Self-injury in children with intellectual disability

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Introduction

This five-part guide has been written to help parents and carers of children with intellectual disability to understand what self-injury is, what can cause self-injury and which interventions may help to reduce self-injury. It should be noted that this guide is intended to be comprehensive and reasonably technical, and therefore has been designed for parents who are interested in developing an in-depth understanding of self-injury. This guide focuses on children with profound to moderate intellectual disability, who may also have co-occurring diagnoses like autism or a genetic syndrome (1). Part One describes what self-injury is and how common it is. Part Two focuses on the characteristics of children who may show self-injury, and Part Three explores some of the potential causes of self-injury. Part Four gives guidance on assessments for self-injury that may be helpful for understanding the behaviour, and Part Five discusses some interventions that may help to reduce self-injury for some children. A glossary of key terms (highlighted in blue) and a list of useful resources are provided at the end of this guide.

Part One – What is self-injury?

What is self-injury?

Self-injury refers to non-accidental behaviours that are initiated by a person themselves (for example, by your child or someone within your care) that have potential to lead to physical harm[1]. The 'physical harm' aspect of the definition of self-injury helps us distinguish these behaviours from other behaviours that might look similar, such as repetitive behaviours (e.g., hand flapping), so it's important to consider if all aspects of the definition of self-injury are met when thinking about behaviours. Some examples of behaviours that would be considered self-injury are head banging, hand biting or scratching. Keep in mind that some types of self-injury (e.g., head banging) may result in physical harm that is internal and perhaps harder to see and identify. It is possible for a person to show more than one type (topography) of self-injury.

Self-injurious behaviours are:

1. Initiated by the person themselves
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)

Language and self-injury

It's important to note that these behaviours can sometimes also be called 'challenging behaviours' because of the impact they can have on people's wellbeing. You may hear the terms 'challenging behaviour', 'behaviours that challenge' or 'behaviours of concern' used by professionals and services working with your child. These terms emphasise the challenges faced by both children who show difficult behaviours and by those who care for such children. However, it's important to remember that these terms are used to cover a wide range of behaviours such as: self-injury, aggression, destruction, hyperactivity and a strong insistence on sameness. Therefore, it is helpful to be really specific when describing the types of behaviour a child shows. More specific definitions can help with tailored assessment and interventions.

How common is self-injury?

Self-injury is primarily shown by children who have intellectual disability. In this population, the estimated prevalence of self-injury (or how common self-injury is) is between 4% - 36% (2–4). Variation in estimates is to be expected and is often due to differences in the way self-injury is defined and how research is conducted. If you are reading research about self-injury, here are some considerations to bear in mind:

- **Where were the participants recruited from?** Sometimes researchers work in collaboration with service providers (such as those working within the NHS) to explore self-injury. In clinical settings such as these, estimates of how common and how severe self-injury is will likely be higher than in participants recruited from within the community.
- **How did researchers ask about self-injury?** A common method of exploring a behaviour is to

1 Self-injury (primarily seen in children who have a profound to moderate intellectual disability), is not the same as self-harm (primarily seen in children with a mild or no intellectual disability). For support and information regarding self-harm behaviours, please visit https://www.cpft.nhs.uk/self-harm-/.

ask parents or caregivers to answer some questions about their child. Try and see if researchers have used a validated questionnaire measure (such as the Challenging Behaviour Questionnaire[2] (sometimes called the CBQ)), rather than simply asking if behaviours are present or absent. Other methods of exploring behaviours include direct observations with a child themselves, or analysis of video footage. All of these would lead to slightly different estimates of a behaviour.

- **When did the study take place?** Over the past few decades the way we understand self-injury and other behaviours in people with intellectual disability has advanced hugely. The provision of support and services also changes over time, so be mindful of how 'up to date' the information you are reading is.

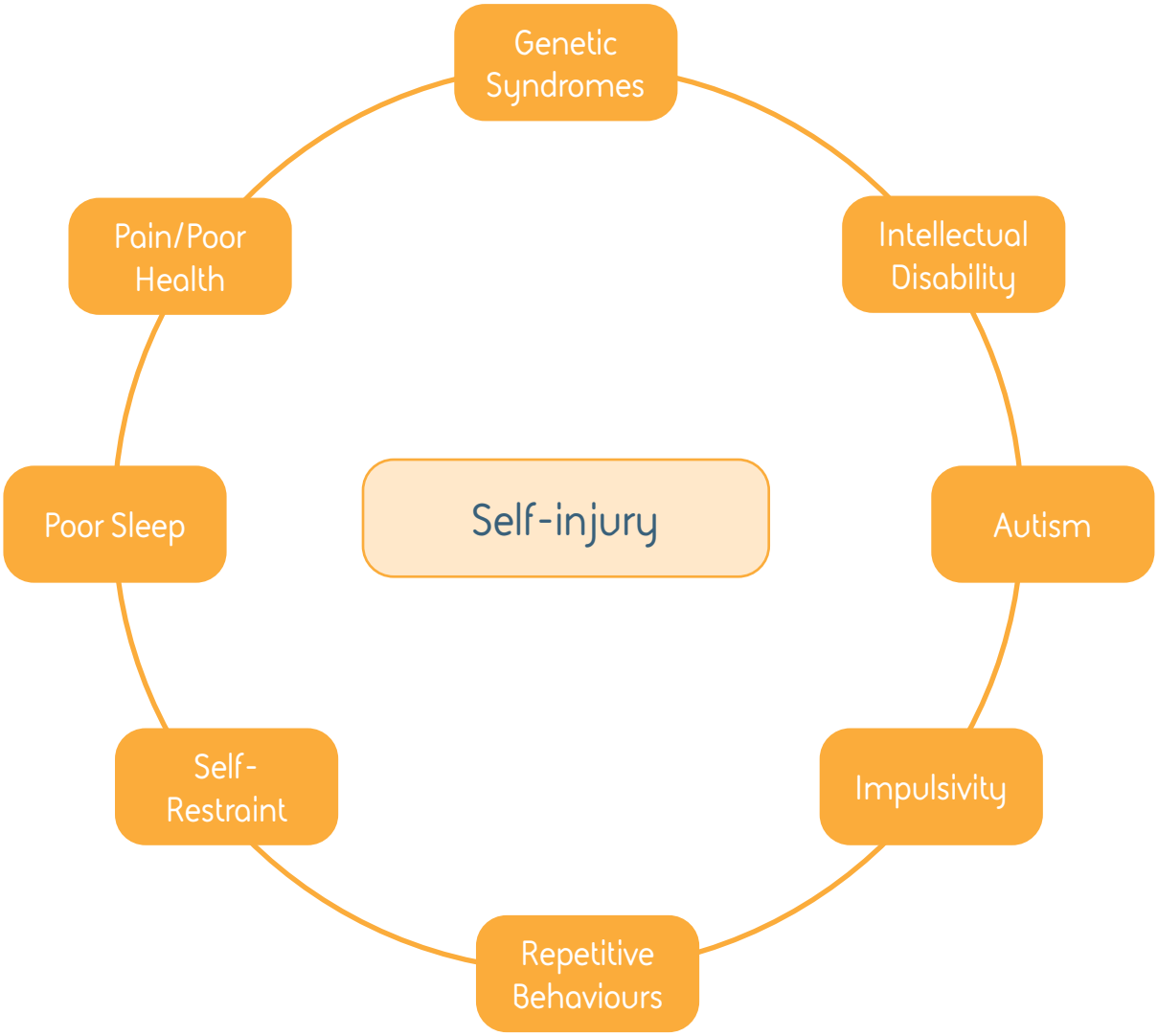
Another important consideration when thinking about the prevalence of self-injury is that behaviours are not static and will often change over time throughout a person's life. Research has sought to understand how self-injury changes over a person's lifetime, by pooling together all the available data on self-injury across the lifespan (4). Researchers found that self-injury was common in children and the prevalence increases with age up to around 30 years, after which it decreases. It is important therefore to be aware that self-injury in childhood can often persist into adulthood, and to ensure that children receive appropriate assessment and intervention as soon as the behaviour appears.

2 You can freely access the CBQ alongside many other validated questionnaire measures via the FIND website: https://www.findresources.co.uk/professionals/login

Part Two – Who is likely to show self-injury?

So far we've covered what self-injury is and how common it is within people who have intellectual disability. Importantly, there are other person characteristics and factors that mean someone may be more or less likely to show self-injury. In this section, we'll discuss some groups of people for whom we know self-injury might be more common and some person characteristics that may increase an individual's likelihood of showing self-injury.

