

# Literature review: Understanding the needs of people with mental health conditions and/or learning disabilities and the implications for the Pension, Disability and Carers Service

by Andrew Butters, Mike Webster and Matt Hill

**Department for Work and Pensions**

**Research Report No 654**

# **Literature review**

**Understanding the needs of people with mental health conditions and/or learning disabilities and the implications for the Pension, Disability and Carers Service**

**Andrew Butters, Mike Webster and Matt Hill**

A report of research carried out by Frontline Consultants on behalf of the Department for Work and Pensions

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# Abbreviations

AA	Attendance Allowance
CAMHS	Child and Adolescent Mental Health Services
DCLG	Department for Communities and Local Government
DCS	Disability and Carers Service (former name of service)
DH	Department of Health
DLA	Disability Living Allowance
DWP	Department for Work and Pensions
ICT	Information and Communications Technology
PDCS	Pension, Disability and Carers Service
SCIE	Social Care Institute for Excellence
YAP	Young Active People



# Summary

This report contains the findings of a review of the literature on the needs, preferences and experiences of people with mental health conditions and/or learning disabilities when accessing benefits, specifically Disability Living Allowance (DLA) and Attendance Allowance (AA).

## Needs of people with mental health conditions and/or learning disabilities (Chapter 2)

People with mental health conditions and/or learning disabilities are two heterogeneous groups which cover people with a very diverse range of needs and preferences (Section 2.1). Good practice services therefore deliver a personalised approach built around the needs of the individual.

Mental health influences and is influenced by a broad and complex range of factors cutting across a range of different spheres of life – such as health (both physical and mental), employment, housing, leisure and social networks – and therefore a strong multi-agency approach is required which addresses needs holistically (Section 2.1). People in these groups, particularly those with more severe conditions and those of older age, are more liable to experience social exclusion and this presents significant barriers to them acquiring information and advice about eligibility for benefits and accessing any support they need to make a claim. For example:

- people with learning disabilities often have very limited friendship groups and may have limited contact with family – two of the channels through which many people hear about DLA and AA (Section 2.4);
- conditions such as dementia frequently go undiagnosed, possibly making it less likely that the person will become aware of their potential eligibility for benefits (Section 2.3);
- services for children are often not as joined-up as they need to be and this presents barriers to them accessing a full range of support, particularly so for those making the transition to adult services (Section 2.3).

## The role and extent of use of advocacy (Section 2.6)

Advocates play an important role in ensuring that the needs of individuals in these groups are met, including facilitating access to services. The evidence shows that advocacy is effective in reducing barriers faced by vulnerable people, and the Pension, Disability and Carers Service (PDCS) may wish to consider how it can improve access to, or provide directly, such support for its customers. Advocacy can take many forms on a spectrum from formal to informal, and the literature presents a range of different models of support. There has been an increase in advocacy provision following the emphasis placed on this in *Valuing People* but the literature suggests that provision remains patchy – both from a geographical perspective and from the perspective of meeting the needs of particular groups. For example, one piece of research found ‘serious gaps’ in provision for African and Caribbean men, who have higher prevalence of mental health conditions.

## Gaps in service provision (Section 3.1)

There is limited coverage in the literature regarding gaps in services for these groups, but some themes emerge.

### **Missed or inaccurate diagnosis**

For example, only about a third of people with dementia receive a formal diagnosis at any time in their illness.

### **Hard-to-reach groups**

The literature identifies a number of groups that, as a result of the complexity of their need, often receive a poor service from statutory agencies and experience greater social exclusion, for example drug and alcohol misusers and the homeless who often have mental health problems.

### **Lack of joined-up working**

This causes particular problems for children, older adults, and those with complex needs such as mental health conditions and/or learning disabilities.

## Good practice in providing services (Section 3.2)

There is a strong body of literature on good practice in providing services for people with mental health conditions and/or learning disabilities, particularly from the field of social care. A key over-arching theme is the emphasis on personalised services: giving individuals more choice and control over the services they receive and how they access them.

This involves multiple agencies working together to deliver a person-centred approach – ‘listening, learning and focusing on what is important to the person and working with others to act on this and make things happen’. A good example

of a move towards this from a PDCS perspective is the London pilot work on streamlining the AA assessment with the social care assessment.

There is good practice available from other agencies such as the Audit Commission on improving take-up of benefits for those who are eligible from vulnerable and excluded groups. Much of the learning is translatable and the PDCS should consider how this can be applied in the context of DLA and AA.

Good practice in communicating with people with mental health conditions and/or learning disabilities includes:

- user consultation and involvement in design;
- flexibility in when, where and how communications take place;
- continuity of case handling;
- presenting information in a way that aids comprehension.

### Barriers to increased take-up of benefits (Section 3.3)

People with mental health conditions have particular problems with navigating the benefits system and there is concern in the literature that many people with disabilities who are eligible for DLA are not claiming the benefit. A number of barriers to take-up are identified:

#### **Lack of awareness**

People may be unaware of their potential eligibility for benefits as a result of a range of factors, including a lack of formalised routes for informing people about eligibility, such as signposting from other agencies.

#### **Barriers to access**

This includes communication channels and formats that do not meet the needs of people with mental health conditions and/or learning disabilities. They may also take the form of inflexibilities in the way communications with these groups are handled by the Department for Work and Pension's (DWP's) staff, or aspects of the process that make it difficult for customers to disclose their condition and express their communication needs.

#### **Complexity of the application process**

Feedback from customers indicates that claiming for DLA or AA is a long and complex process and presents particular challenges for those with mental health conditions, including a view that the form is more geared towards people with physical rather than mental health conditions.

## Networks, partners and links (Chapter 4)

The literature review identified the key networks, partners and links for PDCS in meeting the needs of people with mental health conditions and/or learning disabilities. These may be:

- *Formal* – with a person's key worker being an important focal point. Also health professionals such as GPs (especially important for older people), other doctors, community psychiatric teams and occupational therapists. Social workers are also an important link and play a key role in informing people about DLA and AA.
- *Informal* – including family members (especially important for people with learning disabilities), voluntary organisations (for example, day centres, help lines and websites), peer support networks and work colleagues.

There may be opportunities for the PDCS to work more closely with its partners. The literature suggests an increased presence in primary care settings may be of help in reaching people with mental health conditions, although further research is required to demonstrate this unequivocally. There may also be potential to strengthen partnerships with secondary care, for example a more joined-up approach to providing information about the full range of services and support available to people with mental health conditions and/or learning disabilities, including benefits advice.

## Satisfaction with the Pension, Disability and Carers Service (Section 5.1)

Research has identified that people with mental health conditions 'often have problems' using PDCS services. Based on the DCS Customer Service Survey 2008, they are less likely to be satisfied with the claims process than are customers in general. There is little information currently published on satisfaction levels for people with learning disabilities.

## Channel preferences and digital inclusion (Chapter 5)

Telephone is the preferred communication channel for most people with a mental health condition or learning disability (Section 5.2). However, a higher than average proportion of people in these groups will struggle to concentrate for longer calls. People with learning disabilities may also struggle to navigate 'call routing' systems and the lack of non-verbal communication on a telephone is likely to present a significant communication barrier for them (Section 5.3).

People with mental health conditions and/or learning disabilities are both more likely to correspond in writing than customers in general. Some will prefer face-to-face contact but the literature suggests customers are not consistently made aware the availability of this option. The key advantages of face-to-face communication are that it enables non-verbal communication, and increases the opportunity for staff to build rapport with the customer and to identify their communication needs. It may also enable an advocate to be present. A disadvantage of face-to-face communication for some is that busy or loud contexts might aggravate their mental health condition (Sections 5.2 and 5.3).

People with mental health conditions and/or learning disabilities reflect the wider population in that there is a wide range of experience and level of comfort with electronic communications, and in broad terms it decreases for older age groups (Sections 5.4 and 5.5). The majority of people with a learning disability have access to a computer, but many with mental health conditions do not. The web is becoming an increasingly important and trusted source of mental health information in general, but customers in this group are more likely to lack confidence and proficiency in Information and Communications Technology. The design and format of written and electronic communications, including websites, is crucial, particularly so for people with learning disabilities and cognitive impairment. Users with mental health conditions should be involved in the design process so that channels and materials make it easy for them to find and understand the information they need.

## Recommended next steps

The literature review has highlighted a number of implications for the PDCS. Our recommended next steps are summarised in Chapter 7.



# 1 Introduction

## 1.1 Background and policy context

Many of us will experience a mental health problem at some point in our lives. It is estimated that one in six adults has a mental health problem of varying severity at any given point in time (Department of Health (DH), 2007a). Problems range from mild depression and anxiety through to psychosis and severe personality disorders. Problems may be temporary or long term, or may fluctuate in incidence and severity during the course of a person's lifetime.

The prevalence of mental ill-health is not evenly distributed across the country. (DH, 2009a, p14). There are strong links between mental health conditions and social exclusion (ibid, p68). People with mental health problems tend to have fewer qualifications, find it harder to get work, have lower incomes, and live in areas with higher socio-economic deprivation (ibid, p14). Linked to this, they are also more likely to experience difficulties in accessing services and receiving a full range of support in line with their needs (ibid, p22).

In July 2009 the DH launched *New Horizons*, a consultation on a new vision for mental health and wellbeing. *New Horizons* is focused on the promotion of mental health and wellbeing across the population, and improving the quality and accessibility of services. Of its key themes (summarised in Figure 1.1), tackling stigma and discrimination, social inclusion and personalisation are particularly pertinent to this literature review and emerge as key strands in the discussion.

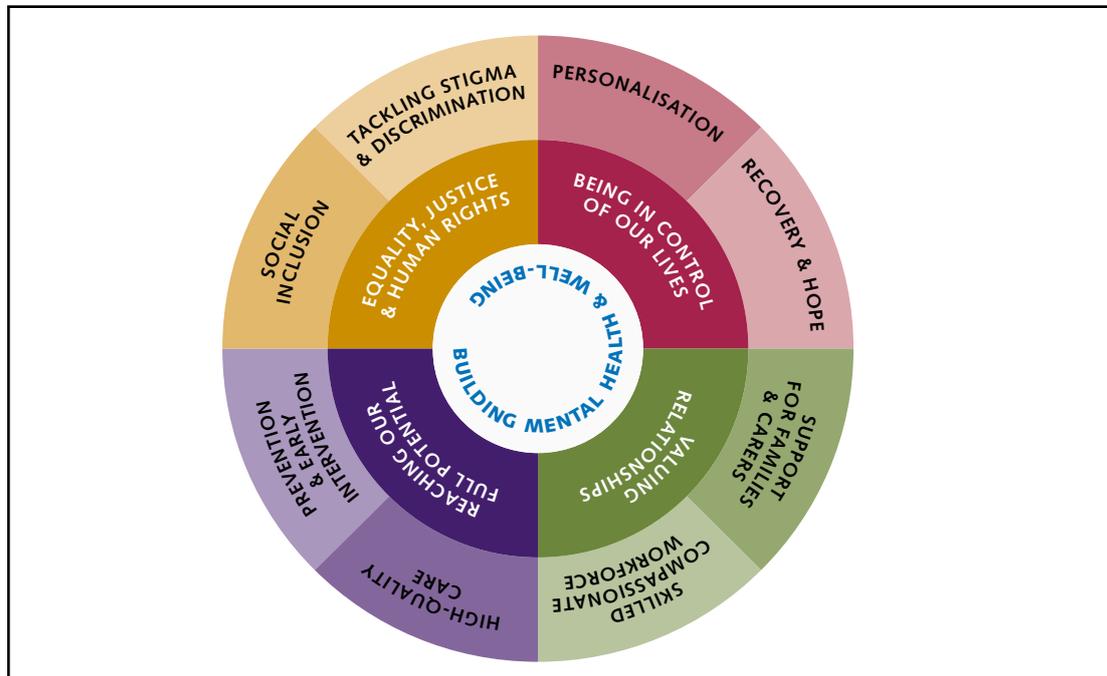
Around 1.5 million people in the United Kingdom have a learning disability<sup>1</sup>. This equates to around three in every 100 people. Of these, an estimated 65,000 children and 145,000 adults have severe or profound learning disabilities<sup>2</sup>. A learning disability affects someone's ability to understand new or complex things and to cope independently. Most develop before a child is born, during birth, or because of a serious illness in early childhood.

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<sup>1</sup> Department for Communities and Local Government: *Digital Exclusion Profiling of Vulnerable Groups: Adults with Learning Disabilities*

<sup>2</sup> DH: *Valuing People*

**Figure 1.1 Key themes in *New Horizons***



In common with people with mental health problems, people with learning disabilities also face many forms of disadvantage. They are more likely to experience health problems, to be unemployed, and to have limited friendships and relationships. They face particular barriers when accessing services – particularly related to communicating their needs, and making sense of the information they are presented with – and many will need some form of advocate or intermediary to help with this.

