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## **CHILDREN AND YOUNG PEOPLE WITH LEARNING DISABILITIES - UNDERSTANDING THEIR MENTAL HEALTH**

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# Contents

<b>Introduction .....</b>	<b>1</b>
<b>1. Mental health.....</b>	<b>2</b>
a. Good mental health	
b. Resilience	
c. Five ways to wellbeing	
d. Children and resilience	
<b>2. Introduction to mental health problems.....</b>	<b>5</b>
a. Children and young people	
b. People with learning disabilities	
c. Mental illnesses	
i. Depression	
ii. Anxiety	
iii. Serious mental illnesses	
d. Treatment and support	
<b>3. Learning disabilities and mental health problems .....</b>	<b>11</b>
a. Autism	
b. Foetal Alcohol Syndrome	
<b>4. Identifying mental health problems in children with learning disabilities... </b>	<b>14</b>
a. What is usual?	
b. Causes of change	
c. Context, duration, intensity and frequency of your concerns	
d. Symptoms of mental health problems	
i. Depression and learning disabilities	
ii. Anxiety and learning disabilities	
iii. Obsessive behaviour and learning disabilities	
iv. Serious mental illness and learning disabilities	

## 5. What to do .....21

- a. Recording your concerns
- b. Who to talk to
  - i. Sharing your concerns
  - ii. Talking to parents
- c. What you can do
  - i. In school
  - ii. CAMHS
- d. In a crisis
  - i. Panic attacks
  - ii. Self-harm
  - iii. Suicidal behaviour
  - iv. Aggressive behaviour

## 6. Further support and information .....30

## 7. Resources .....31

- a. Making Sense of Mental Health – *National Association of Special Schools*
- b. Mental Health First Aid for Intellectual Disabilities – *Mental Health First Aid Australia*
- c. Person Centred Plan – *Foundation for People with Learning Disabilities*
- d. Friends for Life – *Foundation for People with Learning Disabilities*
- e. Resilience and Results – *Children and Young People’s Mental Health Coalition*
- f. Resilience-based approaches to working with children and young people with complex needs – *Professor Angie Hart, Boing Boing*
- g. Children with special needs and their grief – *Child Bereavement UK*
- h. Moving On – *Foundation for People with Learning Disabilities*
- i. Standards and Audit Tool for Whole School Mental Health (Wellbeing)  
– *Marnie Aston*
- j. Six Relaxation Sessions for Children – *Lin Hunt, Sherbrook Primary School*
- k. Zippy’s Friends for Children with SEN – *Partnership for Children*

# INTRODUCTION

This information pack is intended to provide a basic introduction to mental wellbeing and mental health problems before considering mental health problems in children and young people with learning disabilities in more depth.

This introduction to the subject is supported by a range of different resources that may be useful for all those working with children and young people with learning disabilities, including details of different programmes that support mental health, as well as practical resources that can be used to support children.

This is a BOND publication led by BOND partner organisation the Mental Health Foundation. For more information please contact Barbara McIntosh on [bmcintosh@mentalhealth.org.uk](mailto:bmcintosh@mentalhealth.org.uk) or 020 7803 1100.

# 1 MENTAL HEALTH

**We all have mental health. Mental health relates to how we think, feel, behave and interact with other people.**

## Good mental health and wellbeing

At its simplest, **good mental health** is the absence of a mental disorder or mental health problem. Adults, children and young people with good mental health are likely to have high levels of **mental wellbeing**. The World Health Organisation has defined mental wellbeing as

*‘a state of mind in which an individual is able to realise his or her own abilities, can cope with the normal stresses of life, can work productively, and is able to make a contribution to his or her community.’<sup>1</sup>*

It can be helpful to understand wellbeing as being made up of two key elements

1. **Feeling good**
2. **Functioning well**

**Feeling good** means experiencing positive emotions like happiness, contentment and enjoyment. It also includes feelings like curiosity, engagement and safety.

**Functioning well** is about how a person is able to function in the world. This

includes having positive relationships and social connections, as well as feeling in control of your life and having a sense of purpose.

Mental wellbeing does not mean being happy all the time and it does not mean you won't experience negative or painful emotions such as grief, loss, or failure, which are a normal part of life. People with high levels of wellbeing will still experience these feelings, but are likely to be better able to cope with them without it having a significant impact on their mental health.

Good mental wellbeing is closely linked to good mental health, but they are not quite the same thing. Someone who has been diagnosed with a mental health problem may experience high levels of wellbeing for some of the time, but would be more likely to experience periods of low wellbeing than someone without a mental health problem. Equally, supporting people who have low levels of wellbeing can help to prevent the development of mental health problems, particularly depression, stress and anxiety, and supporting the wellbeing of people with mental health problems can support recovery and improve health outcomes.

Our mental health and wellbeing are strongly influenced not only by our individual attributes, such as age, personality, gender or genetics, but also by the circumstances in which we find ourselves and the environment in which we live.

## Resilience

People are more likely to maintain high levels of wellbeing and protect their mental health if they are resilient. Resilience is the ability to cope with life's challenges and to recover from, or adapt to, adversity.

We are not born with a fixed capacity for resilience. Resilience is something that can be learned and improved, as well as eroded or worn down by difficult circumstances, so a person's resilience may change over their lifetime.

Resilience is important because it can help to protect against the development of mental health problems. People with high resilience are more likely to cope with difficult experiences whilst maintaining

high levels of wellbeing. And good levels of resilience can help people to recover more quickly if they do experience mental health problems.

## Five ways to wellbeing

The New Economics Foundation has identified and set out five evidence-based things that we can all do to improve our wellbeing and resilience. These are:

### Connect...

With the people around you. With family, friends, colleagues and neighbours. At home, work, school or in your local community. Think of these as the cornerstones of your life and invest time in developing them. Building these connections will support and enrich you every day.

### Be active...

Go for a walk or run. Step outside. Cycle. Play a game. Garden. Dance. Exercising makes you feel good. Most importantly, discover a physical activity you enjoy and that suits your level of mobility and fitness.

### Take notice...

Be curious. Catch sight of the beautiful. Remark on the unusual. Notice the changing seasons. Savour the moment, whether you are walking to work, eating lunch or talking to friends. Be aware of the world around you and what you are feeling. Reflecting on your experiences will help you appreciate what matters to you.

### Keep learning...

Try something new. Rediscover an old interest. Sign up for that course. Take on a different responsibility at work. Fix a bike. Learn to play an instrument or how to cook your favourite food. Set a challenge you will enjoy achieving. Learning new things will make you more confident as well as being fun.

### Give...

Do something nice for a friend, or a stranger. Thank someone. Smile. Volunteer your time. Join a community group. Look out, as well as in. Seeing yourself, and your happiness, linked to the wider community can be incredibly rewarding and creates connections with the people around you.

*New Economics Foundation 2008<sup>2</sup>*

These are not just things that we should do by ourselves. Community groups, schools, services, and facilities also play a role in promoting the five ways to wellbeing to those they come in contact with and supporting people to take part in them.

## Children and resilience

Things that can help keep children and young people mentally well include:

- being in good physical health, eating a balanced diet and getting regular exercise
- having time and the freedom to play, indoors and outdoors
- being part of a family that gets along well most of the time
- going to a school that looks after the well-being of all its pupils
- taking part in local activities for young people.

Other factors are also important, including:

- feeling loved, trusted, understood, valued and safe
- being interested in life and having opportunities to enjoy themselves
- being hopeful and optimistic
- being able to learn and having opportunities to succeed
- accepting who they are and recognising what they are good at
- having a sense of belonging in their family, school and community
- feeling they have some control over their own life
- having the strength to cope when something is wrong (resilience) and the ability to solve problems.

Research has suggested that effective resilience strategies for adolescence and early adulthood include strong social support networks, the presence of a least one supportive parent, a committed mentor, positive school experiences, a sense of mastery and autonomy, participation in extra-curricular activities, the capacity to re-frame adversities so that the beneficial is recognised, the ability to help others and 'make a difference', and not to be sheltered from challenging situations<sup>3</sup>. For 10 – 20 year olds school is one of the key environments in which mental health problems can be identified and mental health support can be provided.



## 2 MENTAL HEALTH PROBLEMS

Just as we can develop problems with our physical health, mental health problems will be experienced by many of us over the course of our lives. Mental health problems range from the worries we all experience as a part of our everyday life, to serious long term conditions that can be very difficult to manage and have a huge impact on people's lives.

