



# Division of Clinical Psychology

Faculty for People with  
Learning Disabilities



The  
British  
Psychological  
Society

## Commissioning Clinical Psychology services for adults with learning disabilities

*Version 13.3.11*

*'Commissioning should be a powerful way of improving the quality of services experienced by people.*

*By commissioning we mean the process of translating aspirations and need into timely and good services for users which meet their needs, promote their independence, provide choice, are cost effective and support the whole community.'*

**(Joint Review of Commissioning for People with Learning Disabilities and Complex Needs, 2009)**

If you have problems reading this document and would like it in a different format, please contact us with your specific requirements.

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**ISBN: 978-1-85433-715-3**

Printed and published by the British Psychological Society.

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## Foreword

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This document has been produced by the Faculty for Learning Disabilities of the British Psychological Society. It is aimed primarily at commissioners of services, but we hope it will also be useful to Trusts, Social Services and service providers. We also hope it will be useful to families, carers and people with learning disabilities. It gives a description of what you can expect from us as clinical psychologists who work with adults with learning disabilities, and how you can judge whether or not our work has been effective. Our aim, as psychologists, is to promote valued, inclusive lives for people with learning disabilities; much of our work is with those with the most complex needs and this values base guides our clinical interventions.

We have not looked at the needs of children with learning disabilities, as we consider that to be the remit of those who work specifically with children.

The guide considers the nature of the work you might want from us, looks briefly at the extent of the need, the evidence base for what should be delivered, the outcomes that can be expected and some of the risks that might occur if services for people with specific needs are not commissioned effectively.

We have not specified 'ideal' budgets or grades of staff: we hope that there will be a dialogue between clinical psychologists, their employers and commissioners to determine the optimum skill mix required for the needs of the population served.

We realise that we are now working in times of severe economic constraint, and that service delivery will have to focus on priority areas of need. We hope that this document will assist in supporting more effective service delivery and closer scrutiny of outcomes.

This document is in electronic format, and our intention – as a Faculty – is to update it regularly in line with best practice guidance and developing service models. It has been produced in consultation with members of the Faculty, and we would like to acknowledge the work done by Debra Moore (of Debra Moore Associates) in assisting us in producing this guidance.

We hope you find it useful, and would be happy to receive any comments at:  
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## Executive summary

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*Commissioning Clinical Psychology services for adults with learning disabilities* has been prepared by members of the Faculty for Learning Disabilities of the British Psychological Society's Division of Clinical Psychology. It has been developed to support the commissioning and provision of clinical psychology services and to consider how this fits with the wider landscape of support to adults with learning disabilities and their families. Although the focus of the document is on the unique contribution of clinical and other applied psychologists, it is emphasised that they usually work as part of a wider multi-disciplinary team.

The guide sets out to clarify the role of clinical psychologists and how this contributes to achieving the aims and objectives within current policy and guidance for people with learning disabilities. It describes how psychologists work within specialist health services and with colleagues in mainstream health and social care, in order to ensure that people with learning disabilities and their families receive support that is person-centred, effective, safe and dignified.

Clinical psychologists are key members of any modern specialist learning disability health service. This guide is designed to support the commissioners of these services by providing information, advice and evidence of the positive contribution psychologists can make to the lives of people with learning disabilities. At a time of unprecedented service change and financial restraint, it is essential that this scarce resource is used effectively to ensure the best possible outcomes within the available funding. The profession should take a lead role in redesigning and reconfiguring high quality services that are cost effective. The guide describes nine of the core areas where psychologists are likely to have a central role in promoting effective services for adults with learning disabilities. In each of these core areas the guide outlines the need for psychology provision, the evidence-base, and good practice that is required to deliver an excellent service. Each section outlines the outcomes that commissioners and service users should expect when such provision is in place. It describes the contribution that can be expected from a psychology service and the potential risks if the psychology service is not available or is ineffective.

The nine key areas include:

1. Assessment of capacity;
2. People who show behaviours that challenge services;
3. People with mental health problems;
4. People with autistic spectrum conditions;
5. People with dementia or who are at risk of developing dementia;
6. Offenders and those at risk of offending;
7. People with profound and multiple learning disabilities;
8. People with physical health needs including those who require support from mainstream NHS;
9. Supporting parents who have learning disabilities.

Other sections of the document outline the core role and skills of psychologists, the need for service provision to include everyone by planning for the needs of people from Black and Minority Ethnic Groups and newly-arrived communities, the leadership role in supporting the strategic direction of services and the organisation and delivery of psychology provision. In the current economic climate, clinical psychologists have a particularly important role to play in shaping services that are of high quality, are innovative, effective, provide value for money and promote approaches that prevent the breakdown of people's support in their communities.

In drafting the document, the Faculty has taken the decision to avoid making recommendations about the numbers and grades of psychologists who should be employed within a specified geographical area. Such decisions depend upon the needs of the local population, the range of local provision and other factors that will vary from area to area. However, we urge commissioners and service managers to consider the contribution that psychologists can make to achieving positive outcomes for people with learning disabilities in the different areas of service delivery.

Clinical psychologists work alongside the other members of the multi-disciplinary team in order to support mainstream practice and directly serve people with the most complex needs. They make use of a range of psychological models and areas of research to provide effective and person-centred support to people who are at the greatest risk of service breakdown. The core skills include assessment, formulation, intervention, evaluation and research, and developing the capacity and effectiveness of services.

Clinical psychologists have many positive contributions to make to specialist health services. For the purpose of this document nine specific areas of work are considered. Future revisions will add to these sections and consider the emerging evidence base in these and other areas.

# Introduction

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This guide has been developed to support the commissioning and provision of clinical psychology services and to consider how this fits with the wider landscape of support to adults with learning disabilities and their families. Although the focus of the document is about the unique contribution of clinical and other applied psychologists, it is emphasised that they work as part of a wider multi-disciplinary team.

Clinical psychologists are essential members of specialist adult learning disability health services working in inpatient and community teams and with a range of agencies and sectors to support the individual and their family.

This guide aims to:

- Support commissioners by clarifying the role and describing the work of clinical psychologists and how this contributes to achieving the aims and objectives within current policy and guidance for people with learning disabilities.
- Support partnership working within specialist health services and with colleagues in mainstream health and social care.
- Ensure that clinical psychology services are provided in a manner that meets the primary aim of supporting people and families with person-centred, effective, safe and dignified interventions.

## Background

People with learning disabilities are a diverse group with a range of needs and wishes. People with learning disabilities are defined as having *a significant impairment both in intellectual functioning and in adaptive behaviour, with onset in childhood*. This group does not include people who may have more specific learning difficulties or conditions such as dyslexia or people who have acquired brain injury after the age of 18 years.

Figures suggest there are approximately 974,000 adults with learning disabilities in England and of these 145,000 will have a severe or profound learning disability. Within this population research suggests there will be higher than average number of younger English adults with more severe learning disabilities who belong to Bangladeshi and Pakistani South Asian minority ethnic communities.

In Northern Ireland, there are 16,366 adults and children with learning disabilities known to services – with 4468 of these having a severe or profound learning disability.

Whilst there are few population statistics about this group of people, evidence suggests that the numbers of people with more profound needs are rising due to a range of factors including advances in medical technology.

Overall, it is predicted that the number of people with learning disabilities in England will have risen by 15 per cent between 2001 and 2011, while the numbers of people aged 50 and over will have risen by 53 per cent between 2001 and 2021.

The first key objective in *World Class Commissioning* (DoH, 2007) is to understand the size and the needs of the population. Unfortunately, for many commissioners, the information available about local people with learning disabilities and particularly those with complex needs is often patchy and incomplete.

Initiatives such as the Public Health Observatory for Learning Disabilities ([www.ihal.org.uk](http://www.ihal.org.uk)) will, in time, make a positive contribution to data and knowledge management. However, along with colleagues in social care, specialist health professionals such as clinical psychologists should be engaged with commissioners in helping to build up a robust picture of local current and future needs. This information can contribute to local mechanisms such as the Joint Strategic Needs Assessments (JSNA).

For commissioners, understanding the needs and wishes of people with learning disabilities will require increased listening to what people and families say they want and the key vehicle for this is person-centred planning.

Clinical psychologists are able to support a person-centred approach and work with commissioners and providers to ensure that supports are constructed in a person-centred way. They are also in a position to give advice about appropriate ways to engage people with learning disabilities actively in the commissioning process.

There has been increasing interest and concern about the commissioning and provision of health services for adults with learning disabilities. A number of high profile investigations and reports have raised important issues about the safety and effectiveness of both mainstream NHS and Specialist Adult Learning Disability Health Services.

This drive to improve the physical, mental and emotional health of people with learning disabilities has been reflected in Government policies across the UK and the initiatives which have been instigated such as NHS Campus Closure Programmes and provision of health checks.

*World Class Commissioning* (DoH, 2007) is about delivering better health and well-being for the local population, about improving health outcomes and reducing inequalities – ‘*adding years to life and life to years*’. Unfortunately, for people with learning disabilities, on the whole, it is a valued but distant ideal. The inequalities experienced by people with learning disabilities are well documented and widespread. They face prejudice and discrimination in many different areas but importantly, there is now significant evidence that they often experience problems accessing health care and equal treatment.

These poor experiences in health care not only impact on physical health but also mental health and well-being. The inability of local health services to support people appropriately has a distressing impact on the individual and their family and can often result in distant (and usually more expensive) placements. People with learning disabilities constitute one of the most vulnerable groups in society. Decades of institutional provision and poor investment have left a legacy in many areas where people are supported in restrictive and impoverished settings.

Commissioners need to ensure that the services they commission uphold the articles of the Human Rights Act 1995 and other related legislation and guidance such as Deprivation of Liberty Safeguards 2007 and the Mental Capacity Act 2005.

Clinical psychologists have a unique contribution to make in these areas using their skills and knowledge to assess and determine an individual’s ability to make decisions and facilitate choice and control in day-to-day life as well as when contemplating major change or treatment.

*World Class Commissioning* (DoH, 2007) recognises that there needs to be a real partnership and relationship with local clinicians to improve health outcomes.

Clinical psychologists are well placed to support commissioners and providers to determine and deliver the types of services and supports that will support people with learning disabilities and their families in a safe, dignified and effective manner.

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## Using the guide

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Clinical psychologists are key members of any modern specialist learning disability health service. This guide is designed to support the commissioners of these services by providing information, advice and evidence of the positive contribution psychologists can make to the lives of people with learning disabilities.

This guide specifically describes the contribution made by clinical psychologists who are registered as such with the Health Professions Council. A number of services employ a range of other applied psychologists to provide specific psychological skills depending on the needs of the service – this can include *counselling psychologists* and *forensic psychologists*. By utilising the principles outlined by *New Ways of Working*, psychology services will also make use of a range of other people with psychological skills and competencies in order to meet the needs of local communities. These roles may include *assistant psychologists*, *behavioural assistants*, *counsellors*, *clinical assistants* and a variety of other job titles that have been developed to deliver specific tasks.