Figure 1: Who is likely to show self-injury?



Genetic Syndromes

There are a number of genetic syndromes that can cause intellectual disability. Some of these genetic syndromes are also 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). Additionally, some forms (topographies) of self-injury are more common in specific genetic syndromes. For example, compared to other syndromes, lip and finger biting is more common in Lesch-Nyhan syndrome, hair pulling is more common in Cri du Chat syndrome and scratching and skin picking are more common in Prader-Willi syndrome. So, knowing about a child's genetic syndrome can help us to understand which behaviours they might be more likely to show.

Importantly, if a child shows these topographies of self-injury, it does not necessarily mean that

they have one of these syndromes. It is also important to know that just because specific 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 relevant 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/) or the website Further Inform Neurogenetic Disorders (FIND, https://www.findresources.co.uk/) could be helpful.

Degree of intellectual disability

Self-injury is closely associated with severity of intellectual disability, such that children with more severe intellectual disability are more likely to demonstrate self-injury (5). This trend is also apparent within many genetic syndromes, such as Prader-Willi and Cornelia de Lange, and people who are autistic[3]. But it's important to note this is not always the case, such as in Fragile X and Cri du Chat syndromes where self-injury is not more common in those with more severe intellectual disability. Some possible reasons why a greater degree of intellectual disability might be associated with self-injury are outlined below:

- A person with a more severe intellectual disability may have more limited adaptive behaviour and communication. This might mean that they have fewer communication strategies available to them, and therefore self-injury occurs because they are trying to make their needs or wants known to a parent or caregiver.
- A person with a more severe intellectual disability may also have an increase in painful health problems that may lead to self-injury (pain and self-injury is discussed in more detail in Part 3 of this guide).
- A person with a more severe intellectual disability may also have a co-occurring diagnosis of autism or a genetic syndrome which research has found leads to an increased likelihood of self-injury.

Therefore, if a person has a severe intellectual disability it's important to consider their internal environment (e.g., painful health conditions) and their external environment (e.g., communication opportunities available) to help further understand self-injury. Further details will be outlined in Part 3.

Autism

There is growing evidence to suggest that the prevalence of self-injury is higher for autistic children compared to non-autistic children (6), and higher still for people who are autistic and have a co-occurring intellectual disability (7). Interestingly, within a number of genetic syndromes (such as Fragile X and Cornelia de Lange), a higher score on a screening measure of autism is often associated with higher levels of self-injury, suggesting that within groups at high risk for self-injury, such as some genetic syndromes, autism characteristics further increase the likelihood of self-injury. Some of the reasons why autism and autism characteristics increase the likelihood of self-injury might be similar to those that apply to all children with intellectual disability, outlined above.

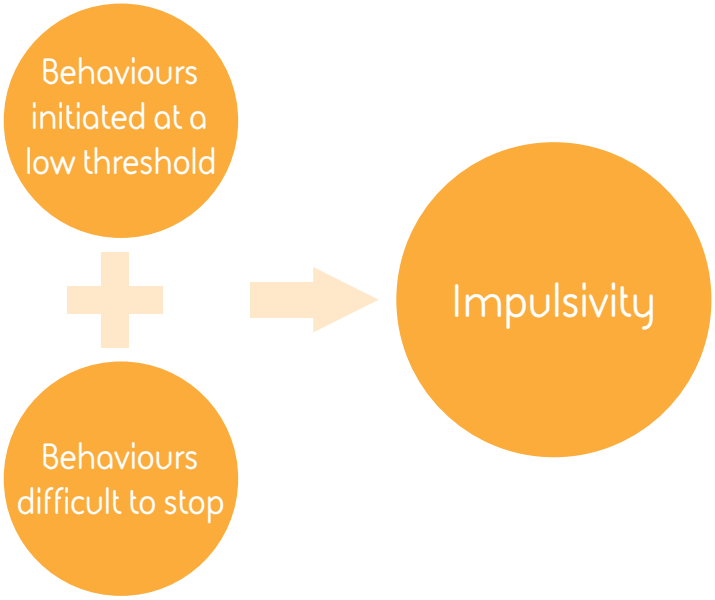
3 Authors have opted to use identity first language within this guide, but acknowledge the current and ongoing debate regarding autism terminology and understand this may not be the preferred terminology for all people. The neurodiversity movement champions descriptions portraying autism as a way of being, and rejects the idea that a persons' autism can be separated from their identity. Additionally, evidence suggests the majority of autistic individuals and their families to endorse the term 'autistic' (41). Therefore, the descriptors 'autistic person/people/individual' and 'autism' are used within this guide.

Repetitive Behaviours

Repetitive behaviours such as hand flapping, finger flicking or rocking are often associated with self-injury. One possible reason for this association could be that repetitive behaviours are very common in autistic people who may be more likely to show self-injury. Another potential reason for the association is related to the complex early development of self-injury, with some researchers suggesting that early repetitive behaviours may develop into later self-injury. This development is thought to occur gradually as repetitive behaviours are reinforced (made more likely) over time. The role of reinforcement in the development of self-injury will be discussed in more detail in Part 3. However, it is important to note that repetitive behaviours are also associated with other behaviours, such as aggression, and as such repetitive behaviours are unlikely to be uniquely linked to self-injury.

Impulsivity

Impulsivity is defined as when someone's inhibition is impaired due to a cognitive difference (meaning they may display quite impulsive behaviour)[4].



The Operant Model

When considering who is most likely to show self-injury, it's important to consider *how* self-injury may develop. There is good research evidence supporting the operant model of self-injury which suggests behaviours can develop through a process of learning within the context of a person's environment. Within this model, it's thought that self-injury is used by an individual as a method of communication, with the first step to supporting and reducing self-injury being to try and understand the context and communicative reasons behind why a person may show self-injury.

See the later section on Operant Learning Theory within this guide for a detailed explanation of the operant model of self-injury.

Impulsivity can manifest in many ways, including a child struggling to wait for things or being upset when activities are delayed. Children with high impulsivity may find classroom settings and rules (such as sitting for long periods of time or raising their hand before speaking) particularly challenging. Recently, researchers have been interested in how impulsivity may relate to behaviours such as self-injury in children with intellectual disability, who are autistic or who have a genetic syndrome. So far, evidence suggests that children who are more impulsive are more likely to show self-injury, with impulsivity predicting the likelihood of self-injury over 10 years (8). One reason that impulsivity and self-injury may be associated is linked to broader ideas around behavioural control. Children who display self-injury and are also highly impulsive may find that their self-injury is more likely to be triggered by particular environments or tasks (such as a classroom setting or particular part

4 For more information on cognitive differences, please see the recently published Cerebra Parent Guide (30).

of a routine). The role of the environment in the development of self-injury will be discussed further in Part 3. It's also thought that for children who are more impulsive, once they begin to show self-injury they may find it more difficult to stop or 'put the brakes' on this behaviour.

Poor Sleep

Poor sleep is difficult to define, but can include issues with the quality, timing and duration of sleep (for example, not getting enough sleep or struggling to sleep at appropriate times), as well as specific sleep disorders such as parasomnias (strange sleep behaviours) or sleep-related breathing disorders. Sleep is important for every aspect of wake, and it is likely that persistent poor sleep impacts all daytime behaviour. Research suggests that children and adults who experience poor sleep may be more likely to show self-injury (9, 10). These studies have mainly focused on individuals who do not have intellectual disability, but there is some evidence that individuals with intellectual disability who show self-injury sleep less and have more variable sleep than individuals with intellectual disability who do not show self-injury (11). One reason that sleep and self-injury may be linked is because tiredness can make difficult tasks or unpleasant situations more difficult or unpleasant. For an individual with intellectual disability, self-injury may function as a way of communicating that they would like a change to their environment. The role of the environment in the development of self-injury will be discussed further in Part 3.

Part Three – Why does my child self-injure?

In this section, we'll consider some of the known causes of self-injury with a particular focus on how self-injury might develop and be maintained. These are important things to consider when trying to support someone who shows self-injury and should always be considered alongside interventions to reduce behaviours (covered in Part 5 of this guide).

