themselves, a few of which are problematic. One crucial requirement is that applicants must be eligible for social housing and have the desire and ability to live in the community. Furthermore, applicants will not be eligible if they are already receiving accommodation support services under the NSW Government Boarding House Reform Strategy. This is especially significant because boarding houses are for-profit organisations and therefore, do not receive government funding. This has led to serious concerns about the safety, health, welfare and rights of residents. Additionally, since the Boarding House Reform Program itself was poorly managed and failed to take into account the ongoing nature of disability assistance, most residents failed to experience significant reforms or increased standards of living under it. This has led to a situation in which a large number of mentally ill residents are ineligible for HASI because they are supposedly receiving support through the Boarding Houses Reform Program. As a result of poor management, implementation and lack of understanding by HASI, residents fail to experience significant benefits.

Through analysis of HASI and the groups included and excluded within it, it is clear that greater consideration is needed to ensure that the individuals most in need of disability funding are given adequate support. Currently, the power to decide which applicants are successful and how much funding they are entitled to receive lies entirely with HASI service providers. This takes control away from the clients themselves and prevents them from receiving the personalised support that would be most beneficial to them. The NDIS must take these marginalised groups into account when assessing its selection criteria and conferral of powers to decision-making bodies. (See Appendix A regarding HASI and the boarding house situation).

7. Issues concerning the National Disability Insurance Scheme

Despite the overwhelming support from the state, territory, and federal governments for a NDIS, a number of concerns about the new model have arisen. These concerns include the model's definition of disability, services for forensic patients, the use of person centred approaches in practice, media coverage, and potential defamation charges that could result from the new model. State community health organisations have also expressed concern over the withdrawal of block funding. These issues will be discussed in more detail below.

7.1 Definition of 'Disability'

There is a degree of ambiguity about the definition and scope of the term 'disability'. It is questionable whether funding is available for every case of disability, particularly if the disability has a disruptive effect on an individual's decision-making ability. For example, there is uncertainty about how the NDIS can apply to individuals with social disorders such as Antisocial Personality Disorder. The subjection of such individuals to involuntary treatment is not an example of Self-directed funding at all. Furthermore, individuals with intellectual disabilities may lack the requisite ability and knowledge to make informed choices about the services they need.

In cases such as these, it is therefore essential to balance the desires of the individual and the individual's needs (determined by the service providers).

7.2 Costs

7.2.1 Budget

Disability support services currently cost more than $7 billion a year, with $2.3 billion from the federal government and approximately $4.7 billion from states and territories. Sharing of costs in the new system is currently a topic of discussion between Commonwealth and state disability ministers and treasurers. It is estimated that if properly funded, the NDIS would cost $13.5 billion a year, almost double the current level of spending. The federal government expects each state to maintain if their current level of funding, and is persuading Victoria, which spends $8378 per person per year, to increase its funding level. The May budget reveals that $1 billion will be immediately directed into the launch to "kick-start" the NDIS. This comprises an initial $84 million down payment in 2012-13, which will grow to $363 million in 2015-16. Continual funding over the next four years will follow. The federal government is asking launch participants to contribute a total of $288 million over these four years, during which states are asked to share care and support costs. Although this commitment demonstrates the government's resolution to improve disability services, the total amount is disappointing to some campaigners.

The May budget also reveals the precise distribution of this early funding. More than a third of the funds will go towards care and support, $155 million towards employment of program coordinators and $123 million towards preparing the disability sector to provide new services, presumably through measures such as staff training. Coordination of NDIS implementation is expected to cost $53 million. An additional $250 million will be spent constructing an information system that measures the effectiveness of new services, with a further $17 million going towards research and allocation. Finally, $59 million will go towards assessment of eligibility of potential candidates and determination of how much they will receive. Additionally, almost $60 million will be provided into 600 businesses to support 20,000 jobs held by people with disabilities.[22]

7.2.2 Funding and Allocation Concerns

Several concerns have arisen regarding the funding and allocation for the NDIS. Firstly, the state governments have criticised the government's commitment of $1 billion for the first four years, as detailed in the May budget. Andrew Constance, the NSW Minister for Disability Services, described it as "hopelessly inadequate", showing a lack of dedication to the NDIS and the government's willingness to take advantage of a sector with vulnerable consumers and small expectations.[23] False hope may be created for many consumers who receive little or no money for years, as it is a much smaller budget than the $3.9 billion recommended by the Productivity Commission. The budget would be less than $3.9 billion as $650 million would go into administration and only $450 million would go towards actual funding.[24]