*"Mental disorders comprise a broad range of problems, with different symptoms. However, they are generally characterized by some combination of abnormal thoughts, emotions, behaviour and relationships with others. Examples are schizophrenia, depression...and disorders due to drug abuse. Most of these disorders can be successfully treated."*<sup>4</sup>

It is estimated that **one person in four** will be affected by a mental health problem each year:

- Anxiety and depression are the most common problems, with about 1 in 10 people affected at any given time<sup>5</sup>. Anxiety and depression can be severe and long-lasting and have a big impact on people's ability to lead their daily life.
- Between 1 and 2 in every 100 people will experience a serious mental health problem such as bipolar disorder, psychosis or schizophrenia<sup>6</sup>. People affected may hear voices, see things no one else sees, hold unusual beliefs that are not in line with what is generally accepted as real, feel unrealistically powerful or feel worthless, with a loss of interest in daily life.

### Children and young people

One in ten children and young people in the UK aged between 5 and 16 have a diagnosable mental health problem, and one in five of these have more than one of the main types of mental disorder<sup>7</sup>. Up to one in six young adults aged between 16 and 24 will be experiencing anxiety and depression at any one time<sup>8</sup>, and one in 15 young people aged 15 to 25 are thought to self-harm<sup>9</sup>. The average age for the onset of psychosis and for schizophrenia is around 22, and three quarters of all mental health disorders will be evident by the mid-20s<sup>10</sup>. Children and adolescents with learning disabilities are over six times more likely to have a diagnosable psychiatric disorder than their peers who do not have learning disabilities (see 'Learning Disabilities and Mental Health' below).

Mostly things that happen to children don't lead to mental health problems on their own, but traumatic events can trigger problems for children and young people who are already vulnerable. Changes often act as triggers: moving home or school or the birth of a new brother or sister, for example. Some children start school feel excited about making new friends and doing new activities, but there may also be some who feel anxious about entering a new environment.

Teenagers often experience emotional turmoil as their minds and bodies develop. An important part of growing up is working out and accepting who you are. Some young people find it hard to make this transition to adulthood and may experiment with alcohol, drugs or other substances that can affect mental health.

## People with learning disabilities

Research demonstrates that an estimated 25-40% of people with learning disabilities have mental health problems. Evidence compiled by the Public Health Observatory for Learning Disability shows the following:

- A prevalence rate of 3% for schizophrenia amongst people with learning disabilities (three times greater than for the general population), with higher rates for people of South Asian origin
- Levels of anxiety and depression are similar to those of the general population (though higher in people with Down's syndrome).
- The prevalence rate of a diagnosable psychiatric disorder is 36% in children and adolescents with learning disabilities, as opposed to 8% in those who do not have a learning disability.

Mental health problems may be worsened for those with greater support needs, particularly if they are unable to communicate about their feelings or communicate their distress (it may result in this behaviour mistakenly being seen to be challenging). As a result, changes in emotional wellbeing in children and adults with high support needs may easily be overlooked by those who care for them, particularly if they have high levels of medical needs.

Research by the Foundation for People with Learning Disabilities clearly identified that people with profound and multiple learning disabilities do experience mental health problems, often for reasons similar to those of the general population<sup>11</sup>.

However, identifying the signs and symptoms that indicate changes in the emotional and mental wellbeing of people with profound and multiple learning disabilities takes longer, and it is often

family members who are best-placed to identify such changes.

Some key factors that often contribute to a change in emotional well-being include physical health, loss and bereavement (this could be a change of support or bus driver who takes the child to school, as well as the loss of a family member), change and transition to adulthood.

## Mental illnesses

### Depression

Depression affects more children and young people today than in the last few decades, but it is still more common in adults. Teenagers are more likely to experience depression than young children.

Depression is a common mental disorder that causes people to experience depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration. Depression is different from feeling down or sad. Unhappiness is something which everyone feels at one time or another, usually due to a particular cause. A person suffering from depression will experience intense emotions of anxiety, hopelessness, negativity and helplessness, and the feelings stay with them instead of going away.

Younger children experiencing depression may show symptoms in a different way to adults or teenagers. For example, they might lose interest in school or in play, refuse to go to school, become more tearful, withdrawn, irritable or moody than usual. They may also become more disruptive at school, or have violent or aggressive outbursts.

## Anxiety

Anyone can have feelings of anxiety, including children and young people. Anxious feelings often occur in response to a stressful situation and include: feeling scared or panicky, feeling irritable, having negative thoughts or worries, feeling shaky, dizzy or sick, breathing fast, sweating, having tense muscles or palpitations. Sometimes these feelings can be helpful, for example, by increasing a person's ability to perform in a race or exam. These feelings are normal.

However, anxiety can become a problem when the symptoms are more intense or long-lasting and begin to interfere with a person's concentration and ability to do routine tasks. People may: avoid situations that could provoke feelings of anxiety, feel embarrassed or ashamed a lot of the time, not have the confidence to face new challenges, or have problems eating and sleeping. This interference with daily living, as much as the symptoms themselves, may lead a person to seek help.

Anxiety disorders come in various forms, and include generalised anxiety disorder (GAD), social anxiety disorder, phobias, panic attacks, obsessive compulsive disorder and post-traumatic stress disorder (PTSD).

## Serious mental illnesses

Serious mental illnesses such as psychosis, schizophrenia and bipolar disorder are rarely diagnosed in children and young people before the age of 14. However, many young people will experience their first episode of a serious mental illness in their late teens or early 20s. The average age for the onset of psychosis and for schizophrenia is around 22<sup>12</sup>.

## Psychosis

Psychosis describes the distortion of a person's perception of reality, often accompanied by delusions (irrational and unfounded beliefs) and/or hallucinations (seeing, hearing, smelling, sensing things that other people can't). People experiencing psychosis can also have muddled or blocked thinking (thought disorder), can at times seem unusually excited or withdrawn and avoid contact with people, and might not realise that there is anything wrong with themselves (lack of insight). People often experience their first episode of psychosis in their late teens or in their early 20s.

Psychosis is a symptom of some of the more severe forms of mental health problems, such as bi-polar disorder, schizophrenia, substance abuse or some forms of personality disorder.

## Schizophrenia

Schizophrenia is a serious mental illness characterised by disturbances in a person's thoughts, perceptions, emotions and behaviour. Schizophrenia is an umbrella diagnosis used to describe a wide range of symptoms. During an episode of schizophrenia, a person may lose touch with reality, see or hear things that are not there, hold irrational or unfounded beliefs, and appear to act strangely because they are responding to these delusions and hallucinations. An episode of schizophrenia can last for several weeks and can be very frightening. Schizophrenia is most commonly diagnosed between the ages of 18 and 35.

## Bipolar disorder

Diagnoses of bipolar disorder in younger children are rare, but young people may experience their first bipolar episode in their late teens or early 20s.

Bipolar disorder, also known as manic depression, is a mood disorder characterised by swings in a person's mood from high to low - euphoric to depressed. In the high phase (also referred to as hypomania), someone with bipolar disorder may have huge amounts of energy and feel little need for sleep. They may think and talk faster than usual, and their thoughts may jump rapidly from one subject to another, making conversation difficult. They may also have what are called 'grandiose' ideas or delusions about their abilities and powers, and a loss of judgement. People in a high phase can get themselves into all sorts of difficulties that they would normally avoid – they may leave their job, spend money they don't have, or give away all their possessions.

In a low (or depressive) phase, people feel hopeless, despairing and lethargic, become full of self-blame and self-doubt and have difficulty concentrating. This can make it difficult to cope with everyday life. People may withdraw from friends and social contacts, and may feel suicidal.

## Treatment and support

### Talking therapies

Talking therapies involve talking to someone who is trained to help deal with negative feelings. They can help anyone who is experiencing distress. Talking therapies give people the chance to explore their thoughts and feelings and the effect they have on their behaviour and mood. Describing what's going on in your head and how that makes you feel can help you notice any patterns which it may be helpful to change. It can help you work out where your negative feelings and ideas come from and why they are there. Understanding all this can help people make positive changes by thinking or acting differently. Talking therapies can

help people to take greater control of their lives and improve their confidence.

Talking therapies may also be referred to as:

- talking treatments
- counselling
- psychological therapies or treatments
- psychotherapies

Types of talking therapies include:

- Cognitive behavioural therapies (CBT)
- Dialectic behaviour therapy (DBT)
- Psychodynamic therapies
- Humanistic therapies
- Other kinds of talking therapy
- Support and information

Assessments and treatments for children and young people with mental health problems put a lot of emphasis on talking and on understanding the problem in order to work out the best way to tackle it. For young children, this may be done through play. Talking therapies and counselling for children often involved the whole family.

Talking therapies can work well for people with learning disabilities who are more able to communicate, but may not be appropriate for those with more complex disabilities.

### Medication

For some people, drugs are a short-term solution used to get them over an immediate crisis. For other people, drugs are an on-going, long-term treatment that enables them to live with severe and enduring mental health problems. Many people do not want to stay on medication for years, but it can help some people to lead the kind of lives they want to lead, without relapses and re-admissions to hospital.

