



all about people

## Frequently asked questions (FAQs) about learning disabilities

BILD has developed these frequently asked questions about learning disabilities based on enquiries we regularly receive.

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## Understanding Learning Disability

### 1. What is a learning disability?

The term learning disability is a label and a label only ever describes one aspect of a person; a person with a learning disability is always a person first. When providing support the emphasis should always be on the person's rights, dignity and individuality; people should not be labelled unnecessarily but the term learning disability is often used in health and social services. As such, it can be helpful to understand what this means. *Valuing People: a new strategy for learning disability for the 21<sup>st</sup> Century* (Department of Health, 2001) explains that it includes the presence of:

- a significantly reduced ability to understand new or complex information and to learn new skills;
- a reduced ability to cope independently;
- an impairment that started before adulthood, with a lasting effect on development.

A person with a learning disability may find it harder to understand, learn and remember new things, meaning they may have problems with a range of things such as communication, being aware of risks or managing everyday tasks. However, while a learning disability cannot be 'cured', with the right support it will have less of an impact on the person's life; leading to the individual learning new skills and living a full life.

### *References*

Department of Health (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: Department of Health. <http://bit.ly/17DUyVN>

## **2. What are the possible causes of a person's learning disability?**

People with a learning disability, like the rest of us, dislike being labelled and always described in terms of their disability; those providing support for them should value and respect their individuality. However, it may be useful to know the causes of someone's learning disability; for example, some syndromes or impairments are associated with certain medical conditions. Understanding the possible cause will help support them to stay healthy.

For many people, the cause of their learning disability is never known, but for others this can be identified. The possible causes are usually grouped into the four categories listed below:

- Before birth or pre-natal: this covers genetic or 'congenital' causes, including Down's syndrome or Fragile X syndrome, as well as other things that affect a baby before it is born, such as drug or alcohol use by the mother.
- During birth or peri-natal: this includes oxygen deprivation during birth, which can lead to brain damage. It can also include injury to the baby because of complications during birth, and difficulties resulting from premature birth.
- After birth or post-natal: covers causes such as illnesses, injury or environmental conditions, for example, meningitis, brain injury or children being deprived of attention to their basic needs - undernourished, neglected or physically abused.
- Multiple causes: this refers to when a person's learning disability is caused by a combination of before, during and after birth factors.

### **3. What is the difference between the terms *learning disabilities*, *learning difficulties* and *intellectual disabilities*?**

Language changes all the time and the words we use to describe a particular impairment or disability have evolved over the years as a result of listening to people with personal experience and due to changing values and attitudes in society. BILD itself has reflected these changing social attitudes and so has made the progression over 43 years from terminology such as 'mental subnormality', 'mental retardation' in the 1970s, 'mental handicap' in the 1980s to 'learning disability' today. It is quite probable that the terms will change again in the future.

Although definitions may be important in some contexts, the emphasis should always be on the person's rights, dignity and individuality and not 'labelling' people unnecessarily. However, it is important to know and understand what these words mean, and recognise that the meaning can change depending upon the country you live in and the services you may come into contact with.

*Learning disability* and *learning difficulty* are the most commonly used terms in the UK, and are sometimes used interchangeably in the context of health and social care for adults. However, in some settings these terms may have different meanings. The term *learning difficulty* is used in educational settings in the UK to include those individuals who have 'specific learning difficulties', such as dyslexia, but who do not have a significant general impairment of intelligence.

Some people prefer the term *learning difficulty* over the term *learning disability*, having embraced what is called the *social model of disability*. The *social model of disability* and the *medical model of disability* developed as a way of explaining the differences in attitudes towards people learning disabilities, including people with learning disabilities.

The *medical model of disability* considers the person to be ill, needing to be 'treated' or 'cured'. Services that took this approach were traditionally run by non-disabled people, assuming that people with the same label required the same treatment, which would often focus on enabling them to better fit in with the non-disabled world. This has been replaced in the UK by the *social model of disability*.

The *social model of disability* draws the distinction between disability and impairment. Impairment means the loss or lack of functioning in a part of the body, resulting in physical differences or limitations. Disability refers to the meaning society attaches to the person with an impairment, how they respond to it and the disadvantage or restrictions placed upon them. "It is the negative attitudes, the inflexible organisational procedures, the inaccessible information and the barriers in

the built environment that restrict the lives of 'disabled people' (CHANGE – [www.changepeople.co.uk](http://www.changepeople.co.uk)) The social model is a rights-based approach. For people with learning disabilities, the social model helps to focus on capabilities rather than deficits.

The term *intellectual disability* is growing in usage across English speaking countries, and may be favoured by professional groups in the UK, parts of Europe, USA and Australia as part of a shared language and approach to supporting people. In 2010, a report by Professor Jim Mansell, for the Department of Health, called *Raising our sights: services for adults with profound intellectual and multiple disabilities* used the term intellectual disability instead of learning disability.

#### **4. I have heard the terms *profound, severe, moderate and mild learning disability*. What do these mean?**

The term *learning disability* covers a broad range of individuals, each with different strengths and capabilities, as well as needs. Knowing the degree of intellectual impairment a person has tells you very little about who they are, but these terms may help the person and those who support them in understanding the needs they may have, and the kinds of support they may require. When providing care and support the person should always come first and the label or category second.

In the UK we have used the terms *profound, severe, moderate and mild* to describe people with learning disabilities, but there are no clear dividing lines between the groups. Furthermore, there is no clear cut off point between people with mild learning disabilities and the general population and you may hear the term *borderline learning disability* being used.

In the past, diagnosis of a learning disability and understanding of a person's needs was based on IQ scores; today the importance of a holistic approach is recognised, and IQ testing forms only one small part of assessing someone's strengths and needs. Assessments of adaptive function focuses on how people can manage their daily living skills and what support they may need; this form of assessment is considered more useful in assessing the impact of any learning disability on a person than an intelligence test.

