Research Summary

Self-injurious behaviour in children with an intellectual disability

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Self-injurious behaviour in children with an intellectual disability

This research summary 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 research summary 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/.

What is self-injury?

Self-injury is often described as a type of challenging behaviour because of its impact on the well-being of the person showing the behaviour. The term 'challenging behaviour' or 'behaviours that challenge' are widely used by services as they emphasise the challenges faced by those who care for children who show difficult behaviours. However, these terms cover a wide range of behaviours including: self-injury, aggression, destruction, fire setting, absconding, hyperactivity and a strong insistence on sameness for example.

These behaviours are very different and the causes of each, as well as the most effective interventions, may differ in some important ways. Also, different people use the terms 'challenging behaviour' and 'behaviours that challenge' to mean different things at different times. In order to find and use the right information about self-injury it is important to be clear about the behaviours that are included under this term and ensure that any information given on challenging behaviour is applicable to self-injury.

A definition of self-injury

Researchers have defined self-injury as "an act initiated by an individual that leads directly to physical harm"[1]. The outcome of physical harm is important as it distinguishes self-injury from other behaviours that might look similar, such as some types of repetitive behaviour (e.g. hand flapping). However, the harm part of the definition may miss younger children with an intellectual disability who are showing behaviours, such as head banging, that we normally think of as being self-injury, but are less likely to inflict physical harm as the children are so small. Additionally, some behaviours such as head banging may result in physical harm that is internal, and harder to identify by observers.

The harm part of the definition can also include behaviours such as smoking, which is very different from the behaviours that are normally thought of as self-injury. Sometimes, behaviours such as self-induced vomiting are called self-injury but this should probably be considered separately. For this research summary we will use the term self-injury to cover behaviours that an individual shows that are:

1. initiated by the person,
2. non-accidental and
3. 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.

Prevalence and persistence of self-injury

Within the total population of people with intellectual disability, estimates of the prevalence of self-injury (the proportion of people with an intellectual disability who show self-injury) vary from 4% to 24%[2, 3]. Variability in estimates is related to the differences in the way in which the studies are conducted (for example, how the behaviours are defined, whether visible signs of injury are necessary for a behaviour to be 'counted' and which group of people were in the study). Studies investigating the prevalence of self-injury in children are fewer in number and typically employ small samples. As a result the figures are very variable. However, in one large study of nearly 1,000 children with severe intellectual disability it was estimated that about 17% showed at least one type of self-injury and about 5% (around 1 in 20) showed self-injury that was considered severe[4].

A recent review of the prevalence data across studies showed that prevalence rises significantly with age up to approximately 30 years of age and then decreases[5]. 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. Although fewer studies have investigated the persistence of self-injury, the available data suggest that self-injury can be very persistent over many years[6]. 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 who show self-injury

Genetic disorders

There are a number of genetic disorders that can cause intellectual disability. Some of these genetic disorders are associated with an increased likelihood of self-injury (e.g. Lesch-Nyhan, Cornelia de Lange, Cri du Chat, fragile X, Prader-Willi and Smith-Magenis syndromes). Some forms of self-injury are more common in these genetic disorders. For example, compared to other syndrome groups, lip and finger biting is more common in Lesch-Nyhan syndrome, hair pulling is more common in Cri du Chat syndrome and scratching and picking are more common in Prader-Willi syndrome. If a child shows self-injury or any of these behaviours, it does not necessarily mean that he or she has one of these syndromes. It is also important to know that just because these behaviours are more common in these syndromes, it does not mean that the behaviours are inevitable or that they cannot be reduced with the right intervention. More information about these syndromes and the behaviours that people show can be found via the syndrome support groups on the internet . If a syndrome is so rare that it does not have a support group, then the charity UNIQUE (https://www.rarechromo.org/) can be helpful.

Degree of intellectual disability

Self-injury is closely associated with severity of intellectual disability, so that children with a more severe intellectual disability are more likely to demonstrate self-injury[7]. This trend is apparent within many genetic syndromes, such as Prader-Willi and Cornelia de Lange, but not all, so that there does not appear to be an association between severity of intellectual disability and self-injury in individuals with fragile X and Cri du Chat syndromes.

It is not clear why a greater degree of intellectual disability might be associated with self-injury. Some possible reasons are that children with a more severe degree of intellectual disability may:

- also have more health problems, which lead to pain, which in turn leads to self-injury (see below),
- have more limited adaptive behaviour, including an ineffective communication system, which means the self-injurious behaviours may be more likely to become a way in which children can make their needs known (see below)
- are more likely to have autism which is associated with self-injury (see below)
- be more impulsive (i.e. less able to control their own behaviour, see below) which is associated with self-injury
- show more repetitive behaviours (see below)
- be in environments which are less stimulating and/or less likely to offer the right kind and level of activities and support for communication.

Autism

There is growing evidence that suggests that the prevalence of self-injury is higher within children who have autism compared to those without autism[7] and this is also true for those children with an intellectual disability. Also, within a number of genetic syndromes (such as fragile X and Cornelia de Lange), a higher score on a screening measure of autism is associated with self-injury, suggesting that within groups at high risk for self-injury, such as some genetic syndromes, autism characteristics add to the risk. It is not clear why autism is associated with self-injury but some of the reasons might be those that apply to all children with intellectual disability. Consequently, the assessment process and interventions should be similar.

