



Self-Injurious Behaviors in Individuals with Autism and/or Other Developmental Disabilities

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Introduction

Self-injurious behavior (SIB) is one of the most devastating and challenging-to-treat behaviors of people with an autism spectrum disorder or a related developmental disability. The types of behavior vary greatly, but they all can lead to tissue damage, ranging from mild (e.g., redness, bruising) to moderate (e.g., bleeding) to severe (e.g., fractures) (Edleson & Johnson, 2016). SIB is fairly common in individuals with Autism Spectrum Disorder, a study by Baghdadli et al. (2003) found that 50% of a sample of 222 young children (ages 6 and under) with ASD was reported to exhibit SIB, with 14.6% engaging in severe SIB (Handen et al., 2018). The majority of children were exhibiting these behaviors since their early childhood and they typically display this behavior daily over more than one time period (Akram et al., 2017). In addition, a large scale survey was conducted involving adults with intellectual disabilities that documented a prevalence rate of 14% for some form of self-injury. More recently, surveys have shown that these behaviors are more common in those with autism, with estimates as high as



50% in young children. In addition, adults with autism are more likely to engage in self-injury than those with intellectual disabilities (Edelson & Johnson, 2016).

Self-injurious behavior can present in a variety of ways and will typically look different for every child. SIB is considered a challenging or “aberrant” behavior. While aggressive behavior (i.e., headbutting, screaming, scratching, punching, etc.) is the more common conception of





challenging behavior, it may also include self-injurious behavior, inappropriate sexualized behavior, or damage to property (Hext et al, 2018). It should, however, be noted that individuals who engage in SIB are more likely to engage in aggressive behavior as well as disruptive and destructive behaviors. Lack of verbal communication, deficits in receptive and expressive language, significant social-skills deficits, and sleep disturbances have been associated with an increased risk of SIB (Edelson & Johnson, 2016).

Self-injurious behavior has the potential to cause extreme bodily harm for individuals with developmental disorders. In a study by Richards et al. (2012), among the most commonly reported behaviors, 15.9% of the sample were rated as moderate or severe on “Hits or Slaps Self” by both parents and teachers. The next most frequently reported behaviors were “Gouges/Eats Inedible Objects” and “Physically Harms Self” (Richards et al. 2012; Handen et al., 2018). It can, however, present in less damaging ways. Across the range of neurodevelopmental disorders, the expression and severity of SIB is variable and dependent on multiple factors, including diagnosis and individual differences. Head banging, skin picking, face slapping, and self-biting are a few examples of manifestations of the SIB phenotype in autism (Flowers et al., 2020). In addition to the potential of serious bodily harm, SIB can impede the development of appropriate adaptive skills and resultant quality of life (Minshawi et al., 2015).

A multitude of things can cause an individual to display self-injurious behavior. One of which could be the inability of an individual with ASD to efficiently and spontaneously communicate their wants and needs in a clear and consistent manner. This breakdown in communication is thought to be one of the reasons that individuals with developmental disabilities self-injure (Williams et al., 2018). When individuals display these behaviors, first-line recommendations include non-pharmacological strategies such as involving the parents and professionals in helping to soothe the person you are supporting, using toys and electronics for distraction, and using mitts on the individuals’ hands to limit self-injury. A helmet to protect the head can be used in patients with severe agitation and self-injury (Schweitzer et al., 2016). Further de-escalation techniques will be discussed later in the training.

AUTISM, HEAD BANGING AND OTHER SELF HARMING BEHAVIOR

WHAT TRIGGERS HEAD BANGING?

IN PAIN 	ATTEMPTING TO COMMUNICATE 
ATTENTION SEEKING 	SENSORY OVERLOAD 

CAN HEAD BANGING CAUSE BRAIN DAMAGE?

THEIR HEADS ARE DESIGNED TO HANDLE IMPACT FROM LEARNING TO WALK AND HEAD BANGING WILL RARELY CAUSE MORE TRAUMA THAN A SLIP AND FALL ACCIDENT AT THIS AGE. HOWEVER, AS CHILDREN GET OLDER, THEY ARE AT A HIGHER RISK FOR CAUSING LASTING DAMAGE.

HOW CAN I PROTECT MY CHILD FROM SELF-HARM?


YOUR PEDIATRICIAN SHOULD BE YOUR PRIMARY SOURCE OF INFORMATION ON HOW TO BEST HELP A HEAD BANGING CHILD. HE/SHE WILL BE ABLE TO DIAGNOSE THE EXTENT TO WHICH YOUR CHILD COULD INJURE HIM/HERSELF, HELP YOU IDENTIFY WHY YOUR CHILD HEAD BANGS, AND OFFER SOLUTIONS AND ALTERNATIVES FOR YOUR CHILD.

