

Essential Guide to Self Injurious Behaviour and Autism



RESEARCH AUTISM
IMPROVING THE QUALITY OF LIFE
IDENTIFICATION INTERVENTION INCLUSION

Introduction

This guide examines the evidence on self injurious behaviour in people on the autism spectrum.

It examines the evidence on some of the interventions designed to prevent or reduce that behaviour.

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

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

Key findings

- The term 'self injurious behaviour' usually refers to any behaviour, initiated by the individual, which directly results in physical harm to that individual
- That behaviour may include head banging, hand or arm biting, hair pulling, eye gouging, face or head slapping or punching, skin picking, scratching or pinching
- Self injurious behaviour is very common in people on the autism spectrum and is usually associated with one or more "risk factors":
 - Internal risk factors include specific genetic syndromes or painful medical conditions
 - interpersonal factors include learnt behaviours and being mistreated by other people
 - external factors include a lack of control over the person's living environment or the use of inappropriate interventions
- There are a number of interventions (treatments, services and other forms of support) commonly used to prevent or reduce self injurious behaviours in autistic people
- These interventions include psychological techniques, medications, and other approaches
- NICE and SCIE have developed guidance on how to support people with challenging behaviours such as self injurious behaviour. They note that:
- Challenging behaviours can usually be prevented or reduced if the right kind of support is provided. That support should be flexible and personalised to the needs and circumstances of individual families
- 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
- 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 self injurious behaviours?

Self injurious behaviour is very common in people on the autism spectrum and more common in people who also have learning disabilities.

Sometimes the self injurious behaviour is transitory and short in duration, lasting only days or weeks, while at other times it can persist for months or years.

What are self injurious behaviours ?

Self injurious behaviours are sometimes defined as “Any behaviour, initiated by the individual, which directly results in physical harm to that individual. Physical harm (includes) bruising, lacerations, bleeding, bone fractures and breakages, and other tissue damage.”

Specific forms of self injurious behaviour found in people on the autism spectrum include: head banging; hand or arm biting; hair, teeth and fingernail pulling; eye gouging or poking; face or head slapping or punching; skin picking, scratching or pinching; forceful head shaking; dislocation of joints; pica (persistent eating of non-nutritive substances).

What causes self injurious behaviours ?

It can be difficult to be sure why an individual self injures although, in practice, that behaviour may arise from, and then be maintained (kept going), by a range of different factors.

Some people on the autism spectrum may be more at risk of self injury than other people because of the following risk factors. However, the fact that one or more risk factors are present does not necessarily mean that a specific person will self injure, it just makes it more likely.

Internal risk factors (those to do with the person themselves, irrespective of what is going on in their current environment, or the people with whom they are interacting). They include

- Severity of autism, including core features such as restricted and repetitive behaviours and difficulties with social communication and social interaction
- Diagnosis of a learning disability and the severity of that learning disability
- Specific genetic conditions, such as Lesch–Nyhan syndrome and fragile X syndrome
- Physiological problems, such as difficulties with sensory processing and arousal/motor control
- Medical problems, such as migraine (severe headache) and reflux (heartburn)
- Mental health problems, such as anxiety and depression
- Irregularities in neurotransmitters (brain chemicals), such as dopamine and endorphins
- An existing history of self-injury or the presence of other challenging behaviours

Interpersonal risk factors (those involving relationships between two or more people). They include

- Learnt behaviour, where the person has learnt that other people behave differently when they injure themselves. For example, other people may pay them attention in order to stop them injuring themselves; they may give them desirable items such as snacks in order to stop them injuring themselves; or they may allow the person to not do things they don't want to do, such as go to bed, in order to stop them injuring themselves
- Inappropriate behaviour by other people. For example, other people may not listen to what they are trying to say, they may tell them off or shout at them, or they may treat adults like children
- Deliberate mistreatment by other people. For example, other people may be bullying or abusing them (as happened at the residential care home, Winterbourne View).

External risk factors (those in which the person is not central. They involve what is going on around the person but the person generally has little or no control over them). They include

- having a lack of control within their living environment. For example, some people may have little or no choice about where they live, who they live with, and who supports them; they may have no control over what goes on in their home; they may have no control over some of the 'systems' they have to cope with
- use of inappropriate interventions. For example, some medications and some psychological techniques may increase self injurious behaviours in some people on the autism spectrum.

What interventions are available?

There are numerous interventions (treatments, services and other forms of support) designed to prevent or reduce self injurious behaviours in people on the autism spectrum. Most interventions are

- the same as those designed to help people on the autism spectrum deal with other challenging behaviours
- the same as those designed to help other people deal with self injurious behaviours

These interventions fall into three main categories: psychological techniques, medications and other approaches. In practice, these approaches may overlap. For example, a psychologist may suggest the use of medications or physical exercise alongside a behaviour support plan.

We believe that, whichever interventions are used, it is important to treat the person with respect, listen to what they say and give them choices over their lives.

Psychological Techniques

Psychological techniques (many based on the principles of applied behaviour analysis and often incorporated into a behaviour support plan) include

- providing a more effective way for the person to tell you what they want. For example, you could teach the person to use picture cards or sign language
- providing more structure and routine. For example, you could build a range of activities into the person's day to minimise boredom and reduce opportunities for self injury. You could also use a visual schedule to show them what they are expected to do and when
- changing the way you ask the person to do things. For example, you could make sure you don't ask the person to do too many difficult things all at once and give them regular breaks
- letting the person have the thing that they want, such as a snack or toy, but only if they behave in an alternative, more desirable way instead of injuring themselves

“Punishment-based” psychological techniques, such as physical restraint, should only be used with extreme caution and following established guidance on safeguarding (see page 5).

