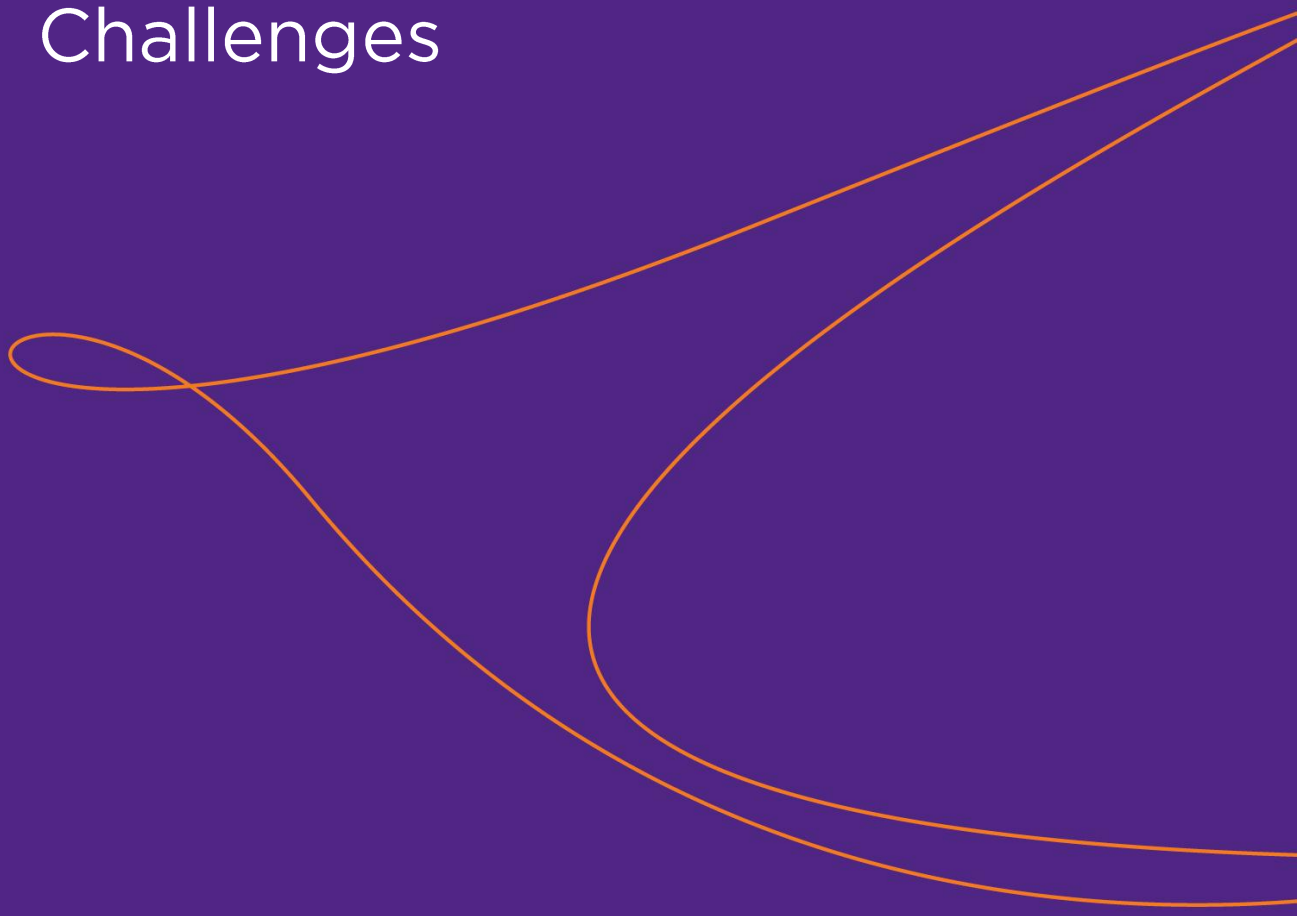
Self Directed Funding and the Community Managed Mental Health Sector: Opportunities and Challenges



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Executive Summary

On 10 August 2011, the Australian Government released the *Productivity Commission's Disability Care and Support Inquiry Report.* The Inquiry is part of the Australian Government's ten year *National Disability Strategy* developed with State and Territory governments, the Australian Local Government Association, and in consultation with People With Disability Australia (PWD) and the Carer Council. The Government cites as drivers of their reform: human rights, social inclusion and planning to meet the needs and costs of an ageing population.

During the inquiry process, the Mental Health Coordinating Council (MHCC) participated in a number of consultations and made two submissions to the Productivity Commission in 2010/ 2011.

The Productivity Commission has recommended that the Commonwealth Government take over regulating and funding disability care and support in Australia under a National Disability Insurance Scheme (NDIS). The Commission also recommends that funding for disability care and support is doubled. Extensive reforms are recommended including the introduction of individual budgets ('self-directed funding') for people with a disability which they could use to purchase specialist or mainstream services that meet their needs, as defined in an individual plan approved by the NDIS. This would establish a market for disability services in which service providers compete to attract consumers and charge a fee for service. It would also mean that service providers would no longer receive block funding for direct service delivery.

Following advocacy from the community, the Productivity Commission recommended that people with a psychosocial disability are eligible for intensive support under the NDIS. The Productivity Commission estimates that 57,000 people with a psychosocial disability will be eligible.

State and territory governments have expressed in-principle support for a NDIS. However, it is unclear whether they will support the Commonwealth Government taking over regulation of disability care and support. It is also unclear which of the Commission's recommendations they will endorse, including the degree to which people with a psychosocial disability should be included in the NDIS. The framework and implementation of the National Disability Insurance Scheme (NDIS) will require several years of consultation and planning.

The state and territory peak community mental health organisations support in-principle the inclusion of people with a psychosocial disability in the NDIS and their access to an individual budget as it is consistent with the peaks' philosophy that recovery is about self-determination - developing individual ways to lead a fulfilling life whilst managing the effects of mental illness.

However, state and territory peak community mental health organisations have a number of concerns regarding the model proposed by the Productivity Commission, including:

- the potential for an unregulated market to affect viability and provision of a diverse range of community managed mental health organisations;
- the potential for competition between service providers to drive down wages and conditions for the community managed mental health sector workforce;
- potential for the competitive and individualistic orientation of the new system to undermine the collaborative work undertaken by CMOs;
- the risk that where smaller CMOs fail to compete there may be a loss of specialised skills and knowledge;
- the potential that future budget cuts to the NDIS results in higher disability entry eligibility requirements in an environment of reduced support options;
- the extent to which the service system under the NDIS is designed to respond to fluctuating and episodic levels of mental health.

- the risk that people not eligible for individual packages under the NDIS will have reduced access to support services;
- the need to ensure that the assessment process used by the NDIA are appropriately specialised;
- the risk of a reduced focus on systemic and structural issues as funds are largely only sufficient to support individuals;
- the implications of different implementation processes within states and territories particularly where disability and mental health services are separate.

The extent to which the reforms are beneficial for people with a psychosocial disability and community managed mental health organisations hinges on whether these issues are considered and safety nets put in place.

It is imperative that the community managed mental health sector is treated as a key stakeholder in discussions about these reforms and that the transition occurs within a change management framework for the sector.

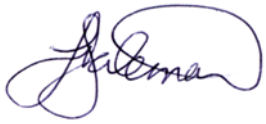
It is for this reason that MHCC present the opportunities and challenges of self-directed funding and direct payments in this discussion paper to inform and open conversation on implications and responses to this emerging service reform.

This Discussion Paper aims to:

- describe the Productivity Commission's proposed reforms
- look at the 'choice of provider' and 'self-directed funding' models proposed by the Productivity Commission
- look at the models of self -directed funding in place for people with a psychosocial disability internationally
- look at the international evidence of outcomes of self -directed funding on people with a psychosocial disability
- look at the impacts of self- directed funding on community managed mental health organisations in the UK
- Discuss the potential impacts on community managed mental health organisations in NSW

This Discussion Paper concludes with a summary of issues and questions for discussion by the community managed mental health sector which will also be disseminated via an online survey in future when there is an increased understanding of the issues.

Thank you for your interest and participation in exploring the positive outcomes and potential impacts on mental health consumers and their families and carers as planning for introduction of an NDIS occurs in Australia.



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Glossary

Community Managed Organisations (CMOs) operate in the non-government, not-for-profit sector. *Non-profit organisations are usually governed or managed by elected [*boards or*] committees, drawn from a cross-section of the community, who have relevant interests or experience in the services provided by the organisation*.[1]

Consumer - a person who uses a service. In this paper users of mental health services are referred to as consumers.

Council of Australian Governments (CoAG) *is the peak intergovernmental forum in Australia. COAG comprises the Prime Minister, State Premiers, Territory Chief Ministers and the President of the Australian Local Government Association (ALGA). The role of COAG is to initiate, develop and monitor the implementation of policy reforms that are of national significance*.[2]

Disability Support Organisations (DSOs) - the Productivity Commission recommends that these be established to provide support and information to people with a disability to help them develop a plan for spending their personal budget and to help them buy services, under a 'self-directed care' system.

Families and Carers-Carers *are usually family members who provide support to children or adults who have a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who are frail. Carers can be parents, partners, brothers, sisters, friends or children of any age. Carers may care for a few hours a week or all day, every day. Some carers are eligible for government benefits, while others are employed or have a private income.*[3]

National Disability Insurance Scheme (NDIS) - the Productivity Commission recommends that this be established *to provide all Australians with insurance for the costs of support if they or a family member acquire a disability.* [4]

National Disability Insurance Agency (NDIA) - the Productivity Commission recommends that this be established to administer the National Disability Insurance Scheme.

Peer - A Peer Worker is someone with a lived experience of mental illness who works for an organisation providing services / support to people with mental illness (in the context of this paper) and supports others experiencing mental illness in facilitating their own recovery.

Psychosocial Disability is the term used to describe the experience of disability for people with impairments and the limitations of social inclusion that consumers experience as a result of mental health conditions.[5]

This is the terminology preferred by the Mental Health Coordinating Council. However, where the publication being referenced uses another term, that term is used instead because the author is often describing a particular target group, for example, people deemed to be eligible for a particular program.

'Self-directed funding' or 'direct payments' are cash payments paid directly to a person with a disability so that they can purchase services of choice within parameters set by the responsible authority. Self-directed funding is usually one of a number of options that people with a disability are offered under a 'self-directed care' system for managing their 'personal' or 'individual' budget.