Secondly, there are discrepancies regarding the number of people who are eligible to receive funding under the NDIS. At Labor's national conference in September 2011, the Prime Minister

[22] Dan Harrison, 'Canberra involves states in $1 billion support scheme', *Sydney Morning Herald*, 9 May 2012 <http://www.smh.com.au/business/federal-budget/canberra-involves-states-in-1-billion-support-scheme-20120508-1yb8t.html#ixzz1uWKq37mb>.
[23] Imre Salusinszky and Sue Dunleavy, 'State to revel on disability scheme', *The Australian*, 15 May 2012 <http://everyaustraliancounts.com.au/states-to-rebel-on-disability-scheme/>.
[24] Peter van Onselen, 'Disability scheme is great, in theory', *Weekend Australian*, 12 May 2012 <http://everyaustraliancounts.com.au/money-and-detail-post-budget-ndis-analysis/>.

implied that approximately 2 million Australians could be eligible, and yet the Productivity Commission's recommendation states that it aims to provide funding to 410,000 people. However, since there are approximately 4 million people with disabilities in Australia, a large majority will inevitably receive less than promised or nothing at all. Moreover, the increased funding directed towards the NDIS may be contradictory as it has been matched by cutbacks within other funding areas such as the Disability Support Pension, which was subject to significant budget cuts in May 2011/12. Also, there has been greater use of NewStart, a lower payment compared to the Disability Support Pension. This has been described as a "sleight of hand", where support for the NDIS masks and draws attention away from the significant cuts and savings that have been made in other areas of disability support.[25]

Thirdly, it is crucial for the government to provide more specific information about the group of people who can receive support under the NDIS, the criteria for selection and the parties who make the decisions. The current failure of the government to release explicit information about these issues may lead to concerns that the outcomes of the NDIS will be unsatisfactory for individuals who do not meet the selection criteria and fail to qualify for support This mirrors the inadequate support received by residents of boarding houses through HASI.

The government appears to be addressing this crucial issue by claiming to allow people with disabilities greater control over the services provided to them through more individualised funding.[26] Consumers would have greater benefits through support packages tailored to their individual needs. Consumers would have the ability to choose their own providers, ask intermediaries to assemble tailored packages for them, cash out packages and distribute to areas of need. In order to provide personalised funding to consumers, the NDIS requires a higher level of user input into its designer, the National Disability Insurance Agency, as well as an increased emphasis placed on research, in order to ensure success.[27] The Agency needs to be created and reported to all Australian governments. It needs an independent commercial board, an advisory council and clear guidelines to ensure sustainability and efficiency. It must also be protected from political influence through black-letter legislation.

7.3 Political Landscape

7.3.1 Supporters and stakeholders

The NDIS was proposed by the Productivity Commission in 2011 following a thorough investigation of the unsatisfactory nature of existing disability funding services. However the Productivity Commission, as an independent government research body, is actively involved in campaigning, reporting and making recommendations on a wide range of social, economic and environmental issues.

The central stakeholder behind the push for the NDIS is the National Disability Alliance, which is made up of National Disability Services, Carers Australia and the Australian Federation of Disability Organisations. Throughout their campaign, the Alliance has organised numerous 'Make it Real' rallies on 30 April 2012 across Australia including the Sydney rally, where the Prime Minister announced the rollout of the NDIS in July 2013 and the inclusion of NDIS funding in the May budget. Over 10,000 people attended the rallies, including a number of well known political figures who have campaigned for the NDIS in recent years. Political figures included

[25] Karen Soldatic, *Giving and taking away: NDIS and disability pension reform* (14 October 2011) The Conversation <http://theconversation.edu.au/giving-and-taking-away-ndis-and-disability-pension-reform-3230>.
[26] Prime Minister of Australia, 'Designing a National Disability Insurance Scheme' (Media release, 3 December 2011) <http://www.pm.gov.au/press-office/designing-national-disability-insurance-scheme>.
[27] Niki Ellis, *Lessons for the National Disability Insurance Scheme* (30 April 2012) The Conversation < http://theconversation.edu.au/lessons-for-the-national-disability-insurance-scheme-2889>.