Repetitive behaviours

There are numerous reports of the association between repetitive behaviours, such as hand flapping and rocking, and self-injury. This could be explained by the association between self-injury and autism, which is diagnosed based on the presence of repetitive behaviours and social impairments, but this is unlikely. It has also been proposed that self-injury might develop from repetitive behaviours following reinforcement in the environment (a reward of some kind which makes the behaviour more likely; see operant learning models below for a more detailed explanation). However, a similar association between aggression and repetitive behaviour indicates that the link between self-injury and repetitive behaviour is not unique and thus self-injury is unlikely to develop solely from repetitive behaviour.

Impulsivity

Recently, a number of researchers have reported an association between impulsivity (cannot wait, upset if there is a delay for things) and self-injury within children with an intellectual disability and, in particular, those diagnosed with autism and those who have particular genetic disorders, such as Smith-Magenis syndrome. This association may suggest that children who are more impulsive, find it harder to stop themselves engaging in self-injury in the first place, and that once they are showing self-injury, find it hard to stop showing the behaviour.

Self-restraint and preferred imposed restraint

Self-restraint is where a child might seek restriction of their own movements, for example by wrapping their arms or legs in clothes, pushing their hands into tight spaces or covering their hands. Preferred imposed restraint is where a child shows a need or desire for protective clothing, such as gloves or arm splints. Preferred imposed restraint usually becomes evident because children:

1. help to put the item on,
2. become distressed and anxious when someone starts to remove the item and
3. often try to restrict their movements in another way when they do not have the item they prefer. It is not clear why children show self-restraint or a preference for imposed restraint but one explanation is that the children are finding it difficult to control their own behaviour. If restraints, such as splints, gloves etc., are used to help with self-injury or if self restraint is occurring, it is very important to seek professional advice.

Low mood and a lack of interest in day-to-day activities

It has been proposed by some researchers that self-injury in people with an intellectual disability is a symptom of depression, because individuals with self-injury have been observed to show signs of low mood and people showing low mood are also more likely to self-injure. Whilst an association between self-injury and low mood is apparent, others have contested the notion that self-injury is a symptom of depression[8]. Indeed, there are numerous alternative explanations for why low mood might be associated with self-injury. For example, they might both have a shared cause and thus are likely to co-occur. To illustrate, an under stimulating or coercive environment might lead to both self-injury and low mood. Pain and discomfort is another obvious reason that self-injury and low mood might be associated (see below). Over the last decade, a number of studies have shown that pain is associated with both self-injury and low mood[9, 10]. In summary, at present there is not enough evidence to say that self-injury is a symptom of depression or that depression causes self-injury.

The causes of self-injury

Pain and discomfort

The evidence: Research indicates that individuals with an intellectual disability are significantly more likely to experience health problems and associated pain and discomfort than individuals without an intellectual disability[11]. Health conditions common to individuals with an intellectual disability include epilepsy and osteoporosis as well as disorders of the skin and gastrointestinal, respiratory and cardiovascular systems. Whilst health conditions and associated pain are not inevitable for children with an intellectual disability, the difficulties children with severe intellectual disability have in communicating pain and discomfort means that such health conditions can go undetected and thus untreated. This is a significant issue since several research studies have demonstrated a link between pain and self-injury, so that children who appear to be in pain show more frequent self-injury[12].

Why might the experience of pain be associated with self-injury? Some children may show self-injury at the site of painful health conditions, for example hitting their ear when they have an ear infection, in an attempt to 'get at' the source of pain. Alternatively, according to the gate control theory of pain[13], individuals may engage in self-injurious behaviour in order to relieve the pain experienced at another body site. So, the child seeks stimulation to produce pain relief. This is a bit like rubbing your head when you have banged it; the rubbing stimulates different nerve fibres and this blocks (gates) the signal from the pain fibres, at least in the short term. Self-injury at another body site can work like this and thus the self-injury is rewarded by pain being temporarily stopped.

In order to reward the self-injury, the pain relief produced by self-injury must be greater than the pain caused by self-injury (see section on operant learning theory: sensory stimulation, below).

There is another way in which the experience of pain might be associated with self-injury. Heightened pain thresholds in people with genetic syndromes, such as Smith-Magenis, Prader-Willi and Cornelia

de Lange, might also explain the high prevalence of self-injury in these syndromes, since children feel less pain in association with self-injury and thus there are fewer costs associated with the behaviour when it occurs for another reason.

Signs of pain in non-communicating children: Since children with a severe intellectual disability are often unable to communicate pain to carers, much of the research literature has been dedicated to investigating other signs of pain in these children. The Non-Communicating Child Pain Checklist[14] was specifically developed to be completed by carers of children with a severe intellectual disability to help professionals identify pain. It includes questions related to vocal sounds, social behaviours, facial expressions, activity levels, the body, eating and sleeping, all of which have been found to be important to the detection of pain in children with a severe intellectual disability. Children who are unable to communicate might also appear lower in mood than usual.

Being alert to health problems: As noted above, individuals with an intellectual disability are prone to health problems and resultant pain and discomfort, which is associated with self-injury. Research findings indicate that many health problems experienced by individuals with an intellectual disability are avoidable and exacerbated by problems with identifying ill health[15]. It is imperative therefore, that carers of individuals with an intellectual disability are alert to health problems so that they can be quickly treated. Any changes in mood, sleeping, eating, sociability, facial expression, activity, posture or vocal sounds made is enough to warrant a consultation with a GP.

Seeking treatment and advocacy: Unfortunately, some individuals with an intellectual disability continue to face barriers to accessing good quality and effective health care. Services might not routinely make adjustments to meet the needs of individuals with an intellectual disability, such as longer appointment times[16]. A lack of knowledge regarding health conditions in individuals with an intellectual disability can also cause healthcare professionals to perceive ill health in this population as inevitable, when in reality effective treatment could reduce or eradicate the problem. In this instance, parents and carers need to act as assertive advocates for their children, ensuring that they receive the best possible care.

