

Factsheet – 13

Challenging behaviour in adults

This factsheet explains how adults born deafblind may try to communicate in ways that may distress us, or which may endanger us or them. It also briefly describes how Sense works with these deafblind people to help them interact with the world around them and to improve their quality of life.

What is challenging behaviour?

Sense's definition of challenging behaviour is: 'any significant behaviour shown by a deafblind person that places any individual at unacceptable risk'.

The risk in this definition is not only of physical harm, but also of exclusion from society and from activities the deafblind person might enjoy. If someone's behaviour means they cannot join in activities, that behaviour is challenging. The outcome of the challenging behaviour defines whether it is challenging or not – not the behaviour itself.

Whether a behaviour is challenging or not often depends on context. For example, if Joe sings at the top of his voice in the middle of the cinema, you could expect some angry reactions – but you would not if Joe were at the Last Night of the Proms.

Forms of challenging behaviour

Challenging behaviour comes in many forms. Some people may use aggressive behaviour, others may harm themselves. Some attack the things around them. Not all challenging behaviour is physically harmful. When someone behaves inappropriately – for example, stripping in public, or refusing to move - this is also challenging behaviour because it puts them at risk. And if someone behaves passively, this is challenging behaviour, again because of the effect it has on that person's life, and because it makes them vulnerable. Finally, repetitive, 'stereotypic' or self-stimulatory behaviour may be challenging if it prevents someone from joining in other activities or it hurts them.

The label 'challenging behaviour'

Not everyone likes the term 'challenging behaviour', because it is so easily used as a label for people. Some prefer to talk about challenging communication. Whatever term we use, it is important never to say that someone 'has challenging behaviour' – it is not a disease, nor a diagnosis. It is more useful to say something like 'about once a week Angela slaps her face two or three times'. The person, not the behaviour, should always be our focus.

Avoid jumping to conclusions

It is impossible to generalise about what particular types of behaviour mean; each individual will be telling us something different with their behaviour. For example, if you have known Lilly for five years and in all that time she has never hit herself, how would you interpret her suddenly moaning one night, and banging her ear? It would be a fair guess that she has earache. But if her neighbour Jim did the same thing, you might think that he is unhappy because his parents have been unable to visit for weeks – because he tends to bang his ear whenever he is unhappy.

The real reason that challenging behaviour is challenging is because it can be so hard for us to understand. It is all too easy for people to assume that someone is angry or spoilt when they do not understand why someone is behaving in a certain way. And that assumption can stop us from trying to find out what the behaviour means. Without that understanding we cannot hope to help the person communicate more effectively.

Communication is at the core

When a child throws a tantrum, we know that it is disagreeing with us, and showing its feelings in its behaviour. Over time, small children learn better ways to express their disagreement because we can talk to them and find out what's wrong, and show them how to tell us what they want.

Someone born deafblind may never have been able to develop these communication skills. And what begins in childhood as an expression of anger and frustration may in adulthood be their only way of telling people what they want.

For example, Will has a small amount of vision and no hearing. He has only two signs, for a drink and for the toilet. This morning he woke with a terrible headache, so when a support worker put a pair of swimming goggles in his hand, he was less than enthusiastic. He pushed them away. But the staff member put them back in his hand. Will threw them to the floor.

It would be easy to be frustrated or angry at Will's behaviour, if one did not know why he rejected the goggles. And it is often hard to work out why someone is behaving in a particular way. We can be sure though that they are trying to tell us something.

The key to understanding challenging behaviour is not to pigeonhole people. Will is a person with a headache who doesn't want to go swimming – he is not someone with challenging behaviour. And challenging behaviour is *never* 'just attention seeking': it is always an attempt to communicate or understand what is going on.

Challenging behaviour as a response to deafblindness

Challenging behaviour is completely understandable. People born deafblind often have to use challenging behaviour to communicate because they have major difficulties communicating through speech or sign, and understanding the world around them. Their deafblindness removes the mechanisms others use to learn about the world, the people around them, and themselves.

The world and other people can seem very confusing and frightening to someone born deafblind. None responds to their situation in the same way: everyone has a different personality and background, and their deafblindness will affect them

differently too. So it's not surprising that while one person may respond to fear or anxiety by banging their head, another may retreat into themselves completely.

Though stereotypical behaviour, such as rocking or gouging, is often described as challenging behaviour, it too is a very normal response to congenital deafblindness. It is one way for a deafblind person to find where they are in space. When someone bangs their body – the head, chest, or throat especially – the person can feel vibrations, and even if the banging is quite violent it may be pleasant for the person doing it.