*Valuing People Now*, published by the Department of Health (DH) in January 2009, is the three-year strategy for people with learning disabilities. Based on a consultation in 2008, it sets out how people with learning disabilities and their families will be supported. It picks up key themes around ensuring the diverse needs of different groups are met, personalisation, improving health care, improving opportunities for work and education, advocacy and safeguarding. Many of these strands are picked up in this report.

## 1.2 Disability Living Allowance and Attendance Allowance

Disability Living Allowance (DLA) and Attendance Allowance (AA) are tax-free benefits for children and adults who need help with personal care or have difficulties in getting around because they are physically or mentally disabled. DLA is for children and working-age adults, whereas AA covers those aged 65 or over. DLA and AA awards are not affected by a person's income or savings, or whether they are in work.

AA can be paid at a lower or a higher rate, whereas DLA consists of two components:

- A care component that can be paid at three rates: low, middle or high.
- A mobility component that can be paid at two rates: low or high.

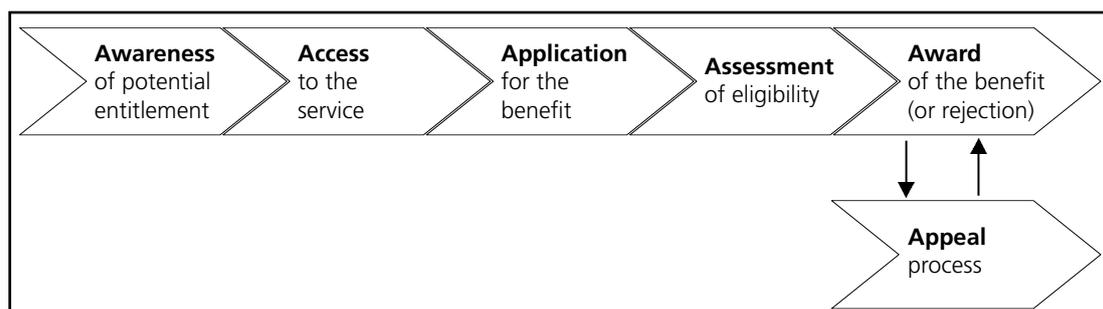
People with mental health conditions and/or learning disabilities may be eligible for the care component if their condition impacts on their daily life, for example making it difficult to remember to take medication, eat properly and regularly, wash regularly, deal with forms and letters and communicate with others.

They may also be eligible for the mobility component. For people with mental health conditions this is likely to be because they need someone with them when in unfamiliar places, for example because of panic attacks, anxiety, hearing voices, paranoia or risk of self-harm. People with learning disabilities may be eligible for the mobility component at the higher rate if they are getting the care component at the highest rate, are severely mentally impaired and have severe behavioural problems needing constant supervision.

To claim for DLA the person must have been needing help in their daily activities for at least three months, and such help must be expected to be needed for at least a further six months. To claim for AA the person must have been needing help for at least six months.

Making a claim for either DLA or AA involves completing a form which enables the Pension, Disability and Carers Service (PDCS) to assess the claim against its eligibility criteria, which include a range of factors related to the person's condition and their ability to carry out day-to-day tasks independently. Eligibility for DLA and AA is not based on medical diagnosis but on needs arising from the disability. However, healthcare professionals responsible for the person are sometimes required to provide a statement as part of the claim form. In some instances, an independent medical examination is also required to assess eligibility. An appeals process is built into the system for those who wish to challenge their claim decision. Figure 1.2 summarises the customer journey involved from initially becoming aware of their potential eligibility for DLA or AA through to award being granted or declined.

**Figure 1.2: Customer journey in claiming for DLA or AA**



### 1.3 Scope of this review

The focus of this literature review is on understanding the needs of those with mental health conditions and/or learning disabilities, and the implications of this for the PDCS. PDCS is keen to identify the particular needs of these groups and any barriers they face in accessing the PDCS service, to ensure that processes do not disadvantage them.

Carers (and Carer's Allowance) fall outside the scope of this review, unless the carer themselves have a mental health condition or learning disability.

Whilst we could not identify an authoritative definition for 'mental health condition', we will assume this to incorporate both mental health problems and mental illness, defined as follows:

#### ***Mental health problem***

*'Mental health problems generally refer to difficulties we may experience with our mental health that affect us in our everyday lives. Mental health problems can affect the way we feel, the way we think and the way we function. Mental health problems include conditions described as personality disorders and also dementia. They can be mild or serious, fleeting or long-lasting.'*

*(DH 2009a, p10)*

#### ***Mental illness***

*'Mental illness refers to more serious mental health problems that often require treatment in specialist services. Someone with a serious mental illness may have long periods when they are well and are able to manage their illness. Many people with mild and serious mental health problems are able to live productive, fulfilling lives.'*

*(DH 2009a, p10)*

The review covers all those falling within these definitions, regardless of whether they have been formally diagnosed, or are accessing professional support or treatment for their condition.

We define a **learning disability** according to the three core components identified by the DH:

- *'a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with*
- *a reduced ability to cope independently (impaired social functioning)*
- *which started before adulthood, with a lasting effect on development'*

*(DH, 2009b – Valuing People Now)*

The review covers the full age range. Where it has been possible from the literature, the needs of different age groups have been segmented as follows:

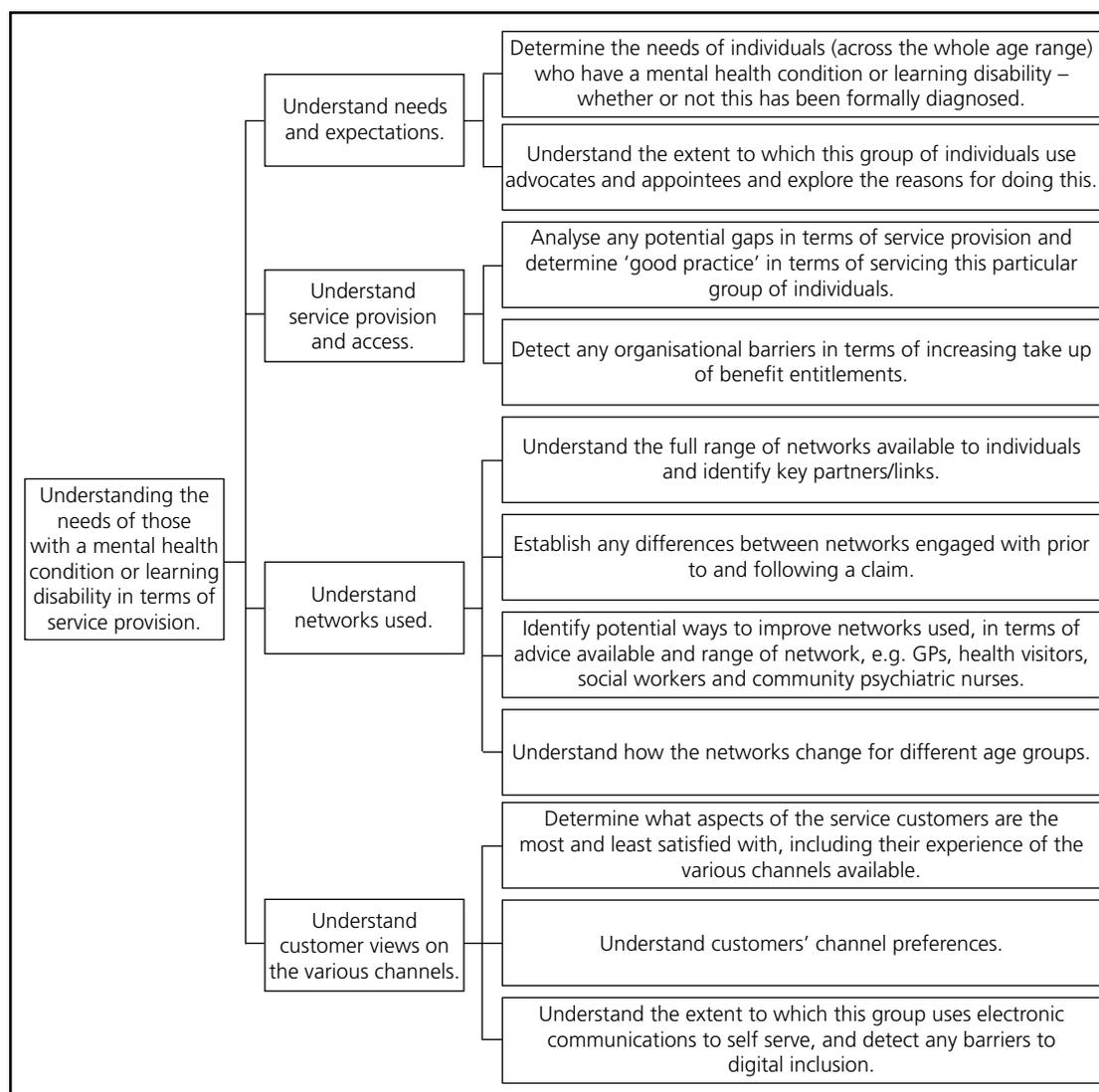
- children (age 15 and under);
- working-age adults;
- older adults (age 65 and over).

The review covers both those who are claiming DLA/AA and those who are not. Where possible from the literature, the discussion segments the client groups by those receiving DLA/AA and those not receiving DLA/AA.

## 1.4 Research objectives

The research objectives are shown in Figure 1.3.

**Figure 1.3 Research objectives**



The objectives have been grouped according to four key categories which we identified and agreed with PDCS before the start of the review:

- needs and expectations
- service provision and access
- networks
- channel preferences

## 1.5 Methodology

We ensured a systematic approach to meeting the research objectives by developing an issue tree, setting out the key questions that needed to be answered from the literature to satisfy each objective. Following the set up meeting for the project, we agreed the issue tree with PDCS.

The literature search comprised three main elements:

- **Web-based search**

A web-based literature search was carried out using the key words from the issue tree via a range of search engines to identify a range of published literature available online.

- **Database search**

We accessed a range of literature databases via the Scottish Health library, which includes access to a vast range of publications including those held by the British Library. Again, a search was carried out using defined key terms from the issue tree.

- **Internal document search**

We asked PDCS to search internally for any unpublished documents of relevance to the review.

We reviewed the literature against the following criteria:

- Relevance – is the literature relevant to this study?
- Credibility – has a sound approach been used?
- Objectivity – have the biases been addressed?
- Applicability – are the findings applicable to PDCS?
- Balance – is the literature balanced and based on evidence?

A full reference section can be found at the back of the report.

We pulled together the findings from the review and presented these in interim form to the PDCS on 10 November 2009.

This report contains our findings from the review in full, together with our analysis of the implications for PDCS, and recommended next steps.

## 2 Understanding needs

### 2.1 Understanding needs: overarching themes

There is a reasonably large body of literature identifying the generic needs of those with mental health conditions and/or learning disabilities. These two groups of people are generally dealt with separately in the literature since they are viewed as having very different sets of needs. This is also reflected in service provision within health and social care, where these two groups would often be accessing different services and professionals – although clearly there are significant areas of overlap. For example, people with learning disabilities are considerably more likely than the general population to have a mental health condition (Department for Communities and Local Government (DCLG), 2008b, p13). Both groups may well be accessing some form of support from social services, but the nature of that support may differ significantly.

An important starting point when understanding the needs of these groups is that people with mental health conditions and/or learning disabilities do not constitute homogenous groups. The literature reveals very clearly that within these two very broad groups, there is substantial variety in the types of condition people have, what their experience of this condition is, and the manner in which their condition impacts on their day-to-day life (Wiggan and Talbot, 2006). Good practice services understand this variety and respond effectively to the needs of different users. This is strongly reflected in the literature related to personalisation of services, which we explore in more detail in Section 3.2.

A key theme within the literature is the need to approach the needs of these groups holistically. The Department of Health's (DH's) view is that 'Employment, housing and a strong social network are as important to a person's mental health as the treatment they receive' (DH, 2007b). In particular, there are strong links between mental problems, unemployment and social deprivation:

*'The links between poverty, social deprivation and mental health problems are clear. There is also a strong association between income inequality – relative poverty – and poor mental well-being and health. People with mental health problems tend to have fewer qualifications, find it harder to get work, have*

*lower incomes, may well be homeless and are more likely to live in areas of high socio-economic deprivation. Fifteen per cent of children in the lowest socio-economic group develop mental health problems, compared with just 5 per cent of children in the highest.'*

(DH, 2009, p14)

The literature also points to the inter-relationships between physical and mental health conditions and the likelihood that many people with mental health conditions will also be experiencing physical health problems.