Further information about identifying painful health conditions in children and adults with intellectual disability is available in the Cerebra parent guide to pain: https://www.cerebra.org.uk/help-and-information/guides-for-parents/pain-in-children-with-severe-intellectual-disability-a-guide-for-parents/

Operant learning theory

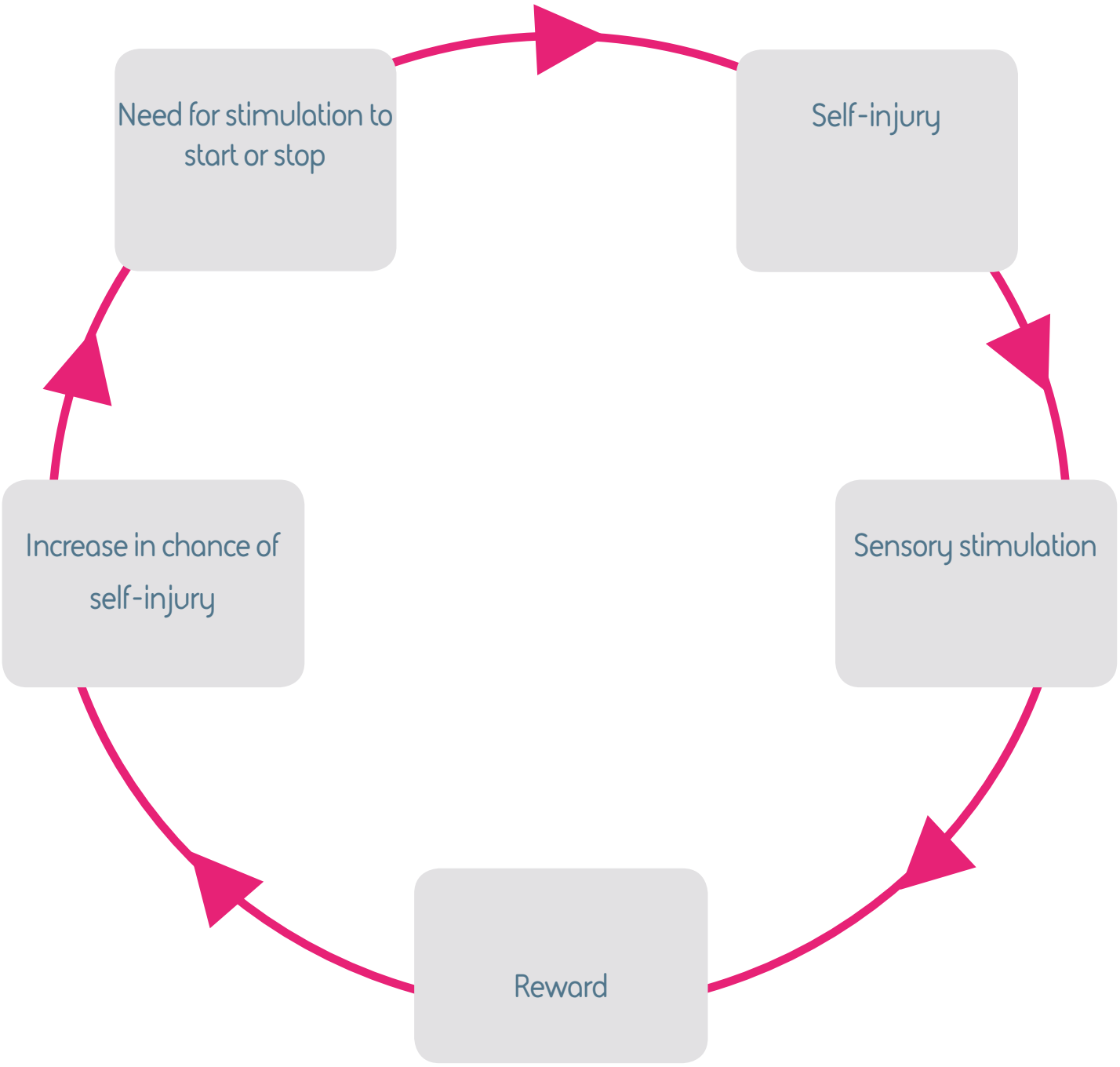
There is very good scientific evidence for operant learning theory accounts of self-injury which suggest that self-injury is a learned behaviour because of the positive or negative reinforcement from others or stimulation that happens after the behaviour. Positive reinforcement describes the presentation 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, for example a demand to carry out a task stops, so that the child learns that self-injury will lead to unpleasant things stopping or being removed. 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 responses of others to the behaviours (positive and negative reinforcement) and
- mutual reinforcement.

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. For example, some children with severe and profound intellectual disabilities have poor vision and hearing and thus receive little or very distorted sensory stimulation. Eye poking, a form of self-injury, provides sensory stimulation that children can find pleasant (it leads to bright flashes when the nerve cells in the eye are physically pressed), and thus they are rewarded for eye poking through positive reinforcement, which leads to more eye poking in the future. The removal or reduction of pain (described above) is an example of how sensory stimulation might negatively reinforce self-injury. Figure 1 shows the sequence of events involved in the positive and negative sensory reinforcement of self-injury