The document can be read from beginning to end or commissioners can ‘dip in’ to a specific section. Nine of the sections describe some of the key ‘clinical areas’ where psychologists are likely to have a central role within an authority. These areas include:

1. Assessment of capacity.
2. People who show behaviours that challenge services.
3. People with mental health problems.
4. People with autistic spectrum conditions.
5. People with dementia or who are at risk of developing dementia.
6. Offenders and those at risk of offending.
7. People with profound and multiple learning disabilities.
8. People with physical health needs including those who require support from mainstream NHS.
9. Supporting parents who have learning disabilities.

Each of these sections is organised in the same format:

- *Background* – demographics and the need for a psychological perspective.
- *Evidence-base* and good practice in this area.
- *Elements of an excellent service*.
- *Expected outcomes* when an excellent service (including psychology provision) is available.
- *Expected contribution* from a psychology service in order to deliver individualised outcomes.

- *Potential risks* to individuals and commissioners if the psychology service is not available and effective.

Other sections include guidance about meeting the needs of people from *Black and Minority Ethnic Groups*. In addition, there are sections on the *leadership role* of psychologists and the *organisation of psychology services* in order that they can best deliver the outcomes that are described in the guide.

The guide provides links to other resources that provide more in-depth information and materials on particular issues or subjects such as commissioning secure health services for people with learning disabilities.

# The core role of clinical psychologists in specialist adult learning disability health services

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Clinical psychologists provide a unique contribution to the aim of specialist learning disability services which is to support mainstream practice and directly serve those with the most complex needs (DH, 2007). Psychologists are trained to understand human behaviour within the context of the person and their environment. They are expected to synthesise information and to work proactively in complex organisational situations with some of the most complex service users. Psychologists work to achieve the following outcomes:

## Person related:

- Better psychological services for those who are at greatest risk.
- Psychological services that are more responsive and person-centred.
- Improvement of local provision of support/care including health promotion and prevention.
- Prevention of inappropriate admissions to in-patient settings.
- Increased continuity of care for people who have long-term difficulties or special support needs.
- Supporting people to enjoy increased choice and control.
- Managing and reducing risk in complex situations.
- Reducing distress and improving quality of life for people with learning disability through planned psychological interventions.
- Ability to demonstrate effective outcomes.
- Supporting staff and family carers.
- Promoting social inclusion.
- Recognition and understanding of diversity.

## Service related:

- Reduction in the inappropriate use of out of area placements.
- Improved understanding by all agencies of the psychological needs of people who use services.
- Enabling services to become more psychologically minded in their approach.
- Developing capacity of multi-disciplinary teams and services.
- Providing services that are delivered efficiently.
- Working with commissioners and services to bring about innovation and service improvements.
- Supporting continuous service improvement through an emphasis on outcomes and quality.
- Development of effective care pathways within services and in partnership with a range of care providers and mainstream services.

# Core skills of clinical psychologists

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Clinical psychologists draw on a number of different theories and areas of research to guide their work. The core skills of all psychologists are assessment, formulation, intervention, service development, evaluation and research.

## Assessment

Psychologists will use a variety of different types of assessment to help to understand both the nature of an individual's learning disabilities and the reasons for their behaviour or their psychological difficulties/mental health problems. Assessments may be carried out with an individual (e.g. measures of cognitive ability, mood or beliefs; understanding the context within which a behaviour occurs); via a carer (e.g. to find out how far a carer thinks that someone's behaviour has changed); or at an organisational level (to find out what is preventing a particular service from supporting someone differently).

## Formulation

The assessment information is then used to develop hypotheses about why a behaviour is occurring and what is maintaining it, or why people experience events as they do. Psychologists draw upon a range of different models to provide the best possible way of understanding the situation. This will usually lead to the psychologist developing a number of provisional hypotheses that will guide the intervention. Psychologists are particularly skilled at 'seeing the whole picture' and helping teams to manage a diverse, and often competing, set of issues (e.g. addressing short-term risks alongside Human Rights issues and the long-term need for change).

## Intervention

An intervention should follow directly from the formulation. It is likely to include a number of different elements, each of which results from the hypotheses that were developed in the formulation. Psychologists will use the best available evidence-base to design an intervention. Interventions may be provided at an individual level (e.g. by helping someone to understand why they have offended and what steps they can take in the future to behave in different ways), or at a systems level (e.g. by building the capacity in a whole team through training workshops, or through interventions in groups and with families). Interventions may aim to respond to a particular set of problems or risk issues, but equally important is the development of 'preventative strategies'. Psychologists are experienced at working with staff in other agencies (e.g. social care providers, housing) to deliver interventions in places where the person lives or works

## Evaluation and research

Evaluation is an important part of the psychologist's role. This will include evaluating whether an individual intervention is effective, and hence whether the formulation accurately reflects the reasons for the behaviour occurring. At a wider level, psychologists

are often asked to evaluate the effectiveness of a particular aspect of a service. In many services, psychologists are leading on the implementation of routine outcome measures in clinical practice. Psychologists also have an important role in using research knowledge to develop effective services, and generating new research knowledge by systematically evaluating different services and models.

## **Developing the capacity and effectiveness of services**

Psychologists provide specific training on a number of issues, with the aim of enabling carers and others to understand the nature of the person's learning disability, challenging behaviour or other needs, as well as how to support them effectively in order to improve the capability of local providers. They provide supervision and support to colleagues, support staff and carers in relation to behavioural interventions and other therapeutic approaches. Psychologists have a significant part to play in bringing about innovation and change management at team and organisational levels; this is brought about through the breadth of clinical expertise and training, knowledge of the evidence-base and skills at influencing systems.

## **Resources**

Department of Health (2007). *Commissioning Specialist Adult Learning Disability Health Services*.

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_079987](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_079987)

General information about clinical psychology and the work of the British Psychological Society can be found on the Society's website: [www.bps.org.uk](http://www.bps.org.uk).

Most psychologists who work with adults who have a learning disability contribute to the British Psychological Society's Faculty for Learning Disabilities. Information about this faculty can be found at: [www.bps.org.uk/dcp-ld/about/about\\_home.cfm](http://www.bps.org.uk/dcp-ld/about/about_home.cfm)

# Assessment of capacity

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## Background

The Mental Capacity Act (MCA) 2005 placed in statute the process by which decisions are to be made on behalf of adults (over the age of 16) who lack the capacity to make them for themselves. It also provides a statutory definition of incapacity, and the steps that must be taken before incapacity is determined. Lack of capacity is decision-specific, but the first part of the two-stage test for it, is that the person must suffer from a mental disorder. Learning disability is clearly recognised as a mental disorder in this context, and people with learning disabilities may, therefore, fall under the jurisdiction of the Act. About 974,000 people in England have a learning disability (about two per cent of the population); 796,000 of them are aged 20 or over.

## Trends

Since the implementation of the MCA 2005, there has been an increase in requests for specialist assessment of capacity. These have typically come from social services and also acute hospitals, with a focus on capacity to decide where to live, how to manage money and consent to treatment. Psychologists are frequently asked to carry out these assessments as part of their role in a community learning disabilities team, or to provide support to other people to enable them to establish whether the person they are supporting has the capacity to make a specific decision.

## Evidence base and good practice

The British Psychological Society published guidelines relating to the assessment of capacity in 2006. These outlined good practice for psychologists when carrying out assessments of capacity, taking account of their competencies in psychometric assessment and interpretation as well the requirement to understand the legal framework. Capacity assessment consists of a two-stage test. The first part is that the person suffers from a mental disorder (in this case a learning disability), which may need to be determined through the use of psychometric assessment. The second is that it must be demonstrated that the person cannot:

- understand the information relevant to the decision;
- retain that information;
- use or weigh that information as part of the process of making the decision;
- communicate their decision (whether by talking, sign language or other means).

The person only needs to be unable to do one part of this test to be considered to lack capacity. Assessment of capacity requires that the local decision-maker is able to make relevant information accessible, use skilled interviewing techniques and then interpret the responses in order to make a judgement based on the balance of probability. Psychologists may be called upon to conduct detailed assessments in complex situations to assist the decision-maker.

Information about methods of assessment and relevant areas of questioning is included in the British Psychological Society's guidance, and also in the joint BMA/Law Society publication on the assessment of capacity.

## **Elements of an excellent service**

- Clear pathway for referral for capacity assessments in complex situations.
- Clear pathway for advice and support to enable other decision-makers to undertake their responsibilities under the Act.
- Identified individuals who are skilled in undertaking assessments, and who can also advise others.
- Understanding of the relationship between mental capacity issues and safeguarding adults issues.
- Consent to treatment protocols in place and audited, with system for acting on findings.
- Good understanding of best interests decision-making.
- Expertise in adapting information in order to enable people with learning disabilities to make as many decisions for themselves as they can.
- Training on implementation of MCA 2005 is available and undertaken by staff.
- Trained Best Interests Assessors for the Deprivation of Liberty Safeguards.

## **Expected outcomes**

- Increase in numbers of people with learning disabilities where consent to treatment has been formally assessed.
- Increase in numbers of referrals from acute hospitals for assistance with assessing and enhancing capacity.
- Documented decision-making process for those who lack capacity.
- Improved management of decisions such as managing money, residence.
- Increase in reporting and management of safeguarding adults issues.

## **Psychology contribution to delivering individualised outcomes and quality indicators**

- Development of care pathway for capacity assessment.
- Specialised assessment of capacity in relation to a number of different decisions (e.g. treatment, where to live, managing money, getting married, consent to sexual relationship, making a will, etc.).
- Training frontline staff on capacity issues.
- Supervision and training of other staff who need to consider capacity issues.
- Chairing Best Interests meetings, particularly where there are complex issues and dilemmas.
- Auditing capacity and best interests processes.
- Carrying out Best Interests Assessments under the Deprivation of Liberty Safeguards.

## Potential risks if services not available/not effective

- Breaches of law relating to capacity.
- Residential care services becoming unduly restrictive, such that it amounts to Deprivation of Liberty. People with challenging behaviour are likely to be especially susceptible to these responses.
- Breaches of Human Rights law.
- Consent issues not addressed in a way that meets the needs of people with learning disabilities.
- Challenges in Court of Protection.
- Claims of failure to meet professional standards.

## Resources

For further information about Human Rights Act:

[www.justice.gov.uk/about/human-rights.htm](http://www.justice.gov.uk/about/human-rights.htm)

For further information about the Mental Capacity Act including Deprivation of Liberty Safeguards:

<http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/MentalCapacityAct2005/index.htm>

For further information about estimates of the number of people in England who have a learning disability: CeDR People with learning disabilities in England (2008).

