

# Individualised funding for New Zealand mental health services: a discussion paper

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# Executive summary

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Individualised funding is a payment arrangement that enables people to choose the care provision they receive and manage those services themselves. It is a mechanism for purchasing support services where the person can manage the resources allocated to them (Synergia, 2011). In countries, such as the United Kingdom, individualised funding has been a crucial aspect of personalisation, in which the focus is on meeting service user needs in ways that work for them, and where people are in charge of arranging and managing their own support services. It has been suggested that individualised funding supports individuals to have more choice and control over their lives, and this contributes to their wellbeing.

Individualised funding is now available to some people using disability services in New Zealand. In New Zealand's mental health and addiction sector, the most common funding allocation methods reported by planners and funders are the rollover of historical contracts or use of evidence of effectiveness to reprioritise services and allocate funds (Mental Health Commission, 2010). Packages of Care may be the closest approach to individualised funding used in mental health. Available in primary and secondary care, Packages of Care is a funding mechanism aimed at tailoring support to meet individual needs. However, funding stays with the service not the person.

A study by the Mental Health Commission (2010) identified a range of concerns with current mental health funding arrangements in New Zealand including: a focus on input and outputs rather than effectiveness; funding tied to secondary care rather than early intervention; poor service integration between primary and secondary; and lack of funding flexibility. Some of these concerns were echoed in *Blueprint II* (2012) which called for more personalised care, stronger partnerships between service users, family and providers, and greater alignment between the funding of disability and mental health services (Mental Health Commission, 2012b). A recent article in *NZ Doctor* reports that community services (NGOs) are being "driven into the ground" due to a lack of additional funding to offset cost increases (Platform Trust, 2014).

The purpose of this paper is to provide information that will support discussions about individualised funding options for the New Zealand mental health and addiction context. The paper summarises the current literature to: identify the types of individualised funding mechanisms and their characteristics; where and how they have been set up; the outcomes to date; and crucial service and workforce development considerations when implementing individualised funding.

Individualised funding programmes have been implemented in the United States, Canada, Australia and the United Kingdom from as early as the 1980s to fund health, personal and social care. Many of the programmes in these countries are available for older people and people experiencing mental health conditions, as well as people with disabilities.

In general, outcomes for people and their families accessing individualised funding are positive. Most people report increased ability and flexibility to choose a wider range of services to address their health needs. Increased satisfaction with service delivery and fewer unmet needs have been noted in evaluation studies of individualised

funding mechanisms. Recipients have reported better psychological wellbeing and greater motivation and confidence than those receiving usual care (Davidson et al., 2012; Forder et al., 2012).

However, most evaluation studies also identified a range of factors that negatively impacted on outcomes. These include: paternalistic attitudes of staff limiting people's access to individualised funding (particularly access by people experiencing mental health conditions); lower access rates for more at-risk population groups such as black and ethnic minority groups in the United Kingdom and Aboriginal and Torres Strait Islanders in Australia; heightened stress as a result of managing a personal or individual budget; and insufficient resourcing and administrative support.

If individualised funding is to be a viable option for people who experience mental health and addiction conditions, robust support structures need to be developed. This would enable people who use services to access and use this funding mechanism, underpinned by the principles and philosophy of personalisation.

Evaluations of individualised funding programmes have revealed a number of programme features that support successful implementation. Key components to successful implementation include: provision of good information; active outreach to marginalised or at risk groups; transparent decision making regarding resource allocation; availability of ongoing third party support to assist with the management of finances and employment relations; supportive staff attitudes and the willingness to pass control to the person using services; adequate funding including costs of related administration; and careful policy development and planned implementation.

It is also important to acknowledge that evaluation studies have tended to focus on the health and wellbeing outcomes of only those people who are eligible to receive health and social care services. It is unclear what impact the widespread use of individual funding has on the overall availability of health and social care support services. This is likely to be a source of uncertainty and anxiety for some New Zealand health services considering individualised funding. Some New Zealand disability providers question what would happen to the employment market and predict that changes could mean that more staff will have to be employed on a temporary or casual basis in response to fluidity of demand (Matthews, 2013).

Given this understandable uncertainty about the impact of individual funding on the overall supply and quality of health and social support, if this model was considered further it would be very important to include key stakeholders (service users/ tāngata whaiora, families and whānau, providers, cultural leaders and staff members) in related planning and policy development from the outset.

Policy and planning development would also need to consider whether sufficient ongoing funding could be made available to ensure sustainability. Individualised funding models require significant administrative investment, particularly upfront. In both Australia and New Zealand the costs associated with individualised funding were underestimated, forcing host agencies to work to unrealistic schedules (Fisher et al., 2010; Laragy & Ottmann, 2011; Synergia, 2011).

An international evaluation study of individual funding reported resistance and aversion to risk among teams working with mental health service users or with older people (Glendinning et al., 2008). However, in the last decade New Zealand has invested in developing recovery competencies (O'Hagan, 2001) as well as developing and implementing the *Let's get real* framework of knowledge, skills, values and attitudes<sup>1</sup> needed to support a service user-centred New Zealand mental health and addiction workforce. So although New Zealand is behind other countries with respect to the use of individualised funding approaches in mental health, it is possible that the workforce is better equipped to implement self-direction mechanisms compared to other jurisdictions.

Following this discussion paper, the next step could be the formation of a collaborative New Zealand-based personalisation community of interest group. The group could potentially bring together representatives, leaders and experts from funding, the Ministry of Health, service users and the sector. The group could further consider the application of individualised funding for New Zealand's mental health and addiction sector in light of national priorities, and whether the individualised funding mechanism is an important new strategy to achieve better, more person-centred care. Lessons from the implementation of individualised funding models in the disability sector in New Zealand would need to be considered. If individualised funding was promoted as an important component of work to improve the personalisation of New Zealand's mental health and addiction services, small scale pilots with discrete timeframes run in urban, provincial and rural settings could be considered.

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<sup>1</sup> See here for information about *Let's get real*: <http://www.tepou.co.nz/supporting-workforce/lets-get-real>

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# 1.0 Introduction

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The purpose of this paper is to provide information that will support discussion about individualised funding options for the New Zealand mental health and addiction context. Individualised funding has been implemented in many western countries to manage social services. It aims to empower people using services by increasing their choice and control over service delivery. In New Zealand individualised funding is available to some people who receive disability services but it is not available to people who use mental health and/or addiction services.

This paper summarises the current literature to:

- identify the types of individualised funding mechanisms and their characteristics
- outline where and how they have been set up
- report on the outcomes to date, with a focus on people using mental health services
- identify key service and workforce development considerations when implementing individualised funding.

This paper has been primarily developed to support an informed discussion of ideas about the personalisation of services and the associated individualised funding mechanisms. This paper will be of interest to those working in the field of mental health and addiction, in particular policy makers, planners and funders, and leaders representing service users, district health board (DHB) provider arms and NGO services.

This paper begins with a background to individualised funding in the New Zealand context. Section Two provides a summary and overview of the different types of individualised funding models that operate overseas and in New Zealand's disability sector. The evidence base for the effectiveness of individualised funding and related approaches is rapidly developing and current information is presented in Section Three. The implications for service and workforce development are discussed in Section Four. The paper ends by summarising key considerations for the application of individualised funding in the New Zealand mental health and addiction context and identifying potential next steps.

## What is individualised funding?

Individualised funding is a payment arrangement that allows people to directly manage their own care and service provision. It is a mechanism for purchasing support services where the person can directly manage the resources allocated to them. The arrangement gives people greater flexibility, choice and control over the support they are allocated (Synergia, 2011).

There are a variety of funding and resource allocation programmes in operation internationally which are designed to enable people to have greater choice and control over their lives. These programmes are different from traditional block funding models where providers are contracted to deliver services to individuals. Some programmes allow the payment of funds directly to an individual; others only permit the payment of funds to a host provider to administer on an individual's behalf. Various agencies and entities are able to operate as a financial intermediary.

Most programmes involve some form of needs assessment and the development of a personalised plan that sets out an individual's needs and goals. The amount of funding received by the individual is based on these assessments. Criteria for who can be employed by someone in receipt of individualised funding differ between programmes, as well as the type of service and/or equipment that can be purchased through individual funding. These programmes have a common goal to achieve greater personalisation of service delivery.

Personalisation has been described as:

. . . respecting a person's human rights, dignity and autonomy, and their right to shape and determine the way they lead their life. Personalised support and services are designed for the purposes of independence, wellbeing and dignity. Every person who receives support should have choice and control regardless of the care setting (HM Government, 2011, p. 32).

## 2.0 Methodology

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The literature and reports that were reviewed for this discussion paper were identified through a number of strategies. An initial search of SCOPUS (the largest abstract and citation database of peer-reviewed literature: scientific journals, books and conference proceedings), Web of Science and Google Scholar was completed in 2012 using combinations of the following search terms: personal budget(s); individual budget; individualised funding; direct payment; cash for care; cash for counselling; personalisation; person-centred; self-directed; support; mental health; and outcome. This search was repeated in early 2014 to identify recent published literature.