Other reasons for challenging behaviour

When Sense's challenging behaviour teams try to analyse why someone is behaving in a particular way, they have to take many possibilities into account. The primary reason that people use challenging behaviour is the need to communicate. But there are other reasons too, such as brain injury, epilepsy, hormone imbalance, diet, and psychiatric disorders, and these possibilities must all be taken into account when assessing someone's behaviour.

The effects of challenging behaviour on others

Challenging behaviour affects not only the deafblind person but also those around them: their family, other deafblind people, staff, neighbours, the public, and the professionals who work with them.

For families in particular challenging behaviour can be especially difficult. If they are looking after an adult who uses challenging behaviour, they may have little support, and feel very isolated. They may worry about what would happen if their child hurt someone. They may be distressed by their child's distress. They may be wondering desperately what their child is trying to tell them. They often also worry about the future for the person they care for. And all too often they fear that they are somehow to blame.

If you are in this position, you may find it helpful to get in touch with Sense. Not only do we have experts in challenging behaviour, but we also have networks of families in the same position with whom you can share your experiences.

Challenging behaviour is difficult to deal with. Even professionals trained in challenging behaviour, with years of experience, freely admit that they don't always know what is going on. They too can find some behaviours particularly hard to handle. And they can feel guilt, or feelings of failure, even though they too will have done their best. Challenging behaviour is challenging to *all* of us.

Sense and challenging behaviour

The good news is that Sense's years of working with people born deafblind have enabled our staff to develop expertise in helping them, and their families. This help can come in various forms. Sense's family liaison officers work closely with families, for example, giving them a wide range of support. The most intensive support is given in Sense's residential and day care units: here teams work for months and years to find out the source of an individual's challenging behaviour, and to find ways of helping them.

The core of Sense's work is to enable each deafblind person to have enjoy life, and to feel fulfilled: enabling them to communicate effectively is an integral part of this.

Therefore Sense's approach to challenging behaviour is always to seek to meet people's needs before they get to the point of challenging behaviour. Sense teams try first to find out what triggers someone's behaviour, by looking at what is

happening in their life. This will be done by a careful and systematic appraisal. Only once they have decided the source of the problem will they begin to work out ways to reduce the challenging behaviour. For example, if someone's behaviour is a response to being asked to do something they don't like, can staff give them more help in that activity? Do they actually need to do that activity? Can staff help them to understand it and enjoy it?

This can be a long process, so Sense staff often need to put short-term strategies into place in order to reduce challenging behaviour immediately while they spend time working out a long-term strategy.

Helping someone with challenging behaviour is often extremely complex: by the time someone reaches adulthood there are often many factors contributing to their behaviour and it takes time, patience and skill to unpick them and to find solutions. It can take weeks, months, or even years to help someone change their behaviour. But though this can be painstaking and slow work, it is always effective in the end.

Avoiding generalisations

Because the reasons for someone's challenging behaviour are always individual, there are no short cuts. It is impossible to say, for example, that if someone screams in Sainsbury's, it is because they hate bright lights and bustle, so they should be gently led away and never go shopping again. This may be true of one person – but for another, perhaps they always feel bad in Sainsbury's because Sainsbury's day is Monday. Maybe on Mondays they are really tired after a busy Sunday at home with the family. So they need to stay at home on Monday and go shopping on Tuesdays. For this reason it is impossible to give guidance on how to respond to a particular situation or behaviour.

Punishment

Sense's policy on challenging behaviour is absolutely clear: staff never punish anyone for their behaviour, in any way, even by withholding something relatively minor. Behaviour is after all a form of communication, and Sense wants to make communication easier, not to shut it down by punishing it.

Restraint

One aspect of supporting someone who uses challenging behaviour that can raise hackles is when staff use physical restraint or medication. In some non-Sense homes both measures are widely used as a matter of course. But Sense believes strongly that they should only be used when absolutely necessary, and should always be kept to a minimum. Neither may be used unless the exact measure has been agreed in advance by the management team – and in the case of medication, prescribed by a doctor. Sense always puts the rights and needs of the deafblind person first.

Making decisions on behalf of a deafblind person

Sometimes it can be difficult to balance someone's rights with their needs, when communication is a challenge and it is not clear how much someone understands.