[www.lancs.ac.uk/staff/emersone/FASSWeb/Emerson\\_08\\_PWLDinEngland.pdf](http://www.lancs.ac.uk/staff/emersone/FASSWeb/Emerson_08_PWLDinEngland.pdf)

For resources on the assessment of capacity and determining best interests, please see the following:

British Psychological Society (2006). *Assessment of capacity in adults; interim guidance for psychologists*. [www.bps.org.uk](http://www.bps.org.uk)

British Psychological Society (2007). *Guidance on determining the best interests of adults who lack the capacity to make a decision (or decisions) for themselves* (Edited by T. Joyce). [www.bps.org.uk](http://www.bps.org.uk)

British Psychological Society (2010). *Audit tool for mental capacity assessments*. [www.bps.org.uk](http://www.bps.org.uk)

National End of Life Care Programme. *The route to success in end of life care – achieving quality for people with learning disabilities*. [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

# People whose behaviours challenge services

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## Background

### *Demographic*

Across the UK, it is likely that 24 per 100,000 of the general population present a serious challenge at any one time. A few of these people will present such a challenge continuously, but many people will move into and out of this group depending both on changes in their characteristics and on how well services meet their needs over time. Research in the UK suggests that between 20 to 30 per cent of children with learning disabilities experience behavioural difficulties compared to four to 10 per cent of children without cognitive impairments. In the UK population 16 to 41 per cent of adults with learning disabilities may present challenging behaviours, depending on the assessment techniques used.

### *Trends*

Transfer from institutional to community services has not reduced the incidence of challenging behaviours despite improvements in people's quality of life (DH, 2007).

The increased number of young people with autistic spectrum conditions is placing extra demand on services. Challenging behaviour is often implicated in the placement of children with learning disabilities in residential special schools. These placements are often disruptive of ties with families and local communities so that there are often additional problems obtaining appropriate local services once responsibility for the young person transfers from children's to adult services. The continued use of residential special schools away from people's homes presents significant problems for adult services.

### *Data*

In 2006 over 11,000 people with learning disabilities in England were supported in out of area placements (SCIE, 2008). Having behaviours that challenge services was the most frequent characteristic of this group, with a lack of appropriate provision being cited as the most likely reason for such placements.

Challenging behaviours generally emerge in childhood and are highly persistent into adulthood. Those placed out of area are generally young and male, and often have a diagnosis of autism.

The SCIE review found that despite their claims to be specialist provision, out of area placements were often of poor quality – 37 per cent of people placed out of area had no behavioural support plan; over 50 per cent had no access to psychology; over 40 per cent had no access to psychiatry; and there were low numbers of person centred plans or health action plans.

## Evidence base and good practice

The Mansell Report (DH, 2007) identifies the need to develop and expand the capacity of local services to understand and respond to challenging behaviours in order to support people locally and avoid the inappropriate use of expensive out of area placements that are of low quality. Mansell concludes that successful services require:

- Commitment of frontline staff and professionals to develop excellent local services, with sustained support from managers.
- A focus on individualisation – a thorough knowledge of the person and their experiences, leading to a personalised package of care.
- A well trained and supported workforce that provides evidence-based support to individuals.

*Challenging Behaviour: a unified approach* (RCPsych, BPS & RCS&LT, 2007) reviews the evidence for the need for individualised assessment and interventions within a framework of Positive Behavioural Support (PBS), based on the principles of Applied Behavioural Analysis. It highlights the features of ‘capable environments’ that will lead to better outcomes for people.

Despite the evidence of the effectiveness of PBS (BPS, 2004), studies show that the majority of interventions in services do not follow the available guidance and are not formally written down or evaluated. There is often an over-reliance on medications without an appropriate evidence-base.

The Health Care Commission has published a number of reports relating to maltreatment and abuse of people with learning disabilities in specialist inpatient settings. A key area of concern has been the inappropriate use of physical restraint.

## Elements of an ‘excellent service’

- Early intervention in childhood.
- Effective transition planning into adult services.
- Knowledge of the demographics of the local population, including those who are at risk of out of area placements.
- A range of local supports where people live and work.
- Capable workforce in all settings to ensure the suitability of local provision.
- Speedy response from skilled practitioners, with access to local supports when problems occur.
- Stepped care approach to assessment, formulation and intervention including appropriate use of Assessment and Treatment Units and access to general health provision.
- Locally-based individualised and specialised housing and support provision.
- Ability to demonstrate positive outcomes for individuals.
- Up-to-date information about the numbers and needs of people who are placed out of area.
- Appropriate use of assistive technology to enable people to be supported safely in the home and community.

## Expected outcomes

- Increased use of evidence-based interventions.
- Reductions in the frequency and severity of challenging behaviour of individuals.
- Reduction in the use of medication, including polypharmacy.
- Reduction in the use of one-to-one support packages as the mechanism for managing risk.

- Reduction in the use of out of area placements.
- Reduction in harm to the person and to others.
- Better quality of life.
- Greater social inclusion.
- Increased carer support and satisfaction.
- Reduction in staff stress.
- A more skilled and knowledgeable workforce.

## **Psychology contribution to delivering individualised outcomes and quality indicators**

- Lead on the development of care pathways for assessment, intervention and support.
- Lead on the development of protocols for the delivery of the care pathway.
- Lead on the development of individualised assessments including risk, behaviour, environment.
- Lead on the process of returning people from out of area placements.
- Lead on the development of multi-disciplinary formulations that help services to understand how to support the people they care for.
- Develop and train others to deliver specific evidence-based interventions for individuals, for example, anger management, behavioural support plan, risk management, adapted CBT, alternatives to physical and mechanical restraint.
- Develop specific evidence-based interventions for whole services, for example, systemic approaches with staff and carers, environmental adaptations, stress management, emotional support, supervision for managers, advice on training and capable workforce.
- Advising on developing and maintaining a service of excellence.
- Developing and monitoring outcomes for individuals and services.
- Auditing and reviewing services.

## **Potential risks if services not available/not effective**

- Increased costs of one-to-one or out of area placements.
- More complaints.
- Potential safeguarding issues.
- Reliance on restrictive practices.
- Increase in abuse or harm to self and others.
- Carer breakdown.

## Resources

British Institute for Learning Disabilities (BILD). [www.bild.org.uk/behavioursupport.htm](http://www.bild.org.uk/behavioursupport.htm)

Department of Health (2007). *Services for people with learning disabilities and challenging behaviour or mental health needs (Revised)*.

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/  
PublicationsPolicyAndGuidance/DH\\_080129](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080129)

Person-Centred Active Support. [www.personcentredactivesupport.com/](http://www.personcentredactivesupport.com/)

RCPsych, BPS & RCS&LT (2007). *Challenging Behaviour: a unified approach*.

[www.bps.org.uk/sites/default/files/documents/challenging behaviour – a unified  
approach.pdf](http://www.bps.org.uk/sites/default/files/documents/challenging%20behaviour%20-%20a%20unified%20approach.pdf)

*SCIE Knowledge Review 20 – Commissioning person-centred, cost effective, local support for people with learning disabilities* (2008).

[www.scie.org.uk/publications/knowledgereviews/kr20.asp](http://www.scie.org.uk/publications/knowledgereviews/kr20.asp)

The Challenging Behaviour Foundation. [www.thecbf.org.uk/](http://www.thecbf.org.uk/)

# People with mental health problems

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## Background

### *Demographic*

It is now recognised that people with learning disabilities experience the full range of mental health problems. Estimates on prevalence vary, but studies indicate that 25 to 40 per cent of people with learning disabilities also have additional mental health needs. People with borderline learning disabilities experience higher rates of mental ill health than the general population, but receive fewer treatments.

### *Trends*

There is increasing evidence that people with learning disabilities are being more effectively diagnosed and treated for their mental health problems. This requires distinctive clinical skills to assess, treat and support people, through the use of both generic and specialist services including acute admission facilities, outreach services in the community, psychological therapy and long term support.

### *Data*

Government policy has set a clear expectation that people who have learning disabilities and mental health problems should be able to access mainstream mental health services as appropriate. However, the reality for many people with learning disabilities is that their access to, and treatment from, mainstream mental health services is often poor.

Unsurprisingly, all nine localities involved in a Joint Review of Commissioning for people with learning disabilities and complex needs reported problems with access and/or the treatment provided by local mental health services.

It is also acknowledged that for some people with learning disabilities, the use of mainstream mental health services such as an acute psychiatric ward will be inappropriate and they may be better served by the local specialist adult learning disability team.

The results of a review of 28 studies on adults (excluding children, adolescents, older adults and forensic populations) with learning disabilities using general adult services since beginning of 2003 reveals some interesting data. Evidence regarding referral to general community and inpatient mental health services indicates reduced access of people with learning disabilities. The mean length of stay for people with learning disabilities was found to be longer for people admitted to specialist learning disabilities beds than those admitted to general psychiatric beds. Studies using qualitative approaches to look at the inpatient environment found specialist inpatient units provided caring staff, positive environment, practical help and respite function, although was negatively rated by people with learning disabilities as causing isolation. People with learning disabilities rated general psychiatric wards more positively in terms of supportive peer relationships, but they were negatively rated in terms of staff being unfriendly or harmful, poor environment, lack of freedom, feeling upset by others' behaviour, and feeling vulnerable. Carers were more likely to rate specialist learning disabilities units more positively. Extra help and staff training are necessary to improve access to mainstream psychiatric services where these are the only alternative.

## Evidence base and good practice

Clinical psychologists have been instrumental in developing local protocols for working with people with learning disabilities who have significant mental health problems. Depending upon the individual's particular circumstances, their needs may be best met by the Learning Disability service, the mainstream mental health service or by both of those services working together to offer the individual the most appropriate mix of skills and expertise available within both services. The Care Quality Commission includes standards from the Greenlight toolkit as quality standards for mental health and learning disability trusts – psychologists are involved in the process of ensuring that these standards are being met locally. Many Strategic Health Authorities and commissioners also use these standards as part of the CQUIN process. Department of Health guidance on *Commissioning Specialist Adult Learning Disability Health Services* gives more detail on this area and it is recommended this document be read in conjunction with this guidance.

There is an increasing evidence base for the use of psychological therapies with people with learning disabilities including of cognitive-behavioural, psychodynamic and systemic psychotherapies, as well as other approaches recommended by the National Institute for Health and Clinical Excellence (NICE) such as Eye Movement Desensitisation and Reprocessing, and Dialectical Behaviour Therapy. However, clinicians providing these treatments need a specialist understanding of how to adapt these to the needs of each individual person with learning disabilities because of their underlying cognitive deficits and different life experiences.