The following websites were useful sources of relevant reports: Social Policy Research Unit (SPRU), University of York (<http://www.york.ac.uk/inst/spru/index.html>); Centre for Mental Health <http://www.centreformentalhealth.org.uk/> and, in particular, a literature review by the Centre for Inclusion and Citizenship was a useful source of information about the North American context. Other useful websites included: <http://www.scie.org.uk/topic/keyissues/personalisation> and [http://www.thinklocalactpersonal.org.uk/About\\_us/](http://www.thinklocalactpersonal.org.uk/About_us/).

Initial advice and expertise was sought from people with experience in implementing individualised funding methods both overseas and in the New Zealand disability sector, including David Todd, Gordon Boxall, Rob Gill and Helen Lockett. These experts also identified useful sources of literature about individualised funding and related policy developments.

Information about practical funding issues in the New Zealand mental health sector was gathered from sector experts.

## Limitations

Given the level of resource available there was no intention to complete a systematic review. The findings are presented as an initial exploration of what is currently known about individualised funding approaches. There are important differences between the populations and health systems of each country, and also within countries between states, counties or boroughs, where individualised funding approaches are being used. These differences have implications for the extent to which aspects of each programmes could be transferred or implemented in the New Zealand context.

## 3.0 Background

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In New Zealand, various frameworks and tools have been developed to support the mental health and addiction workforce to use client-centred or person-centred approaches to service delivery. The service user movement has advocated strongly for a recovery approach to be incorporated into all models of service delivery. The recovery approach has been reinforced in policy documents, workforce development plans and in the *Let's get real* framework that aims to ensure mental health and addiction services and staff are delivering people-centred approaches to support recovery (Mental Health Commission, 1998; Ministry of Health, 2005a, 2005b; O'Hagan, 2001).

Considerable investment has been made in up-skilling the mental health and addiction workforce, as well as improving overall system performance, so that people-centred skills, values and practices are embedded. This emphasis has continued in the most recent service development plan, *Rising to the Challenge* (Ministry of Health, 2012b). Both the recovery approach and personalisation are driven by the belief in self-determination and the right to full citizenship for people who experience mental health problems (Alakeson & Perkins, 2012). Arguably, the direction of mental health policy in New Zealand is consistent with the values that underpin personalisation and person-centred service delivery.

## Funding for mental health and addiction services in New Zealand

### How the sector is funded

Historically, mental health and addiction service delivery in New Zealand was underfunded. In 1998 the *Blueprint for Mental Health Services in New Zealand* provided detailed resource guidelines so that the three per cent of the population who experienced the most severe mental health problems would be able to access services (Mental Health Commission, 1998). *Blueprint* resourcing guidelines were incorporated into the DHB operational policy framework which meant that, "DHBs had to spend mental health funding only on mental health services, effectively creating a Vote: mental health by proxy" (Mental Health Commission, 2010, p. 5). In other words, funding for mental health services was ring-fenced and DHBs could not spend this money on non-mental health services. The ring-fence and increased investment has led to greatly improved access to services

for people with the most severe mental health conditions. It also reinforced the separate funding for disability and mental health services in New Zealand.

Primary mental health services have been funded by the Ministry of Health through primary health organisations (PHOs) since 2005, to primarily address the needs of people with mild to moderate mental health and/or substance abuse problems. Early primary mental health initiatives were evaluated (Dowell, et al., 2008) and demonstrated sufficiently positive results to argue for additional funding. The Ministry now funds primary mental health care in all PHOs. In 2011/12 funding totalled \$23.8M. This funding includes 120 primary mental health clinical roles, extended consultations with general practitioners, screening and brief intervention, and Packages of Care (PoCs). PoCs are funding mechanisms that cover a variety of services such as cognitive behavioural therapy, medication reviews, counselling and other psychosocial interventions (Ministry of Health, 2014).

In 2010 the Mental Health Commission completed a study of the funding allocation methods used by DHB mental health funding and planning portfolio managers. The most common funding allocation methods reported were the rollover of historical contracts with minor adjustments, and the use of evidence of effectiveness to reprioritise services and allocate funds (Mental Health Commission, 2010).

The funding allocation strategies that were seldom used included:

- giving people using services, or their agents, real or nominal budgets to buy services
- funding online therapy services
- system outcome gain/risk sharing with providers (eg acute bed days)
- a capitated funding approach (Mental Health Commission, 2010:11).

A very small group of people using mental health services (approximately ten people) with high needs and complex issues have received special funding through Needs Assessment and Service Co-ordination (NASC) packages to address their particular conditions (Woodcock, 2012). For example, one person who could only be managed in a secure unit was moved into his own house with support workers.

The NASC PoCs offered through secondary mental health services and the PoCs available in primary care for people with mild to moderate mental health and addiction conditions are funding mechanisms aimed at tailoring support to meet individual needs.

The PoCs provide a pool of money held by the service that can be accessed by individuals as a result of needs assessment and spent in a flexible way to meet the identified needs of the person using the service. In secondary care funding is often spent on respite or supported accommodation. In primary care this funding tends to be spent on four to six sessions of talking therapy. However, increasingly these packages are being used in more creative ways to meet the needs of people and their family and whānau (Woodcock, 2012). There is variability in how much involvement the person using services has in deciding what services to include in their package, however this funding mechanism is probably the closest to individualised funding that New Zealand's current mental health service provides.

## Concerns about current funding models

Despite improved access rates and services for people with the highest levels of need, concern has arisen about the unintended outcomes of dedicated funding for mental health services. The study by the Mental Health Commission found people were concerned that:

- funding decisions are based on inputs and outputs rather than on evidence of effectiveness
- there is a lack of incentives for improving outcomes for service users
- there is a lack of service integration between primary and secondary care
- funding is tied to secondary services rather than to early intervention
- and that there is a lack of funding flexibility to meet the needs of service users (Mental Health Commission, 2010).

A major concern is the (poor) transition between secondary and primary services. Under the care of secondary services a person using services may have various support structures in place, however, when the person is discharged from secondary services the funding ends even though some of their support needs may still exist. The funding stays with the service rather than following the person using the service (Woodcock, 2012). An overarching goal identified in *Rising to the Challenge* (2012b) is to build infrastructure for better integration between primary and specialist services (p.5).

A recent article in *NZ Doctor* reports that funding for New Zealand NGOs has reached a critical point. Marion Blake, chief executive of Platform Trust, a national network of mental health and addiction NGOs, said community services are being “driven into the ground” due to a lack of additional funding to offset cost increases, inconsistent pricing of services across the country and an overly bureaucratic contracting system.

In the last five years only four out of the 20 DHBs have consistently passed on the contribution to cost pressure (CCP) increase that DHBs receive from government to meet inflationary and other cost increases. Yet we live and provide services in the same communities and face the same rising costs. On top of that, DHBs often fund NGO mental health and addiction services at a lower rate than their own services, and prices paid vary dramatically across the country. This compromises our ability to meet the cost of delivering services and offer comparable pay to our staff. (Platform Trust, 2014).

In response Platform Trust has launched the Fair Funding campaign (<http://www.fairfunding.org.nz/media>) to seek an urgent restoration of a sustainable funding path for the mental health and addiction NGO sector. In 2012/13 NGOs supported more than 50,000 New Zealanders experiencing mental health and addiction problems, supporting people to remain in their communities as they regained wellness. Support includes providing (or finding) housing, education and employment, as well as working alongside other health providers. In New Zealand around 90 per cent of people experiencing mental health and/or addiction problems are supported in the community (Platform Trust, 2014).

## Calls for change

There have been calls for changes to the way mental health services are funded and the need to increase the flexibility of funding arrangements. The authors of *Blueprint II* argued that, “self care, personalised care and shared care planning tools are being implemented in other parts of the health sector, mental health needs to be part of these developments” (Mental Health Commission, 2012b:31). *Blueprint II* also made a case for stronger partnerships between people using services, their family and whānau and providers so that people can direct and lead their own pathway to recovery (Mental Health Commission, 2012a). Furthermore *Blueprint II* advocates for greater alignment between the funding of disability and mental health services.

Mental health and addiction and disability support service policy makers need to align their policies on partnerships and individualised approaches at a national level. This includes reducing barriers to shared funding of individualised responses to complex needs across disability and mental health funding streams. (Mental Health Commission, 2012b, p. 38)

There is no specific mention of the use of individualised funding in *Rising to the Challenge* but one of the guiding principles is to, “personalise services to the particular needs of the service user and their family and whānau” (Ministry of Health, 2012b, p. 7). It states the Ministry of Health will oversee the development and implementation of a planning and funding framework that will provide guidance on service configuration, planning methods and results-based funding. The ring-fence is to be maintained until 2017 (at least) when it will be reviewed once a nationally consistent performance framework for mental health and addiction systems has been developed and implemented (Ministry of Health, 2012b).

