



A Psychological Perspective on Self-harming Behaviours within Intellectual and Developmental Disabilities

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Overview

- What is self-harm?
- What does the literature tell us?
- Why do people with Intellectual & Developmental Disabilities self-harm?
- What works: Psychological Interventions for Self-Harming behaviours
- Summary



Is this self-harm?



What is self-harm?

Definitions

*“Deliberate injury to oneself, typically as a manifestation of a mental condition” ~ **Oxford dictionary***

*“Self-harm refers to an intentional act of self-poisoning or self-injury, irrespective of the motivation or apparent purpose of the act, and is an expression of emotional distress” ~ **NICE***

*“Nonsuicidal self-injury (NSSI), defined as the deliberate, self-inflicted destruction of body tissue without suicidal intent” ~ **DSM-5***

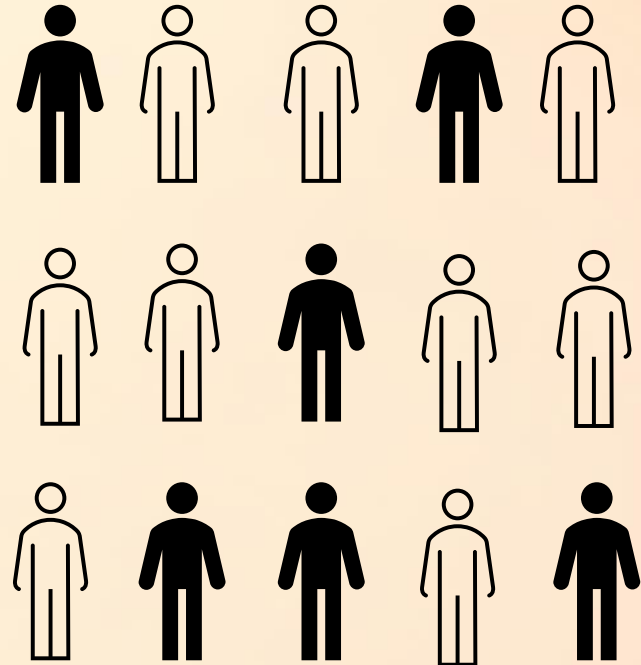
*“Any deliberate act of self-poisoning or self-injury without suicidal intent” ~ **Samaritans***

What does the literature tell us?

What the literature says (a recap from Dr Temple's presentation)

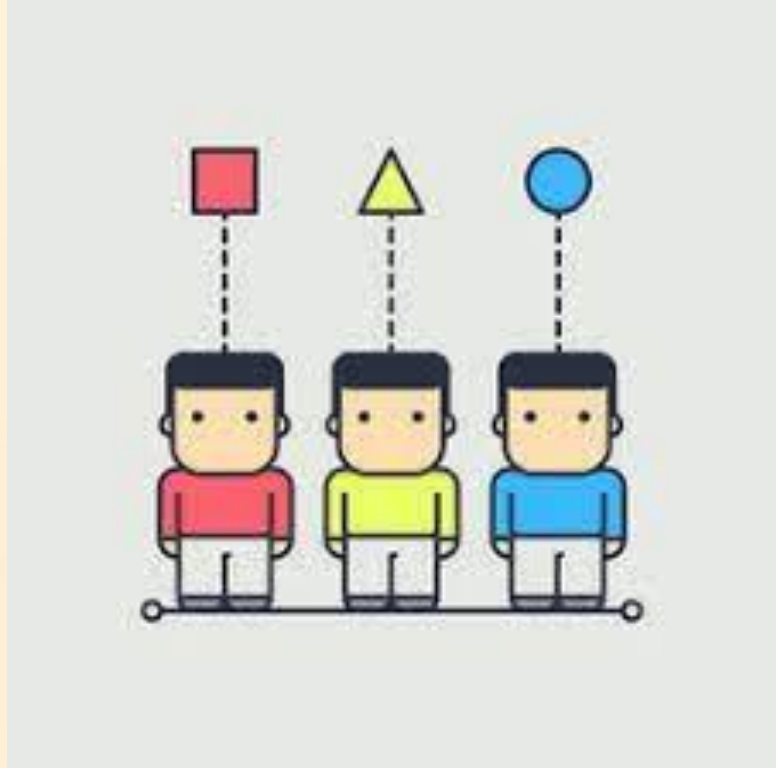
- **Prevalence:**

- Self-Injurious Behaviour (SIB) has a high prevalence rate among individuals with **severe intellectual disabilities (ID)**
- Prevalence rates of SIB among individuals with **ASD and ID are higher** than for individuals with ID alone.
- Richard et al (2012) found Self-injurious behaviour was **displayed by 50% of the ASD sample** (higher prevalence than other 2 groups compared. Within the **ASD group**, the presence of self-injury was associated with significantly **higher levels of impulsivity** and **hyperactivity, negative affect** and significantly **lower levels of ability and speech**.



