

Learning Disabilities

Positive Practice Guide

January 2009

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1. Background and policy framework

- 1.1 People with learning disabilities are among the most vulnerable and socially excluded in our society.
- 1.2 *Valuing People*¹ states that Learning Disability includes the presence:
 - a significantly reduced ability to understand new or complex information, to learn new skills, with;
 - a reduced ability to cope independently;
 - a lasting effect on development which started before adulthood.
- 1.3 This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, e.g. an IQ below 70, is not a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need.
- 1.4 It is estimated that 985,000 people in England have a learning disability (2% of the general population) and that 145,000 have severe or profound learning disabilities, most of whom are known to services. The remainder have a mild or moderate learning disability and are less likely to be known by services. The Centre for Disability Research, Lancaster University predicted that there will be an 11% increase in the total number of people with learning disabilities between 2001 and 2021.
- 1.5 The Foundation for Learning Disabilities estimates that 25–40% of people with learning disabilities also have additional mental health needs. *Valuing People* highlighted that most psychiatric disorders are more common among people with learning disabilities than in the general population.
- 1.6 Most people with learning disabilities have poorer health than the rest of the population, although despite this their access to the NHS is often poor.

1 Department of Health (2001) *Valuing People: A new Strategy for Learning Disability for the 21st Century*, London, Department of Health

- 1.7 The Michael Inquiry report *Healthcare for all* (2008)² stated that the health care needs of people with a learning disability do not appear to represent a priority for the NHS and they are often not visible or identifiable to health services.
- 1.8 The *National Service Framework for Mental Health*³ applies to all adults of working age, with the aim of improving quality, tackling variations in access to care, increasing the effectiveness of care and enhancing user and carer experience of mental health services. A person with a learning disability who has a mental illness should be able to access services and be treated in the same way as anyone else with reasonable adjustments being made in accordance with the Disability Discrimination Act (2005) and the Disability Equality Duty (2006).
- 1.9 The Green Light Toolkit was developed by the Valuing People Support Team⁴ to help mental health services to assess the standard of accessibility of services to people with learning disabilities. The Healthcare Commission has included assessing mental health trusts against these standards as part of their 2008/09 annual health care assessment.
- 1.10 *Healthcare for all* found convincing evidence that people with learning disabilities have higher levels of unmet need and receive less effective treatment, despite the fact that the Disability Discrimination Act set out a clear framework for the delivery of equal treatment.
- 1.11 While these reports and recommendations are based on experiences of primary care and acute general hospital care, they can apply equally to mental health care for people with learning disabilities. It is particularly important that mental health problems are identified as early as possible.

2 Sir Jonathan Michael (2008) *Healthcare for all: Report of the independent inquiry into access to healthcare for people with learning disabilities*

3 Department of Health (1999) *National Service Framework for Mental Health: Modern Standards and Service Models*, London, Department of Health

4 www.valuingpeople.gov.uk

2. Understanding the needs of people with learning disabilities

- 2.1 Commissioners need to understand the local demographic profiles of and epidemiological data about their local community, in order to provide Improving Access to Psychological Therapies (IAPT) services that are appropriate for the whole population. Local Joint Strategic Needs Assessments (JSNAs) must take account of and reflect the needs of all individuals, including those with a learning disability.
- 2.2 People with learning disabilities can experience the full range of mental health problems; however, it can be difficult to identify the prevalence of depression and anxiety among people with learning disabilities. Many people with learning disabilities are not able to express their feelings easily in words, which can mask the clinical presentation of a mental health problem and cause difficulty in making an accurate diagnosis. Service providers must be aware that people with learning disabilities may have complex needs such as behavioural problems and inability to express themselves using words. IAPT services must be flexible in recognising and responding appropriately to these needs.
- 2.3 However, over recent years, more mainstream assessment tools for mental health have been adapted for people with a learning disability and some specialist assessments have been developed, such as PAS-ADD, which should be familiar to mental health practitioners.
- 2.4 It is important that mental health services and learning disability services work collaboratively to ensure that services are both available and effective for people with learning disabilities. Some areas have developed local joint protocols but, unfortunately, this type of partnership working still does not happen in many areas. Commissioners of mental health services need to work with commissioners of learning disability services to ensure that this is an accepted requirement and that cohesion across IAPT services exists.