## Funding for disability services in New Zealand

In contrast, individualised funding is available for people who meet disability criteria under the New Zealand Public Health and Disability Act 2000 (Ministry of Health, 2012a; New Zealand Parliament, 2000).<sup>2</sup> In 2012 approximately 1,400 disabled people with personal care and home management needs were using individualised funding.

Individualised funding originated in Christchurch in the late 1990s and developed in an ad hoc manner in different parts of the country until it was endorsed by the Ministry of Health in 2003 (Gill, 2012). Funding is paid to a host provider; there are no direct payments to individuals. People who receive individualised funding have the power to decide:

- who provides the support in their home and how much they are paid
- when the support is provided

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<sup>2</sup> The Ministry funds a range of Disability Support Services. These are available to people who have a physical, intellectual or sensory disability (or a combination of these) which: is likely to continue for at least six months; limits their ability to function independently, to the extent that ongoing support is required. These are mainly younger people under the age of 65 years. The Ministry of Health does not generally fund disability support services for people with: personal health conditions such as diabetes or asthma; mental health and addiction conditions such as schizophrenia, severe depression or long-term addiction to alcohol and drugs; conditions more commonly associated with ageing such as Alzheimer’s disease.

- what type of support is provided (as long as it meets the criteria in the service specification) (Synergia, 2011, p. 13).

Host providers support people with disabilities to manage their individualised funding arrangements. The amount of management support is flexible with some people taking care of most aspects of employment arrangements. Host providers deliver coaching and support to their clients. The funding is provided annually so people have the ability to save up some of their allocated budget in order to spend more at particular times of the year (Synergia, 2011).

## The New Model

A new model for supporting disabled people was approved by the New Zealand Cabinet in 2010 (Office for Disability Issues, 2012). It is characterised by a shift from centre-based to facilitation-based models of support service delivery. The model begins with the disabled person in their community and support is designed around them.

Three New Model demonstration projects are currently underway in New Zealand.

1. Local Area Coordination in the Western Bay of Plenty has four components: provision of better information and personal assistance via Local Area Coordinators; moving towards giving more funding rather than types and levels of services and increased use of self-assessment; more choice and control over what people can buy; and better evaluation and accountability (Foxx, 2012).
2. The Choice in Community Living Initiative (Auckland and Hamilton) is exploring alternatives to residential care for people currently in, or likely to enter, residential services (Foxx, 2012).
3. The Enabling Good Lives Demonstration in Christchurch. In Christchurch, an independent working group provided advice to the Office of Disability Issues on improvements to day activity support. Their report, *Enabling Good Lives*, recommended that disabled people should be enabled to do everyday things in everyday places, in communities. The group advocated that flexible and individualised support funding should be made available from multiple government agencies. In 2013, Cabinet approved funding for the Enabling Good Lives demonstration in Christchurch. The demonstration involves increased involvement of disabled people in decision-making, independent facilitation and support with planning, and the pooling of funds from the Ministries of Health, Social Development and Education for allocation through individualised funding. An evaluation of this model is underway (Turia, 2013).

## Summary

Person-centered approaches to mental health and addiction service delivery have been long been advocated by the New Zealand service user movement and are a strong feature in policy documents, competency guidelines and workforce development plans (Ministry of Health, 2005a; 2008; 2012b). Historically, mental health service delivery was underfunded but in 1998 ring-fenced funding for the three per cent of the population who experienced the most severe problems led to greatly improved access to services. More recently the Ministry of Health began funding primary mental health services through primary health organisations.

The two most common funding allocation methods reported by planners and funders are the rollover of historical contracts or the use of evidence of effectiveness to reprioritise services and allocate funds (Mental Health Commission, 2010). In contrast, individualised funding is available to some people with disabilities in New Zealand. Funding is paid to a host provider, and the person requiring services decides what social supports to purchase and when. The host provider supports the person to manage these funding and employment arrangements. The closest funding mechanism to individualised funding that New Zealand's current mental health service provides is Packages of Care, aimed at tailoring support to meet individual needs following a needs assessment.

A study by the Mental Health Commission (2010) identified a range of concerns with current mental health funding arrangements including: a focus on input and outputs rather than effectiveness; funding tied to secondary care rather than early intervention; poor service integration; and lack of funding flexibility. Some of these concerns were echoed in *Blueprint II* which called for more personalised care; stronger partnerships between service users, family and providers; and a greater alignment between the funding of disability and mental health services (Mental Health Commission, 2012b). Furthermore, a recent article in *NZ Doctor* reports that community services (NGOs) are being “driven into the ground” due to a lack of additional funding to offset cost increases (Platform Trust, 2014).

While *Rising to the Challenge* (2012b) does not specifically mention individualised funding, one of its guiding principles is the personalisation of services to meet the particular needs of the service user, their family and whānau.

## 4.0 Funding and planning mechanisms

Individualised funding for health and social care service delivery has been implemented in many western countries with the aim of empowering people using services by increasing their choice and control over service delivery. These models vary across jurisdictions and are influenced by the cultural context and public policy framework within which they are administered (Bennett and Bijoux Ltd, 2009, p. 5).

A variety of terms are used to describe the way funding is actually delivered to health and social care recipients and the wider policy or programme approaches. These terms include: direct payments; individual funding; individualised funding; self-directed care; cash for counselling; consumer-directed care; individual budgets; personal budgets and personal health budgets.

Table 1 provides an overview of some of the international and local individualised funding approaches and includes a brief summary of each term. Appendix A provides a summary of further analysis of other international programmes that were identified by the recent Personal Budgets and health evidence review. The review was conducted by the Centre for Health Services Studies (2013) as part of the United Kingdom's personalisation agenda.

**Table 1: Overview of international and local individualised funding approaches**

Name and country	Definition	Purpose	Mental health eligibility
Direct Payments (United Kingdom, Australia and the United States)	Cash payment to an individual so they can purchase goods and/or services to meet their health and/or social care needs.	Health, personal and social care	Yes
Individual Budget (England)	Allocation of a dollar amount based on an assessment of social care needs. Individuals can choose how budget is delivered.	Social care	Yes
Personal Budget and Personal Health Budget (United Kingdom)	Implemented in 2009. After an initial needs assessment a person is provided with a budget and supported to develop a plan to use the budget in ways that will benefit their health and wellbeing.	Health	Yes
Housebound Aid and Attendance Allowance Programme (United States)	Cash payments to veterans and their surviving spouses.	Health, personal and social care	Not known

Name and country	Definition	Purpose	Mental health eligibility
Consumer-directed Family Support (United States)	Individuals and families develop a plan with a service facilitator and choose which services to purchase. The state acts as the fiscal agent. Paid caregivers are often family members of the person with developmental disabilities.	Respite, personal and social care	No
Cash for Counselling and Self-directed Care (United States)	Based on providing individuals with a budget to purchase goods and services instead of, or in addition to, direct service provision. Slow uptake for mental health service users.	Health and social care	Yes
Individual Funding (Australia)	Local area co-ordinators support individuals and families to plan and purchase supports through direct funding. Portable funds can be held by providers or facilitators or paid directly to individuals.	Respite, personal and social care	Yes
Individualised Funding (Canada)	Allocation of a budget (can be from multiple funders), planning support and facilitation.	Personal and social care	Yes
Individualised Funding (New Zealand)	Funding is paid to a host provider, and an individual (and/or their nominated representative or welfare guardian) has the power to decide who provides support and how much they are paid, when support is provided and the type of support. There are no direct payments to individuals.	Personal care and social care <sup>3</sup>	No
The New Model (New Zealand)	Facilitation based model of support service delivery. Three demonstration projects are underway—Local Area Co-ordination in Western Bay of Plenty, Enabling Good Lives (which will include individualised funding from multiple government agencies) in Christchurch, and Choice in Community Living in Auckland and Waikato.	Personal and social care	No

<sup>3</sup> Depending on the practice of the service co-ordinator with funding authority.

In the following section more detailed information is provided about the main types of individual funding mechanisms used and the distinguishing features of some example programmes that deliver these funding arrangements.

## Direct payments

Direct payments are cash payments paid directly to an individual (or indirectly to a nominated representative) instead of to a service. The individual manages and purchases their own support needs. These programmes are purely about the method of payment for service. They do not include supplementary support services to assist people to manage these payments. As individualised funding approaches have developed, most programmes now include some other support processes to accompany direct payments (see other sections: *Self-directed Support* and *Management by Host*).

### Example programmes

**Direct Payments (UK).** This programme was introduced in 1997 as part of a response to many years of disability activism aimed at improving the quality of life, community participation and choices available to people with disabilities. While also available to them, the uptake of direct payments by people with mental health conditions was low (Ridley & Jones, 2003). As individualised funding approaches have developed in the United Kingdom other support processes now accompany direct payments.

**For who:** Available to people who qualified for community care services. This includes people with intellectual disabilities, physical disabilities, mental health conditions and older people.

**For what:** Recipients can use a direct payment to purchase personal and respite care or access leisure, education and social opportunities (Warner, 2006).