Figure 1. Positive and negative sensory reinforcement of self-injury



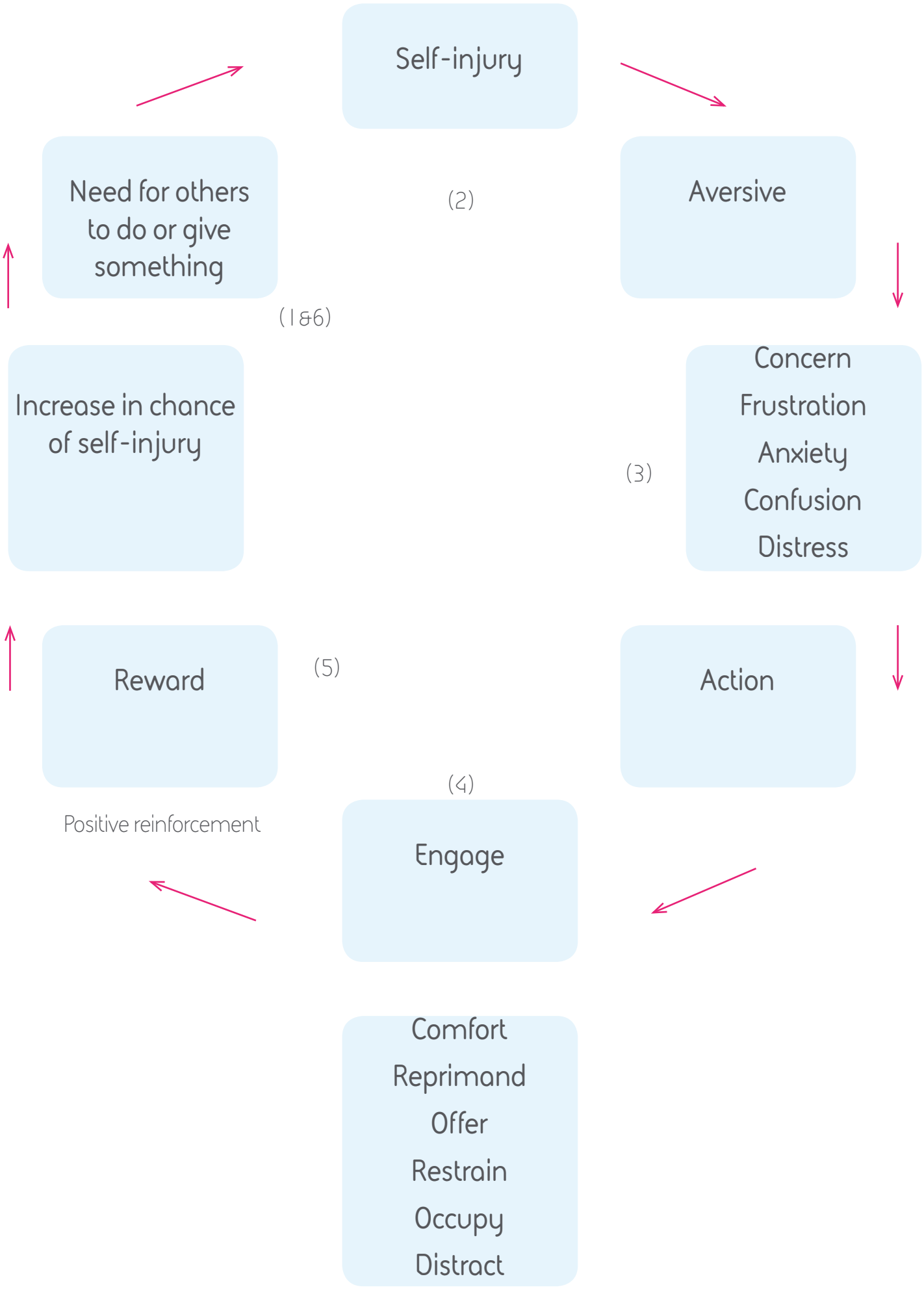
Social reinforcement

Positive social 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, its presence following self-injury leads to positive reinforcement. Figure 2 shows the sequence of events that occur when self-injury occurs because of positive social reinforcement and the sequence is listed here (the numbers in Figure 2 refer to the numbers in the sequence):

1. The child is alone and has no stimulation and, in the first instance, may self-injure either because it gives rise to pleasant sensory stimulation or because it relieves discomfort. Self-injury could also be the end result of some forms of contact repetitive behaviours (see above) or simply a chance act (an accidental bump of the head). For whatever reason, the first instance of the self-injury occurs.
2. When the self-injury occurs it is seen by another person (e.g. parent or carer).
3. The other person finds the self-injury unpleasant or aversive and consequently acts to stop the self-injury from recurring or tries to find out the reason for the self-injury.
4. The other person engages with the child who has just shown self-injurious behaviour and whilst preventing further instances of self-injury and trying to find the cause, may comfort, distract or restrain the child or use any combination of these strategies.
5. The child finds this contact with the other person pleasant and rewarding (positively reinforcing). This makes it more likely that the next time the person is alone and without contact they will self-injure.
6. Once again, the child is alone and has no stimulation (and thus motivated to seek contact). Self-injury occurs because in the past it has led to rewarding social contact with another person. (Go to 2 above).

Once this process has occurred a number of times the child will very quickly learn to self-injure because it leads to rewarding attention from another person. This is not to say that the child necessarily intends to injure him or herself or intends to gain the attention of someone else. It is an entirely natural process whereby a self-injurious behaviour is so unpleasant that it evokes an entirely natural protective reaction from another person and the contact with that person is also naturally rewarding or reinforcing for the child.