Nicola Roxon, the Attorney-General of Australia, and Graeme Innes AM, Australia's Disability Discrimination Commissioner.[28]

7.3.2 Political pressures and motives

The NDIS has received positive feedback from the general public and disability campaigner. However, legitimate concern that the current atmosphere of expectation and apprehension surrounding the NDIS will result in disappointment and frustration. This has prompted Anthony Kerin, the President of the Australian Lawyer's Association (ALA), to ask the government for an honest response regarding which individuals will receive support. Kerin views the government's failure to provide honest information as the misleading "vulnerable Australians" in order to improve Labor's prospects of re-election.[29] Julia Gillard is aware of the immense public support that the proposed NDIS has garnered since its development and has spoken at the Make it Real rallies in April. She claims to clearly understand that the security of her position and government may improve if through demonstrating that she can listen and respond to public opinion. She also understands the strong support for the NDIS within parliament and the Australian political sphere, which can greatly influence her individual position. The grand announcements, rapid implementation and heavy funding may therefore be seen as a desperate bid for public support from a dying government trying to appeal to voters in an area in which it knows it will receive a positive response.[30]

A further issue concerns the urgency and enthusiasm with which the NDIS will be implemented and demonstrated by the Prime Minister's insistence on delivering the first stage of the NDIS a full year ahead of the timetable set out by the Productivity Commission, and the inclusion of the NDIS launch within the May budget. An additional $8 billion is a highly significant amount of money in the context of the federal budget. The Commonwealth's rush to promote the NDIS while the states seemingly lag behind leads to concerns that the Commonwealth is aiming to gain public approval. Such approval may be attained in several ways. Firstly, by demonstrating its commitment to providing disability funding, the government can gain increased support from the community, public figures as well as the disability service providers themselves who will receive the money. To the service providers, the promise of an additional $8 billion may effectively amount to an attractive bribe paid for political support. Secondly, by pushing the launch date forward, the government can also make it appear as though the states are delaying federal plans to improve conditions for disabled individuals. This concern is especially valid when considering the fact that NSW, Queensland, Victoria and Western Australia—which make up half of Australian states and territories, and all extremely influential and highly populated—are all Liberal states. There is a possibility that the Labor government's ulterior motive in actively promoting and allocating money towards the NDIS is not entirely driven by concern for disabled Australians. They may also intend to create an atmosphere of disapproval towards the Liberal state parties and the Australian Liberal Party in order to bolster their own re-election prospects.

This explanation reveals the reasons for the highly unusual support for the NDIS by the Opposition leader, Tony Abbott, which in itself suggests possible hidden motives. It is possible that the Opposition may also understand the consequences of any political maneuvering by the government and thus is trying to increase its own approval rating by distancing itself from the

[28] Pro Bono Australia, *Disability Community Applauds Launch of NDIS* (2012) <http://www.probonoaustralia.com.au/news/2012/05/disability-community-applauds-launch-ndis>.
[29] Stephanie Quine, *ALA questions Macklin's NDIS promise* (19 April 2012) Lawyers Weekly <http://www.lawyersweekly.com.au/news/ala-questions-macklins-ndis-promise>.
[30] Lema Samandar and Adam Bennett, 'NDIS welcomed but cost questions linger', *The Canberra Times* (online), 30 April 2012 <http://www.canberratimes.com.au/breaking-news-national/ndis-welcomed-but-cost-questions-linger-20120430-1xu9i.html>.

states and showing its reasonableness and commitment to providing support for disabled people.

Through this analysis, it is clear that although political motives are difficult to ascertain, disability funding can very easily become a political arena in which battles can be fought at the expense of vulnerable consumers who often cannot voice their own concerns. It provides an extremely good opportunity because the parties can struggle diplomatically and at the same time appear to the public as though they are supporting and assisting the disadvantaged. Therefore, since both the government and opposition's level of commitment are currently unclear, it is important to place ongoing pressure on the government to focus on the implementation and results of the NDIS and ensure that it is fully, not partially implemented and funded in all respects.

7.4 Services for Forensic Patients

As the framework for the NDIS is broad, it does not specifically mention the unique services required by forensic patients, making it difficult to determine whether forensic patients are included in the scheme.