People with *profound intellectual and multiple disabilities* may have the highest levels of care needs in our communities. They have a profound intellectual disability (an IQ of less than 20) and in addition they may have other disabilities such as visual, hearing or movement impairments, or they may have autism or epilepsy. Most people in this group need support with mobility and many have complex health

needs requiring extensive support. They may have considerable difficulty communicating, doing so non-verbally, and characteristically have very limited understanding. In addition, some people may need support with behaviour that is seen as challenging.

People with a *severe learning disability* have an IQ of between 20 and 35; they may often use basic words and gestures to communicate their needs. Many need a high level of support with everyday activities, but they may be able to look after some if not all of their own personal care needs. Some people may have additional medical needs and some need support with mobility issues.

People with a *moderate learning disability* have an IQ of 35 to 50 and are likely to have some language skills that mean they can communicate about their day to day needs and wishes. Some people may need more support caring for themselves, but many will be able to carry out day to day tasks.

People with a *mild learning disability* have an IQ of 50 to 70 and are usually able to hold a conversation and communicate most of their needs and wishes. They may need some support to understand abstract or complex ideas. People are often independent in caring for themselves and doing many everyday tasks. They usually have some basic reading and writing skills. People with a mild learning disability quite often go undiagnosed.

## **Further Information and Resources**

For more information, please read the BILD 'Learning Disability' fact sheet available here: [www.bild.org.uk/information/factsheets/](http://www.bild.org.uk/information/factsheets/)

'An introduction to supporting people with a learning disability' - a BILD book in our *Good Support Series*: [www.bild.org.uk/our-services/books/good-support/an-introduction-to-supporting-people-learning-disability/](http://www.bild.org.uk/our-services/books/good-support/an-introduction-to-supporting-people-learning-disability/)

'Crossing boundaries: change and continuity in the history of learning disability' – a BILD book in our People's Life Stories section: [www.bild.org.uk/our-services/books/peoples-life-stories/](http://www.bild.org.uk/our-services/books/peoples-life-stories/)

Improving Health and Lives (IHAL) Public health Observatory, part of Public Health England: [www.improvinghealthandlives.org.uk/](http://www.improvinghealthandlives.org.uk/)

For Mencap's definition of a learning disability, please see [www.mencap.org.uk/definition](http://www.mencap.org.uk/definition)

Contact a Family provides support, information and advice aimed at parents of children with a disability. This includes an A-Z Directory of medical information including specific syndromes and conditions. Their free phone helpline is 0808 808 3555. [www.cafamily.org.uk/advice-and-support/](http://www.cafamily.org.uk/advice-and-support/)

## **5. How many people have learning disabilities?**

According to the Public health England website (<https://www.improvinghealthandlives.org.uk/numbers/howmany/>), it is estimated that there are about twenty people in every thousand who have some form of learning disability. However, out of the twenty people in every thousand with learning disabilities, only five of these people are known and supported by the local health and social services. The rest are living independently with no special help.

## **Understanding Autism**

### **6. What are Autistic Spectrum Conditions?**

Just as there are a number of accepted terms for a learning disability, autistic spectrum conditions (ASC) may also be referred to as autistic spectrum disorders (ASD), or simply autism. These terms change as a result of listening to people's personal experiences, changing attitudes and values and new research. ASD is still used in more clinical or research based settings and the term autism is still widely accepted as an umbrella term. BILD uses the term ASC as we believe it is a more neutral description and less of a medical term. However, the use of this term only describes one aspect of the person, and we must remember that each person is an individual with their own personality and strengths.

ASC is a developmental disability, meaning that it begins in infancy or early childhood and results in the delayed development of abilities such as language. Autism affects the individual throughout their life.

A model called the *triad of impairments* is still widely used to understand ASC and the person's main areas of difficulty. The triad includes:

- difficulties with social interaction and relationships
- difficulties with language and communication

- difficulties with ways of thinking

In addition, it is now increasingly understood that people with ASC experience their senses differently to others.

Autism is a spectrum of conditions, and it has a different impact on different people. Although there are some shared characteristics, we should treat everyone as individuals and take steps to understand *their* experiences of ASC.

Having autism does not mean that the person has a learning disability, but some individuals may have both; this must be taken into consideration when providing support to ensure that it meets each person's individual needs. While autism leads to some difficulties and challenges, it is vital to recognise each person's strengths and abilities when working in person centred ways.

For more information see the BILD Books Section *Understanding Autism* :  
[www.bild.org.uk/our-services/books/books-understanding-autism/](http://www.bild.org.uk/our-services/books/books-understanding-autism/)

The National Autistic Society provides information, support, and services, campaigning for a better world for people with autism. Please see their website at [www.autism.org.uk](http://www.autism.org.uk). They offer an Autism Helpline – 0808 800 4104.

## Health and Wellbeing

### 7. How do we support people to stay physically and mentally healthy?

People with a learning disability have more health care needs than the general population, but they may use health services less. There are higher rates of epilepsy, visual and hearing impairments, psychiatric illness and obesity in people with a learning disability compared to the general population. About 50% of people with a learning disability will have at least one significant health problem, 25% will have a physical disability and 30% will have epilepsy. These are often long term conditions for which the person needs ongoing healthcare support.

However, many people with learning disabilities have had their health needs neglected and overlooked. There are many reasons for this including a lack of understanding of learning disabilities by healthcare staff, the challenges of communication and the failure of some health services to make reasonable adjustments to meet the needs of disabled people. A reasonable adjustment is a



reasonable step that is taken to prevent a person with disabilities suffering a substantial disadvantage compared with people who are not disabled.