Some people are reluctant to take medication at all, and doctors also vary in how often they prescribe it, and in what doses. All kinds of treatment have some placebo effect and some drug trials have found only slight differences between the effects of placebos and active drugs.

Although medication is easier to administer than talking therapies or exercise programmes, for example – which are also effective for many mental health problems – many medications have side effects, and people may have problems when they stop taking the medication. Abuse of medication that has been prescribed to treat a mental health problem can cause additional problems.

Most research into medications for mental health problems has focused on adults, rather than children. Children and young people need to be assessed by a specialist before they are prescribed any drugs. There is a lot of evidence that talking therapies can be effective for children and young people, but drugs may also help in some cases.

## Self-management

There are many different ways that people experiencing mental health problems can manage their own mental health. For example, they may practise spiritual activities, use peer support or eat or avoid certain foods. This is often called self-help or self-management.

Self-management has another, more specific, meaning when it describes the way that people can learn to control long-term health problems. Increasing numbers of people with a physical health problem use self-management to help them control their symptoms.

People with mental health problems can use a similar strategy to control serious

mental health problems such as bi-polar disorder or schizophrenia. Through self-management, many people gain the confidence, skills and knowledge to better manage their mental health and gain more control of their lives at a time when they may feel they have lost control.

Self-management can have as positive an impact on mental health as medical treatment, enabling people to lead fuller, more active lives. Research has shown that it can help boost the self-esteem of people with bi-polar disorder and lower the risk that they will consider suicide.

Many people are using self-management without realising it, but formal self-management skills can be learnt on courses, usually run by people with direct experience of mental ill health. The courses help people understand how their own mental health problems affect them and how to recognise the early signs and prevent or minimise the impact of an episode of ill health. They are based on the principle that individuals know best what works for them.

During their training, participants typically learn to:

- recognise what triggers a crisis in their own mental health
- read the warning signs of a possible crisis
- identify if any particular actions can prevent a crisis developing
- figure out which coping strategies work best for them in a crisis
- tap into other sources of support like local groups for people experiencing similar distress
- build ongoing coping strategies into a mentally healthy lifestyle
- compile an action plan
- draw up an advance directive setting out how they would like to be treated if they ever lack the capacity to make decisions about their treatment in the future.

Self-management is more often available for adults, but can also be effective for teenagers and young people. The use of self-management skills by people with learning disabilities has not been widely researched, but anecdotally we know that people who receive the right support can do well with self-management.

## 3 LEARNING DISABILITIES AND MENTAL HEALTH

Children and adults with learning disabilities are not exempt from experiencing mental health problems. In fact, children with learning disabilities are at much greater risk of having mental health problems than the general population.

Children and adolescents with learning disabilities are over six times more likely to have a diagnosable psychiatric disorder than their peers who do not have learning disabilities. In total, over one in three children and adolescents with a learning disability in Britain (36%) have a diagnosable psychiatric disorder<sup>13</sup>.

Children and young people with learning disabilities are also much more likely to live in poverty, to have few friends and to have additional long term health problems and disabilities such as epilepsy and sensory impairments. Children with learning disabilities can find it hard to build social relationships, and are more likely to say that they have difficulties getting on with their peers than children without learning disabilities<sup>14</sup>. A learning disability is also likely to reduce a child's capacity for finding creative and adaptive solutions to life's challenges. All of these factors are known to have a negative impact on mental health, putting people with learning disabilities at greater risk of developing mental health problems.

The increased risk of having a mental health problem cuts across all types of psychiatric disorders. Children with learning disabilities are:

- 33 times more likely to have an autistic spectrum disorder than the general population
- 8 times more likely to have ADHD
- 6 times more likely to have a conduct disorder
- 4 times more likely to have an emotional disorder
- 3 times more likely to experience schizophrenia
- 1.7 times more likely to have a depressive disorder<sup>15</sup>

These problems may be worsened for those with greater support needs, particularly if they are unable to communicate about their feelings or communicate their distress.



# Autism

Autistic Spectrum Disorder (ASD) is a term used to describe a number of symptoms and behaviours which affect the way in which a group of people understand and react to the world around them.

It's an umbrella term which includes autism, Asperger syndrome and pervasive developmental disorders. All of these autistic spectrum disorders have an onset before the age of three. The cause is still unknown, although in some cases they can be passed down genetically.

People with autism can also have a learning disability, ranging from those requiring minimal support to lead an active life through to those requiring lifelong, specialist support. Recent research by the Learning Disabilities Observatory indicates that around 20-30% of people with learning disabilities have an ASD<sup>16</sup>.

Being diagnosed with Asperger syndrome does not constitute having a learning disability.

## How an Autistic Spectrum Disorder affects people

As a 'spectrum disorder', the symptoms and characteristics of autism can present themselves in a variety of combinations, ranging from extremely mild to severe. All children and adults with an ASD will have the following core symptoms in what is known as the 'triad' of impairments:

### 1. Non-verbal and verbal communication

- People with an ASD have difficulty in understanding the communication and language of others, and in communicating themselves.
- Many children are delayed in learning to speak and a small minority do not develop much functional speech. This does not mean they cannot communicate, as they use other methods to communicate their needs.
- People with an ASD tend to have a literal understanding of language, so the use of metaphors such as 'it's raining cats and dogs' should be avoided.

### 2. Social understanding and social behaviour

- People with an ASD have difficulty understanding the social behaviour of others and can behave in socially inappropriate ways.

- People with an ASD have difficulty empathising with others, and as a result are unable to read social contexts.
- Children with an ASD often find it hard to play and communicate with other children, because of their difficulties with empathy.

### 3. Imagining and thinking/behaving flexibly

- Children with an ASD find it difficult to engage in imaginative play, so they tend to spend more time in solitary play.
- Children with an ASD can have an excellent memory concerning toys or activities they are passionate about. People with an ASD tend to have particular interests in specific topics or activities, which they may pursue obsessively.
- People with an ASD often find change difficult to cope with, and have a preference for routine. They may also struggle to transfer skills to other activities.

In addition to the above 'triad', some people with an ASD are very sensitive to certain sounds, sights, tastes and textures. This can affect their responses to things like clothes, food or noise. Some people with autism may require 24-hour support, whereas others may be able to lead more independent lives.

## How many people have an autistic spectrum disorder?

- Approximately 1% of the population has an autistic spectrum condition.
- The prevalence rate of autistic spectrum conditions is higher in men than it is in women (1.8% vs. 0.2%).
- 60-70% of people who have an autistic spectrum condition will also have a learning disability.<sup>17</sup>

## Autism and mental health

People with an ASD are at much higher risk of developing a mental health problem than the general population. 70 % children with ASD will have a mental health concern at some point in their life and 40% will have two or more. This high prevalence rate of mental health problems is reflected in the use of Child and Adolescent Mental Health Services: 1 in 10 of the children who use CAMHS have autism<sup>18</sup>.



# Foetal Alcohol Syndrome

Foetal (or Fetal) Alcohol Syndrome (FAS) was first discovered in 1973 by doctors in the United States. The condition describes a number of foetal abnormalities which occur in the babies of women who have abused alcohol during their pregnancy, affecting the way a baby's brain develops.

'Foetal Alcohol Spectrum Disorder' is the umbrella term for the range of preventable alcohol-related birth defects, which are a direct result of prenatal alcohol exposure, and it is used for those who are diagnosed with some, but not all, of the symptoms of FAS.

## How many people are affected?

Foetal Alcohol Syndrome is believed to affect as many as 1 in 500 babies born in Western countries, with worldwide estimates at 0.97 cases per 1000 births. The amount of data available for the number of babies affected in the United Kingdom is limited

According to the British Medical Association, FASD is in fact the most common, non-genetic cause of learning disability in the UK, although it is often misdiagnosed as autism, Asperger Syndrome or Attention Deficit Hyperactivity Disorder (ADHD) <sup>19</sup>.

## What are the signs and symptoms?

The damage caused by alcohol to a developing foetus depends on factors such as the level of alcohol consumed, the pattern of alcohol exposure, and the stage of pregnancy during which alcohol is consumed by the mother. The effects of FAS are lifelong, significantly impacting on the life of the individual and their families.

Children affected by FAS have distinct facial features, which can include a smaller head size, small or narrow eyes and a thin upper lip.

Further symptoms which can present themselves include hearing problems, a weak immune system, epilepsy, liver damage, cerebral palsy or hormonal difficulties.

Children affected by Foetal Alcohol Spectrum Disorder (FASD), including FAS, can also experience learning difficulties, problems with language, a lack of awareness of social boundaries, an inability to grasp instructions, egocentricity, mixing reality and fiction, and hyperactivity and poor attention.

