**MINISTRY OF SOCIAL DEVELOPMENT**
TE MANATŪ WHAKAHIATO ORA

# Evidence Brief

# Individual disability support services

## 2012

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## Date of publication

This report was completed in 2012, and published in the MSD Research Archive website in September 2019.

## ISBN

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# Individual disability support services

This report looks at evidence from other countries where individual disability support services offer better outcomes for disabled people and their families, including employment, social interaction, good health and a home of their own.

- There has been a shift internationally from traditional provision of disability services to more individual service provision that provides a personal framework of support and funding to people with disabilities.

- The overall emergent trends in types of disability services provided from the international literature are:

  – self-directed care and self-determination

  – individual funding

  – independent living with services provided in the community.

- Within the literature, individual disability support services:

  – often provide high levels of information and support for users that is appropriate to their needs

  – contain ongoing review systems for both the individual's plan and the service, to ensure that plans and services are kept up to date and are relevant to changes in policy

  – are locally defined.

- A person's outcome is typically affected by disability type, education level and support structures. People with physical disabilities and more education were more likely to achieve their employment goals.

- Evidence on what works to move people with health and disability problems into work is limited. There are no interventions that are universally successful and there is a tendency for programmes to combine elements of service, which contributes to the difficulty of isolating 'what works for whom'.

Developing new or expanding existing services to help people with disabilities participate more in their communities and enter the workforce is challenging. In recent years, there has been a move away from 'block' funding disability support services and greater interest in the provision of individual disability support services.[1] These are services that offer an individual or personal framework of support to people with disabilities and can include individual budgets, vocational assistance, personal plans and co-production of services (Fisher et al 2010; Foster et al 2006).

The state provision of disability support services in Organisation for Economic Development and Co-operation (OECD) countries over the past two decades has been influenced by several factors (Fisher et al 2010):

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[1] Individual support is also known as individualised, personal, personalised support or person-centred planning. Individual support is used here for reasons of plain English.

- increased demand for disability support services. While this is largely driven by an ageing population (the incidence of disability increases with age), the provision of services for working age disabled people is affected

- reduced availability of workers to provide disability support services. Such workers have typically been women and more options are now available to them

- fewer workers available to finance an increasingly overstretched public sector. Most industrialised countries will or already have shrinking working-age populations relative to those who are dependent. Services are increasingly targeted at those most in need

- a decline in the availability of family carers, leading to an increase in the need for formal care and support services. This has occurred as family sizes have fallen and more women have entered the paid workforce

- increased consumer pressure for more personalised, consumer-oriented services. This has included a greater demand for people with disabilities to be involved in the design and provision of services

- medical and technological advances that provide the possibility of an improved quality of life for people with disabilities

- the emergence and growth of the rights of people with disabilities. The emphasis is on the empowerment of disabled people – that is, people have the power to exert choice and therefore maximise control in their lives (Morris 1997).

- the large growth in the number of people with health or disability problems on incapacity benefits

- changing views on the role of the state in the provision of services to support those who are disabled.

Within this context, there has been a move towards the provision of more individual services for people with disabilities.


## Common aspects of the delivery

While individual support services have different focuses, the literature identifies several common themes in how these services are delivered.

**Traditional or completely co-production:** Traditional disability services are state provided and funded, typically based on 'block' funding where a government or contracted provider is funded to provide a defined disability support type to a defined number of people (Fisher et al 2010; Foster et al 2006). Co-production of services, on the other hand, are based on reciprocity between professionals, users, their families and neighbours. Services can also be anywhere in between.

**Differing levels of support:** People with disabilities require different levels of support. Some may require limited or a small amount of support, such as transport, while others may require substantial support, such as in-home care. Furthermore, some people may only require support on a temporary basis while others may require ongoing support.

For example, the Australian Disability Insurance Scheme provides three tiers of support: insurance in the event of a significant disability; general information for Australians affected by a disability; and targeted support for people with significant care and support needs (Productivity Commission 2011a).

**Information:** Information is often tailor-made for people with disabilities, supporting them to choose the type of support they may need (Carr 2010). This can be provided through guidelines, facilitators, co-ordinators and case managers (Fisher et al 2010) and can come from government agencies, service providers and/or advocacy organisations.