**Healthbound Aid and Attendance Allowance Programme (US).** For the past 45 years veterans and their surviving spouses have received cash payments instead of home help, personal care or other services (Powers, Sowers, & Singer, 2006).

**For who:** Veterans and their surviving spouses.

**For what:** Recipients can spend the funds on whatever will best meet their health and personal needs.

**Special Services at Home (Canada).** This programme started in 1982, providing families with the option to self-administer their disability supports. Since its early development this programme has evolved into a self-directed support-based approach with facilitators to support people's use of their personal budgets.

**For who:** People with disabilities.

**For what:** Home based care.

## Self-directed support

As individual funding has evolved, supports including planning, budgeting, facilitation and co-ordination have been added to programmes, resulting in these funding mechanisms becoming part of a broader personalised or individualised way of delivering services. Self-directed support uses a mechanism whereby funds can either be

paid directly to the person using services or managed via a host or third party. Additional features aimed at supporting the person's use of this funding include:

- an assessment of personal needs
- transparent resource allocation systems
- personalised support plans.

### Example programmes

**Individual Budgets (UK).** This programme was piloted in England in 13 local authority areas. Individual budgets included a self-assessment of needs by the person using services and the use of a RAS (resource allocation system) that translated the assessment into points which led to a sum of money. People were then helped to develop a personalised support plan outlining the support and services they planned to purchase to meet their needs and achieve their desired outcomes. The money could be deployed as a direct payment to the person or via a third party payment option.

**For who:** People with mental health conditions and/or learning or physical disabilities.

**For what:** A wide range of services including personal care and help with household tasks, and for social, leisure and educational activities (Glendinning et al., 2008).

**Personal Budgets and Personal Health Budgets (UK).** These programmes were introduced in 2009 as a central element of personalised health delivery in England and the transformation of the National Health Service (NHS) (Davidson et al., 2012). Personal budgets work in a similar way to individual budgets. The distinguishing feature is the plan is assessed for any clinical or other risks and then signed off by a panel from the primary care trust.

**For who:** People with mental health conditions, learning or physical disabilities.

**For what:** A wide range of health care services.

**Cash and Counselling and Self-directed Care (US).** These programmes were established in the 1990s to try to improve the traditional Medicaid service by giving people using services greater control over their health care budgets. The programmes work in a similar way to the United Kingdom's personal health budgets. The results from a randomised control trial (RCT) of demonstration sites were positive and Cash and Counselling programmes now operate across the United States (Barczyk & Lincove, 2010; Carlson, Foster, Dale, & Brown, 2007; NRCPS, 2012). The Self-directed Care model includes the following components.

Participants:

- can use cash payments to purchase a wide range of goods and services from providers and suppliers of their own choice
- are supported by counsellors who provided advice and help them to develop management plans
- are able to carry over funds in order to maintain emergency reserves or to purchase equipment
- can pay their personal assistants directly and are also able to use the services of an intermediary to manage employment obligations if they wish; most of the paid caregivers were family members (Doty, 1998).

Similar to the lower rates observed in the Direct Payments programme, implementation of the Self-directed Care model has been slow for people using mental health services. In 2008, less than 400 people were accessing self-directed care in the United States public mental health system (Alakeson, 2008).

**For who:** Older people, adults with disabilities, children with developmental disabilities, people with mental health conditions.

**For what:** Health and social care.

**Local Area Co-ordination (Australia).** This programme began in 1988 in order to increase the self-sufficiency of people with intellectual disabilities (Lord & Hutchison, 2003). The programme also helps people to build their own support networks. In Western Australia all disability funding is individualised and there are no block contracts to service providers (Fisher et al., 2010).

**For who:** People with cognitive, sensory, physical and psychiatric disabilities.

**For what:** A range of support services including respite and personal care, education, leisure, professional, employment, accommodation and equipment (Lord & Hutchison, 2003).

**National Disability Insurance Scheme (NDIS) (Australia).** This is a new national funding scheme for people with disabilities. It is being introduced gradually throughout Australia, with the first stage of the scheme rolled out in South Australia, Tasmania, the Barwon area of Victoria and the Hunter area in New South Wales on 1 July 2013. The Australian Capital Territory and Northern Territory joined the launch in July 2014. Similar to the Local Area Co-ordination approach, planners develop a plan with the funding recipient that is tailored to their goals and aspirations. Significant online support has been developed to assist this scheme's roll out

<http://www.ndis.gov.au/>

**For who:** People with disabilities.

**For what:** Access to mainstream and community supports, to support informal care and fund reasonable and necessary supports, including early intervention.

## Management by Host

Programmes using this individualised funding method often included features of the self-directed support programmes. The main difference is these programmes require a host provider to manage the funds. The host provider is expected to provide specialisation in finance and human resource management. The person using services maintains control over what is purchased and when.

### Example programmes

**Consumer directed family support (US).** Developed in the 1980s, individuals and their families build a plan with a service facilitator and choose which services to purchase. The state acts as the fiscal agent.

**For who:** Families who have relatives with a developmental disability.

**For What:** Common services include respite care, personal assistance, home modifications, assistive devices, employment and/or social and recreational services, therapies and transportation. Many of the paid caregivers are family members.

**Individualised Funding (NZ).** This programme originated in the late 1990s and developed in an ad hoc manner in different parts of the country until it was endorsed by the Ministry of Health in 2003 (Gill, 2012). Funding is paid to a host provider that supports people with disabilities to manage their individualised funding arrangements. People who receive individualised funding have the power to decide who provides the support in their home and how much they are paid, when the support is provided and what type of support is provided (as long as it meets the criteria in the service specification) (Synergia, 2011, p. 13). Host providers deliver coaching and support to their clients.

**For who:** People with disabilities.

**For what:** Personal care and social care.

## Summary

Individualised funding programmes have been employed in countries such as the United States, Canada, Australia and the United Kingdom since the 1980s to fund health, personal and social care. Programmes either pay the funds directly to the person using services or via a host organisation specialising in finance and human resource management. Regardless of the payment method, the focus is on ensuring the person using services maintains control over what is purchased and when. Programmes tend to offer support to help people use their funding effectively. This includes needs assessment and the development of personal plans. Many programmes include older people and people experiencing mental health problems, as well as people with disabilities. However, there has been a lower uptake of the individualised funding models by people who experience mental health problems.

## 5.0 Evidence of outcomes

There are well-designed evaluation studies from the United Kingdom and the United States providing evidence about the outcomes associated with individualised funding approaches for different groups of service users, carers and organisations. Most research to date has been conducted on the use of individualised funding mechanisms for people with physical and/or intellectual disabilities. The findings of this research are presented in this section according to the key outcomes that have been studied. Firstly the benefits of individualised funding are summarised. Factors that may result in negative outcomes are then identified.

In both the United Kingdom and the United States the uptake of individualised funding by people using mental health services has been slow compared to people with other health conditions. However, the research findings are promising for people experiencing mental health problems.

### Improved service delivery

An early study of the United Kingdom's Direct Payments system found that recipients experienced greater consistency and reliability of support people and much improved service delivery (Stainton & Boyce, 2004). A longitudinal study of the Consumer-directed Family Support Programme in the United States compared

outcomes for a random sample of families who had been in the programme for nine years with a random sample of families on the waiting list for the programme (Caldwell & Heller, 2007). The study found that families on the programme had significantly fewer unmet needs compared to families on the waiting list. Programme families were significantly more satisfied with the services they received compared to the control group.

Similar results were noted in the randomised controlled trial that accompanied the Cash and Counselling demonstration programmes in Arkansas, New Jersey and Florida. At nine months follow-up participants in the treatment group (who received the intervention) were more likely to receive paid care, had greater satisfaction with their care and had fewer unmet needs than control group members (Carlson et al., 2007). The take home message from one study was that if a person was mentally ill they were better off in the Cash and Counselling programme rather than in traditional treatment (Shen et al., 2008, p. 99).

### **Better relationships with service providers**

One of the few longitudinal studies of the United Kingdom's Direct Payments system reported that an important benefit was the enjoyment recipients derived from the company of personal assistants (who had been chosen by the direct payment recipient) (Arksey & Baxter, 2012). In an in-depth study with people using mental health services participants talked about being able to recruit support workers with whom they felt compatible, and reported they felt less dependent on informal sources of support such as family members (Spandler & Vick, 2006).

### **Improvements in emotional wellbeing and quality of life**

An independent evaluation was run alongside the introduction of personal health budgets in the United Kingdom. The evaluation compared outcomes associated with conventional service delivery with those associated with the receipt of a personal health budget (Forder et al., 2012). Overall, after 12 months the evaluation found the use of a personal health budget (of more than £1000) was associated with a significant improvement in care-related quality of life and psychological wellbeing. Personal health budgets did not appear to have a significant impact on health status per se over the 12 month follow-up (Forder et al., 2012). Therefore, in the short-term the use of a personal health budget was associated with an improved sense of wellbeing rather than improvements in the actual health condition that a person lived with.