Meeting the mental health needs of people with learning disabilities requires a consideration of how new initiatives such as Improving Access to Psychological Therapies (IAPT) will be applied and what measures may need to be taken to ensure equal access.

IAPT focuses on 'common' mental health problems, i.e. depression and anxiety, which are addressed in primary care, or even prior to the involvement of primary care services.

In January 2009 positive practice guidance was issued relating to people with learning disabilities and IAPT. The guidance identifies four key barriers to access:

- **Social restriction** including lack of support to access their GP or other services.
- **Challenging behaviour** may prevent people from being able to express feelings in words and underlying causes of behaviour is often not identified.
- **General practitioners** and other primary care professionals report lack of skills and knowledge to engage effectively with people with LD and experience time constraints which may present barriers.
- **Specialist mental health services** for a range of reasons (including lack of confidence) do not support effective access of people with learning disabilities to the service.

The Department of Health *New Horizons* programme is developing a shared national vision for health and well-being. Commissioners and providers will need to work together to ensure people with learning disabilities and mental health needs benefit from this new initiative.

## Elements of an ‘excellent service’

- Known demographics of people with learning disabilities with mental health problems in the local area.
- Multi-agency mental health strategy that reflects the principles and objectives of the Greenlight toolkit.
- Multi-agency care pathway for assessment, diagnosis, treatment and support of people with learning disabilities who have mental health problems.
- Multi-disciplinary approach to assessment and diagnosis and support.
- Prompt access to assessment and diagnostic services.
- Person-centred care using the Care Programme Approach.
- Effective care management and review system.
- Prompt access to the full range of medical, psychological, therapeutic and social interventions.
- Prompt access to appropriate in-patient and crisis resolution and home treatment services as required.
- Support is available to family carers and service providers.
- Capable workforce able to deliver excellence in mental health care for people with learning disabilities.
- Focus on recovery.

## Expected outcomes

- Increase in prompt differential diagnosis of the person’s difficulties.
- Appropriate access to mainstream mental health services.
- Increase in other conditions being treated promptly.
- Increase in accurate diagnosis of mental health problems.
- Reduction in behaviours which challenge.
- Increase in quality of life indicators for the person.
- Reduction in moves to other placements.
- Reduction in the need for emergency one-to-one cover.
- Reduction in out of area placements.
- Increased carer support and satisfaction.
- Reduction in staff stress.

## Psychology contribution to delivering individualised outcomes and quality indicators

- Work with other senior professionals on Greenlight toolkit, CQC standards and CQUIN targets.
- Lead on determination of appropriateness of IAPT services for people with learning disabilities and pathways across services.
- Lead on development of care pathways across MH and LD services.
- Lead on development of risk management frameworks.
- Support the development of protocols for joint working between services.
- Advise on developing and maintaining a service of excellence.

- Individualised assessment of the person across the range of mental health issues.
- Auditing and reviewing services.
- Adapting common psychological therapies to make them accessible to people with cognitive impairments. This applies to the main therapeutic modalities of cognitive-behavioural, psychodynamic and systemic psychotherapies, as well as other approaches recommended by NICE such as Eye Movement Desensitisation and Reprocessing, Cognitive Analytical Therapy and Dialectical Behaviour Therapy.
- To act as responsible clinician for offenders detained under the Mental Health Act and on Supervised Community Treatment Orders.
- Contribute to multidisciplinary approaches to relapse prevention.
- Developing and monitoring outcomes for individuals and services.
- Provide support, training and supervision to other professionals working with people with LD and mental health problems in the local health economy.

### Potential risks if services not available/not effective

- Increased costs of one-to-one support packages.
- New ‘in area’ or out of area placements.
- Trusts do not comply with CQC standards around Greenlight toolkit.
- Trusts do not achieve CQUIN quality targets.
- Vulnerable service users fall between mainstream mental health and specialist learning disability services when they require mental health services.
- Less access to home-based assessment and intervention of mental health issues.
- Less access to appropriate psychological interventions.
- Increase in in-patient stays.
- More complaints.
- Potential safeguarding issues.
- Increase in Serious and Untoward Incidents such as abuse, harm or death to self and others.
- Carer breakdown.

### Resources

Department of Health (2007). *Commissioning Specialist Adult Learning Disability Health Services*. [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_079987](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_079987)

Department of Health (2009). *No Health without Mental Health*. [www.dh.gov.uk/prod\\_consum-dh/groups/dh-digitalassets/documents/digitalasset/dh\\_124058.pdf](http://www.dh.gov.uk/prod_consum-dh/groups/dh-digitalassets/documents/digitalasset/dh_124058.pdf)

Green Light Toolkit. <http://valuingpeople.gov.uk/dynamic/valuingpeople146.jsp>

*IAPT Positive Practice Guide – Learning disabilities*.

[www.iapt.nhs.uk/silo/files/learning-disabilities-positive-practice-guide.pdf](http://www.iapt.nhs.uk/silo/files/learning-disabilities-positive-practice-guide.pdf)

Mental Health in Learning Disabilities Electronic Network.

[www.estiacentre.org/mhildnetwork.html](http://www.estiacentre.org/mhildnetwork.html)

# People with autistic spectrum conditions

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## Background

### *Demographic*

The National Audit Office (2009) reports that there are an estimated 400,000 adults with an Autistic Spectrum Condition (ASC) in England, and that about half of people with an ASC have a learning disability. This suggests that there are at least 200,000 adults with a learning disability and an ASC in England (which is more than 20 per cent of the estimated population of 974,000 adults with a learning disability).

*Valuing People Now* (DH, 2009) highlights that adults with a learning disability and an ASC are one of the most excluded groups in society.

### *Trends*

The number of people thought to have an ASC has increased hugely over the last 30 years. Baron-Cohen et al. (2009) report that in 1978 the consensus prevalence estimate of people with an ASC was four in 10,000 (0.04 per cent). Their research, however, resulted in a 2009 prevalence estimate of 157 per 10,000 (1.6 per cent). This suggests that there will be a big increase in demand for services for people with an ASC, and that all services, including those for adults with a learning disability, will need to develop and adapt accordingly.

## Evidence base and good practice

*Fulfilling and Rewarding Lives*, the Department of Health strategy for adults with autism in England (2010), and the implementation guidance provide a focus for development of services in five key areas of services:

- increasing awareness and understanding of autism among frontline professionals;
- developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment;
- improving access for adults with autism to the services and support they need to live independently within the community;
- helping adults with autism into work;
- enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.

As discussed elsewhere in this document, people with a learning disability placed ‘out of area’ are at an increased likelihood of poor outcomes. Although a small number of people with a learning disability and an ASC may need specialist services that cannot be provided in-area, most of this group’s needs should be able to be met locally, often at lower cost than out-of-area provision. However, approximately two-thirds of Local Authorities and NHS bodies who responded to a survey said that they found it fairly/very difficult to find appropriate local support and housing for people with autism (National Audit Office, 2009).

## Elements of an excellent service

- Services provided 'in-area'.
- Data routinely collected on the number of people with a learning disability and an ASC, the number of people in this group placed 'out-of area' and the cost of these 'out of area' placements.
- A clear care pathway, including provision for diagnosis, assessment of strengths and needs and access to post-diagnosis services.
- Ability to support people with any difficulties they have resulting from their ASC, including any challenging behaviour or mental health problem.
- A strategy for developing the skills of the local workforce in recognising and working with people with a learning disability and an ASC.
- Links into a wider local strategy for supporting people with an ASC.
- Specialised local housing providers who are able to provide a range of appropriate supports in non-congregate settings

## Expected outcomes

- Improved quality of life for adults with a learning disability and ASC
- Reduced use of 'out-of area' provision, leading to lower costs.
- Workforce skilled in identifying and supporting people with a learning disability and an ASC, resulting in more choice and opportunities for this group and fewer placement breakdowns.
- More people with a learning disability and an ASC accessing the services they need.

## Expected contribution from a psychology service

The range of core skills of applied psychologists mean they can take lead roles throughout service provision for people with a learning disability and an ASC, in areas including:

- Diagnosis and post-diagnosis support, including education about ASCs.
- Assessment of individual strengths and needs.
- Providing assessment and evidence-based psychological interventions for any additional challenging behaviour or mental health problem.
- Providing assessment and intervention in other areas of need often associated with this group (e.g. understanding and use of social skills, understanding of relationships, etc.).
- Training social care staff and other professionals (e.g. GPs, CTPLD staff, CMHT staff, etc.) in the local area.
- Evaluating outcomes.
- Supporting commissioners to collect data on people with a learning disability and an ASC.
- Providing leadership in service development.
- Contributing to the development of wider local strategy and service provision for people with an ASC.

## Potential risks if services not available/not effective

- Poorer individual outcomes for people with a learning disability and an ASC.
- Higher levels of unmet need, leading to more frequent placement breakdown and use of expensive ‘out of area’ or inpatient services to manage crises.
- Disjointed local services, contributing to poorer outcomes and higher costs.
- Limited availability of data for service planning and development.
- Limited skill in the local social care workforce, necessitating greater use of ‘out of area’ placements.
- Increase in complaints from families

## Resources

Baron-Cohen, S., Scott, F.J., Allison, C., Williams, J., Bolton, P., Matthews, F.E. & Brayne, C. (2009). Autism Spectrum Prevalence: A school-based UK population study. *British Journal of Psychiatry*. <http://bjp.rcpsych.org/cgi/reprint/194/6/500>

Department of Health (2009). *Valuing People Now: A new three-year strategy for people with learning disabilities*. [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_093377](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377)

Department of Health (2010). *Fulfilling and Rewarding Lives: The strategy for adults with autism in England*. [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113369](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369)

National Audit Office (2009). *Supporting people with autism through adulthood. Report by Comptroller and Auditor-General HC 556 Session 2008–2009*. [www.nao.org.uk/publications/0809/autism.aspx](http://www.nao.org.uk/publications/0809/autism.aspx)

# Dementia and people with learning disabilities

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## Background

### *Demographic*

As with the general population, dementia is a growing issue in services for people with learning disabilities as a result of increased life expectancy. There is increasing evidence that people with learning disabilities in general are at increased risk of developing dementia, whilst the incidence is much higher for people with Down's syndrome. Within this group the rates of dementia in people are:

40 to 49 years	10 per cent to 25 per cent
50 to 59 years	20 per cent to 50 per cent
60+ years	30 per cent to 75 per cent.

### *Trends*

It is estimated that by 2020 the proportion of people with learning disabilities over 65 years of age will have doubled and that over a third of all people with learning disabilities will be over 50 years of age. There is a much greater awareness of the risk of dementia by both staff and family carers, and the number of people being referred for concerns is increasing annually.

### *Data*

Within one county in England there are 345 adults with Down's syndrome over the age of 30, and 25 per cent have suspected or diagnosed dementia.