Introduction

The Australian Government released the Productivity Commission's Disability Care and Support Inquiry Report in August 2011 which is part of the Australian Government's ten year National Disability Strategy developed with State and Territory governments, the Australian Local Government Association, and in consultation with People With Disability Australia and the Carer Council. The National Disability Strategy acknowledges that Australians with disability not only have worse life outcomes compared to Australians without disability but worse life outcomes compared to people with disability in similar countries.[6]

The Productivity Commission in its report describes the current system 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.* [7]

A key reform proposed by the Productivity Commission is the introduction of greater consumer choice and control through 'choice of provider' and 'self-directed funding' options. This is consistent with the Australian Government's stated commitment in the National Disability Strategy to establish:

> *A sustainable disability support system which is person-centred and self-directed, maximising opportunities for independence and participation in the economic, social and cultural life of the community (Policy Direction 1 under Personal and Community Support).* [8]

The introduction of self-directed funding internationally has been a response to sustained lobbying by disabled peoples' organisations. The concept was pioneered by people with a disability in North America and is part of the 'independent living movement' which redefined disability as:

> *…being the social, cultural and attitudinal barriers to disabled people participating as equal citizens, rather than in terms of individual impairment.*[9]

Self-directed funding has been introduced in most Western European countries and parts of North America.[10] It has been an option for people receiving adult social care in the UK since 1997.[11] The Social Policy Research Centre (2010) in their report, *Effectiveness of Individual Funding Approaches for Disability Support*, provides the following definition of individual funding:

> *The core of individual funding is that it is a portable package of funds allocated for a particular person who is supported to choose how to spend it on their disability support needs.*
>
> *Characteristics of the way individual funding is organised that vary are:*
>
> - *Who holds and manages the funds*
> - *Which parts of it are portable*
> - *Which disability support types it can be spent on from which parts of the market*.[12]

Whilst supporting greater consumer power and choice, the Mental Health Coordinating Council (MHCC) has concerns about the potential of a self – directed funding model to reduce the range and diversity of services available to people with psychosocial disability. [13]

Likewise, concerns have been expressed about the assessment of people with a psychosocial disability under the Productivity Commission's proposed arrangements and whether the arrangements premised on permanent disability, will support recovery and rehabilitation philosophy and practice with regards to people with an episodic psychosocial disability.[14]

The Productivity Commission recognises that as well as providing services to individuals, CMOs play an important role in developing social capital through community engagement, community building and advocacy[15]. The Productivity Commission recognises that the continuation of these 'public good' type activities is essential in creating a more inclusive society for people with disabilities.[16] The Productivity Commission recommends that block funding to CMOs for these types of activities by Australian governments should continue and also proposes that a small amount of NDIS funding be provided for such activities. [17]

Whilst, the Australian Government has supported the vision of the Productivity Commission's report it is still in the process of responding to specific recommendations. The Council of Australian Governments (CoAG) has established a Select Council of Treasurers and Disability Services Ministers to consider the recommendations.[18] The Council recently agreed to bring the timetable for reform proposed by the Productivity Commission forward by a year. This means that launch sites will begin operating in mid-2013[19]. In the meantime, some 'foundation reforms' will be progressed, including a national approach to assessment, quality standards and disability services workforce strategy.

It is timely for the community managed mental health sector to develop a position from which it can prepare to maximise opportunities arising from the reforms, and address the challenging aspects of reform.

The Productivity Commission's proposed reforms

The Productivity Commission's Report proposes the establishment of two insurance schemes:

1. A National Disability Insurance Scheme (NDIS) to provide long term care and support to all Australians with a "significant and ongoing" disability. This includes an estimated 57,000 people with a psychosocial disability associated with a mental illness.[20]

2. A smaller National Injury Insurance Scheme (NIIS) to provide lifetime care and support to people with catastrophic injuries from accidents occurring in the community or at home.[21]

The NDIS will cover an estimated 410,000 new and existing cases of disability.[22] The NIIS will cover only new incidence of catastrophic injury, estimated at 900 to 1,000 cases per year.[23] The NDIS would cost an additional $6.5 billion above current spending which would effectively double the current government expenditure on disability care and support to $13.5 billion per annum.[24]

It is proposed that the Australian Government direct payments from consolidated revenue or a levy into a National Disability Insurance Premium Fund using "an agreed formula entrenched in legislation".[25] One of the benefits of the insurance model is that there would be an incentive to minimise long term costs by providing early intervention, where this is likely to be cost effective. For example, there would be a disincentive to keep people in hospital due to insufficient funds being made available for minor home modifications.[26]

The NDIS has three tiers of customers:[27]

Tier 1: all Australian permanent residents are insured against the costs of care for disability that meets the eligibility criteria

Tier 2: anyone with, or affected by, a disability will be able to access information and be referred to mainstream services, disability services and community support

Tier 3: people with a permanent disability below the age for an aged pension who meet the following criteria will be provided with individual case management and support:

- [..] *have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support* (major physical disabilities, cognitive impairments, including intellectual disability and "significant and enduring psychiatric disability.[28]
- are in an identified early intervention group (e.g., autism, acquired brain injury and newly diagnosed degenerative conditions).

There is also some support for carers and a discretionary category for: *people who have large identifiable benefits from support that would otherwise not be realised*.[29]

Tier 1

The Productivity Commission proposes that, as well as providing insurance for Australians against the costs of disability care and support, the National Disability Insurance Agency (NDIA) established to regulate the NDIS, plays a role in public awareness campaigns and promoting social inclusion.[30]

It is proposed that it would generally support public awareness campaigns run by others. At times, though it may directly fund and carry out public awareness programs.[31]

It is also proposed that the NDIA plays a role in promoting social inclusion through working in partnership with the community sector and agencies such as the Australian Human Rights Commission to target campaigns to areas problems of discrimination are common. The NDIA could also recognise and encourage the inclusive practices and initiatives of private enterprise. [32]

The NDIA would also provide information about the NDIS and work with disability organisations to assist them to provide information about the NDIS through their own networks. [33]

Tier 2

In the Productivity Commission's model, Tier 2 encompasses a number of activities not provided through an individual budget. This includes information and referral as well as activities with a collectivist or 'public good' orientation such as community capacity building, community engagement and advocacy. [34]

Information and Referral

The Productivity Commission proposes that the NDIA provides information and referral to people affected by disability and Australians generally. A centralised internet data base would be established with information on ranges of products and services, price, availability and links to measures of performance and quality.[35] It is also proposed that the NDIA provide general information about specific disabilities including their expected impacts and the most effective care and support options.[36]

The NDIA would provide referrals to mainstream services and community support groups. The Productivity Commission notes that it is important that the NDIA builds upon, rather than displaces, the role of the community sector in providing information.[37] However, it is not clear what the role for the community sector will be or how the provision of information from a centralised source such as the NDIA will impact on the demand for information from community managed organisations.

Community Capacity Building and Community Engagement

The Productivity Commission recognises that activities which build social capital need to be block funded.[38] It proposes that the NDIS provide a small amount of funding for such activities.[39] The NDIA will seek a compact with the not for profit sector to redirect voluntary and philanthropic resources, freed up by full funding for the cost of service delivery, into promoting community engagement and employment.[40] It expects state, territory and local governments to continue to fund community capacity building initiatives.[41]

Advocacy

It also expects the Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs and state and territory governments to continue to block fund not for profit organisations whose primary function is advocacy.[42] This is so that they are genuinely independent from the NDIS and able to assure people with a disability that they are serving their best interests first and foremost. For the same reason, advocacy organisations would not be eligible for funding to provide services or as a DSO.[43] The NDIS may provide some funding for advocacy but it would be through an intermediary arrangement so that it is not provided directly from the NDIA to organisations.

Tier 3

The main role of the NDIS and the majority of its funding will be for the tier 3 customers. Under these arrangements, NDIS will fund the range of long term disability supports currently provided by specialist providers, including:[44]

- Personal care
- Community access supports
- Respite
- Specialist accommodation support
- Domestic assistance
- Transport assistance
- Aids and appliances and home and vehicle modifications
- Specialist employment services and specialist transition to work programs

- Therapies
- Local area coordination and development
- Crisis/emergency support, including emergency accommodation and respite services
- Guide dogs and assistance dogs.

In terms of people with a psychosocial disability, the services provided under the NDIS would include rehabilitation and recovery focussed support and care such as: *home-based outreach, day programs and other forms of group support, as well as respite services*.[45]

Memoranda of Understanding with states and territories governments will be needed to determine the boundaries of the NDIS in funding accommodation support services. The Productivity Commission proposes that the NDIS would cover services to support people with a psychosocial disability in accommodation which does not have a clinical focus such as resident rehabilitation (non-clinical), social housing and private rental. MHCC disagrees with the Productivity Commission's proposal not to cover support services in residential rehabilitation with a clinical base, if this means 24 hour supported community residential services, such as 'extended HASI'. CMOs rather than the NSW Government will provide accommodation support services under this model so it should be included in the scope of the NDIS.

The NDIS will not provide income support or fund mainstream services such as health, public housing, public transport and education and employment services.[46]

The Productivity Commission notes that Memoranda of Understanding will be needed to clarify the roles of case managers, currently appointed and funded by mental health, and NDIS local area coordinators who will need to work together to provide a coordinated system of care, including joint planning and information sharing. MHCC notes that this role clarification also needs to include case managers working in CMOs. The Productivity Commission suggests appointing central case managers/care coordinators to work across the mental health sector and NDIS to ensure that holistic care is provided.[47]

To establish an infrastructure to ensure that there are national standards and entitlements, a NDIA would be created, independent from service providers, and would have the following key functions in relation to tier 3:[48]

- Assess needs and determine individual plans and budgets
- Authorise funding of services and supports
- Oversee the system at a local level through local coordinators
- Build capacity amongst participants and providers
- Build local community capacity for inclusiveness
- Determine efficient prices for the supports provided
- Purchase some goods and services centrally
- Manage costs and future liabilities
- Provide advice to, and monitor, fund holders
- Collect and analyse data on service utilisation, outcomes and efficacy of interventions
- Research function
- Innovation fund

- House an internal but independent review process overseen by the Inspector General for complaints, mediation, appeals and quality assurance.

This model will also require the establishment of a new type of organisation, Disability Support Organisations (DSOs), funded under the NDIS to act as brokers.[49] Their key functions would be to:

- Provide personal planning services and individual guidance to people with disability
- Assemble individual packages of support from specialist and mainstream providers
- Undertake administration tasks for people using self-directed funding
- Link people with disabilities to the community by developing the capacity of mainstream organisations to be more inclusive.

The consumer choice models proposed by the Productivity Commission

The Productivity Commission proposes two broad ways that people with a disability, or carers acting on their behalf, could exercise consumer choice. Within each there are a number of options:

Choice of Provider

After the NDIA conducts an assessment and consultation with the person with a disability, they are given a package of supports comprising a designated list of individualised supports described in quantity terms e.g., 20 hours of personal care per week.[50] This is like a package of vouchers which the person could take to the service of their choice. The NDIA would then reimburse the service provider at a rate regulated by the NDIA.[51]

There are a number of options for exercising choice under the 'Choice of Provider' approach:[52]

- The person could ask a DSO to bring together a package of services on their behalf
- The person could approach services directly and could choose one service provider for one need and another for a different need
- People could switch to another DSO and/or service provider if these organisations did not meet their needs well.