Qualitative interviews included in the evaluation found that:

People given a personal health budget specifically for a mental health condition reported improvements in wellbeing, stress levels, managing their health condition on a day-to-day basis, their use of emergency services for crisis episodes, and in preparing for episodes of ill health. (Davidson et al., 2012:6)

Personal health budgets were described as life-changing by some of the interviewees (Davidson et al., 2012). Some people were surprised at how good they felt when they were in a position to manage their own health. Respondents reported an increase in motivation to do more for themselves and to increase their wellbeing, for example by doing more exercise. Others reported increased confidence and a better social life. Most of the budget holders in the qualitative study reported a positive impact on their health (Davidson et al., 2012).

In Florida, a study that followed 106 people using mental health services across a 19-month period showed evidence of positive outcomes from the use of self-directed funding. Participants spent more days in community rather than inpatient settings in the year after joining the programme, had higher functional scores, and a larger proportion were in training and paid employment (Cook et al., 2008). Participants who were part of the self-directed care programme were making greater use of routine care and supported employment, and significantly less use of crisis stabilisation and crisis support compared to non-participants (Mental Health Program Office, 2007 in Alakeson, 2010, p. 7).

### Increased flexibility and self-determinism

Evaluations of all three types of individual funding rolled out in the United Kingdom (Direct Payments, Individual Budgets and Personal Budgets) reported that recipients valued the flexibility and control over when and where care was provided. Budget holders were able to choose from a wider range of services, for example gym memberships, physiotherapy and alternative therapies. They could also choose between different carers and take part in everyday activities that were unrelated to their mental health status. As a result of these factors people were more able to organise support around their own lives rather than organising their lives around the support that was available to them (Spandler & Vick, 2006). Budget holders could also choose when care was provided and the timing of appointments (Davidson et al., 2012). These outcomes were consistently experienced across user groups, including people who experience mental health conditions.

The evaluation of Individualised Funding in New Zealand to date has found that people receiving it appreciated the greater control and flexibility compared to traditional service provision (Synergia, 2011). There was support to expand the services that can be covered by individual funding (which at the time included only Home and Community Support Services).

### Development of new skills

People in the United Kingdom's Direct Payment evaluation studies also reported the development of new skills through the experience of managing their direct payment, such as improved interpersonal and supervisory skills, accounting and money management (Arksey & Baxter, 2012).

### Carers<sup>4</sup>

Research on carers' experiences of individual budgets and personal budgets found positive impacts. Moran et al. (2012) explored the impact of individual budgets on the carers of people with disabilities, older people and people with mental health conditions. Carers in the Individualised Funding group were significantly more likely to report being fully occupied in activities of their choice compared to those in the control group. They were more likely to report feeling in control of their daily lives and able to provide the kind of support they wanted to, but the difference was not significant (Moran et al., 2012).

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<sup>4</sup> The term carer is used in the United Kingdom and Australia. In New Zealand the equivalent term is families and whanau.

Carers reported that the benefits of Individual Budgets were, “greater choice, control and use of time; improved quality of life for the service user; and enhanced family relationships” (Moran et al., 2012, p. 472). Other benefits included: extra free time to visit friends and relatives and engage in other activities; less feelings of guilt when taking time for self; and more quality time with the service user or other family members (Moran et al., 2012). Furthermore, people using services reported improvements in emotional wellbeing because they knew the demands on their partners and/or family members, particularly mothers, had decreased (Arksey & Baxter, 2012).

Some carers reported negative experiences with Individual Budgets. The time spent managing the Individual Budget and co-ordinating support had a negative impact on one carer’s relationship with their partner. Another person reported poor mental health due to the stress of setting up an Individual Budget. However, both outcomes were seen as temporary (Moran et al., 2012).

## **Barriers and challenges identified through the evaluation studies**

Individualised funding arrangements do not benefit all people and in a few cases created additional stress. Evaluation studies have identified factors that create barriers to the uptake of individualised funding arrangements, or that contribute towards negative experiences or outcomes for people using services.

### **Attitudes of professionals**

In the United Kingdom, some mental health professionals were acting as gatekeepers to direct payments and only offering this option to particular ‘types’ of service users; for example those with a stable lifestyle or with a significant other who could help them manage payments (Spandler & Vick, 2006). Widespread difficulties were reported in relation to implementing individual budgets with people who experience mental health conditions because of the alleged paternalistic and protective attitudes of frontline staff and difficulties in working with NHS partners in what were often jointly funded and managed services (Glendinning et al., 2008).

### **Inequitable access**

Evaluations of the early Direct Payments programme in the United Kingdom found that service users who were able to clearly express their needs were also more likely to be offered a direct payment. The evaluation data showed that only small numbers of people from black and ethnic minority groups were using direct payments (Spandler & Vick, 2006). Similarly, an in-depth qualitative study with disabled people and their families in Queensland found that individual funding mechanisms were unable to address fundamental problems with access to services. This study reported that the limited availability of funding meant that people using services, and in particular indigenous people, were not registering their need for services because they believed they would never qualify for an individual funding package (Spall, McDonald, & Zetlin, 2005).

### **Difficulties with the new approach**

In the United Kingdom, people using mental health services and physically disabled people were the most satisfied with their individual budget; older people had the lowest levels of satisfaction. Older people with an individual budget reported lower psychological wellbeing possibly because they felt management of the budget was a burden (Glendinning et al., 2008).

Most personal health budget holders were comfortable making choices about their health but some found making the 'right' choice was difficult and wanted more professional advice (Davidson et al., 2012). Some people receiving direct payments experienced challenges with employing personal assistants and negotiating complex tasks (Spandler & Vick, 2006). Some found it challenging to exercise choice and to take up control after years of mental distress and previous experiences within the mental health system (Spandler & Vick, 2006).

A small minority did not believe the personal budget had a positive impact on their health. These tended to be people who didn't understand the personal health budgets or had problems with implementation. Some budget holders felt their choices were limited due to the lack of services in their area or because their choices were refused by the panel which approved their budget (Davidson et al., 2012). Both carers and budget holders could experience enormous stress when local authorities could not agree on what was to be funded and/or required different accountability systems (Davidson et al., 2012).

### Limited funding

The Direct Payments evaluation identified resource restrictions that meant insufficient funds were set aside for set-up costs and for contingency in case of an emergency (Spandler & Vick, 2006).

In Australia it was reported in 2010 that the average management cost for an individualised funding package was 14 per cent and there were differing opinions among officials about whether individualised funding had increased costs overall. Some individualised funding packages were not large enough to cover all of the supports that the person needed. In these cases, informal supports or service providers were covering the additional costs or the person did not get the support they needed (Fisher et al., 2010). In some cases service providers reported that management demands had decreased as a result of individual funding when people using services had taken over the management of their own care. Other providers reported a greater workload as a result of the increased administration associated with managing multiple individual contracts versus a single block contract (Fisher et al., 2010). Laragy & Ottmann (2011) found that insufficient financial resources were restricting the implementation of an individualised funding programme in Victoria, and that there were not enough funds available to meet recipients' needs.

## Summary

In general, individualised funding outcomes for people using services and their family/carers are positive. Most people report increased ability and flexibility to choose a wider range of services to address their health needs. Increased satisfaction with service delivery and fewer unmet needs have been noted in evaluation studies of individualised funding mechanisms. Recipients have reported better psychological wellbeing, greater motivation and confidence. One study of the use of self-directed funding by people who experience mental health conditions found that participants were making greater use of routine care and supported employment and significantly less use of crisis stabilisation and crisis support compared to non-participants (Mental Health Program Office, 2007 in Alakeson, 2010, p. 7). Participants also spent more days in the community rather than inpatient settings in the year after joining the programme, had higher functional scores and a larger proportion were in training and paid employment (Cook, Russell, Grey, & Jonikas, 2008).

However, most evaluation studies also identified a range of factors that negatively impacted on outcomes. These included paternalistic attitudes of staff limiting people's access to individualised funding and lower access rates for more 'at risk' population groups such as black and ethnic minority groups in the United Kingdom, and indigenous people in Australia. Some service users, particularly older people, were dissatisfied with the new approach. They did not want to manage their own budget, found decision-making regarding possible care difficult and needed more professional support. Some people reported heightened stress when funding panels refused their choices. Finally, insufficient resourcing and administrative support restricted the implementation of individualised funding programmes in some instances.

If direct payments are to be a viable option for many mental health service users, a robust support structure needs to be developed to enable service users to access and use them, and that the implementation of direct payments needs to be underpinned by the principles and philosophy of the independent living movement (Spandler & Vick, 2006, p. 113).

It is also important to acknowledge that the evaluation studies focused on the health and wellbeing outcomes of individual health and social care recipients who are eligible to receive services. Most studies were not designed to examine the impacts of introducing individualised funding mechanisms on the overall health and social care system. It is unclear what impact the widespread use of individualised funding will have on the overall availability of health and social care support.

## 6.0 Implications for service and workforce development

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There is a growing evidence base from the United Kingdom and the United States about the workforce development needs associated with the implementation of self-directed funding and planning mechanisms.

Several qualitative studies from different countries provide rich, detailed information about what works and what doesn't when implementing individualised funding approaches.