## Evidence base and good practice

In 2006 the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) published a joint clinical guideline on the management of dementia. This document recommended a co-ordinated and integrated approach to assessment, treatment and care, together with the development of appropriate assessment and support services for the person and carers.

The National Dementia Strategy (2009) identified key actions and activities for commissioners and providers to support the needs of this group of people. Psychologists have a key role in both the assessment and diagnostic process, but also in helping others to understand the issues presented by the dementia and adapt the care and the environment to ensure the best quality of life of the person with learning disabilities and dementia. The model assumes that carers who know and understand the person, understand what the dementia brings, and who can adapt the care accordingly, will enable the person to have a quality life, and reduce the impact on other people that they live with.

Guidance on assessment, diagnosis, treatment and support of people with learning disabilities and dementia has been written by the British Psychological Society and the Royal College of Psychiatry (2009). The guidance emphasises the need for effective and timely assessment, diagnosis, and treatment for people with learning disabilities suspected or confirmed as having dementia and to ensure quality support to them, their family and

other carers. Given the risk of early onset of dementia, it is advised that every adult with Down's syndrome is assessed to establish a baseline against which to compare future changes in functioning. The document recommends how environments can be adapted to ensure that people who develop dementia can be supported in ways that maximise their quality of life. A set of 'good practice standards' is provided, against which commissioners and service providers can audit their services.

## Elements of an 'excellent service'

- Known demographics including a database of all adults with learning disabilities including identification of people with Down's syndrome and those in out of area placements.
- Multi-agency dementia strategy.
- Multi-agency care pathway for assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia.
- Multi-disciplinary approach to assessment and diagnosis and support.
- Prompt access to assessment and diagnostic services including baseline assessment for people with Down's syndrome by the age of 30.
- Person-centred dementia care.
- Effective care management and review system.
- Prompt access to the full range of medical, psychological, therapeutic and social interventions.
- All living and day service environments are dementia friendly.
- The person is supported to remain in their familiar home with additional supports provided in a timely manner.
- Support is available to family carers and service providers.
- There is a capable workforce able to deliver excellence in dementia care.
- End of Life care follows the requirements of the National End of Life Strategy.

## Expected outcomes

- Increase in prompt differential diagnosis of the person's difficulties.
- Increase in other conditions being treated promptly.
- Increase in accurate diagnosis of dementia.
- Reduction in behavioural difficulties.
- Increase in quality of life indicators for the person.
- Reduction in moves to other placements.
- Reduction in the need for emergency one-to-one cover.
- Reduction in out of area placements.
- Increased carer support and satisfaction.
- Reduction in staff stress.

## Psychology contribution to delivering individualised outcomes and quality indicators

- Lead on development of dementia strategy.
- Lead on development of care pathway.
- Develop protocol for delivery of care pathway.
- Individualised assessment of the person.
- Formulation.
- Differential diagnosis.
- Specific evidence-based interventions for individuals, for example, reminiscence, anxiety management, behavioural support plan, risk management.
- Specific evidence-based interventions for services, for example, understanding model of dementia care, systemic approaches with staff and carers, environmental adaptations, stress management, emotional support, supervision for managers, advice on training and capable workforce.
- Advising on developing and maintaining a service of excellence.
- Developing and monitoring outcomes for individuals and services.
- Auditing and reviewing services.
- Delivery of training to staff and carers.

## Potential risks if services not available/not effective

- Increased costs of one-to-one, new in area or out of area placements.
- More complaints.
- Potential safeguarding issues.
- Increase in behaviours leading to abuse or harm to self and others.
- Carer breakdown.

## Resources

BPS/RCPsych (2009). *Dementia guidelines for people with learning disabilities*.  
[www.dcp-ld.bps.org.uk/dcp-ld/publications/publications\\_home.cfm](http://www.dcp-ld.bps.org.uk/dcp-ld/publications/publications_home.cfm)

National Dementia Strategy.  
[www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_094051.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_094051.pdf)

NICE/SCIE. *Guideline to improve care for people with dementia*.  
[www.nice.org.uk/guidance/index.jsp?action=download&o=30323](http://www.nice.org.uk/guidance/index.jsp?action=download&o=30323)

# Offenders and those at risk of offending

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## Background

### *Demographic*

Offenders with learning disabilities generally fall in the mild range of intellectual disability. This is because a person requires *mens rea* before they can be considered culpable for an illegal act. Individuals of cognitive function lower than mild learning disabilities would not normally be considered to have *mens rea*. With that caveat in mind, a small percentage of people with learning disabilities are known to commit the full range of offences known to mainstream criminal services. Studies on the prevalence of offenders with learning disabilities in a range of criminal populations have found hugely diverse percentages from zero to around 30 per cent.

### *Data*

The most common offences are associated with verbal and physical aggression, as is the case in mainstream criminal populations. Sexual offences and alcohol-related offences feature relatively frequently. Fire raising, theft and alcohol-related offences are recorded at low but consistent levels.

## Evidence base and good practice

Specialist learning disability health services range from community-based teams to in-patient provision and many have a forensic service at low, medium or high levels of security. As part of the multi-disciplinary team, psychologists are delivering a range of programmes and treatments to this population including adapted sex offender treatment programmes, anger management, enhanced thinking skills and substance misuse. Psychologists play a key role in developing thorough risk assessments and risk management plans so that people can be supported in the least restrictive environment.

Psychologists can provide invaluable support at each stage of the criminal justice system to support people with learning disabilities to receive fair and equal treatment. The need to support offenders with learning disabilities has an increasing profile and the publication of the Prison Reform Trust *No One Knows* in 2008 has provided a clearer picture of the issues facing this group. The report estimates that up to 30 per cent of the prison population have learning disabilities or difficulties and provides evidence of the poor support and treatment experienced by many offenders with learning disabilities including bullying, harassment and discrimination.

Policy drivers to ensure people with learning disabilities are cared for as close to home as possible and in the least restrictive setting have a particular relevance for this group. Many people with learning disabilities and forensic needs are in high cost distant placements and at risk of getting 'stuck' in the system. By working in partnership with commissioners, psychologists are well placed to ensure that where appropriate, people are able to live closer to home and 'step down' to conditions of lesser security.

Clinical psychologists have been in the forefront of innovation using a range of techniques, such as exploring how far the *Good Lives* model used by forensic services can be adapted for people with mild disabilities.

## **Elements of an ‘excellent service’**

- Known demographics of people with learning disabilities who offend in the local area including in the Criminal Justice system.
- Multi-agency strategy for offenders with learning disabilities.
- Multi-agency care pathway for assessment, diagnosis, treatment and support of people with learning disabilities who offend or are at risk of offending.
- Court diversion processes that address the needs of people with learning disabilities.
- Multi-disciplinary approach to assessment and diagnosis and support.
- Prompt access to assessment and diagnostic services.
- Person-centred care.
- Effective risk management both within and across agencies including prison, probation, police, MAPPA, health and social services.
- Effective care management and review system.
- Prompt access to the full range of medical, psychological, therapeutic and social interventions within the community including offender treatment programmes.
- Prompt access to appropriate locked rehabilitation, low secure, medium secure and high secure services as required.
- Support is available to family carers and service providers.
- There is a capable workforce able to deliver excellence in for people with learning disabilities who offend or are at risk of offending.

## **Expected outcomes**

- Increase in prompt differential diagnosis of the person’s difficulties.
- Increase in the risk being managed promptly.
- Increase in accurate diagnosis of likelihood of offending.
- Reduction in offending.
- Increase in quality of life indicators for the person.
- Reduction in moves to other placements.
- Reduction in the need for emergency one-to-one cover.
- Reduction in out of area placements.
- Increased carer support and satisfaction.
- Reduction in staff stress.

## **Psychology contribution to delivering individualised outcomes and quality indicators**

- Work with other agencies on strategy for offenders with learning disabilities.
- Lead on development of care pathway across all forensic and learning disability services.
- Support the development of protocols for joint working between services.
- Work collaboratively with other professionals and agencies to protect the public.
- Individualised assessment of the person for offending behaviour and other co-morbid conditions; adapt assessment for people with all degrees of learning disabilities to identify treatability and treatment needs.
- Assessments as part of a low secure gate keeping role.

- Formulation.
- Differential diagnosis.
- Providing inreach to prisons.
- Adapting common psychological therapies and offender treatment programmes to make them accessible to people with cognitive impairments who offend. This applies to the main therapeutic modalities of cognitive-behavioural, psychodynamic and systemic psychotherapies.
- Deliver therapies (e.g. adapted sex offender treatment groups) in collaboration with other agency staff such as probation.
- To act as responsible clinician for offenders detained under the mental health act and on supervised community treatment orders.
- Relapse prevention.
- Risk management.
- Advising on developing and maintaining a service of excellence.
- Developing and monitoring outcomes for individuals and services.
- Auditing and reviewing services.
- Provide support, training and supervision to other professionals in the local health economy.

### **Potential risks if services not available/not effective**

- Increased costs of one-to-one, low secure, medium secure and high secure placements.
- Increase in use of prison.
- Increase in behaviours leading to offending, abuse or harm to self and others.
- Potential safeguarding issues.
- More complaints.
- Carer breakdown.
- Increase in negative publicity about services.

### **Resources**

G. Murphy (2006). *Breaking the Cycle – better help for people with learning disabilities at risk of offending – a framework for the north-west region*. [www.nwtdt.com/](http://www.nwtdt.com/)

Department of Health (2009). *Lord Bradley's Review of people with mental health problems or learning disabilities in the criminal justice system*.  
[www.dh.gov.uk/en/Publicationsandstatistics/Publications/  
 PublicationsPolicyAndGuidance/DH\\_098694](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_098694)

Prison Reform Trust (2008). *No-One Knows – Learning Disabilities and Learning Difficulties in Prison*. [www.prisonreformtrust.org.uk/uploads/documents/NOKNL.pdf](http://www.prisonreformtrust.org.uk/uploads/documents/NOKNL.pdf)

For Government guidance on the commissioning and standards for secure services.  
[www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/  
 digitalasset/dh\\_126177.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_126177.pdf)

# People with profound and multiple learning disabilities

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## Background

### *Demographics*

People with profound and multiple learning disabilities are among the most disabled individuals in our community. They have a profound intellectual disability and consequently severely limited understanding. In addition they have multiple disabilities which may include impairments of vision, hearing, and movement as well as other problems like epilepsy and autism. Some people have in addition problems of challenging behaviour such as self-injury (DH, 2010).

They are a relatively small, easily identifiable group with undeniable needs for support. It is estimated that there are just over 16,000 adults with profound and multiple disabilities in England now. This is about 0.03 per cent of the general population. It is likely that the incidence in Scotland, Wales and Northern Ireland is similar.