Under this approach the person has a limited capacity to trade off components of their support package. Service providers would be expected to offer consumers a choice of services that meet their needs. (This implies that service providers are large enough to provide a range of programs or have very flexible modes of delivery).[53]

A variant of this approach (which would probably not be made available in the short term) is to give the person their individual package components in separate dollar parcels rather than as entitlements for quantities of supports.[54] This would mean that the person could trade off supports within a specific component or negotiate a better price or service from a service provider. For example, a person could purchase 10 hours of personal support delivered in the evening at a higher cost, rather than 15 hours of lower cost personal support delivered during the day.

Self-Directed Funding

After the NDIA conducts an assessment and consultation with the person with a disability they are given an individualised package of supports, but could choose to cash out these supports and manage their own budget.[55] What this means in effect, is that they can trade off resources from one part of their support package to others in order to tailor the mixture and type of services they receive. For example, the person may forgo some hours of community care for a greater amount of community access. They could also employ a personal carer themselves at wages determined with the carer rather than purchase the service through a specialist disability provider.[56]

There are a number of options for exercising consumer choice within this model which allow consumers to opt for a greater or lesser degree of choice and effort:[57]

- Pay a service provider for a package of supports (a service provider may be able to provide a cheaper or better suite of supports than the person assembling their own from many suppliers)
- Use a DSO to plan their supports and manage the administrative aspects of these services e.g., the workers compensation coverage for their personal carer
- Assemble and manage all of their own supports.

The Productivity Commission notes that people with a significant psychiatric disability may not be able to self-direct their funding themselves. However, their carers (such as their partner or parents) or guardians (if under guardianship) may be able to act as their agent under self-directed funding.[58] During the assessment phase, the NDIA would determine whether a person, or others involved in their care and support, has the capacity to self-direct funding.[59]

The Productivity Commission anticipates that only a minority of people will opt for self-directed funding and that this number would build slowly over time. 'Direct funding' has been an option in the UK since 1997 and just over 10% of people under age 65 completely manage their own budget.[60] However, the Productivity Commission intends to learn from the experience of implementation in the UK so that take up is not as slow in Australia.[61]

Self-directed funding models

'Self-directed funding' or 'direct payments' are cash payments paid directly to a person with a disability so that they can purchase the services of their choice within parameters set by the responsible authority. Self-directed funding is usually one of a number of options that people with a disability are offered for managing their 'personal' or 'individual' budget.[62] Self-directed funding is part of a model of service delivery to people with disability referred to as 'self-directed care', 'consumer directed care' or by the names of the specific national policies and approaches used such as 'Personalisation' in the UK and 'Cash and Counseling' in the US.

Self-directed care models usually have the following components:

- Individual assessment – a professional together with the person with disability and other people they choose to involve undertake an assessment of the person's needs, goals and aspirations. In this model self-assessment forms an important element.
- Personal budget – the person is told up-front what the financial allocation to meet their needs will be.

- Person-centred planning – the person and others they choose to involve develop a plan setting out how they will spend their allocation to meet their needs. The plan must be approved by the relevant authority.

- Choice in the way the personal budget can be managed which may include transferring the money to existing service providers, having an independent agency broker services for them or receiving a direct payment (self-directed funding)

- Support brokerage – the person is offered support to help them develop a spending plan and also offered support to manage their budget and the administrative and financial responsibilities that direct payments entail, for example responsibilities involved in employing a personal assistant and accounting for the expenditure

Currently, no Australian states and territories have self-directed funding schemes to which people with a psychosocial disability are eligible.

Western Australia is preparing for a four year pilot project to assist 100 people with: '*a severe and persistent mental illness',* who have been in a mental health inpatient setting for longer than 3 months to make a successful transition to living in the community by June 2012. This will include funds for individualised packages of support (the Individualised Community Living Program) as well as housing. It aims to provide people with a mental illness, their families, carers and supporters with greater choice and control over the supports and services they access based on individual planning that is holistic, enhances social inclusion and focuses on personal recovery. However, no mention is made of self-directed funding being an option.[63]

Although self-directed funding has been introduced into the social care systems of most Western European countries and parts of North America, few of the schemes have extended eligibility to people with a psychosocial disability.[64] Those that have include Nova Scotia and Newfoundland in Canada,[65] Florida, Maryland, Michigan, Oregon and Tennessee in the United States[66] and the UK. Most of the literature found is from the UK and this model will be discussed in greater detail (p.9).

USA

Self-directed care programs have been progressively implemented in the US since the 1970's driven by the Individual Living Movement and disability rights advocates. By 1988, for example, 46% of attendant care programs allowed beneficiaries to hire and manage their caregivers directly.[67] However, until the 1990's these have largely been small state funded programs not integrated into public policy.[68]

This changed in 1998 with the implementation of Cash and Counselling Demonstration and Evaluation projects driven by a public/private partnership between the Office of the Assistant Secretary for Planning and Evaluation (ASPE) within the US Department of Health and Human Services and the Robert Wood Johnson Foundation.[69]

Under these projects, each consumer is given a monthly budget to hire personal carers and to purchase care-related goods and services in accordance with a personal plan. In some projects this is in addition to directly provided services but in others it replaces them.[70] Consumers who opt for self-directed funding can access support brokerage (*counseling*) which provides information and advice on available options, assistance in accessing mainstream services and assistance with financial management. In most projects, only people eligible for Medicaid Waiver programs are eligible. These are people with disability and low assets that meet certain criteria.
In 1998, 'Cash and Counseling' was piloted in randomised control trials in Arkansas, Florida, and New Jersey with a further 12 states involved in pilots in 2004. Eligibility was not extended to people with a 'mental illness' until 2002.[71]

The first pilot project involving people with a 'mental illness' was in Florida in 2002; this was extended in 2007. A further four states were also funded to conduct pilots (Iowa, Maryland, Michigan, Oregon and Texas). There are a number of differences in the models implemented by the participating states.

- In some states the scope of self-direction is limited to purchasing 'recovery support services' to support a chosen goal (Iowa, Oregon) whilst in others consumers can purchase traditional mental health services giving them a choice of mental health provider (Florida, Maryland and Michigan) and also the right to purchase 'non-traditional alternative' services such as self-help, wellness or exercise.[72]

- In some states self-directed care is a substitute for some traditional mental health services whilst in others it is received in addition to them. In Florida, for example, consumers must opt out of case management or assertive outreach to participate.[73]

- The organisation managing the program varies and includes consumer run organisations, county mental health services, existing service providers and managed health care companies.[74]

- The availability and extent of brokerage support varies. Oregon provides intensive support for a year to people in the early stages of recovery who have not lived independently for many years, whilst in Florida participants are expected to be largely autonomous managing paperwork and following rules and processes.[75]

- The level of involvement of peers is significant but varies from management of the program to provision of brokerage support or provision of services by qualified peers.[76]

UK

In the UK direct funding preceded the introduction of a self-directed care model.

Since 1996, Local Authorities in the UK have been able to offer adults eligible for social care a cash equivalent to directly provided services which they could use to purchase services from the non-government or private sector or to hire their own personal assistant.[77] However, this was largely bolted onto the traditional system of care.[78] Low take up and limited purchasing options led to pressure for a more fundamental transformation of the social care system.[79] It was also made mandatory in 2003 for Local Authorities to offer direct payments to those eligible.[80] 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.[81]

In 2003, the national social enterprise, In Control, was funded to pioneer a new model of social care. The In Control model, which included personal budgets, was piloted across six local authorities from 2003 to 2005 with people with learning disabilities. A second evaluation was conducted to investigate how the model worked for people with physical disabilities, sensory disabilities, older people and people with mental health problems.[82]

In 2005, the Department of Health released a Green Paper proposing greater opportunities for older and disabled people to exercise choice and control over the way their support needs were met. It aimed to build on the experience of direct payments and the In Control pilot projects. Thirteen local authorities were selected to pilot 'individual budgets' from 2005 to 2007.

The key features were that service users were to:

- have a greater role in the assessment of their needs
- be provided with information on their individual budget prior to developing their individual plan
- be provided with funding from other sources (social security, employment support, housing) as well as adult social care in an integrated package
- have greater flexibility in the way they choose to spend their individual budget to meet their goals including buying "ordinary commercial or community services (e.g. gym membership rather than day centre attendance)" or paying relatives and friends for assistance
- have access to support with planning and information from a source which was independent of the services themselves on the availability and costs of different support options
- have a range of options in the way their personal budget could be managed which in included direct cash payments, care manager-managed 'virtual budgets', provider-managed individual service funds, and payments to third party individuals and Trusts (not all options were available in each pilot site).[83]

In four of the 13 pilot sites individual budgets were delivered in mental health service settings.[84]

In 2007, the UK Government in partnership with representatives from the private and voluntary sectors published *Putting people first: a shared vision and commitment to the transformation of adult social care.* Self-directed support and the introduction of personal budgets for all adults eligible for social care are a key aspect of these reforms which are referred to as 'the personalisation agenda'.[85]

Between October 2008 and November 2010, the UK mental health charity, Mind, was funded to promote direct payments and individual budgets for people who use mental health services to improve up-take.[86]

Table 1 describes the current UK self-directed care model and compares it to the model proposed by the Productivity Commission.

Table 1

	Personal Budgets UK	**Proposed NDIS Australia**
Who determines eligibility	Local authority Adult Social Care Departments based on 'Fair Access to Care' criteria[87] which assess the seriousness and imminence of risk to independence without support. Is means and asset tested	NDIA with definitions based on functional and condition specific criteria (see page 4 for more detail)
Who undertakes assessment	Each person completes a self-assessment with help from their Care Coordinator who is usually a member of their local community mental health team	A trained assessor engaged by the NDIA along with self-assessment by the person themselves. Person can choose to involve any others from their 'circle of care'. An NDIA local area coordinator (LAC) is also involved. Each person has their own LAC who is their on-going point of contact with the NDIS[88].