CAN AN AUTISM HELMET PROTECT MY CHILD?

PROVIDING YOUR CHILD WITH A MEDICAL HELMET AS PRESCRIBED BY YOUR PEDIATRICIAN AND PADDING AREAS OF YOUR HOME THAT YOUR CHILD TYPICALLY HEAD BANGS, ESPECIALLY ANY CORNERS OR UNEVEN SURFACES, WILL REDUCE THE RISK OF PHYSICAL INJURY OCCURRING.

TREATMENT FOR SELF INJURIOUS BEHAVIOR IN AUTISM

TREATMENT FOR YOUR CHILD CAN TAKE MANY FORMS AND WILL MOST LIKELY BE A PROCESS OF TRIAL AND ERROR. IN-HOME ACCOMMODATIONS CAN BE MADE TO HELP AN OVERSTIMULATED CHILD INCLUDING PROVIDING THEM WITH NOISE-CANCELLING HEADPHONES, ALLOWING HIM/HER TO REST IN A LOW-LIT OR DARK, TIDY, MONOCHROMATIC ENVIRONMENT, OR IDENTIFYING A FAVORITE PIECE OF CLOTHING.


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SIB Across the Lifespan

Self-injurious behavior can present differently depending on the age of the individual, and it can present at different points in life. Researchers report high rate of physically dangerous challenging behavior among children with ASD. They further indicated lack of awareness and sincere effort for early diagnosis and intervention on the part of stake holders. In addition, children with autism have been observed to be at a greater risk of developing SIB compared to those with other developmental disabilities (Akram et al., 2017).

SIB may also appear during puberty or increase in severity during puberty. While puberty is not always the cause of an increase in challenging behaviors, many parents report that the onset of adolescence in their autistic child is associated with the appearance of, or the increase in, disruptive behaviors, including aggression and self-injury. These changes in behavior have generally been attributed to the hormonal changes occurring during the teenage years. However, there have been no formal studies to examine this hypothesis among individuals with ASD (Edelson & Johnson, 2016). We will further explore other “causes” of SIB later in the training, as puberty is only one of many causes.

Oftentimes, individuals with ASD who display SIB are more likely to have a dual diagnosis of ASD and a co-occurring mental health condition. This is more commonly seen in adults with ASD but can present in children with ASD as well. However, mental health, selfinjury and suicidality in autism are poorly understood and under-researched, with a shortage of professionals trained in both autism and mental health, lack of appropriate assessment tools and therapies for this group (Camm-Crosbie et al., 2019). Little is known about autistic adults’ experiences of receiving treatment and support for mental health problems, selfinjury, and suicidality. Recent participatory research by Nguyen and Harper (2023) emphasizes that autistic adults benefit from being active collaborators in designing treatment approaches for SIB and co-occurring mental health conditions., with a majority of studies being quantitative. Autistic people feel their voices have been excluded from research, so a participatory approach is advocated in research (Camm-Crosbie et al., 2019).

Restrictive Repetitive Behavior

Ritualistic and restrictive repetitive behavior, especially self-injurious behavior, can affect socialization and interfere with behavior in learning environments. Severe self-injurious behavior not only has the potential to result in serious and long lasting medical conditions in persons with autism, but it can also contribute to immense distress and devastation among their families and caregivers (Flowers et al., 2020).

RRB (restrictive repetitive behavior) is a core symptom of ASD and is generally readily identified in older children. Self-injurious behavior (SIB) is an extreme form of RRB manifested in various neurodevelopmental disorders and genetic syndromes, including autism, Fragile X, Lesch–Nyhan syndrome, Prader–Willi syndrome, Smith–Magenis syndrome, and intellectual disabilities (ID) in general (Flowers et al., 2020). Minshawi et al. (2015) also cited Cornelia de

Lange Syndrome (CdLS) and Cri du Chat Syndrome (CdCS) as genetic syndromes that are more likely to display SIB as a symptom.