The *Confidential Inquiry into the Premature Deaths of People with Learning Disabilities* (Heslop et al, 2013) found that men with a learning disability died on average 13 years early, and women with learning disabilities died on average 20 years earlier than men and women in the general population. Many people with a learning disability died prematurely because of a delay or problem with their treatment.

A number of other reports and investigations into the poor healthcare experiences of people with a learning disability are now available. These include:

[Valuing People \(2001\)](#)

[Treat Me Right! \(2004\)](#)

[Our Health, Our Care, Our Say \(2006\)](#)

[Death by Indifference \(2007\)](#)

[Healthcare for all: report of the independent inquiry into access to health care for people with learning disabilities Sir Jonathon Michael \(2008\)](#)

[Valuing People Now \(2009\)](#)

[Six Lives \(2009\)](#)

[Six lives progress report on healthcare for people with learning disabilities \(2013\)](#)

[Prescribing of psychiatric drugs to people with a learning disability or autism \(2015\)](#)

[Public Health England](#)

People with learning disabilities are also at an increased risk of developing mental health problems compared to the general population, with some studies suggesting as many as 20-30% of people with a learning disability will have some kind of psychiatric or psychological difficulties. Common mental health problems such as anxiety and depression occur more frequently among this group of people. This is sometimes referred to as a dual diagnosis of learning disability and mental health, or simply as a dual diagnosis.

Sometimes, the mental health needs of people with a learning disability are difficult to diagnose and treat, in part due to communication difficulties and/or because the problem may present differently in people with learning disabilities. The symptoms of mental ill health may be wrongly attributed to the individual's learning disability, which is referred to as diagnostic overshadowing, which then means that they do not get the correct help and support. People with learning disabilities should have access to specialist support to address these needs; the first step in getting this support is to visit your GP and discuss your concerns.

There are various additional biological, psychological and social factors which mean that people with learning disabilities are at greater risk of mental health problems. However, as well as a range of adapted psychological and therapeutic treatment and support options, there are a number of factors that can reduce the vulnerability of a person with learning disabilities to mental health problems. These factors include increasing the person's choice and control within their own life, and supporting them to feel safe and secure with a good social network.

Working in a person centred way is recognised to support good mental health and wellbeing. Supporting a person in a holistic and strengths focused approach can help protect them from developing mental health problems. By ensuring that people have access to do the things they want to do and the things they enjoy on a regular basis, and lead a full and active life we can help reduce the risk of mental health problems.

### **For more information:**

BILD Books on Health and Wellbeing: [www.bild.org.uk/our-services/books/health-and-well-being/](http://www.bild.org.uk/our-services/books/health-and-well-being/)

Visit Improving Health and Lives Public Health Observatory (IHAL) for information on the health of people with learning disabilities and their use of healthcare services: [www.improvinghealthandlives.org.uk/](http://www.improvinghealthandlives.org.uk/)

Easy Health website has easy read information to help explain health issues and treatments at [www.easyhealth.org.uk](http://www.easyhealth.org.uk)

Easy Read Health Wales – [www.easyreadhealthwales.org.uk](http://www.easyreadhealthwales.org.uk)

See Mencap's 'Getting it Right' campaign to ensure equal access to healthcare for people with learning disabilities: [www.mencap.org.uk/campaigns/take-action/getting-it-right](http://www.mencap.org.uk/campaigns/take-action/getting-it-right)

For more information about improving mental health services for people with a learning disability visit the NDTI website: [http://www.ndti.org.uk/uploads/files/Green\\_Light\\_Toolkit\\_22\\_Nov\\_2013\\_final.pdf](http://www.ndti.org.uk/uploads/files/Green_Light_Toolkit_22_Nov_2013_final.pdf)

### **References**

Heslop, P, Marriott, A, Fleming, P, Hoghton, M Russ, L and Blair, P (2013). *Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD)*. Bristol: CIPOLD. [www.bris.ac.uk/cipold/](http://www.bris.ac.uk/cipold/)

## 8. What are 'reasonable adjustments'?

Health and care services are legally required to make 'reasonable adjustments' for people with learning disabilities under the Equality Act (2010), ensuring equal and fair treatment.

Mencap started a campaign called 'Getting it Right', which was developed with health care professionals and their professional associations to establish key actions to ensure that people with learning disabilities and autism have equal access to health care.

Some examples of reasonable adjustments include:

- Providing accessible information to people with learning disabilities
- Having nurses with specialist knowledge or skills to support the care and treatment of individuals
- Giving longer appointment times

Improving Health and Lives (IHAL) maintains a database of examples of reasonable adjustments made across NHS services. This information can be found at:

[www.improvinghealthandlives.org.uk/projects/reasonableadjustments](http://www.improvinghealthandlives.org.uk/projects/reasonableadjustments)

See Mencap's 'Getting it Right' campaign to ensure equal access to healthcare for people with learning disabilities <http://www.mencap.org.uk/campaigns/take-action/getting-it-right>

## Good Support

People with learning disabilities want to be able to make choices and decisions about the things that affect their lives; having good support enables them to do this.

## 9. What does good care and support look like?

People with learning disabilities should be valued equally, participate fully in their communities and be treated with dignity and respect. In developing good support organisations should work in partnership to provide holistic and person centred services. In order to achieve this, support should uphold a number of basic principles and values:

**Rights:** the rights of people with learning disabilities are protected by law, and particularly by the Human Rights Act (1998). People with learning disabilities, their families and carers have an important role in promoting and upholding these rights.

**Choice and control:** people with learning disabilities need to have a wide range of options and information, knowing the advantages and disadvantages of each and are able to decide for themselves which ones best suits and that this choice is respected.

**Independence:** although people with learning disabilities are taking more control over their own lives, they are still often on the receiving end of other people's decision making and planning. In promoting independence, we should empower the individual to make choices and have more control over their own lives.