What the literature says cont.

- Individual Characteristics:
- Cooper et al (2009) investigated risk markers for persistence of self-injury - demonstrated that **lower ability, ADHD, visual impairments, compromised communication** and **ASD** were associated with SIB - but that only lower ability, ADHD and visual impairments were independently associated with self-injury over time.



What the literature says cont.

- **Risk Factors:**

- A meta-analysis of 22 prevalence and case-control revealed that the likelihood of displaying SIB was **significantly increased among individuals with ASD** and those with **more severe intellectual and communication**
- Duerden and colleagues (2012) found that significant factors in predicting SIB also proved to be core features of ASD—i.e., **sensory processing abnormalities, insistence on sameness, and social communication impairments**. A lower non-verbal cognitive ability was also predictive of SIB.
- Richard et al (2012) found that **health conditions and problems with behavioural inhibition** also correlates to SIB



Why do people with Intellectual and
Developmental Disabilities self-
harm?

In people with learning disabilities, self-harming behaviour can serve various functions



**SOCIAL
ATTENTION**



SENSORY



**GETTING
THINGS**

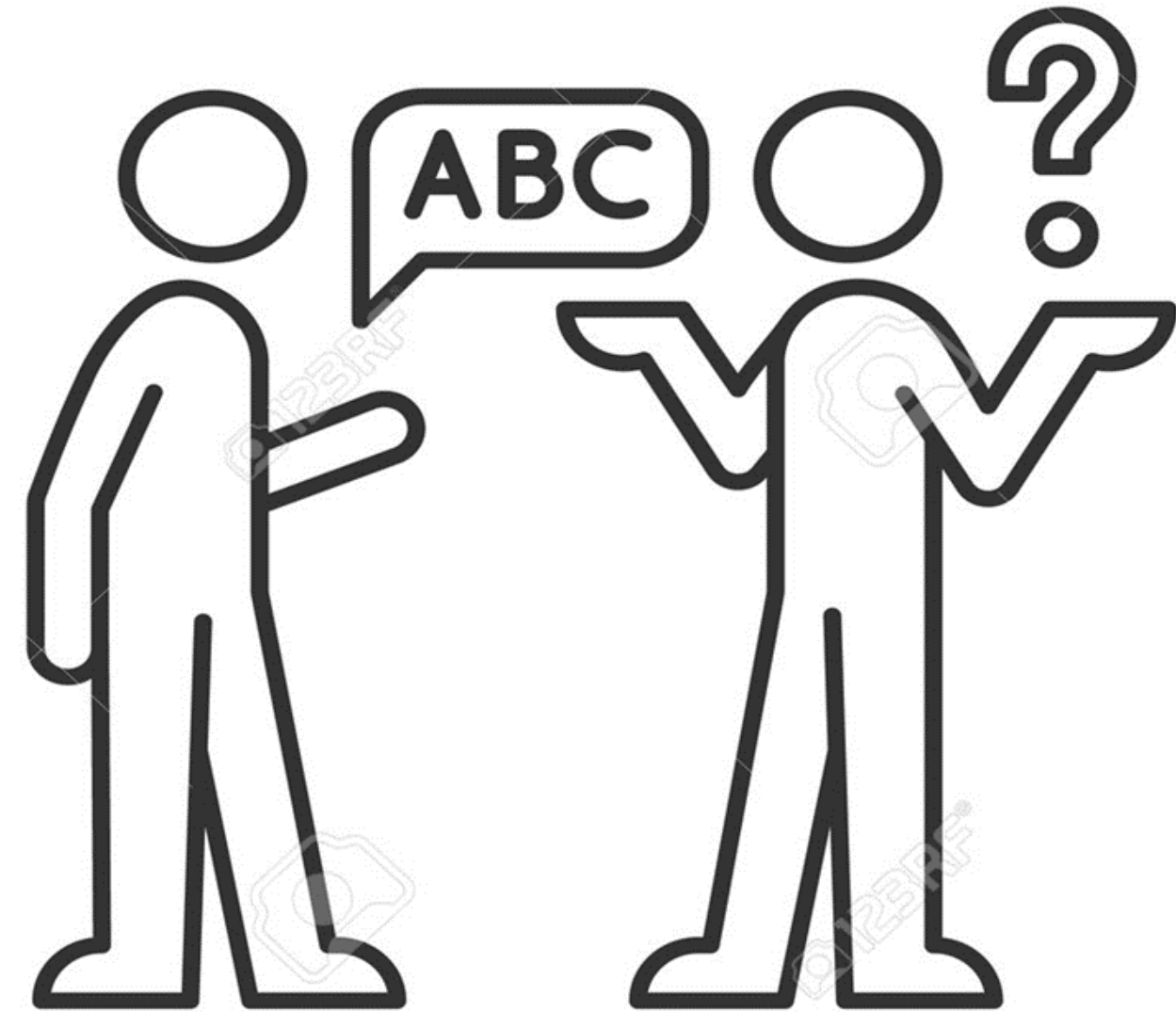


ESCAPE



Coping Mechanism

- Some individuals with learning disabilities may engage in self-harming behaviour as a way to cope with overwhelming emotions or distress.
- It can be a maladaptive coping strategy to release or distract from emotional pain, anxiety, or frustration.



Communication

- For some individuals with learning disabilities who may have difficulty expressing their thoughts or emotions verbally, self-harming behaviour can serve as a way to communicate their distress or seek attention.
- It may be a form of expressing unmet needs or a way to elicit a response from caregivers or others.

Function Based Approach

- Based on this literature, it has been determined that the most common **communicative functions** of SIB and other problems behaviours are to:
 - (1) obtain social attention from others;
 - (2) gain access to tangible items in the environment (e.g., food, toys, others preferred items);
 - (3) avoid or escape from demands (e.g., school work, daily living tasks);
 - (4) obtain automatic or sensory stimulation (Carr and LeBlanc 2003; Iwata et al. 1994a).