Neurodevelopmental Disorder/Genetic Syndrome	Definition
Autism	<p>- Autism spectrum disorder (ASD) is a condition that affects the development of social and communication skills. It includes features of four conditions which were once thought to be separate syndromes - autistic disorder, Asperger syndrome, childhood disintegrative disorder, and pervasive developmental disorder. Signs and symptoms often become apparent in the first 2-3 years of life and vary significantly from person to person. Common symptoms shared by people with ASD include restrictive and repetitive behaviors, social impairment, and communication difficulties (GARD, 2021)</p>
Fragile X	<p>-Other Names: Marker X Syndrome; Martin-Bell Syndrome; FRAXA Syndrome; Fra(X) Syndrome; FXS - Fragile X syndrome is a genetic condition involving changes in part of the X chromosome. This condition causes a range of developmental problems including learning disabilities and cognitive impairment. It is the most common form of inherited intellectual disability in males and a significant cause of intellectual disability in females (GARD, 2021)</p>

Lesch-Nyhan Syndrome	<p>-Other Names: LNS; HPRT Deficiency, Complete; Choroathetosis self-mutilation syndrome; Complete HPRT Deficiency Complete; Hypoxanthine-Guanine Phosphoribosyltransferase Deficiency - Lesch Nyhan syndrome is a condition characterized by neurological and behavioral abnormalities and the overproduction of uric acid in the body. It occurs almost exclusively in males. Signs and symptoms may include</p>
	<p>inflammatory arthritis, kidney stones, bladder stones, and moderate cognitive disability. Nervous system and behavioral disturbances also occur, such as involuntary muscle movements and selfinjury (including biting and head banging). (GARD,2021)</p>
Prader-Willi Syndrome	<p>- Other Names: PWS; Willi-Prader syndrome; Prader-Labhart-Willi syndrome - In infancy, Prader-Willi syndrome (PWS) is characterized by weak muscle tone (hypotonia), feeding difficulties, poor growth, and delayed development. In later infancy or early childhood, affected children develop an extreme appetite, which leads to overeating and obesity (GARD, 2021)</p>
Smith-Magenis Syndrome	<p>- Other Names: SMS; Chromosome 17p11.2 deletion syndrome -The major features of SmithMagenis syndrome include mild to moderate intellectual disability, delayed speech and motor skills, distinctive facial features, sleep disturbances, skeletal and dental abnormalities, and behavioral problems (GARD, 2021)</p>

Cornelia de Lange Syndrome	-Other Names: Brachmann de Lange Syndrome; CDLS; De Lange Syndrome; Typus Degenerativus Amstelodamensis - Cornelia de Lange syndrome (CdLS) is a developmental disorder that affects many parts of the body. The severity of the condition and the associated signs and symptoms can vary widely, but may include distinctive facial characteristics, growth delays, intellectual disability, and limb defects (GARD, 2021)
Cri du Chat Syndrome	-Other Names: Cat Cry Syndrome; 5p Minus Syndrome; Chromosome 5p Deletion Syndrome; 5p- Syndrome; Monosomy 5p; 5p Deletion syndrome; 5p- Syndrome - Cri du chat syndrome is present from birth and affects growth and development. Infants with this condition often have a high-pitched cat-like cry, small head size,
	and a characteristic facial appearance. They may have trouble breathing and feeding difficulties. People with this condition typically have intellectual disability, developmental and speech delay, and behavioral issues (GARD, 2021)

Manifestation is more ambiguous and more difficult to define in infants and younger children, particularly because repetitive behavior is both common and developmentally appropriate in this population (Flowers et al., 2020). Repetitive behavior is definitely common and developmentally appropriate in neurotypical children as well as children with Autism Spectrum Disorder and/or another type of intellectual/developmental disability. Many children will display repetitive behaviors, such as clapping their hands more than one would typically clap their hands as an adult.

Babies and young children tend to be very repetitive, as that is one way that they are able to express themselves at that age when they are non-verbal. Not only are restrictive repetitive behaviors seen in neurotypical children, but self-injurious behavior is also seen in this population. SIB occurs across a variety of populations. Mild forms of SIB are occasionally seen in typically developing children and adults. For example, young children may throw tantrums in which they bang their heads, and older children and adults may bite their nails to the quick or pick their skin (Minshawi et al., 2020). As the child gets older, the SIB may be more prevalent

and will be easier to diagnose due to the child's increased age, as SIB in neurotypical child will usually fade away as they age. The most common types of self-injury seen in individuals with autism include head-banging, hand-biting, excessive self-rubbing, and excessive self-scratching (Flowers et al., 2020).

