

## **CONSUMER CONTROLLED FUNDING**

### **Draft 10/02/2012: Assessing the Formation of the NDIS**

#### **Contents**

1. Introduction
2. Justification for a New Approach and Funding Model
3. Development of the National Disability Insurance Scheme (NDIS)
4. Breadth of Application of the National Disability Insurance Scheme
5. Issues Concerning the National Disability Insurance Scheme
  - a. Definition of 'Disability'
  - b. Use of Person Centred Approaches in Practice
  - c. Withdrawal of Block Funding
  - d. Media Coverage
  - e. Defamation
6. Definition of Other Relevant Terms
7. Current Implementation Across the World
  - a. United Kingdom
  - b. United States of America
8. Outcomes from Self-Directing Funding Studies
9. Positive Impacts of Self-Directed Funding on Consumers and Service Providers
10. Negative Impacts on Consumers and Service Providers

#### **Introduction**

The Productivity Commission in its report in August 2011 declared that the provision of services to people with disability is 'unfair and inefficient'.<sup>1</sup> This is consistent with the OUR PICK Report accusation of corruption, although the commission proposes a rational solution. The Australian Government has embraced the Productivity Commission Report and the proposed National Disability Insurance Scheme that gives authority and choice to consumers.

That funding model has proven to be successful in the United States and the United Kingdom with 'overwhelmingly positive effects' including improved recovery and more efficient use of resources. This funding approach, as a "bottom up" rather than "top down" approach is obviously more effective and it begs the question as to why it has taken so long to be adopted. The change has been described by UK organisations, Mind and Richmond Fellowship, as "not being something that can simply be added but rather as affecting everything".<sup>2</sup>

---

<sup>1</sup> Australian Government Productivity Commission, 'Disability Care and Support Inquiry Report', August 2011

<sup>2</sup> Self Directed Funding and the Community Managed Mental Health Sector: Opportunities and Challenges, November 2011, MHCC, p. 18

This paper looks at the development of the NDIS, and its proposal by the Australian Productivity Commission, as well as issues to be addressed. It also discusses definitions of terms especially the basis and origin of them, particularly in the NSW frame of reference. It then analyses the extent to which self-directed funding impacts on individuals' ability to exercise consumer choice and control, seen both by the current inadequacies of the status quo and the successes of overseas programs. This paper aims to provide a conclusive understanding of the historical, principled and practical issues surrounding the NDIS.

### **Justification for a New Approach and Funding Model**

The Productivity Commission describes the current funding system in Australia for people with disabilities as:

'...Underfunded, unfair, fragmented, and inefficient. It gives people with a disability little choice, no certainty of access to appropriate supports and little scope to participate in the community...and a system marked by invisible deprivation and lost opportunities<sup>3</sup>.'

For this reason the Productivity Commission has recommended that the Australian Government implement a new funding program with 'greater consumer choice and control' by enabling individuals to choose their services providers.<sup>4</sup>

Patient or consumer centered care is health care that is respectful of and responsive to the preferences, needs and values of patients and consumers. Different definitions and terminology have been used to describe the concepts in this area but key components of patient centered approaches include:

- Treating patients, consumers, carers and families with dignity and respect
- Encouraging and supporting participation in decision making by patients, consumers, carers and families
- Communicating and sharing information with patients, consumers, carers and families
- Fostering collaboration with patients, consumers, carers, families and health professionals in program and policy development, and in health service design, delivery and evaluation

Self-directed funding enables individuals with disabilities and others requiring support to increase their independence and improve their personal self-determination. The approach empowers persons with

---

<sup>3</sup> Australian Government Productivity Commission, 'Disability Care and Support Inquiry Report', August 2011

<sup>4</sup> Ibid

disabilities to take control of their own lives, thereby encouraging social inclusion, and directly challenging their devaluation.

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 and outcomes by increasing safety, cost effectiveness, as well as the satisfaction of patients, family, and staff.

In NSW people with a disability along with their families and carers have expressed the need for greater choice and control over the support and services they access in their daily lives. These individuals have provided personal accounts of how inflexible supports and services impact their ability to lead the lives they wish to lead.

### **Development of the National Disability Insurance Scheme**

In mid February of 2010, Nick Sherry of Kevin Rudd's Labor Government referred the Australian Productivity Commission to begin an inquiry into a National Disability Insurance Scheme, fulfilling an election promise from 2007. The inquiry, beginning in April of that year and concluding on the 31<sup>st</sup> of July 2011, focused on whether an NDIS should be adopted and in what form.<sup>5</sup> This period coincided with the release of the Justice Action 'Our Pick' report in July of 2010.