### *Trends*

It is estimated that the number of adults with profound and multiple disabilities is likely to increase by an average of 1.8 per cent each year to 2026. In a 'district' with a population of 250,000, the number of adults with profound and multiple disabilities is expected to increase from about 78 in 2009 to 105 in 2026.

This rate will be higher in communities that have a younger demographic profile or a greater number of citizens from Pakistani and Bangladeshi communities, where the incidence of learning disabilities is greater.

### *Data*

Research by Mencap shows that most parents of children and adults with profound and multiple disabilities spend more than 10 hours per day on essential physical care. A third of these parents said their caring role was continuous and meant they were caring for their son or daughter 24 hours a day, while more than half of parents were spending over eight hours per day on therapeutic and educational activities. Parents were woken up, on average, three times a night by the need to care for their son or daughter. Nearly half of families interviewed received no support from outside the family to help with care tasks and less than a quarter received more than two hours support a week to help them cope at home with care tasks. The study showed that 37 per cent of families were in contact with eight or more professionals and 80 per cent felt that professionals were poorly co-ordinated. People with profound and multiple disabilities experience a much higher mortality rate than the rest of the population, but many live well into adult life.

## Evidence base and good practice

*Raising our sights: services for adults with profound intellectual and multiple disabilities* (DH, 2010) highlights examples of good practice to support adults with profound and multiple disabilities. Where families are supported to make the most of the 'personalisation' agenda, they are in general shown to be getting what they and their families needed and wanted. The report identifies a number of elements that make for a good service:

- All the examples of good practice involved designing and delivering arrangements tailored to the individual person's needs and preferences.
- Good services treat the family as the expert. In all the examples of good practice families had taken a leading role to get what they needed for their disabled family member.
- Good services focus on quality of staff relationships with the disabled person. Staff need to have a warm, respectful and caring relationship with the person.
- Good services sustain the package of care. If basic supplies like incontinence pads and other equipment are not readily available, the quality of life of the disabled person is undermined.
- Assistive technology such as microswitches, electric wheelchairs and communication aids can greatly enhance quality of life.

## Elements of an 'excellent service'

- Use of information technology to increase the person's choice and control.
- Individualised support tailored to the person's needs and preferences.
- Families are seen as the experts by other services (e.g. GPs and acute hospital staff).
- 'Personalisation' includes adults with profound and multiple disabilities in a way that leads to improved quality of life.
- Development of independent advocacy arrangements to represent the interests of adults with profound and multiple disabilities.
- The development of more effective transition arrangements with the provision of proper planning and timely provision of appropriate services as people move into adulthood.
- Local agencies have up-to-date information about the number, needs and circumstances of people in their area currently and projected in the future to enable effective planning of services.
- Local workforce plans ensure that the social care workforce, including personal assistants, are trained in person-centred approaches to communication and support that meet the needs of adults with profound and multiple disabilities.
- Improved access to communication aids and assistive technology as a means of enhancing quality of life.
- Access to further education and other meaningful daytime activities outside the home.
- Access to a range of suitable short breaks.
- Co-ordinated inter-agency policies and practices to ensure people receive the support they need, when and where they need it.

## Expected outcomes

- Increased availability of information technology to aid communication and choice making.
- Increased opportunities to indicate preferences and control their environment, through the development of developmentally appropriate communication.
- Increased use of self-directed services, including individualised budgets to control and direct the services they need.

- Improved quality of life.
- Lower costs on families (including non-monetary costs).
- Lower needs in other areas (e.g. health).
- Improved access to advice and support for families.
- Greater access to independent advocacy for individuals and their families.
- Improved quality of transition from children's to adult services.
- Reduced stress and burnout in families and paid staff.
- Increased opportunities to indicate preferences and control their environment.
- Reduced pain and distress.

## Psychology contribution to delivering individualised outcomes and quality indicators

- Lead on development of care pathways.
- Carry out, and support others, to perform a range of assessments.
- Work with other professionals to develop and train staff and carers to deliver specific evidence-based interventions (e.g. Intensive Interaction) for individuals.
- Develop specific evidence-based interventions for whole services (e.g. person-centred active support).
- Advise on developing and maintaining a service of excellence.
- Developing and monitoring outcomes for individuals and services.
- Auditing and reviewing services.
- Assessment and interventions for individuals who self-injure.
- Development of alternatives to restraints.
- Lead on the promotion of decision-making within the MCA.

## Potential risks if services not available/effective

- Increase in interventions involving physical restraint and possible safeguarding issues.
- Carer breakdown and the resultant dependence on alternative support packages.
- Increase in behaviours leading to abuse or harm to the person.
- Perpetuating the marginalisation and exclusion of one of the most neglected and needy groups of people in our society.

## Resources

*Commissioning services and support for people with learning disabilities and complex needs* (2009).  
[www.cqc.org.uk/\\_db/\\_documents/Report\\_for\\_commissioning\\_LD\\_joint\\_review.pdf](http://www.cqc.org.uk/_db/_documents/Report_for_commissioning_LD_joint_review.pdf)

Department of Health (2010). *Raising our sights: Services for adults with profound intellectual and multiple disabilities. A report by Professor Jim Mansell.*  
[www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_117961.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117961.pdf)

Mencap (2001). *No ordinary life: The support needs of families caring for children and adults with profound and multiple learning disabilities*. London: Royal Society for Mentally Handicapped Children and Adults.

[www.mencap.org.uk/document.asp?id=1671&audGroup=&subjectLevel2=&subjectId=&sorter=1&origin=pageType&pageType=112&pageno=&searchPhrase=](http://www.mencap.org.uk/document.asp?id=1671&audGroup=&subjectLevel2=&subjectId=&sorter=1&origin=pageType&pageType=112&pageno=&searchPhrase=)

Mencap (2006). *Breaking point – families still need a break: A report on the continuing problem of caring without a break for children and adults with severe and profound learning disabilities*.

London: Royal Society for Mentally Handicapped Children and Adults.

[www.mencap.org.uk/document.asp?id=297](http://www.mencap.org.uk/document.asp?id=297)

# People with physical health needs

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## Background

### *Demographic*

People with learning disabilities have higher levels of ill health and much higher rates of premature death than the population as a whole. It is estimated that people with learning disabilities are 58 times more likely to die prematurely. People with learning disabilities have higher rates of obesity, coronary heart disease, respiratory disease, hearing impairment, dementia, osteoporosis and epilepsy. Some 26 per cent of people with learning disabilities are admitted to hospital each year compared with 14 per cent of the general population.

### *Trends*

The evidence from a series of reports and inquiries shows that the National Health Service (NHS) is not yet commissioning or providing services in ways that adequately meet these health needs. This contributes to preventable ill health, poor quality of life and – at worst – premature deaths.

Sir Jonathan Michael's independent inquiry found that these inequalities arise in part because:

- people with learning disabilities find it harder to access assessment and treatment for general health care;
- health care providers make insufficient adjustments for communication problems, difficulty in understanding, or the individual preferences of people with learning disabilities;
- parents and carers struggle to be accepted as effective partners in care;
- health service staff have very limited knowledge about learning disabilities and are unfamiliar with the legislative framework;
- partnership working and communication are poor;
- although there are examples of good practice, witnesses have also described appalling examples of discrimination, abuse and neglect.

### *Data*

People with learning disabilities tend to have markedly worse health than the population as a whole. The 2006 Disability Rights Commission report estimated that people with learning disabilities are two-and-a-half times more likely to have health problems.

There is widespread evidence of the burden of specific disease:

- around one person in three with learning disabilities is obese, compared with one person in five of the general population;
- coronary heart disease (CHD) is the second most common cause of death in people with learning disabilities;
- the incidence of respiratory disease is three times higher in people with learning difficulties than in the general population;
- some 40 per cent of people with learning disabilities have a hearing impairment and many have common visual impairments;

- the rate of dementia is four times higher and the rate of schizophrenia three times higher than in the general population;
- people with learning disabilities tend to have substantially less bone density and experience higher levels of osteoporosis;
- epilepsy is over 20 times more common in people with learning disabilities than in the general population. Sudden unexplained death in epilepsy is five times more common in people with learning disabilities than in others with epilepsy.

Ill health has an obvious impact on quality of life for people with learning disabilities. Both adults and children with learning disabilities are at an increased risk of early death. Those under the age of 50 are 55 times more likely to die prematurely. For those over 50, the risk is 58 times more likely. The Government has agreed Sir Jonathan Michael's recommendation to establish a confidential inquiry to improve the evidence base on how to reduce the incidence of premature death ([www.ihal.org.uk](http://www.ihal.org.uk)).

## Evidence base and good practice

Securing the right services for people with learning disabilities is not just a matter of good commissioning practice. The Disability Discrimination Act 1995 places a duty on all health and social care organisations not to discriminate against disabled people or provide them with a poorer quality of service. It obliges organisations to make 'reasonable adjustments' to reflect the needs of disabled people.

*Valuing People Now* includes the Government's response to the independent inquiry chaired by Sir Jonathan Michael. The inquiry found that 'people with learning disabilities appear to receive less effective care than they are entitled to receive' and made ten recommendations to address these inequalities. The key recommendations for PCTs concern better leadership, better use of data to commission and monitor care, identifying and acting on health needs (through Joint Strategic Needs Assessments and Local Area Agreements) and securing general health services, including primary care, that make reasonable adjustments for people with learning disabilities.

The then Secretary of State for Health commissioned the independent inquiry following Mencap's report, *Death by Indifference*, which highlighted the cases of six people with learning disabilities who died while in the care of the NHS. The Parliamentary and Health Service Ombudsman and Local Government Ombudsman have recently reported on these individual cases. The Ombudsmen recommended that all NHS and social care organisations should urgently review the effectiveness of their systems – and their capacity/capability – for understanding and meeting the additional and often complex needs of people with learning disabilities. PCTs and other organisations were expected to report to their Boards by March 2010 on the action they had taken.

The Operating Framework for 2009/10 reinforced the importance of PCTs securing general health services that make reasonable adjustments for people with learning disabilities, monitoring uptake of annual health checks, and having systems in place to improve the overall quality of health care for people with learning disabilities.

These objectives align strongly with the emphasis in the NHS *Next Stage Review* and in the *World Class Commissioning* framework on more personalised services, a greater focus on health and well-being, and working in partnership with local authorities and other sectors.

## Elements of an ‘excellent’ service

- Good data and information on people with learning disabilities and their journey through the general health care system.
- Good awareness in primary care of the health needs of people with learning disabilities.
- Priority given to people with learning disabilities.
- Good awareness of the additional needs of people with learning disabilities and their co-morbidities.
- Effective monitoring or performance management of providers’ compliance with the legislative framework.
- Comprehensive training for health care staff about learning disabilities.