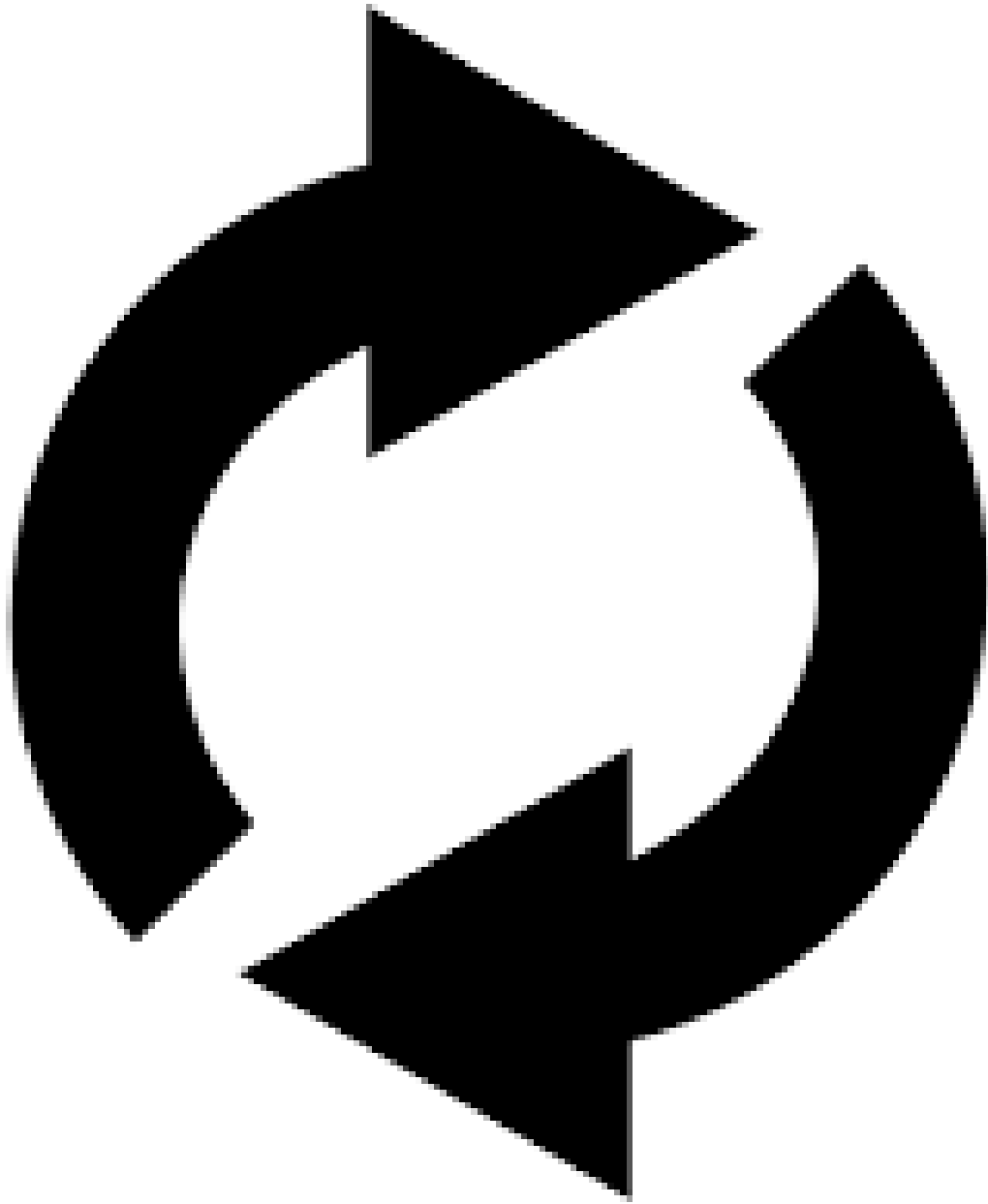
Sensory stimulation

Self-harming behaviour can also provide sensory stimulation, such as the release of endorphins, which can temporarily alleviate emotional numbness or provide a temporary "high" or relief.



Control or self-punishment

- In some cases, self-harming behaviour may be related to a desire for control or self-punishment.
- Individuals with learning disabilities may feel a lack of control or struggle with low self-esteem, and self-harming behaviour may provide a temporary sense of control or relief from perceived failure or self-blame.



Habit or repetition

Self-harming behaviour can become a habit or a repetitive behaviour pattern, which may be difficult to break without appropriate intervention.



Pain/Physical Health

- Self-harming behaviours may be due to underlying physical health difficulties or undetected pain
- People with intellectual disabilities and developmental disorders are less able to self-report pain and may use self-harming behaviours as a way to communicate this

Nock & Prinstein (2004)

- Proposed four primary functions of Self Mutilation Behaviour (SMB) along two dichotomous dimensions: contingencies that are **automatic** (i.e., within oneself) versus **social** and reinforcement that is **positive** (i.e., followed by favourable stimulus) and **negative** (i.e., followed by removal of aversive stimulus)
- Confirmatory factor analyses and reliability analyses supported the structural validity and reliability of this **four-function model**, with adolescents reporting engagement in SMB for:
 - **Automatic negative reinforcement** (e.g., “To stop bad feelings”)
 - **Automatic positive reinforcement** (e.g., “To feel something, even if it is pain”)
 - **Social negative reinforcement** (e.g., “To avoid doing something unpleasant you do not want to do”)
 - **Social positive reinforcement** (e.g., “To get attention”).

Klonsky (2007): Functions of DSH

- Klonsky (2007) found that:
 - (a) acute negative affect precedes self-injury
 - (b) decreased negative affect and relief are present after self-injury
 - (c) self-injury is most often performed with intent to alleviate negative affect.
- Studies also provide strong support for:
 - ❖ self-punishment function
 - ❖ anti-dissociation- to end the experience of depersonalization or dissociation
 - ❖ interpersonal-influence- to seek help from or manipulate others
 - ❖ anti-suicide- avoid impulse to engage in suicide
 - ❖ sensation-seeking- generate excitement
 - ❖ interpersonal boundaries functions- assert one's autonomy or distinction between self and other