At the end of the inquiry period, the Australian Productivity Commission released the 'Productivity Commission's Disability Care and Support Inquiry Report' in August 2011. The report recommended that the Federal Government take over the funding of disability care support in Australia under a National Disability Insurance Scheme (NDIS). The Productivity Commission recommended that NDIS be established 'to provide all Australians with insurance for the costs of support if they or a family member acquire a disability' just like Medicare.<sup>6</sup> The NDIS will transform the way services are currently funded and will ensure people with a disability, their families and supporters will all have appropriate support, care, therapy and equipment.<sup>7</sup> The proposed NDIS would fund a range of long-term disability supports that are currently being provided by specialists. These include: personal care, community access, support, respite, specialist accommodation support, domestic assistance, therapies, and guide dogs.

The NDIS has a flexible function as it can provide improved networking

---

<sup>5</sup> Mental Health Coordinating Council 'Self-Directed Funding Discussion Paper', October 2011

<sup>6</sup> Ibid p.14

<sup>7</sup> [www.everyaustraliancounts.com.au](http://www.everyaustraliancounts.com.au)

for community, people with disability and organisations, make sure that the consumers (patients, their families and supporters) receive the best quality services.<sup>8</sup> The NDIS is a broad framework and does not specifically mention the unique services needed for forensic patients. This highlights the issue as to whether forensic patients are included in the scheme.

The Productivity Commission proposes that people with a disability (or their carers acting on their behalf) could exercise consumer choice by approaching and choosing their own service providers or switching to another provider if the first does not meet their needs. The Productivity Commission also recommends that through the self-directed funding scheme individuals could choose to cash out their package of supports from one part of their support package to another in order to tailor the type of services they receive to their own needs.

"We have continued to maintain that a National Disability Insurance Scheme must provide:

- Certainty of funding, to provide life-time supports to people with disability, their families and carers;
- Simplicity in gaining access to specialist disability and universal services;
- Fairness in the application of eligibility criteria, assessment and support to people irrespective of where they live or their disability; and
- Choice to give people with disability, their families and carers control over their supports.<sup>9</sup>

It is now up to governments across Australia to use the good work done by the Productivity Commission to make a NDIS a workable, sustainable reality.

States and territory governments have 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."

The NDIS ensures that any Australian with a disability will have access to the care and support they should receive or need to participate in society,

---

<sup>8</sup> <http://tinyurl.com/6snkufz>

<sup>9</sup> Mental Health Coordinating Council, "Self Directed Funding and the Community Managed Mental Health Sector: Opportunities and Challenges", November 2011, p.8

no matter where they live, how they acquired their disability or if they were born with a disability.<sup>10</sup> However, this scheme does not mention if forensic patients are included in the scheme, or if they have their own pick for treatments, therapies, personal care or which communities they really want to join.

"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."<sup>11</sup>

After the initial presentation of the NDIS report in August of 2011, the main Australian political parties (including the governing Labor party) pledged their support for an NDIS. This was reaffirmed in December of 2011, where an NDIS officially became part of the Labor Party Policy Platform.

However, State and Territory community health organisations are concerned about the model recommended by the Productivity Commission such as the potential for competition between service providers to drive down wages and conditions for those in the mental health sector workforce.

### **Breadth of Application of the National Disability Insurance Scheme**

The new funding model is proposed for individuals with 'disabilities'. We are not sure why the focus is especially on individuals with disabilities (as opposed to all individuals who consume government provided services). In order to explore whether individuals with disabilities warrant self-directed funding more than ordinary service consumers, this paper will now discuss the definition of disability.

According to 1980 classification from World Health Organisation (WHO), disability can be described in three dimensions: impairment, disability and handicap. Based on this definition, the Productivity Commission's Report on Government Services 2002 defines disability in three aspects, which are: body impairment, activity restriction and participation restriction. Generally speaking, people lacking self-care, mobility or communication abilities can be defined as being disabled.

---

<sup>10</sup> <http://tinyurl.com/6vnej96>

<sup>11</sup> Media release: The Hon Ted Baillieu MP

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.

Commonwealth *Disability Discrimination Act 1992* (DDA)

The DDA includes:

- total or partial loss of the person’s bodily or mental functions
- total or partial loss of a part of the body
- the presence in the body of organisms causing disease or illness
- the presence in the body of organisms 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.

The definition includes a disability that:

- presently exists, or
- previously existed but no longer exists, or
- may exist in the future, or
- is imputed to a person.

A disability can stop you from doing some of the things that you want to do. Most disabilities cannot be cured and are with a person for life. People can be born with a disability or may develop a disability later because of an illness or accident.