Physical health affects our mental health, and vice versa. The most mentally healthy people also have the lowest rates of cardiovascular disease. Conversely, people with a physical illness are more likely to develop a mental health problem – an estimated 70 per cent of general hospital beds are occupied by older people, of whom up to a half are assessed as suffering from cognitive problems and a third with depression. People with severe mental health problems die younger than other people. Some studies have shown that on average it is 25 years earlier. Such people also develop illnesses such as strokes and coronary heart disease before the age of 55 more often. They can also find it harder to access screening services and other primary care services. (DH, 2009, p15)

Therefore mental health conditions and/or learning disabilities cannot be viewed in isolation from wider issues of social exclusion and inequality. Those with mental health conditions are more likely than others to have a wide-ranging and complex set of physical, social and economic needs, and to experience greater barriers in accessing services (explored in Section 3.3). In this context, services provided by a range of government departments and agencies (including the Department for Work and Pensions (DWP)) are of equal importance to the health service in sustaining and improving people's mental health and enabling them to live long and fulfilled lives, and strong multi-agency working is required.

## 2.2 Understanding needs: people with mental health conditions

In *Managing Mental Health and Employment* (DWP, 2008) the DWP identify a range of factors that service users described as contributing to a better state of mental health. These are:

- prescribed medications, counselling or therapy and the coping strategies acquired from these;
- workplace factors and the benefits of work itself;
- social networks, including the support of family and close friends, maintenance of an active social life, and the companionship provided by pets;

- life-style factors, including maintaining good physical health, religious or spiritual involvement and a healthy 'work-life balance';
- development of personal insight and understanding of their mental health.

This work by the DWP forms part of an emerging body of literature focused on the links between mental health and employment. Employment rates for people with mental health conditions are considerably lower than the population average (DH, 2009a, p68). Work in itself is widely recognised as being beneficial to a person's mental health and to supporting social inclusion. **A particular concern relating to Disability Living Allowance (DLA) is that many people currently receiving DLA fear that starting work would trigger a review of their entitlement and could lead to them losing the benefit. Even though this is an inaccurate perception, this represents a barrier to those with mental health conditions entering the workplace that needs to be addressed (DWP, 2008).**

Social inclusion is related to various other factors alongside unemployment and is a key strand running through the literature. *New Horizons* (DH, 2009, p22) identifies that people with mental health conditions may find it difficult to discuss their condition with others – often due to the stigma that is sometimes attached to mental health conditions. This can exacerbate mental health problems through leading to poorer engagement with social networks and hampering access to services. Tackling stigma has become a major priority for health services in recent years.

The literature also explores the financial needs of those with mental health conditions. For example, people with mental health conditions are nearly three times more likely to be in debt, and one in four tenants with mental health problems has rent arrears and is at risk of losing their home (DCLG, 2008a). **Receiving DLA or Attendance Allowance (AA) can make a significant difference to a person's financial position, and therefore it is important that all those who are entitled to DLA and AA receive it.**

### 2.3 How needs change with age

Some publications, most notably *New Horizons*, identify the varying needs of different age groups of those with mental health conditions. For older adults, depression is the most common mental health disorder (DH, 2009a, p87). Between 13 and 16 per cent of people will have depression that is sufficiently severe to require treatment. Older people living in residential and nursing care homes are particularly at risk, with up to 50 per cent having clinically severe depression, but only between ten and 15 per cent receiving treatment for this (DH, 2009a, p89). Older adults are also much more likely to suffer from cognitive impairment, with an estimated half of all older adults in acute hospital beds having some form of cognitive impairment, including dementia and delirium. The majority of these patients are not known to specialist mental health services, and their problems are not diagnosed. In fact, currently only about a third of people with dementia receive a formal diagnosis at any time in their illness (DH, 2009a, p95).

Since retirement brings a reduction in income for the majority of older people, some older people struggle financially and there are indications that debt may become more common for this age group (DH, 2009a, p84). Access to good financial and benefits advice will therefore become increasingly important.

Older people are more at risk of social isolation in general, and this can be exacerbated by mental health problems. Older people may have less regular contact with family and friends. Also the stigma of a mental health condition can potentially compound the stigma associated with old age and lead to increased isolation (DH, 2009a, p81). Older people are more likely to visit their GP regularly and those with mental health conditions view a sympathetic and understanding GP as being very important (DH, 2009a, p87). **Advice and information received from a GP about other services (including potential eligibility for AA) may therefore be critical.**

Children with mental health conditions are also likely to have particular areas of need which are related to their age. The National Child and Adolescent Mental Health Services (CAMHS) Review found a need to improve services for children with mental health conditions so that they become more holistic and child centred: so that their mental health needs are assessed alongside all their other needs, and they receive an individualised package of care which is driven by their personal circumstances (DH, 2008, p11). Clearly this can not be delivered by health services alone. One key aspect of this holistic approach is identified as ensuring that children have access to information about the full range of services available locally to help them, supplied in a range of formats to suit their preferences (ibid, p10). The Connexions service is one of the available networks for young people in providing such information in a one-stop shop ([www.connexions-direct.com](http://www.connexions-direct.com)).

**Good web-based help and information is likely to be of increased importance for the younger audience** (DCLG, 2008a and 2008b) and sites need to be designed so they are child-friendly. **Parents and carers play a particularly important role for this age group and many children will hear about benefits through this route** (DWP, 2009) so communications need to reflect their needs and preferences also.

The evidence shows that the transition from child to adult services does not always happen smoothly (DH, 2009a, p39). In a health context, the reasons for this are normally around poor communication between agencies, differences in styles of working and differences in eligibility criteria (ibid, p39). Ensuring good planning and communication as children approach this age, and identifying a lead person who makes sure that the transition goes smoothly, have been shown to be good practice in a health context, and some of this learning may be translatable to the context of benefits and the service PDCS provides for this age group.

Table 2.1 Needs relating to advice on and access to benefits

	Awareness of potential entitlement	Access to the service	Application for the benefit
<b>Adults with mental health conditions</b>	<ul style="list-style-type: none"> <li>Some evidence that increased benefits information in primary care may increase awareness.</li> <li>Increasing use of ICT for information and social networking.</li> </ul>	<ul style="list-style-type: none"> <li>Telephone will be preferred means of access for most.</li> <li>Some will need face-to-face contact because of condition.</li> <li>Channel preferences may vary by point in time for same person.</li> <li>Increasing use of internet to self serve.</li> <li>May need flexibility in timing or length of contact, e.g. 'bite-sized chunks'.</li> </ul>	<ul style="list-style-type: none"> <li>Most find the DLA forms difficult to complete and would like them simplified.</li> <li>Some find the forms are not geared towards people with mental health problems.</li> </ul>
<b>Children with mental health conditions</b>	<ul style="list-style-type: none"> <li>Key networks likely to be friends, family, carers, key worker, GP.</li> <li>Multi-agency working improving for children but there may still be gaps.</li> <li>More confident than adults with use of ICT.</li> </ul>	<ul style="list-style-type: none"> <li>Overall services could be more child-friendly.</li> <li>More likely to need help from carer or appointee.</li> </ul>	<ul style="list-style-type: none"> <li>May need help with application process from family or carer.</li> </ul>
<b>Older adults with mental health conditions</b>	<ul style="list-style-type: none"> <li>May be in hospital or residential care.</li> <li>Increased chance of social exclusion.</li> <li>Condition may not have been diagnosed e.g. dementia or depression.</li> <li>GP plays an important role.</li> <li>Less likely to use ICT.</li> <li>Less likely to hear about benefits through informal channels.</li> </ul>	<ul style="list-style-type: none"> <li>Physical conditions may compound access difficulties, e.g. hearing on the telephone.</li> <li>Less likely to use internet to self serve.</li> <li>Websites should be tailored for ease of navigation for the cognitively impaired.</li> </ul>	<ul style="list-style-type: none"> <li>AA forms considered very complex and difficult to complete.</li> </ul>

Continued

Table 2.1 Continued

	Awareness of potential entitlement	Access to the service	Application for the benefit
<b>People with severe mental health conditions</b>	<ul style="list-style-type: none"> <li>• Likely to be in regular contact with secondary care services.</li> <li>• Key worker plays a crucial role in helping to navigate the system.</li> <li>• Internet may provide a 'safe' way of accessing information.</li> <li>• Unlikely to be in work.</li> <li>• May have multiple barriers, e.g. homeless, drug users, prison.</li> </ul>	<ul style="list-style-type: none"> <li>• May be specific access barriers relating to their condition, e.g. 'hearing voices' on the telephone or anxiety in public places.</li> <li>• May be specific times when contact is easier, e.g. to fit with medication, mood.</li> </ul>	<ul style="list-style-type: none"> <li>• Most find the DLA forms difficult to complete and would like them simplified.</li> <li>• Some find the forms are not geared towards people with mental health problems.</li> </ul>
<b>People with learning disabilities</b>	<ul style="list-style-type: none"> <li>• More likely to find out about benefits from family or carer.</li> <li>• Limited contact with friends.</li> <li>• Most have access to computer and many use the internet, e.g. for social networking, but may need adaptations to make use of this technology.</li> </ul>	<ul style="list-style-type: none"> <li>• Likely to need support from an advocate or appointee to ensure needs met.</li> <li>• Telephone preferred channel for most – but are barriers, e.g. lack of visual prompts.</li> <li>• Combining visual and verbal methods can aid understanding.</li> <li>• Written communications and websites should use plain English, plain backgrounds and use of pictures to aid understanding.</li> <li>• Interactive material can aid understanding.</li> </ul>	<ul style="list-style-type: none"> <li>• Forms need to use plain English and visual prompts combined with narrative.</li> </ul>

## 2.4 Understanding needs: people with learning disabilities

In common with people with mental health conditions, people with learning disabilities are likely to have a varied and complex set of needs and it is important to assess the needs of each person individually (DCLG, 2008b, p13). They are likely to find some everyday activities, such as reading, writing and speaking, significantly more challenging (DCLG, 2008b, p13) and this may cause significant barriers when they are accessing services (explored in more detail in Section 3.3). **They may need help with time keeping and remembering things – which clearly has implications in terms of meeting pre-planned appointments with services.** They are less likely to have regular contact with friends and family, although peer support groups are an important social activity for some (DCLG, 2008b, p21). They are much more likely to be reliant on others for some aspects of daily living; for example over half of people with learning disabilities say someone else decides how much money they can spend each week (DCLG, 2008b, p7). **Therefore for some, claiming and spending DLA or AA will require support from a carer, intermediary or advocate.**

People with learning disabilities may be marginalised within the community and suffer negative attitudes from others. Less than ten per cent of adults with learning disabilities are in work (DCLG, 2008b, p7). They are also potentially more vulnerable to bullying and manipulation (DCLG, 2008b, p12) and services should be designed to counteract this. Advocates and appointees may play an important role in ensuring their voice is heard and their needs met (explored in more detail in Section 2.6). **The literature points to transition points in terms of both age and events (DCLG, 2008b, p29).** A key transition point in terms of age is that from childhood (pre 16) to young person (16 plus). This transition throws up many questions; for example around whether the young person will continue with education or move into employment, and what role day services will play. The evidence shows that if suitable support and opportunities are made available at this stage then the life opportunities of people with learning disabilities can be significantly improved as well as their sense of inclusion (DCLG, 2008b, p29). Event-based transitions might include changing accommodation or finding employment. Again, effective interventions by services at these points can significantly improve the life opportunities of the individual by putting more choice and control in their hands (ibid, p29).

## 2.5 Needs relating to advice on and access to benefits

Table 2.1 summarises the key findings from the literature regarding the needs and preferences of people with mental health conditions and/or learning disabilities relating to advice on and access to benefits. This is categorised according to their needs at the first three key stages in the customer journey, relating to awareness of potential entitlement, access to the PDCS service, and application for the benefit. This summarises the key findings which are expounded in more detail in the following sections of the report.

## 2.6 The role and extent of use of advocacy

The Independent Advocacy Campaign defines advocacy as ‘taking action to help people say what they want, secure their rights, represent their interests and obtain services they need’ (Lewington and Clipson, 2004, p11). There is a strong body of literature setting out good practice in advocacy and why and how it can be helpful to service users, particularly those with mental health conditions and/or learning disabilities. Barnes *et al.* (2002) identify the core purposes of advocacy as:

- to help to safeguard the rights of service users – both rights under mental health policy and law, and rights as citizens;
- to empower service users to make informed decisions about their care and treatment and to take greater control over their lives;
- to support service users to get their views heard;
- to represent the views of service users;
- to support service users in seeking resolution to issues which concern them;
- to protect service users who are particularly vulnerable for reasons of their illness or lack of capacity to make informed decisions;
- to feedback issues raised by service users to service providers so that services can be constantly improved.