**Personal plans:** Many individual support services feature personal plans that, for example, can help people with disabilities and their family through transition periods, such as leaving school, or set out strategies for overcoming barriers and/or entering employment. Plans are often flexible, dependent on the level of support needed and what services are available.

**Locally defined:** A recent trend, according to the literature, is for support services for people with disabilities to be responsive to local needs rather than be provided in a 'one-size-fits-all' model. Services are becoming more responsive to the needs of disabled people within their area and to the needs of their community, such as the *Putting People First* strategy within the United Kingdom (Malley & Netten 2009; Department of Health 2010).

**Ongoing review systems:** The needs of people with disabilities can often change, particularly for people with cyclical conditions. Ongoing review mechanisms ensure that plans and supports are flexible enough to change with a person's needs. Furthermore, ongoing review mechanisms at an organisational level ensure that services can be kept up to date with relevant policy changes.

# Government approaches to personal support

## Australia

A recent inquiry of disability support services in Australia found support services to be "underfunded, unfair, fragmented, and inefficient" giving people with disability "little choice, no certainty of access to appropriate supports and little scope to participate in the community" (Productivity Commission 2011b, p 3). The National Disability Insurance Scheme (NDIS) was created in response.

The NDIS[2] will provide all Australians who have a significant and ongoing disability with long-term care and support.[3] NDIS will have three tiers of support (Productivity Commission 2011a):

- tier 1 providing insurance against the costs of support in the event of a significant disability

- tier 2 providing general information about care and support options to Australians affected by a disability, by providing linkages and referrals to services for which the NDIS is not directly responsible

- tier 3 targeting the smaller group of people with significant care and support needs, which will involve:

  – developing personal plans, and assessing the nature, frequency and intensity of a person's needs, taking into consideration what natural supports are available, such as family and community

  – translating these assessments into an individual support package funded by the NDIS and delivered through the individual's chosen service provider, organised by a disability support organisation or managed directly.

NDIS will be implemented in mid-2013 for around 10,000 people with significant and permanent disabilities in South Australia, Tasmania, the Australian Capital Territory, the Hunter Valley region in New South Wales and the Barwon area of Victoria. The Australian Government has committed $1 billion to support this first stage.

## United Kingdom

Within the United Kingdom (UK), national government sets policies and guidelines for local authorities to follow. Over the past 15 years, UK disability policy has been shifting from traditional models of welfare towards a more individual approach where disabled people are expected to provide their own care (Sapey 2010). This strategy has been reinforced by several national strategies, such as Person-centred planning, Improving the Life Chances of Disabled People and Putting People First.

**Person-centred planning** (PCP) guidelines were introduced in the UK as a means of increasing the extent to which supports were tailored to the needs and aspirations of

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[2]   As well as a smaller National Injury Insurance Scheme (NIIS) covering the lifetime care and support needs of people who suffer a catastrophic injury.

[3]   Income would not be included in NDIS. Private insurance and the Australian Government's income support system would continue to provide this support.

people with learning disabilities.[4] PCP sets out guidelines and key activities to be undertaken by local services and systems driven by partnership boards through the setting up of PCP implementation groups to oversee and develop local frameworks.

An evaluation of PCP found that it led to improved life experiences for people with learning disabilities with positive benefits in the areas of community involvement, contact with friends and family and choice. However, participants' risks of harm also increased, because they were "leading busier and more varied lives", which was "likely to have involved an increase in some predictable risk (eg from traffic)" (Robertson et al 2005, p 104).

**Improving the Life Chances of Disabled People** (Prime Minister's Strategy Unit 2005) is a government report that sets out a vision and strategy for improving the life chances of people with disabilities. It outlines four main areas for future strategy to respond to:

- helping people to achieve independent living

- improving support for families with young disabled children

- facilitating a smooth transition into adulthood

- improving support and incentives for getting and staying in employment.

**Putting People First** is based on that strategy. It sets out a new agenda for councils aimed at transforming adult social care, placing emphasis squarely on delivering improved outcomes for people through individual services (Malley & Netten 2009; Department of Health 2010). This agenda is based around four main elements:

- universal services, such as transport, health, education, housing, and access to information and advice

- early intervention and prevention, through supporting people who need help to stay independent for as long as possible

- social capital, through care and support that individuals can get from their community

- choice and control, which shape services to meet people's needs.