## Information

Access to good quality information is essential for the effective implementation of individualised funding approaches (Heslop & Williams, 2009; Laragy & Ottmann, 2011). Information and advice was greatly appreciated by personal budget holders in the United Kingdom pilot sites. At the beginning of the process potential recipients need to know that individualised funding options exist and that they are eligible for them. Active outreach to marginalised groups and working through trusted networks to explain how personal budgets can help to set up support that is in tune with people's relationships and cultural needs was seen as important (Newbronner et al., 2011).

Information should be provided both verbally and in writing, and people also need time to absorb and understand the information provided. There was evidence from the evaluation of personal health budgets that some people did not use all their budgets due to lack of information (Davidson et al., 2012). Brokers need to be proactive about providing information as some people did not feel comfortable asking a lot of questions (Davidson et al., 2012). The NDIS in Australia has developed a wide variety of resources to step recipients through the process (<http://www.ndis.gov.au>).

Limited access to individualised funding programmes may have the potential to exacerbate existing inequities. For example in Queensland researchers found that some people using services, in particular indigenous people, were not registering their needs because of the perception they would never qualify for services due to existing high levels of unmet need (Spall et al., 2005).

Case studies about the experience of mental health and older budget holders found that access to clinical advice about the suitability of a particular service or a piece of equipment early on in the planning process was helpful for some interviewees (Newbronner et al., 2011). Involving clinicians early on in the support planning process rather than at the plan approval stage was seen as important because people became disappointed and frustrated when their plans were turned down. Also budget holders wanted input and advice from professionals (Davidson et al., 2012).

Clear guidelines about what budgets can be used for and transparent decision-making processes are useful.

...clear information about the size of the budget, how the amount has been arrived at, and the fact that it is a personalised allocation are all fundamental to the principles of personal budgets in both health and social care and need to underpin any longer-term roll-out of the programme. (Davidson et al., 2012, p. 51)

A nine month evaluation of personal health budgets also found that it was important to discuss management options as part of review processes, as people may become more confident about managing their budget and may wish to move to direct payment options (Davidson et al., 2012).

## Good quality, ongoing support

Case studies about the use of personal health budgets by mental health service users and older people found that many budget holders were able to manage their budget with little or no support, but for some people support from a third party was crucial (Newbrunner et al., 2011). The evaluation of self-directed care in the United States found the option to have a representative (such as a friend or a relative) to help service users who were unable or not wanting to manage all-cash (direct payment) options was a very important feature of the programme that helped people with mental health conditions to successfully implement the cash option (Shen et al., 2008).

It is important that support continues over time and is not only available during the set-up phase of an individualised funding arrangement. In their longitudinal study of the use of direct payments Arksey & Baxter (2012) found that the needs and circumstances of direct payment recipients changed over time and it was useful to be able to access advice and support along the way when questions or issues arose. In case studies about personal budgets the level of support required by budget holders was closely linked to the monitoring systems that were in place in a particular site. Less support was required for less onerous accountability requirements (Newbrunner et al., 2011).

Personal budget holders needed quick and easy access to high quality support and brokerage services (Newbrunner et al., 2011). Coyle (2011) suggests the co-production of goals by the person using services and support person is particularly valuable. Person-centred planning and thinking tools, and outcomes-focused support plans alongside staff training are all required for implementing personal budgets in mental health services (Coyle, 2011).

It is important for personal budget holders to be able to call on back-up for support when managing employment relations, for example if someone doesn't have confidence to fire an unsuitable carer (Davidson et al., 2012). Informal carers also valued support with recruiting paid carers (Davidson et al., 2012). Regular contact from the personal health budget lead officer was helpful for personal health budget holders. People were disappointed when there had been little contact. Regular contact also helped with motivation to continue activities, for example attending the gym (Davidson et al., 2012). Case studies about personal health budget use by people accessing mental health services and older people found that staff needed support training and sufficient time to work with budget holders (Newbrunner et al., 2011). The need to strengthen risk assessment and risk management as part of the support planning process was also identified as an area for further development, particularly with a greater use of self-assessment tools (Newbrunner et al., 2011).

## Knowledge and attitudes

The evaluation of the Individual Budget pilot programme found that most sites reported major challenges in changing the attitudes and culture of care managers and other staff, regardless of which user groups were being offered Individual Budgets. However, particular resistance and aversion to risk was reported among some teams working with mental health service users and older people (Glendinning et al., 2008). Managing cultural change, in particular acknowledging and addressing any concerns of frontline staff, was found to be an important part of the implementation phase of the personal health budgets in the United Kingdom. Evaluators suggest that

negative attitudes of organisational representatives may have resulted in poorer outcomes for budget holders in some areas (along with less choice and flexibility in the model implemented) (Forder et al., 2012).

Workforce and service capability have been identified as barriers to the use of self-directed care approaches for people using mental health services in the United States. This was because many mental health professionals have backgrounds in therapeutic models, rather than service co-ordination (Powers et al., 2006). As a result services and professionals may lack the knowledge, skills and networks required to promote the service user's capacity for self-direction as a way to support recovery. In the United States, mental health service user leaders are working to expand empowerment models and person-directed services (Powers et al., 2006).

Stigma and discrimination also appear to be barriers. When commenting on the slow progress made with person-directed services for individuals with mental health conditions, Powers et al. note that:

The evolution toward person-direction in mental health conflicts with traditional stereotypes of the inability or unwillingness of people with psychiatric disabilities to manage their lives. Self-determination is viewed as a privilege tied to adherence, rather than as a fundamental human right. (2006, p. 67)

The evaluation of personal budgets found a positive attitude from the support broker at the start of the support planning process encouraged a positive outlook. This was in contrast to other interactions with health, welfare or benefit services where the focus tended to be on the negative aspects of ill-health or disability (Davidson et al., 2012).

## Working conditions

Various concerns have been expressed about the use of individualised funding approaches and potential impacts on the working conditions of support workers. These include the negative impacts on personal assistants such as low pay, poor working conditions and limited bargaining power (Hall, 2011). However, several studies report positive working relationships between the personal assistants and support workers employed by direct payment recipients (Coyle, 2011; Spandler, 2004). Poor working conditions may be a result of under-funding of support work in general rather than as a result of direct payments specifically. However, there is evidence from Queensland that direct payment recipients were negotiating lower hourly rates with support workers in order to address reductions in their levels of care (Spall et al., 2005).

In most countries individual funding arrangements enable people using services to employ family members, and this may be one of the main reasons why people opt for direct payments (Arksey & Baxter, 2012). In most cases this seemed to work well. However, there is a need to think about the long-term implications of employing family members at the outset (Arksey & Baxter, 2012). For example, a family member may rely on the income from the person using services and this can create challenges for the relationship if circumstances change and their services are no longer required.

## Systems and infrastructure

Kendrick argues that, “when people are offered the chance to negotiate the design, funding and operation of their service arrangement, it transforms services from being ‘set’ or ‘fixed’ models and makes them much more flexible and responsive to the specific requirements of the end user of the eventual service arrangement” (2011, p. 64). But this does not mean that the service they end up with will be entirely satisfactory; it will be as good as what the person is able to negotiate from the service options available at that time. Therefore, despite comparative advantages over traditional service delivery, self-directed approaches still require the availability of high quality, best practice interventions.

Newbrunner et al. (2011) found the supply of services was not keeping up with the preferences of personal budget holders, particularly mental health service users, even in areas where direct payments had been in place for some time. The researchers concluded there is a need for local authorities and trusts to actively create provider services that meet the preferences of budget holders. In the qualitative study of personal budget holders by Davidson et al. (2012) some people reported their desired choices had been turned down because the services they wished to access were not available in their area or because the panel had refused their choices.

The flexibility of service format and delivery created by self-directed planning can challenge services, “...however, to meet the needs of people who challenge services because of their complex needs, personalised approaches seem better suited as opposed to traditionally commissioned service responses” (Coyle, 2011, p. 802).

Factors that support the implementation of successful system and infrastructure changes necessary to support individualised funding models include: strong project leadership and a clear action plan; training for staff in specialist services; development of a self-assessment tool; establishment of a resource allocation system; working with all sectors; engaging people and families; and partnerships with lead agencies.

In the United States, health practitioner acts (for example, state nursing acts) have been identified as a barrier to the expansion of individualised funding (Powers et al., 2006). This is because the acts limit a nurse’s ability to delegate some clinical tasks to unlicensed personnel. This, presumably, restricts the ability of people using services to choose who delivers particular supports as part of their recovery plans. Similar obstacles may also exist in the New Zealand context.

The main barriers to the implementation of Self-directed Care for mental health service users were, “the absence of a strong evidence base, uncertainty over the appropriate scope of self-directed care and the absence of a sustainable source of funding” (Alakeson, 2008, p. 792). Medicaid in the United States was established to fund services but many of the purchases needed by services users included goods and support with employment or housing, which are not covered by Medicaid.

