



Factsheet

Self-injurious behaviour in children
with an intellectual disability



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Thank you.

Self-injurious behaviour in children with an intellectual disability

Aims

This factsheet has been written to help parents and carers of children with an intellectual disability to understand what self-injury is, what the causes are and which interventions are effective. The factsheet focuses on children with profound to moderate intellectual disability, who may also have autism or a genetic syndrome.

For children with mild intellectual disability the causes of self-injury and the most effective interventions may be different and more information can be found at <https://youngminds.org.uk/find-help/for-parents/parents-guide-to-support-a-z/parents-guide-to-support-self-harm/>.

This is the shortened version of the 'Self-injury' research summary for an easy read. If you would like more detail and further information on specific assessment and intervention techniques please download the full version of this factsheet from the Cerebra website.

What is self-injury?

Researchers have defined self-injury as "an act initiated by an individual that leads directly to physical harm".

For this briefing we will use the term self-injury to cover behaviours that an individual shows that are:

- initiated by the person,
- non-accidental and
- lead directly to physical damage (e.g. bruising) or physical change (e.g. tooth marks or reddening of the skin) normally considered undesirable in the short term.

The most common forms of these behaviours are:

- scratching,
- biting,
- hitting (usually the face or head) and banging the head or other body parts on objects.

These are the sort of behaviours that are covered in this factsheet.

Prevalence and persistence of self-injury

In children with severe intellectual disability, an estimated 17% show at least one type of self-injury and about 5% (around 1 in 20) show self-injury that is considered severe. Prevalence tends to rise significantly with age up to approximately 30 years of age and then decreases.

This seems to suggest that self-injury begins as children get older but it is also possible that the self-injury might be present at an early age but it is not causing any observable harm, so is not 'classified' as self-injury. Available research data suggest that self-injury can be very persistent over many years. It is important that carers and clinicians are aware of the likely persistence of self-injury to ensure that children receive appropriate assessment and intervention as soon as the behaviour appears.

The characteristics of children with intellectual disability who also show self-injury often include those with:

- Genetic disorders (e.g. Lesch-Nyhan, Cornelia de Lange, Cri du Chat, fragile X, Prader-Willi and Smith-Magenis syndromes)
- A greater degree of intellectual disability
- Autism
- Repetitive behaviours (e.g. hand flapping and rocking)
- Impulsivity
- Low mood

The causes of self-injury

Pain and discomfort

Children and adults with an intellectual disability are significantly more likely to experience health problems and associated pain and discomfort than those without an intellectual disability. Health conditions that are common include epilepsy and osteoporosis as well as disorders of the skin and gastrointestinal, respiratory and cardiovascular systems.

The difficulties children with severe intellectual disability have in communicating pain and discomfort means that such health conditions can go undetected and thus untreated, leading to self-injury in an attempt to relieve the pain. In addition, some children with genetic syndromes (e.g. Smith-Magenis, Prader-Willi and Cornelia de Lange) may have heightened pain thresholds, so may not feel the immediate pain associated with self-injury, therefore experiencing fewer costs associated with injuring themselves.

Thus, it is really important that parent carers and professionals are alert to health problems in children with intellectual disabilities so they can be quickly treated. Any changes in mood, sleeping, eating, sociability, facial expression, activity, posture or vocal sounds are enough to consider a consultation with a GP.

Operant learning theory

A learned behaviour gains positive or negative reinforcement or stimulation after the behaviour and so makes that behaviour more likely to happen again. Positive reinforcement describes the presentation of something rewarding, for example being comforted or held by someone, following self-injury.

Over time and with this experience of positive reinforcement, children associate self-injury with a reward, and thus self-injure because it leads to a reward.

Negative reinforcement (commonly confused with punishment but it is very different) involves the removal of something unpleasant following self-injury. Different children will find different things unpleasant or rewarding, but there are commonalities across children with intellectual disabilities.

There are a number of ways that operant learning works to cause self-injury and make it increase over time. The main ways are through:

- Sensory stimulation

The physical stimulation provided by self-injury might be perceived as pleasurable by a child and thus make self-injury more likely to occur again through positive reinforcement.

- The responses of others to the behaviours (positive and negative reinforcement)

Social contact with others can be highly rewarding, even if it consists of a reprimand, direction to do something else or brief contact. When a child experiences social contact as rewarding, this is positive reinforcement for self-injury.

- Mutual reinforcement.

The descriptions above of the process of rewarding self-injurious behaviour focused only on the way in which the child is rewarded. It is important to also think about the other person in this interaction and how their behaviour is also rewarded.

For a more detailed account of how operant learning works in each of these situations, please see the full version of this briefing.

Assessment of self-injury

However infrequent the self-injury, it is important to establish what might the cause might be before moving on to intervention. Unfortunately, as discussed, individuals with an intellectual disability are more likely to experience a range of health problems and consequently pain and discomfort and thus potential health problems should always be ruled out. A consultation with the GP should be sought as soon as possible, particularly if self-injury has begun recently and suddenly and is accompanied by other changes in mood or sleep.