Pain and Discomfort

The most important cause to consider when trying to understand a person's self-injury is the possibility that they may be experiencing pain or discomfort. When talking about pain or discomfort, we mean potential internal sources of pain (such as an ear infection or reflux) rather than pain or discomfort directly caused by the self-injury (although this is also important to consider). Research highlights that people who have intellectual disability are significantly more likely to experience a range of health problems that may lead to pain or discomfort (12). Some examples include skin conditions, gastrointestinal issues or reflux, and respiratory conditions. Although these health conditions may not impact all people with an intellectual disability, health conditions are more likely to go undetected and untreated because of difficulties in the identification and diagnosis of health problems for people with intellectual disability. It can be really challenging to identify if a person is in pain or discomfort, particularly if they also have intellectual disability or speak few or no words. It may be difficult for them to communicate their pain in the ways we may typically expect, such as responding to questions such as 'where does it hurt?' or 'is it a sharp pain or an ache'? It can also be really challenging for people with intellectual disability to identify the pain themselves, or distinguish it from other internal states.

There is research evidence to suggest that untreated pain may be associated with the development and maintenance of behaviours such as self-injury (13), therefore it is important to consider pain or discomfort first when trying to understand the cause of a person's self-injury.

When considering pain or discomfort, it might be helpful to think about the topographies (or types) and location of self-injury as a starting point. For example, some children may show self-injury at the site (or location) of the pain itself, perhaps hitting their ear when they have an ear infection. In these instances the self-injury may be a direct attempt to try to remove or reduce the pain the child is experiencing. However, there are other links between pain and self-injury, such as 'gate control' theories of pain (14). Here, it is suggested that people may show self-injury to relieve pain (for example, a child experiencing reflux may pull their hair), with acute signals blocking chronic signals. Through pain-gating, self-injury at any location may relieve in the short-term pain or discomfort from a part of the body.

Pain or discomfort and self-injury – how to know if a person might be in pain and what to do

You may find these resources helpful for assessing pain and advocating for your child

Signs and identification – As discussed, people with intellectual disability or who speak few or no words may find it difficult to communicate if they are in pain. Some important things to consider are a person's typical vocal sounds, social behaviours, facial expressions, activity levels, eating and sleeping, all of which have been found to be important to the detection of pain in children with a severe intellectual disability. Free tools to help you consider pain through behaviours are:

- The Non-Communicating Child Pain Checklist (15) – a checklist specifically developed to be completed by carers of children with a severe intellectual disability to help professionals identify pain.
- The FLACC (16) – An infographic that allows parents, caregivers or professionals to observe a person in their own environment and identify behaviours that may be related to pain or discomfort.
- The BeWell Checklist (17) – A resource to help you consider why a person may be experiencing a range of behaviours, with pain or discomfort as one of the possible explanations.

Be alert to health problems – Remember that people who have intellectual disability are more likely to experience a range of health problems. Be alert to any signs or changes in the person you care for, particularly in mood, sleeping, eating, sociability, facial expression, activity, posture or vocal sounds made – this may be enough to warrant a consultation with a GP.

Seek treatment and advocacy – Unfortunately, some individuals with 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 intellectual disability. A lack of knowledge regarding health conditions in people with intellectual disability can also cause healthcare professionals to perceive ill health in this population as inevitable, when in reality 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 resources - 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-andinformation/guides-for-parents/pain-in-children-with-severe-intellectual-disability-a-guide-forparents/

Learning Theory

Learning theory describes how learning can occur via positive or negative reinforcement. The theory suggests behaviours are more likely to occur again in a particular context (an antecedent condition) if they are followed by a reinforcing consequence. Antecedents can be related to the environment, or related to internal states such as being tired or anxious. Researchers and clinicians have been interested in learning theory as it provides a possible explanation as to how self-injury might gain a function and how it might carry on (be maintained) over time. The antecedent, behaviour, consequence or 'ABC' model is a really useful tool to help us unpack the potential patterns that may surround and reinforce a person's self-injury (see Part 4 for specific examples of the ABC model in relation to self-injury and Appendix A for a blank ABC chart to complete in relation to your child's self-injury). In this model, the 'ABC' have specific definitions;

- **Antecedent** – Also sometimes known as a 'trigger'; this is the event that occurs before the self-injury. For example, this could involve a teacher working with a child on a particular task.
- **Behaviour** – For the purposes of our understanding, this is the self-injury (but can be any behaviour).
- **Consequence** – This is what happens after the behaviour occurs - an action or response that follows a person's behaviour. For example, this could involve a teacher removing the task an individual found aversive.

There is good scientific and clinical evidence for learning theory explanations of self-injury. This evidence tells us that self-injury is often a learned behaviour that doesn't happen at random. Often self-injury will be more likely to occur in the future in the presence of particular antecedents because the self-injury has been at least sometimes followed by a reinforcing consequence.

Of course, different children will find different things unpleasant or rewarding but children with intellectual disability may have some things in common they find difficult. In these cases, there are a number of ways that learning theory can explain the presence and maintenance of self-injury. The main ways are through:

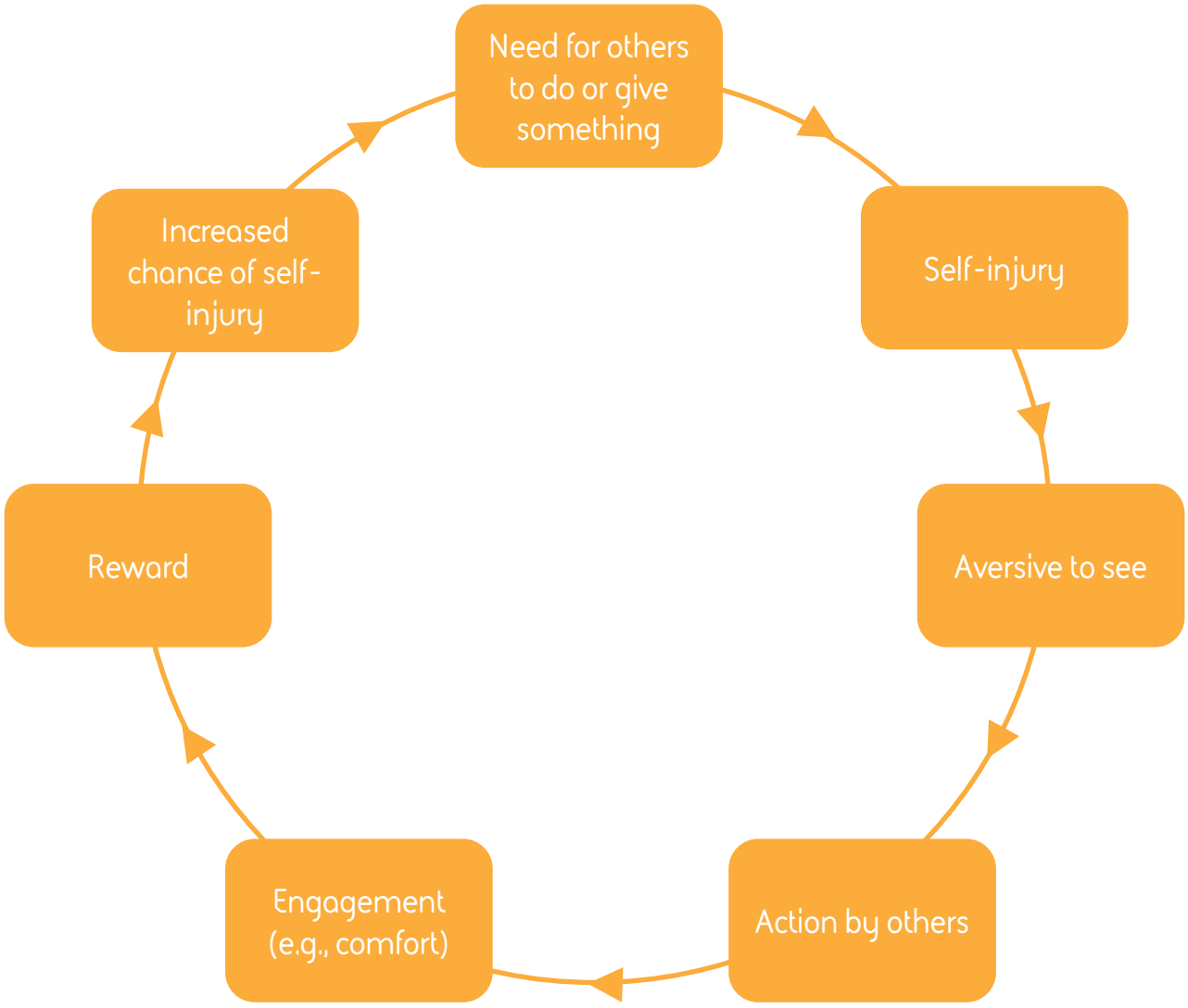
Positive reinforcement refers to the process that happens when a consequence adds something that the individual child likes, such as gaining the attention of a preferred person, being comforted, or perhaps access to a desired object (e.g., a toy), following a behaviour. The more times that these reinforcing consequences (adding something the child likes) follow the behaviour (self-injury) in particular situations or contexts, the more likely the same behaviour is likely to occur in future in the same or very similar circumstances.