Many children experience a range of these behavioural and social difficulties, which without the proper support can lead to difficulties making friends and being left behind at school. Many children go into care as they develop behaviours that their families find too 'challenging' to handle. 90% of all people with FAS will also have some form of mental health issue and 40% - 50% will become involved in the criminal justice system. The Adolescent and Children's Trust (TACT) report that a disproportionate number of looked after children have FASD and are often misdiagnosed as having behavioural problems<sup>20</sup>.

## What support is available?

There is no cure for FAS. Children may, however, be referred to paediatricians, who are able to investigate problems further with psychologists, psychiatrists, speech and language therapists, and specialists for organ abnormalities.

What people with FAS need to help them lead safe and fulfilling lives:

- Reduction in environmental stimulation
- Teaching in short time frames as they cannot retain lots of information over long periods
- Support in reading and understanding other people emotions
- A structured environment
- Personalised working plans

# 4

## IDENTIFYING MENTAL HEALTH PROBLEMS IN CHILDREN WITH LEARNING DISABILITIES

If a child has a mild learning disability or has a good level of verbal communication, they may have similar symptoms to the general population. Those with a more significant degree of disability, particularly those who have difficulties with verbal communication, are more likely to display mental health problems through changes in behaviour and behavioural problems, including challenging behaviour.

It can be difficult to diagnose mental health problems in children with learning disabilities. This can be because:

- Behaviour difficulties are attributed to the child's learning disability
- They have unusual/infrequent presentation of symptoms
- They might not express the symptoms clinicians would usually look for
- Medicines taken for physical health problems may mask mental health symptoms

The presentation of mental health problems in people with a learning disability will depend on:

- The cause of their disability
- Their level of disability
- Their personality
- Their cultural background
- Environmental factors

### What is 'usual'?

If you are concerned about a child or young person and have a 'gut feeling' they may be experiencing a mental health problem, it can be helpful to think about what exactly has changed about them or their behaviour which has raised these concerns. In order to do this, you need to have a clear idea of what is 'usual' for the child or young person: what are their usual characteristics, behaviours and reactions?

This could be things like:

- What do they like doing to relax?
- What makes them sad or angry?
- What makes them happy?
- How do they like to socialise?

The National Association for Special Schools (NASS) suggest that you look at seven key areas of a child's life when you are considering what is 'usual' for them and where you might notice changes that indicate mental health problems:

#### 1. Relationships

- E.g. What do they like doing with others? How do they interact with those around them? Who do they like to spend time with?

#### 2. Behaviour

- Are they usually calm and relaxed?

#### 3. Emotions

- How do they show that they are happy or sad?

#### 4. Thinking and Learning

- What tasks do they enjoy? How long can they concentrate for?

#### 4. Physical Appearance

- What is their usual posture or skin tone?

#### 5. Communication

- Do they normally make eye contact, use sign language or gestures?

#### 6. Daily activities

- What are the activities they enjoy? How do they usually feed or sleep?

If you begin to notice changes in one or more of these areas of life, start thinking about what might have caused these changes and whether this might be the result of the development of a mental health problem.

## Causes of change

There are a whole range of things that can have an impact on our mental health and cause us to act in a different way to normal. These can be factors that are internal to us (e.g. our feelings and reactions to situations, pain or illness) or external (e.g. changes in our environment, how other people behave).

Think about what might have changed to cause a difference in someone's behaviour. For a child or young person with a learning disability, some causes of change might be:

### External

- Lack of social opportunities
- Transition
- Loneliness
- Bereavement

- Lack of stimulation
- Moving house
- Change of staff
- Change of routine
- Parental separation
- Failure in activities
- Weather

### Internal

- Physical illness
- Pain
- Puberty
- Medication
- Missing home

It may be that you can identify the cause of the change in the child's behaviour, and this can help you to provide tailored support. However, be aware that not all changes in behaviour result from an obvious cause.

## Person Centred Plans

When thinking about what is usual for a child, it can be useful to create a person-centred plan for the child, or look at their existing plan.

Person centred planning is a way of helping a person to plan all aspects of their life, ensuring that the individual remains central to the creation of any plan which will affect them. The person is at the centre of the planning process and with support decides who they would like to help them record their plans and who can help them make plans for their future possible.

### The purpose of Person Centred Planning is to:

- Encourage the person to think about their life now and in the future
- Allow them to make their own decisions and take control of their life
- Decide who they want to help them and how
- Help them build a Circle of Support
- Give them a voice

### Key questions that should be included in person centred planning are:

- Who are the important people in a person's life?
- What are the person's strengths (or gifts)?
- What is important to the person now and in the future (their dreams)?
- What kinds of support will the person need to achieve the future they want?
- What do we need to do? (Action planning).

Person centred plans will therefore include a great deal of information about the child or young person. You may be able to use a child's plan to identify any changes in their life or to look at areas where a problem might be developing.

For a booklet which can be used to create a person centred plan for a child or young person, see Resource C at the end of this information pack.

## Context, duration, intensity and frequency of your concerns

It is also important to consider your concerns in terms of the context, duration, intensity and frequency of the change in someone's behaviour.

### Context

Is the change that is concerning you happening in a particular environment, or at a particular time of day? Asking these questions can help you to think about the cause of the change that is causing you concern, and whether there might be a specific situation which is difficult for the child or young person. Think about:

- Where the change in the child's behaviour is happening. Is it at home, at school, at meal times, in certain rooms?
- Is there a particular time of day when the child becomes more upset?
- Who is around when changes in behaviour occur? E.g. specific members of staff, or other children or young people?
- In what environment do the changes happen? For example, is it hot, cold, noisy, dark, or quiet?

### Duration

It can also be important to consider the duration of the change that is causing you concern. This can give an indication of the impact the concern is having on the child's quality of life.

- How long does each incidence happen for?
- How long does it take to calm them down?
- How long does it take for them to recover from any distress?
- How long does it take for them to return to their usual self?

### Intensity

You also need to assess the intensity of the problem you are concerned about, and you can do this by thinking about the impact the change is having on the child's life.

- What impact is it having on their life?
- What impact is the concern having on their peers, staff or family?
- How is the concern affecting you?
- Can you distract the child from the concern?
- How easily can you calm them down?

### Frequency

Thinking about the frequency of the changes that are making you concerned can help you to consider the severity of the problem.

- How often do you see the change?
- Is it every day or once a month?
- Is it normally in the morning or evening?

Considering these aspects of your concerns will help you to build a picture of how often changes in a child's behaviour occur, when they occur and for how long, and whether they are increasing in intensity. It is important to think about these things over a couple of weeks, as this can help you assess whether the changes are temporary or are related to a specific problem that can be resolved, or whether an on-going mental health problem might be developing.

## Symptoms of mental health problems

There are some specific symptoms of mental health problems in people with learning disabilities that you may be able to identify. The following section lists common symptoms for depression, anxiety disorders, obsessive behaviour and serious mental illnesses such as schizophrenia and bipolar disorder.

## Depression and learning disabilities

Depression is the most common mental disorder experienced by people with a learning disability. However, it can be difficult to diagnose depression in someone with a learning disability, because some of the symptoms of depression experienced by the general population can be a part of the 'usual' behaviour or presentation of someone with a learning disability. It is therefore important to consider whether there have been any changes in the person's usual behaviour that might in fact signal depression.

Mental Health First Aid has put together a helpful table that lists how the signs and symptoms exhibited by people in the general population might be seen in people with learning disabilities:

### Common symptoms of depression

Common symptoms that you might see in someone experiencing depression:

- Increased tearfulness, crying without any reason
- Irritability
- Restlessness
- Aggression
- Self-injurious behaviour
- Property damage
- Changes in appetite – eating too little or too much
- Severe sleep disturbance – difficulty sleeping or waking up too early in the morning
- Weight loss
- Total social withdrawal
- Unwillingness to use speech
- Slowness in thought and movement
- Deterioration in social and self-help skills