7.5 Use of Person Centred Approaches (PCAs) in Practice

Person Centred Approaches (PCAs) such as the proposed NDIS are designed to place the individual with disability at the centre of the decision making process. It allows the individual to decide on how the funding will be spent to assist them. Ironically however, in the draft of the document 'Ten Year Roadmap for National Mental Health Reform', PCAs are referred to as:

> "An approach to service which embraces a philosophy of respect for, and a partnership with people receiving services. A collaborative effort consisting of consumers, consumers' families, friends and mental health professionals."[31]

The use of vague phrases such as 'philosophy of respect' and 'collaborative effort' implies that the person receiving services is in fact neither empowered nor at the centre of the decision-making processes.

7.6 Media Coverage

There has been some controversy regarding the nature of media coverage on the NDIS. Whilst the bipartisan agreement on the NDIS has led to overall constructive and tangible reform, it has also meant that media coverage has been less focused and substantive than it would be, were it the focus of a major political struggle. As such, much of the political rhetoric surrounding the NDIS focuses on the scale of the reform (namely the size of the government funding) rather than a detailed examination of its bureaucratic processes. Consequently, the significance of the shift towards a Self-directed funding model is understated. It is relegated in the mid to late sections of media pieces, often using descriptors such as "a focus on individual choice" or "person-centred". Such language is sometimes lost in the rest of the piece, disguising the significance of the unprecedented reform.

7.7 Defamation

There has also been some concern about whether organisations such as Justice Action, which assess the suitability of service providers for the benefit of NDIS funding recipients, can be

[31] Australian Government Department of Health and Ageing, *Ten Year Roadmap for National Mental Health Reform Draft* (2012), Australian Government Department of Health and Ageing, <http://tinyurl.com/73d3gx2> at 18 January 2012.

subject to defamation actions. The following guidelines explain the legal issues at stake as per the *Defamation Act* 2005 (NSW).

Firstly, only individuals and "excepted corporations" can sue for defamation. 'Excepted corporations' are either not-for-profit organisations or corporations that hire less than ten people. However, individuals from a 'non-excepted corporation', who are singled out, can be sued for defamation.

Secondly, a defamation claim can be made when communicating (including by oral means) information that lowers or injures the reputation (personal or professional) of someone. This includes communicating defamatory material printed elsewhere. Merely repeating defamatory material and passing it still qualifies as defamation.[32]

Thirdly, if the defendant can prove that the accusation was substantially true, then there is no defamation claim.

Fourthly, a number of other defences are available, provided no malice was intended. The defence of 'honest opinion' requires that the accusation was an opinion, not a statement of fact, that the defendant believed the accusation was honest, that the accusation is a issue of public interest and that it is based on non-defamatory and substantially true facts. If one is reporting defamatory accusations recorded in a public document, then this is a defence. Likewise, if the accusation was sourced from a public proceeding and included in the report of that proceeding on behalf of the public interest, it is also a defence.

Justice Action and other organisations issue opinions based on identifiable facts, without malice and with the public interest in mind. This means they will generally be safe from a defamation suit, even from a small corporation or not-for-profit group. Repeating unreliable information however needs to be avoided.

7.8 Withdrawal of Block Funding

The introduction of Self-directed funding as part of the proposed NDIS has concerned state and territory non-governmental health organisations who have no guaranteed funding under the system and would therefore need to market themselves in order to attract consumers. The cost for organisations to reorientate themselves so that they can operate within the Self-directed funding framework may be significant, especially for smaller organisations which lack the requisite financial resources. For example, organisations may be encouraged to merge in order to pool resources and attract consumers, resulting in significant job losses.

8 Current Implementation Around the World

8.1 Australia

Currently, no Australian states and territories have Self-directed funding schemes for which people with a psychosocial disability are eligible. Western Australia is preparing for a four year pilot project to assist 100 individuals with severe and persistent mental illness and those who have been in a mental health patient setting for longer than 3 months. The aim of this project is to allow individuals with a disability to make a successful transition back into the community by June 2012. The funds provided will be for individualised packages of support (the Individualised Community Living Program) as well as housing. The project aims to provide people with a mental illness, their families, carers, and supporters with greater choice and control over the

[32] *Defamation Act* 2005 (NSW) s4. Provided you had some editorial control over passing the information on, or knew that the material was defamatory.

support and services they access. However, Self-directed funding has not been mentioned as an option.