Who determines allocation	Local Authority adult social care professionals based on local authority's Resource Allocation System. If the cost of care is higher than a certain amount, it must be presented to the local authority panel comprising senior practitioners/managers of Adult Social Care teams.	NDIA would cost the assessment using a benchmark average profile of needs
Who supports consumer to develop an individual plan	Usually the individual and their Care Coordinator. Could be developed with a broker, friend or family member but the plan must be agreed with the Care Coordinator. Support plan must be approved by the local authority.	Family, friends, others strongly connected to them or a DSO. DSOs would be independent from the NDIA and service providers. The funding proposal must be approved by the NDIA.
Who holds and manages the funds	Person can choose: • To manage it themselves via a direct payment into a bank account • Have the council or a third party, such as a service provider, manage it and buy/provide services on their behalf • Have it managed by an Individual Service Fund, independent care provider, family member or friend • A combination of these methods	Under the self-directed funding option the person can choose: • to manage it themselves via direct payment into a bank account • have a DSO manage their package • pay a service provider for a package of supports Under the 'choice of provider' option the NDIA holds the funds and pays service providers, the person is given a package of supports rather than the cash—a bit like having a book of vouchers. People could also choose a mix of both models cashing out only part of their package.
What part of the allocation is portable	The whole allocation is portable but subject to an approved plan. Plans costing above a certain amount have to be approved by local authority panels of social care professionals. Flexibility varies from one local authority to another.	Person can allocate their individual budget to any mix of preferred specialist and mainstream goods and services, subject to the requirements that the person spend the budget in areas related to his or her disability needs and consistent with the agreed funding proposal
What disability support types can it be spent on from which parts of the market	Social care needs, including support with daily living, leisure activities, special equipment, finding a job or learning new skills. Can purchase services from social services, the private sector, the voluntary sector, neighbours, friends or family members.	For people with a psychosocial disability, it could be spent on "*community-based disability support needs" such as "home-based outreach, day programs and other forms of group support, as well as respite services."*

Who brokers services	No standardised approach. It could be: • Social worker or care coordinator • Friend or family member • A voluntary organisation (NGO) • An advocate • Professional brokerage service • User-led organisation • Direct Payment Support Service	People could choose to: • Purchase their own services • have a DSO broker services for them • share the responsibility with a DSO • pay a service provider for a package of supports, if they were able to provide a better or cheaper suite of services than the person assembling their own from many suppliers[89]

Sources: Audit Commission UK, *Financial Management of Personal Budgets, Challenges and Opportunities for Councils*, Local Government, October 2010; personal communication with Karen Patten, National Personalisation Lead, Richmond Fellowship, UK; Productivity Commission, Disability Care and Support, Report No 54. [90]

This discussion paper only looks at personal budgets in social care. However, it is worth noting that the UK Government is also introducing personal health budgets whereby people will choose which health services they wish to purchase based on a personal plan. The UK Government's mental health outcomes strategy, *No health without mental health* published in 2011 states that:

[..].*Government will take steps to extend as much as possible the availability of personal health budgets to people with mental health problems.*[91]

In the longer term, it is likely that personal budgets in social care and personal health budgets will be integrated.

Impacts of self-directed funding on consumers with a mental illness

In spite of widespread concerns that self-directed funding may not be appropriate for people with a psychosocial disability as their condition fluctuates and they may not always be well enough to manage a personal budget, the outcomes of pilot programs are overwhelmingly positive.

USA

Although the numbers of people with a serious mental illness receiving self-directed funding in the US are small, high quality data is available from the rigorously evaluated pilot programs.

Take Up

In 2008, there were fewer than 400 people in the public mental health system in the US accessing self-directed funding under programs and pilot programs in five states.[92] Part of the reason for this relates to the need for governments to find a sustainable funding source for these programs. The programs that have been established have been those that started as experimental pilots, for example, in Florida.

Outcomes

Data from the Self-Directed Care pilot program in Northeast Florida showed that a year after joining the program participants spent less time in psychiatric inpatient and criminal justice settings and had significantly better functioning. The program established that people with a serious mental illness were able to manage a personal budget to purchase goods, services and supports in accordance with a recovery plan and many had been able to meet their recovery goals, such as: *furthering their education, living in an apartment or working at a job*.[93]

Evidence from Florida also showed that people self-directing funding were more likely to make use of routine and early intervention services and less likely to make use of crisis services than a matched sample of consumers who were not self-directing funding.[94]

In Oregon, where intensive support was provided to people with a serious mental illness early in their recovery for one year, there were significant increases in employment and participation in education.[95]

In New Jersey participants with a mental illness were randomly assigned either to the self-directed funding pilot or to traditional Medicaid services.[96] Those who received self –directed funding were:[97]

- [..] *..more likely to receive personal care services and were more satisfied with their paid caregiver's reliability schedule, performance, and overall care arrangement.."*
- [..]*..more satisfied with their quality of life…."*
- [..]*..had fewer unmet needs related to household activities, transportation and routine health care at home."*
- [..]*..had no more injuries or other adverse health problems than those without mental illness* (participating in self-directed funding).

There were no significant differences in cost between people with a mental illness and people without a mental illness participating in self-directed funding and there was no significant difference in total costs between people with a mental illness receiving self-directed funding and those receiving traditional services. Personal care costs were higher for people receiving self-directed funding, whether or not they had a mental illness, compared to those receiving traditional services.[98] This appeared to be because people receiving traditional services did not always get the service to which they were entitled.

The evaluation of the New Jersey pilot concludes that consumers with a mental illness were able to manage self-directed funding successfully but notes that there were three features of the program which assisted them to do so:[99]

- Being able to appoint a representative, including family members or a friend, to help them manage their 'cash option' responsibilities
- Access to consultants (support brokerage)
- Access to a bookkeeping service to assist them to manage their financial responsibilities

UK

Take Up

The UK mental health charity, Mind, reported that in 2008 there were 3,373 'direct payment users with mental health support needs' and that this was low compared to other impairment groups.[100] Mind also noted the significant variation between local authorities in the extent to which they make direct payments to people with mental health support needs.

Outcomes

There have been two evaluations which provide data on service users with mental health support needs in receipt of direct payments.

Between 2001 and 2003, there was a national pilot of direct payments in mental health involving 58 service users. Most had complex/severe mental health needs.[101] The research included 27 interviews with service users.[102]

Spandler and Vick (2009) reported that the direct payment packages were "relatively small" with 56% of service users being paid for less than 10 hours assistance per week. Nevertheless, half of all service users employed a personal assistant to provide social and personal support including assisting them with daily activities, helping them access community and leisure facilities or providing respite and night sits.[103]

The benefits reported by service users who had been able to recruit their own personal assistant were:[104]

- Finding someone they could trust and feel comfortable with
- Companionship and accompanying them to engage in social and leisure activities
- Decreased dependence on friends and family
- Able to reduce the strain in existing care arrangements by providing some financial compensation to their carer
- Being able to negotiate advance directives setting out how they would like to be treated in the event of a crisis.

Direct payments were also used for transport, education, short breaks, arts activities and accessing mainstream leisure services[105] . Spandler and Vick (2009) comment that:

> *In many instances, direct payments enabled clients to take part in 'ordinary' activities which were non-stigmatising and not mental health focused, professionalised or medicalised*.[106]

Growth in self-worth among service users was also reported and Spandler and Vick (2009) conclude that direct funding provides the opportunity for people with mental health support needs to pursue their own self defined goals and aims and that is crucial to recovery. As with the evaluations from the US, they emphasise that: *a robust support infrastructure* is fundamental.[107] They note that direct payments in the UK: *rarely included additional costs for setting up, support with administration and contingency monies*.[108] They also observed a number of ways in which the philosophy of independent living was compromised in the implementation of direct payments including through: resource limitations; restrictive eligibility criteria; lack of understanding of the independent living philosophy by mental health professionals and agreeing services to be purchased at the outset rather than needs to be met thus limiting the ability of recipients to readily change services to meet changing needs.

Spandler and Vick (2009) also note that in addition to formal eligibility criteria, mental health professionals imposed their own "highly selective criteria" in determining who would be offered a direct payment:

> *These included being more likely to offer direct payments to clients who had a 'significant other' who could help them manage payments or to those who were considered as being more trustworthy and as having a stable lifestyle. Also service users who were more able to express their needs and clarify the type of support arrangements they wanted or those that workers considered would benefit 'therapeutically' from receiving direct payments were more likely to be offered them.*[109]

Ethnic minorities were under-represented in the pilots and more work was necessary to ensure equitable access.
Richmond Fellowship UK informed MHCC, in September 2011, that due to lack of opportunity, few people with a mental illness in the UK have been able to take up the option of self-directed funding. Nevertheless, there are significant benefits to them from the broader self-directed care model, particularly, improved choice and control through better assessments, personalised planning and more tailored and flexible services.[110]

Barriers

Richmond Fellowship UK also identified a number of ways in which the implementation of personalisation in the UK is making it difficult for people with a psychosocial disability to access self-directed funding.

Budget cuts mean that fewer people with a disability are eligible for self-directed care. Although the eligibility framework issued by the Department of Health was intended to bring about a more consistent, fairer and transparent system for the allocation of social care services, local authorities may determine, for instance, that only people meeting the highest criterion ('critical risk to independence)'will be eligible[111]. Eligibility is therefore inequitable as it is based on local budget and political decisions. [112]

The Department of Health (February 2010) notes that some people who ought to be receiving support were rendered ineligible due to local authorities raising their eligibility threshold[113]. This led to an inquiry in the UK into the application of the eligibility criteria and their impact on people[114]. Pending a wider reform of the care and support system foreshadowed in the Care and Support Green Paper, the Department of Health issued new guidance to local authorities warning them that:

……*limiting access through raising eligibility criteria has only a modest and short-term effect on expenditure* and advising them to *ensure that the application of eligibility criteria is firmly situated within this wider context of personalisation, including a strong emphasis on prevention, early intervention and support for carers.*[115]

In practice, however, the Department of Health acknowledges that it will not be possible for local authorities to invest large amounts of funding into prevention and early intervention schemes[116]. The Department of Health suggests that local authorities address the unmet need by supporting the development of universal and open-access services, building capacity in user and carer-led organisations and providing people who are ineligible for individual funding with information and active referral to other sources of support and assistance to develop their own support plans. [117]

These are similar to what the Productivity Commission recommends is available under Tier 2 of its model. What it means in effect is that if thresholds for access to individual packages are raised, people who require specialist disability services may not receive them and there will be a shifting of costs onto mainstream services and the voluntary sector.

One of the main barriers to take up of self-directed care in the UK by people who are eligible is a lack of available brokerage support in many areas. This is particularly problematic for people with a psychosocial disability, as agency responsibility for them is split between local authority adult social care departments and community mental health. Therefore, there is less incentive for local authorities to tender for support brokerage for them. The role of supporting the client to develop a personal plan then falls upon Care Coordinators in Community Mental Health services who receive no extra funding and whose departments are not responsible for implementing the reforms. The extent to which Care Coordinators fulfil this role is therefore patchy but personal plans cannot be finalised without their involvement.

Establishing people on a personal budget is a very lengthy bureaucratic process in the UK. , The Richmond Fellowship (UK) successfully acquired funding from a North London local authority to help develop and improve processes for mental health consumers. . Though the target of supporting 10 people was met, the process of establishing mental health consumers on a personal budget was a lengthy one. After 18 months, 4 consumers were only part of the way through the process. The Richmond Fellowship in the UK report that budget cuts had exacerbated the problem through increased scrutiny of personal plans by local authority panels.[118] Rejections of plans led to lengthy development processes as well as less flexibility for consumers.