Negative reinforcement refers to the process that happens when a consequence takes away something that the individual child dislikes, such as a demanding academic task at school or something that other children may like (e.g., social contact), following a behaviour. The more times that these reinforcing consequences (taking away something the child dislikes) follow the behaviour (self-injury) in particular situations or contexts, the more likely the same behaviour is likely to occur in future in the same or very similar circumstances.

1. The responses of others to the behaviours

Other people can, often unintentionally, reinforce self-injury in multiple ways. For some children, social contact with other people can be highly rewarding and if this social contact follows self-injury this may increase the likelihood of self-injury occurring again in similar situations due to positive reinforcement.

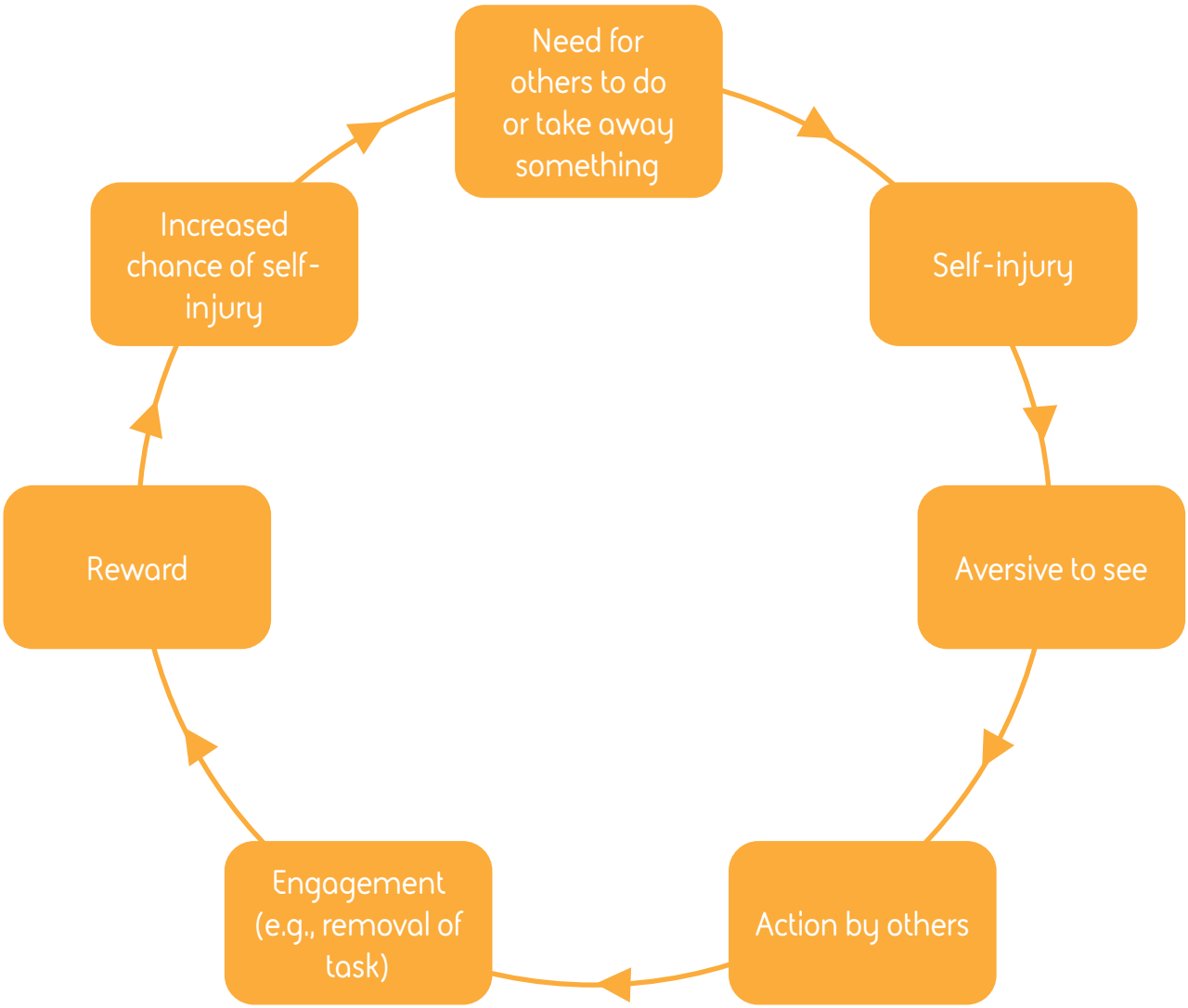
Figure 2: An example of how social contact can positively reinforce self-injury.



Once this process has occurred a number of times, a child will very quickly learn to self-injure in particular situations to gain rewarding attention from another person. This is not to say that the child necessarily intends to injure themselves or intends to gain the attention of someone else. It is an entirely natural process, whereby self-injury 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

The actions of other people can equally lead to self-injury through the process of negative reinforcement. For example, if a child perceives some sort of social contact as unpleasant or aversive, particularly when it involves an unwanted demand, and this is removed in response to self-injury, this may make the self-injury more likely in the future. A common demand many parents, caregivers or professionals can relate to is the presentation of a task that a child may find difficult, boring or unpleasant, such as brushing their teeth.

Figure 3: An example of how social contact can negatively reinforce self-injury.



It's important to remember that these reinforcement processes can also interact with other factors. There is some evidence that some short- or medium-term factors can influence or set the scene for the learning process. These factors include things like fatigue, hunger and pain. For example, children with intellectual disabilities may experience demands to be more aversive if and when they are in pain, are tired or hungry. Because the demands are experienced as more unpleasant, self-injury is even more likely to occur when these background factors are present. The same argument can be made for positive reinforcement; attention from others, for example, might be more reinforcing when someone is tired or in pain (3).

2. Sensory stimulation

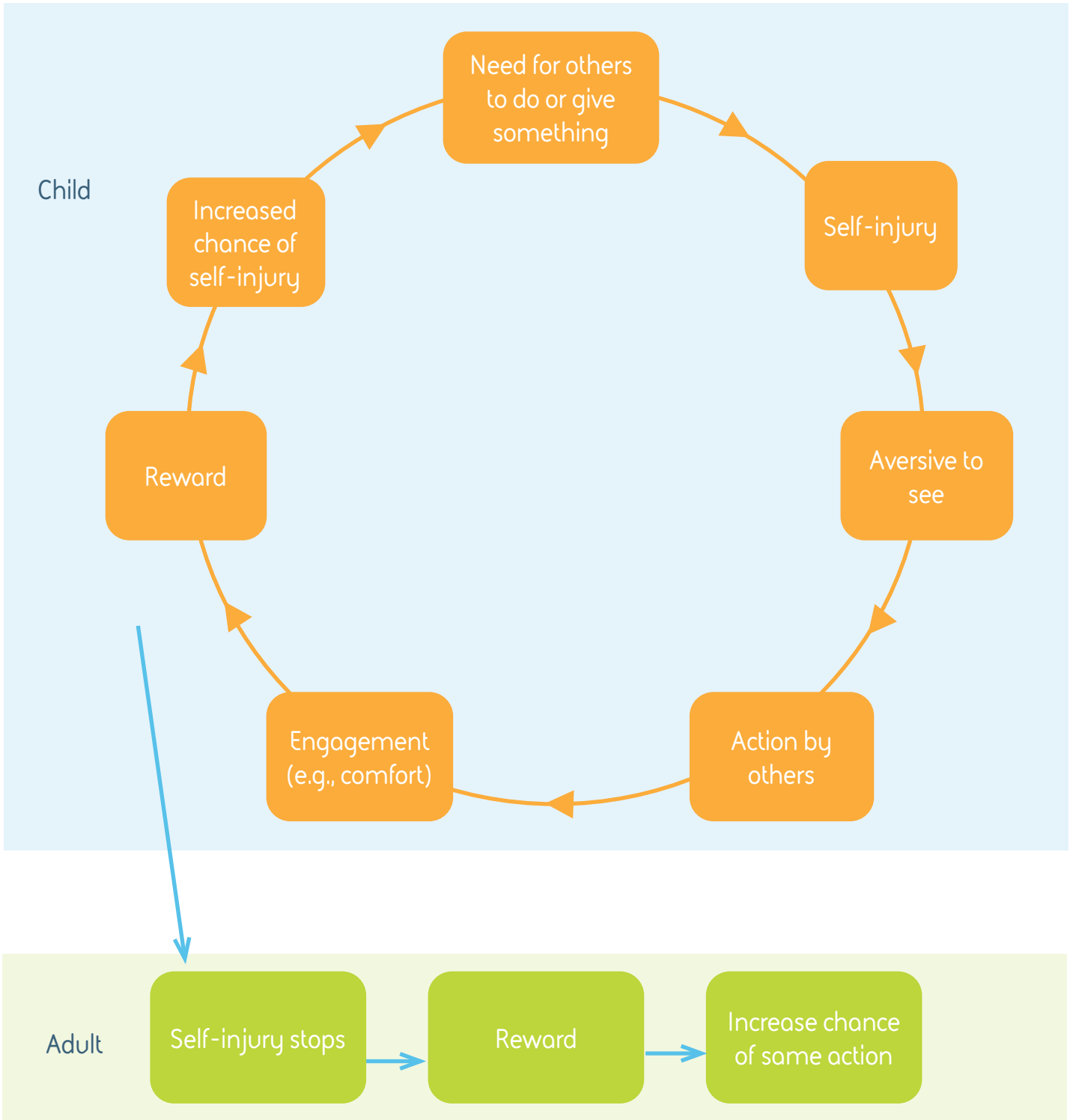
It is thought that for some children, the physical stimulation provided by self-injury might be perceived as pleasurable and perhaps make self-injury more likely to occur through positive reinforcement.