Putting People First was implemented over three years and funded by a grant of £85 million in 2008/09, £195 million in 2009/10 and £240 million in 2010/11. Several case studies have been done highlighting how different practices are emerging from each council. Lessons can be drawn from these case studies.

- Effective partnerships with user-led organisations (local co-production organisations run and controlled by people with disabilities) helped local authorities design and develop local services (Cole 2010).

- Effective contact and response systems with access to services contributed to continuity, for example, when a staff member took a call they were responsible for seeing it to completion (Witham 2010).

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[4]  This was in response to the 2001 Department of Health White Paper (*Valuing People*) and later provided evidence for the Putting People First guidelines. See: https://www.gov.uk/government/publications/valuing-people-a-new-strategy-for-learning-disability-for-the-21st-century; http://www.cpa.org.uk/cpa/putting_people_first.pdf

- Comprehensive support was needed for people with mental health issues and was able to focus on spending their budget in a way that would help them achieve **their** identified needs and desired outcomes (Dixon 2010).

- Group events were an effective way of getting providers on board, but more targeted interventions were needed for providers who were less engaged with the local authority (Humble 2010).

- Frequent reviews and updated strategies ensured that stakeholders remained engaged and local strategies remained current with government policy (Thompson 2010).

## Individual funding

Individual funding or budgets[5] are often defined as a package of funding "to be spent on the disability support services of a particular person in the way that best suits them, including support type and who provides the support" (Fisher et al 2010, p 7). Offering people with disabilities the option of controlling their entitled funding is part of many support services. People with disabilities are able to combine the support they receive and decide how best it can be spent to meet their needs. Individual funding has three characteristics:

- it can be held by the service provider; direct payments to the client, family or carer; or held by a financial facilitator

- it is portable between agencies and/or between facilitators

- it can be spent on multiple service providers or on open market and multiple service providers.

In most countries where individual support services have been introduced, the majority of people choose providers or financial facilitators to organise their support rather than manage their own payments (Fisher et al 2010). The flexibility of individual funding has meant that a greater diversity of goods and services can be accessed (Alakeson 2010).

In a literature review of individual funding services across Australia, Fisher et al (2010) found that most people reported experiencing personal wellbeing, physical health and mental health at levels similar to the Australian population norm and attributed this to a greater control of their own support. Recipients were more likely to be male, non-indigenous and not from a culturally or linguistically diverse background, and were also more likely to be between ages 19 and 60 rather than younger or older (Fisher et al 2010). Other common themes the review found included:

- disability type typically affected a person's outcome:
  – people with severe communication or cognitive disabilities had lower levels of satisfaction, which was attributed to the complications of involving them in the support planning process. In most cases, the relevant service provider was able to address the limitation by working closely with the family

- independent funding promoted independent living, usually in the community with family or friends rather than a residential home or unfamiliar area

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5   Also known as direct funding, direct payments, personal budgets, self-determination, self-management, self-managed care and consumer or self-directed care.

- common concerns were raised over limitations of what funding packages could be spent on and over individual funding packages alienating people with disabilities from support in the traditional disability system.

Comparing individual funding with previous types of service delivery in Australia, the costs to governments did not change. Rather, individual funding was a mix of cost savings and cost increases. Savings were made through lower administrative costs for service providers and better alignment of services, though during the transition period costs were higher due to new systems and management and reporting structures being established (Fisher et al 2010). A similar finding was found in the UK (Department of Health 2008).

**Australia**

**My Place**[6] in Western Australia offers individuals and families a choice of three models of individual funding: shared management; shared co-ordination and provider management (Fisher et al 2010; Fynn 2011). Service co-ordinators specialise in one of four types of support (home sharer; co-resident; mentor; and community and home) and are responsible for between nine and 15 individuals.

The review system is one of the strengths of My Place. It is evaluated every three years against the Quality Management Framework and compliance with the Disability Services Standards, the most recent review being in 2011. Recommendations are made to improve the service and keep it relevant to policy and changes in participant needs (Fynn 2011).