**Table 2.2 Advocacy models**

<b>Casework/formal advocacy</b>	Advocacy provided by paid advocacy ‘caseworkers’ under the auspices of a formal advocacy scheme. Advocates work with a number of service users on a short to medium-term basis and adopt a problem-solving approach.
<b>Citizen advocacy</b>	One-to-one, volunteer-based advocacy. Usually long term, with the benefit that the citizen advocate is completely independent of health and social care systems.
<b>Peer advocacy</b>	Service users or ex-service users supporting each other to speak up.
<b>Collective advocacy</b>	Groups of service users coming together to speak out on collective issues, for example via Patients Councils.
<b>Self advocacy</b>	Service users being supported and feeling empowered to speak for themselves.

Source: Henderson and Pochin, 2001.

The literature identifies a wide range of models of advocacy and different forms of support provided, as summarised in Table 2.2. Self-advocacy is growing increasingly prominent within the literature and is closely tied to the personalisation agenda within social care. Advocacy may be provided formally – for example, by support workers, social services or voluntary support groups such as Citizens Advice – or informally by family or friends. However those falling under the Mental Health Act have a right to specialist advocacy, and local authorities and health authorities must ensure that such services are available for these service users in their area.

The literature describes the increase in the profile, funding and provision of advocacy over the last 20 to 30 years, and particularly within the last ten years (Social Care Institute for Excellence (SCIE), 2009; Hussein *et al.*, 2006). The emphasis placed on advocacy in *Valuing People* (DH, 2001) and *Valuing People Now* (DH, 2007) together with the introduction of a statutory right to advocacy for some groups under the Mental Health Act (from 2005) have been key drivers of this. There are now many hundreds of small, local mental health advocacy schemes around the country. Many of these are entirely independent and often user-led, whilst others are run and managed by larger charities such as Mind, Rethink and the Richmond Fellowship (Henderson, 2003, p8).

Whilst it is clear that the extent of advocacy provision has significantly increased in recent years, there is little coverage in the literature regarding the extent to which those with mental health conditions and/or learning disabilities are accessing these services, and their experience of using them. Although our review uncovered a number of local area evaluations of advocacy commissioned by local authorities, we did not find any national reviews of advocacy services within the last few years. However, going back a little further, Henderson reported in 2003 that 'despite the large number of schemes, **advocacy provision remains patchy**, with some areas well served and others lacking'. Lewington and Clipson (2004) also identified a number of shortcomings in provision of and access to advocacy services, particularly for those with physical, sensory, communication, and profound and multiple impairments. Their work found that, although these groups were likely to benefit from the support of an independent advocate, there was inadequate provision for them, and where provision was being accessed it was not always meeting their needs. The main causes of this were identified as lack of funding and lack of appropriate skills and experience with working with these groups. More recently, the SCIE have identified 'serious gaps' in the provision of advocacy services for African and Caribbean men, despite their over-representation in the mental health system (Newbigging *et al.*, 2007).

Research carried out by the DWP in 2007 provides insight into some of the situations where customers use advocates and appointees when engaging with DWP services, and their reasons for doing this (DWP, 2007). Formal third-party advocacy was used where customers received established and ongoing support with their day-to-day living, for example, the support of an occupational therapist or a Barnardo's support worker. Advocacy from a formal agency such as Citizens Advice was more likely in the event of a problem when making or changing a claim. Interviewees in this research described the beneficial role of their advocate in giving them more confidence, and in knowing that support is there if their condition causes them difficulty at any stage of their engagement with the DWP. Informal support was normally provided by family and friends, and the most common reason for using this instead of formal support was the convenience and flexibility it offered. The research found that both staff and customers could see a number of benefits of formal advocates over informal ones.

Research indicates that customers are more likely to be successful in their claim for DLA if they receive professional or 'informed' assistance with the application form itself (Banks and Lawrence, 2005, p303). It is therefore critical that the PDCS ensure that those who face particular barriers to access as a result of their mental health condition or learning disability have access to the full range of support that they need in communicating their needs and navigating the application process – whether from advocates or otherwise. **Because advocacy plays such an important role in overcoming these barriers particularly for the most excluded groups, we suggest that the PDCS will need to work closely with its partners to ensure access to advocacy services.**

## 2.7 Chapter 2 summary – understanding needs

### 2.7.1 Key findings

- People with mental health conditions and/or learning disabilities do not represent homogenous groups.
- They are more liable to experience wider factors associated with social exclusion and this can present barriers to them accessing information and support.
- The literature advocates a strongly personalised approach to service provision for them.
- Receiving DLA or AA can make a significant difference to a person's financial position, and therefore it is important that all those who are entitled to DLA and AA receive it.
- There is concern in the literature that some people receiving DLA or AA fear that entering employment may trigger a review of their eligibility to receive the benefit, even though this is not actually the case.
- Parents and carers play a particularly important role for the under 16s and many children will hear about benefits through this route.
- Good web-based help and information is likely to be of increased importance for the younger audience.
- People in these groups may need help with timekeeping and remembering things – which has implications in terms of meeting pre-planned appointments with services.
- Advocates can play an important role in removing some of these barriers, but advocacy provision is patchy, both geographically and in terms of meeting the needs of particular groups.
- Older people are more likely to visit their GP regularly, and those with mental health conditions view a sympathetic and understanding GP as being very important – therefore advice and information received from a GP about other services is likely to be critical.

### **2.7.2 Recommendations**

- Ensure staff have the training to understand the impact of mental health conditions and/or learning disabilities.
- Increase staff awareness of the different communication needs of these groups.
- Ensure good web-based information is available, tailored to the needs and preferences of different age groups.
- Ensure that awareness-raising communications reach parents and carers as well as potential customers.
- Communicate clearly that entitlement for DLA/AA is not related to income or employment status.
- Improve links with and signposting to advocacy services.



# 3 Service provision and access

## 3.1 Gaps in service provision

There was no coverage in the literature of gaps in service provision specifically related to the Pension, Disability and Carers Service (PDCS). However, there was some coverage regarding gaps in services in general for those with mental health conditions and/or learning disabilities, with a few key themes emerging. Firstly, there may be gaps resulting from missed or inaccurate diagnosis of conditions (Department for Communities and Local Government (DCLG), 2008a). The reasons for missed diagnosis might include inadequate provision of services, the failure of services to effectively reach out to hard-to-reach groups, or barriers to individuals accessing services (discussed in the next chapter). One example of an area where missed diagnosis is particularly prominent relates to dementia, where it is estimated that only about one third of people with the condition receive a formal diagnosis at any time in their illness (Department of Health (DH), 2009a, p95). Even though eligibility for Disability Living Allowance (DLA) and Attendance Allowance (AA) is not based on diagnosis but on assessment of need, we might hypothesise that if a person's condition has not been diagnosed they will be less likely to claim for one of these benefits – because they will be less likely to be aware of their potential eligibility or to hear about this from health professionals. However, we could not identify any evidence in the literature to either support or disprove this hypothesis. Further research may therefore be required in this area.

Secondly, the literature identifies a number of hard-to-reach groups that are at greater risk of experiencing mental health problems but that, because of the complexity of their need, often receive a poor service from statutory agencies and experience greater levels of social exclusion. The most notable groups are summarised in Table 3.1.

**Table 3.1 Hard-to-reach groups**

<b>Drug and alcohol misusers</b>	An estimated 30 to 50 per cent of those misusing drugs have a mental health problem. Approximately 50 per cent of adults dependent on alcohol report a mental health problem.
<b>Prisoners</b>	The prison population exhibits very high rates of mental health problems. Seventy-two per cent of male and 70 per cent of female sentenced prisoners have two or more mental health disorders. Prevalence rates for psychotic disorders are high. DLA/AA are not normally payable to prisoners, depending on the nature of the sentence.
<b>The homeless</b>	One in four deaths amongst homeless people is due to suicide. The data shows that an estimated 30 to 50 per cent of rough sleepers have mental health problems.
<b>Refugees</b>	Refugees experience higher rates of both common and severe mental health problems. Studies show two-thirds of refugees experience depression or anxiety.  Rates of psychosis among white people migrating to predominantly white communities are twice as high as the general population, and four times as high among black people.
<b>Post traumatic stress disorder</b>	This condition is often not recognised for a variety of reasons, including the person affected not wanting to talk about their experiences, or a tendency on the part of the individual and of professionals to focus on the range of symptoms that go along with it rather than the underlying condition. This can therefore inhibit access to help for those affected.
<b>Learning disabilities</b>	Approximately 25-40 per cent of people with learning disabilities experience risk factors associated with mental health problems.

Source: DCLG, 2008a.

Thirdly, the literature points to instances of a lack of joined up working between agencies to meet individual needs (DCLG, 2009a). This applies across a range of areas but is particularly pertinent in the case of people with complex needs (such as the groups listed in the first column of Table 3.1), together with older people and also children. *New Horizons* stresses that addressing the complex and often broad-ranging needs of older people with mental health conditions:

*'...requires multi-agency interventions at multiple levels. Local authorities, health services, third sector agencies and communities all have a role to play in tackling the barriers to continued mental health and well-being into older age.'*

(DH, 2009a)

Similarly, the final report of the National Child and Adolescent Mental Health Services (CAMHS) Review identified that:

*'Administrative and legal processes, unhelpful thresholds for access to services and some entrenched professional views can 'parcel up' children into individual services and prevent their needs being met in a holistic, flexible and responsive way, or leave their needs unaddressed.'*

(DH, 2008)

The same report identifies particular problems with gaps in services in the transition from child to adult services, which is well evidenced in the literature.

## 3.2 Good practice in providing services

There is a strong body of literature which highlights good practice in providing services for people with mental health conditions and/or learning disabilities, particularly from the field of social care.

One of the strong over-arching themes is the emphasis on personalising services. This includes giving individuals more choice and control over what support and help they access and how they access it. It also includes providing more flexible and coordinated support which is tailored to the needs of the individual.

One of the key mechanisms for achieving this, in a health context, will be the introduction of personal budgets for some people with mental health conditions. Personal budgets have been used for some time in a social care context and are currently being piloted in the health service.

Strongly related to this are person-centred approaches which are defined as:

*'...a systematic way to generate understanding of a person with developmental disability as a contributing community member.'*

(Lewington and Clipson, 2004)

Again this has grown largely out of the social care literature, and relates in particular to planning for the needs of people with learning disabilities, but it clearly has applicability to others services also. For example, Sanderson (2004) argues that the person-centred approach is about:

*'...listening, learning and focusing on what is important to the person and working with others to act on this and make things happen.'*

(Sanderson, 2004)

Taking a person-centred approach, by implication, means that **multiple agencies must work together effectively** to deal with the needs of the individual in a holistic manner. Support should be integrated across different life domains, such as health, employment and social. In the case of children, the National CAMHS Review emphasised the importance of children's mental health needs 'being assessed alongside all their other needs, no matter where the need is initially identified' (DH, 2008). This should result in an 'individualised package of care' which addresses both their care and wider support needs, tailored to their personal circumstances.

One of the key implications of personalisation and joined up working for benefits services is that, as far as possible, **single assessments should be carried out and information shared between agencies to avoid individuals having to supply the same information about their circumstances to different agencies**. DH wants to move towards 'a comprehensive single assessment followed by sharing of information with other agencies as appropriate' (DH, 2009a, p59). One example of emerging good practice in this area is two pilots in London that have explored the potential for streamlining the application and assessment process for AA with

social care assessment. The results have been positive, showing significant benefits for both customers and the agencies involved. The new approach was found to improve access, reduce duplication and increase the speed of the process (DWP, 2008).

The Audit Commission website (2009) identifies good practice in increasing take-up of those eligible for benefits, particularly for vulnerable and excluded groups, as implemented by local councils. Although this comes from a different context to DLA and AA, many of the principles may be transferable. The review found that **'tailored promotional work designed to suit the profile of the community can help to increase the success of take-up campaigns'**. They found that successful take-up campaigns included:

- producing flyers and posters and distributing them across a range of venues including leisure facilities, doctors' and dentists' surgeries, landlords, voluntary sectors agencies and religious centres;
- placing articles in the local newspaper, including 'entitlement checkers';
- producing bulletins to raise awareness;
- good web-based information;
- mail shots to households in more deprived areas.

The Audit Commission also identifies the importance of working innovatively with partners to increase benefit take-up. For example, one council worked with The Pension Service, attending 'flu-jab clinics and community centres to encourage pensioners to take up benefits. Another acted on feedback from local voluntary organisations and the Citizen's Advice Bureau regarding lack of accessibility for local elderly residents, and set up a targeted outreach team to address this.