Other Causes of SIB

I think it is safe to say that most of us act differently when we are physically or mentally uncomfortable. If you have a migraine, or a stomachache, you will typically not be especially happy and talkative, and may even be more irritable than usual. The same thing goes for individuals with ASD and other intellectual/developmental disabilities. If they are feeling extremely uncomfortable and are unable to adequately express that, they may become irritable and act out in a way that presents a danger to themselves and/or others. A consensus group identified a variety of atypical and disruptive behaviors observed in association with GI disorders, including facial grimacing and neck stretching, chewing on non-edibles such as shirt sleeves, putting pressure on the abdomen, constant eating and drinking, unusual gulping, and chest tapping, as well as aggression, motor stereotypies, SIBs, and disturbed sleep patterns (Edelson & Johnson, 2016)

If the person that you are supporting is non-verbal, they might have stomach pain or a headache and will be unable to tell you. Being in pain with no way to communicate that you are in pain, uncomfortable, and need help could definitely be extremely frustrating. If you notice a "significant" (depends on the individual) change in behaviors, this is something that you should take note of and report. If you are comfortable with having this conversation, you should bring up concerns with parents as well. There may be additional medical conditions that they are aware of and that you are not aware of and having this information could increase the quality of care that you are able to provide.

De-Escalation in SIB

DE-ESCALATION techniques for defusing meltdowns

- | | |
|--|---------------------------|
| 1. DON'T YELL TO BE HEARD OVER A SCREAMING CHILD | 2. AVOID MAKING DEMANDS |
| 3. VALIDATE THEIR FEELINGS, NOT ACTIONS | 4. DON'T TRY TO REASON |
| 5. BE AWARE OF YOUR BODY LANGUAGE | 6. RESPECT PERSONAL SPACE |
| 7. GET ON YOUR CHILD'S LEVEL | 8. USE A DISTRACTION |
| 9. ACKNOWLEDGE YOUR CHILD'S RIGHT FOR REFUSAL | 10. REFLECTIVE LISTENING |
| 11. SILENCE | 12. BE NON-JUDGEMENTAL |
| 13. ANSWER QUESTIONS + IGNORE VERBAL AGGRESSION | 14. MOVEMENT BREAK |
| 15. AVOID THE WORD "NO" | 16. DECREASE STIMULATION |
| 17. DEEP BREATHING EXERCISES | 18. CALMING VISUALS |

help
EXTRAORDINARY
TOOLS FOR RAISING AN EXTRAORDINARY PERSON

that you are supporting displays self-injurious behavior.

The potentially life-threatening nature of SIB, along with the stress placed on a multitude of caregivers and resources, highlights the importance of developing successful treatments for this behavior. Using evidence-based assessment and treatment algorithms and having clinicians who are properly trained to provide care for such individuals in the community will help to minimize restrictive placements (Minshawi et al., 2015). **It should be said that Pikes Peak Respite Services does not condone the use of restraints by our caregivers.**

If you took the Crisis Stabilization, DeEscalation Techniques, Positive Behavior Support, and Behavior Intervention Training, you probably remember hearing about ABC (Antecedent, Behavior, Consequence). This is important enough that I am going to have you read about it a second time. If you are able to identify the antecedent of the person supported, and the behavior that follows, you will have a chance to stop the negative behavior before it starts. This is especially important (and necessary) if the individual

- ABC (Antecedent, Behavior, Consequence)
 - Antecedent
 - What Happened Just Before the Behavior Occurred
 - Other Events that Occurred Throughout the Day that Could Affect the Behavior.
 - Observing
 - The Child
 - The Environment
 - Adults
 - Interaction Events
 - Behavior
 - Level or Intensity of the Behavior
 - Be as Specific as Possible
 - Replicability
 - Consequence

- What Occurred Immediately After the Behavior
- Is There a Consistent Response to the Behavior
- Observing
 - The Child
 - The Environment
 - Adults
 - Interaction Effects (Autism Partnership Foundation, 2019)

If there is no antecedent, or if the behavior escalates before you are able to halt the behavior, you will need to implement de-escalation techniques. If the person that you are supporting is already escalated, approaching them in an aggressive way could further escalate the situation. If it is safe, it is important to approach them how you usually would, or approach them in a calmer way than you usually would. Good de-escalation prevents the occurrence of more serious incidents and should be instigated at the first sign of an escalating situation. The qualities of good de-escalators include:

- The Use of Verbal and Non-Verbal Skills
- Confidence without Arrogance
- Autonomy-Confirming Interventions
- Use of Appropriate Humor
- “Connection” with the Person Supported
- Balance between Support and Control
- Non-Punitive Approaches
- Empathy
- A Soft, Calm, and Gentle Approach (Hext et al, 2018)

Another source stated that the five points to better de-escalation are:

- Keep out of Personal Space
- Turn Sideways
- Talk Slower and Lower
- Model the Behavior in Which the Child Needs to Engage
- Show a Change of Face (i.e., Seek Help and Advice) (Brown, 2014)

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