

Essential Guide to Challenging Behaviours and Autism



RESEARCH AUTISM
IMPROVING THE QUALITY OF LIFE
IDENTIFICATION INTERVENTION INCLUSION

Introduction



This guide examines the evidence on challenging behaviours in people on the autism spectrum.

It examines guidance from the National Institute for Health and Care Excellence (NICE) and the Social Care Institute for Excellence (SCIE).

It also examines the research evidence on some of the interventions designed to prevent or reduce those behaviours.

It is not intended to provide advice or recommendations on what you should or should not do about challenging behaviours in a specific individual.

Key findings

- The term 'challenging behaviours' usually refers to those behaviours which are likely to cause significant harm or disruption or which may result in someone being excluded from everyday activities
- NICE and SCIE have each developed guidance on how to support people with challenging behaviours. They note that:
 - Challenging behaviours are often caused as much by the way someone is supported - or not supported - as by their autism
 - Challenging behaviours often occur when someone has problems understanding what is happening around them or communicating what they want or need
 - Challenging behaviours may also be caused by anxiety and stress, sensory processing differences, underlying medical conditions, and specific situations that the person finds distressing
 - Challenging behaviours can usually be prevented or reduced if the right kind of support is provided
 - Support should be flexible and personalised to the needs and circumstances of individual families
 - Support may be available from specialist services, although all service providers should aim to understand and resolve challenging behaviours
 - A comprehensive behaviour assessment should include: a functional assessment of behaviour, a medical health check, a mental health check, a sensory profile, a communication assessment, and an assessment of any social and environmental factors that may affect behaviour
 - A behaviour support plan should be developed, setting out what is likely to trigger the behaviour and how families and services should respond.

How many people have challenging behaviours?

- Challenging behaviours are common in people on the autism spectrum and occur more frequently than in many other developmental conditions
- Challenging behaviours are more common in people on the autism spectrum who have a learning disability.

What are challenging behaviours ?

For some people, the term challenging behaviours is wide-ranging and refers to anything an individual may do which is inappropriate or which stops them taking part in every day activities or affects their ability to learn and to develop. So it can include problems as diverse as refusing food, staying awake all night, wetting the bed, removing clothes in public or flicking fingers. Of course, what seems challenging to one person may seem perfectly reasonable to someone else.

For some people, the term is narrower and refers only to those behaviours which are likely to cause significant harm to people on the autism spectrum or to other people. So it is restricted to problems such as aggression, self injury, destruction of property, temper tantrums, defiance and oppositionality, restricted and repetitive behaviours, or wandering off unsupervised.

What causes challenging behaviours ?

Challenging behaviours are often caused as much by the way someone is supported - or not supported - as by their autism. In addition, some people on the autism spectrum may:

- struggle to understand what is happening around them or struggle to communicate their emotional and physical needs
- feel they have no control over what happens to them or the chance to make choices about what they want to do
- be in pain or discomfort as a result of physical problems such as ear ache or stomach ache
- have sensory processing differences, which can cause an aversion to noise or bright lighting or difficulties knowing where their bodies are in space
- be reacting to change or unfamiliar situations or events. Many autistic individuals find it difficult to cope with change of any kind, however trivial
- not be comfortable in social situations, such as having to meet new people, look people in the eye or answer questions
- be asked to do more than they can cope with, such as a task that is too difficult, too long, or uninteresting
- want something they can't have, such as access to a preferred activity or toy
- be being bullied, which may make them more aggressive or withdrawn
- be reacting to the side effects of medications or other interventions
- once in a while, be tired, fed up or just having an 'off day'.

Some challenging behaviours may have been learnt. For example, if parents or teachers pay attention to or give-in to challenging behaviour in order to avoid further outbursts, a child may continue that behaviour. So, if the child is excluded from classroom activities (and is therefore able to avoid situations they dislike), they may continue that behaviour.

Some challenging behaviour may have several causes and these causes may occur at the same time, making it harder to work out what is going on. For example an adult may be responding to physical pain but may also be responding to the reactions of the other people around them because they have learnt that this get results.

Other issues such as parental stress, anxiety, lack of sleep, money or housing worries can all have an effect on parents and carers which may worsen the child's challenging behaviours. In such cases, individuals and families will need support to deal with these issues.