8.2 United Kingdom and North America

The implementation of Self-directed funding was first championed by disabled peoples' organisations in North America who advocated for a shift in the balance of power between people and the services upon which they relied. These organisations included the Centre on Human Policy's Rehabilitation Research and Training Centre (RRTC) on Community Integration.[33] As a result, Self-directed funding has now been introduced in most Western European countries and parts of North America.

PCAs in the U.K. and North America are most often used for persons with learning and developmental disabilities. However, the approach has become increasingly prominent in other areas of society, where traditional methods of service delivery have left people including children, persons with physical disabilities, persons with mental health issues, and the elderly, disempowered.

Although Self-directed funding has been introduced into the social healthcare systems of most Western European countries and parts of North America, only a few of these schemes have extended eligibility to people with a psychosocial disability. Countries that have extended eligibility include Nova Scotia and Newfoundland in Canada, Florida, Maryland, Michigan, Oregon, and Tennessee in the U.S. as well the U.K. As most of the literature in this area originates from the U.K., this report will discuss the U.K. model.

9. Outcomes from Self-directing Funding Studies

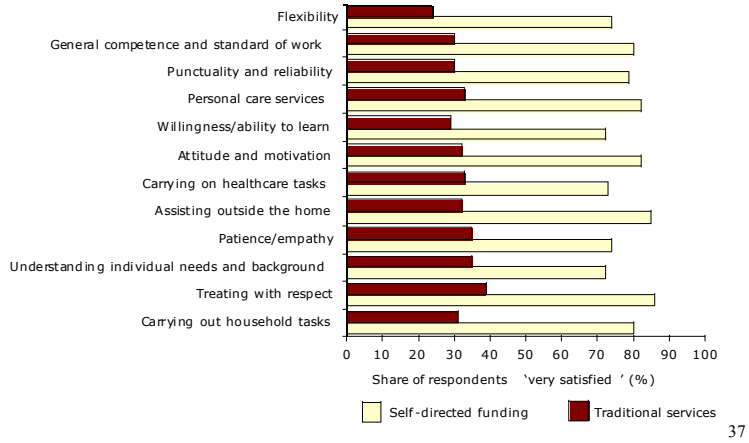
9.1 The United Kingdom

In the U.K., direct funding preceded the introduction of a Self-directed care model. Direct payments were formally introduced in 1997 where money was paid directly to individuals by local authorities based on an assessment of personal needs.[34] Individuals could then use these payments to access the most appropriate care and support for their own needs. However, this was largely bolted onto the traditional system of care. Low take up and limited purchasing options led to pressure for a more fundamental transformation of the social care system. In 2003, it became mandatory for Local Authorities to offer direct payments to all those eligible. Individuals with a mental health problem were eligible for direct payments under the legislation but research found that they were the group least likely to be receiving these payments.

The introduction of individual budgets saw both positive and negative outcomes. Regular reports and reviews of personal health budgets carried out by the National Health Service in the U.K. have found a variety of outcomes. The majority of individuals receiving direct payments have reported an increase in their quality of life. For example, having access to a wheelchair meant they could participate in more social activities. Increases in general health and wellbeing as well as psychological wellbeing were attained through services such as gyms, counseling and therapy. Almost all patients reported that they felt an increase in control over their daily lives and social care. However, those whose payments were being controlled by a third party were disappointed with the long delays and the approval and delivery of services. However, the early evaluation of the program found that older patients felt less satisfied with their social care services.[35]

[33] Mental Health Coordinating Council 2011, *Self-directed Funding and the Community Managed Mental Health Sector: Opportunities and Challenges* (November 2011) 2.
[34] National Mental Health Confederation, *Personal Health Budgets* January (2009, UK) 5-6.
[35] National Mental Health Confederation, *Personal Health Budgets* January (2009, UK) 5-6.

Adams and Godwin conducted one of the largest and most thorough examinations of Self-directed funding in the U.K. The study collected information from 526 people with disability and carers hiring support workers (the employers) and 486 personal assistants[36]. Overall they found that 79% of people on the Self-directed funding program were 'very satisfied' in their services compared to 26% who were receiving traditional services.



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Data Source: Adams and Godwin (2008) 29.

