

INFORMATION SHEET

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Understanding Challenging Behaviour

This information sheet may be useful for families who are:

- Supporting a family member whose behaviour could be described as challenging.
- Looking to understand why behaviour that challenges occurs.



Understanding Challenging Behaviour is the first information sheet in this series. It is recommended that it is read alongside 'Finding the Causes of Challenging Behaviour: Part 2" and 'Positive Behaviour Support Planning: Part 3".

What is it?



The term "challenging behaviour" has been used to refer to the "difficult" or "problem" behaviours which may be shown by children or adults with a learning disability. Such behaviours include aggression (e.g., hitting, kicking, biting), destruction (e.g., ripping clothes, breaking

windows, throwing objects), self-injury (e.g., head banging, self-biting, skin picking), sexualised behaviours and many other behaviours (e.g., running off, screaming, eating inedible objects). an different things to different people.

Characteristically, challenging behaviour puts the safety of the person or others at risk or has a significant impact on the person's or other people's quality of life. Quality of life refers to the standard of health, comfort, and happiness experienced by an individual. It encompasses various aspects such as emotional, physical, material, and social well-being. The term is inherently subjective, and it is important to remember it can me

Terminology

Other terms used to refer to challenging behaviour include 'behaviour described as challenging' and 'behaviours of concern'. The Challenging Behaviour Foundation uses the term 'challenging behaviour' and this will be used throughout this information sheet. For more information about terminology see our <u>website</u>. Regardless of what term is used, it is important to remember that 'challenging behaviour' is not a medical diagnosis. It refers to the way in which the person's behaviour presents a challenge to others. It is the behaviour which is described as challenging, not the person.

Challenging behaviour is not limited to people with learning disabilities, but the term has been particularly applied in this context. The severity of challenging behaviour can vary greatly. Very serious injury (e.g., blindness, brain damage) can result from some sorts of behaviour. (e.g., eye poking or head banging) and, in such cases, urgent action is required to limit or reverse the effects. In many cases, however, the term is used to refer to behaviour which does not have such immediately serious consequences but is, nonetheless, very upsetting, disruptive, or stressful, and results in limits being placed on the person living a full life.

It is relatively common for individuals with a learning disability to exhibit challenging behaviour, especially those with severe learning disabilities. Prevalence rates range from 5% to 15% in educational, health, or social care services for people with learning disabilities. These rates are higher among teenagers and young adults in their early 20s, and in specific settings, such as hospitals, where the rates can be as high as 30% to 40% (NICE Guidance, 2015).

On the other hand, seriously violent behaviour (especially involving the use of weapons) is less common amongst adults with learning disabilities than other adults.



Why does it happen?

There is no simple answer to this question. It is helpful to remember, however, that most people without learning disabilities display lots of challenging behaviour very early in their lives. The "terrible twos" usually don't last but only because most 2-year-olds develop a range of communication and social skills which enable them to get what they want and need rather more easily. Many children with learning disabilities do not develop such skills to anything like the same extent and are left with much the same needs as their peers, but much less effective ways of getting them met.

The child (or adult) who can't communicate what they want may initially display challenging behaviour as a way of communicating dismay at not getting something and, over time, this may become a behaviour that is recognised by others as "asking" for something. Such children may have other difficulties which arise directly or indirectly from conditions associated with, or accompanying, their learning disability. These include autism, sensory impairment, and epilepsy. Not being able to see very well, for example, may contribute to the development of eye poking since it is an effective way of generating unusual and interesting visual stimulation.

As children grow they also become exposed at home and at school to at least some of the demands made on other children but are much less able to handle them. Such demands may include having to wait, to take turns or to participate in activities they find difficult or don't like. In such circumstances challenging behaviour may be a very effective way of escaping from the situation. In the past, and still currently to an extent, society has had rather unhelpful ways of responding to people with learning disabilities – such as putting them in large groups in out of the way places. Such hospitals, institutions or units have often been characterised by severe social and material deprivation and abuse, factors likely to worsen and in some cases create challenging behaviour.

Although very large old-fashioned institutions have closed, there are other settings where similar cultures and environments can develop – if people are put in these environments their behaviour can become more challenging and the experience can be traumatic both for individuals and their families.

For example, the Government has acknowledged that too many people with learning disabilities end up in mental health hospitals unnecessarily where they are at greater risk of restrictive practices. Restrictive practices refer to interventions or actions that limit an individual's movement, freedom, or access to their environment. Restrictive practices can include physical restraint, seclusion, and the use of mechanical or chemical restraints. Governments have made a commitment to address this and move people into community settings with the right support.

Challenging behaviour can, of course, also arise in otherwise competent and caring families, schools, or other settings, because it is by no means easy to identify and respond constructively to the additional needs sometimes associated with a severe learning disability. In general, many cases of challenging behaviour appear to be effective ways for a person with learning disability to control what is going on around them. This may reflect their lack of more usual methods of control or making choices, such as communication skills or daily living skills.

