

## 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

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

### Needs of people with mental health conditions or learning disabilities

People with mental health conditions or learning disabilities are two heterogeneous groups with a diverse range of needs and preferences who could benefit from 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 physical health, employment, housing, and social networks.

Individuals with mental health conditions or learning disabilities, particularly those with more severe medical conditions and those of older age, are more liable than the general population to experience social exclusion. This can present significant barriers to acquiring information and advice about eligibility for benefits and accessing support to make a claim. For example:

- people with learning disabilities often have limited friendship groups and may have limited contact with family – two of the channels through which many people hear about DLA and AA;
- conditions such as dementia frequently go undiagnosed, possibly making it less likely that the person will become aware of their potential eligibility for benefits;
- the social stigma can discourage people from seeking help when they suspect something may be wrong, which may delay diagnosis and intervention.

### The role and extent of use of advocacy

Using advocates is effective in reducing barriers faced by vulnerable people and there has been an increase in advocacy provision following the emphasis placed on this in *Valuing People*. There is some evidence though 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 a mental health condition.

### Gaps in service provision

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

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### *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*

A number of hard-to-reach groups are at greater risk of mental health problems, e.g. drug and alcohol misusers or the homeless. Their needs are complex and they often receive a poor service from statutory agencies as a result.

### *Lack of joined-up working*

This causes particular problems for children in the transition from child to adult services, older adults, and those with complex or more severe needs.

### **Good practice when providing services to these groups**

There is a strong body of literature on good practice when providing services for people with mental health conditions or learning disabilities, particularly from the field of social care. A key theme is the emphasis on personalised services: giving individuals more choice and control over the services they receive and how they access them. 'Listening, learning and focussing 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 Pension, Disability and Carers Service (PDCS) perspective is the London pilot work on streamlining the Attendance Allowance (AA) assessment with social care assessment.

Good practice in communicating with people with mental health conditions 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**

People with mental health conditions have particular problems with navigating the benefits system and 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 or learning disabilities. They may also take the form of inflexibilities in the way communications with these groups are handled by Department for Work and Pensions (DWP) 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

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

**Formal** – with a person’s key worker being an important focal point. Other health professionals such as GPs (especially important for older people), other doctors, community psychiatric teams, occupational therapists, social workers can also be 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 providing information about the full range of services and support available to people with mental health conditions or learning disabilities, including benefits advice. (Secondary care is a term that generally refers to treatment received in a hospital environment either as an outpatient or an inpatient. Primary Care is generally treatment from a GP)

## Satisfaction with the Pension, Disability and Carers Service

Research has identified that people with mental health conditions often have problems using PDCS services. Based on the Disability and Carers Service (DCS) Customer Service Survey, 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

Telephone is the preferred communication channel for most people with a mental health condition or learning disability. 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.

People with mental health conditions 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.

People with mental health conditions 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 majority of people with a learning disability have access to a computer, but many with mental health conditions do not.

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.

The full report of these research findings is published by the Department for Work and Pensions (ISBN 978 1 84712 772 3. Research Report 654. July 2010).

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