Impacts on community managed organisations

The introduction of a self-directed care model for people with a psychosocial disability has major implications for mental health CMOs as it requires a complete transformation of the service system. The social care system is transformed into a market place in which people with a disability choose how they will spend their personal budget to meet their needs. There are significant challenges for CMOs in this transition as well as some opportunities.

Challenges

Providing different services

In countries where self-directed care has been introduced, funding bodies have phased out block funding to community organisations which must then rely on the individual funding that clients bring with them. In the UK, for example, the Richmond Fellowship has a number of four year contracts where full block funding was provided in year one reducing to a small percentage over the lifetime of the contract..[119]

The transformation to this approach also means that in order to attract and retain clients, CMOs must provide the type of services that clients want, in the way and at the times that they want to receive them. There is evidence from the UK that clients want different services to those that have traditionally been provided, for example, there is less demand for residential and day care services and more demand for personal assistants and support with activities such as gardening, shopping and recreation.[120] There is less demand for specialist services and more demand for facilitating social inclusion, such as support to access mainstream leisure, sports and social activities.[121] Research has also found that people with personal budgets spend part of it on a diverse range of mainstream goods and services that support their individual goals and further their social inclusion, such as buying art materials, buying shoes, being able to buy Christmas presents for their children, joining a dating agency, taking driving lessons and buying gym membership.[122]

The UK mental health charity Mind is supporting its 170 affiliate organisations to make the transition to self-directed care and early adopters are developing flexible 'menus' of services for clients with a personal budget. They are also involving service users in the design of services ('co-production').

Richmond Fellowship has introduced a 'core and flexi' model into supported housing for people with a psychosocial disability with high needs. Instead of having a staff member available 24 hours a day, a staff member is available during 'core hours' and time is available for one to one support with each consumer to support a chosen goal.[123]

Operating like a business

There are challenges in terms of funding and workforce in how CMOs deal with irregular use of their services by clients[124]

The transition to self-directed care means that CMOs have to adjust to operating like a business, for example, marketing their services, invoicing service users and chasing late payments.[125] It also means taking on a greater degree of risk. Mind says:

> *It is not unlike starting a new business where you can work out needs, costs, cash flows, marketing strategies and break-even points, but until you try you cannot be sure if you have it right the first time, and may need to tweak costings, menus, types of service on offer, marketing and promotion several times. For example, Norwich Mind have adjusted their menus four times.*[126]

A key message from the UK is that CMOs should prepare by having a clear idea of what their services cost at an individual level, including full costing of staff, infrastructure and overheads. This helps organisations transition to the new funding arrangements and perhaps advocate for transitional funding. It is also needed in a self-directed care model where individuals and organisations contracting with service providers will need to compare service options.[127]

Threats to the viability of services

The UK mental health charities Mind and the Richmond Fellowship are both part the way through the transition to working under the self-directed care model. They both have a range of initiatives to support their local branches or local associations through the transition.[128]Providing information about the impact of self-directed care ('personalisation') on community managed mental health organisations and the service system, Mind points out that:

Personalisation is not something that can just be added, it affects everything….including:

- *Staffing terms and dynamics*
- *Relationship dynamics [with service users]*
- *Finance and accounting systems*
- *Service redesigns*
- *Buildings*
- *Marketing and businesses processes*
- *Costings*
- *Governance and governing documents*
- *Risk taking*[129]

CMOs need be able to draw on a source of funds to develop and market personalised services and trial new ways of doing things. Larger organisations may have such reserves but small organisations may be at risk of closure without access to transition funding.[130] Small organisations may also be at risk, in the longer term, because they lack the marketing budgets of larger operators.[131]

The withdrawal of block funding and changes in tendering by funding bodies ('commissioning of services') towards fewer providers, larger tenders and reduced costs are leading to widespread mergers of community mental health organisations in the UK. It is usually the 'back office functions' of finance, human resources and marketing that are merged as well as senior executives and boards. The diversity of front-line programs and services is usually retained.[132] (See further comment p.23)

Many community-managed mental health organisations have to charge service users who are not entitled to a personal budget. In order to subsidise these services they are offering '"well-being' services to the general public.[133]

Competition is also driving down costs with some organisations employing staff with a lower skill level. However, the changes are also leading to new ways of working with clients that some staff find more creative and satisfying.[134]

Threats to the service system

The implementation of these reforms in the context of significant budget cuts in the UK is leading to a reduction in services for people with lower level mental health support needs who are not eligible for self-directed care with concerns that their health may deteriorate.[135] The journal Mental Health Today (February 2010) expressed similar concerns suggesting that choices of consumers with personal budgets may undermine the service system available to other mental health consumers leaving under-subscribed services, such as day centres, at risk of closure. [136]

Similarly, Mind expresses concern about the potential for the service system to be undermined:

> [..]*…a focus on individually tailored support arrangements should not detract from necessary investment in improving directly provided services for those who still want them or need them, or addressing social inequalities and alleviating mental distress.*[137]

It is unclear, whether people with a disability who are not eligible for an individual package will be able to access any direct services without paying under the NDIS model. The Productivity Commission states that people with a disability who are not eligible for Tier 3 services will be eligible for Tier 2 services. However, it is unclear whether Tier 2 services will encompass much more for individuals than information and referral. It seems unlikely, even with a doubled budget, that all the people with a disability who require intensive support will be receive funding, given the low base in the current system from which the Scheme would be starting.

Mind also points to a risk that the focus on the individual in self-directed care may detract from the need to focus on the systemic and structural factors that create social exclusion, which is associated with poor mental health. In fact, it is important that a focus on the social determinants of health more broadly is not lost. The World Health Organisation provides the following definition:

> *The social determinants of health are the conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries.*[138]

Research into the social determinants of health, for example, has found that death rates and illness are correlated with socio economic status, even after controlling for unhealthy behaviours[139]. Similarly, socio-economic status has been found to impact directly and indirectly on rates of mental illness with higher rates of mental illness amongst low and middle income earners[140]. Factors such as inequality, discrimination, and stigma need to be addressed through public policy and a rights-based framework which has a focus on social groups and the operation of power. As the social determinants of health are the circumstances in which people live, improving health equity involves change to systems and institutions which are broader than health and social care such as more affordable housing, fair and decent employment and measures to address disadvantage in early childhood.[141]

Another challenge for the service system, is how individual budgets will impact on collaborative programs such as the Housing and Accommodation Support Initiative (HASI). HASI is a partnership program funded by the NSW Government that ensures stable housing linked to specialist support for people with mental illness[142]. HASI operates as a three-way partnership in service delivery:

- Accommodation support and rehabilitation associated with disability is provided by NGOs (funded by NSW Health).
- Clinical care is provided by specialist mental health services.
- Long-term, secure, and affordable housing and property and tenancy management services are provided by public and community housing (funded by the Department of Housing).[143]

Where HASI operates, non-government providers are contracted to provide accommodation support services to the local HASI clients[144]. The involvement of a defined number of service partners has made close service coordination and frequent communication at the local level possible. The accommodation support service (CMO) performs the role of support services coordinator. [145]

Under a system where people have an individual budget there could be many different specialist and mainstream services involved in the provision of support. It is not clear how close service coordination and frequent communication between service partners would work.

There is a risk that the individualistic and competitive orientation of service delivery under the NDIS may undermine the cross-organisational and collaborative work of CMOs which typically involves shared understandings and information and pooled in-kind resources.

Opportunities

Providing new types of services

The implementation of self-directed care in the UK has provided opportunities for community managed mental health organisations to attract additional funding from government and local authorities as well as service users through providing new types of services.[146]There is an emerging demand for support brokerage and assistance with hiring personal assistants.

In a self-directed care system, people with a psychosocial disability need good information, support and advocacy to assistant them to develop a spending plan and to make informed choices on how they wish to manage their budget and which services to purchase. There is also a role for organisations to assist people to manage their budget or to hold their budget for them and put together packages of services which meet their stated needs.[147] An organisation purchasing services on behalf of a number of personal budget holders may be able to negotiate better prices than could someone acting alone.

Community managed mental health organisations may be well placed to compete for funding for support brokerage as they understand the needs of people with a psychosocial disability and are able to offer them more effective support. There is also evidence from the US that people with a psychosocial disability prefer to access support from user-led organisations where support is provided by peers.[148]Consumers who were self-directing funding in Oregon and Florida identified that this was a feature that they valued in the self-directed funding model. They stated that they felt more able to develop an equal partnership and that peers also provided them with a role model as well as understanding and knowledge of the system based on learned experience.[149]

In the UK, the Richmond Fellowship is tendering for a support brokerage role in West London. Croydon Mind is in a partnership with three other organisations to pilot a brokerage service for people getting personal budgets. In the future, Southend Mind will be providing support planning in partnership with the current brokerage service in their area.

Many people with a psychosocial disability are choosing to use their personal budget to hire personal assistants. However, this means taking on the full responsibilities of an employer which many people may not wish to do. There may also be 'safeguarding' concerns. It would be difficult for individuals to undertake background checks or establish whether personal assistants are suitably trained and qualified. Individuals may also find it difficult to organise cover in the event that their personal assistant was ill or on holiday. Individuals may lack the knowledge and experience required of an employer, for example, putting the occupational health and safety of personal assistants at risk or making unreasonable demands. There may, therefore, be a role for CMOs to recruit, train and oversight personal assistants.

In the UK there is a shortage of trained and skilled personal assistants. It is estimated that by 2025, the number of personal assistants will need to increase nine fold to meet the increased demand arising from personal budgets.[150] The literature from the UK states that non-government organisations could have a role in shaping the market for personal assistants and providing personal assistants in the form of user or staff led cooperatives. It is suggested that this may also be a way of redeploying the workforce displaced from community managed services during these reforms.[151]

Southend Mind, in the UK, is an example of a community managed mental health organisation planning to provide personal assistants to respond to this gap in the market.[152]

Solent Mind, in the UK, point out that many people with a psychosocial disability will not be eligible for a personal budget. So where block funding has been withdrawn it important to look for opportunities to provide services that meet needs that can be purchased at a reasonable cost. Solent Mind is developing options like sharing support time and group support.[153]

In the UK, there are examples emerging of personal budget holders pooling money to pay for a service, e.g., a group art activity. Harlock (2011) suggests that as there is a limit to the amount of market influence individual service users can exert, there may be a need for new forms of support to emerge which are user-led based on 'self-help, peer and mutual support'.[154] There may a role for community managed mental health organisations in empowering and supporting users to make pooled purchases.

The opportunity under the reforms to ensure that the fee for service fully covers the cost of delivering the service, may mean that CMOs have more capacity to undertake advocacy on behalf of their clients or community of interest.