This research also found that the **design of the benefits claim form can improve take-up**. They found that 'a well designed form helps to reduce the barriers to making a claim, encourages customers to give better information and helps to reduce claim processing times' (Audit Commission, 2009).

The PDCS will need to consider how it can implement good practice such as this in improving access for vulnerable and excluded groups such as those with mental health conditions and/or learning disabilities, and particularly older people. As shown by the Audit Commission, this may need to include focussed communications activity including media campaigns that reach those most likely to be eligible through channels that are appropriate to them, and communicate clearly the eligibility criteria for the benefits. However, more work would be required to understand whether such an approach would be appropriate and effective in the context of PDCS benefits.

Some of the literature highlights good practice in communicating with people with mental health conditions and/or learning disabilities. Some of the key principles are:

- **User involvement and consultation in design**

This is critical in ensuring that communication channels meet the needs of people with learning disabilities and mental health conditions. Mencap and Young Active People (YAP) (now young.Mencap) are cited as good practice websites that have been designed in consultation with users to meet their communication needs (DCLG, 2008b, p35). It is important that this consultation actually shapes the design of communications and is not seen as tokenistic (Allen, 2007).

- **Flexibility**

Research into Jobcentre Plus found that staff working in the service should not be bound by rigid scripts, time limits or specific communication methods (Department for Work and Pensions (DWP) 2007). Some of this learning may be transferable to PDCS. For example, some customer's conditions may mean that it is easier for them to have several 'bite-sized' telephone calls or meetings rather than doing it all in one go (DWP 2007, p32). Some customers prefer to arrange a time to be called back which fits with their daily routine, others might prefer to choose a time which suits them and how they are feeling at that point. Also, **due to the fluctuating nature of many mental health conditions, the same person may want to engage differently with the same service at different points in time.**

- **Using a range of communication channels**

People with mental health conditions and/or learning disabilities are not homogenous groups and channel preferences vary markedly, some related to the person's condition and some to other factors such as age and personality. This is explored in more detail in Sections 5.2 – 5.4.

- **Continuity of case handling**

This enables staff to develop rapport with the customer. In instances where the case needs to be passed to another colleague, staff should capture and share information on any communication needs which have been disclosed or identified (DWP, 2007, p46).

In addition, some of the literature draws out good practice relating specifically to communicating with people with learning disabilities, as summarised in Table 3.2.

**Table 3.2 Good practice in communicating with people with learning disabilities**

Use of videos, pictures and interactive DVDs	Use of videos and pictures can facilitate communication and comprehension among customers who find text-based communication challenging. Interactive DVDs support customers in working at their own pace, in their own time.
Appropriate use of technology	This could include specially designed hardware and software, such as voice recognition and voice dictation software, and specialised keyboards.
Clear written communications	Inserting symbols and pictures into text can aid comprehension, for example to illustrate situations and events. Written communication should be in simple, clear text, using easy-to-read fonts on a plain background colour.
Clear verbal communications	Presence of an advocate where desired by the customer, taking longer to explain questions where appropriate.

Source: DCLG, 2008b.

### 3.3 Barriers to increased take-up of benefits

There is concern in the literature that many people with disabilities who are eligible for DLA do not claim the benefit (Banks and Lawrence, 2005, p302). The extent to which this applies to people with mental health conditions and/or learning disabilities is not known, is difficult to approximate, and is not within the scope of this literature review. The DWP may wish to explore this issue further.

Some portions of the literature explore the organisational barriers which people with mental health conditions and/or learning disabilities face when accessing benefits. Wiggan and Talbot (2006) highlight that **mental health users have particular problems with the complexity of the benefits system, exacerbated by rapid and ongoing changes in their circumstance and compounded by a lack of awareness about how to access appropriate advice** (Wiggan and Talbot, 2006).

Some of the key organisational barriers relate to agencies not working effectively together, and the barrier of securing ownership and support from other agencies to a common agenda. For example, Banks and Lawrence (2005) found that if other partners and agencies provide advice and assistance around DLA, the 'financial implications in terms of the amount of time that social workers, voluntary organisations, welfare rights officers and health professionals spend on providing this assistance must be considerable' (Banks and Lawrence, 2005, p313). They note that GPs are particularly wary of having such advice services based out of their practices.

Children and older adults face particular barriers as a result of a lack of a joined-up approach from agencies. *New Horizons* stresses that meeting the needs of older people 'requires multi-agency interventions at multiple levels. Local authorities, health services, third sector agencies and communities all have a role to play in tackling the barriers to continued mental health and wellbeing into older age'

(DH, 2009a, p81). Meanwhile, the National CAHMS Review found that 'children and young people say that services are not as well known, accessible, responsive or child-centred as they should be' (DH, 2007). **The PDCS will need to work ever more closely with its partners in delivering support to individuals that is built around the needs of the person rather than the convenience of organisations.**

The PDCS Equality Scheme provides particular insight into some of the specific barriers that people with mental health conditions encounter when engaging with the service:

*'We talked to customers with mental health disabilities. They told us about these things that can make things hard for them. They **often have problems using our services**. They said our **leaflets are hard to understand**. They said our **claim forms are scary** because they are very long and hard to understand. Most want us to contact them by telephone, not by letter. Many have a care plan from their care worker, but they did not know this is important and should be sent in with their claim. **It may be hard for them to tell us about their needs and how their mental health disability affects them**. Sometimes they do not understand the letters we send them showing our decision on their claim. As a result, **they do not understand our decision**.'*

(PDCS Equality Scheme 2008-11, emphasis mine)

These organisational barriers may be experienced at various points throughout the customer journey from becoming aware of their potential eligibility for the benefit through to decision on award. Table 3.3 summarises the key barriers identified from the literature, and these are explored in more detail in the narrative that follows.

**Table 3.3 Barriers to take-up during the customer journeys**

<b>Awareness</b>	<b>Access</b>	<b>Application</b>
<ul style="list-style-type: none"> <li>• unaware of potential eligibility/poorly publicised</li> <li>• lack of formalised routes for informing about DLA/AA – reliant on informal networks</li> <li>• condition undiagnosed or mis-diagnosed</li> <li>• other professionals/agencies do not 'signpost' to PDCS</li> <li>• lack of access to the web</li> </ul>	<ul style="list-style-type: none"> <li>• written communications not tailored to needs</li> <li>• communication channel not appropriate to the person's condition</li> <li>• physical setting aggravates the condition</li> <li>• inflexible approach from staff</li> <li>• stigma</li> <li>• difficulties in disclosing/expressing communication needs</li> </ul>	<ul style="list-style-type: none"> <li>• complex application form and process</li> <li>• process more geared towards physical than mental health conditions</li> <li>• form is too long</li> <li>• people not aware of support available for filling-in the application form</li> </ul>

### 3.3.1 Lack of awareness

Banks and Lawrence report that 'lack of information regarding the existence of the benefit and ignorance or misconceptions concerning the criteria for eligibility are the first notable barriers to application' (Banks and Lawrence, 2005, p302). They go on to analyse this, identifying that the most frequently cited sources of information about the benefit are 'casual sources' such as friends and relatives, with less than ten per cent of claimants having heard about the benefit from their GP or GP's surgery. This is likely to cause particular barriers to awareness for people with mental health conditions and/or learning disabilities because, as identified in Section 2.2, they may be more likely to experience social exclusion, have more limited networks of friends and family, and potentially be more reliant on professionals such as their GP or key worker. Whilst of course GPs are not expected to be providers of benefits advice, the literature does suggest extending benefits advice into primary care may have advantages in reaching certain subsets of those with mental health conditions or learning disabilities. (Wiggin and Talbot, 2006). Banks and Lawrence note that, in general, **advice and 'signposting' about disability benefits from other agencies and professionals could be significantly improved, and that the advice should be made available through more formal routes as well as informal networks.**

Many of the people in the Banks and Lawrence study simply did not think that DLA applied to them (Banks and Lawrence, 2005, p305) and this appears to be a particular issue amongst those with mental health problems.

### 3.3.2 Barriers to access

Barriers to access include unclear written communications and communication channels that do not match the preference of the customer (PDCS Equality Scheme 2008-11). It could also include physical environments that are unhelpful for their condition, for example crowded waiting rooms and lengthy waiting times could result in increased anxiety for people with some forms of mental health condition (Wiggin and Talbot, 2006). Both people with mental health conditions and/or learning disabilities are likely to **require a more flexible approach to communications** from the service in line with their needs and preferences. For example, telephone calls where the staff member sticks very rigidly to a script, or is under pressure to complete the call quickly, may well create a barrier to understanding or lead to increased anxiety (DWP, 2008, p21). MIND indicate that an additional barrier is that for some of the more common and often short term expressions of mental distress, such as anxiety and depression, **over-familiarity can lead to staff underestimating how severe and incapacitating these conditions can be** (DWP, 2008, p16).

The literature reveals that particular barriers to access for those with mental health conditions may include:

- lack of confidence about social interaction (because of stigma of mental illness, lack of understanding among the general public and service providers about mental illness);

- barriers due to inappropriate communication channels for their condition, for example if face-to-face contact increases anxiety, or telephone contact triggers confusion due to hearing voices;
- possible anxieties about leaving their home, using public transport, attending meetings/appointments without a helper;
- less likely than the general population to have access to a telephone/computer;
- lack of knowledge/skill/confidence in using computers;
- fears associated with using computers (possibly linked to illness, possibly just 'fear of the unknown').

(DCLG, 2008a; DWP, 2007; DH, 2009a, Wiggan and Talbot, 2006)

Particular barriers to access for people with learning disabilities may include:

- barriers due to stigma;
- barriers due to inappropriate communication channels, for example if they need visual/face-to-face communication rather than written/telephone;
- may need adaptations to make use of computers;
- negative self images, and low self-esteem, which can put people off accessing services and seeking help;
- 'learned helplessness and passivity', which can prevent people with learning disabilities from seeking help or advice themselves. They may have developed a reliance on others (carers/family/partners) to do things for them, making it difficult to develop new skills for independent living;
- not knowing where to go for help, and not always feeling able to access help even if it was known where to look.

(DCLG, 2008a; DWP, 2007; DH, 2009a, Wiggan and Talbot, 2006)

Research by the DWP on access to Jobcentre Plus services by those with specific communication barriers (DWP, 2008) identified a barrier related to the point at which a person discloses, or is asked to disclose, their condition and any associated communication needs:

*'A big issue in the study was the point at which the disclosure of barriers took place during the call. At present, unless the customer volunteers this information, the question about communication barriers does not appear until a long way through the script...'*

*'Jobcentre Plus expect people to pick up the phone and say, "hello, my name is blah, blah, blah and I've got a mental health problem, I need some adjustments, help me". And for the most part people with mental health problems are very unlikely to do that...'*

*'...staff interviewed generally focused on communication barriers brought about by physical disabilities and language, rather than hidden disabilities such as mental health and learning difficulties.'*

(DWP, 2008, p30)

### 3.3.3 Complexity of the application process

The literature describes a complex and lengthy application process for DLA and AA which represents a potential barrier to take-up in general, but particularly for those with mental health conditions and/or learning disabilities. The DCS Customer Service Survey 2008 (DWP, 2008) found that a higher proportion of customers with learning disabilities (67 per cent), communication difficulties (64 per cent) and psychological or behavioural disabilities (61 per cent), than average (53 per cent) would like easier-to-understand claim forms.

Similarly, research carried out in Scotland in 2005 on a sample of 528 people who had applied for DLA found that 97.3 per cent of customers in general found the DLA claim form difficult to complete. Several respondents thought the form was too long, and others felt that **the forms were not always appropriate for people with mental health problems** or sensory impairments (Banks and Lawrence, 2005, p306). Other research conducted by the DWP found that:

*'...the mainstream AA application process was described by an experienced service provider as 'the most time consuming of all' those procedures relating to accessing welfare benefits. Other interviewees described it as 'off-putting' and 'a deterrent' to potential claimants.'*

(DWP Research Report No. 534, 2008)

### 3.3.4 Barriers resulting from assessment, appeal and award processes

The literature does not explicitly cover these areas, and further research would be required to identify whether people with mental health problems and learning disabilities experience barriers in the latter stages of the claim process as well as near the start, and whether this results in lower success rates from applications for these groups.

The literature does however hint at some potential issues:

- Assessment – research identifies that, where an independent medical examination takes place, customer satisfaction with this process varies greatly and some customers report that they did not feel the examiner understood their condition. Further work would be required to identify if this is a particular issue for people with mental health conditions and/or learning disabilities.
- Appeal process – the research indicates this can be a long and stressful process. Potentially this may disproportionately impact on people with some mental health conditions, for example if their condition is triggered or amplified by stress.