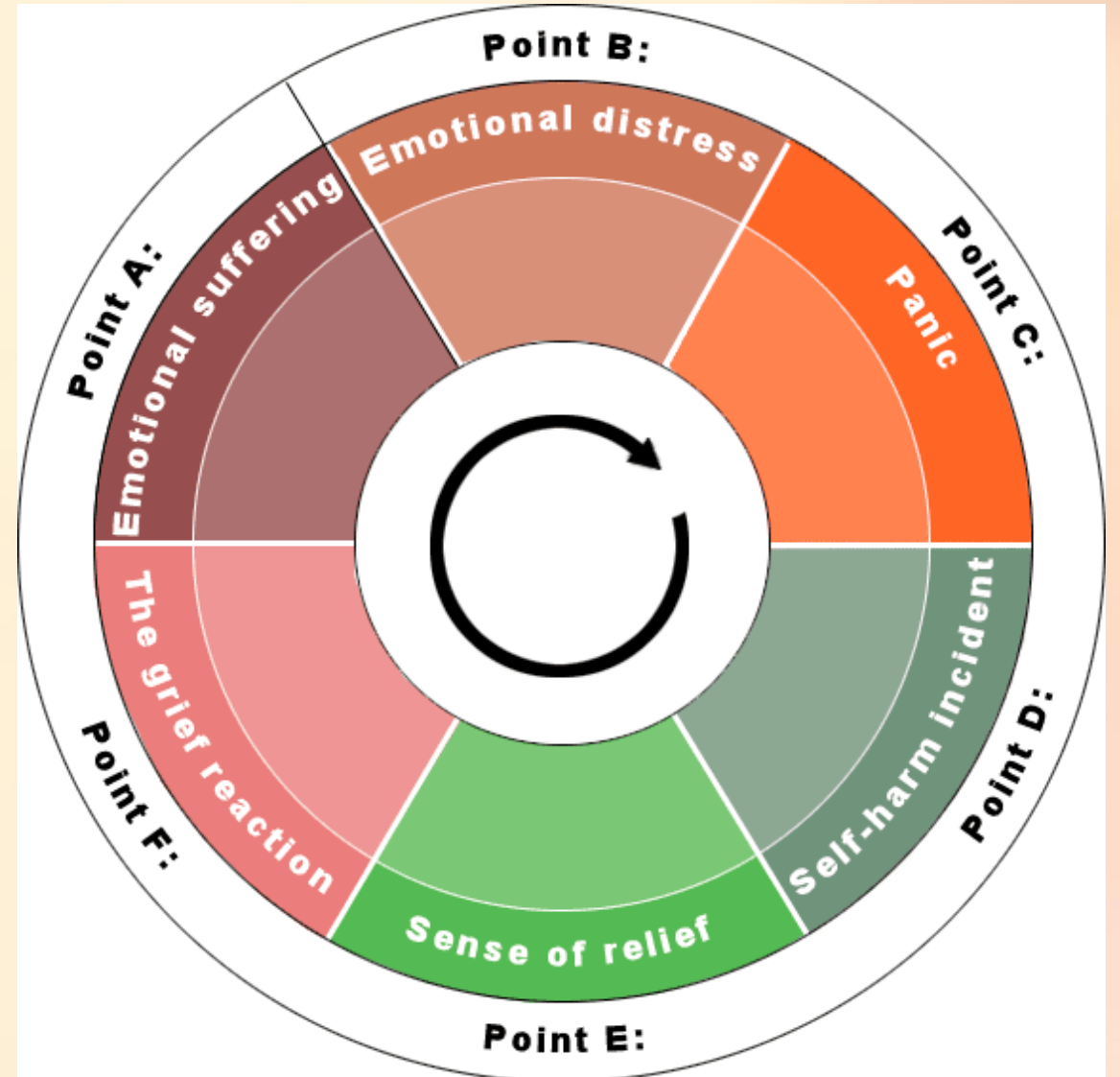
Klonsky et al. (2014): Functions of DSH

- Systematically reviewed the empirical evidence for **7 functional theories**. These papers highlighted several key questions about why people engage in Non-Suicidal Self-Injury (NSSI).
 - ❖ First, by a wide margin, NSSI most commonly functions to (temporarily) **alleviate overwhelming negative emotion**. Intense negative emotions precede NSSI, and the performance of NSSI results in reduced negative emotions as well as feelings of calm and relief.
 - ❖ Second, slightly more than one-half of people report that they **self-injure as a form of self-directed anger or self-punishment** (consistent with work by Hooley and colleagues) suggesting that **self-criticism** has a causal relation to NSSI.
 - ❖ Third, NSSI can serve **multiple other functions**, such as a **desire to influence others** or to produce a **physical sign of emotional distress**, but each of these functions is relevant only to a minority of people who self-injure. Further, the different functions of NSSI can be divided into 2 superordinate categories: **intrapersonal-self-focused** (for example, emotion regulation and self-punishment); and **interpersonal-other-focused** (for example, influencing others).