The **Direct Funding Pilot** in conjunction with the Attendant Care Program (ACP) in New South Wales provides support through direct payments to individuals to spend on the open market (Fisher & Campbell-McLean 2008). The ACP has three funding models: employer model, co-operative model and direct funding. In both the employer and co-operative models, funds are paid by the Department of Ageing, Disability and Home Care to a service provider who is responsible for management of funds and reporting.

An evaluation compared recipients of the employer and co-operative models to directly funded recipients and found the latter had better outcomes (Fisher & Campbell-McLean 2008). Directly funded participants were able to change their support in response to their specific needs, such as improving their access to education, work or shopping. These outcomes include:

- higher average personal wellbeing and physical health

- active social networks

- a higher participation or increased participation in paid work, study or community activities.

However, some outcomes can be explained by the different profile of directly funded recipients, compared with the two other models. Directly funded participants were predominantly male, lived with family members who described themselves in an extension or back-up care role and all were employed, retired or studying at the time of the evaluation. Only 62 percent of employer and co-operative models were employed, retired or studying (Fisher & Campbell-McLean 2008).

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[6] For more details, see: https://www.myplace.org.au/index.html

**United Kingdom**

In the UK, individual funding has been in place since 1996. Recent reforms are aimed at increasing the use of individual funding by bringing several streams of funding together.

The **Right to Control** is a legal right for people with disabilities within the UK giving them greater choice and control over their funding (Tu et al 2012).The Right to Control has been piloted in seven 'Trailblazer' areas across Britain since December 2010. An evaluation of how the different sites have implemented the Right to Control found (Tu et al 2012):

- little variation within the management structures adopted, with sites adopting a strategic board, an operational team and a local co-production team

- all sites, bar one, trained frontline staff to deliver the Right to Control, meaning that staff continued to use their own assessment procedures

- the one exception created a centralised delivery team with staff members seconded from various partners. While this model was more streamlined, staff have raised questions about its sustainability, because it is more resource intensive and required additional funding beyond set-up costs

- defining the role of the organisation was a challenge for all Trailblazer sites, having an established user-led organisation involved early was a major success factor

- sites that had experience with other individual support initiatives were able to make the implementation smoother and challenges easier to manage

- the decision-making process was slower for sites that had to engage with more local authorities and Jobcentre Plus offices

- sustaining commitment and engagement, particularly in the face of budget cuts, affected the continuity of leadership and staff morale

- some frontline staff felt that the Right to Control was encouraging closer partnerships between the agencies involved and that they were moving away from the 'design then consult' way of working. Other staff lacked awareness and understanding of the Right to Control, which was reflected by many customers lacking awareness and understanding of the Right to Control

- in areas with a centralised delivery model, customers were aware of the Right to Control and more likely to follow the intended customer journey model. Greater control and choice is likely to improve as sites take action to educate providers and respond to local needs.

**Canada**

**Community Living British Columbia** (CLBC) was created following the Community Living Authority Act, which brought about the devolution of services for individuals with developmental disabilities to the CLBC. Services were transferred in July 2005 and the transformation was complete in July 2006 (Community Living British Columbia 2006).

CLBC is a Crown agency that provides funding for support and services for people with developmental disabilities.[7] Funding can either be direct, managed by the individual, their family member or representative, or by an approved Host Agency that will

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[7] For more information, see www.communitylivingbc.ca/individuals-families/individualized-funding/

administer the funds and work with the individual and their family (Community Living British Columbia 2006).

A review of CLBC (Queenswood Consulting Group 2011) found that in the six years the CLBC had been operating:

- projecting caseload growth had caused concern. While high numbers of younger people going onto CLBC on turning 19 was predictable, the large number of adults going onto CLBC during their lifetime was less easy to predict

- linking caseload projections to cost projection had been challenging because of the nature of individual services, however, over time it was predicted that this would become more accurate as better data was acquired

- savings of $24.87 million have been found through contract efficiencies, which has been reinvested in the organisation, allowing CLBC to expand the reach of its services

- significant improvements had been made to performance measures and reporting capabilities, however, measurements needed to be better linked to one another to accurately measure need, service delivery, options and outcomes.