Working in ways that better support recovery

Both the Richmond Fellowship and Mind view self-directed care as providing the opportunity to work with people with psychosocial disability in new ways that are better aligned with a recovery approach.[155] Mind says that the personalisation agenda:

> [..]…*supports a user-centred concept of 'recovery' in which recovery is a personal journey of learning to live well, despite the continuing or long-term presence of mental health support needs*.[156]

Mind consider the values underpinning personalisation which are consistent with a recovery approach as a focus on strengths, connections, access to community resources and public services, control and resilience.[157]

Similarly, consumers who were self-directing funding in Oregon and Florida said that they valued the focus of the program on providing consistent support to help them stay well, establishing and sustaining a life in the community and expecting them to have some control of their own lives.[158]

Richmond Fellowship UK report, for example, that their 'core and flexi' approach in supported housing is leading to better problem solving and a greater degree of independence amongst residents.[159]

Influencing local decision making

Finally, the literature from the UK emphasises that there are opportunities for CMOs to shape the direction that self-directed care takes, if they engage in discussions early with funding bodies, service users and potential partners.

> *A lot of statutory agencies are uncertain about implementing personalisation. Organisations that are proactive in developing personalised services are often in a position to influence local decision making and negotiate around funding, including transitional funding to set up and run new types of services* (Mind, 2011).[160]

Implications for people with a psychosocial disability and community managed mental health organisations in NSW

This section sets out the likely implications for people with a psychosocial disability and the community managed mental health sector if the recommendations of the Productivity Commission are accepted and implemented by Australian governments.

Better long term funding of community mental health services

Foremost among the possible benefits is increased funding for services to people with a psychosocial disability who are eligible for individually tailored funded supports. The Productivity Commission states:

> *Community mental health services will be strengthened by the extra resources provided through the NDIS* [161] and […] *given the relatively small share of resources currently directed to non-clinical mental health supports, the introduction of the NDIS will represent a significant increase in staffing levels*.[162].

The Productivity Commission also claim that funding for community mental health services may be more sustainable:

> *The NDIS would bring to community support for people with psychiatric disabilities, the advantages of an insurance model, with its certainty, long-term perspectives, governance and data mining approaches*.[163]

As the NDIS would be funded as an insurance scheme, an ability to predict short and long-term costs and risks would be vital to the sustainability of the Scheme. This would require quality data and systems of analysis which are integrated into decision-making. Data systems would need to be nationally compatible, capture information about service providers and also outcomes for people with a disability. The Productivity Commission proposes that a longitudinal data base of Scheme participants' information is established to provide data on lifetime costs by disability type. There may be benefits to the community managed mental health sector from improved data analysis such as understanding of the real costs of delivering services, projected increases in the costs of delivering services, trends in the use of services and information on the efficacy of different types of services for people with a psychosocial disability.[164]

Implications for people with a psychosocial disability

Assessment

The proposed NDIA would provide a clear single point of entry for consumers to find out if they are eligible for funded supports. Consumers would answer a short set of questions which determined whether they were likely to be eligible. People who were not likely to be eligible would be referred to information services or connected with services outside of the NDIS.[165]

Consumers who were likely to be eligible would complete an initial self-assessment questionnaire and personal plan. They could use their informal support network to help them or access formal support through the NDIA or a DSO.[166] They would then be assessed by an NDIA assessor using a nationally consistent assessment tool and their medical reports.[167] They could choose to involve their 'circle of support' in the assessment. The assessor would be an allied health professional trained in the national assessment process. Consumers would also be connected with a Local Area Coordinator with who they would remain in contact.

There is a question of the extent to which NDIA assessors will have the expertise and experience of undertaking effective assessments of people with a psychosocial disability. There is a risk of a 'one size fits all' type assessment and, given that many people experience fluctuating symptoms, a risk that they could be inappropriately excluded. Many submissions to the Productivity Commission inquiry from community managed organisations providing services to people with a psychosocial disability expressed concerns in this regard, some pointing to previous efforts to establish such systems, such as the Job Capacity Assessor system and various disability services officers' programs implemented by Centrelink, which *failed to deliver valid or reliable assessment*, and were *universally criticised by disability employment services*.[168]

However, the Productivity Commission does state that there will be scope for specialisation under the NDIS, at least in urban areas,[169] and the sector may need to advocate for specialised assessors in each area for people with a psychosocial disability. The sector should also continue to advocate for the involvement of people with a psychosocial disability and their carers in the development of the assessment system and tools.

The proposed system does allow people to involve carers, service providers and DSOs in their assessment who can advocate for them.

Another concern is how well the NDIS will respond to fluctuating levels of psychosocial disability. An essential component of recovery philosophy and practice is a focus on maintaining wellness. If people with a psychosocial disability are ineligible for funding during periods when they have fewer or no symptoms they may have to drop out of the services which are helping to sustain their recovery. The community managed mental health sector needs to ensure that the processes for assessment, plans and budgets under the NDIS support recovery philosophy and practice.

Greater choice and control

Under the system proposed by the Productivity Commission, the assessor would send their assessment of the person with a psychosocial disability to the NDIA. The NDIA would cost their assessment and determine a draft support package which set out the types and quantities of services and supports to be funded. This would be discussed with the person and once agreed, the person could choose one or several service providers to provide supports to them, or to have a DSO manage their package. They may have the option of self-directing their funding, if the assessor determined that they had the capacity. If they do not have the capacity, they may still be able to self-direct funding through an agent (carer, guardian).[170]

This would provide people with a psychosocial disability with more opportunity to identify how they want to live their lives and the supports they need. It would also provide greater choice of service providers, including the choice to access mainstream or commercial services, for example, for wellness or leisure activities.[171]

Support with personal plans and budgets

A key barrier to self-directed care for people with a psychosocial disability in the UK system is that support with the development of a personal plan and the management of a personal budget is ad hoc, varies by area, and often falls upon care coordinators in community mental health services. The Productivity Commission proposes the establishment of DSOs that are integral to the system. DSOs would be available to assist people to develop personal plans, to broker services for them and assist them to manage their personal budgets. In order to give people with a disability the confidence that their interests are paramount, DSOs would be established as organisations that are separate from the NDIA (though funded by it) and service providers.

Again, there is the question of the extent to which the proposed system will allow for specialisation and whether DSOs will have the skills and expertise to provide effective support to people with a psychosocial disability. There may be the opportunity for DSOs to specialise in providing services to people with a psychosocial disability or to employ specialised staff.

Services for people not eligible for a funded package

Under the model proposed by the Productivity Commission, people with a disability who are not eligible for a funded package (Tier 3), are eligible for Tier 2 services. Tier 2 services provided by the NDIA would include disability specific information and referral to mainstream organisations. Other organisations may receive funding to provide Tier 2 services including information, referral, web-based information and: *developing connections between people with a disability and the wider community*.[172] .Only a small proportion of NDIS funding will be available for Tier 1 and 2 services.

It is unclear what support services would be available to people with a psychosocial disability ineligible for a funded package. In the UK many people with a psychosocial disability are not eligible for a funded package, and funding has been diverted away from services for people with lower level needs to pay for funded packages. This could undermine services with a focus on prevention, early intervention or providing lower levels of support to assist people through a difficult period.

The Productivity Commission report seems to suggest that as these reforms would be implemented in the context of the doubling of the budget for disability care and support, that more rather than fewer people will be eligible. However given the experience in the UK, this is a key area of concern. The community managed mental health sector should be engaged with the development of the eligibility criteria and assessment tools for people with a psychosocial disability under the NDIS.

Implications for the community managed mental health sector

Challenges

Withdrawal of block funding

As with self-directed care in other countries, the model proposed by the Productivity Commission involves the withdrawal of block funding, except in some limited situations:

> *While consumer payments to providers (or through DSOs) should become the industry norm over time, there may still be a role for some block funding where markets would otherwise not support key services. Specific areas where block funding may be required are: crisis care; rural areas; community capacity building, some individual capacity building [advocacy]; to support disadvantaged groups (such as indigenous Australians) and as a tool to promote innovation, experimentation and research.*[173]

Organisations whose primary role is advocacy would also remain block funded but would not be eligible for funding from the NDIS to provide services or support brokerage as a DSO. This would be to ensure their advocacy role was not compromised through a conflict of interest.[174]

The withdrawal of block funding means that CMOs would need to bill clients or the NDIS on a per service use basis[175] This would be a major change for CMOs which would no longer have certainty of funding and would need to market themselves to attract clients under both the 'choice of provider' and 'self-directed funding' options available to people with a psychosocial disability. The Productivity Commission acknowledges that this could affect the viability of some organisations:

> *It is possible that in the transition to a consumer choice model, some consumers will lose access to a service that they are happy with, as other customers who were previously dissatisfied are given the ability to leave it (making the particular service unviable overall). However, this will be offset by the additional funding to disability services after the introduction of the NDIS, which will take place in market conditions where demand already significantly exceeds supply. This means that, in general, services will tend to be expanding rather than contracting and consumers will likely have more service options rather than less. Also, overall revenue uncertainty in the disability services industry will be much lower than other sectors, as it is based on hypothecated income. In this context, it is likely that exits will be concentrated among providers whose services are valued the least. In any event, much of the costs incurred through increased uncertainty will be transitory, as service providers adjust to the new business environment and adopt practises that have been long accepted in other sectors*.[176]

There will be significant costs for CMOs in reorienting themselves to operate in this system. Smaller organisations that lack reserves of funding that they can access to restructure their operations and trial new types of services, may be at a disadvantage. In the UK, withdrawal of block funding has led to widespread partnerships and mergers in the mental health sector.

To protect their viability, small community organisations may need to look at ways of sharing costs such as pooled back office functions and at partnerships. However, there are risks in pooled arrangements and in mergers where jobs become more generic and specialised knowledge and skills are lost.

The Productivity Commission proposes that the transition occur gradually and it states that the NDIA will provide assistance, advice and transition funding.[177] Block funding for new Tier 3 activities may also be available.[178] However gradually it is introduced, the withdrawal of block funding risks the demise of smaller community organisations with specialist local knowledge.

The Productivity Commission is aware of the risk of undermining the system if some organisations become unviable and close. They discuss the need for "complementary initiatives" to ensure that there are a reasonable number of competing service providers in a local area and adequate funding to ensure that there are not waiting lists which would deter people from exercising their right to move to another service provider.[179] However, safeguards put in place on the number of competing organisations does not equate to safeguards for smaller organisations. Markets tend to favour larger organisations.