Signs and Symptoms in the General Population	Intellectual Disability Equivalents
1. Depressed or irritable mood	Apathetic, sad or angry facial expression; lack of emotional reactivity; upset; crying; tantrums; verbal and physical aggression that don't match the situation
2. Markedly diminished interest or pleasure in most activities	Withdrawal; loss of interest in usual reinforcers (rewarding activities); refusal to participate in favoured leisure activities or work; change in ability to watch TV or listen to music, unable to be cheered up
3. Significant weight loss; decrease or increase in appetite	Tantrums at meals; refusal to eat or lack of interest in food, stealing food; refusing activities; hoarding food in room
4. Difficulty sleeping or sleeping too much	May or may not be able to self-report sleep problems; if living with others or in a staffed situation, others/staff may report going to bed quite late; any change in sleeping habits; difficulty going to sleep; being up during the night; difficulty waking or waking very early; frequent day time napping; tantrums or activity during sleeping hours; noted sleeping or napping during the day
5. Rapid or slowed thought and movement	Pacing, hyperactivity, restlessness or being fidgety, decreased energy, passivity; development of obsessional slowness in activities of daily living; increase or decrease in vocalizations or speech, muteness; whispering; monosyllables; increase in self-injurious behaviour or aggression that don't match the situation.
6. Fatigue or loss of energy	Appears tired, tiring quickly; refuses leisure activities or work, withdraws to room; loss of daily living skills; refusal to perform personal care tasks; incontinence due to lack of energy/motivation to go to the bathroom; work production decrease; lack of interest in joining activities; just watches TV; sitting for long periods of time.
7. Feelings of worthlessness	Statements such as "I'm stupid", "I'm bad", "I'm not normal", "nobody likes me", seeming to seek punishment blaming themselves. If someone is nonverbal or has difficulty communicating verbally to express their displeasure frustration or depression they are left with little else but to express this through often aggressive or self harm behaviours.
8. Diminished ability to think or concentrate	Poor performance at work; change in leisure habits and hobbies; appearing distracted, decrease in completion of tasks; needing more instruction or support to complete tasks; loss of previously mastered skills; decrease in IQ upon testing.
9. Recurrent thoughts of death; suicidal behaviour or statements	Preoccupation with the deaths of family members and friends; preoccupation with funerals; fascination with violent TV shows/movies; spontaneous comments about death; talking about committing suicide.
	Other symptoms may include excessive need for reassurance, unresponsiveness to preferred staff, complaints of unspecific aches and pains.

*Intellectual Disability: Mental Health First Aid Manual*<sup>21</sup>

## Anxiety and learning disabilities

Anxiety problems in children with a learning disability can be overlooked due to communication difficulties.

Children and young people with learning disabilities may not have insight into their emotions or feelings, and can struggle to communicate these feelings verbally. Therefore it can sometimes be more useful to look at observable behaviours they may exhibit rather than relying on their own reports of their feelings. It is also worth noting that children with learning disabilities are more likely to talk about the physical sensations of anxiety because of the difficulty of describing their emotional state.

In children with more severe learning disabilities, symptoms of anxiety can often be misdiagnosed as challenging behaviour. The more profound the disability, the more likely a child will demonstrate anxiety through their behaviour,

Some conditions such as autism, Asperger's Syndrome and ADHD can have increased anxiety as part of the symptoms, which may be due to neurological differences in the way the brain functions. Children and young people with these conditions can really benefit from help to recognise and manage their anxiety, although the underlying condition will remain.

### Common Symptoms

Common symptoms of anxiety that might be described by children and young people include:

#### Emotions

- Irritability
- Impatience
- Anger
- Confusion
- Feeling on edge
- Nervousness
- Excessive fear

#### Thoughts

- Worry about past/future events
- Mind racing or going blank
- Poorer concentration and memory
- Trouble making decisions

#### Physical

- Dry mouth
- Pounding heart or rapid heartbeat
- Chest pain
- Blushing
- Shortness of breath
- Dizziness
- Headache
- Sweating
- Tingling or numbness
- Sweating
- Stomach pains
- Nausea, vomiting, diarrhoea
- Muscle aches and pains (neck, shoulders, back)
- Restlessness
- Tremors, shaking
- Difficulty sleeping

#### Common symptoms you may observe in a child's behaviour include:

- Avoiding situations or people
- Obsessive compulsive behaviour
- Distress in social situations
- Increased use of alcohol, other drugs
- Self-injurious behaviour
- Aggressive, disruptive, defiant
- Self-soothing behaviours
- Clingy or over demanding
- Withdrawal
- Over-activity
- Seeming to freeze
- Repetitive questioning



## Obsessive behaviour and learning disabilities

It can be difficult to distinguish between compulsions that are symptomatic of obsessive anxiety disorders and stereotypic behaviour in a person with a learning disability. Typically individuals engaged in stereotypic behaviour do not seem to want to stop the behaviour and do not seem to be distressed by it. In contrast, people with compulsive behaviours may try to resist performing the behaviours, which causes distress.

Five types of compulsion are common in people with a learning disability:

- Ordering compulsions (e.g. arranging objects/people into certain spots).
- Completeness/incompleteness compulsions (e.g. closing doors, dressing and undressing).
- Cleaning/tidiness compulsions (e.g. repeatedly cleaning one body part, must take out the rubbish when full).
- Checking/touching compulsions (e.g. touches items repeatedly)
- Grooming compulsions (e.g. checks self in mirror excessively).

## Serious mental illnesses and learning disabilities

Diagnosis of a serious mental illness such as schizophrenia or bipolar disorder in someone with a learning disability is difficult and rarely made, particularly in children and young people with a learning disability. Diagnoses of these illnesses often rely on people's description of their internal experiences, which people with a learning disability may be unable to articulate clearly. However, there are some common symptoms of psychosis, schizophrenia and bipolar disorder of which it is worth being aware.

## Common Symptoms

### Psychosis:

- Hearing people talking when nobody is around
- Seeing things that are not really there
- Developing strange thoughts
- Behaving in an odd manner
- Difficulty in thinking clearly
- Losing interest in daily activities

### Schizophrenia

- Delusions – false beliefs, such as being persecuted or being under outside control
- Hallucinations – false perceptions, such as seeing, hearing, feelings, tasting or smelling things which are not actually there
- Difficulties with thinking, concentration and memory
- Loss of motivation
- Social withdrawal

### Bipolar disorder

- Depression
  - see symptoms listed above
- Mania
  - increased energy and over-activity
  - Elevated mood
  - Need for less sleep than usual
  - Irritability
  - Rapid thinking and speech
  - Lack of inhibitions
  - Grandiose delusions
  - Lack of insight

The difference between mania and depression for people with a learning disability is not as distinct as it is for the general population. People with a learning disability are also more likely to experience rapid cycling (more than four episodes of either mania or depression in a year) than the general population.



# 5 WHAT TO DO

## Recording your concerns

If you feel a problem may be developing for a child's mental health, it can be helpful to begin recording your concerns about a child's behaviour or are symptoms they may be displaying as and when they occur. This can give you a much clearer idea of whether any patterns are developing, and whether you might need to escalate your concern. A record will also help you if you need to share or describe your concerns to other members of the team supporting the child.

You should think about recording your concerns against each of the aspects of a child's life that are outlined above, as well as details about context, duration, intensity and frequency of the change in behaviour or symptom of a mental health problem. This will build a clear as picture of the child's behaviour as possible. NASS provide a useful recording sheet as part of their Making Sense of Mental Health training (see Resource A).

**If you are worried that a child may be in danger of harming themselves or others, or is experiencing a mental health crisis, you should seek help and advice from a care professional immediately.**

**If you have any safeguarding concerns, you should consult your school's safeguarding policy and contact the safeguarding lead in your school as soon as possible.**

## Who to talk to

If you feel a child is developing a mental health problem, you need to share your concerns and observations with the appropriate member(s) of staff in your school. This will depend on what role you play in the child's life. The appropriate

member of staff could be a member of support staff, a teacher, the child's key worker, the Head of Education, the school nurse, or the Head of Care. It may be appropriate to raise your concerns in interdisciplinary team meetings, where a psychologist or behaviour specialist may be present.

## Sharing your concerns with families

You will also need to think about when to share your concerns with the child's families. This will be different for every child, depending on their circumstances. Consider whose role it might be in your school to talk to the child's parents, and nominate them as a family link. In many cases, this family link will be the child's key worker.

### Tips for talking to parents

- Never talk to families/carers about your concerns where the pupil will overhear
- Never talk about the pupil in hearing of other parents
- Avoid using jargon
- Listen carefully to any anxieties or questions expressed by parents and do not offer any hasty solutions
- When you cannot provide an answer, admit this and say you will find out from someone else- make sure you keep this promise!
- Make a record of conversations which express concerns about pupils
- Make sure families/carers are informed about any potential visits from other professionals
- Be honest when asked about pupil progress but use positive language the expresses interest and demonstration you are working to achieve the best outcome
- Be aware of and sensitive to the anxieties families/carers may feel about their child and how this may affect their response to you

*NASS Making Sense of Mental Health<sup>22</sup>*

## What you can do

### In school

There may be a certain level of support that can be provided for the child within the school setting. These could be simple things such as improving opportunities for socialising, changing the child's activities or staff, or providing greater support over periods of transition. See the resources at the end of this document for further advice and information about specific programs that support the mental health of people with learning disabilities.

There may also be other resources available to the school that you can explore, including

- behavioural support
- music or art therapy
- support from a GP or psychiatrist.

### CAMHS

If further support is needed, it might be necessary to council your local Child and Adolescent Mental Health Service (CAMHS), who provide NHS mental health support for children and young people. The person whose responsibility it is to contact CAMHS varies, it may be senior school management, medical staff, social workers, multidisciplinary team members or the local community learning disability team.