Having ruled out pain as a potential cause of self-injury, environmental factors should be considered. Professionals working with children with intellectual disabilities who show self-injury commonly ask parents and carers to fill in ABC charts, in order to obtain details about what happens before, during and after an episode of self-injury. ABC sheets are fairly straightforward and do not necessarily require the support of a professional to complete. ABC sheets allow a reasonably detailed assessment of the cause of self-injury, including its Antecedents (precursor to behaviour), Behaviours (the actual self-injurious behaviour) and Consequences (what immediately follows the behaviour).

The full version of this factsheet provides more detail on how to use ABC charts.

Clinical Psychologists and Applied Behaviour Analysts have a range of specialist techniques for the assessment of more frequent and severe self-injury. In order to assess the potential causes of the behaviour, functional analytic techniques are used. The quickest and simplest technique uses questionnaires which, when completed by parents and carers who know the child well, can indicate the causes of self-injury. These questionnaires contain questions regarding the types of situations in which self-injury occurs.

Natural observations are another method commonly used with the child being observed across a range of settings (e.g. at home and school). This method is often the initial stage of assessment and is used to obtain a detailed description of the self-injury and what happens before and after. Analogues (or experimental functional analysis) are a more objective technique which involve exposing the child to a range of situations (high or low levels of adult attention for example). By observing the frequency of self-injury across situations, it is possible to determine the potential causes of the behaviour (e.g. high frequency self-injury during periods of high task demand would suggest the behaviour is maintained by demand escape).

Interventions

There are a number of techniques that can be used to try and reduce self-injury once assessment of the self-injury is complete. These involve both reducing rewards for the self-injury, changing the triggers to self-injury and also increasing the child's ability to communicate their needs. At all stages of an intervention the safety of the child is paramount and it is important to record the frequency of self-injury to see if the intervention is working.

Complete descriptions of these interventions are provided in the full version of this briefing.

When to seek professional advice

If you have made attempts to avoid reinforcing the self-injury and find that the behaviour is continuing at the same level or becoming more frequent or intense then, you should contact your GP and request a referral to your local service. Due to the potential persistence of self-injury, it is important to obtain professional support as soon as it appears that attempts to reduce it have not been successful.

Medication

A range of medications has been widely used to treat self-injury in individuals with an intellectual disability, including those typically used to treat anxiety, depression, epilepsy and psychosis. Generally, interventions based on Applied Behaviour Analysis should be tried before medication, if medication is to be used at all. Given the numerous and potentially harmful side effects of such medications, they should be prescribed as a last resort and their effects very carefully monitored.

Summary

This 'quicklook' factsheet provides an introduction into self-injury and its assessment and intervention. The full research summary provides more detailed information.

For children with intellectual disabilities and their parent/carers, self-injury is a significant issue due to its high prevalence and persistence. Children with specific genetic syndromes, a more severe degree of intellectual disability, autism and impulsive or repetitive behaviours are at greater risk of demonstrating self-injury. When self-injury does occur, there is much that parents and carers can do to reduce its frequency and severity and potentially eradicate the behaviour.

It is imperative that every child demonstrating self-injury receives a thorough medical examination to rule out any health conditions causing pain and discomfort. Following this, parents and carers should begin to examine the potential influence of the environment, including their own behaviour, on self-injury.

The recording of antecedents and consequences in ABC charts can also highlight potential causes and reinforcers for self-injury. The most common reinforcers to consider are sensory and social, whereby self-injury results in the provision or cessation of sensory stimulation or social contact.

When it comes to intervention, the safety of the child is paramount, and thus if there are any concerns that avoiding reinforcement of behaviour could lead to serious injury, other strategies should be employed, such as avoiding aversive antecedents (e.g. reducing the aversiveness of tasks).

In more complex cases of self-injury, where there might be more subtle or multiple reinforcers and thus attempts to avoid reinforcement are not successful, parents and carers should seek professional advice from their local intellectual disabilities service.

Despite the expertise of professionals, it is parents and carers who spend the majority of time with and know the child who self-injures and thus their involvement is vital to the effective treatment of self-injury.

References for the information contained in this factsheet can be found in the full text version.

About Cerebra Centre for Neurodevelopmental Disorders (CNDD)

The Cerebra Centre for Neurodevelopmental Disorders (CNDD) is headed by Professor Chris Oliver and situated within the School of Psychology at the University of Birmingham. The centre has been funded by Cerebra since 2008 and is the largest of its kind in the UK.

At the centre, clinical and academic psychologists, undergraduate and postgraduate students and volunteers conduct high quality research into emotional, cognitive and behavioural difference and disorder in children and adults with neurodevelopmental disorders. More information about their research can be found on the projects page of their website. In addition to carrying out research, they also translate the latest findings into effective and practical assessments and interventions. This enables the provision of information, advice and support to parents, carers and professionals.

The research work conducted at the Cerebra Centre includes the study of numerous different neurodevelopmental disorders. The majority of these are rare genetic syndromes, which have not been the subject of a great deal of research due to their rarity. CNDD believe that research in these groups is crucial in order to raise awareness of these underrepresented groups and thus enhance the quality of life of affected individuals. The research group are currently looking for participants for a range of research projects, details can be found on their website or facebook page.

The findings of this report are those of the author, not necessarily those of Cerebra.

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