## Expected outcomes

- Ensuring that health care providers make reasonable adjustments, as required by the Disability Discrimination Act.
- Increase in the number of person-centred care plans and health action plans.
- Increase in collaborative working with GP practices, PCTs, acute health providers, local authorities and local Learning Disability Partnership Boards.
- Increasing access to general health services that meet the individual needs identified in annual health checks.
- Increasing effective communication with service users and their families and carers to ensure that their needs, choices and preferences are understood and that services are available to reflect individual choices.
- Decreasing diagnostic overshadowing/overcoming the risk that people’s reports of physical ill health or unusual behaviours are viewed as part of learning disabilities, and so are not investigated or treated.
- Increase in staff understanding and practice re issues of confidentiality, consent and mental capacity legislation for adults with learning disabilities.
- Improvement in training of those providing health care across primary care, community services and hospital care.
- Increased partnership working with patients, advocates, families and across professional boundaries.

## Psychology contribution to delivering individualised outcomes and quality indicators

A key concern highlighted across these and other reports has been the lack of skills, knowledge and positive attitudes evident in the wider NHS in relation to people with learning disabilities. Psychologists have a valuable role to play in enabling people to access mainstream NHS services and in supporting their colleagues who work in these services to meet the needs of this group. For example, psychologists are well placed to provide training and specifically, to help mainstream professionals address complex issues such as capacity and consent.

Additional disabilities, particularly sensory impairments and their consequences may not always be fully understood by those caring for someone with learning disabilities. It is not uncommon for people to exhibit ‘challenging behaviours’ as a consequence of unmet physical need or pain. Psychologists can work with the individual and their carers to help them to detect patterns of behaviour that may signal an underlying health need and reduce the risk of ‘diagnostic overshadowing’.

Supporting people to develop their own plans to address their health needs, including making use of tools such as health action plans is a key policy objective. Psychologists have a range of skills to support self-care and an individual and their families understanding of health needs.

Psychologists are able to use the evidence base to meet the physical health needs of people with learning disabilities, and to identify gaps in the evidence base to develop innovative approaches to meeting health needs.

Psychologists are also involved in helping to develop the health strategy for the local area in collaboration with other providers. They can also lead on audit, evaluation and research into health needs of people with learning disabilities.

## **Potential risks if services not available/not effective**

- Poorer health care for people with learning disabilities.
- Non or late diagnosis of treatable or preventable health needs.
- Poor compliance with mental capacity legislation.
- Potential safeguarding issues.
- More complaints.
- Increase in behaviours that challenge.
- Greater and earlier mortality.

## **Resources**

Directed Enhanced Scheme for annual health checks for people with learning disabilities.  
[www.pcc.nhs.uk/management-of-health-for-people-with-learning-disa](http://www.pcc.nhs.uk/management-of-health-for-people-with-learning-disa)

UK Health and Learning Disability Network.  
[www.learningdisabilities.org.uk/information/have-your-say/the-uk-learning-disability-and-health-network/?locale=en](http://www.learningdisabilities.org.uk/information/have-your-say/the-uk-learning-disability-and-health-network/?locale=en)

Valuing People Support Team website – health pages.  
<http://valuingpeople.gov.uk/dynamic/valuingpeople118.jsp>

# Supporting parents who have learning disabilities

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## Background

### *Demographic*

There are large variations in estimates of the number of parents in the UK who have learning disabilities from 23,000 to 250,000 (DoH & DfES, 2007). In reality it is very difficult to obtain reliable estimates of numbers due to variations in the definition of learning disabilities over time and across services. Many parents with learning disabilities may well not be known to learning disability services. Some services work with people who would not be considered to have a learning disability as defined by international classification systems. The literature that is available tends to reflect those families who are known to social care services and focuses primarily on mothers.

Between 40 to 60 per cent of these parents will have their children removed from their care permanently. Children within these families are at risk of developmental delay, especially related to cognitive and language skill areas, doing less well at school and having greater behavioural difficulties, even when compared to other families of similar socio-economic backgrounds

### *Trends*

There have been an increasing number of people with learning disabilities becoming parents during the last century, partly as a result of changing attitudes towards sexuality and people with learning disabilities. International research is beginning to show that the number of parents with learning disabilities is steadily growing. Anecdotally there appears to be more referrals to learning disability services for such parents than there were 10 to 15 years ago.

### *Data*

Since 1988 the Special Parenting Service in Cornwall (total population 500,000) has worked with more than 850 families where one or both parents have had a learning disability.

## Evidence base and good practice

There is evidence that parents with learning disabilities can learn and develop their parenting knowledge and skills as long as the interventions are tailored and adapted to take account of the parents' learning disabilities. The evidence is reviewed in the British Psychological Society's *Good Practice Guidance* (BPS, 2011, in press) and shows that parents with learning disabilities are capable of love and affection, they can learn and maintain with support a range of parenting skills involving both practical (e.g. child care and housekeeping) and relationship skills.

In recent years there have been a few specialised resources published to assist families with their parenting skills (e.g. CHANGE, BILD). Parents with learning disabilities are likely to require support with their parenting throughout the duration of a child's life, although the nature and extent of the support can vary. Services for parents vary across the UK and in all but a few areas there are no specific services developed for this very vulnerable group.

There have been three key reports published in the UK within the last 10 years that relate to parents with learning disabilities.

*A Jigsaw of Services* (Goodinge, 2000), inspected services across the country for all disabled parents (including those with learning disabilities) and found:

- A lack of co-ordination.
- Failure of professional collaboration.
- A gender bias towards women.
- Support services tended to be reactive and crisis-driven which immediately sets up problematic relationships with parents.

Tarleton, Ward and Howarth (2006) in their review of examples of good practice, *Finding the Right Support*, found an increase in positive practice in some services across the UK in relation to empowering parents with learning disabilities, raising awareness of their needs and the development of multi-agency support for these parents. They also emphasise that parents with learning disabilities often enter the child protection system due to concerns of perceived neglect by services, which are often due to the parents' cognitive impairments and the impact of social and economic deprivation rather than the result of abuse.

In 2007, the Department of Health published *Good Practice Guidance on Working with Parents with a Learning Disability* (DoH & DfES, 2007). It identified five key features of good practice in relation to working with parents with learning disabilities:

- Accessible information and communication.
- Clear and co-ordinated referral assessment procedures and processes.
- Support based on assessments of their needs and strengths.
- Long-term support.
- Access to independent advocacy.

## Elements of an 'excellent service'

- Known demographics – how many parents with learning disabilities are there?
- Early identification of parents or potential parents.
- Agencies make referral into the learning disability services as early in pregnancy as is possible.
- Prompt assessments of whether or not the person has a learning disability – clear and efficient eligibility process.
- Multi-agency strategy for parents with learning disabilities.
- Multi-agency care pathway for how these parents are assessed in a co-ordinated way.
- Family-centred approach – rather than services that are focused solely upon either the parent or the child.
- The child's welfare remains of paramount importance across all agencies.
- Effective links between children's and learning disability services.
- Pooling of budgets in funding support for these families.
- Interventions/support available to parents on a long-term basis, and these are responsive to the changing needs of parents and children. 'The best predictor of future parental competency for parents with intellectual disabilities is the quality and frequency of social and practical support available to them on a daily basis' (McGaw, 1998, p.200).
- Interventions that are *preventative* rather than *crisis driven*.

- Facilitation to access local services.
- Interventions/groups specifically aimed at parents with learning disabilities.
- Access to advocacy for parents.

## **Expected outcomes**

- Clear identification of parents who have a learning disability
- Interventions targeted at this group of vulnerable parents and children
- Thorough multi-agency assessments of parenting skills that highlight areas where interventions may be required.
- Ongoing support and interventions throughout the duration of the child's minority
- Services working together in a systematic and co-ordinated approach

## **Psychology contribution to delivering individualised outcomes and quality indicators**

- Individualised assessment of the parent, for example, intellectual functioning, reading, numeracy skills, memory, and functional skills.
- Recommendations made as to how to optimise a parent's learning and skill acquisition.
- Work in partnership with other agencies in providing a comprehensive assessment of parenting skills.
- Provide guidance to other agencies in how to ensure that their interventions are tailored that take into account parents' learning disability.
- Provide advice, training, support and supervision to mainstream services, for example, family centres, health visitors who will also support these parents.
- Development of specialist groups for parents with learning disabilities (e.g. in Oxfordshire they have been piloting groups aimed at improving parenting competencies called 'Play Matters' and 'Keeping our Kids Safe').
- Evaluating efficacy of interventions.
- Developing and monitoring outcomes for individuals and their families.

## **Potential risks if services not available/not effective**

- Individual risk factors and the consequences for the children, for example, developmental delay, behaviour difficulties, lower academic achievement.
- Over representation of these families within child protection services.
- Increasing numbers of children permanently removed from their parents care – costly both financially and in terms of outcomes for the children.
- Poor compliance with Human Rights Act.
- Risk of multiple pregnancies to replace 'lost' children.

## Resources

- Baum, S., Gray, G. & Stevens, S. (2011, in press). *Good Practice Guidance for Clinical Psychologists when Assessing Parents with Learning Disabilities*. Leicester: British Psychological Society. [www.bps.org.uk/dcp-ld/about/about\\_home.cfm](http://www.bps.org.uk/dcp-ld/about/about_home.cfm)
- Department of Health & Department for Education and Skills (2007). *Good practice guidance on working with parents with a learning disability*. London: HMSO. [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_075119](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075119)
- Department of Health (2008). *Joint Committee of Human Rights: A life like any other? Human rights of adults with learning disabilities*. London: The Stationery Office. [www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf](http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf)
- McGaw, S. (2007). *Parent Assessment Manual* (3rd ed.). Truro: Pill Creek Publishing. [www.pamsweb.co.uk](http://www.pamsweb.co.uk)

## Including Everyone

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Across UK Government policy documents there is an emphasis on ensuring that the needs of people with learning disabilities from Black and Minority Ethnic communities (BME) and newly-arrived communities are understood and met. It is well known that such groups often face 'double discrimination' and prejudice resulting in poor access to services and unmet need.

People with learning disabilities from BME communities are the focus of an annual census of people with learning disabilities in inpatient mental health and learning disability hospitals. The census 'Count Me In' is conducted by the Care Quality Commission and has highlighted higher admission rates for people with learning disabilities of Mixed White/Black people, Black Caribbean and Other Black ethnic groups.

Psychologists are well placed to ensure that services take real and appropriate actions which result in positive outcomes for black and minority ethnic people with learning disabilities and for their carers.