## General tips for working with people who have an intellectual disability and mental health problems:

- Use **appropriate language**
  - speak clearly and slowly
  - speak in a calm, quiet voice
  - use simple, short statements or questions
  - avoid using abstract ideas and jargon
  - be specific
  - use a normal tone, don't shout or raise your voice
  - use non-threatening language (including body language)
- Ask **one question** or make **one request at a time**. Keep the conversation simple
- **Avoid using leading questions**. People with intellectual disability are often suggestible and will tell you what they think you want to hear or what they think is the 'right' answer
- Use **open questions** where possible, e.g. "how are you feeling?" or "tell me about.....". Closed questions may be useful to clarify something, however be careful they are not leading questions
- Stop from time to time and **check the person's understanding**. If you are not sure that they have understood ask them to explain to you in their own words what you have just asked or told them
- **Don't assume** that the person's ability to express themselves is an indication of how much they understand or vice versa
- **Be patient, give the person time to respond**
- **Don't assume** the person with an intellectual disability will be able to **generalise skills** learnt in one context or situation automatically to another
- **Don't pretend to understand if you don't**. Use checking questions or paraphrasing to assist your understanding. Ask them to repeat what they have said in another way if they can
- Ask the person or their carer/support person if they have a preferred or **augmentative method of communicating**. Use **visual aids** when appropriate if possible. The use of drawings, pictures, etc. can help you to give information in a way the person may be more likely to understand
- Be prepared to **repeat the information** more than once if necessary
- **Listen** to the person. **Don't be judgemental, critical or flippant** in your response
- Appear **calm, relaxed and confident**
- **Reassure** the person
- **Keep an upbeat attitude** and let them know you are available and supportive
- **Do not make any promises that can't be kept**
- Ensure the **privacy, respect and dignity** of the person
- If the person is alone **ask whether they have family or a support worker that you can contact**. They may have contact details for these people in their wallet/purse.

## In a crisis

You may come into contact with a child who is experiencing a mental health crisis, such as a panic attack or a psychotic episode. The information below gives information of how you can help, and is taken largely from the invaluable resource *Mental Health First Aid for Intellectual Disabilities* (see Resource B).

### **Panic attacks**

Someone having a panic attack experiences a sudden and intense sensation of fear. They may feel they have lost control and feel desperate to get out of the situation that has triggered their anxiety. Symptoms of panic attacks include:

- rapid breathing
- feeling breathless
- sweating
- feeling very hot or cold
- feeling sick
- feeling faint or dizzy
- tingling fingers
- shivering or shaking
- racing heart or irregular heartbeat (palpitations).
- chest pain or discomfort
- feelings of unreality or being detached from oneself.
- fears of losing control or going crazy
- fear of dying

The problem may get worse if over-breathing sets in because this triggers sensations such as confusion, cramps, pains and feelings of weakness. The symptoms of a severe panic attack can be quite similar to a heart attack and someone experiencing one may be convinced they are going to die.

#### **What should I do if I think someone is having a panic attack?**

If the person says that they have had panic attacks before, and believe that

they are having one now, ask them if they need any kind of help, and give it to them.

#### **What if I am uncertain whether the person is really having a panic attack, and not something more serious like a heart attack?**

The symptoms of a panic attack sometimes resemble the symptoms of a heart attack or other medical problem. It is not possible to be totally sure that a person is having a panic attack. Only a medical professional can tell if it is something more serious. If the person has not had a panic attack before, and doesn't think they are having one now, you should follow physical first aid guidelines. The first step is to help the person into a supported sitting position, e.g. against a wall. Ask the person, or check to see, if they are wearing a medical alert bracelet or necklace. If they are, follow the instructions on the alert or seek medical assistance. If the person loses consciousness, apply physical first aid principles. Check for breathing and pulse, and call an ambulance.

#### **What should I say and do if I know the person is having a panic attack?**

Reassure the person that they are experiencing a panic attack. It is important that you remain calm and that you do not start to panic yourself. Speak to the person in a reassuring but firm manner, and be patient. Speak clearly and slowly and use short sentences. Invite the person to sit down somewhere comfortable. You could also get them to focus their attention and thinking on something visible like clothes or jewellery they are wearing. Rather than making assumptions about what the person needs, ask them directly what they think might help. Do not belittle the person's experience. Acknowledge that the terror

feels very real, but reassure them that a panic attack, while very frightening is not life threatening or dangerous. Reassure them that they are safe and that the symptoms will pass.

### **What should I say and do when the panic attack has ended?**

After the panic attack has subsided, ask the person if they know where they can get information about panic attacks. If they don't know, offer some suggestions. Tell the person that if the panic attacks recur, and are causing them distress, they should speak to an appropriate health professional. You should be aware of the range of professional help available for panic attacks in your community. Reassure the person that there are effective treatments available for panic attacks and panic disorder.

### **Self-harm**

People with a learning disability, especially those with more complex needs, often engage in self injurious behaviour (SIB). Very commonly, SIB is a result of the person's inability to communicate a range of emotions, needs and wants.

- Cutting, scratching, or pinching skin, enough to cause bleeding or a mark which remains on the skin
- Banging or punching objects or self to the point of bruising or bleeding
- Ripping and tearing skin
- Carving words or patterns into skin
- Interfering with the healing of wounds
- Burning skin with cigarettes, matches or hot water
- Compulsively pulling out large amounts of hair
- Deliberately overdosing on medications when this is NOT meant as a suicide attempt.

In addition to those listed above, common

types of self-injury in people with a learning disability include:

- head hitting
- self biting
- eye gouging
- repeated vomiting
- eating non-edible substances (pica)

### **How should I talk with someone who is deliberately injuring themselves?**

Let the person know that you have noticed the injuries. Avoid expressing a strong negative reaction to the self-injury and discuss it calmly with the person. It is important that you have reflected on your own state of mind and are sure you are prepared to calmly deal with their answer when asking the person about their self-injury.

Understand that self-injury is a coping mechanism, and therefore, 'stopping self-injury' should not be the focus of the conversation. Instead, look at ways to relieve the distress. Do not trivialise the feelings or situations which have led to the self-injury. Do not punish the person, especially by threatening to withdraw care.

### **What should I do if I witness someone deliberately injuring themselves?**

If you have interrupted someone in the act of self-injury, intervene in a supportive and non-judgemental way. Remain calm and avoid expressions of shock or anger. Express your concern for the person's wellbeing. Ask whether you can do anything to alleviate the distress. Ask if any medical attention is needed.

### **Suicidal behaviour**

Suicidal thinking and high risk taking behaviour in those with a learning disability should always be investigated.

The method chosen by a person with a learning disability may not have any lethal potential but may have been chosen because the person believed it would be fatal, so the intent is still there. Research has found that the seriousness of the suicidal behaviour does not always link with the level of intention to die. This may be more pronounced amongst people with a learning disability due to their inability to link cause and effect and greater impulsivity.

Important signs that a person may be suicidal are:

- Threatening to hurt or kill themselves
- Looking for ways to kill themselves; seeking access to pills, weapons, or other means
- Talking, drawing or writing about death, dying or suicide
- Hopelessness
- Rage, anger, seeking revenge
- Acting recklessly or engaging in risk activities, seemingly without thinking
- Feeling trapped, like there's no way out
- Increasing alcohol or drug use
- Withdrawing from friends, family or society
- Anxiety, agitation, unable to sleep or sleeping all the time
- Dramatic changes in mood
- No reason for living, no sense of purpose in life.
- People may show one or may of these signs and some may show signs not on this list.

If you have seen some warning signs of the person feeling suicidal, engage the person in discussion about your observations. If you suspect someone may be at risk of suicide, let the person know that you are concerned about them and are willing to help. It is important to ask them directly about suicidal thoughts. Do not avoid using the word 'suicide'. It is important to ask the question without dread, and without expressing a negative judgement. The question must be direct

and to the point. For example, you could ask:

- "Are you having thought of suicide?" or
- "Are you thinking about killing yourself?"

The person with a learning disability may not understand the term 'suicide'. You may need to use the words such as "kill yourself" or 'make yourself die" instead. Use concrete terms, and avoid words with double meanings or idioms. Remember to check their understanding by asking them to explain in their own words what they have heard.

People with a learning disability may often want to give you what they think is the "right" answer. Therefore they may say "yes" when in fact the answer is "no" or vice versa. It is important to tell them that you want to hear how they are really feeling and that you are not there to judge them. You're there to help them either way.

If you appear confident in the face of the suicide crisis, this can be reassuring for the suicidal person. Although some people think that asking about suicide can put the idea in the person's mind, this is not true. Another myth is that someone who talks about suicide isn't really serious. Remember that talking about suicide may be a way for the person to indicate just how badly they are feeling.