What interventions (treatments, therapies and other approaches) are available?

General Principles

The Social Care Institute for Excellence (SCIE) is an independent charity that promotes good practice in social care services for adults and children throughout the UK. According to SCIE

- Challenging behaviours can usually be prevented or reduced if the right kind of support is provided
- Support should be flexible and personalised to the needs and circumstances of individual families
- Support should be available from the behaviour support team or equivalent service [such as the local autism team if it exists]
- A comprehensive behaviour assessment should include: a functional assessment of behaviour, a medical health check, a mental health check, a communication assessment, and an assessment of any social and environmental factors that may affect behaviour [we think a sensory profile is also important]
- A behaviour support plan should be developed, setting out what is likely to trigger the behaviour and how families and services should respond.

Source: Social Care Institute for Excellence (2010). Challenging behaviours: a guide for family carers on getting the right support for adults. London: SCIE

Specific interventions

There are various interventions which may help to prevent or reduce challenging behaviours in some people on the autism spectrum. For example,

- Medical interventions may help to treat specific physical disorders (such as stomach ache)
- Psychotherapeutic interventions may help to treat specific mental health problems (such as cognitive behavioural therapy for anxiety)
- Behavioural techniques (such as rewarding the person to learn new behaviours which are less harmful)
- Augmentative and alternative communication systems (such as PECS) may provide the person with a more effective means to communicate
- Assistive and augmentative technology (such as visual schedules on computer apps) may provide information about what the person is expected to do and when

If the behaviour appears to be directly related to anxiety and stress in specific situations, then you can change the situation in which the behaviour occurs. Sometimes, relatively simple changes can have a significant impact (for example removing noise or clutter in the room or allowing a child to stay in the school library during play times if they find play times stressful).

Medications

If challenging behaviours are pervasive, long standing or very severe, then medications such as antipsychotics may be considered. However medications should only be used under the direction of a suitably qualified practitioner, such as a paediatrician or psychiatrist, and only after there has been no or limited response to other interventions. The effects should be carefully monitored and reviewed on a regular basis and the medication withdrawn if no significant benefits are seen. Some medications have significant side effects or interactions with other substances. Some medications can actually make some challenging behaviours worse.

National Institute for Health and Care Excellence

The National Institute for Health and Care Excellence (NICE) is a UK government body which supports healthcare professionals and others to make sure that the care they provide is of the best possible quality and offers the best value for money. The following is a summary of the NICE guidance on challenging behaviours in people on the autism spectrum*.

Before initiating other interventions for challenging behaviour, you should address any identified factors that may trigger the behaviour by offering:

- the appropriate care for physical disorders
- treatment for any coexisting mental disorders
- interventions aimed at changing the physical or social environment.

Once you have tried these, you may need to consider a psychosocial intervention. When deciding on the nature and content of a psychosocial intervention, use a functional analysis. The functional analysis should facilitate the targeting of interventions that address the function(s) of problem behaviour(s)

In addition to the functional analysis, base the choice of intervention(s) on:

- the nature and severity of the behaviour
- the person's physical needs and capabilities
- the physical and social environment
- the capacity of staff and families, partners or carers to provide support
- the preferences of the person with autism (and family, partner or carers)
- past history of care and support.

Psychosocial interventions for challenging behaviour

Psychosocial interventions for challenging behaviour should be based on behavioural principles and informed by a functional analysis of behaviour. They should include:

- clearly identified target behaviour(s)
- a focus on outcomes that are linked to quality of life
- assessment and modification of environmental factors
- a clearly defined intervention strategy
- a clear schedule of reinforcement, and capacity to offer reinforcement promptly and contingently on demonstration of the desired behaviour
- a specified timescale to meet intervention goals
- a systematic measure of the target behaviour(s) taken before and after the intervention to ascertain whether the agreed outcomes are being met.

Combined interventions for challenging behaviour

Consider antipsychotic medication in conjunction with a psychosocial intervention for challenging behaviour when there has been no or limited response to other interventions. Antipsychotic medication should be prescribed by a specialist and quality of life outcomes monitored carefully. Review the effects of the medication after 3–4 weeks and discontinue it if there is no indication of a clinically important response at 6 weeks.