- Award – research has indicated ‘inconsistencies in award decision making’ which potentially may particularly impact on people with mental health conditions, due to the increased complexity and variability of these conditions in terms of how they impact on day-to-day living, compared with some physical disabilities – therefore making award decision making more complex.

(Banks and Lawrence, 2005)

## 3.4 Chapter 3 summary – understanding service provision and access

### 3.4.1 Key findings

- The research reveals that mental health users have particular problems with the complexity of the benefits system, exacerbated by rapid and ongoing changes in their circumstances and compounded by a lack of awareness about how to access appropriate advice.
- A lack of joined-up working between agencies causes particular problems for children, older adults, and those with complex needs.
- Taking a person-centred approach means that multiple agencies must work together effectively to meet the needs of the individual – for example, where possible single assessments should be carried out and information shared between agencies to avoid individuals having to supply the same information about their circumstances to different agencies.
- The literature suggests that advice and ‘signposting’ about disability benefits from other agencies and professionals could be significantly improved, and that the advice should be made available through more formal routes as well as informal networks.
- Good practice in communicating with these groups involves:
  - user involvement in design;
  - flexibility in when, where and how new or existing customers engage with services;
  - presenting information in a way that aids comprehension.

### 3.4.2 Recommendations

- Consider carrying out further research to establish if there are any gaps in service provision from PDCS for potential and existing customers with mental health conditions and/or learning disabilities.
- Increase awareness of potential eligibility for particular conditions which are commonly undiagnosed, e.g. dementia.

- Increase customer awareness of different ways to access the service, e.g. face to face.
- Consider implications when revising claim forms.
- Involve people with mental health conditions and/or learning disabilities in the design of the application form to ensure it is tailored to their needs.
- Consider carrying out further research to understand whether and to what extent people with mental health conditions and/or learning disabilities who are potentially eligible for DLA/AA are not claiming, and why.
- Compare appeal rates for those with mental health conditions and/or learning disabilities with other groups, e.g. are they more likely at to drop out, and if so why?
- Explore opportunities to improve the appeal process.

# 4 Networks, partners and links

## 4.1 Networks, partners and links

Literature on networks relating to the identified research objectives was found to be patchy. Whilst there is a reasonable body of literature covering the types of networks and partners these groups commonly engage with, there is less detail on how effectively these networks and partners interface with benefits advice services.

Claimants for Disability Living Allowance (DLA) and Attendance Allowance (AA) may make contact directly with the Department for Work and Pensions (DWP), or may be referred from another service such as a hospital, GP or local authority, by a charity, or by a family member or carer. The literature details the formal and informal networks that people with mental health conditions and/or learning disabilities most commonly engage with, and these are summarised in Table 4.1.

**Table 4.1 Formal and informal networks, partners and links**

	<b>Mental health</b>	<b>Learning disabilities</b>
<b>Formal</b>	<ul style="list-style-type: none"> <li>• key worker/support worker</li> <li>• community psychiatric teams</li> <li>• occupational therapist</li> <li>• GP</li> <li>• social worker</li> </ul>	<ul style="list-style-type: none"> <li>• doctors</li> <li>• nurses</li> <li>• occupational therapist</li> <li>• advocates</li> <li>• community care</li> <li>• social worker</li> </ul>
<b>Informal</b>	<ul style="list-style-type: none"> <li>• workplace</li> <li>• librarian</li> <li>• help lines/websites such as SANE, Samaritans</li> <li>• local offices of national organisations (e.g. MIND)</li> <li>• Citizens Advice Bureau</li> <li>• online support networks</li> </ul>	<ul style="list-style-type: none"> <li>• family members provide a huge range of support</li> <li>• voluntary organisations, e.g. day centres, employment projects and befriending schemes</li> <li>• community and online support networks</li> </ul>

Source: Department for Communities and Local Government (DCLG) Digital Exclusion Profiling October 2008.

The literature suggests that **DLA claimants are particularly reliant on informal networks such as family and friends to let them know about the benefit** (Banks and Lawrence, 2005, p302). The Disability and Carers Service (DCS) Customer Service Survey 2008 found that overall, family and friends continue to be the main source of information about DCS allowances, with just over one-third (35 per cent) of customers having first heard about the service in this way, but for customers with mental health conditions this was lower (29 per cent) (DCLG, 2008b, p257).

Family members provide a huge range of support to people with learning disabilities (DCLG, 2008b) but this group are less likely to have regular contact with friends, with one in three saying they do not have any contact with friends and many others only having contact with other people with learning disabilities (DCLG, 2008b, p7). They are therefore likely to be very reliant on family members in hearing about their potential eligibility to claim. Customers with mental health conditions and/or learning disabilities are both more likely than others to find out about benefits from a carer (DCLG, 2008b, 257).

The health sector has an important role to play in signposting patients to other services, including benefits advice, though arguably they could play a much greater role. The DCS Customer Service Survey 2008 found that around one in five people hear about DCS allowances from another public service. Other research has shown that they are comparatively unlikely to hear about DLA from a GP, with less than ten per cent finding out through this route (Banks and Lawrence, 2005, p302).

Table 4.2 details the key venues identified in the literature where people with mental health conditions and/or learning disabilities are likely to access support. Some of the literature highlights that **delivering welfare rights advice in a primary care setting can improve access to this advice for hard-to-reach groups, including people with mental health problems, and older people in particular** (Wiggan and Talbot, 2006). The literature suggests that GPs are often quite resistant to increased availability of benefits help and advice in their practices (Abbott and Hobby, 2003), although these authors suggest that 'they might be persuaded to change their minds if they were made aware that, for example, over half of the patients likely to use the service were eligible for disability benefit, and therefore, that advice services can help to reduce health and social inequalities locally'. Some of the literature is more sceptical about the value of increasing access to benefits advice within GP practices, suggesting that people with mental health problems are not necessarily heavy users of GP-based services (Abbott and Hobby, 2003).

**Table 4.2 Key venues****Venues where people with mental health conditions and/or learning disabilities may access support**

- GP surgeries
- day centres/'drop in centres'
- libraries
- leisure centres
- parks
- voluntary workplaces (e.g. community gardening projects, animal shelters, charity shops, etc)
- community colleges/further education colleges
- local arts centres
- Jobcentre
- social housing association offices/facilities
- psychiatric care home

Source: DCLG Digital Exclusion Profiling October 2008.

There may be other opportunities for the DWP to work more closely with health sector partners. For example, in secondary care some mental health trusts are developing 'information prescriptions' which are intended to provide patients with the full range of information they need not just about health services locally but also about other relevant services (Department of Health (DH), 2009a, p63). **Linking information and advice on benefits into health service initiatives such as these could provide an opportunity to increase awareness of potential eligibility for DLA and AA** and to ensure that people access a holistic support.

Table 4.3 summarises a piece of research into where people with mental health conditions go to for health information. It therefore highlights some of the key channels that could be used for information and advice relating to benefits for this group, if partnership working can be improved between the DWP and these networks.

**Table 4.3 Preferred sources of mental health information**

Rank	Source of information on mental health issues
1	Mental health professional
2	GP
3	Leaflets from the National Health Service or voluntary sector organisations
4	Someone else with the same mental health problem
5	Television or radio programmes
6	Friend or family member
7	Newspaper or magazine articles
8	Internet
9	Charity or voluntary organisation telephone helpline
10	Home medical encyclopaedia or similar books

Source: Powell and Clarke, 2006.

Social workers are identified as a relatively common source of information about DLA and AA (Banks and Lawrence, 2005, p302). Charities also play an important role but schemes and type of advice offered varies by area. For example, Rethink run a Reconnect Floating Support Service focused on supporting older people with dementia, which includes helping them to claim benefits and maximise their income, but this only covers certain parts of the south of England (DH, 2009a, p93).

There is an increasing awareness in the literature of the linkages between mental health conditions and debt, and some partners such as the Money Advice Liaison Group, the Royal College of Psychiatrists and the Citizens Advice Bureau are seeking to provide better advice to this group, including advice on benefits (DH, 2009a, p54).

The literature identifies some differences in the networks that different age groups engage with. For example, younger customers are more likely to hear about allowances from family and friends, whereas older customers are less likely to. Unsurprisingly, younger customers are in broad terms more likely to be comfortable with use of technology and online communications (DCLG, 2008a) but it would be unwise to take this generalisation too far, for example with some of the literature identifying a growing group of 'silver surfers'.

In terms of health settings, older people are more likely to be seeing a GP more frequently, and are more likely to be in an acute hospital setting, with up to 70 per cent of acute hospital beds currently occupied by older people (DH, 2009a, p94). There are also many thousands of older people living in residential and nursing care homes, whom the DH identify as being a group particularly vulnerable to social exclusion. However, it should be noted that if an older person is in hospital they do not always continue to receive AA beyond the 28th day of their stay.

## 4.2 Chapter 4 summary – understanding networks used

### 4.2.1 Key findings

- Both formal and informal networks are important for engaging people with mental health conditions and/or learning disabilities.
- Formal networks are likely to include the person's key worker as a key focal point, also GPs and other health professionals such as community psychiatric teams and occupational therapists.
- Some of the literature highlights that delivering welfare rights advice in a primary care setting can improve access to this advice for hard-to-reach groups, including people with mental health problems, and older people in particular, although this is challenged by some.
- Linking information and advice on benefits into health service initiatives such as information prescriptions could provide an opportunity to increase awareness of potential eligibility for DLA and AA.

- Informally, family members play a particularly important role, together with voluntary organisations (e.g. day centres) and peer support networks.

#### **4.2.2 Recommendations**

- Investigate the potential for greater working with partner organisations to improve information provision, e.g. GPs, Primary Care Trusts, care/nursing homes, voluntary organisations.
- Work more closely with partners to improve information provision.
- Work with voluntary organisations to widen awareness of their services.
- Ensure that awareness-raising communications reach parents and carers as well as potential customers.



# 5 Customer satisfaction and channel preferences

## 5.1 Satisfaction with the Pension, Disability and Carers Service

The most comprehensive and up to date information available about satisfaction with Pension, Disability and Carers Service (PDCS) services comes from the Disability and Carers Service (DCS) Customer Service Survey 2008. This data reveals that **customers with mental health conditions tend to be among those least satisfied with the DCS** (52 per cent satisfaction rate compared with the average across all customers of 78 per cent). This group is more likely than customers in general to say that each aspect of the claim process is important, but less likely to be satisfied with the process. In particular, one in four claims they have experienced difficulties or problems when dealing with the DCS, compared with around one in six overall. This finding is corroborated by research to inform the PDCS Equality Scheme 2008-11 which found that people with mental health conditions 'often have problems using our services'.

Of those mental health customers who reported a problem, the most common are:

- challenging the decision on their claim (57 per cent of those that reported a problem);
- a lack of communication or not being kept informed (43 per cent);
- being given different answers to the same question by different staff (38 per cent).

There are some age-related differences in satisfaction levels. Overall, Attendance Allowance (AA) customers (age 65 or over) are much more likely to be satisfied with the service they receive than claimants of other benefits. It is not identified in the report on the customer service data whether there are any differences in satisfaction levels for AA claimants with mental health conditions and those with physical conditions, though this information could probably be obtained using the raw data set.

Satisfaction with the DCS is considerably higher for appointees of children than for customers overall. For instance, they are much more likely to agree that the DCS:

- provides them with an accurate and efficient service;
- keeps them informed;
- is accessible;
- uses clear written and spoken English;
- can be trusted.

The report on the customer survey provides no detail on the satisfaction with services of those with learning disabilities.

## 5.2 Channel preferences: mental health

As we have previously discussed, people with mental health conditions and/or learning disabilities do not represent homogenous groups, and as such there is likely to be considerable variation in their preferred channels for accessing services and a personalised approach needs to be adopted:

*'We've got so many vast, different needs across the board that you will find different people, what works for each one will work differently for the other.'*

(Department for Work and Pensions (DWP), 2007, p38)

Additionally, because of the nature of many mental health conditions, channel preferences for the same individual may well change at different points in time, as their experience of their condition fluctuates:

*'Mental health difficulties cover a whole range of conditions from temporary through to longer term, and take many forms. Many conditions are both temporary and fluctuating in severity, which means that individuals may have barriers at one point in time but not at another. For example, people with paranoia may find the telephone very problematic, but perhaps only on a spasmodic basis.'*

(DWP, 2007, p16)

This principle notwithstanding, there are some overall patterns which emerge from the literature regarding channel preferences. Although customers with mental health problems use written communications more commonly than other users, overall the **telephone is the preferred choice for most customers in this group** (PDCS equality scheme 2008-11; DWP, 2007, p25). However, some individuals may experience particular issues related to their condition when using the telephone, for example:

- some may struggle to concentrate for longer calls, or need to take medication;
- for some the telephone can trigger their mental health condition and make the communication barrier worse, e.g. increased stress, anxiety or paranoia:

*'Especially [for those] who...have heard voices, telephones can be extremely difficult for people and there's a couple of issues. If somebody is currently hearing voices obviously it's then difficult to speak on the phone with somebody else, but also if they have done so in the past then that could be a very scary experience to hear a voice that seems to be coming out of nowhere, that can sort of just bring back memories that people don't really want.'*

((ReThink) DWP 2007, p17)

Face-to-face communication will therefore be the preferred option for some. Research carried out by the DWP on access to Jobcentre Plus services found that **staff found it easier to identify communication barriers face to face than over the telephone, and they also found it easier to build rapport and make necessary adaptations with customers face to face** (DWP, 2007, p46).