**Inclusion:** this is being able to participate in all aspects of life from work and education, to accessing services, to going out and meeting people. It also requires that people have the right support to be able to do this.

These principles were outlined in *Valuing People: a new strategy for learning disability for the 21<sup>st</sup> Century* (Department of Health, 2001) and *Valuing People Now* (Department of Health, 2009) and apply to the provision of health and social care for people with learning disabilities in England.

In Wales *Learning Disability Strategy – section 7 guidance on service principles and service responses* (2011) demonstrates a commitment to promoting equal rights and full citizenship for people with learning disabilities.

*The keys to life: improving quality of life for people with learning disabilities* (Scottish Government, 2013) detailed their key principles that should be central to the care and support of people with learning disabilities in Scotland. People with learning disabilities should be free from harm, should have access to local services and should work in partnership with others to ensure they have access to resources, giving them choice and control in their own lives.

Similar ideas are found in the Northern Ireland strategy *Equal Lives: Review of policy and services for people with a learning disability in Northern Ireland* (Department of Health, Social Services and Public Safety, 2005). It was highlighted that people with a learning disability in Northern Ireland did not enjoy the same opportunities as everyone else and it wished to challenge this by focusing on five core values: citizenship, social inclusion, empowerment, working together and individual support.

## For more information:

See the BILD Factsheets on Advocacy, Communication and Human Rights:

<http://www.bild.org.uk/information/factsheets/>

BILD Books on person centred approaches when supporting people with a learning disability: <http://www.bild.org.uk/our-services/books/good-support/person-centred-approaches-when-supportingpeople/>

## References

Department of Health (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: Department of Health. <http://bit.ly/17DUyVN>

Department of Health (2009). *Valuing People Now. A new three year strategy for people with learning disabilities – making it happen for everyone*. London: Department of Health. <http://bit.ly/1fywmHd>

Welsh Assembly Government (2011). *Learning Disability Strategy – section 7 guidance*. Cardiff: Welsh Assembly Government: <http://gov.wales/docs/dhss/publications/110126section7en.pdf>

Scottish Government (2013): *The Keys to Life: Improving the quality of life for people with learning disabilities*. Edinburgh: Scottish Government: <http://www.gov.scot/resource/0042/00424389.pdf>

Northern Ireland Department of Health, Social Services and Public Safety (2005). *Equal Lives: Review of policy and services for people with a learning disability in Northern Ireland*. Belfast: Department of Health, Social Services and Public Safety: [www.dhsspsni.gov.uk/equallivesreport.pdf](http://www.dhsspsni.gov.uk/equallivesreport.pdf)

Northern Ireland Department of Health, Social Services and Public Safety (2015). *Service framework for Learning Disability*. Belfast: Department of Health, Social Services and Public Safety: [http://www.dhsspsni.gov.uk/learning\\_disability\\_service\\_framework\\_-\\_full\\_document\\_revised\\_jan\\_2015\\_.pdf](http://www.dhsspsni.gov.uk/learning_disability_service_framework_-_full_document_revised_jan_2015_.pdf)

## 10. What is person centred support?

“Person centred approaches are a way of commissioning, producing and organising services, rooting in listening to what people want to help them live in their

communities as they choose” (Department of Health). Person centred planning and support is based on the understanding that all people with disabilities are entitled to the same choices, opportunities and rights as everyone else in their communities.

Person centred support for people with learning disabilities ensures that they are at the centre of all decision-making affecting their life, putting the individual’s needs and choices at the centre of the care and support provided. For people to have control over their lives they need to be supported by people who have person centred thinking skills and values.

An understanding of the history, preferences, wishes and needs of the individual with learning disabilities should influence the day-to-day support provided. Person centred support is a way of asking what people want, what support they need and how they can get it. The aim is to ensure that they have great and fulfilled lives in their local communities.

Recent government policies, across all four countries of the UK, have promoted the development of person centred services and support. They focus on people having more choice, control and independence.

An example of person centred support is in the use of person centred planning, which provides a structure to help us continually listen and learn about what is important to a person now and in the future and to act on this in alliance with friends and family. This is a process for continual listening and learning, focusing on what is important to someone now and in the future.

Person centred planning has five key features:

- The person is at the centre
- Family and friends are partners in planning
- The plan reflects what is important to the person (now or in the future), their capacities and what support they require.
- The plan helps to build the persons’ place in the community and helps the community to welcome them. It is not just about services and reflects what is possible, not just what is available.
- The plan results in ongoing listening, learning and further action. Putting the plan into action helps the person to achieve what they want from life. (Helen Sanderson Associates)

There are a range of practical person centred thinking tools and approaches which can include:

- PATH – (Planning Alternative Tomorrows with Hope)
- Personal Futures Planning
- Essential Lifestyle Planning
- MAPS (Making Action Plans) –

It is very easy to commit tremendous energy and enthusiasm to creating a “person centred plan.” However, it is the delivery of what is in the plan that is most important to ensure that the individual’s chosen way of life, rituals and routines are supported. Michael Smull is one of the leaders in developing person centred planning and emphasises that “in developing person centred plans, we need to be sure we are focused on helping people get better lives and not just better paper.”

As part of the drive behind person centred support, personalisation – which means that every person who receives support, whether provided by statutory services or funded by themselves, will have choice and control over the shape of that support in all care settings - has been used to bring about wider changes to social care so that the whole system of delivering support is person centred. Part of this has been the increasing move towards direct payments and personal or individual budgets.

*For more information:*

BILD Good Support Series - ‘Person centred approaches when supporting people with a learning disability’: [www.bild.org.uk/our-services/books/good-support/person-centred-approaches-when-supportingpeople/](http://www.bild.org.uk/our-services/books/good-support/person-centred-approaches-when-supportingpeople/)

Helen Sanderson Associates:

<http://www.helensandersonassociates.co.uk/>

## **11. What is advocacy?**

Advocacy, according to [Mind](#), seeks to ensure that people are able to speak out, to express their views and defend their rights. It is an important way for people with a learning disability to have more choice and control in their lives; it is about speaking up, either for yourself or someone else. There are different types of advocacy but they all operate on certain basic principles and approaches.