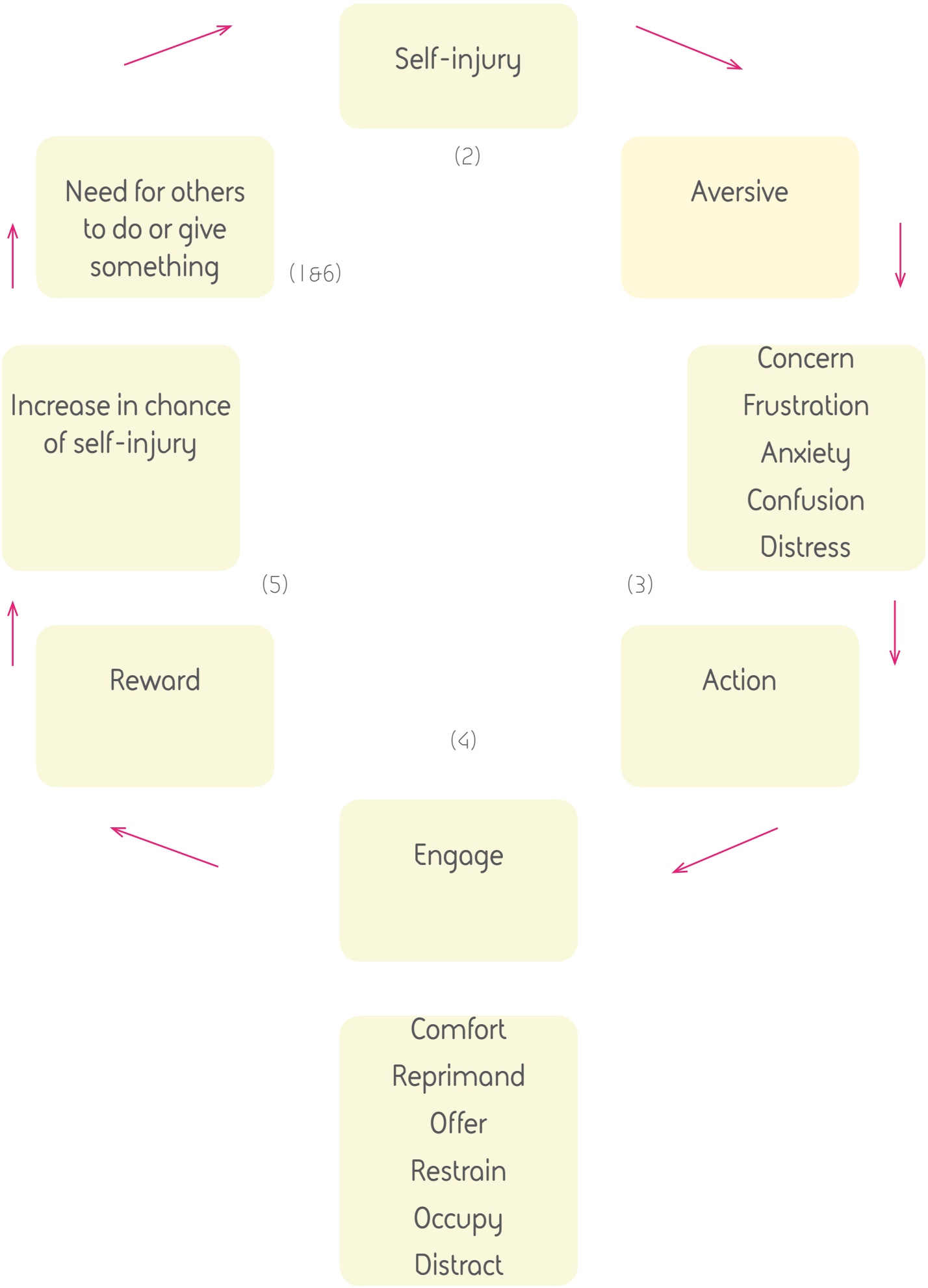
Figure 2. Social reinforcement of self-injurious behaviour: positive reinforcement



Negative social reinforcement: Escape from task demands or other things that are unpleasant: Children with intellectual disabilities will experience some forms of social contact as unpleasant or aversive, particularly when it involves an unwanted demand. The most common demand is the presentation of tasks that the child finds difficult, boring, unpleasant or unrewarding and consequently does not want to complete. This learning process for this type of reward is shown in Figure 3 and refers to the sequence of events that are listed here (the numbers in Figure 3 refer to the numbers in this sequence):

1. The child is asked to complete a task which they find difficult, unrewarding, painful, boring or any combination of these factors.
2. The self-injurious behaviour occurs by chance or as part of a "tantrum" in which the child accidentally self-injures.
3. The other person finds the self-injury unpleasant or aversive and as a result, does something to prevent another self-injurious response or tend to the results of the self-injury.
4. The other person engages with the child in order to prevent the self-injury. The response that the other person is making at this point may be no different to that described in the positive example given above. The important point here is that whilst engaging with the child the unpleasant task stops, at least temporarily.
5. The child finds this removal of the unpleasant task rewarding. This makes it more likely that the next time the child is presented with an unpleasant task (and they are thus motivated to escape the task) they will self-injure.
6. The child is being asked to carry out a task which they do not want to do as they find it difficult, hard work, painful, unrewarding or any combination of these factors. (Go to 2 above).