However, the same research found staff were wary of going down the route of face-to-face interviews with customers to fill out applications because they were conscious of the significant increase in time involved. Face-to-face contact may not be suitable for some people with mental health conditions, for instance if loud or busy contexts aggravate their condition.

Customers with severe mental health problems are more likely to have a preference for using intermediaries rather than accessing services direct. Research has shown they are probably aware of a wide range of sources of help, but their key worker is likely to be the key focal point in helping them to navigate the system.

### 5.3 Channel preferences: learning disabilities

For many people with learning disabilities, **a combination of reading and listening to the same information is the best way of taking something in** (DCLG, 2008b, p22). Therefore there may be a preference to receive information, support and advice using a mix of face-to-face communication and ICT such as email, internet or telephone support. (Department for Communities and Local Government (DCLG), 2008b, p22).

That principle notwithstanding, the DCS Customer Service Survey 2008 found a **strong preference for telephone communications, with 74 per cent of people with learning disabilities saying this was the best way to get in touch with them**. However, the literature points to a number of potential difficulties and barriers with telephone contact with this group, for example:

- call routing via numbered options caused confusion for some customers;
- some struggling to concentrate for longer calls, or needing to take medication.

(DCLG, 2008b; DWP, 2007)

Face-to face-communications are the preferred option for some. The principle reasons for this are likely to be:

- because **non-verbal communication is important** to them in understanding and being understood;
- because it provides an opportunity for advocates or appointees to be a part of the meeting and to help with the communication process.

The literature reveals a number of particular issues to consider in communicating with people with learning disabilities. These are:

- that the person's communication needs may not always be outwardly perceptible, and that this can potentially cause problems and increased stress for the individual;
- that the person is likely to find long conversations and lots of questions difficult to manage, as intense and extensive periods of concentration might leave them tired and confused;
- that people with learning disabilities are in general terms more vulnerable to coercion and manipulation, and care must be taken to ensure their views and needs are fully taken into account, particularly if there is no advocate or appointee involved.

(DCLG, 2008b)

## 5.4 Use of electronic communications: mental health

Unsurprisingly, given that people with mental health conditions represent a wide group, primary research has found 'varying levels of comfort and skills in using ICT' (DCLG, 2008a, p4).

From a health perspective, the internet is playing a significant and increasing part as a source of information for people with mental health conditions. Research has found that over 20 per cent of people with a history of mental health problems have used the internet as a source of health information (Powell and Clarke, 2006). In the same research, the relative importance of the internet was demonstrated by 24 per cent of the study population identifying it as one of the top three information sources they would use if they were to have a mental health problem.

Taking a wider perspective, people with mental health problems are unlikely to have a computer at home due to the expense, but may have access to the internet through, for example, day centres or libraries (DCLG, 2008a, p4). When used, the internet provides a variety of functions for the group, including social networking, seeking employment and leisure. For some it provides an unthreatening environment in which to have contact with others. A common barrier faced by the group is a lack of ICT skills and a lack of opportunity to develop or refresh their skills (DCLG, 2008a, p4). Digital television is commonly available to the group.

The potential barriers to digital inclusion for people with mental health problems can therefore be summarised as:

- lack of access to a computer;
- lack of confidence and skills in using ICT;
- lack of effective support in using ICT.

**Older people are in broad terms more likely to experience barriers with use of technology and online communications than younger people** (DCLG, 2008a). However, it is possible to make adaptations to websites that can make them easier to navigate for older people, particularly those with cognitive impairment:

*'The style and layout had to be clear and easy to follow. Graphics were kept to a minimum to reduce download time for those not connected to broadband or with slower computers. A colour scheme and format was applied throughout to assist people who may be cognitively impaired.'*

(Pearson and Rawlings, 2008, p12)

## 5.5 Use of electronic communications: learning disabilities

The majority in this group are likely to have access to a computer (DCLG, 2004, p43). However, in common with people with mental health problems, the experience of and level of confidence with computers is likely to vary greatly amongst people with learning disabilities:

*'The perspectives of people with learning disabilities about computers and the Internet, differed, with some describing using them on a daily basis and others using them much more irregularly. Indeed, the level of people's computer literacy was quite broad-ranging. In terms of formal learning, a few people had gone on computer courses to 'keep up', as it was felt there was so much reliance on technology in modern living.'*

(DCLG, 2008b, p23)

They are likely to use computers and the internet for:

- finding basic information (travel/cinema times/places to go, etc);
- web browsing to find 'interest' sites (e.g. fan sites, downloading music, gaming sites etc);
- socialising and connecting with other people, particularly by younger people (e.g. Facebook, Myspace, and Mencap's specialised social network site for young people with learning disabilities – Young Active People (YAP) (now young. Mencap).

(DCLG, 2008b, p23)

The **design of websites can present a significant barrier to digital inclusion for people in this group**, because of the key importance of the way in which information is presented in enabling the person to access and understand the information. Websites are more attractive and accessible when writing is bigger with simple fonts and Mencap and YAP (now young.Mencap) are cited in the literature as examples of good practice.

Most people with learning disabilities are likely to have a mobile telephone (DCLG, 2008b, p23) although there are a number of associated barriers with these:

- 'text-speak' can be confusing;
- some users find modern mobile phones difficult to operate;
- some users need voice-activation to make and receive calls.

Other forms of ICT which may play a role are digital television – to which most in this group have access – and interactive DVDs for learning, which can be particularly valuable for people in this group because of the combination of visual and verbal information, and because they enable people to learn in the own way at their own speed (DCLG, 2008b, p24).

As with people with mental health conditions and with the general population, there is a noticeable age factor in use of ICT amongst people with learning disabilities, with the younger people (under 35) considerably more comfortable and familiar with using ICT. Older people were considerably more reluctant to engage with ICT, and moreover, be interested in doing so (DCLG, 2008b).

## 5.6 Chapter 5 summary – understanding satisfaction and channel preferences

### 5.6.1 Key findings

- Customers with mental health conditions tend to be among those least satisfied with the DCS.
- Telephone is the preferred communication channel for most people with a mental health condition or learning disability.
- However, the evidence suggests staff find it easier to identify communication barriers face to face than over the telephone, and they also found it easier to build rapport and make necessary adaptations with customers face to face.
- People with mental health conditions and/or learning disabilities reflect the wider population in that there is a wide range of experience and level of comfort with electronic communications, and in broad terms it decreases for older age groups.
- The design and format of written and electronic communications, including websites, is crucial, particularly so for people with learning disabilities and cognitive impairment.

### **5.6.2 Recommendations**

- Develop information/advice in a greater range of formats, e.g. interactive DVDs, digital television.
- Involve people with mental health conditions and/or learning disabilities in the design of communication tools, e.g. websites and written materials.
- Gain further insight into the needs and preferences of those with specific mental health conditions/learning disabilities.
- Explore satisfaction levels for these groups with the PDCS medical examination process, e.g. using survey data.
- Utilise appropriate technologies (e.g. voice recognition software) to improve ease of access for people with communication barriers resulting from their mental health condition or learning disability.



## 6 Conclusions and key implications for PDCS

People with mental health conditions and/or learning disabilities face a range of barriers to accessing Disability Living Allowance (DLA) and Attendance Allowance (AA). These occur throughout the customer journey from initially becoming aware of potential eligibility for DLA or AA, through to making a claim and a decision to award/not award being reached. Some of the barriers result from broad and complex forces of social exclusion facing these groups: such as stigma, unemployment and social isolation. Other barriers result from a lack of a joined-up approach amongst agencies and professionals in supplying information about the full range of services and support available to individuals, or at least signposting the way to such information. Other barriers result from the channels through which people gain access to information and advice on DLA, and the way in which communications take place, being inappropriate for their needs. Compounding these, the complexity of the application process itself presents particular challenges for those with mental health conditions and/or learning disabilities.

For this reason, the literature suggests that people in these groups are potentially being disadvantaged and do not always have the same opportunity to access DLA and AA as people with physical disabilities. To understand these issues more fully, we recommend that PDCS:

- carries out further detailed analysis to understand more fully the barriers to accessing the PDCS service faced by people with specific categories of mental illness and learning disability;
- raises awareness of eligibility criteria for DLA and AA through channels that are likely to reach these groups;
- equips staff to deliver an increasingly personalised service that meets the diverse needs of customers with mental health conditions and/or learning disabilities in a flexible and responsive way;

- works closely with partners to generate better availability of information about PDCS benefits through services, networks and locations that represent the best channels to engage people in these groups;
- closely involves customers from these groups in the design of communication tools and materials;
- continues the work to simplify and shorten the application process with particular reference to the specific challenges that these groups face;
- works with partners to increase access to advocates for people who would benefit from this.

## 7 Next steps

The review of the literature has highlighted a number of important implications for the Pensions, Disability and Carers Service (PDCS). Our recommended next steps are summarised in Table 7.1.

Table 7.1 Recommended next steps

Awareness of potential entitlement	Access to the service	Application for the benefit
<ul style="list-style-type: none"> <li>• Investigate the potential for greater working with partner organisations to improve information provision, e.g. GPs, Primary Care Trusts, care/nursing homes, voluntary organisations.</li> <li>• Develop information/advice in a greater range of formats, e.g. interactive DVDs, digital television.</li> <li>• Increase awareness of potential eligibility for particular conditions which are commonly undiagnosed, e.g. dementia.</li> <li>• Involve people with mental health conditions and/or learning disabilities in the design of communication tools, e.g. websites and written materials.</li> <li>• Gain further insight into the needs and preferences of those with specific mental health conditions/learning disabilities.</li> <li>• Communicate clearly that entitlement for Disability Living Allowance (DLA)/Attendance Allowance (AA) is not related to income or employment status.</li> <li>• Ensure that awareness-raising communications reach parents and carers as well as potential customers.</li> </ul>	<ul style="list-style-type: none"> <li>• Increase staff awareness of the different communication needs of these groups.</li> <li>• Increase customer awareness of different ways to access the service, e.g. face to face.</li> <li>• Ensure good web-based information is available, tailored to the needs and preferences of different age groups.</li> <li>• Consider carrying out further research to establish if there are any gaps in service provision from PDCS for potential and existing customers with mental health conditions and/or learning disabilities.</li> <li>• Utilise appropriate technologies (e.g. voice recognition software) to improve ease of access for people with communication barriers resulting from their mental health condition or learning disability.</li> </ul>	<ul style="list-style-type: none"> <li>• Consider implications when revising claim forms.</li> <li>• Involve people with mental health conditions and/or learning disabilities in design of the application form to ensure tailored to their needs.</li> <li>• Work with voluntary organisations to widen awareness of their services.</li> <li>• Improve links with and signposting to advocacy services.</li> </ul>

Continued

Table 7.1 Continued

Assessment of eligibility	Award of the benefit (or rejection)	Appeal process
<ul style="list-style-type: none"> <li>• Explore satisfaction levels for these groups with the PDCS medical examination process, e.g. using survey data.</li> <li>• Ensure staff have the training to understand the impact of mental health conditions and/or learning disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>• Consider carrying out further research to understand whether and to what extent people with mental health conditions and/or learning disabilities who are potentially eligible for DLA/AA are not claiming, and why.</li> </ul>	<ul style="list-style-type: none"> <li>• Compare appeal rates for those with mental health conditions and/or learning disabilities with other groups, e.g. are they more likely to drop out, and if so why?</li> <li>• Explore opportunities to improve the appeal process.</li> </ul>



# References

Abbott, S. and Hobby, L. (2003). *Who uses welfare benefits advice services in primary care?* Health and Social Care in the Community. Vol 11 No 2 Mar 2003, pp. 168-174.

Adamson, J., Ben-Shlomo, Y., Chaturvedi, N. and Donovan, J. (2009). *Exploring the impact of patient views on 'appropriate' use of services and help seeking: a mixed method study.* British Journal of General Practitioners, 2009; 59(564): e226-e233.