Advocacy supports people to express their views, preferences and decisions and works to ensure that following that things happen in the right way. It defends the rights and inclusion of people who are isolated and excluded and speaks up for them in an objective way.

Advocacy can take a number of forms, but independent advocacy such as citizen advocacy, peer advocacy and self-advocacy is different to the roles played by family members and support workers.

Independent advocacy groups can be a lifeline for people with learning disabilities. The person may need support through different life issues, and many groups provide opportunities to socialise and gain confidence through interaction with others in similar circumstances.

You can find out about advocacy groups in your area by speaking to your local social services' learning disability team or local authority.

### **Useful Contacts:**

Advocacy Quality Performance Mark

Telephone: 01225 789135

Website: [www.qualityadvocacy.org.uk/](http://www.qualityadvocacy.org.uk/)

All Wales People First

Tel: 01554 784905

Website: [www.allwalespeople1st.co.uk/](http://www.allwalespeople1st.co.uk/)

Mencap - Empower Me

Tel: 0808 8081111

Email: [help@mencap.org.uk](mailto:help@mencap.org.uk)

Website: [www.mencap.org.uk/what-we-do/our-services/advocacy/empower-me](http://www.mencap.org.uk/what-we-do/our-services/advocacy/empower-me)

People First

Tel: 0208 8741377

Website: <http://peoplefirstltd.com/>

People First Scotland

Tel: 0131 478 7707

Email: [peoplefirst1@btconnect.com](mailto:peoplefirst1@btconnect.com)

Website: [www.peoplefirstscotland.org](http://www.peoplefirstscotland.org)

Scottish Independent Advocacy Alliance

Tel: 0131 5566443 Email: [enquiry@siaa.org.uk](mailto:enquiry@siaa.org.uk)

Website: [www.siaa.org.uk/](http://www.siaa.org.uk/)



## Positive Behaviour Support

### 12. What is *positive behaviour support* and what does it have to do with behaviour that may be described as 'challenging'?

Behaviour may be described as 'challenging' for a number of reasons, for example:

- other people find the behaviour difficult to manage or understand
- the behaviour presents a risk to the person, their friends and family or other people who spend time with them
- the behaviour is not appropriate for the environment in which it is being exhibited
- the behaviour is not appropriate when thinking about the person's age and abilities

A person may behave in *challenging* ways for many reasons, and they must be understood if a suitable alternative is to be found. Understanding the factors that contribute to this behaviour will enable you to provide good support to that individual, and this is where *positive behaviour support (PBS)* helps.

Positive Behaviour Support (PBS) is an approach which promotes the individuality, rights and dignity of the person. It is based on person centred principles of encouraging independence, developing and sustaining relationships, personalising support and positive communication. PBS seeks to achieve change for the person by using a framework for developing an understanding of the behaviour of the individual and supporting them to develop alternatives. This approach aims to reduce the use of restrictive interventions and is evidence-based. It promotes the use behavioural assessments, interventions and lifestyle changes that aim to enhance the quality of life of the person.

Around half of all people with learning disabilities and behaviour described as challenging are subject to physical interventions. BILD has developed its Positive Behaviour Support Mission to challenge the misuse of restrictive practices including the use of seclusion, the misuse of time out, chemical restraint, physical intervention, and mechanical restraint when supporting people whose behaviour organisations find challenging.

#### For more information:

The BILD Code of Practice: <http://www.bild.org.uk/our-services/books/positive-behaviour-support/bild-code-of-practice/>

The BILD PBS Mission: <http://www.bild.org.uk/our-services/positive-behaviour-support/pbsmission/>

The PBS section of the BILD website: <http://www.bild.org.uk/our-services/positive-behaviour-support/>

BILD Books about Positive Behaviour Support: <http://www.bild.org.uk/our-services/positive-behaviour-support/pbsresources/pbspublishing/>

See the BILD Fact sheets on Chemical restraint, De-escalation and deaf people, Key considerations in physical interventions. Self-Injurious behaviour, and Time Out and Seclusion: <http://www.bild.org.uk/information/factsheets/>

### **13. I work in a special school and have seen calm or time out rooms being used to manage behaviour - is this right?**

The use of *calm* or *time out* rooms can be a source of concern for many professionals, as it is felt that such rooms may in fact deprive people of their liberty and in many instances, be illegal. The use of these rooms may more closely resemble seclusion than time out.

*Time out* is a behaviour change strategy, implemented as part of a wider behaviour support plan. It is arguably a punitive strategy and should not be implemented where more appropriate and less aversive and harmful strategies can be used.

*Seclusion* has been defined in *Positive and Proactive Care: reducing restrictive interventions* (Department of Health, 2014) as:

‘The supervised confinement and isolation of a person, away from other users of services, in an area from which the person is prevented from leaving. Its sole aim is the containment of severely disturbed behavior which is likely to cause harm to others.’

It should only ever be used for people detained under the Mental Health Act, and only as a last resort. Seclusion should not be used as a punishment or threat, or as part of a treatment programme, because of shortage of staff, or where there is a risk of self harm or suicide. If, outside of this Act, a practice resembles seclusion, regardless of what it may be referred to locally, it is seclusion.

However, the legislation relating to children in schools often relies on local interpretation and use of good practice guides rather than firm directions by law. Therefore, sometimes practices exist 'under the radar'.