Figure 3. Social reinforcement of self-injurious behaviour: negative reinforcement

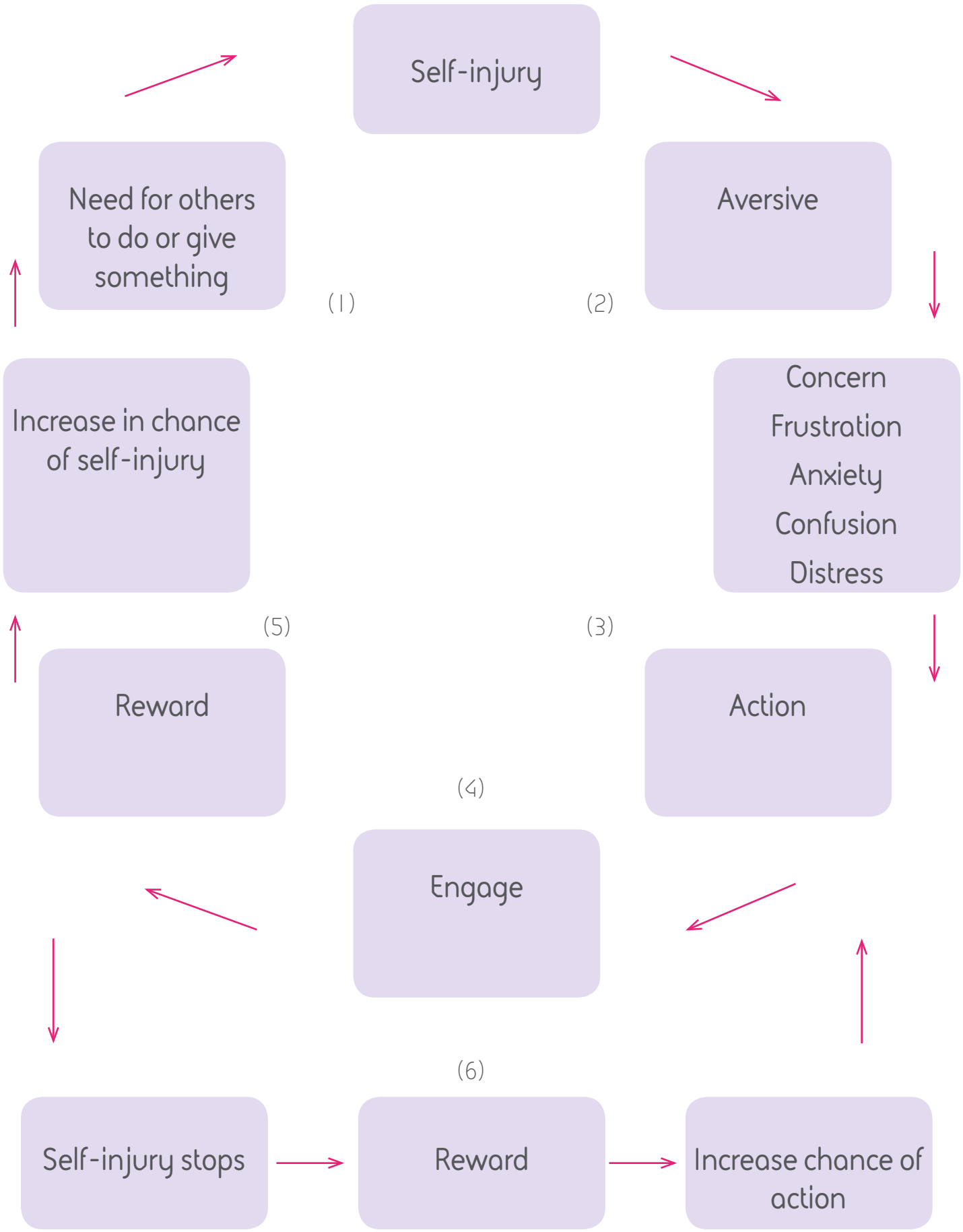


Operant learning can interact with other factors: There is now some evidence that some short or medium term factors can influence the operant learning process. These factors include things like fatigue, hunger and pain. This probably occurs because children with intellectual disabilities will experience demands to be more aversive if and when they are in pain, are tired or hungry so that the demands are experienced as more unpleasant and so the self-injury is more likely to occur in these situations. The same argument can be made for positive reinforcement; attention from others might be more rewarding when someone is tired or in pain.

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[17]. If we consider this process within the positive reinforcement example that we have looked at above (Figure 2), then we can see that not only is the other person rewarding the child but the child is also rewarding the other person. Figure 4 refers to the sequence of events that are listed here (the numbers in Figure 4 refer to the numbers in this sequence):

1. The child is on their own and has no stimulation. Initially, the child may show self-injurious behaviour either because it gives rise to pleasant sensory stimulation or because it relieves discomfort or as the end result of a stereotyped behaviour or it is simply a chance act.
2. The self-injury occurs and is seen by another person (parent or carer).
3. The other person finds the self-injury unpleasant or aversive and consequently acts to stop the self-injury from recurring or tries to find out the reason for the self-injury.
4. The other person engages with the child who has just shown self-injury and whilst preventing further instances of self-injury and trying to find the cause may comfort, distract or restrain the person or use any combination of these strategies.
5. As the child has now received a reward there is no longer any motivation for the self-injury to continue and the self-injury stops.
6. As the self-injury has now stopped the other person has been rewarded by the removal of the unpleasant event (the self-injury). This reward is the feeling of relief that happens when a child stops self-injuring, even for a short period of time.
7. As the response by the other person to the self-injury is rewarded it makes it more likely that the person will make the same response to the self-injury in the future and so reward the child again.

Figure 4. Mutual reinforcement of self-injury



It is worth thinking about some other things that are always occurring in this process. One is what happens if the other person does not make a rewarding response to the self-injury. Under these circumstances, the child will still have a need for the reward and so the self-injury will continue. As the self-injury continues so the other person will present more things until they eventually hit on the right thing and then the child will stop the self-injury. In this way the person is inadvertently taught by the child precisely how to reward the self-injury.