Ways to improve access to services and improved outcomes include developing dedicated posts to support particular groups. For example, in Sheffield there is a high proportion of service users from South Asian communities. The Sheffield Learning Disability Case Register has identified the proportion of school leavers over the next number of years who will be from this community. In response to this, the Learning Disability Service has developed a new 'BME Clinical Assistant' post. The post-holder is a psychology graduate who is fluent in Punjabi and Urdu languages and acts as a bridge between the local community, families and the Learning Disability Service. She is trained in the 'Family Partnership Model' and supports both psychologists and speech and language therapists to ensure that the needs of people with profound and multiple disabilities and their family carers receive high quality care that is culturally sensitive.

## Psychology contribution to delivering individualised outcomes and quality indicators

- Use evidence-based research to inform their practice.
- Be culturally competent in the assessment, formulation and intervention work with people from BME communities and their carers.
- Be trained to work with interpreters, voluntary sector and families and undertake race equality impact assessments.

## Resources

Count Me In: National mental health and ethnicity census.

[www.mhac.org.uk/census/census2009.php](http://www.mhac.org.uk/census/census2009.php)

Ethnicity Training Network. [www.etn.leeds.ac.uk](http://www.etn.leeds.ac.uk)

National Advisory Group on Learning Disability and Ethnicity.

[www.fpld.org.uk/our-work/community-and-inclusion/national-advisory-group-on-learning-disabilities-and-ethnicity/](http://www.fpld.org.uk/our-work/community-and-inclusion/national-advisory-group-on-learning-disabilities-and-ethnicity/)

National Learning Disability and Ethnicity Network. [www.lden.org.uk/](http://www.lden.org.uk/)

## Leadership and supporting the strategic direction

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Clinical psychologists are in a key position to support commissioners and providers of learning disability services to achieve the aims and objectives set out in current policy and guidance of which there is an overarching theme of ‘personalisation’. This is clearly articulated in *Putting People First* (DH, 2007) and in Lord Darzi’s report *High Quality Health for All* (2008).

Key elements of this agenda are:

- maximising access to universal services;
- promoting independence;
- early intervention and prevention.

To achieve this will require significant changes in the way services are commissioned and shifts in patterns of provision, as increasing numbers of people are offered a personal budget.

This section contains examples of the type of work undertaken by psychologists to support people with learning disabilities and their families and to increase their choice and control.

### Reducing out of area placements and providing services close to home

For a number of years there has been increasing concern about the numbers of people with learning disabilities in distant placements in health and social care. A recent SCIE Knowledge Review (20) identified the extremely high number of CSSR-funded placements by local authority borough and by region.

Supporting commissioners to develop good local services for their population and particularly those with the most complex needs requires skilled and competent specialist learning disability services including psychology. Psychologists have a range of skills to support commissioners with service design, delivery and evaluation as well as direct interventions with individuals themselves.

### Psychology contribution to delivering individualised outcomes and quality indicators

- **Liase with care commissioners** to identify people who could realistically return to their local community.
- **Provide leadership in multidisciplinary risk assessment and review**, assuring the highest standards of ethical, effective and evidence-based practice whilst considering cost issues
- **Conduct complex multi-theoretical assessments and clinical care plans**, integrated with other professional roles and putting the client at the centre of intervention, and calling on the carers and family context.
- **Develop a range of key pathways** that improve people’s access to efficient and effective care systems.

- **Lead in the design of support packages** taking account of potential risks, and provide the necessary training to staff who will provide the support.
- **Evaluate the effect of returning home using a range of objective and subjective methods;** how well interventions were implemented, and their effectiveness.
- **Support other professionals and carers via consultation/supervision to create and maintain a culture of capability in meeting needs locally.** This could be on an ongoing basis, or the psychologist could help design and review local services, consistent with the Mansell report.

## Leadership and innovation in teams

Clinical and other applied psychologists have important roles to play in achieving improved outcomes from team working. This includes helping to achieve the best design and operation for teams, effective individual service planning, peer consultation and support processes, and reflective practice. Psychologists have a breadth of skills in providing consultancy to organisations on organisational and systems improvements. In response to the challenges set out in *Equity and Excellence, Liberating the NHS*, psychologists in many services are taking a lead role in the redesign of teams and whole systems as part of the local QIPP projects. They will often take a lead in supporting teams to:

- Work in multi- or inter-disciplinary ways, maximising the effectiveness of the individuals within the teams.
- Developing clear and achievable objectives.
- Developing innovative ways of working.
- Measuring outcomes and evaluating the effectiveness of the team.
- Driving up excellence.
- Decision making in complex situations.
- Developing evidence-based care pathways.

The BPS document *Working Psychologically in Teams* provides examples of ways in which psychologists can contribute to effective team working.

## Outcome measures

With their training and experience in research methodologies, clinical psychologists are well placed to lead on the development and implementation of routine outcome measures in clinical practice (e.g. CORE-LD).

Clinical psychologists should provide a key element to leadership in services and teams. Leadership by psychologists is provided throughout the breadth of services. Clinical psychologists have a broad knowledge base and extensive training in psychological theory and practice, equipping them to operate effectively at an individual, team or service level, and take on transformational leadership roles.

They are trained to use the core skills of assessment, formulation, intervention and evaluation across the full range of the organisation. Depending on their level of experience, psychologists should be adopting leadership roles in:

- Delivering care to service users who have complex needs. This may include helping support staff to change their practices to deliver more appropriate or effective care

- Designing more effective and responsive services. In many areas, psychologists are members of Partnership Boards or senior management teams, and contribute to the development of new services. They are playing a central role in the development of effective Intensive Support Teams and organisational responses to those people who are inappropriately placed out of area.
- Clinical psychologists often have a formal leadership role beyond the psychology service. This includes such roles as multi disciplinary team leader, service manager and clinical director.
- Clinical psychologists can be expected to take a lead role in the development of routine outcome measures for pathways or whole services. They have expertise in the selection of appropriate measures, the design of evaluation processes, and analysis of the effectiveness of interventions.
- As *Payment by Results* approaches are developed in services for people with learning disabilities, clinical psychologists should play a lead role in setting up effective processes to implement and evaluate outcomes.
- Clinical psychologists are well placed to take a lead role in the CQUIN processes in specialist health trusts.

## Supporting innovative treatment services

The Health care Commission has highlighted many limitations in the therapeutic services provided to vulnerable and challenging individuals. Psychologists have been in the forefront of innovation using a range of techniques, such as exploring how far the *Good Lives* model used by forensic services can be adapted for people with mild disabilities. Other psychologists have introduced a Dutch approach which utilises developmental psychology to enable staff and carers to comprehend the individual's personhood. This systemic approach goes beyond problem-solving concerning challenging behaviour. It assumes that carers who understand and know how to compensate for the person's 'vulnerable self' will enable the person to manage their emotional world more effectively, which in turn reduces challenges. The technique draws tacit knowledge into the therapeutic discussion by starting from staff and family experiences as they relate to the person, an approach which carers find extremely positive.

Future versions of this guidance will consider other emerging areas of innovative practice by clinical psychologists.

# Organising the delivery of psychology services

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Psychologists are a scarce and expensive resource. It is important that they are managed and organised in ways that maximise their effectiveness and ensure value for money. They are core members of multi-disciplinary teams and provide a strong leadership role in teams. One of the unique contributions of psychologists is their ability to ‘formulate’ in complex situations. This section addresses some of the factors that should be considered by the commissioners of psychology services.

## Skill mix and New Ways of Working

In recent years there has been a rapid growth in demand from users and carers for psychological services. At the same time there has been a parallel growth in government policy making it clear that services should increase and improve the level of psychological care in services, and the availability of psychological interventions. The evidence base demonstrating the effectiveness of psychological interventions has grown in the last 20 years, and there is a need for the whole workforce to increase their level of psychological understanding and care. Applied psychologists make an important contribution to the training, supervision, mentoring and development of psychologically informed services.

Psychologists are at the forefront in the *New Ways of Working* (NWW) initiatives, aimed at improving the contribution and application of psychology to new and innovative practices. This has come out of the NIMHE National Workforce Programme in 2003 and looks at changing the practices of the current workforce. This has included developing extended roles beyond the scope of current professional practice, and bringing new people into the workforce in new roles at assistant and practitioner levels.

There is a long tradition of this type of approach within applied psychology. A variety of different roles have been developed which are aimed at ensuring people have easy access to psychological input from practitioners who have the most appropriate level of skill and training for the level of presenting problem. Psychology services across the UK have developed a variety of different posts including:

- **Assistant psychologists.** These are usually graduate psychologists who take on a range of assessments, interventions, research and evaluations under the supervision of a qualified clinical psychologist. They can provide a highly cost-effective support in situations that require psychological input that does not have to be from a qualified clinician. [www.bps.org.uk/downloadfile.cfm?file\\_uid=F33F19E3-1143-DFD0-7ED7-8CC2B5186D05&ext=pdf](http://www.bps.org.uk/downloadfile.cfm?file_uid=F33F19E3-1143-DFD0-7ED7-8CC2B5186D05&ext=pdf)
- **Counsellors.** Many services that provide Talking Treatments employ counsellors to deliver one-to-one therapy, thus enabling qualified clinical psychologists to carry out a range of other tasks.
- **Approved Clinicians.** The new Mental Health Act has provided the opportunity for a number of clinical psychologists to take on the Approved Clinician role. This provides opportunities for a different skill-mix in teams. [www.bps.org.uk/the-society/organisation-and-governance/professional-practice-board/ppb-activities/new\\_ways\\_of\\_working\\_for\\_applied\\_psychologists.cfm](http://www.bps.org.uk/the-society/organisation-and-governance/professional-practice-board/ppb-activities/new_ways_of_working_for_applied_psychologists.cfm)

- **BME clinical assistants and Family Partnership workers.** In several parts of the UK where there are high proportions of BME or newly-arrived communities, psychologists have been involved in the development of posts that are specifically aimed at improving the psychological care to this group of people.
- **Behavioural assistant.** Many services have developed ‘behavioural assistant’ posts that provide assessment and interventions for people who challenge services, by following protocols within a ‘challenging behaviour care-pathway’.

*Organising, Managing and Leading Psychology Services* (BPS, 2007) provides examples of how psychologists can contribute to the development of effective services, and how they should be organised to ensure that this limited resource is managed as effectively as possible. The framework also outlines the leadership development tasks that are likely to be undertaken by psychologists at different levels of the organisation. It is important that an effective psychology service has the appropriate number of staff with the right skill mix to meet the needs of the local population. A variety of different Service Level Agreements are in place throughout the UK. Individual psychology service structures depend to a large extent on the needs of the population and design of local services.

The British Psychological Society publication *Clinical Psychology Leadership Development Framework* (BPS, 2011) sets out the core leadership competencies that can be expected of psychologists from pre-qualification to director levels of the profession.

## Resources

British Psychological Society (2007). *New Ways of Working for Applied Psychologists in Health and Social Care: The end of the beginning*. [www.bps.org.uk](http://www.bps.org.uk)



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ISBN 978-1-85433-715-3