- 2.5 IAPT services may have to take a flexible approach to providing psychological therapies that are effective for people with learning disabilities, including offering:
- materials in easy-to-understand formats;
 - assessments and National Institute for Health and Clinical Excellence (NICE) approved psychological interventions which have been adapted to meet the needs of people with learning disabilities;
 - appointments at specific times or on specific dates, perhaps coinciding with individual needs or carer availability;
 - longer sessions than usually provided to take account of the person's varying levels of understanding and need;
 - additional support from therapists or requiring the presence of a carer or independent advocate;
 - engagement (where available) with strategic primary healthcare facilitators for people with learning disabilities to support access to assessment and services; and
 - engagement with Community Learning Disability Team (CLDT) members who may already be involved or able to work collaboratively with IAPT services.

3. Removing barriers to access

- 3.1 **Social restriction** of people with learning disabilities may prevent them from accessing IAPT services. Many people with learning disabilities will have experienced restrictions such as rejection, lack of social support, education failure and lack of job opportunities. Additionally, many people with learning disabilities find it difficult or require support to access their GP or other services.
- 3.2 **Challenging behaviour** may prevent people with learning disabilities accessing psychological therapy services. It is estimated that 15% of adults with severe learning disabilities have a severe associated behavioural disorder, either as a direct result of their disability or because of underlying psychiatric problems (Reid 1995). People with learning disabilities are not always able to express their feelings in words and may use their behaviour or actions to express themselves. Their actions may be considered challenging and the need for a referral to assess underlying causes is often not identified or supported.
- 3.3 **General practitioners (GPs)** and other primary care professionals may also prevent people with learning disabilities accessing psychological therapy services. GPs and other primary care professionals may:
- have time constraints in their surgeries that prevent them from diagnosing mental health problems effectively in people with learning disabilities;
 - recognise symptoms of depression or anxiety but fail to recognise that people with learning disabilities can be treated with psychological therapies;
 - not have awareness or knowledge of specially adapted assessments available to support diagnosis of mental health problems in people with learning disabilities;
 - mistakenly believe that the symptoms of depression or anxiety are merely 'difficult' or 'challenging' behavioural problems; and/or
 - not have the skills to identify and manage mental health problems in people with learning disabilities.

3.4 **Specialist mental health services** may prevent people with learning disabilities accessing services providing psychological therapies because they:

- lack confidence in working with people with learning disabilities;
- have concerns about their ability or skills to build a therapeutic relationship with people with learning disabilities;
- consider that psychological therapies would be better used on other people with greater cognitive abilities; and
- have fears for the vulnerability of a person with learning disabilities within a specialist or acute mental health environment.

4. Engaging with people with learning disabilities

4.1 Proper and effective engagement with people with learning disabilities is essential if the individual's needs are to be met. Ensuring proper engagement can be addressed by:

- monitoring uptake of IAPT services by people with learning disabilities;
- identifying the successful and unsuccessful referral pathways;
- recognising that CLDT staff, support staff, family members, carers and advocates can play an important role in identifying mental health problems in people with learning disabilities and should be a key part of the referral pathway into the IAPT service;
- recognising that people with learning disabilities themselves may be a potential resource to the IAPT service (e.g. as volunteers or paid workers including playing a part in recruiting staff);
- advertising psychological therapies in ways that are acceptable and meaningful to people with learning disabilities, such as providing leaflets or audio/DVDs in easy-to-understand formats; and
- commissioning local voluntary sector and advocacy groups specialising in learning disability to raise awareness and support people with learning disabilities to access IAPT services.

4.2 Commissioners will want to ensure that the location of IAPT services encourages engagement with people with learning disabilities. A location that offers some form of anonymity would help to engage people who fear the stigma of having mental health problems, or who feel isolated from – or anxious about using – statutory services.

4.3 In designing how IAPT services will identify what people with learning disabilities like or do not like about them and how to adapt them in response, IAPT services should work collaboratively with organisations such as:

- specialist voluntary sector organisations;
- Learning Disability Partnership Boards;
- self advocates;
- advocacy groups;
- local authorities; and
- specialist learning disability health services.

5. Training and developing the workforce

- 5.1 It is an important principle that the IAPT workforce should reflect and be representative of the local community. The capacity and capability of therapists must be appropriate for the people they will be seeing.
- 5.2 Commissioners should understand their local population and demographic profile in order to commission an IAPT service with the appropriate size, skill mix and make-up of therapists.
- 5.3 Commissioners have a duty to ensure that services are equally accessible to people with learning disabilities and will want to ensure that therapists are able to provide the level of care that is required to those with additional needs.
- 5.4 Staff training helps avoid inequalities by improving disability awareness competences and overcoming any professional bias and personal prejudices in the IAPT workforce. All staff should be trained to be sensitive to and aware of the specific needs of individuals with learning disabilities in line with human rights and disability discrimination law.
- 5.5 The workforce should also reflect the communities in which they work. Supporting and training people with learning disabilities to become part of the IAPT service workforce will benefit both the service and potential patients.

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