Schools are permitted to use reasonable and proportionate force, although *Use of Reasonable Force: Advice for Headteachers, Staff and Governing Bodies* (Department of Education, 2013) stresses that force should never be used as a punishment - it is always unlawful. It also states that every school must have a clear behaviour policy, but it does not make reference to the interpretation of 'force', or indeed the use of rooms to restrict or restrain.

As a result of this 'grey area' organisations may believe that they are acting within the law, but the 'Blue Room' case proves otherwise; a high court judge ruled that an 18 year old man with autism and severe learning disabilities, who was placed in a padded seclusion room more than six times a day while at school was unlawfully deprived of his liberty.

The Mental Health Act Code of Practice (2008) clearly states that 'Time out should never include the use of a locked room', but should remove the reinforcers of that behaviour; whether that means removing the person himself or the stimuli within the room, which might be the other people present.

However, the use of such a room as a last resort emergency measure, as a way of managing an incident where people's safety is at risk, may be defensible as a single last resort approach. That incident should then be the subject of detailed discussion and review, and a method of addressing this more suitably without the need for seclusion established.

At the point where it is being used regularly as a method of managing somebody's behaviour or as punishment it becomes unlawful under the Human Rights Act 1998 (articles 3 and 5), and potentially if the child is over 16, under the Mental Capacity Act 2005.

### **For more information:**

BILD Factsheet on Time Out and Seclusion:

<http://www.bild.org.uk/EasySiteWeb/GatewayLink.aspx?allId=2526>

BILD Books about Positive Behaviour Support: <http://www.bild.org.uk/our-services/books/positive-behaviour-support/>

## Education

### New Reforms

In England the Children and Families Act 2014 has introduced major reforms to the ways in which children and young people with special educational needs are supported. There is now a strong emphasis on education, health and social care working together to make a real difference to how a child or young person lives their lives.

The key changes introduced in September 2014 include:

- A clear transparent “local offer” of services across education, health and social care with children, young people and parents being involved in developing and reviewing
- Education, Health and Care (EHC) plans replacing statements of educational need and assessments with the option of a personal budget for families and young people who want this
- A strong emphasis on children, young people and families participating in the decision making and their views being taken into account
- A stronger focus on preparing for adulthood including better planning for transition into paid employment and independent living

### Transition

Better planning will include the development of a “whole life” approach to moving between children’s and adult services and supports. Under the Care Act 2014, the local authority must carry out an adult care transition assessment where there is a significant benefit to a young person or their carer in doing so and if they are likely to have needs for care or support after turning 18.

Local authorities must continue to provide a young person with children’s services until they reach a conclusion about their situation as an adult. This will mean that there can no longer be any gap in provision.

### Information and advice.

Local authorities must provide parents, children and young people with information and advice in relation to Special Educational Needs (SEN). This advice should be free, accurate, confidential and accessible. It should be impartial and provided at arm’s length from the local authority. The information and advice will include matters relating to health and social care alongside information, advice and support on the take up and management of personal budgets.

The Information, Advice and Support Services Network (IASSN) provides advice and support to carers and parents. In addition, their website [www.iassnetwork.org.uk](http://www.iassnetwork.org.uk) provides the contact details of the local information, advice and support service in every area.

### **Resolving disagreements.**

Each local authority must make arrangements for independent disagreement resolution (including mediation) across the special educational, health and social care provision. In addition, complaints can be made under the local authority's complaints procedure.

From 2016, there will be a new system for appealing local authority decisions made under part 1 of the 2014 Care Act.

Following the response from the local authority, the next step would be to write to the Secretary of State for Education. To support this, you will need to list the steps already taken and the responses received. All information should be sent to: The Secretary of State, Department for Education, Castle View House, East Lane, Runcorn, WA7 2GJ.

Ofsted will be able to investigate some complaints about schools, providing the school's and local authority's procedures have been followed first, and that the issue affects the whole school. They do not usually investigate concerns to do with individual children.

To speak to Ofsted about your complaint, you can contact them on 0300 1234 234, or email [enquiries@ofsted.gov.uk](mailto:enquiries@ofsted.gov.uk). In order to make a formal complaint write to: Enquiries, National Business Unit, Ofsted, 5<sup>th</sup>, 6<sup>th</sup> and 7<sup>th</sup> Floors, Piccadilly Gate, Store Street, Manchester, M1 2WD.

If the concern is about an independent school, then you should contact the Independent and Boarding Team, Department for Education, Mowden Hall, Staindrop Road, Darlington, DL3 9BG.

Further information can be obtained from the "Special educational needs and disability (SEND) code of practice: 0 – 25 years (2014) Gov.uk (Department of Education: Department of Health)

Contact a Family – this charity has a SEN National Advice Service which provides comprehensive advice on a broad range of issues relating to special educational needs. Their helpline is 0808 808 3555; email [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk) and their website is [www.cafamily.org.uk](http://www.cafamily.org.uk)

## **Useful contacts:**

ACE (The Advisory Centre for Education)

Tel: 0300 0115142

Website: [www.ace-ed.org.uk](http://www.ace-ed.org.uk)

Council for Disabled Children

Tel: 0207 843 1900

Website: [www.councilfordisabledchildren.org.uk/](http://www.councilfordisabledchildren.org.uk/)

IPSEA (Independent Panel for Special Education Advice)

Tel: 0800 0184016

Website: [www.ipsea.org.uk/](http://www.ipsea.org.uk/)

Local Government Ombudsman

Tel: 0300 0610614

Website: [www.lgo.org.uk/publications/fact-sheets/complaints-about-special-educational-needs/](http://www.lgo.org.uk/publications/fact-sheets/complaints-about-special-educational-needs/)

National Parent Partnership Network

Tel: 020 7843 6958

Email: [nppn@ncb.org.uk](mailto:nppn@ncb.org.uk)

Website: [www.parentpartnership.org.uk/](http://www.parentpartnership.org.uk/)

SOS! SEN!