* Sources:

- Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (2012). London: National Institute for Health and Clinical Excellence.
- The management and support of children and young people on the autism spectrum. (2013). London: National Institute for Health and Clinical Excellence.

Literature review

The information in this guide is based on a systematic evaluation of research reviews, and clinical guidance, on the topic of challenging behaviours in people on the autism spectrum. We searched a range of databases (such as CINAHL, Medline, Psycinfo) and identified 30 scientific reviews on this topic. We also examined the guidance published by NICE and SCIE. You can see details of our search strategy and the reviews we identified at <http://researchautism.net/challenging-behaviour-and-autism>

Summary of evidence

- Challenging behaviours are very common in people on the autism spectrum and more common in people who also have learning disabilities
- Challenging behaviours often occur when someone has problems understanding what is happening around them or communicating what they want or need
- Challenging behaviours may also be associated with a number of other factors including anxiety and stress, sensory processing differences, underlying medical conditions, and specific situations that the person finds distressing
- There is no very strong research evidence to suggest any specific interventions are effective in preventing or reducing challenging behaviours in people on the autism spectrum
- There is some strong research evidence to suggest that some medications, such as antipsychotics, may be helpful in reducing challenging behaviours in some people on the autism spectrum. However, medications often have significant side effects and should only be used under the direction of a suitably qualified practitioner, such as a paediatrician or psychiatrist, and only after there has been no or limited response to other interventions.
- There is some limited research evidence to suggest that undertaking a functional analysis to determine the underlying functions of (reasons for) the behaviour may result in more effective interventions being used
- There is some limited research evidence to suggest that some behavioural techniques (such as functional communication training) may be helpful in helping to prevent or reduce challenging behaviours in some people on the autism spectrum
- There is some limited research evidence to suggest that some forms of assistive and augmentative technology / augmentative and alternative communication (such as voice output communication aids) may be helpful in helping to prevent or reduce challenging behaviours in some people on the autism spectrum.

Future research

There is a need for further research into challenging behaviour by people on the autism spectrum and the most effective interventions to overcome those behaviours. Specifically there is a need for studies which

- are more scientifically rigorous and robust (such as randomised controlled trials)
- provide more comprehensive, standardised assessment methods of challenging behaviours in people on the autism spectrum
- identify which interventions may be most effective for which types of challenging behaviours in which groups of individuals on the autism spectrum
- involve autistic people to review the ethical basis of interventions in this area.

Other reading

- Addison M. (2013) Finding the causes of challenging behaviour: Part 2 . Chatham: Challenging Behaviour Foundation.
- Addison M. et al. (2014) Positive behaviour support planning: Part 3: Summary . Chatham: Challenging Behaviour Foundation
- Autism Speaks (2012) Challenging behaviors tool kit . New York, NY: Autism Speaks.
- McGill P. (2012) Understanding challenging behaviour: Part 1. Chatham: Challenging Behaviour Foundation.
- Mills R. et al. (In press) 10 rules for ensuring people with learning disabilities and autism develop challenging behaviour and maybe what to do about it. Brighton: Pavilion.
- National Autistic Society (2013) Challenging behaviour in children with an ASD. London: National Autistic Society.
- Scope [date not stated]. Challenging behaviour. London: Scope.

Organisations

- Challenging Behaviour Foundation. Website. www.challengingbehaviour.org.uk

Further information

You can find more information on this topic (including sources of evidence, glossary of terms used etc.) on Research Autism's website at <http://researchautism.net/challenging-behaviour-and-autism>

Essential Guides

Our "Essential Guides" provide key information about autism topics for a lay audience. They are not designed to provide specific advice for individual cases. However they do provide guidance on how to think through what may help.

Research Autism

The Research Autism information service is part of the National Autistic Society, which is the leading UK charity for autistic people (including those with Asperger syndrome) and their families.

Disclaimer

The information published in this guide has been written by non-medically qualified individuals. Any such information should be therefore be treated with care. The fact that we mention an intervention does not necessarily mean that we think it is effective. The fact that we list a publication or organisation does not necessarily mean that we agree with its findings or position on this issue.

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