Example – Some children with severe to profound intellectual disabilities have poor vision and hearing and may therefore receive little or very distorted sensory stimulation. Eye poking, a form of self-injury, provides sensory stimulation that children can find pleasant. This is because it leads to bright flashes when the nerve cells in the eye are physically pressed. A child may be engage in eye poking perhaps when they lack other stimulation, this leads to the reinforcing sensory stimulation, which leads to more eye poking in the future in the same situation.

3. Mutual reinforcement.

We've now discussed both positive and negative reinforcement and how a particular chain of events can lead to a reinforcing outcome for a person. But it's important to consider that for those around a child showing self-injury, this chain of actions can be equally reinforcing. In Figure 4 you can see the initial cycle of positive reinforcement we described earlier, with the addition of the negative reinforcement a parent or caregiver might also receive as a result of responding to the self-injury. Over time, and unintentionally, these cycles can get locked together in a process known as mutual reinforcement. It is important to acknowledge the role of mutual reinforcement in the maintenance of self-injury, especially when considering which intervention strategy to try (see Part 5).

Figure 4: Mutual reinforcement cycle of self-injury



It is worth remembering that these processes do not describe every outcome that might occur in a real-life setting. For example, what happens if the other person does not make a reinforcing response to the self-injury? Under these circumstances, the child is likely to continue self-injuring until the consequence or a similar consequence happens. As the self-injury continues the other person may try more things until they eventually hit on the reinforcing response and then the child will stop or reduce the self-injury. In this way the adult is inadvertently 'taught' by the child precisely how to reward the self-injury.

Example 1

Eden is 9 years old and lives at home with her parents and one brother. She was diagnosed with autism at age 7, and is able to communicate using short sentences. She loves to go on walks with her dog, take part in art and craft activities and bake. She has shown self-injury for the last year in the form of hitting her legs and pressing on her eyes with her fingers.

Background Information

Eden's parents noticed that she tends to show self-injury by hitting her legs either when her favourite colouring book has been taken away, or when she is alone for brief periods of time. Eden's school teacher also noted that Eden tends to hit her legs after the colouring book has been removed. Eden's teacher also noticed that she engages in eye pressing after a classroom task has been set.

Both Eden's parents and teacher completed an ABC chart (Part 4). This confirmed a pattern of leg hitting following periods of low social attention and the removal of the colouring book, and eye pressing following task demand both at home and at school.

What can be done to help?

Eden's parents or teacher may avoid presenting Eden with known triggers of self-injury, for example, they may allow Eden to have constant access to her colouring book, and always provide social contact. However, this may not be useful or possible long-term.

- *Communication strategies* – it may be helpful to teach Eden alternate communication strategies to communicate her wants and needs. For example, Eden could be taught to respond verbally with a simple sentence, using the Picture Exchange Communication System (PECS) symbols or makaton signing, or with a big mack (a red button with a pre-recorded message). This would help Eden to communicate her desire to take a break from a task, for example.
- *Visual schedules* – scheduling may be useful in making tasks more predictable for Eden. Verbal or visual cues, such as 'now and next' boards, may be helpful guides to inform Eden when low social attention may occur, preferred items may be removed, and tasks be presented.

Interactions between learning processes and autism characteristics and genetic syndromes

So far, we've discussed in detail the learning model and how it may lead to an increased likelihood of self-injury obtaining a function over time. But, once again it's important to consider how this might operate within particular contexts, such as for children who may be autistic or have a genetic syndrome. As previously mentioned, people who are autistic and/or have a genetic syndrome are more likely to show self-injury, and research suggests that in these instances an increased likelihood may be additionally influenced by an environment (as through the operant model previously described) (18). For example, in Lesch-Nyhan, a syndrome where self-injury is very common (indicating a strong genetic influence in self-injury), the environment has been shown to still have an impact on the frequency of self-injury. Children with Lesch-Nyhan syndrome are more likely to self-injure during periods of low social interaction. More recently, researchers have also identified motivational differences that are important too, so that children with particular genetic syndromes appear to have a strong motivation for particular types of reinforcers (19). For example, children with Smith-Magenis Syndrome appear to have an unusually strong motivation for social contact, so that they show more frequent self-injury when social contact is not available. In contrast, escape from social contact has been demonstrated as motivation for self-injury in Fragile X, Cornelia de Lange and Rett syndromes.

Self-restraint

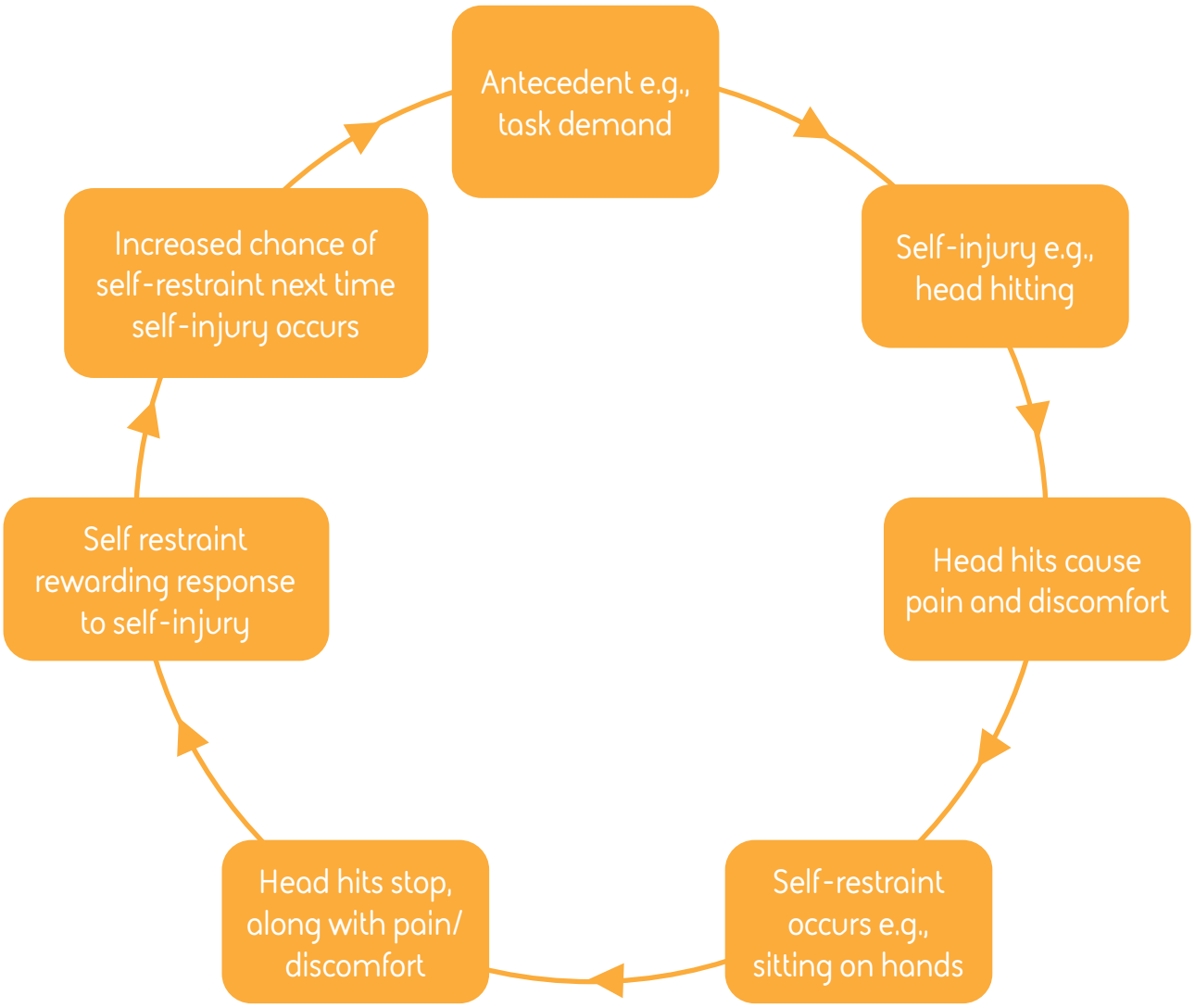
Self-restraint refers to when a child intentionally restricts their own body movement, and in many cases this restriction may function to stop their self-injury. There are four categories that describe the different ways a child may self-restrain:

1. Restricting movements using **clothing** or **materials**
    - For example, by pushing hands in pockets, pulling sleeves over hands or wrapping material such as blankets or towels tightly around the body
2. Restricting movement using **own body**
    - For example, by sitting on hands or sitting or lying in a position that restricts the movement of arms or hands
3. Restricting movement using **objects**
    - For example, by clinging onto an object without playing with, manipulating or using it, or pushing hands into tight spaces like sofa cushions
4. Showing a **preference for imposed restraint**
    - For example, by asking or gesturing for someone to hold hands or arms, or seeking a mechanical restraint device

Some self-restraint behaviours are common across all groups of people, including typically developing children and adults. However, we know that self-restraint is common in autistic children and children with intellectual disability. A recent study reviewed all of the existing survey data on self-restraint, and found that over one third (39%) of autistic individuals with or without intellectual disability self-restrain (20). We also know that children who show self-injury are more likely to show self-restraint than children who do not self-injure (21), and so we are particularly interested in understanding self-restraint shown by children who self-injure.

There are many reasons why a child may show self-restraint. Self-restraint behaviours may bring comfort, warmth or enjoyable sensory input (22). However, researchers have noticed a close link between self-injurious and self-restraint behaviours (23), suggesting the two behaviours might sometimes be related. One way we can understand this is through the learning theory approach (see Part 3). Let's take an example where the self-injury is head-hitting and the self-restraint is sitting on hands. We may see that the child head-hits in response to a triggering antecedent, but then soon after they sit on their hands – the self-restraint replaces the self-injury. Any pain or discomfort caused by the self-injury stops when the self-injury does, and this removal of discomfort acts to negatively reinforce the self-restraint. This means the next time self-injury occurs, self-restraint is also more likely to occur. This cycle of reinforcement is shown in Figure 5.

Figure 5: How self-injury and self-restraint may develop



Researchers are interested in whether self-restraint may occur in response to more impulsive self-injury (e.g. (21)) or serve as a protective tool against self-injury. Self-restraint may become concerning when it occurs most or all of the time, as prolonged self-restraint may reduce ability to engage in adaptive functioning skills (24), and seeking constant physical restraint may impact muscular development and physical mobility (25,26).

You may be able to identify self-restraint that is related to self-injury when:

- The child initiates self-restraint without being told or encouraged to
- The self-restraint is incompatible with self-injury, such that the child is unable to self-injure while self-restraining
- An object, item or device appears to have control (known as 'stimulus control') over the child's behaviour, such that they will not self-injure when wearing or holding this item (this item may or may not restrict child's movement)
- The child shows preference for the behaviour, such that they engage in self-restraint (including seeking restraint devices) most or all of the time, and become anxious and/or show self-injury when they are no longer able to self-restrain.

Therefore, self-restraint behaviours alone may not be concerning. However, if self-restraint appears to occur alongside self-injury and becomes a preferred behaviour, it is possible the self-restraint is functioning to manage the self-injury (see Part 5 for more on the use of restraint to manage self-injury).

To summarise, it is therefore really important to consider the individual causes of self-injury outlined above as part of the picture, rather than the whole picture. Pain, the operant model and person characteristics (such as if a person is autistic or has a genetic syndrome) can all interact with each other when it comes to understanding self-injury. Though these characteristics do not guarantee a person will show self-injury, they can increase the likelihood of someone showing self-injury so they are important to consider.

Example 2

Jamie is 6 years old and lives at home with his parents and two sisters. He was diagnosed with a moderate intellectual disability at age 5. He loves to swim, listen to music and go the aquarium. He has shown self-injury for the past month.

Background Information

Jamie has recently started showing self-injury in the form of forcefully hitting his right ear with his fist. The self-injury seems to occur sporadically throughout the day, and Jamie's parents have noticed the self-injury is happening more often. Jamie's parents recorded what happens before and after the self-injury using an ABC chart (Part 4), and cannot see a clear pattern of triggers or consequences, except that the self-injury almost always occurs at the site of the ear. So, Jamie's parents took him to the GP to investigate any medical problems with Jamie's ear. Results revealed Jamie had an ongoing ear infection in his right ear (the site of the self-injury).

Less often, Jamie shows self-injury by biting his hands. Jamie usually self-restrains after biting his hands, for example by sitting on his hands or trapping them under his jumper.

What can be done to help?

- Jamie was immediately given treatment for his ear infection, and Jamie's parents quickly noticed a reduction in self-injury.
- **Pain** – always consider pain as a cause for self-injury that occurs out of the blue
- **Self-restraint** – Keep an eye on the self-injury and self-restraint (i.e., hand biting followed by restricting hand movement). The display of both behaviours may not necessarily be cause for concern. However, if these behaviours become more frequent, last longer, and Jamie becomes anxious or upset when he is unable to self-restrain, then self-restraint may be becoming a preferred behaviour. It may then be appropriate to explore possible functions of the self-injury and teach alternative communication strategies.

Part Four – Where do I start if my child shows self-injury?

In this section, we'll cover ways of assessing self-injury which can be a useful place to start before intervening. We'll consider some of the principles introduced so far within this guide and provide some useful ways they can be put into practice when assessing self-injury.

However infrequent a person's self-injury is, it is important to establish what the cause might be before moving on to intervention. A useful starting point for establishing cause is the PEACE acronym; **P**ain, **E**nvironment, **A**nxiety, **C**ontrol and **E**xhaustion. Below, we'll consider each of these areas using the information we've learnt throughout this guide.

Peace
Environment
Anxiety
Control
Exhaustion

P-Pain

Unfortunately, as discussed, individuals with intellectual disability are more likely to experience a range of health problems and consequently pain and discomfort. Therefore, potential health problems should always be ruled out first. A consultation with the person's GP should be sought as soon as possible, particularly if self-injury has begun recently and suddenly, and seems unrelated to the environment around the child. The tools in Part 1 can help you to identify if the person you care for may be showing signs of pain and discomfort.

E-Environment

Having ruled out pain as a potential cause of self-injury, environmental factors should then be considered. You may be familiar with methods such as an ABC chart that professionals may ask you to complete to try and understand more about a person's self-injury. This method allows us to consider detailed information about the environment, specifically what happens before, during and after an episode of self-injury. ABC charts are straightforward to complete and can be used without the support of a professional as a starting point to understand more about a person's behaviour.

The charts allow a reasonably detailed assessment of the cause of self-injury, including its Antecedents (what happens before the self-injury), Behaviours (the self-injury) and Consequences (what happens after the self-injury).

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, or being presented with a difficult task. Antecedents can be viewed as a trigger for the behaviour, just as being hungry triggers food-seeking behaviour.

Behaviours: these are the self-injury shown by the child. The self-injury may occur in one or more form.

Consequences: these are the events, behaviours or sensations that immediately follow a behaviour. In the examples in Figures 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.

It is important to understand that sometimes different types of self-injury may occur just after different Antecedents, and may be followed by different Consequences. Other times, different types of self-injury may occur just after the same Antecedents, and may be followed by the same Consequences. This is why it is helpful to keep a record of these ABCs to help understand a person's behaviour. It is important to collect as much information as possible to form a comprehensive picture of an individual's behaviours. It may also be helpful to work with a relevant professional to interpret information collected. Figure 6 includes a completed ABC chart and describes the types of reinforcement that appear to be important. A blank ABC chart is included for your use in Appendix A.