9.2 The United States

Self-directed funding, also known as individualised funding and self-determination funding in the U.S., is a choice that has been successfully operating for disabled individuals.[38] The most sophisticated studies on Self-directed funding have been undertaken in the U.S., comparing the impacts of Self-directed funding against control groups of people receiving traditional care. The Australian Productivity Commission has examined 27 U.S. studies into Self-directed funding, spanning the last 25 years. The evaluations have consistently found that Self-directed funding provides significant benefits to people with disabilities and their families compared with traditional agency-based services[39]. Studies in the U.S. are very similar to those in the U.K. in that most outcomes are positive and most respondents reported the same results.

An international conference on Individualised Funding and Self-Determination Funding in July 2000 attracted 1000 people to join the forum. They shared, discussed and built on the concept of funding, and more importantly it put individualised funding into action.[40] There is fewer unmet needs and higher service satisfaction in the individualised funding and greater control over their own lives.[41] The outcomes consistently found that Self-directed funding provides positive outcomes to disabled individuals and their families. Positive outcomes included greater satisfaction with care and life, a sense of control and a higher quality of care and confidence in care.[42] Furthermore, Head and Conroy's 2005 study found people had more outings; an average of 35 per month compared with a baseline of 25; quality of life increased from 69 to 81 points on a scale of 0-100 as measured by an instrument examining 15 dimensions of quality life, and more satisfaction in both care and life was found as there was an increase of 0.25 points on a scale from 1- 5.[43]

A trial of Self-directed care in Northeast Florida showed that mental health patients who Self-

[36] Australian Government Productivity Commission, *Disability Care & Support: Appendix E Impacts of Self-directed funding*, vol 11 (E8-E9).
[37] Perceptions of the quality of personal services under Self-directed versus traditional service models.
Australian Government Productivity Commission, *Disability Care & Support: Appendix E Impacts of Self-directed funding*, vol 11 (E7).
[38] Ontario Adult Autism Research and Support Network, Individualized Approaches to Supporting People with Disabilities <http://www.uoguelph.ca/oaar/STRATEGIES5.shtml> at 22 January 2012.
[39] Australian Government Productivity Commission, *Disability Care & Support: Appendix E Impacts of Self-directed funding*, vol 11 (E9-E10).
[40] Ibid E7.
[41] Ibid.
[42] Ibid E1.
[43] Ibid E9-E10.

directed their own funding were more likely to use early intervention services and less likely to use crisis services, compared to those who did not receive Self-directed funding.[44] Similarly, a study conducted in New Jersey found that mental health patients who received Self-directed funding were more satisfied with their quality of life, more likely to receive personal care services and had fewer unmet household needs.[45]

10. Positive Impacts of Self-directed Funding for Consumers and Service Providers

Allowing individuals with disabilities to decide how they wish to spend their funding budget is a significantly positive improvement in society. Self-directed funding allows people with disabilities to feel more independent and empowered. It provides individuals, carers, and supporters with greater choice and control over what services they wish to spend their money on. Self-directed funding also allows individuals to spend their money on social activities, which positively promotes community integration and social inclusion. Funding can be used in ways to help individuals gain employment, which is a desired outcome for The Commission.

Under a reasonable scenario, The Commission estimates that there could be an additional employment growth of 220 000 by 2050.[46] The scheme would also benefit the community in other ways. For example, the likelihood of recidivism of prisoners with mental illness could be reduced if these individuals were able to readily access services such as education and counseling.

The implementation of Self-directed funding models overseas has resulted in increased market competition. This increased competition has driven consumer costs down.[47] Studies have also shown that Self-directed funding costs less to meet individuals' needs than traditional forms of care.[48] Most studies focus mainly on the direct expenditure on services by individuals with a disability, while others focus on implementation costs, and costs for the family. Zarb & Nadash from the UK found that Self-directed funding costs 39.2% less than traditional models, whilst other studies such as Conroy et al. in Michigan US found Self-directed funding only costs 6.7% less than traditional models.[49]

11. Negative Impacts on Consumers and Service Providers

Despite the success of Self-directing funding models, these models have also had some adverse impacts on consumers and service providers. Although under Self-directed funding schemes, individuals with disabilities should have autonomy and control of what services their funding goes towards, unfortunately not all individuals are aware of this. Furthermore, even though Self-directed funding schemes are based on the principles of freedom of choice, people still have to purchase their services 'within parameters set by the responsible authority'.[50] Also, the direction and ways in which individuals choose to spend their money is not flexible.