Interactions between operant learning and autism characteristics and genetic syndromes

As discussed above, self-injury is more common in some syndrome groups and children with autism than others, so these characteristics of children must somehow make self-injury more likely to happen. However, it is clear from a number of studies that self-injury shown by children with genetic syndromes that are associated with self-injury might still be influenced by environmental events[18]. Even in Lesch-Nyhan, a syndrome associated with highly prevalent self-injury (indicating a strong genetic influence in self-injury), the environment has been shown to have an impact on the frequency of self-injury, so that children with Lesch-Nyhan are more likely to self-injure during periods of low social interaction. More recently, researchers have also identified motivational differences that are important, so that children with particular genetic syndromes appear to have a strong motivation for particular types of reinforcement[19]. For example, children with Smith- Magenis appear to have an unusually strong motivation for social contact, so that they show more frequent self-injury when social contact is not available. Similarly escape from social contact has been demonstrated as motivation for self-injury in fragile X, Cornelia de Lange and Rett syndrome.

Assessment

However infrequent the self-injury, it is important to establish what 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 as a first course of action. A consultation with the GP should be sought as soon as possible, particularly if self-injury has begun recently and suddenly.

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, Behaviours and Consequences.

Antecedents: these are events or situations that occur immediately before any behaviour. In the examples in figures 2 and 3, this may be being left unattended, (if the self-injury is reinforced by adult attention) or being presented with a difficult task (if the behaviour is reinforced by escape from demand). Antecedents can be viewed as a trigger for the behaviour, just as being hungry triggers food seeking behaviour.

Behaviours: these are the self-injurious behaviours shown by the child.

Consequences: these are the events, behaviours or sensations that immediately follow a behaviour. In the examples in figures 1, 2 and 3 these may include physical attention (e.g. hugs), verbal reprimands, removal of a difficult task or the flashing lights seen by a child engaging in eye pressing. Consequences are usually reinforcing but if the consequence is not the usual reinforcer (i.e. the difficult task is not removed after self-injury as usual), then the behaviour will often escalate in intensity until the

reinforcer is presented.

Figure 5 includes a completed ABC chart and describes the types of reinforcement that appears to be important.

Figure 5. Using ABC charts to assess self-injury

	Antecedant	Behaviour	Consequence
1	Child is alone	Child presses on eye	Nothing
2	Parent is talking to a friend	Child bangs head on floor	Parent stops talking and picks up child
3	Parent asks child to put toys away	Child bites hand	Parent takes child to another room
4	Parent is on the telephone	Child slaps face repeatedly	Parent puts phone down and distracts child with a biscuit
5	Parent and child are folding clothes together	Child bites fingers	Parent goes into another room
6	Parent and child are folding clothes together	Child bites fingers	Parent takes child into another room
7	Child is playing on own	Child hits head	Nothing
8	Parent and child are playing together	Child slaps face	Parent distracts child with a favourite toy
9	Parent is playing with child's sibling	Child bangs head	Parent encourages child to join in
10	Parent is washing a child's face	Child bites hand	Parent goes to another room

- Items 1 and 7 are probably examples of sensory reinforcement. There is no obvious consequence in terms of behaviour by another person, the stimulation from the behaviour is the reinforcer.
- Items 2 and 9 are probably examples of positive social reinforcement, as the self-injurious behaviour results in attention from the parent and there was no attention before the self-injury.
- Items 3 and 6 are examples of negative reinforcement by escape from a demand as the self-injurious behaviour results in the demand being removed (in these examples by the child escaping the room altogether).

- Items 4 and 8 are examples of positive reinforcement by access to tangibles (things and events rather than just attention) as self-injury results in access to food (item 4) or a preferred item (item 8).
- Items 5 and 10 are examples of negative reinforcement by avoidance of social contact or tasks as self-injury results in the adult moving away from the child.

ABC sheets should be completed following incidents of self-injury observed during a typical week (although length of assessment can vary depending on frequency of the behaviour, usually about 20 incidents is enough to identify a pattern). Patterns within the information should then be investigated, looking for examples of positive and negative reinforcement. Once you have established the potential causes of self-injury, you can then alter your responses to the behaviour accordingly alongside other changes (see below). To assess the effectiveness of your intervention, record the frequency of self-injury before and during the intervention. A reduction in the frequency of self-injury over the same time period would indicate that you successfully understood the causes of the self-injury and modified your behaviour accordingly.

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. Examples of these questionnaires are the Questions about Behavioral Function[20] and the Motivation Assessment Scale[21]. 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

Recording the frequency of self-injury

Before starting any intervention it is important to know how frequently the behaviours occur so that it is possible to see if an intervention is effective when it is tried. To do this everyone who cares for the child should record the number of times they observe the self-injury. This information can also help detect days and times when self-injury is more common and so provide clues as to what might be happening at these times to cause self-injury. Once an intervention has started, records can be kept and reviewed to see if an intervention is working.

The safety of the child is paramount

Whilst it is important to try and reduce the frequency of self-injury, the safety of the child is paramount and thus any changes to how the behaviour is responded to must be considered carefully. To illustrate, an effective intervention for self-injury reinforced by adult attention would be to ensure that adult attention is not provided following an episode of self-injury.

However, if the self-injury demonstrated by the child poses a risk of injury, this is not the right course of action. So, for example, if a child were to bang their head on the corner of a table, there is a risk that they could cause serious damage to their face and head in this situation. Consequently, it is better to prevent the continuation of this behaviour by responding but to do so in a way that is not reinforcing. This may mean protecting the child but not giving any eye contact at all or speaking at all whilst doing so.