### **How to assist**

#### **How should I talk with someone who is suicidal?**

It is important to:

- Tell the suicidal person that you care and that you want to help them
- Express empathy for the person and what they are going through
- Clearly state that thoughts of suicide are often associated with a treatable mental illness, as this may instil a sense of hope

for the person.

- Tell the person that thoughts of suicide are common and do not have to be acted on. Suicidal thoughts are often a plea for help and a desperate attempt to escape from problems and distressing feelings. You should encourage the suicidal person to do most of the talking, if they are able to. They need the opportunity to talk about their feelings and their reasons for wanting to die and may feel great relief at being able to do this. It may be helpful to talk about some of the specific problems the person is experiencing. Discuss ways to deal with problems which seem impossible to cope with, but do not attempt to 'solve' the problems yourself.

### **How to assist**

If the person becomes aggressive, ensure your own safety at all times. Remain as calm as possible and try to create a calm, non-threatening environment when attempting to de-escalate the situation. At all times you should try to ensure the privacy, dignity and respect of the person you are trying to assist. For a person with a learning disability there may already be a crisis plan in place, check if this is the case. If not one should be developed as soon as possible.

## **Aggressive behaviour**

### **How to assess**

Aggression has different components to it – verbal (e.g. insults or threats), behavioural (pounding, throwing things, violating personal space) and emotional (e.g. raised voice, looks angry). What is perceived as aggression can vary between individuals and across cultures. It is best to prevent aggression and therefore take de-escalation action as soon as you perceive it. If you are concerned that the person is becoming aggressive, you need to take steps to protect yourself and others.



## How to de-escalate the situation

- Speak to the person slowly, clearly and confidently with a gentle, caring tone of voice.
- Be firm but avoid raising your voice or talking too fast.
- Listen carefully to what the person says.
- Do not respond in a hostile, disciplinary or challenging manner. This includes both verbal and body language.
- Do not argue with the person.
- Ask them to explain what has upset them.
- Give the person time to respond.
- Acknowledge what the person has said but do not agree or disagree with them. E.g. do not pretend that you can see or hear the hallucinations or delusions. Do not try to reason with them about their delusions and hallucinations.
- Consider taking a break from the conversation to allow the person a chance to calm down.
- Reassure them if they are worried.
- Do not make promises that cannot be kept.
- Comply with reasonable requests. This will provide the person with a feeling that they are somewhat 'in control'.
- Be non-judgemental and avoid using threatening language. Be aware that the person may overreact to negative or critical words; therefore, use positive words (such as "stay calm") instead of negative words (such as "don't fight").
- Stay calm and avoid nervous behaviour (e.g. shuffling your feet, fidgeting, making abrupt movements).
- Adopt a neutral stance and keep your hands at your side, avoid folding your arms or pointing and do not stand directly in front of the person.
- Do not restrict the person's movement or try to restrain them unless in self defence, (e.g. if he or she wants to pace up and down the room).
- Do not threaten them as this may increase fear or prompt aggressive behaviour.
- Remain aware that the person's symptoms or fear causing their aggression might be exacerbated if you take certain steps (e.g. involve the police).
- Make eye contact (but remember some people, such as those with autism, may find this threatening). Keep eye contact natural, glance away occasionally to avoid staring.
- Stay at the same level as the person – if they are sitting, you should sit, if they are standing you should stand. Consider inviting the person to sit down if they are standing.



Take any threats or warnings seriously, particularly if the person believes they are being persecuted. If you are frightened, seek outside help immediately. You should never put yourself at risk, always ensure you have access to an exit and are aware of potential hazards in the environment. Consider whether the environment can be altered to prevent the situation escalating. If the person's aggression escalates out of control at any time, you should remove yourself from the situation and call for emergency assistance (e.g. the mental health crisis team, ambulance or the police). When you call the police tell them that the person has a mental illness and a learning disability and may require medical help. Ask if possible that they send a plain-clothes police officer so the person will feel less threatened.

You may also need to think about the safety of others where the person is volatile particularly if you are supporting a person with a learning disability living or working in a group situation; Make sure others are aware of the situation. Ask other staff members to support other people present and keep the area clear of other clients and distractions while you help the person.

If you suspect that the person's aggression is related to the mental health problem, to assist the police in their response, you should tell them that this is the case and that you need their help to obtain medical treatment and to control the person's aggressive behaviour. Aggressive behaviour is frequently associated with intoxication with alcohol or another drug. If this is the case, and you decide to call the police, tell the police that you believe the person is intoxicated, and what substances you believe have been used. In either case, you should tell the police whether or not the person is armed.

## 6 FURTHER SUPPORT AND INFORMATION

The following organisations offer a range of information and support on learning disabilities and mental health issues:

### **Foundation for People with Learning Disabilities**

Information, research and service improvement for people with learning disabilities

[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

### **Mencap**

Specialist support, advice and information for people with learning disabilities

[www.mencap.org.uk](http://www.mencap.org.uk)

### **Mental Health Foundation**

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

### **Mind**

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

### **National Association of Special Schools**

Membership organisation working with and for special schools in the voluntary and private sectors within the UK

[www.nasschools.org.uk](http://www.nasschools.org.uk)

### **National Autistic Society**

Information, support and services for people with autism

[www.autism.org.uk](http://www.autism.org.uk)

### **Relate**

Support for the parents of children and young people experiencing difficulties

[www.relateforparents.org.uk](http://www.relateforparents.org.uk)

### **Young Minds**

Information and advice about the mental health of children and young people.

[www.youngminds.org.uk](http://www.youngminds.org.uk)

### **Youth Access**

Provider of young people's advice and counselling services

[www.youthaccess.org.uk](http://www.youthaccess.org.uk)

# 7 RESOURCES

## **Resource A. Making Sense of Mental Health – National Association of Special Schools**

‘Making Sense of Mental Health’ is an e-learning resource for staff working in schools with children and young people who have complex SEN. The e-learning training aims to increase staff knowledge about mental health and how this relates to children with disabilities. It also provides a new model of responding to the mental health needs of pupils by addressing issues such as, the identification of mental health concerns, resources for recording this information, and information about sharing and signposting concerns both within the work setting and externally to other professionals, such as CAMHS.

Download an information flyer here  
[www.nassschools.org.uk/files/Flyer%20FINAL.pdf](http://www.nassschools.org.uk/files/Flyer%20FINAL.pdf)  
To find out more visit [www.nassschools.org.uk](http://www.nassschools.org.uk)

## **Resource B. Intellectual Disability - Mental Health First Aid Manual**

The Mental Health First Aid Manual for Intellectual Disabilities has been developed in Australia as part of the Mental Health First Aid programme.

The purpose of the manual is to provide guidance on how to support people with a learning disability who are experiencing difficulties associated with emerging mental health problems, including mental health crises. There is also information in the manual that will help those with little or no experience interacting with someone who has a learning disability.

<http://www.mhfa.com.au/cms/wp-content/uploads/2012/09/2nd-Edn-ID-MHFA-Manual-Sept-2012-small.pdf>

## **Resource C. Person Centred Planning – Foundation for People with Learning Disabilities**

Person centred planning (PCP) provides a way of helping a person plan all aspects of their life, thus ensuring that the individual remains central to the creation of any plan which will affect them. ‘My Personal Planning Book’ is designed to help people with learning disabilities create a detailed personal plan.

[www.learningdisabilities.org.uk/content/assets/pdf/publications/personal\\_planning\\_book1.pdf](http://www.learningdisabilities.org.uk/content/assets/pdf/publications/personal_planning_book1.pdf)

## **Resource D. Friends for Life – Foundation for People With Learning Disabilities**

The FRIENDS for Life – Learning Disabilities development project aimed to adapt activities in the internationally recognised “FRIENDS for Life” programme to be accessible for children and young people with learning disabilities. The adaptations were based on relevant research, “expert opinion”, our own combined experience (70+ years!) with feedback from the pupils, families and session leaders.

FRIENDS for Life is a group programme that teaches children and young people techniques to cope with anxiety and promote well-being, social and emotional skills and resilience. It is usually delivered in school-based groups. Research on FRIENDS for Life shows reduced anxiety and depression, increased coping skills and self-esteem with improvements maintained up to 6 years follow-up. (Barrett 2006; Stallard et al 2007).

FRIENDS for Life was developed in Australia by Professor Paula Barrett, from a previously strong evidence-base for effective anxiety interventions of Professor Phillip Kendall in the USA. It is the only programme of its kind endorsed by the World Health Organisation, as “efficacious across the entire spectrum, as a universal prevention program, as a targeted prevention program and as a treatment”.

“FRIENDS for Life” enables children to learn the following skills:

- Identify “anxiety increasing” thoughts and to replace them with more helpful thoughts,
- Identify anxious (and other difficult feelings) and learn to manage them,
- Learn to overcome problems rather than avoid them.