The traditional funding model, block funding, involved supplying individuals with essential and necessary services for their situation whether it be accommodation, legal services or health services. However, as Self-directed funding allows individuals to choose how they spend their funding, many individuals have spent their funding on leisure and social activities such as gym memberships, electronics and furniture rather than essential services.[51] In countries where Self-

[44] Mental Health Coordinating Council, *Self-directed Funding Discussion Paper* (October 2011) 14.
[45] Ibid.
[46] Australian Government Productivity Commission, *Disability Care & Support: Appendix E Impacts of Self-directed funding*, vol 11 (E9-E10).
[47] Ibid
[48] Ibid.
[49] Ibid.
[50] Mental Health Coordinating Council, *Self-directed Funding Discussion Paper* (October 2011) 14.
[51] Ibid.

directed care has already been implemented, some service organisations that had previously received block funding have not been able to cope with the heavy market competition and have consequently had to close down. This has disadvantaged consumers who are eligible for the Self-directed funding scheme as they were reliant on the services provided by these organisations.

12. Conclusion

It is clear this analysis that the benefits in fulfilment and efficiency achieved through a Self-directed funding system over a system directed by the service providers, suggests that the NDIS must properly and appropriately take into account the input of the disabled individuals who are receiving funding. This would create enormous cost benefits and ensure that vulnerable individuals receive the full benefits of the services without becoming embroiled in a political struggle over which they have no control.

The Australian government has the power to make meaningful changes on the basis of the findings of the Productivity Commission to make NDIS a sustainable reality. However, it is equally important for a Self-directed funding scheme to be implemented as soon as possible whether the NDIS is implemented or not, because the issue of disability funding is not dependent on the government or budget allocations but on the needs of disabled people themselves. It is crucial that a Self-directed funding system is implemented now, so that current as well as future money is redirected towards greater control of the services which are available to them.

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14. Appendix

HASI and boarding house situation

HASI

The selection process is administered entirely by the accommodation support provider, who develops the priority list according to the relative needs assessment and conducts client interviews. This raises concerns about accountability and transparency, because although the process of determining the relative needs assessment must adhere to Standard 1 of the *Disability Services Act 1993* (NSW), which requires that clear criteria be established, there is no standard in relation to the processing of outcomes.

Furthermore, the client selection process is made by local selection committee meetings, which include representatives from AMHS (Area Mental Health Services), ASPs (Accommodation Support Providers) and housing organizations. The most common variation in selection processes emerged around the issue of people's capacity to participate in rehabilitation, from which a possibility exists that the selection process screens out people with complex needs because they are perceived to have a lower capacity to participate in rehabilitation activities which are vital in order to successfully exit the program. While the perceived aim of this service is to support an individual's recovery process, there is always the lingering question as to who can be effectively supported. There is a concern that the clients with less complex needs are prioritised over others as they have greater capacity to develop independent living skills in a short timeframe than others. This would undermine the value of the support system and divert large sums of money from new and more receptive clients.

A further issue lies in the referral pathways utilised to identify and select target group. It was reported that 78% of referrals made to HASI came from AMHS and hospitals.[52] Thus, AMHS possess an influential role in identifying and selecting clients. However, further research needs to be done as to why most referrals come from health organizations. Furthermore, confusion arises regarding referral pathways due to multiplicity of providers and availability of different support levels. Consequently, ASPs continue to receive some inappropriate referrals.

Boarding houses

Boarding houses containing 2 or more people with disabilities are sometimes known as Licensed Residential Centres (LRCs). There are an estimated 455 boarding houses in NSW containing over 5000 residents, of which 31 are licensed and contain 687 residents with mental or intellectual illness.[53] Many were designed for people who, unable to find long-term accommodation and having few alternative options, require a transient form of living. Although boarding house residents are some of the state's most vulnerable people, disability and mental health support often fails to reach them. There are serious concerns about the safety, health, welfare and rights of the residents of licensed boarding houses, and the adequacy of the system

[52] McDermott, S. et al., 2011 '*Evaluation of the Mental Health, Housing and Accommodation Support Initiative (HASI) Second Report'*, UNSW, accessed 13 April 2012, pp 19 <http://www.sprc.unsw.edu.au/media/File/1_SPRC_Report_511.pdf>