## **Issues concerning the National Insurance Disability Scheme**

### Definition of ‘Disability’

There are issues with the use of the term ‘disability’ in the new funding model. Is funding possible for every disability case? Some individuals with social disabilities such as Antisocial Personality Disorder can be unwilling to have treatment and most are now forced to do the treatments. How will this impact the application of self-directing funding to people with

social disorders? Furthermore, those individuals with autism and intellectual disabilities may not have enough and suitable knowledge to make their own choices

### Use of Person Centred Approaches in Practice

Person Centred Approaches (PCAs) are designed to place the individual with a disability at the centre of decision making processes regarding how funding is 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.'<sup>12</sup>

The use of vague phrases such as 'embraces a philosophy of respect' and 'collaborative effort' implies that the person receiving services is not in fact at the centre of decision-making processes.

### Withdrawal of Block Funding

The introduction of self-directed funding means that organisations will not be guaranteed funding and would need to market themselves to attract consumers. The costs for organisations to reorientate themselves to operate as part of the self-directed funding may be significant, especially for those smaller organisations, which lack in reserves for funding. Self-directed funding may encourage organisations to merge in order to pool resources and attract consumers. This may result in job losses and specialised skills being lost in favour of generic skills.

### Media Coverage

There has been some concern about the nature of media coverage concerning the NDIS. Whilst the bipartisan agreement on the NDIS leads to overall constructive and tangible reform, it also means that media coverage on the NDIS is less focused and substantive than if it were the focus of a major political fight. 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 move to a self-directed funding model is understated. It is often referred to in the mid to late sections of a media piece, often using descriptors such as "a focus on individual choice" or "person-centred". Such language is

---

<sup>12</sup> <http://tinyurl.com/73d3gx2>

sometimes lost in the rest of the piece, disguising the significance of the unprecedented reform.

### Defamation

There has also been some concern about whether organisations, like Justice Action, that assess the suitability of service providers for the benefit of NDIS funding recipients, would be subject to defamation actions. The following guidelines explain 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 it and passing it on still qualifies as defamation (provided you had some editorial control over passing the information on, or knew that the material was defamatory). Thirdly, if the defendant can prove that the accusation was substantially true, then there is no defamation claim.

Fourthly, there are a number of other defences 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 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, then that is a defence.

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

### **Definition of Other Relevant Terms**

According to the Mental Health Coordinating Council (MHCC) the term ‘self-directed funding’ refers to cash payments that are directly paid to an



individual with a disability to enable them to buy services of their choice within the parameters set by a responsible authority.<sup>13</sup>

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

1. Individual assessment – a professional together with the person with disability undertaking an assessment of the person’s legal and health needs.
2. Personal budget – the person is told up front how much money will be allocated to their needs.
3. Choice in the way their personal budget can be managed.

The term Person Centred Approaches (PCAs) has been adopted by the States MP for Ageing and Disability Services Andrew Constance as well as State MP for Family and Community services Pru Goward. PCAs place the person with a disability 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 way in which society perceived and treated persons with disabilities. The support and services provided were rigid and inflexible often resulting in persons with disabilities growing more dependent, and feeling disempowered and devalued. The reason behind this is the strong support for people with disabilities to have more control over their lives and futures.

Three core aspects of a person centred approach:

- 1 Person centred planning: planning that is personalised and directed by the person, where possible, with support if needed
- 2 Personalised funding: resources are allocated to provide supports based on the person’s needs, which are identified through the planning process
- 3 Personalised service delivery: delivery involving a combination of formal and informal, public and privately provided services, which are coordinated to deliver the best outcomes for an individual.

### **Current Implementation across the World**

The implementation of self-directed funding was first championed by disabled peoples’ organisations in North America who were advocating 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

---

<sup>13</sup> Mental Health Coordinating Council, ‘Self Directed Funding and the Community Managed Mental Health Sector: Opportunities and Challenges, November 2011, pp. 8

Community Integration.<sup>14</sup> Self-directed funding has now been introduced in most Western European countries and parts of North America.

PCAs 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.

The World Health Organisation (WHO) uses the term 'responsiveness' in preference to 'patient-centred care.' Responsiveness refers to how a healthcare system meets people's expectations regarding respect for people and their wishes, communication between health workers and patients, and waiting times. WHO states that recognising responsiveness is an intrinsic goal of health systems and that responsiveness reinforces the fact that health systems are there to serve people.

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 a severe and persistent mental illness and those who have been in a mental health inpatient setting for longer than 3 months. The aim of this project is to allow individuals with a disability make a successful transition to living in 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 support and services they access. However, no mention is made of self-directed funding being an option.

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

### United Kingdom

In the UK 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

---

<sup>14</sup> Mental Health Coordinating Council, 'Self Directed Funding and the Community Managed Mental Health Sector: Opportunities and Challenges, November 2011, p. 2

assessment of personal needs.<sup>15</sup> Individuals could then use these payments to provide 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. It was made mandatory in 2003 for Local Authority to offer direct payments to all those eligible. People with a mental health problem were eligible for direct payments under the legislation but research found that they were the user group least likely to be receiving them.