Tel: 020 8538 3731

Website: [www.sossen.org.uk/](http://www.sossen.org.uk/)

In case of legal advice:

Coram Children's Legal Centre

Tel: 0808 8020 008

Website: [www.childrenslegalcentre.com](http://www.childrenslegalcentre.com)

Disability Law Service

Tel: 0207 791 9800

Website: [www.dls.org.uk](http://www.dls.org.uk)

## Help, Advice and Support

### 14. How do I obtain an adult diagnosis of learning disability?

Some people may not be diagnosed with a learning disability until much later in life. A diagnosis requires that the person has an impairment of intellectual disability, which can be seen in problems of adaptive functioning, for example self-care, safety and risk, relationships, of lack of social skills, inability to cope with daily living.

An adult requesting a diagnosis of learning disability may only recently have started to experience difficulties in day-to-day life, possibly due to changes in his/her network of support. In addition, they may require a diagnosis to access specialist services and support.

To obtain a diagnosis, the first step should be to speak with the person's GP, who will be able to give support and advice and if necessary make a referral. This is usually sent to the local learning disability team who will include specialist health and social workers. They will ask about the person's medical and life history and be able to carry out any necessary assessments and request any number of interviews and tests required. Depending upon the demand in the local area, this process may take some time. Sometimes several different professionals will work together to an accurate diagnosis, and then make recommendations to ensure the position of effective support for the person in the future.

Previously, a diagnosis of a learning disability and understanding of a person's needs was based on IQ scores; today the importance of a holistic approach is recognised, and IQ testing forms only one small part of assessing someone's strengths and needs. Assessments of adaptive function consider how people can manage with their daily living skills and this approach is considered more useful than an intelligence test in assessing the impact of any learning disability on a person.

More information:

The BILD Learning Disability fact sheet:

<http://www.bild.org.uk/EasySiteWeb/GatewayLink.aspx?alld=2522>

'An introduction to supporting people with a learning disability'- Good Support Series:

<http://www.bild.org.uk/our-services/books/good-support/an-introduction-to-supporting-people-learning-disability/>

BILD Books in the 'People's Life Stories': <http://www.bild.org.uk/our-services/books/communication-is-a-human-right/life-story-books/>

## **15. What support is there for an adult with learning disabilities who still lives with family carers?**

In supporting an adult with learning disabilities who still lives with family carers, local services should work in partnership to ensure that the needs of the whole family are met, recognising the important contribution that family workers can have.

Good practice enables family carers to be equal partners in care and recognise their expertise and knowledge of their family member. When beginning this process, services should agree the best ways to work with and involve families, and how this will be reviewed and evaluated on a regular basis.

Depending on the needs of the individual, there may be a range of support services available to be provided. Some people may have a support worker to help them access the local community; home or domiciliary care; or short breaks services. The individual with a learning disability may also receive a personal budget that can be used to provide tailor made support. Access to all of these services is dependent upon an assessment of the person's needs, which is provided via the local community learning disability team or local authority social services department.

Adults with a learning disability and family carers may get support from a number of different health care or social care workers. These can include:

### **Dieticians**

People with learning disabilities have a range of needs relating to food and nutrition that can be supported by dieticians. They may be involved in the diagnosis and dietary treatment of disease, and aim to provide practical solutions to promote nutritional health and well being. They can offer information and advice as well as providing a plan of care.

### **General Practitioners**

GPs are the first point of contact for most people and have an extensive knowledge of medical conditions to be able to assess a problem and decide on the most appropriate course of action. Their role includes assessment, treatment, preventative work, education and signposting. They have an important role in making sure that



individuals and their families are provided with the right support and will refer on to appropriate professionals.

### **Learning Disability Nurses**

People with learning disabilities often have a wide range of physical and mental health conditions. Learning disability nurses have an extensive range of skills and work in partnership with individuals and their family carers to provide specialist healthcare. They aim to improve or maintain health and wellbeing, enabling people to participate in their local community. By reducing barriers to participation they enable people with a learning disability to lead fulfilling lives.

### **Occupational Therapists**

Occupational therapists work with people with learning disabilities to help them overcome the effects of physical or psychological illness, ageing or accidents. They will carry out an assessment and implement a treatment programme that includes specific activities to promote independence choice and decision making. Within learning disability services, OTs are often called upon to assess adaptive function, independent skills and to support postural care programmes.

### **Physiotherapists**

People with learning disabilities may also have other physical conditions or difficulties for which they require support. Physiotherapists help and treat these problems encouraging and maximising physical movement through health promotion, preventative healthcare treatment and rehabilitation.

### **Psychiatrists**

Psychiatrists deal with the treatment of emotional, behavioural and psychiatric disorders associated with learning disability. They will provide advice and education to individuals, their family carers and other professionals, and their role may be broader than in other branches of psychiatry. Psychiatric intervention has greatly improved the quality of life of people with learning disabilities.

### **Psychologists**

People with learning disabilities may have additional emotional and mental health needs. Psychologists aim to reduce psychological distress, promoting individual approaches to positive health and well being. They may offer support to address

anxiety and depression, serious mental illness, behaviour disorders and making relationships.

## **Social Workers**

Social workers support individuals and families to help improve the quality of their own lives. They aim to develop strong relationships with the people they support and help them to find solutions to their problems. Social workers work closely with the other members of the multi-disciplinary team to protect people from harm and abuse and to support them to live independently.

## **Speech and Language Therapists**

Many people with learning disabilities have communication difficulties. Speech and language therapists will assess and treat speech and language problems to help them communicate more effectively. They also work with people who have eating and swallowing problems. In addition, they may be involved in assessing capacity where the issue of communication may be preventing the individual from decision making.