The take-home message from the United Kingdom experience appears to be that although there have been challenges with the implementation of personalised approaches, few people would choose to return to traditional models of care delivery. As Alakeson argues:

Personal health budgets require significant culture change in the NHS to succeed but many of the pilot sites have demonstrated that this is possible and few staff say that they would go back to the old ways of doing things now that they have worked with Personal Health Budgets and have been able to really put people at the centre of decisions about their care (2012, p.19).

The primary difference between the United Kingdom and New Zealand is that the United Kingdom has a national policy framework for the implementation of personalisation (along with individualised funding mechanisms) across the health and social sectors, whereas New Zealand does not.

## Summary

Evaluations of individualised funding programmes have revealed a number of features important for ensuring successful implementation. Some of these are summarised here:

### Information

- Provision of good information (verbal and in writing) to ensure people know what funding mechanisms exist and for what they are eligible.
- Active outreach to socially isolated people or marginalised groups who may not engage with these funding models.
- Early access to clinical advice regarding suitability of services also helps avoid people being disappointed if plans are later turned down.
- Transparent and simple decision making processes regarding resource allocation and what funding covers.

### Support people

- Availability of third party support to manage funding and employment relations.
- Option to use a representative (eg friend or relative) to help manage funding.
- Ongoing support, with more intensive assistance provided during the set-up phase.
- Regular contact from the support person.
- The right attitudes and skills among staff, including the willingness to pass control to the service user to self-determine, the ability to work with perceived risk, and a focus on service co-ordination rather than therapeutic work.

### Systems

- A carefully planned approach to implementing new funding mechanisms.
- Assurance of adequate levels of funding to sustain the new model, including administration costs.
- Policy framework to guide and support individual funding and personalisation.
- An active approach to create provider services that meet the preferences of budget holders.
- The creation of employment guidelines to protect support workers, eg minimum wages and working condition standards.
- Consider the implications for employing family members, eg potential for financial dependence.

## 7.0 Discussion

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Individualised funding is an extension of market mechanisms aimed at using market-related competition to reduce provider power, drive down costs and improve service quality and responsiveness (Glendinning, 2012). These programmes move away from traditional block funding models in which providers are contracted to deliver services to individuals, to models where people can negotiate the design, funding and operation of their service arrangement. “This transforms services from being ‘set’ or ‘fixed’ models and makes them much more flexible and responsive to the specific requirements of the end user” (Kendrick, 2012, p.64).

Evidence to date shows people with mental health conditions and their families have experienced positive outcomes from individualised funding arrangements compared to traditional forms of service delivery (Alakeson, 2008; Davidson et al., 2012; Forder et al., 2012; Stainton & Boyce, 2004). There have been no adverse effects in terms of health or safety. Individualised funding also costs about the same as traditional forms of service delivery. Based on the evidence available to date it appears that, if implemented well and with sufficient resource, individualised funding is likely to benefit people using mental health services by enabling greater flexibility, choice and control over service delivery.

However, most studies have been designed to evaluate the effectiveness of the funding programme itself; they have not been designed to examine the impacts of introducing individualised funding mechanisms on the overall health and social care system. It is unclear what impact the widespread use of individualised funding will have on the overall availability of health and social care support. This is likely to be a source of uncertainty and anxiety for current New Zealand health services that are contemplating implementing individualised funding. Furthermore, while overall evaluation studies tend to favour the continued implementation of individualised funding models, many challenges have been encountered that need careful considering when assessing the scope for the application of individualised funding mechanisms within New Zealand’s mental health and addiction sector.

Some key considerations include:

### Acknowledging and managing uncertainty for service providers

Individualised funding involves transfer of funding away from providers through service contracts to more indirect funding through a multitude of arrangements with individuals (or their representatives) who hold their own funds. While again I state that I fully support and embrace the concept of disabled people being in control of their lives, I do feel incredibly anxious about the impact of this on the quality of services that disabled people will be able to purchase, the nature of what those services might be, and how the “market” will adjust to the provision of these services (Matthews, 2013).

This quote was provided by David Matthews, chief executive of CCS Disability Action, one of New Zealand’s largest disability providers, as part of his address to the New Zealand Disability Support Network AGM Forum on the new models for individualised funding of disabilities services. He questioned what would happen to the employment market and predicted that changes could mean more staff will have to be employed on a temporary

or casual basis in response to fluidity of demand. He cautioned people not to see Individualised Funding as a, “panacea to the challenges that face disabled people and their families today. Having control over funds does not translate into removing barriers to participation or changing attitudes or creating a more inclusive New Zealand” (Matthews, 2013).

### Stakeholder driven policy development and careful planning

If individualised funding was being seriously considered it would be very important to include stakeholders (service users, families and whānau, providers and staff) in related planning and policy development from the outset, given uncertainty about impacts on the overall supply and quality of health and social support. Careful policy development, driven by stakeholder input, is an important initial steps to ensure those implementing the new funding mechanisms have clear information about why the changes are being considered, what they are and how they would be successfully rolled out within the mental health and addiction sector. It would be important to complete comprehensive sector consultation and national policy and implementation plan development before demonstration sites were introduced for evaluation.

### Sustainable funding

A fundamental role of policy and planning development would be ensuring sufficient ongoing funding to enable the sustainability and durability of any new funding model. Individualised funding models require significant administrative investment, particularly upfront. In both Australia and New Zealand costs associated with individualised funding were underestimated, forcing host agencies to adopt unsustainable service delivery methods (Fisher et al., 2010; Laragy & Ottmann, 2011; Synergia, 2011).

### Paradigm shifts for the workforce

Some evaluation studies of individualised funding reported resistance and aversion to risk among teams working with people using mental health services or with older people. Staff may be experienced managing complex situations on behalf of service users and find it challenging to hand over control to the person accessing services. It would, therefore, be important to acknowledge and address any concerns of frontline staff during policy and planning development, as well as in the initial phases of implementation.

In the past decade New Zealand services and staff have focused on working with strengths-based and recovery-focused models of care. Although New Zealand is well behind other countries with respect to the use of individual funding approaches in mental health, it is possible the workforce is better equipped to implement self-direction mechanisms compared to other jurisdictions.

Packages of Care currently available in both primary and secondary care are funding mechanisms aimed at tailoring support to meet individual needs. They provide a pool of money held by the service that can be accessed as a result of needs assessment, and be spent in a flexible way to meet the identified needs of the person using services. There is variability in how much involvement this person has in deciding what services to include in the package. However this funding mechanism is probably the closest to individualised funding that New Zealand’s current mental health service provides and could perhaps be adapted to become a ‘self-directed support’ individualised funding mechanism.

## Learn from experiences with individualised funding in the disability sector

It will be important to closely consider how individualised funding has been implemented within New Zealand's disability sector. In particular, progress implementing the New Models in Christchurch, the Western Bay of Plenty and Auckland and Hamilton could inform further development of national approaches to individualised funding within New Zealand. Internationally, individualised funding mechanisms often cover a range of social and health services and are available to people using those services, including disability, mental health and older persons.

Given New Zealand's smaller population size compared with other countries that have implemented individualised funding, setting up different individualised funding mechanisms for disability and mental health services could potentially create confusion and fragmentation as a result of differences in systems, use of funding or criteria. Combining these funding streams could lead to economies of scale and support integration across social services. This is a major goal of the new Whānau Ora policy. Current evaluation of the *Enabling Good Lives* demonstration in Christchurch, where funding from the Ministries of Health, Social Development and Education is pooled and allocated as individualised funding for a variety of services for people with disabilities, will provide valuable information about what is possible from a cross-sector perspective.

## Where to next?

1. Assess what can be learned and applied to mental health and addiction services in New Zealand through the implementation and evaluation of individualised funding pilots for the disability sector.
2. Consider forming a community of interest collaborative to further review the United Kingdom's paths to personalisation and the ongoing Australian and American implementation of individualised funding programmes to identify relevance to the New Zealand context. This group could comprise service user leaders, health and social service funding experts, Ministry of Health representation and sector representation. The focus would be on thinking about the application of individualised funding to New Zealand's mental health and addiction sector. Crucial areas for discussion could include whether:
  - adapting current Packages of Care offers an avenue for implementing individualised funding
  - introducing individualised funding addresses funding concerns for NGOs that have recently been emphasised (Platform Trust, 2014)
  - given the strong recovery and person-centred approach already embedded in services, is this funding mechanism the best way to continue to advance the personalisation movement in New Zealand
  - cross-sector individualised funding mechanisms are viable, and how these might fit with Whānau Ora policy.
3. Identify potential strategies for testing the funding mechanism on a small scale and within discrete timeframes, to provide case studies for application in New Zealand mental health and addiction settings. For example, three small pilots of 60 people (of different population groups) could run in an urban, provincial and rural context.

4. Information from the community of interest collaborative group and small-scale pilots could assist the Ministry of Health to consider whether this should be a part of funding and planning policy development for the mental health and addiction sector in New Zealand.