	Antecedents	Behaviour	Consequences
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 distacts 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 to another room
7	Child is playing on their 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 child's face	Child bites hand	Parent goes into another room

- Items 1 and 7 are probably examples of **sensory reinforcement**. There is no obvious consequence in terms of behaviour by another person, but the internal stimulation from the behaviour may be reinforcing for the child.
- Items 2 and 9 are probably examples of **positive social reinforcement**, as the self-injury 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-injury results in the demand being removed (shown 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 attention), as the self-injury results in access to food (item 4) or a preferred toy (item 8).
- Items 5 and 10 are examples of **negative reinforcement by avoidance of social contact** or tasks, as the self-injury results in the adult moving away from the child.

It's best to complete an ABC chart following any incidents of self-injury observed during a typical period of time where an individual is likely to show multiple examples of self-injury (this may be over a week or a month depending on the individual). 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 move towards interventions to try to reduce the self-injury (see Part 5). 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 during the intervention would indicate that you have successfully identified the causes of the self-injury and modified the environment accordingly.

Clinical Psychologists and Applied Behaviour Analysts have a range of specialist techniques in addition to ABC charts 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 Behavioural Function (27) and the Motivation Assessment Scale (28). Natural observations are another method commonly used, with the child being observed across a range of settings (e.g. at home and school).

A-Anxiety

Another important area to consider when trying to further understand a person's self-injury is anxiety. This is our built-in response to danger and can lead to numerous physical and emotional changes internally. For children with intellectual disability who may have difficulties communicating their internal feelings, anxiety can present slightly differently. There may be changes to behaviour (perhaps an increase in repetitive behaviours or self-injury), physical signs such as muscle tension, visible distress or an increase in behaviours that are challenging motivated by wanting to escape from a specific situation. For more information on the signs of anxiety in people with an intellectual disability, as well as assessment and intervention strategies, please visit our Cerebra Anxiety guide (29).

C-Control

Cognitive control is another important factor when trying to fully understand a person's self-injury. Over the past decade, the links between impulsivity and self-injury have become clear with robust evidence confirming their association. Researchers have found that children who are more impulsive are more likely to show self-injury, and that higher levels of impulsivity can predict self-injury ten years later (7,8). It is thought that children who have difficulties with impulsive behaviour may show self-injury more easily in the presence of an antecedent, and find it more difficult to stop the behaviour when a consequence is presented. For more information on cognitive differences in people with an intellectual disability, as well as assessment and intervention strategies, please visit our Cerebra Cognitive Differences guide (30).

E-Exhaustion

Children and adults who show self-injury may be experiencing exhaustion. This could be from a short-term period of sleep disruption (for example, when travelling for a holiday), or a longer period of persistent poor sleep. Initial findings from our own study of sleep and self-injury in autistic children with intellectual disability suggest that there is a link between the severity of self-injury children show and the amount of sleep they get on average in a week (31).

Feeling exhausted can make individuals more likely to show behaviour in response to environmental triggers (Antecedents), even if these would not be as likely to trigger behaviour on days when the person has slept well. Feeling tired may also make Consequences seem more reinforcing. For example, evidence from a small number of studies of children and adults with intellectual disability suggest that when sleep deprivation occurs, individuals are more likely to show self-injury in response to being asked to do a task (32,33).

In some cases, exhaustion may mean that children and adults show self-injury even in situations where they would not usually (32). Our study (31) found that children who had less efficient sleep (because they experienced difficulties falling asleep or extended night waking) were more likely to show more frequent self-injury.

Therefore, if you notice a sudden change in your child's behaviour that does not appear to be related to pain or discomfort, it is a good idea to consider whether they may be experiencing poor sleep. The best way to do this is to keep a diary about their sleep and behaviour (see Appendix B for an example diary). This will help to identify whether they may be struggling to fall asleep, waking frequently or for extended periods overnight, or getting up very early for the day. If you keep a record of your child's self-injury each day, you can start to look for patterns.

For example, you may notice that your child shows high levels of self-injury on a Friday but not on a Tuesday. This may be because they have slept poorly on Thursday night, but better on Monday night. It is also important to consider whether there may be a cumulative effect of poor sleep. For example, your child's self-injury may be worse on the Friday because they have slept poorly for several nights in a row.

If you think that poor sleep may be the cause of your child's self-injury, there are lots of strategies you can try to improve their sleep. These are outlined in the Cerebra Sleep Guide (34).

Part Five-What can I do if my child shows self-injury

So far, we've discussed some of the known causes of self-injury, who might be most likely to show self-injury and how you can begin to assess self-injury. In this section, we'll cover some interventions for self-injury that may be helpful.

Before we begin any intervention for self-injury, we must first have a good understanding of the behaviour which will help us to identify any positive improvement or negative change. Working through the assessment section previously outlined is a good place to start, and there are two additional important things to bear in mind

1. 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 settings, 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.

2. 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 could be to reduce or remove adult attention following an episode of self-injury. However, reducing or removing a reinforcing consequence can sometimes briefly increase the frequency and severity of self-injury. Therefore, if the self-injury demonstrated by the child poses a risk of serious injury, this is not the right course of action. 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 or speaking at all whilst doing so. It's important that intervention for self-injury is delivered with the goals of both removing or reducing self-injury, but also supporting an individual to find appropriate means to access the functions that the self-injury once served.

Interventions[5]

Now you have an accurate understanding of the frequency of self-injury, and have considered the safety of an individual, we can consider some types of interventions that may be useful. 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, you should contact your GP and request a referral to your local service.

5 It is recommended that all interventions for self-injury are done in consultation with appropriate professionals and support.

Replacing self-injury with more adaptive behaviour

Replacing self-injury with more adaptive behaviour is a method of intervention that aims to reinforce appropriate behaviour which serves the same function as self-injury (35). For example, in some of the examples outlined in Figures 2 and 3, this would involve replacing self-injury with a more desirable behaviour that communicates the same need (e.g., signs, picture boards, vocalisations). This can and should be used alongside limiting the normal reinforcement process for self-injury 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 alternate 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 which has been shown to be a successful method for teaching children with a range of intellectual disabilities a functionally equivalent behaviour is called Functional Communication Training. For example, a child that shows self-injury when alone would be taught to communicate a need for attention, such as by pointing to a picture of their caregiver on a picture board. This behaviour, but not self-injury, would be reinforced with adult attention. The precise form of Functional Communication does not really matter. 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 another method that can be an effective way of reducing self-injury. There are several variations of this principle which can be successfully applied (36). 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. Over time, the frequency of self-injury therefore reduces.

Reducing the aversiveness of antecedents

Reducing the aversiveness of antecedents for a particular person is an effective way to reduce the occurrence of self-injury. To assess the nature of the antecedents, record the frequency of self-injury after various antecedents and compare the nature of these antecedents. Remember, a higher frequency of self-injury after one task than another may indicate that the child you care for finds this antecedent more aversive. If it is difficult to decipher what it is about the antecedent that makes it aversive to the child, modify it in small stages, changing one element of it at a time. Self-injury should decrease when you have effectively made the task less aversive. Making the antecedents less difficult is often helpful. For example, if specific tasks are challenging, 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).

Reducing reinforcement (and some 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. However, to be at its most effective, this type of intervention must be conducted consistently every time self-injury is demonstrated, and ethically it should be combined with helping the child to learn a new functionally equivalent replacement behaviour. Everyone working with the child must be made aware of what is likely to trigger self-injury and how best to respond 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 previously learned response. This is called an extinction burst. At this point, providing reinforcement such as adult attention or removal of a task would lead to the accidental reward of more severe forms of self-injury, which can be dangerous and distressing to see. It's therefore suggested that if this approach is used, it's combined with other methods in this guide and the consultation of an experienced professional.

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 may sometimes be advisable when self-injury is severe, in order to avoid permanent injury, but only after all assessments and interventions have been tried and the use of restraints should be continually reviewed (37). 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 autistic children and children with genetic syndromes. Once again 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, 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 those who are not trained might find difficult to detect. They can also offer support to try and break the reinforcement cycle and 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 have been widely used to treat self-injury in individuals with intellectual disability, including those typically used to treat anxiety, depression, epilepsy and psychosis. The evidence base for prescription of these drugs is, however, unconvincing and there is mixed opinion within the field as to the effectiveness of these medications (38). 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 can be small (39). 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.

'PEACE'ing it all together

The PEACE acronym mentioned within Part 4 can be a really useful tool to support a person with self-injury through specific interventions. See some useful ideas and resources below relating to each of the individual PEACE sections. The Cerebra Be Well Checklist is a really brilliant resource that contains further information to support parents and caregivers in a structured way (18,40).