Increased competition

The community managed mental health sector is likely to face increased competition in the provision of services. In other places where self-directed care has been introduced, it has prompted the for-profit sector to enter the market.[180] For profit organisations could offer services to people with a disability, such as providing personal assistants. For profit organisations could compete with community managed organisations by offering cheaper services, for example by employing fewer skilled staff or staff with a lower skill levels. Other types of organisations, such as Medicare Locals, could also enter the market.
Evidence from the US suggests, however, that many people with a psychosocial disability prefer to receive recovery services from peers. The Productivity Commission states that community managed organisations may have several competitive advantages including their ability to engage the community and attract volunteers to provide free services.[181] However, in a more competitive environment there could be a risk of volunteers being used where it would be more appropriate to use skilled staff.

Increased administrative complexity

The reforms proposed by the Productivity Commission would require CMOs to operate more like a business. As the Productivity Commission has recommended that people with a disability be given a range of options for control over their personal budget such as managing it themselves, having an independent organisation manage it for them or having a service provider manage it, CMOs may, for example, need to adjust to managing complex contractual arrangements.[182]

Risks of driving down wages and work conditions

There is a risk that in competing for clients, services will undercut one another by reducing the number of skilled staff or cutting pay or conditions.

However, the NDIA's control over quality and standards may limit the extent to which competition can reduce the skill level of staff. The NDIS will consider the skills needed by support staff when they undertake an individual's need assessment which implies that they may not approve a plan in which services are proposed to be provided by staff with lower skill levels.[183] Service providers will have to be approved by the NDIA and meet their standards.[184]

The Productivity Commission recognises that there will be an increased demand for staff in the disability sector and that shortages may undermine the objectives of the reform. This is particularly the case in mental health. CoAG and the Australian Senate recognise that there are shortages across all mental health professional groups; including in community support services and that wages need to rise to attract people to the workforce. CoAG has already committed to developing a national disability workforce strategy. The Productivity Commission suggest that the NDIS would be a better fit than the clinically oriented mental health system for providing community support to people with a psychosocial disability, where the role of community support workers would be better understood and valued.[185]

Opportunities

New and expanded services

As the Productivity Commission proposes to introduce the reforms to the disability sector in the context of doubled funding, there may be opportunities for CMOs to provide new types of services or expand existing ones.

There is an opportunity for CMOs in partnership with clients and carers to review the types of services they currently provide to ensure that the types of services and how, when and where they are delivered meet the needs and preferences of clients. The additional funding available should provide opportunities to trial new services and modes of delivery. Some CMOs may have wanted to trial such services for some time but been unable to due to the type and amount of funding available.

Smaller CMOs may be able to compete by providing highly specialised or niche services.

There may be opportunities for CMOs to provide personal assistants to people with a psychosocial disability, if the NDIA determines that people with a psychosocial disability are entitled to this type of service. The Productivity Commission notes that the skill set for workers providing support to people with a psychosocial disability is more specialised than attendant care to people with a disability more generally.

The reforms may also free the community managed mental health sector to compete to provide services to people with other disabilities, where a psychosocial disability co-occurs.

The Productivity Commission notes that CMOs might take the opportunity to change their role from the provision of individual supports (Tier 3 in the Productivity Commission's model) to the provision of family supports and community access (Tier 1 or 2 type services). The Productivity Commission intends to establish a compact with CMOs to redirect their voluntary and philanthropic resources to activities promoting community engagement and employment. They state that these resources will be freed up because the NDIS will fully fund services to people with a disability, unlike the current situation where many CMOs are not fully funded by government departments for the services they provide.[186]

Disability Support Organisations

The proposed establishment of DSOs across Australia to assist people with a disability to develop an individual plan and to broker services and assist with the management of a self-directed budget, provides a significant opportunity.

The Productivity Commission notes that the need for assistance from a DSO is likely to be greater amongst people with a psychosocial disability than other disability types[187]. It may be possible to establish specialist DSOs for people with a psychosocial disability. Though the Productivity Commission does not mention specialist DSOs specifically, it does state that there will, in general, be scope for specialisation in urban areas.

However, this is an opportunity to change role rather than expand services, as the Productivity Commission recommends that DSOs be independent from service providers.

Risks

There is a risk that if CoAG does not support the model proposed by the Productivity Commission and instead supports a model where the states administer a disability insurance scheme, that people with a psychosocial disability in NSW will not be eligible. This is because Ageing, Disability and Home Care (ADHC) is driving reforms in NSW to introduce personalised funding by 2014, which would not include people with a psychosocial disability as they are not part of ADHC's administrative and funding responsibility.[188]. This exclusion, based on current departmental arrangements, could be enshrined in the disability insurance scheme in NSW, if a states administered model is agreed. A states run scheme is a distinct possibility, for example, the NSW Government in its submission to the Productivity Commission inquiry expressed a preference for a scheme administered by the states but with national funding and a national framework. [189]

The community managed mental health sector is not traditionally regarded as a stakeholder by ADHC as ADHC is generally not the funding body for services provided by the community managed mental health sector. The community managed mental health sector is not currently treated as a stakeholder by ADHC in discussions about introducing personalised funding for people with a disability in NSW. The sector may need to establish whether its views can be represented through ADHC, NSW Health and/or an alternative mechanism. One mechanism that could be explored is to advocate that the Mental Health Commission/s become active on the issue of the NDIS, undertake consultations with the community managed mental health sector and other stakeholders and represent these views at State and Commonwealth levels.

If the community managed mental health sector engages late in discussions taking place on disability reform, there is a risk that people with a psychosocial disability will be an afterthought in terms of the system design, even if they are ultimately eligible for self-directed care packages. The Community managed mental health sector needs to consider, for instance, if it should be a stakeholder in consultations due to take place in 2012 when the NSW Government announces its proposals for making personalised funding available to people with a disability in NSW.

Summary of issues for discussion by CMOs

1. In a self-directed care system people with a psychosocial disability would have an individual budget that they can choose to spend on specialist, mainstream or commercial services that meet their assessed needs.

    a. Does this align with a recovery model in mental health?

    b. How could you market your services to potential clients and carers?

    c. Are there new types of services that would better meet the needs and preferences of your clients?

    d. Would your organisation be interested in taking the opportunity to change its role, for instance, supporting people with a psychosocial disability to develop an individual plan and purchase services?

2. In a self-directed care system, block funding may be withdrawn and CMOs would need to bill clients or the National Disability Insurance Scheme (NDIS) on a per service use basis. They would also need to be able to cost their services on an individual basis so that the NDIS, brokerage services and clients could compare and contrast available service options.

    a. Are you able to cost your services, including all overheads, on an individual basis?

    b. What steps would your service need to take to be able to do so?

    c. What aspects of your service would need to change to operate in this funding environment?

3. The viability of smaller organisations can be at risk in self-directed care systems which operate like a market where consumers have an individual budget to spend on disability services and can move services taking their funding with them.

    a. Are there ways that services, or the community managed mental health sector as a whole, could collaborate to ensure greater viability and preserve the diversity of services available to clients?

    b. For example, are there opportunities for partnerships, shared back office functions or new organisational structures that could provide for shared costs or pooled resources while maintaining the identity of individual services?

4. In the UK, the focus on funding individual packages for people with higher level needs has led to a reduction of funding for services for people with lower level needs such as programs with a preventive focus. There is a concern that the mental health or well-being of people with lower level needs could deteriorate without access to such services. The Productivity Commission suggests that this will not occur in Australia as the reforms are being implemented in the context of a doubled budget for services. However, it could occur in future if there are funding cuts.

    a. What safeguards does the community managed mental health sector need to advocate be in place to ensure that this does not occur in Australia?

5. Housing and accommodation support programs typically involve close service coordination and frequent communication between service partners at a local level. There may be only one, or a small number, of non-government providers in each local area contracted to provide the accommodation support services to clients.

    a. How would service coordination work if many different specialist and mainstream service providers were involved in providing support services to people with a psychosocial disability in public and social housing?

6. Self-directed care and self-directed funding would establish a disability services market with greater competition between service providers

    a. To what extent does your service currently work collaboratively with other CMOs?

    b. Is there a risk that the introduction of individual budgets and the withdrawal of block funding will undermine and undervalue collaborative work?

7. In the UK, larger community managed mental health organisations have supported their branches or affiliate organisations through the reform, for example, by appointing a national coordinator to lead the organisation through the implementation of the reform or obtaining funding to produce guides and deliver training.

    a. What aspects of the reform would your organisation most need assistance with?

    b. What role could the MHCC play in supporting member organisations?

    c. Are there other organisations that could play a supporting role in the transition?

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[15] Productivity Commission, (31 July 2011), Disability Care and Support, Productivity Commission Inquiry Report, No 54, pp 622-626 and Chapter 4.

[16] Ibid, p622

[17] Ibid, pp222, 622, 624

[18] Council of Australian Governments,.*Meeting, Canberra 19 August 2011, Communiqué*, http://www.coag.gov.au/coag_meeting_outcomes/2011-08-19/docs/COAGCommunique19August2011.pdf, [accessed 23 September 2011].

[19] National Disability Service, National News Update, 21 October 2011

[20] Based on discussions with mental health planning experts, the Commission has assumed that of these 57,000:

- 6,000 (10%) will have intensive support needs including accommodation-based support and assistance with activities of daily living. In the past these individuals were long-term patients within psychiatric hospitals.
- 14,000 (25%) will have high support needs. These individuals may have a history of long term hospitalization and tenancy instability and without support would struggle to live in the community and be at high risk of hospitalization or homelessness
- 6,000 (10%) would have medium support needs, requiring assistance with daily living skills, budgeting and accessing community services
- 31,000 (55%) will have low support needs similar to others with cognitive impairments, such as those with milder intellectual disability. A small amount of weekly support from the NDIS would form part of a broader package which would include ongoing clinical care from the mental health sector. (Appendix M, p.5)

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[24] Ibid, p. 5.

[25] Ibid, p. 6

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[30] Ibid, pp 161 – 162

[31] Ibid, pp 161 – 162

[32] Ibid pp 161 – 162

[33] Ibid, pp 161 – 162

[34] Ibid, p 622

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[48] Ibid, p. 17

[49] Productivity Commission, (31 July 2011), *Disability Care and Support, Report No 54*, p. 416.

[50] ibid, chapter 8

[51] Ibid, p. 347

[52] Ibid, p. 347

[53] Ibid, p. 347

[54] Ibid, p. 348

[55] Ibid, p. 346

[56] Ibid, p. 346

[57] Ibid, pp. 346-7

[58] Ibid, p. 363

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[60] Ibid, p. 352

[61] Ibid, pp. 396-397

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[65] Chopin, N. S., & Findlay, I. M., (2010), *Exploring Key Informants' Experiences with Self-Directed Funding, A Research Report*, Community-University Institute for Social Research and Centre for the Study of Co-operatives, University of Saskatchewan, pp. 80, 81.

[66] Alekson, V.; (July 2008), 'Self Directed Care for Adults with Serious Mental Illness: The Barriers to Progress', *Psychiatric Services*, no 59, pp. 792-794.