For more information see the BILD Factsheet on Family Carers and Personalisation:  
<http://www.bild.org.uk/information/factsheets/>

## **Useful contacts:**

For independent impartial advice:

DIAL (Disability Information Advice Line)

Tel: 0808 8003333

E-mail: [helpline@scope.org.uk](mailto:helpline@scope.org.uk)

Website: <http://www.scope.org.uk/support/disabled-people/local-advice>

Disability Rights UK

Email: [enquiries@disabilityrightsuk.org](mailto:enquiries@disabilityrightsuk.org)

Website: [www.disabilityrights.org](http://www.disabilityrights.org)

DotCommunity

Tel: 0844 2474150 Email: [enquiries@dotcommunity.org.uk](mailto:enquiries@dotcommunity.org.uk)

Website: [www.dotcommunity.co.uk](http://www.dotcommunity.co.uk)

HFT Family Carer Support Service  
Tel: 0808 808 0448  
Email: [familycarersupport@hft.org.uk](mailto:familycarersupport@hft.org.uk)

In Control  
Tel: 01564 821650  
E-mail: [admin@in-control.org.uk](mailto:admin@in-control.org.uk)  
Website: [www.in-control.org.uk](http://www.in-control.org.uk)

National Family Carer Network  
Tel: 07747 460727  
Website: [www.familycarers.org.uk](http://www.familycarers.org.uk)

Shop for Support  
Tel: 0333 6006330  
Email: [info@shop4support.com](mailto:info@shop4support.com)  
Website: [www.shop4support.com](http://www.shop4support.com)

## **16. What support is there for parents with learning disabilities?**

With support people with learning disabilities can be successful parents. However, many have often been denied the right to have a child as it has been assumed that they would be unable to cope. Just as most parents without a learning disability need some kind of support, so to do those with a learning disability; they may need support in their parenting role, or perhaps need to be given information in a different way so that they can understand it and put it into practice. Parents with a learning disability will not necessarily have a child with a learning disability.

Support must be tailored to the individual parent or family, as some may only need support in the first few years, and some may require it until the child grows up. The parents who cope best will be the ones with very supportive family and friends, and who have lots of positive role models.

### **Useful contacts:**

Barnardos  
Website: [www.barnardos.org.uk/](http://www.barnardos.org.uk/)

Best Beginnings  
Tel: 020 74437895  
Website: [www.bestbeginnings.org.uk/parents-with-learning-disabilities](http://www.bestbeginnings.org.uk/parents-with-learning-disabilities)

CHANGE

Tel: 0113 388 0011

Email: [info@changepeople.co.uk](mailto:info@changepeople.co.uk)

Website: [www.changepeople.org/](http://www.changepeople.org/)

Family Action

Tel: 020 72546251

Website: [www.family-action.org.uk/section.aspx?id=782](http://www.family-action.org.uk/section.aspx?id=782)

Norah Fry Research Centre

Tel: 0117 331 0987

Website: [www.bristol.ac.uk/norahfry](http://www.bristol.ac.uk/norahfry)

Scottish Consortium for Learning Disabilities

Website: [http://www.sclld.org.uk/wp-content/uploads/2015/06/Supported\\_Parenting\\_web.pdf](http://www.sclld.org.uk/wp-content/uploads/2015/06/Supported_Parenting_web.pdf)

## **17. How can I make a complaint about health and care services?**

Services work hard to ensure they provide high quality care to people with learning disabilities. However, sometimes things may go wrong and you may want to complain.

Every organisation should have a complaints procedure, and you can ask a member of staff for a copy, or contact their complaints department for more information. This will tell you what the next steps to take will be.

With NHS services you can also complain to the commissioner of the service, by finding the details for your local Clinical Commissioning Group (CCG) or by complaining to NHS England, which commissions most primary care services. You can find your local CCG here: [www.nhs.uk/Service-Search/Clinical-Commissioning-Group/LocationSearch/1](http://www.nhs.uk/Service-Search/Clinical-Commissioning-Group/LocationSearch/1)

If you are still not happy that your complaint has been resolved, you can contact the Parliamentary and Health Service Ombudsman by calling 0345 0154033.

You may find that you require help to make your complaint, and the following organisations can offer support:

Patient Advice and Liaison Service (PALS) are available in all hospitals and can offer advice and support. You can find your local PALS here: [www.nhs.uk/Service-Search/patient-advice-and-liaison-services-\(pals\)/LocationSearch/363](http://www.nhs.uk/Service-Search/patient-advice-and-liaison-services-(pals)/LocationSearch/363)

Citizens Advice Bureau can also offer support in how to make a complaint, and your local service can be found using the website: [www.citizensadvice.org.uk/](http://www.citizensadvice.org.uk/)

You can also get support from your local advocacy service, these may be different across different areas and so you should contact your local authority to find out which organisation to contact in your area

### **For further support regarding the NHS or Social Care:**

Independent complaints advocacy service

Tel: 0845 600 8616

Website: [www.seap.org.uk/icas](http://www.seap.org.uk/icas)

Healthwatch

Tel: 0300 0683000

Website: [www.healthwatch.co.uk/](http://www.healthwatch.co.uk/)

The Care Quality Commission

Tel: 03000 616161

Website: [www.cqc.org.uk](http://www.cqc.org.uk)

### **For complaints involving the abuse of human rights:**

The British Institute of Human Rights

Tel: 0207 8825850

Website: [www.bih.org.uk](http://www.bih.org.uk)

Equality and Human Rights Commission

Website: [www.equalityhumanrights.com](http://www.equalityhumanrights.com)

British Institute of Learning Disabilities  
Birmingham Research Park  
97 Vincent Drive  
Edgbaston  
Birmingham  
B15 2SQ

0121 415 6960  
[enquiries@bild.org.uk](mailto:enquiries@bild.org.uk)  
[www.bild.org.uk](http://www.bild.org.uk)