Alborz, A., McNally, R. and Glendinning, C. (2005). *Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence.* Journal of Health Services Research & Policy, Vol 10, pp.173–182.

Allen, D. (2007). *Information for all.* Mental Health Today, Feb 2007, pp. 16-17.

Audit Commission (2009). <http://www.audit-commission.gov.uk/localgov/goodpractice/benefits/takeup/Pages/Default.aspx>

Banks, P. and Lawrence, M. (2005). *Transparent or opaque?: disabled people in Scotland describe their experience of applying for Disability Living Allowance.* Journal of Social Work. 5(3), December 2005, pp. 299-317.

Barnes, D., Brandon, D. and Webb, T. (2002). *Independent Specialist Advocacy in England and Wales: recommendations for good practice.* Durham: University of Durham.

Berzins, K. M. and Atkinson, J. M. (2009). *Service users' and carers' views of the Named Person provisions under the Mental Health (Care and Treatment) (Scotland) Act 2003.* Journal of Mental Health, 18(3), June 2009, pp. 207-21. ISSN: 0963-8237.

Betteridge, J. and Davis, A. (2006). *Mental health and incapacity for work: an information pack for people claiming incapacity benefit, income support and severe disablement allowance.*

Bird, L. (1998). *Citizens Advice Bureaux services for people with mental health problems: an investigation of seven CABs.*

Boardman, J. and Parsonage, M. (2007). *Delivering the Government's Mental Health Policies*.

Brown, J., Hanlon, P., Turok, I., Webster, D. and Arnott, J. (2009). *Mental health as a reason for claiming incapacity benefit - a comparison of national and local trends*. Journal of Public Health, vol 31, no 1, Mar 2009, pp. 74-80.

Cambell, J. (2008). *Stakeholders' views of legal and advice services for people admitted to psychiatric hospital*. Journal of Social Welfare & Family Law; Oct2008, Vol. 30 Issue 3, pp. 219-232.

Chance, Patrick S. G. (2005). *The mental health needs of older people with learning disability*. Reviews in Clinical Gerontology Reviews in Clinical Gerontology, Vol 15, pp. 245-253.

Clayton, S. et al. (2009). *Media and Internet Ownership and use among mental health outpatients with serious mental illness*. American Journal of Drug and Alcohol Abuse 35 (5), Sep 09, pp. 364-367.

Connexions: [www.connexions-direct.com](http://www.connexions-direct.com)

Davis, A., Davis, A. and O'Kane, M. (2006). *Claiming disability living allowance: an information pack for adults up to age 65 using mental health services, their carers and advocates*.

Department for Communities and Local Government (2008a). *Digital Exclusion Profiling of Vulnerable Groups: Adults with mental health problems – a profile*.

Department for Communities and Local Government (2008b). *Digital Exclusion Profiling of Vulnerable Groups: Adults with Learning Disabilities – a profile*.

Department for Work and Pensions (2008). *Mental Health and Employment*.

Department for Work and Pensions (2008). *Pension, Disability and Carers Service: equality schemes 2008-11*.

Hilton, J. (2008). *Streamlining the assessment of Attendance Allowance applications with social care assessment: an evaluation of two London pilots*, DWP Research Report No. 534, Corporate Document Services, Leeds.

Hay, C. and Slater, A. (2007). *The use of Jobcentre Plus telephony and face-to-face first contact services by customers with specific communication barriers*, DWP Research Report No. 446, Corporate Document Services, Leeds.

Hudson, M., Ray, K., Vegeris, S. and Brooks, S. (2009). *People with mental health conditions and Pathways to Work*, DWP Research Report No. 593.

Department of Health (2007). *Breaking down barriers – the clinical case for change*.

Department of Health (2007). *Capabilities for inclusive practice*.

Department of Health (2008). *Care Programme Approach*.

- Department of Health (2008). *Children and young people in mind: the final report of the National CAMHS Review*.
- Department of Health (2008). *Commissioning for Personalisation: A Framework for Local Authority Commissioners*.
- Department of Health (2008). *Commissioning for Support Planning and Brokerage: a resource tool*.
- Department of Health (2006). *Direct payments for people with mental health problems: A guide to action*.
- Department of Health (2008). *Good Practice in Support Planning and Brokerage*.
- Department of Health (2009). *Improving access to child and adolescent mental health services*.
- Department of Health (2009). *Information sharing and mental health*.
- Department of Health (2007). *Mental Health Grant Guidance 2007-08*.
- Department of Health (1999). *National service framework for mental health: modern standards and service models*.
- Department of Health (2009a). *New Horizons: Towards a shared vision for mental health – Consultation*.
- Department of Health (2007). *Putting People First*.
- Department of Health (2001). *Valuing People*.
- Department of Health (2009b). *Valuing People Now*.
- Department of Health (2009). *Working together for change: using person-centred information for commissioning*.
- Downie, Matthew (2008). *I exist*. Learning Disability Today, Vol 8 (1), pp. 1-45.
- Henderson, R. (2003). *Empowerment through Advocacy*.
- Henderson, R. and Pochin, M. (2001). *A Right Result? Advocacy, justice and empowerment*. Bristol: Policy Press.
- Hill, S. A. and Laugharne, R. (2006). *Decision making and information seeking preferences among psychiatric patients*. Journal of Mental Health. 13(12), February 2006, pp. 75-84. 2006.
- Hirst, M. and Sainsbury, R. (1996). *Social Security and Mental Health: The impact of Disability Living Allowance*. Social Policy Research Unit, Number 6.
- Hussein *et al.* (2006). *Paying the piper and calling the tune? Commissioners' evaluation of advocacy services for people with learning disabilities* Journal of Intellectual Disabilities, Vol. 10, No. 1, pp. 75-91.

Information Centre for Health and Social Care (2006). *Making sense of mental health information*.

Joseph Rowntree Foundation (2005). *Implementing direct payments in mental health Findings*. No 0105 Feb 2005, pp. 1-4.

Lewington, W. and Clipson, C. (2004). *Advocating for Equality*. The Independent Advocacy Campaign.

Lee, M. (2007). *UK Inquiry into Mental Health and Well-Being in Later Life. Improving Services and Support for Older People with Mental Health Problems*.

Lucock, M., Barber, R., Jones, A. and Lovell, J. (2007). *Service users' views of self-help strategies and research in the UK*. Journal of Mental Health Vol 16(6), pp. 795-805.

Lucock, M., Mirza, M. and Sharma, I. (2007). *Service users' views of a self-help pack for anxiety*. Journal of Mental Health Vol 16(5), pp. 635-646.

Mencap: [www.mencap.org.uk](http://www.mencap.org.uk) and <http://young.mencap.org.uk/>

Mental Health Foundation (2003). *A Fair Day's Pay*.

Mental Health Foundation (2007). *Listen up!*

Mental Health Foundation (2008). *Mental Health and Palliative Care Literature Review*.

Mental Health Foundation (2009). *Moving on up*.

Mental Health Foundation: [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

Mental Health Foundation (2007). *Pathways to Policy*.

Mental Health Foundation (2009). *Recovery in Action*.

Mental Health Foundation (2000). *Strategies for Living*.

Mental Health Services of Salford NHS Trust (1998). *Disability Living Allowance for People With Mental Health Problems, Conference Report*.

Mercer, J. (2007). *Wikipedia and 'open source' mental health information*. The Scientific Review of Mental Health Practice. Vol.5(1), 2007, pp. 88-92.

MIND: [www.mind.org.uk](http://www.mind.org.uk)

National Social Inclusion Programme (2009). *Outcomes Framework for Mental Health Services*.

Newbigging, K., McKeown, M., Hunkins-Hutchinson, E. A. and Dr French, B. (2007). *SCIE Knowledge review 15: Mtetezi - Developing mental health advocacy with African and Caribbean men*. Social Care Institute for Excellence.

- Office of the Childrens' Commissioner (2007). *Pushed into the Shadows. Young Peoples' Experiences of Adult Mental Health Facilities.*
- Oh, E., Jorm, A. F. and Wright, A. (2009). *Perceived helpfulness of websites for mental health information: A national survey of young Australians.* Social Psychiatry and Psychiatric Epidemiology. Vol.44(4), Apr 2009, pp. 293-299
- Oliver, V. and Paxton, R. (1999). *Mental health needs and social support in a health information service.* Mental Health Review, Brighton, vol 4, no 2, Jun 1999, pp. 13-17.
- Olver, S., Harden, A., Rees, R., Shepherd, J. and Brunton, G (2008). *Young people and mental health: novel methods for systematic review of research on barriers and facilitators.* Health Education Research, vol 23, no 5, Oct 2008, pp. 770-790.
- Payne, F. (2003). *Is NHS Direct meeting the needs of mental health callers?* Journal of mental health. Vol 12 Iss 1, February 2003, pp. 19-27.
- Pearson, N. and Rawlings, J (2008). *Making the web work for older people.* Journal of Dementia Care. 16(2), March/April 2008, pp. 12-13.
- Powell, J. and Clarke, A. (2006). *Internet information-seeking in mental health: population survey.* British Journal of Psychiatry. 189(3), September 2006, pp. 273-277.
- Powell, J. and Clarke, A. (2006). *Information in mental health: qualitative study of mental health service users.* Health Expectations, vol 9, no 4, Dec 2006, pp. 359-365.
- Rethink (2009). *New Horizons engagement event: people who use mental health services and carers.*
- Richards, D. (2004). *Self-help: Empowering service users or aiding cash strapped mental health services?* Journal of Mental Health 2004, Vol 13 (2) pp. 117-123.
- Rogers, E. S. and Farkas, M. (2009). Chapter Title: *"Making the grade: Identification of evidence-based communication messages."* in Parker, Jerry C (Ed). Thorson, Esther (Ed). (2009). *Health communication in the new media landscape.* (pp. 325-339).
- Royal College of Psychiatrists (2008). *Fair Deal for Mental Health.*
- Sainsbury Centre for Mental Health (2009). *Doing what works.*
- Sainsbury Centre for Mental Health (1998). *Keys to Engagement: Review of Care for People with severe mental illness who are hard to engage with services.*
- Sainsbury Centre for Mental Health (2009). *Removing barriers: the facts about mental health and employment.*

- Saltus, R. (2006). *Improving the quality of access to mental health information and care: the views of health practitioners and social work professionals in Wales*. *Diversity in Health and Social Care*. 3(3), 2006, pp. 183-189.
- Social Care Institute for Excellence (2005). *SCIE Guide 10: Direct payments: answering frequently asked questions*.
- Social Care Institute for Excellence (2009). *SCIE Guide 30: Think child, think parent, think family: a guide to parental mental health and child welfare*.
- Stenger, J. (2009). *The Big Book of Benefits & Mental Health – 2009/10*.
- Tait, L. and Lester, H. (2005). *Encouraging user involvement in mental health services*. *Advances in Psychiatric Treatment* 2005, 11: pp. 168-175.
- Taylor, J. (2009). *What mental health service users want*. *Health Service Journal*, 24-9-09, pp. 22-23.
- Telford, R. and Faulkner, A. (2004). *Learning about service user involvement in mental health research*. *Journal of Mental Health*, Vol 13 (6) pp. 549-559.
- Thorncroft, G. (2001). *Measuring Mental Health Needs*.
- Timms, P. et al. (2005). *Help is at hand' on the Web: what do our readers think?* *Psychiatric Bulletin* 2005; 29 (1): 24-27 (January 2005).
- University of York, Dept of Health Sciences (2009). *Developing evidence based and acceptable stepped care systems in mental health: an operational research study*.
- Watts, J. (2008). *The true value of benefits*. *Learning Disability Practice*. Vol 11 No 8 Oct 2008, pp. 10-12.
- Whitley, R. and Drake, R. E. (2008). *How do clients obtain mental health information? Commentary on "consumer perspectives on information and other inputs to decision-making: implications for evidence-based practice"*. *Community Mental Health Journal*. 44(6), December 2008, pp. 457-458.
- Wiggan, J. and Talbot, C. (2006). *The benefits of welfare rights advice: a review of the literature*. National Association of Welfare Rights Advisors.

This literature review was commissioned to understand the needs, preferences and experiences of people with mental health conditions and learning disabilities when accessing benefits, specifically Disability Living Allowance (DLA) and Attendance Allowance (AA).

The main objectives of the review were to understand the existing evidence related to:

- needs and expectations;
- service provision and access;
- networks;
- channel preferences.

The Pension, Disability and Carers Service (PDCS) is keen to identify the particular needs of these groups and any barriers they may face when accessing PDCS services. This report presents the key findings and implications.

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