[67] Knickman, J. R., & Stone, R. I., (February 2007), 'The Public/private Partnership Behind the Cash and Counseling Demonstration and Evaluation: Its origins, challenges and unresolved issues', *Health Services Research*, no 42, pp. 362-377, p. 365.

[68] Ibid, p. 366

[69] Ibid p. 364

[70] Alekson, V., (November 2007), *The Contribution of Self-Direction to Improving the Quality of Mental Health Services*, US Department of Health and Human Services, p.2. Shen, C., Smyer, M., Mahoney, K. J., Simon-Rusinowitz, L., Shinogle, J., Norstrand, J., Mahoney, E., Schauer, C & del Vecchio, P., (November 2008), 'Consumer Directed Care for Beneficiaries with Mental Illness: Lessons from New Jersey's Cash and Counseling Program', *Psychiatric Services*, no 59, pp. 1299-1306.

[71] All articles from the US use the term mental illness or serious mental illness to define the eligible target group

[72] Alekson, V., (November 2007), *The Contribution of Self-Direction to Improving the Quality of Mental Health Services,* US Department of Health and Human Services, pp. 6-10.

[73] Ibid, pp.6-10

[74] Ibid, pp. 6-10

[75] Ibid, pp. 6-10

[76] Ibid, pp. 6-10

[77] Dickinson, H., and Glasby, J.,(February 2010), *The Personalization Agenda: Implications for the Third Sector,* Third Sector Research Centre, UK, p.6.

[78] Ibid, p6

[79] Harlock, J., (2010), 'Personalisation: Emerging Implications for the Voluntary and Community Sector ', *Voluntary Sector Review*, Vol 1, No 3.

[80] Manthorpe, J., Hindes, J., Martineau, S., Cornes, M., Ridley, J., Spandler, H., Rosengard, A., Hunter, S., Little, S., & Grey, B., (2011), *Self Directed Support: A Review of the Barriers and Facilitators*, Scottish Government Social Research, p. 13.

[81] Carr, S., & Robbins, D., (March 2009), *The Implementation of Individual Budget Schemes in Adult Social Care, Research Briefing 20*, Social Care Institute for Excellence, UK, p. 6.

[82] Carr, S., & Robbins, D., (March 2009), *The Implementation of Individual Budget Schemes in Adult Social Care, Research Briefing 20,* Social Care Institute for Excellence, UK p. 8.

[83] Glendenning, C., Challis, D., Fernanadez, J. L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M.,&Wilberforce., M., (2008), *Evaluation of the Individual Budgets Pilot Programme, Final Report, Individual Budgets Evaluation Network (IBSEN)*, Social Policy Research Unit, University of York, p. 2.

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[86] http://www.mind.org.uk/campaigns_and_issues/policy_and_issues/putting_us_first [accessed 9 September 2011]

[87] Department of Health (UK)(February 2010), *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care, Guidance on Eligibility for Adult Social Care, England 2010*, Crown Copyright, p21. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113154

The eligibility framework is graded into four bands which describe the seriousness of the risk to independence and well-being or other consequences if needs are not addressed:

- Critical-
- Substantial-
- Moderate
- Low

[88] Productivity Commission, (31 July 2011), *Disability Care and Support, Report No 54*, pp. 418, 421. Each person who is judged to be likely to be eligible for an individual package will be appointed a Local Area Coordinator (LAC). The LAC would play a role in the assessment by visiting the person and understanding their situation and the extent of their support and needs. The LAC would provide information about service options that meet the person 's needs and help them to engage with services and community groups. The LAC would check on people periodically, according to their degree of vulnerability and is the contact point for complaints. The LAC would have a role in investigating and resolving complaints and supporting people to transition from one service provider to another. LACs may also have a role in advising businesses and community groups how to make their services more accessible to people with a disability.

[89] Productivity Commission, (31 July 2011), *Disability Care and Support, Report No 54*, p349

[90] Audit Commission UK, (October 2010), *Financial Management of Personal Budgets, Challenges and Opportunities for Councils*, Local Government, UK; Patten, K., National Personalisation Lead, Richmond Fellowship, UK; personal communication; Productivity Commission, (31 July 2011), *Disability Care and Support, Report No 54*

[91]National Mental Health Development Unit, (2011), *Facing Up to the Challenge of Personal Health Budgets, The view of frontline professionals*, http://www.nhsconfed.org/Publications/Documents/Facing_up_to_the_challenge_of_personal_health_budgets.pdf

[92] Alekson, V.; (July 2008), 'Self Directed Care for Adults with Serious Mental Illness: The Barriers to Progress', *Psychiatric Services*, no 59, pp. 792-794

[93] Cook, J. A., Russell, C., Grey, D. D., & Jonikas, J. A., (June 2008), 'Economic Grand Rounds: A Self-Directed Care Model for Mental Health Recovery', *Psychiatric Services*, no 59, pp.600,-602. The evaluation used a pre-post design to follow 106 participants through the first 19 months of the program's operation.44% had a schizophrenia spectrum disorder, 24% depression, 22% bipolar disorder, 4% PTSD, 3% generalized anxiety disorder, 2% panic disorder, 2% psychosis not otherwise specified, 1% multiple personality disorder.

[94] Alekson, V., (November 2007), *The Contribution of Self-Direction to Improving the Quality of Mental Health Services*, US Department of Health and Human Services.

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[96] Shen, C., Smyer, M., Mahoney, K. J., Simon-Rusinowitz, L., Shinogle, J., Norstrand, J., Mahoney, E., Schauer, C & del Vecchio, P., (November 2008), 'Consumer Directed Care for Beneficiaries with Mental Illness: Lessons from New Jersey's Cash and Counseling Program', *Psychiatric Services*, no 59, pp. 1299-1306; Note: the methodology does not include information on the severity of the participants' mental illnesses

[97] Substance Abuse and Mental Health Services Administration (SAMHSA), (April 2010), *Self-/directed Care in Mental Health: Learnings from the Case and Counseling Demonstration Evaluation*, US Department of Health and Human Services. Available: http://store.samhsa.gov/product/Self-Directed-Care-in-Mental-Health/SMA10-4522

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[99] Shen, C., Smyer, M., Mahoney, K. J., Simon-Rusinowitz, L., Shinogle, J., Norstrand, J., Mahoney, E., Schauer, C & del Vecchio, P., (November 2008), 'Consumer Directed Care for Beneficiaries with Mental Illness: Lessons from New Jersey's Cash and Counseling Program', *Psychiatric Services*, no 59, p. 1304

[100] Mind, (2009), *Personalisation in Mental Health: A Review of the Evidence*, Mind

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[102] Spandler, H., & Vick, N., (2006), 'Opportunities for Independent Living Using Direct Payments in Mental Health', *Health and Social Care in the Community*, vol 14, no 2, pp. 107 – 115.

[103] Mind, (2009), *Personalisation in Mental Health: A Review of the Evidence*, Mind

[104] Spandler, H., & Vick, N., (2006), 'Opportunities for Independent Living Using Direct Payments in Mental Health', *Health and Social Care in the Community*, vol 14, no 2, pp. 107 – 115.

[105] Mind, (2009), *Personalisation in Mental Health: A Review of the Evidence*, Mind

[106] Spandler, H., & Vick, N., (2006), 'Opportunities for Independent Living Using Direct Payments in Mental Health', *Health and Social Care in the Community*, vol 14, no 2, pp. 107 – 115, p111.

[107] Ibid, p113

[108] Ibid, p112

[109] Ibid, p112

[110] K. Patten, Richmond Fellowship, UK, personal communication, September 2011.

[111] Department of Health (UK)(February 2010), *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care, Guidance on Eligibility for Adult Social Care, England 2010*, Crown Copyright, p21. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113154_

[112] K. Patten, Richmond Fellowship, UK, personal communication, August 2011

[113] Department of Health (UK)(February 2010), Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care, Guidance on Eligibility for Adult Social Care, England 2010, Crown Copyright, p6. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113154_

[114] Ibid, p8

[115] Ibid, pp 6-7

[116] Ibid, p7

[117] Ibid pp 6-8, 35-36

[118] In the UK expenditure on personal plans beyond a certain amount, which is determined by each local authority, must be approved by a local authority panel of senior adult care professionals.

[119] K. Patten, personal communication, Richmond Fellowship, UK, September 2011.

[120] Harlock, J., (2010), 'Personalisation: Emerging Implications for the Voluntary and Community Sector ', *Voluntary Sector Review*, Vol 1, No 3, pp 371-8

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[122] Dickinson, H., and Glasby, J.,(February 2010), *The Personalization Agenda: Implications for the Third Sector,* Third Sector Research Centre, UK, p. 15; Bamber C., & Flanagan, P., (July-August 2008), Mental health and self-directed support, *Mental Health Today*, p. 27.

[123] K. Patten, Richmond Fellowship, UK, personal communication, September 2011.

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[126] Mind, (June 2011), *Personalised Services, A Travel Guide, 1st edition*, Mind, p. 32.

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[128] There are around 170 local Mind organisations, which are independent organisations, affiliated with Mind.

[129] Cruse, K., Senior Specialist Support Officer, Mind, (August 2011), Personal communication

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[131] 'Let's Get Personal', *Mental Health Today*, February 2010, p. 10.

[132] K. Patten, Richmond Fellowship, UK, personal communication, September 2011.

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[134] K. Patten, Richmond Fellowship, UK, personal communication, September 2011.

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[136] Let's Get Personal', *Mental Health Today*, February 2010, p. 12

[137] Mind, (2009), *Personalisation in Mental Health: A Review of the Evidence*, Mind, p.4.

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[143] Ibid

[144] Ibid

[145] Ibid

[146] K Cruse, Mind, personal communication, August 2011.

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[150] Carr, S., & Robbins, D., (March 2009), *The Implementation of Individual Budget Schemes in Adult Social Care*, Research Briefing 20, Social Care Institute for Excellence, UK, p. 11.

[151] Dickinson, H., and Glasby, J.,(February 2010), *The Personalization Agenda: Implications for the Third Sector*, Third Sector Research Centre, UK, p. 19.

[152] Mind, (June 2011), *Personalised Services, A Travel Guide, 1st edition*, Mind, p. 21.

[153] Ibid, p. 20

[154] Harlock, J., (2010), 'Personalisation: Emerging Implications for the Voluntary and Community Sector ', *Voluntary Sector Review*, Vol 1, p. 376.

[155] K Cruse, Mind, personal communication, August 2011; K. Patten, Richmond Fellowship, UK, personal communication, September 2011

[156] Mind, (2009), *Personalisation in Mental Health: A Review of the Evidence*, Mind, p. 2.

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[161] Productivity Commission, (31 July 2011), *Disability Care and Support, Report No 54*, p. 188

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