## Co-production

There is no agreed definition for the term co-production. However, the different definitions of co-production used in the literature share the notion that users are a potential public service resource (Boyle & Harris 2009; OECD 2011). The OECD (2011) defines co-production as a way of planning, designing, delivering and evaluating public services that draw on direct input from citizens, service users and civil society organisations. Co-production is about how services "work with rather than do unto users" (Cummins & Miller 2007 cited in OECD 2011, p 32). Elements of co-production definitions include:

- users being more directly involved in public services by becoming contributors; undertaking some of the activities formerly carried out by professionals (Boyle & Harris 2009; OECD 2011)

- a focus on delivery of outcomes rather than just the service (Löffler 2009; OECD 2011)

- collaborative relationships between public service professionals and users (Bovaird 2007; Boyle & Harris 2009; Needham & Carr 2009; OECD 2011).

Co-production makes strengthening the core economy of neighbourhood and family the central task of all public services. Boyle and Harris (2009) argue that this means:

- recognising people as assets

- valuing work differently

- promoting reciprocity, giving and receiving

- building social networks.

### United Kingdom

**Headway East London** is a charitable operation that pioneered a challenging co-production approach to 'acquired brain injury'. It focuses on what members (not 'patients') can do rather than what they cannot do and aims to build peer support networks alongside professionals. Headway East London sees this as the best way of

transferring knowledge and building up the ability of people who are helping to run aspects of the service, mentoring new members and doing assessments, inductions or organising projects. This recognises that patients are often experts in their own condition and can also provide vital support to each other (Boyle et al 2010).

The **Expert Patients Programme** is a government peer support scheme aimed at patients living with a long-term health disease (LARCI 2010). Becoming an expert patient allows people with chronic conditions to better support themselves, help others and build support networks. This is an example of user co-delivery of professionally designed services – here professionals dictate service design and planning, but users and community members deliver the service.

An independent evaluation showed the scheme is likely to be cost-effective because there was an overall reduction in service use, which offset the costs of the intervention. There were small gains in psychological well-being, high levels of satisfaction with the course and benefits from being part of a network.

The **My Way Transition Programme** run by the MacIntyre Charity focuses on the transition of young disabled people from school into adulthood. This approach involves holistic, person-centred support planning with facilitators in a brokerage role (Brodhurst et al 2012). Initially, the programme was run in two schools but has recently been expanded to cover the local county with help from the local authority.

A qualitative evaluation of the My Way Transition programme shows that 57 out of the 75 young people who participated experienced positive outcomes (Brodhurst et al 2012). The remaining 18 participants did not experience any change. Interviews conducted at the start of the programme found that a significant number of families had negative experiences with the programme, reporting that transitions had not been successfully planned, were chaotic, and that families were not adequately supported or informed, resulting in poor outcomes for the young person.

The evaluation report highlighted the need to support young people when plans the young person and family agreed on have to change or differ from the aims of local authorities or policy. For example, a young person and family wanting a residential placement when the local authority is in the process of decommissioning local residencies (Brodhurst et al 2012).

## Vocational assistance

The main principles of vocational assistance are to listen and understand the person in their context, work with the person to plan and deliver an agreed rehabilitation pathway and to mobilise support and services to help them achieve an everyday life.

Several professionals are involved in vocational assistance, such as occupational therapists, physiotherapists, psychologists, case managers and disability employment advisers.[8] Factors important to vocational assistance include: counselling, professional practice, personal counselling, rehabilitation case management, workplace disability case management and workplace intervention and programme management (Matthews et al 2010).

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8    For more details, see https://vrassociationuk.com/)?

Important to moving clients into employment through vocational assistance is access to information tailored to the needs of both clients and clinicians, including information on countering incorrect beliefs about work; the benefits of work; disclosure and managing personal information; the impact of earnings on welfare entitlements; employment pathways; job preparation, planning and selection; and managing illness (King et al 2009).