How much should staff and carers impose their own judgements on someone with a learning disability? The Mental Capacity Act 2005 gives clear and useful guidance, emphasising the importance of enabling deafblind people to make their own decisions as far as possible.

Mental Capacity Act

The Mental Capacity Act 2005 protects people over 16 who may lack the capacity to make certain decisions. It has five key principles:

- Every adult has the right to make his or her own decisions, unless it is proved that they do not have the capacity.
- People must be given all practicable help to make their own decisions before being treated as unable to do so.
- Just because someone makes what might seem to be an unwise decision, this does not mean they lack the capacity to make that decision.
- An act done or decision made under the Act for or on behalf of someone who lacks capacity must be done in their best interests.
- Anything done for or on behalf of a person who lacks capacity should minimise restriction of their basic rights and freedoms.

Conclusion

Challenging behaviour is a huge and complex subject. Everyone working in it agrees that there is still much to learn, but that they have made great strides in recent years. It is an exciting field because people's perspectives have changed so radically, from seeking ways to control challenging behaviour, to looking for ways to understand what people are telling us with it. There's still a long way to go, but already pioneers like Sense are making an enormous difference to people's lives.

Sources of help

Sense supports many congenitally deafblind people and because of this it has developed considerable expertise in challenging behaviour. Sense staff work in alliance with other professionals such as psychiatrists and psychologists, GPs and members of social services teams, and these people may also be able to help you.

Other organisations specialising in learning disabilities and with an interest in challenging behaviour include:

British Institute of Learning Disabilities (BILD)

Campion House

Green Street

Kidderminster

Worcs, DY10 1JL

01562 723010

enquiries@bild.org.uk

www.bild.org.uk

The Challenging Behaviour Foundation

The Old Courthouse

New Road Avenue

Chatham, ME4 6BE

01634 838739

info@thecbf.org.uk

www.challengingbehaviour.org.uk

CBF has some excellent factsheets and its DVDs are free to parents.

Deafblind International

Dbi's secretariat is based in India. It is most accessible through its website:

www.deafblindinternational.org

and in its *Review*, which publishes some extremely useful articles. A recent series by David Brown looked at congenitally deafblind people's senses, linking them to behaviour. The *Review* is edited by Eileen Boothroyd, who is based at Sense in London; contact her for copies.

Institute for Applied Behaviour Analysis (IABA)

5777 West Century Boulevard, Suite 675

Los Angeles, California 90045 USA

+1(310) 649 0499

www.iaba.com

You can download some excellent articles from their newsletter online. Look out for those by Gary LaVigna in particular.

Mencap

123 Golden Lane

London EC1Y 0RT

020 7454 0454

information@mencap.org.uk

www.mencap.org.uk

Tizard Centre

University of Kent

Canterbury, Kent CT2 7LZ

01227 764000

<http://www.kent.ac.uk/tizard/>

An academic centre specialising in learning disability. Its members have published some of the most useful papers on challenging behaviour recently.

Written resources

Allen, David (ed), 2002 *Ethical approaches to physical interventions: Responding to challenging behaviour in people with intellectual disabilities*, BILD Publications, Kidderminster, UK.

Emerson, E. (1995) *Challenging behaviour: Analysis and intervention in people with learning difficulties*. Cambridge, Cambridge University Press.

Halle, J.W.(1994) Forward to Carr, E.G., Levin, L., McConnachie, G., Carlson, J.I. Kwmp, D.C., and Smith C.E. *Communication-based intervention for problem behaviour: A user's guide for producing positive change*. Baltimore, Paul H. Brookes.

Lovett, Herbert, 1996 *Learning to listen: Positive approaches and people with difficult behaviour*, Jessica Kingsley Publishers, London, UK.

Mental Health Act 2005: more information from Public Guardianship Office, Archway Tower, 2 Junction Road, London N19 5SZ; tel 0845 330 2900; web www.guardianship.gov.uk ; email makingdecisions@dca.gsi.gov.uk .

Osgood, Tony (2004) '*Suit you sir?*': *Challenging behaviour in learning disability services* downloadable from http://www.paradigm-uk.org/pdf/Articles/suits_you.pdf

Where can I go for help?

If you:

- would like to find out more about deafblindness or the services for deafblind people in your area
- require information in alternative formats including braille, large print, audio or disk - or would like this factsheet to be translated into your first language - please contact Sense's Information Team.

Telephone: 0845 127 0060

Textphone: 0845 127 0062

Fax: 0845 127 0061

Email: info@sense.org.uk

Website: www.sense.org.uk

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