[53] Adele Horin, 'Shocking abuse and neglect revealed in boarding houses across NSW', *The Sydney Morning Herald*, 17 August 2011.

that is meant to protect them.[54] Furthermore, as private, for-profit institutions are not required to adhere to disability service standards, limited government funding is available to residents.[55] Although some forms of financial support exist, they are often not targeted towards mentally ill residents and do not apply equally across boarding houses across the state. It is doubtful that the $834 000 provided to selected boarding houses by the Boarding House Outreach Project (2011), included in the NSW Homelessness Action Plan (HAP), will reach the residents who are most in need of support, especially, its inability to provide funding to the most vulnerable mentally ill people. Residents of boarding houses are not eligible for HASI for two reasons. Firstly, they do not meet the requirement that applicants must be eligible for social housing, because they already have access to stable accommodation. This undermines HASI's objective to provide support for people who are at risk of homelessness as they move in and out of institutions. Eligibility for social housing is a requirement for all stages of HASI except Stage 4B (HASI in the Home), which was implemented in 2007 and provides accommodation support for consumers no matter where they live. However, there has been no indication that boarding house residents have been receiving HASI funding under Stage 4B.

The second reason boarding house residents are ineligible for HASI is that they are ostensibly already receiving support under the 1998 Boarding House Reform Program. This program, implemented by the NSW Department of Aging and Disability, involved provision of funding directed at the short and long term health needs of disabled residents of boarding houses licensed under the *Youth and Community Services Act* 1973 (NSW). In many areas this program was poorly organised and managed because coordinators failed to take into account the ongoing nature of disability assistance in areas such as training and educating staff and assessing and supporting residents in response to their constantly changing personal conditions. Moreover, as for-profit organisations, management was centred on the needs of the institutions themselves rather than the needs of residents,[56] resulting in the failure of much of the funding to reach the target group.

The consequences are deplorable. The reality of the situation is that a large number of mentally ill individuals are ineligible for HASI because they reside at boarding houses licensed under the *Youth and Community Services Act* and are therefore assumed to receive sufficient support under the Boarding House Reform Program, but due to poor management and monitoring, actually receive little funding and do not experience any significant increase in standards of living under the program. The lack of security and protection provided by HASI then leads to an elevated risk of homelessness for residents due to boarding house closure. The closure of 24 boarding houses since 2005/06 (with a loss of 352 beds) has revealed this risk to be valid and highly significant.

A number of reasons for the inadequate level of support are listed here. First, the business strategies and institutionalised nature of the boarding house system, and the lack of external governmental support, which, it has been suggested, ought to provide more detailed and stringent service requirements in licensing agreements and regulatory staff training in order to improve the level of care given to boarding house residents[57]. Secondly, boarding houses managing a large number of residents are clearly unable to provide the full range of support, which residents require in clinical, rehabilitation and advocacy areas. Thirdly, landlords and residents are often unaware of residents' rights.[58] Lastly, the failure of management to provide full and constant support for the majority of residents may be seen as a result of the perceived distinction between "illness" and "disability"[59]. The tendency is for boarding house management

[54] NSW Ombudsman, August 2011, *'More than board and lodging: the need for boarding house reform'*
[55] Williams, Thea, *'Cast adrift when most in need: An inquest into six deaths raises questions over standards of care',* March 31 2012, Sydney Morning Herald
[56] Email from Jenna Bateman to Boarding House Review Team, 29 July 2003, in Mental Health Coordinating Council.
[57] Ibid.
[58] Ibid.
[59] Lynn Godfree, Ian Bridges-Webb, Boarding House Health Promotion Program – A Collaborative Model, Mental Health Coordinating Council, <http://www.mhcc.org.au/documents/LynnGodfree.pdf> at 20 April 2012.

and staff to refer residents for treatment but not improvement in general standards of living. This results in a situation where boarding house residents are often unable to access the range of existing health services for which they are eligible.

Fortunately, small reforms have been achieved. Stronger measures, such as mandatory periodic criminal record checks and harsher penalties for failing to comply with regulations, will be implemented through a bill, which should be next month. All boarding houses will be required to register with NSW Fair Trading, residents will be given greater occupancy rights and government workers will have greater means to monitor the welfare of residents. However, there are still many areas in which significant reforms must be achieved.

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