## United States

The **Federal Vocational Rehabilitation** (VR) programme is the primary publicly available vocational assistance service for adults with disabilities in the United States "designed to link needed restorative human services with individuals who have disabilities" (Premuda-Conti & Lewis 2011, p 53). In the 2006 fiscal year, 1.41 million people with disabilities were supported, involving an expenditure of federal funds of $2.7 billion and a matching state sum of $797.7 million.[9]

An evaluation was undertaken of people with disabilities who accessed VR through the Maryland State Department of Education's Division of Rehabilitation. It investigated which variables affected employment outcomes compared with the employment goals set out in their Individual Plans for Employment (IPE) and found statistically significant differences for gender and disability.

- More men than women were likely to obtain employment in line with their IPE.
- Participants with a mental disability were less likely to achieve their IPE employment goals, compared with those with physical or sensory disabilities.
- Participants who gained employment in line with their IPE goal were more likely to earn higher wages, almost twice as much as participants who gained employment outside their IPE goal.

Levels of education and type of disability were the two main variables that influenced which participants gained work and how much they earned. Participants with physical disabilities were more likely to be educated and therefore earn more (Beveridge & Fabian 2007).

## Australia

The **More Intensive and Flexible Services** (MIFS) pilot was established in 1996 and delivered pre-vocational services and help to people with severe disabilities. The aim of the pilot was to enable and improve the participation of this group of people in existing employment services. MIFS was piloted in Brisbane and East Victoria and ran for four years (Butterworth 2004). Participants developed a relationship with one person who was able to respond to their needs and be understanding and flexible when those needs changed, which was particularly important for episodic conditions.

Funding was individually based, relative to the needs of each participant and paid to case managers to be spent on relevant services delivered to the participant (Butterworth 2004). Many participants of the MIFS achieved positive vocational outcomes and personal improvements in the quality of their life, their ability to cope with their disability and their self-esteem and confidence. However, the MIFS had several administrative and procedural weaknesses. Problems with complexity and

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9    For more information on public spending on disabilities in the United States, see www.bos.frb.org/commdev/cdevfin-disability-market/cdevfin-disability-market.pdf#page=9

system navigation, funding levels, and interaction between non-vocational, pre-vocational and vocational services impacted on pilot participants. The average programme cost was comparable to funding levels of other government programmes, but the administrative expenditure was excessive: 26 percent of total expenditure over four years, compared with 8.4 percent expenditure for similar programmes across all Australian governments (Butterworth 2004).

# What we don't know

There are variations in the outcomes for recipients of individual disability support services based on disability type, education level and support networks, which all influence what an individual will achieve from individual support services (Hasluck & Green 2007). There is also a need to understand the risks associated with individual support services and how they relate to New Zealand (Kendrick 2001).

Support can be irrelevant to the person being supported or their needs, or support and plans can be implemented poorly (Kendrick 2001). When there is not enough support, professionals or informal carers can become substitute decision makers without the person's effective input. Psychiatric disabilities are most commonly susceptible to this (Fisher et al 2010). Further risks can include (Fisher et al 2010; Carr 2010; Chenoweth & Clements 2009):

- procedures for managing individual packages of funding could be too complex and difficult for some people to understand and manage

- control over the funding could pass from agencies to brokers without providing autonomy for the person with a disability

- reduced contact with agency staff could lead to greater isolation and vulnerability to exploitation and abuse

- changing funding responsibility could mean governments evade any further responsibility, either for the individual service user or for service innovation and development

- uptake could be uneven across different groups.

The circumstances and needs are greatly diverse within the population of people with disabilities and health problems. The causes of long-term sick leave are individual and complex, and involve biological, psychological and social factors.

- Employment levels vary significantly, depending on the type of disability.

- Medical diagnosis is not a reliable indicator of when someone can work – especially for those with mild-to-moderate conditions (Waddell & Burton 2006).

- Research on the work environment and employers is limited, but it suggests that:

  – several workplace factors influence employment outcomes

  – employer needs, as well as job readiness, are important. Employers look for employees who they believe have the ability to perform needed tasks and enhance their bottom line.

- People with high levels of self-efficacy and self-determination are more likely to return to or move into work (Brouwer et al 2009; Sampere et al 2012).

Service providers therefore need to be responsive and flexible in meeting the individual needs of benefit recipients (Hasluck & Green 2007).

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