Medications

If the self injurious behaviour is 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 behaviours worse.

Other Approaches

There are numerous other interventions that have been suggested as ways to prevent or reduce self injurious behaviours in people on the autism spectrum (although the research evidence for most of these is very limited). These include

- providing treatments for specific medical problems, such as migraine and reflux
- encouraging people to undertake vigorous physical exercise, such as swimming
- providing alternative sensory experiences. For example you could give people safe edible objects (like carrots) to chew on or give them noise-dampening headphones to block out excessive noise
- providing dietary supplements to change the person's immunological and neurological systems

National Institute for Health and Care Excellence/Social Care Institute for Excellence

The following is a summary of the NICE guidance on challenging behaviours (including self injurious behaviour) in people on the autism spectrum. The guidance from SCIE is similar.

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
- Challenging behaviours: a guide for family carers on getting the right support for adults. (2010). London: Social Care Institute for Excellence
- The management and support of children and young people on the autism spectrum. (2013). London: National Institute for Health and Clinical Excellence

Safeguarding

Please note: Some people on the autism spectrum lack the capacity to consent to interventions. However, they still have the right to be protected from interventions which are painful or hazardous or unduly distressing or restrictive. That right is enshrined in various pieces of legislation, such as the Mental Capacity Act (2005). It is also enshrined in guidance documents, such as Positive and Proactive Care: reducing the need for restrictive interventions (2014) published by the Department of Health. The latter includes the instruction "If a restrictive intervention has to be used, it must always represent the least restrictive option to meet the immediate need."

Literature review

The information in this guide is based on a systematic evaluation of research reviews, and clinical guidance, on the topic of self injurious behaviours in people on the autism spectrum. We searched a range of databases (such as CINAHL, Medline, Psychinfo) and identified 29 scientific reviews on this topic. We also examined the guidance published by NICE, SCIE and other relevant organisations. You can see details of our search strategy and the reviews we identified at <http://researchautism.net/self-injurious-behaviour-autism>

Summary of evidence

- Self injurious behaviours are very common in people on the autism spectrum and more common in people who also have learning disabilities
- Self injurious behaviours may be associated with a range of risk factors including internal factors (such as some genetic conditions), interpersonal factors (such as some learnt behaviour) and external factors (such as peoples' lack of control over their daily lives)
- There is some limited research evidence to suggest that undertaking a functional assessment to determine the underlying functions of (reasons for) the behaviour may result in more effective interventions being used
- There is no very strong research evidence to suggest any specific interventions are effective in preventing or reducing self injurious behaviours in people on the autism spectrum
- There is some limited quality research evidence to suggest that some psychological techniques may help to prevent or reduce self injurious behaviour in some people on the autism spectrum.
- There is some limited quality research evidence to suggest that some medications may also be helpful in reducing self injurious behaviour in some people on the autism spectrum. However, medications often have significant side effects
- There is no high quality research evidence to suggest that other types of intervention are helpful in helping to prevent or reduce self injurious behaviours in people on the autism spectrum, although that does not necessarily mean that they do not work.

Future research

There is a need for further research to examine self injurious behaviours in people on the autism spectrum. There is particular need for studies which

- Identify the risk factors that associated with self injurious behaviour and specific forms of self injurious behaviour in specific groups on the autism spectrum (age, gender, diagnosis, co morbid genetic conditions, IQ etc)
- Identify which groups of people on the autism spectrum with self injurious behaviour might benefit most from which interventions
- involve people on the autism spectrum to review the causes, efficacy and ethical basis of interventions in this area including individuals who may be non-verbal

Other reading

- Fleming B. , Hurley E. , Goth. Key principles for autism interventions. IN: Choosing autism interventions: A research-based guide, (2015) pp. 287-298. Brighton: Pavilion
- Murphy G. H. (2003) Self - injurious behaviour. Chatham, Kent: Challenging Behaviour Foundation
- National Autistic Society (2010) Self-injurious behaviour. London: National Autistic Society
- Paley S. (2008) Self injurious behaviour. Birmingham: British Institute of Learning Disabilities
- Sarris M. (2015) Challenging behavior in autism: Self-injury. Baltimore, MD: Interactive Autism Network
- Positive and Proactive Care: reducing the need for restrictive interventions (2014). London: Department of Health.
- Tidbury, W. (2014). Safeguarding children with autism. London: National Autistic Society.

Organisations

- Challenging Behaviour Foundation. Website www.challengingbehaviour.org.uk
- Self injury Support. Website www.selfinjurysupport.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/self-injurious-behaviour-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

We are the only UK charity exclusively dedicated to research into interventions in autism. We commission, carry out and support high quality, independent research into new and existing health, education, social and other interventions.

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. Version control: Updated by BF at 15.15on 25/02/2016

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Registered Charity No. 1096508

Company No. 8910262

Publication Date: March 2016

Review Date: March 2019

Download from:

<http://www.researchautism.net/publicfiles/pdf/essential-guide-autism-self-injurious-behaviour.pdf>



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