[www.learningdisabilities.org.uk/our-work/health-well-being/friends-for-life](http://www.learningdisabilities.org.uk/our-work/health-well-being/friends-for-life)

## **Resource E. Resilience and Results – Children and Young People’s Mental Health Coalition**

This document was developed by the Children and Young People’s Mental Health Coalition to help schools understand the importance of supporting their pupil’s emotional and mental wellbeing, and what they can do within the school. It also looks at how they can work in partnership with other local agencies and commission additional support for young people with behavioural and emotional difficulties.

While this resourced is not primarily aimed at SEN schools, it contains useful information about the ways all schools can support the mental health of their pupils.

[www.cypmhc.org.uk/media/common/uploads/Final\\_pdf.pdf](http://www.cypmhc.org.uk/media/common/uploads/Final_pdf.pdf)

## **Resource F. Resilience-based approaches to working with children and young people with complex needs – Professor Angie Hart, Boing Boing**

A range of resources to improve the resilience of children who have experienced social disadvantage.

[www.boingboing.org.uk](http://www.boingboing.org.uk)

## Resource G. Child Bereavement UK

Child Bereavement UK produce information sheets which give advice on supporting children and young people with learning disabilities through a bereavement.

Supporting bereaved children and young people with Autistic Spectrum Difficulties (ASD)  
[www.childbereavement.org.uk/Portals/0/Support%20and%20Information/Information%20Sheets/Supporting%20Bereaved%20CYP%20with%20ASD.pdf](http://www.childbereavement.org.uk/Portals/0/Support%20and%20Information/Information%20Sheets/Supporting%20Bereaved%20CYP%20with%20ASD.pdf)

Children with special educational needs and their grief  
<http://www.childbereavement.org.uk/Portals/0/Support%20and%20Information/Information%20Sheets/Children%20with%20SEN%20and%20Their%20Grief.pdf>

## Resource H. Moving On – Foundation for People With Learning Disabilities

If the transition between primary school and secondary school is not well-managed, children with learning disabilities or SEN can end up feeling isolated and vulnerable. Their emotional health suffers and so does their academic performance. A well-planned transition between primary and secondary phases will help remove any barriers to learning and enable them to reach their full academic potential as well as feeling less isolated. The Moving On project has produced resources to support schools to plan successful transitions, including a series of short guides for pupils, teachers and parents.

[www.learningdisabilities.org.uk/our-work/employment-education/moving-on-to-secondary-school](http://www.learningdisabilities.org.uk/our-work/employment-education/moving-on-to-secondary-school)

## Resource I. Standards and Audit Tool for Whole School Mental Health (Wellbeing)

This is a whole school audit and planning tool that focuses on mental health promotion in school communities. There are accompanying questionnaires for young people and adults. In order to promote mental wellbeing in school communities, it is important to have structures, systems and plans in place to ensure that promotion, prevention and intervention of mental wellbeing are effective, and address the needs of the whole community.

This tool uses an ecological model of mental health promotion in school communities (Aston, 2012), to improve knowledge and understanding of mental health issues. It can be used as a framework to promote change, through review of policies, procedures, systems, structures, leadership, relationships and connections, in addition to interventions using appropriate evidence based practice.

This whole school audit and planning tool can be used alongside the whole school questionnaires or can be used alone. The tools have been developed with views from young people regarding mental health promotion in schools.

If you are interested in this Audit Tool or the questionnaires please contact:  
Dr Mamie Aston at: [marnieaston@sky.com](mailto:marnieaston@sky.com)  
OR [marnie.aston@staffordshire.gov.uk](mailto:marnie.aston@staffordshire.gov.uk)

## **Resource J. Six Relaxation Sessions for Children – Lin Hunt, Sherbrook Primary School**

A set of relaxation exercises for use across primary and secondary school, adapted by Lin Hunt for children with learning disabilities. For the full resource please contact [bmcintosh@mentalhealth.org.uk](mailto:bmcintosh@mentalhealth.org.uk).

## **Resource K. Zippy's Friends for Children with SEN – Partnership for Children**

Zippy's Friends is a programme that promotes the mental health and emotional wellbeing of young children. The fundamental concept behind the programme is very simple - if we can teach young children how to cope with difficulties, they should be better able to handle problems and crises in adolescence and adult life. The programme has been developed specifically for five to seven year-old children of all abilities. It teaches them how to cope with everyday difficulties, to identify and talk about their feelings and to explore ways of dealing with them.

The programme is built around a set of six stories. Zippy is a stick insect and his friends are a group of young children, and the stories show them confronting issues that are familiar to young children - friendship, communication, feeling lonely, bullying, dealing with change and loss, and making a new start. Each story is illustrated by brightly coloured pictures.

Partnership for Children have created two supplements for Zippy's Friends for Children with SEN - an Inclusion Supplement for children studying in mainstream schools and a Special Needs Supplement for those in special schools. These adaptations recognise the wide diversity of abilities, needs and ages of children with SEN. For instance, Widgit Symbols and extra visuals and activities are included, and in the Special Needs Supplement each of the stories in Zippy's Friends has been adapted for four levels of learning. The idea is to provide a wide range of resources so that teachers will be able to select those which are most suitable and helpful for their pupils. The Inclusion Supplement was launched in 2013 and the Special Needs Supplement is currently being trialled. To take on Zippy's Friends an LEA or cluster of schools must sign up as the programme includes a one day training course.

For more information contact Caroline Lifford at [caroline.lifford@partnershipforchildren.org.uk](mailto:caroline.lifford@partnershipforchildren.org.uk) or visit [www.partnershipforchildren.org.uk/teachers/zippy-s-friends-for-children-with-special-needs](http://www.partnershipforchildren.org.uk/teachers/zippy-s-friends-for-children-with-special-needs)

The resources not featured at the end of the document may be accessed online via the links provided.

# REFERENCES

- <sup>1</sup> World Health Organisation (2010), Mental Health: strengthening our response. Fact sheet No220
- <sup>2</sup> The New Economics Foundation (2008), Five Ways to Wellbeing: The Evidence
- <sup>3</sup> Newman, T. (2004), What works in building resilience? Barnardo's.
- <sup>4</sup> World Health Organisation (2013) [http://www.who.int/topics/mental\\_disorders/en/](http://www.who.int/topics/mental_disorders/en/) accessed October 2013.
- <sup>5</sup> McManus S, et al. (2009) Adult psychiatric morbidity in England, 2007: Results of a household survey. The Health and Social Care Information Centre, Social Care Statistics
- <sup>6</sup> *Ibid*
- <sup>7</sup> Green, H., McGinnity, A., Meltzer, H., Ford, T., and Goodman, R. (2005) Mental health of children and young people in Great Britain, 2004. A survey carried out by the Office for National Statistics on behalf of the Department of Health and the Scottish Executive
- <sup>8</sup> Children and Young People's Mental Health Coalition (2010) Policy Briefing 3: Young People Involvement
- <sup>9</sup> Mental Health Foundation and Camelot Foundation (2006) Truth Hurts: Report of the National Inquiry into self-harm among Young People.
- <sup>10</sup> Kessler, R., Amminger, G., Aguilar-Gaxiola, S., Alonso, J., Lee, S., and Ustun, T. (2007) Age of onset of mental disorders: A review of recent literature. *Current Opinion in Psychiatry*, 20(4): 359-364
- <sup>11</sup> Foundation for People with Learning Disabilities (2005) Making Us Count
- <sup>12</sup> *Ibid*
- <sup>13</sup> Emerson and Hatton (2007) The Mental Health of Children and Adolescents with Learning Disabilities in Britain. Institute for Health Research, Lancaster University.
- <sup>14</sup> *Ibid*
- <sup>15</sup> *Ibid*
- <sup>16</sup> Emerson and Baines (2012) The Estimated Prevalence of Autism among Adults with Learning Disabilities in England. Learning Disabilities Observatory.
- <sup>17</sup> NHS Information Centre for Health and Social Care (2012), Estimating the Prevalence of Autistic Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey
- <sup>18</sup> National Autistic Society (2010) You Need to Know.

<sup>19</sup> British Medical Association (2007) Fetal Alcohol Spectrum Disorders : A Guide for Healthcare Professionals. BMA, London.

<sup>20</sup> The Adolescent and Children's Trust (TACT) (2010) Evidence to the House of Commons Select Committee on Education on Behaviour and Discipline in Schools

<sup>21</sup> Pappas and Frize (2010) Intellectual Disability: Mental Health First Aid Manual. Mental Health First Aid.

<sup>22</sup> National Association of Special Schools (2013) Making Sense of Mental Health. Accessed October 2013.

<sup>23</sup> Pappas and Frize (2010) Intellectual Disability: Mental Health First Aid Manual. Mental Health First Aid.

<sup>24</sup> *Ibid*