Pain – If you suspect a person is in pain, this must be the first thing that is addressed prior to any other intervention for self-injury. A consultation with the GP should be sought as soon as possible, particularly if self-injury has begun recently and suddenly, and seems unrelated to the environment around the child. The Cerebra Pain Guide provides a comprehensive overview of how to identify if a person is in pain and various strategies for support (42).

Environment – An ABC chart is a really useful tool for considering the impact of the environment on a person's self-injury. Patterns within an ABC chart 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 move towards interventions to try to reduce the self-injury. 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 during the intervention would indicate that you have successfully identified the causes of the self-injury and modified the environment accordingly.

Anxiety – Given anxiety is our bodies built in response, if you recognise changes to a person's body, thinking pattern, emotions or behaviour, it's important to consider that a person may be anxious. For more information on the signs of anxiety in people with intellectual disability, as well as assessment and intervention strategies, please visit our Cerebra Anxiety guide (29).

Control – Over the past decade, the links between impulsivity and self-injury have become clearer. It is thought that children who have difficulties with impulsive behaviour may show self-injury more easily in the presence of an antecedent, and find it more difficult to stop the behaviour when a consequence is presented. If you believe this is the case for the person you care for, you can find more information on cognitive differences in people with intellectual disability, as well as assessment and intervention strategies, in the Cerebra cognitive differences guide (30).

Exhaustion – Children and adults who show self-injury may be experiencing exhaustion. If you notice a sudden change in your child's behaviour that does not appear to be related to pain or discomfort, it is a good idea to consider whether they may be experiencing poor sleep. The best way to do this is to keep a diary about their sleep and behaviour (see Appendix B for an example diary). This will help to identify whether they may be struggling to fall asleep, waking frequently or for extended periods overnight, or getting up very early for the day. If you keep a record of your child's self-injury each day, you can start to look for associations between sleep and daytime behaviour. You can find lots of strategies you to improve a person's sleep outlined in the Cerebra Sleep Guide (34).

Summary

In summary, for children with intellectual disabilities and their parents and carers, self-injury is a really important issue. Self-injury can be highly prevalent and persistent for some groups of people. Children with specific genetic syndromes, a more severe level of intellectual disability, children who are autistic and impulsive or who show repetitive behaviours appear to be at greater risk of showing self-injury. However, it's really important to note that this does not mean self-injury is inevitable for any child with intellectual disability. This guide aims to provide parents and caregivers with some helpful strategies to further understand and potentially reduce self-injury.

As highlighted with the PEACE acronym, the first step to assess anyone showing self-injury is to consider if they may be in pain, through observations and medical assessments where appropriate. Following this, parents and caregivers should work their way through the remaining areas of environment, anxiety, control and exhaustion as discussed. The Cerebra Be Well Checklist is a really brilliant resource that can help parents or caregivers go through this process in a structured way (17,40). Completing an ABC chart and documenting the frequency of self-injury are both really helpful pieces of evidence to bring to any professionals involved in your child's care. Remember that as a parent or caregiver, you are the expert and spend the most time with your child so you are in a good position to begin to document any patterns of behaviour you notice.

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Glossary

Self-injury - Non-accidental behaviours initiated by a person which cause that individual harm (e.g. head banging, hand biting, scratching).

Repetitive behaviours - A wide range of behaviours which are characterised by frequency of repetition (how often they are repeated), inappropriateness (whether they are inappropriate to the context/ setting they are shown in) and invariance (lack of change in the behaviours shown). Such behaviours might include body rocking, hand flapping, lining up or organising objects or repetitive questioning.

Topography – The form or shape of a behaviour, also referred to as how a behaviour looks.

Challenging behaviours - Any behaviour that could potentially cause injury to the individual (self-injurious behaviour) or to those around them (aggressive behaviour), or impact on the individual's day to day life by disrupting activities or restricting which activities are available.

Aggression - Non-accidental behaviours initiated by an individual towards another individual that cause the other individual harm or have the potential to cause them harm (e.g. kicking, hitting).

Destruction – The act of destroying something or the state of being destroyed.

Hyperactivity – Hyperactivity may look like a person having increased movements, impulsive actions or a shorter attention span.

Insistence on sameness – This refers to a persons preference to do or think about the same things over again. It can often be out of comfort but also out of compulsion.

Validated – A questionnaire is validated if it has been shown to provide reliable and accurate results. Analysis of the questionnaire also considers if the questionnaire is measuring what it intends to measure.

Reinforced - A behaviour is reinforced when there is a response to it which acts as a reward of some kind. This reward makes the behaviour more likely. For example when a child experiences social contact as rewarding, if a parent provides this in response to a night waking, the night waking is more likely to continue (i.e. it is reinforced).

Impulsivity – Impulsivity can be thought of as a persons desire to act often quickly or instinctively without thinking.

Function - What a behaviour 'does' for the person who is showing it, e.g. when a child shows self-injury when presented with a demanding task and the task is then removed, the self-injury is said to have the function of escaping a task demand.

Learning theory – This theory suggests behaviour is a result of learning from within the environment, and can be shaped by what happens after a behaviour is shown (the consequence).

Positive reinforcement – Positive reinforcement refers to the addition of something that increases the likelihood of a desired outcome, such as gaining the attention of a preferred person, being comforted, or perhaps access to a desired object. Overtime, if a behaviour predicts a desired outcome (for example showing self-injury consistently leading to the attention of a preferred person), a child may become more likely to show self-injury.

Negative reinforcement – Negative reinforcement (not to be confused with punishment which is very different) is understood in a similar way. Instead of a desired outcome occurring as a result of a behaviour, negative reinforcement refers to something unpleasant being removed as a result of

behaviour (for example, a school task being stopped).

Antecedent – An event or stimulus that precedes a behaviour.

Self-restraint - When a child intentionally restricts their own body movement, and in many cases this restriction may function to stop their self-injury

Anxiety - Anxiety and fear are our body's built-in response to danger. When we are anxious or fearful, our hearts beat faster and blood is directed to our muscles so that we are ready to protect ourselves from the danger by either 'fighting', 'fleeing' or 'freezing'.

Functional Communication Training - A differential reinforcement procedure that involves teaching a person an alternate response that leads to the same consequence and can therefore be used instead of self-injury.

Extinction burst – When the reinforcement of a behaviour (such as self-injury) is stopped, the behaviour can for a short period of time increase in intensity before disappearing.

Appendix A – Blank ABC Chart

	Antecedents	Behaviour	Consequences

Appendix B – Blank Sleep and Behaviour Diary

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday	Note anything unusual about the week? E.g. holiday, health problem...
Time woke up								
Time got up								
Occurance of self-injury 1 (Try to record ABC)								
Occurance of self-injury 2 (Try to record ABC)								
Occurance of self-injury 3 (Try to record ABC)								
Time put to bed								
Time fell asleep								
Night time waking (describe timings, behaviour and response)								
Anything else to note?								

About the Authors

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Caroline Richards, Professor and Senior Lecturer in Neurodevelopmental Conditions, is a Clinical Psychologist and Director of the Cerebra Network for Neurodevelopmental Disorders. Her research focuses on reducing negative clinical outcomes for individuals with neurodevelopmental conditions. A key focus of her research is to identify risk-markers for self-injury in children with neurodevelopmental conditions to understand what drives and maintains behaviours.

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Catherine Laverty is a Research Fellow at the University of Birmingham where she also completed her Masters and PhD. Catherine's PhD focused on exploring the impact of prematurity on social understanding.

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Dr Katherine Marlow

Katherine Marlow completed her PhD at the University of Birmingham. Katherine's PhD focused on understanding self-restraint and self-injurious behaviour in individuals with autism and/or intellectual disabilities. Her research interests include behaviours of concern, executive functions and measurement of behaviour.

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Chris Oliver is Emeritus Professor of Neurodevelopmental Disorders at the University of Birmingham. He trained as a clinical psychologist at Edinburgh University before completing a PhD investigating self-injurious behaviour in people with intellectual disability at the Institute of Psychiatry, London. His research focuses early intervention, behaviour disorders in people with severe intellectual disability and autism spectrum disorder, behavioural phenotypes in genetic syndromes, and neuropsychological and behavioural assessment for people with severe intellectual disability. He has published over 100 Peer-reviewed articles in scientific journals, was Editor in Chief for the Journal of Intellectual Disability Research and serves on a number of scientific advisory committees for syndrome support groups. Sadly, he supports Luton Town Football Club.

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