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 United Kingdom 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 get out more and participate in social activities. Increases in general health and wellbeing as well as psychological wellbeing were gained through services such as gyms, counseling and therapy. Almost all patients reported that they felt they had increased control over their daily lives and social care, however some whose payments were being controlled by a third party were disappointed with the long delays with the approval and delivery of services. Integration into the community and social inclusion offered in some of the social care services offered did consumers state another positive outcome. However, the early evaluation of the program found that older patients felt less satisfied with their social care services.<sup>16</sup>

### United States of America

Self-Directed Funding, also known as individualized funding and self-determination funding in USA, it is a choice that has been successfully operating for people with disabilities.<sup>17</sup>

An International Conference on Individualized Funding and Self-Determination Funding in July 2000 attracted 1000 people to join the forum: sharing, discussing and building the concept of the funding, and more importantly it put the Individualized Funding into action.<sup>18</sup> There are fewer unmet needs and higher service satisfaction in the individualized funding and greater control over their own lives.<sup>19</sup>

---

<sup>15</sup> National Health Service, 'Personal Health Budgets', January 2009, United Kingdom

<sup>16</sup> Ibid.

<sup>17</sup> Individualized Approaches to Supporting People with Disabilities, Research and Support, <http://www.uogulph.ca/STRATEGIES5.shtml>

<sup>18</sup> Ibid

<sup>19</sup> Head and Conroy 2005; Caldwell and Heller 2007 cited Impacts of Self Determination Funding

The statistic consistently found that the self directed funding provide positive outcomes to people with disability and their family, such as, met individual needs had increased; more satisfaction with care and life, sense of control over life improved, higher quality of care and confidence in care.<sup>20</sup> Furthermore, in Head and Conroy study in 2005 found that people had more outing, which is an average of 35 per month compared with a baseline of 25; a higher quality of life from 69 to 81 points on a scale 0-100 as measured by an instrument examining 15 dimensions of quality life, and more satisfaction in both care and life, 0.25 points increase on a scale from 1- 5.<sup>21</sup>

### **Outcomes from Self-Directing Funding Studies**

A trial of self directed care in Northeast Florida showed that mental health patients who self-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.<sup>22</sup> 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.<sup>23</sup>

### **Positive Impacts of Self-Directed Funding on Consumers and Service Providers**

Allowing the disabled to decide how they wish to spend their funding budget is a major positive improvement in society. Self directed funding allows people with disabilities to feel more independent and less disempowered. 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 also be spent in ways to help individuals gain employment, which is a desired outcome for the Productivity Commission. Under a reasonable scenario, the Commission estimates that there could be additional employment growth of 220 000 by 2050.<sup>24</sup> The scheme also benefits the community in other ways, for example allowing prisoners with a mental illness to access the NDIS will promote rehabilitation

---

<sup>20</sup> Impacts of Self Determination Funding, p.9-31

<sup>21</sup> Ibid, p.9-10

<sup>22</sup> Mental Health Coordinating Council ‘Self-Directed Funding Discussion Paper’, October 2011, p. 14

<sup>23</sup> Ibid.

<sup>24</sup> Australian Government Productivity Commission, ‘Disability Care and Support Inquiry’, August 2011

through services such as education and counseling, and hopefully reduce their likelihood of reoffending.

Due to individuals now having a choice of what services they wish to purchase there has been a major increase in market competition, which has resulted in some companies expanding rapidly. In turn, competition will drive down costs in some organisations for example staff wages and the employment of volunteers.<sup>25</sup>

### **Negative Impacts on Consumers and Service Providers**

The successfulness of the new concept of self directed funding has had mixed reviews. Although under this new program disabled persons are supposed to have automatism and control of what services their funding goes towards, unfortunately not all patients have been told this. Even though the program is based around freedom of choice, people still have to purchase their services 'within parameters set by the responsible authority'.<sup>26</sup> Another negative side effect is the direction and ways in which individuals choose to spend their money. Block funding included supplying individuals with essential and necessary services for their situation whether it be accommodation, legal services, health services and so on. However, as a result of personalised budgets individuals can now choose to spend money on leisure and social activities such as gym memberships, electronics, furniture, and joining dating websites.<sup>27</sup>

In countries where self-directed care has already been implemented some service organisations, which had previously been block funded and since had to rely on consumer choice, haven't been able to cope with the heavy market competition and therefore had to close down. In turn this has created more negative consequences as some of those organisations that weren't able to survive may have been necessary services to those who aren't eligible for the self directed funding scheme and thus haven't had any control over the demand for service organisations.

---

<sup>25</sup> Ibid.

<sup>26</sup> Mental Health Coordinating Council 'Self-Directed Funding Discussion Paper', October 2011, p. 14

<sup>27</sup> Ibid