Reducing reinforcement and problems with this method

Ensuring that self-injury is no longer positively or negatively reinforced by the behaviour of others is an effective way of reducing the frequency of self-injury but it does have some problems. To be at its most effective, this type of intervention must be conducted consistently, every time self-injury is demonstrated. Everyone working with the child must be made aware of what is likely to trigger self-injury and how best to respond to when it does occur to avoid reinforcing it. This is where the problem lies because when self-injury fails to produce the consequences it once did, it is likely that the child will show more severe self-injury in order to provoke the desired response. This is called the extinction burst. At this point, reinforcement of self-injury would lead to the reward of more severe forms of self-injury. Thus, although it can be highly distressing to observe a child self-injuring it is important to limit the amount of reinforcement but also ensure the child is safe (see above). It is also important to combine the reduction of reward with other methods that are listed below.

Replacing self-injury with more adaptive behaviour

Replacing self-injury with more adaptive behaviour is a form of intervention which seeks to reinforce appropriate behaviour which has the same antecedents and consequences as self-injury[22]. This can and should be used alongside limiting the normal reward process whilst keeping the child safe. By reinforcing a new behaviour, the self-injury will be 'displaced' as it becomes less effective than the new behaviour. For this method to be effective, the antecedents and consequences of self-injury must be identified and an equivalent behaviour taught. An equivalent behaviour is one which has the same function as self-injury (e.g. also leads to adult attention or task escape). One process for teaching a functionally equivalent behaviour is called Functional Communication Training and is successful with children with a range of intellectual disabilities. To illustrate the process, a child understood to show self-injury when alone would be taught to communicate a need for attention. This behaviour, but not self-injury, would be reinforced with adult attention when demonstrated when alone. The precise form of Functional Communication does not really matter (e.g. signs, picture boards, vocalisations). The most important thing is that the behaviour is more effective than the self-injury (i.e. gets a quicker and more reliable response).

Reinforcement at other times

Reinforcing behaviours other than self-injury is an effective way of reducing self-injury. There are several variations of this principle which can be successfully applied[23]. Differential Reinforcement of Other behaviour (DRO) is when positive reinforcement is provided only when self-injury is not displayed for a specified period of time. Differential Reinforcement of Incompatible behaviours (DRI) aims to eliminate self-injury by reinforcing other behaviours which are incompatible with self-injury. For example, if a child self-injures by hitting their head, reinforcement at times when their hands are occupied could be provided, as the child cannot self-injure whilst this is occurring. Another effective strategy is Non Contingent Reinforcement (NCR). This technique involves providing reinforcement regardless of the presentation of self-injury. Whilst this might lead to a reward following an episode of

self-injury, the inconsistent provision of the reward reduces the association between self-injury and the reward and thus the frequency of self-injury.

Reducing the aversiveness of tasks

If task escape appears to be reinforcing self-injury, reducing the aversiveness of tasks is an effective way to reduce self-injury. To assess the nature of the task aversiveness, record the frequency of self-injury after various tasks and compare the nature of these tasks. Remember, a higher frequency of self-injury after one task than another indicates that this task is more aversive. If it is difficult to decipher what it is about the task that makes it aversive to the child, modify it systematically, changing one element of it at a time. Self-injury should decrease when you have effectively made the task less aversive. Making the task less difficult is often helpful. This can be done by breaking down the task, prompting the child to carry out one simple step at a time. Modifying where the task is conducted can also be helpful (e.g. making sure the child is in a preferred environment during task completion).

Restraints and protective devices

As discussed, self-restraint occurs when a child seeks restriction of their own movements, whilst preferred imposed restraint is where a child shows a need or desire for protective clothing such as gloves or arm splints. The wearing of protective devices can be advisable when self-injury is severe, in order to avoid permanent injury, but only after all assessments and interventions have been tried. If restraints are used, they must be:

1. provided by a physiotherapist or occupational therapist,
2. constantly reviewed to see if they can be removed,
3. part of a programme devised by a Clinical Psychologist or Applied Behaviour Analyst and
4. reduced over time as part of a planned programme. To illustrate, a child might wear an arm splint with an adjustable joint at the elbow, restricting the child's ability to reach and hit their head. Over time more movement can be introduced at the joint and the size of the splints can be faded down to cuffs.

When to seek professional advice

Although the principles behind operant learning and interventions can be understood and applied by parents and carers, the ways in which self-injury is triggered and reinforced can be subtle and difficult to detect. These principles may also be harder to apply to very young children who self-injure, as well as children with autism and genetic disorders. 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. Such services employ nurses, psychologists and psychiatrists who can assess and treat self-injury. The scientific evidence clearly shows that interventions based on Applied Behaviour Analysis are the most effective. Health care professionals should be able to identify antecedents and consequences which untrained professionals might find difficult to detect. They can also offer support to try and break the reinforcement cycle, provide advice as to how best to respond to self-injury to avoid reinforcing it, particularly if it becomes severe. 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. The evidence base upon which prescription of these drugs is based is, however, unconvincing and there is mixed opinion within the field as to the effectiveness of these medications[24]. Generally, interventions based on Applied Behaviour Analysis should be tried before medication, if medication is to be used at all. Naltrexone, an opiate antagonist, is occasionally prescribed and can result in a reduction of the frequency of self-injury, although the improvement, when present can be small[25]. 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

For children with intellectual disabilities, their parents and carers, self-injury is a significant issue due to its high prevalence and persistence. Children with specific genetic syndromes, a more severe level of intellectual disability, autism and impulsive or repetitive behaviours also appear to be at greater risk of demonstrating self-injury. However, that is not to say that self-injury is inevitable for any child with an intellectual disability. Additionally, 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.

Given the established association between pain and self-injury, 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).

Whilst protective devices often reduce the frequency of self-injury, their use must be carefully and closely monitored to prevent negative effects for the child. Protective devices should not be introduced without professional advice or consideration as to how they might be faded. 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.

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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.

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