While the above is a generally accepted account of why challenging behaviour occurs, we should always consider, especially if the behaviour has just arisen or worsened, the possibility that it reflects a physical health problem or emotional disturbance. Children or adults may bang their heads because their ear aches or hit out because they slept poorly the previous night. Understanding the variation in a person's challenging behaviour is often a key to promoting positive change.



What can be done?

Unfortunately, challenging behaviour is not generally like an infection which can be treated by a short-term course of antibiotics. In many cases there will be no "magic bullets"; change may take some time (especially where the behaviour is well established), will almost certainly require changes in the way other people behave and there may be a relapse of the behaviour. Having said all this there is a great deal that can be done to prevent and reduce the incidence of challenging behaviour.

Seeking to prevent challenging behaviour is difficult but possible. Where challenging behaviour arises from a medical condition, a sensory impairment or similar, the more such conditions can be remedied the better. On an everyday basis carers, parents and teachers can try to ensure that the person has what they need when they need it – support, attention, food, drink, preferred activities and so on. It is very important, however, that people are also given the opportunities and the skills to get things for themselves independently or to ask for them rather than these always being available "on a plate". Without the opportunities to use such control, people with learning disabilities will be in much poorer positions when they get into situations (as they inevitably will) where they are expected to fend for themselves and speak up for themselves more. One of the keys to prevention (and also to reduction) is therefore to support the development of communication and independence.



If prevention has failed, early intervention is the next best thing. Parents often complain that their attempts to get help early on are met with bland reassurance ("he'll grow out of it") rather than practical assistance. Of course, children do sometimes "grow out of'" challenging behaviour but we know that in adults with challenging behaviour, their behaviour generally started at a young age and simply got harder to manage. Parents should, therefore, take their child's challenging behaviour seriously especially if it is different to that seen in typically developing children.

What can families do? Getting help is obviously important but, where that is not available or slow to arrive, families should consider the following actions:

- Is the behaviour evidence of a previously undetected health problem? Does the
 person have toothache? Or some other source of pain? Or an infection of some
 kind? Children and adults with learning disabilities often lack the capacity to
 communicate pain or to describe symptoms so early visits to the Doctor or
 Dentist (especially where there are recent changes in behaviour) are well worth
 considering.
- Consider what the child or adult might be trying to say with their behaviour would they say "I can't do this" or "can you help me" or "please can I have..." or some other message?
- Try to check things out for yourself. If you change something does that stop the behaviour? Can you teach the person to tell you what they want without challenging behaviour? For example, does the behaviour happen when you ask the person to do something? If so, is what you are asking too difficult for them, can you give them more help until they are more used to it? Have they understood what you are asking them to do?
- Keep some sort of record of when the behaviour happens and the things you have done to try to figure out what's going on. In a year or two's time you'll find that it's very difficult to remember the details.
- If (and only if) it is safe to do so, then respond as little as possible to the behaviour. Respond as if they were not displaying the behaviour (don't comment on it, don't tell them off, appear not to notice it) and change the situation (distract, divert) as quickly as you can. If distraction or diversion is impossible you may have to leave them on their own, butyou need to be sure that the situation is safe and be able to cope with the behaviour possibly continuing for some time before it stops.
- If it is not safe to ignore the behaviour respond as calmly and unemotionally as possible to prevent the person hurting themselves or others.
- If you do have to respond, better to respond quickly than slowly otherwise you are teaching the person to be more persistent.

Challenging behaviour can be an emotional experience for parents and responding in some of the ways described above (e.g., "unemotionally") is not easy - you may feel very angry or very depressed about the person's behaviour. Don't be ashamed of this and don't bottle it up, instead, talk about it with anyone who will listen and understand.

What happens next?

When an individual child or adult is already showing serious challenging behaviour, a psychologist or other practitioner is likely to want to know as much as possible about the circumstances in which the behaviour occurs. They may try to conduct a "functional assessment" of the behaviours which sheds light on the particular needs this person gets met through their behaviour. They may then be able to suggest ways of preventing the behaviour or ways of responding to it which, over time, reduce its frequency. If they suggest the latter, however, they are also highly likely to want to look at how the person can be taught alternative, more acceptable ways of getting their needs met, a Speech and Language Therapist can help with this.

Consistent, positive behaviour support approaches of this kind carried out in a coordinated fashion (e.g., both at home and school), coupled with strategies to prevent injury or reduce the negative impact of the most serious challenging behaviour, can be very effective, but the investment of time and effort required should not be underestimated.

For more information, please read the two other parts of this information sheet: Finding the Reasons for Challenging Behaviour: Part 2 and Positive Behaviour Support Planning: Part 3

Acknowledgement:

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making a difference to the lives of people with severe learning disabilities

We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email info@thecbf.org.uk, or visit our website: www.challengingbehaviour.org.uk

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