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# Appendix A: Further information on international individualised funding programmes

**Table 2: International programmes: programme development**

Country	Programme Development	Primary motivations	Eligibility	Use
<b>England</b>	Individual (social care) budgets (IB) piloted 2005-07 and subsequently rolled out. Personal health budgets (PHB) piloted 2009- 12, with plans for further rollout.	Part of the wider government agenda to promote choice, autonomy and personalisation of health and social care.	People with long-term care needs. Plan to have all council-funded service users and carers on personal budgets by approx. 2015. PHBs piloted mainly for individuals with a range of long term conditions.	IBs usually used to purchase mainstream services, employ personal assistants (PAs) and pay for leisure activities; sometimes used for wide range of one-off purchases. PHBs used to employ PAs or purchase goods or services that contribute to health goals in personal plan. Not to pay for GP services or emergency health services.
<b>Belgium</b>	Personal Assistance Budget (PAB) introduced 1997 in Flanders region. Personal budget (PGB) piloted in 2008.	To extend autonomy, freedom of choice, and help prevent unnecessary care home places.	People with any major long-term restriction (disability), as long as they apply before they are 65 years old.	PAB can be used to employ a PA. PGB can be used to employ PAs and purchase services from choice of providers. At least 95% of the budget must be used for the payment of salaries.
<b>France</b>	Cash for care piloted in 1994-5; made national in 1997. Expanded in 2002.	Reduce burden on care homes. Increase individual's independence and autonomy.	L'allocation personnalisée à l'autonomie (APA): over 60's with care needs from physical disability or mental illness.	Used to fund specific care packages, and/or to employ a PA.
<b>Germany</b>	Cash payments for care introduced 1995 and extended in 2008 (to include mental illness). Personal budgets piloted 2004-8, with intention to rollout stated in 2008.	Cash payments – cost saving. PBs – increase choice; increase competition; reduce nursing home admission rates; cost saving.	All people 'frequently or to a considerable extent' in need of care because of physical, psychological or mental illness or disability during their daily activities, or for a period of at least 6 months.	To purchase transport, nursing, assistance at workplace, leisure activities, therapy costs, support equipment, etc, and services provided by health insurance/care insurance, when needed regularly and on a supplementary basis. GP costs cannot be paid for.
<b>The Netherlands</b>	Personal budgets introduced 1996. Scope and eligibility significantly scaled back from 2012.	Address limitations in current system; stimulate market to better meet	People with disability, chronic illness, psychiatric problems or age-related impairments. By 2014, only those who would	To buy personal care for help with daily living; nursing care; support services (e.g. day-time activities), and short stay and respite care for short holidays/weekends.

Country	Programme Development	Primary motivations	Eligibility	Use
		needs; promote choice and control.	otherwise have to move into care or nursing home will be able to keep/apply for a budget.	Not allowed for alternative treatments, medical treatments, or treatment by allied health professionals.
<b>Austria</b>	Cash payments introduced in 1993. Covers home care and institutional care, and covers whole population. All state support for home care is through cash allowances.	Promote autonomy, choice and market-driven developments	Those over 3 in need of long-term care (requiring 50+ hours of care per month), due to physical disabilities and/or mental illness. Medical assessment of need conducted.	Largely used to compensate family members for informal care.
<b>US</b>	Cash and counselling piloted 1998-2002. Some states developed self-directed care for adults with serious mental health conditions. In 2012, majority of states offer consumer direction in Medicaid programs. Some allow for consumer direction in non-Medicaid elderly assistance programs and for some veterans services.	Expand options for home and community based long-term care.	Older people and people with disabilities in need of home and community-based long-term care. Some programmes support individuals with serious mental health problems.	Varies between programmes. Can employ PAs and purchase care-related services and goods. States control the range of services and equipment that can be purchased. Some programmes include purchasing of some elements of health care such as skilled nursing and long-term rehabilitative therapies. Some include clinical recovery services for people with serious mental health conditions.
<b>Canada</b>	1997, individualised funding pilot (IQOL) launched in Toronto. Rolled out from 2000. Similar initiatives in other provinces.	Promote home and community based living.	People with developmental disabilities in need of support.	To purchase disability-related supports. Not for costs related to medical supplies or equipment, home renovations, electronic equipment or leisure, recreation & personal/family costs.
<b>Australia</b>	Individual funding first introduced 1988. Small scale projects set up in a number of states. 2010 Government pilot of consumer directed care (CDC) programme for older people.	Promote choice and control; promote more flexible and responsive services.	People with disabilities in need of support. CDC programme specifically for older people in need of support.	CDC programme: includes purchasing of personal assistance, nutrition, home help, transport and emotional support.
<b>Finland</b>	Home care service vouchers, introduced late 1990s. Proposal announced in 2009 to extend vouchers to all municipal health & social services.	Promote choice; stimulate private sector provision	Older people with assessed care needs. Plans to extend eligibility further.	Purchasing of care (and, post 2009, health) services from specified providers.

Country	Programme Development	Primary motivations	Eligibility	Use
Sweden	Assistance allowances introduced by law 1993.	Promote choice, control, and personalisation	Those with major difficulties in daily life (needing more than 20 hours assistance per week).	No restrictions, except it cannot cover medical treatment. Generally used to employ PAs.

Source: Centre for Health Services Studies, 2013, p. 10-12

**Table3: International programmes: programme features**

Country	Can employ family members?	Dependent on a personalised care plan?	Types of support available	Budget setting	Budget deployment	Financial reporting
England	No	Yes	Mixed: health professional (or other in-house), community, peer support.	Locally determined processes. Often use 'indicative budgets' based on best guesses, and/or previous care packages.	Notional budgets, budgets delegated to third parties, or direct payments.	Detailed financial accounting.
Belgium	Yes	Yes (set of assessment tools)	Associations of budget holders are supported and subsidised by the Flemish Fund.	Assessment by multi-disciplinary teams using needs assessment tools with parameters that correspond with nationally fixed budget levels.	Notional budgets (budgets with a drawing right) or direct payments. The choice is not always that of the individual.	Budget holders have to account for all expenditures
France	Yes (not spouse)	Yes (defined by professionals)	No formal support	Level of dependence and disposable income used to determine budget according to nationally set tariffs.	Direct payment, or paid directly to the service provider.	Use of budgets strictly controlled and users must justify expenditure.
Germany	No	Yes	Local authorities provide help with management of the budget.	Determined by a (needs-based) assessment. Equal to cost of alternative agency-directed care.	Direct payment or notional budget.	Accounting always necessary but varies according to locality. Some areas have very strict procedures; others less so.
The Netherlands	Yes (with contract)	Yes (introduced 2012)	Peer support; user-led organisations; independent brokers. A 'social insurance bank' provides free services for salary administration.	Following needs assessment, care levels are categorised; care liaison office officially determines the actual budget according to nationally fixed tariffs (based on averages). Always about 25% lower than equivalent agency-directed service costs.	Direct payment with options to outsource some aspects (e.g. salary administration), delegate in full to 3 <sup>rd</sup> party organisation, or to establish a foundation (e.g. pooling budgets to collectively engage	Budget holders must submit periodic costings of how they spent (all but a tiny percentage of) the money. Costly budget holders are assigned to use a fiscal agent.

Country	Can employ family members?	Dependent on a personalised care plan?	Types of support available	Budget setting	Budget deployment	Financial reporting
					assistants).	
<b>Austria</b>	Yes	No	No formal support.	Monthly budgets calculated based on seven levels of need for care (expressed in terms of hours).	Direct payment. Where individual is cognitively impaired, someone is appointed to manage the budget.	None
<b>US</b>	Sometimes	Yes	Independent professional brokers	Assessment made of number of care hours needed. Budget calculated using number of care hours and cost of care for	Cash and counseling pilot used flexible vouchers. Some states provide cash directly, others use	Budget holders must account for almost all their expenditure.
<b>Canada (IQOL)</b>	No	Yes	Independent professional brokers; community resource facilitators; network facilitators.	Budget based on goal planning. Plans/budgets highly individualised, within a set maximum.	No direct payments. Funds managed by an agency.	Individuals submit 'purchase of service' reports, along with invoices, bi-weekly or monthly.
<b>Australia (CDC)</b>	No	Yes	Care professionals (providers)	Local sites developed budgeting templates. In most cases, providers set budgets to match the subsidy income paid to the provider for that client (even though subsidy funds are often pooled for standard packaged care).	No direct payments. Provider always holds the budget.	Limited responsibilities for individuals.
<b>Finland</b>	No	Yes	Support from municipal care planning team.	Based on needs assessment, reviewed every 6 months.	Service vouchers, given directly to the individual.	No information available.
<b>Sweden</b>	No	-	Individuals can outsource employment responsibilities to the municipality, a cooperative society or a private organisation. Peer support groups and cooperatives assist with various other roles.	Evaluation of needs, with individual's family situation taken into account. Budget is not means-tested.	Direct payment, unless beneficiary specifically requests that it be paid to the chosen service provider.	Budget holder sends simple monthly report of the hours of work carried out by the assistants.

Source: Centre for Health Services Studies, 2013, p. 10-12

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