The Cycle of Self-Harm

Self-harm can be understood as a **vicious cycle**, with emotional and physical pre-factors leading up to the incident followed by post-factors that can maintain the behaviour.

Cycle adapted from Sutton, J. (2007). Healing the Hurt Within 3rd Edition: Understand self-injury and self-harm, and heal the emotional wounds. Hachette UK.



What works?

Psychological Interventions for Self-Harming Behaviours

DON'T

...be dismissive

You're so dramatic.

You just want attention.

...or totally freak out

DO YOU WANT TO DIE?!

WHAT THE #!*@ IS WRONG WITH YOU?!

ARE YOU CRAZY?! YOU'RE CRAZY!

AHHHH!
OMG OMG
OMG OMG

...or Promise to keep it a secret

If you're really my friend, you won't tell!

You know I'm your friend. That's why I'm not going to ignore this.

treat them differently. They're still the same person you know + love.



... I don't know what to say...

LEARN MORE: SIoutreach.org

DO

... calmly assess the situation.

- do they need immediate medical attention?
- what is their current mental/emotional state?
- are they safe right now?

... listen

When I hurt on the outside, the inside hurts less.

I'm so sorry you're hurting.

... seek professional help. Even minor injuries = major red flag.

doctor



therapist



Support group



...offer love + support.

I'm not gonna lie, that was scary...

But nothing you could do would scare me away. I'm here for you.

@introvertdoodles

Psychological Interventions



1. NICE Guidelines
2. Behavioural Theory (Applied Behavioural Analysis & Functional Analysis)
3. Positive Behaviour Support Plans
4. Other modes of therapy

NICE Guidelines

Self-harm: assessment, management and preventing recurrence (NG225, 2022)

Interventions for Self-Harm

- Offer a structured, person-centred, cognitive behavioural therapy (CBT)-informed psychological intervention (for example, CBT or problem-solving therapy) that is specifically tailored for adults who self-harm. Ensure that the intervention:
 - ❖ starts as soon as possible
 - ❖ is typically between 4 and 10 sessions; more sessions may be needed depending on individual needs
 - ❖ is tailored to the person's needs and preferences.

NICE Guidelines (NG225, 2022) cont.

- For children and young people with significant emotional dysregulation difficulties who have frequent episodes of self-harm, consider **dialectical behaviour therapy adapted for adolescents (DBT-A)**. Take into account the age of the child or young person and any planned transition between services.
- Healthcare staff should be appropriately trained and supervised in the therapy they are offering to people who self-harm.
- Consider developing a safety plan in partnership with people who have self-harmed (details of plan are listed in guidelines).

NICE Guidelines

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (NG11, 2015)

Psychological and Environmental Interventions for behaviour that challenges:

- Consider personalised interventions that are based on **behavioural and cognitive behavioural principles and a functional assessment of behaviour**, are tailored to the range of settings in which they spend time, and consist of:
 - ❖ Clear targeted behaviours with agreed outcomes
 - ❖ Assessment and modification of environmental factors that could trigger or maintain the behaviour (for example, altering task demands for avoidant behaviours)
 - ❖ Addressing staff and family member or carer responses to behaviour that challenge
 - ❖ A clear schedule of reinforcement of desired behaviour and the capacity to offer reinforcement promptly
 - ❖ A specified timescale to meet intervention goals (modifying intervention strategies that do not lead to change within a specified time).

1. Behavioural Theory: Applied Behavioural Analysis

- One approach to understanding the aetiology and treatment of SIB in individuals with ASD and other developmental disabilities is derived from behavioral/learning theory.
- Behaviourism in psychological sciences is derived from the work of Skinner. Broadly defined, behaviour is anything an individual does while he or she is interacting with the physical environment (Skinner, 1938).
- More specifically, **behaviour** is the physical properties of the action (e.g., hitting one's head with a closed fist), as well as the environmental variables that influenced the behaviour in advance (**i.e., the antecedents**) and the outcomes that are related to the behaviours' occurrence (**i.e., the consequences**) (Skinner 1938).
- This **antecedent-behaviour-consequence** contingency, are the principles of operant behaviour that underlie the basis of **Applied Behaviour Analysis (ABA)** which will apply to the behavioral reinforcement that occurs in some instances of SIB among people with ASD.

Behavioural Theory cont.

- **Functional Behavioural Assessments (FBA)**
- Antecedents and consequences surrounding SIB will be different for every person, it is first necessary for a clinician to identify the factors surrounding SIB in an individual (known as FBA)
- 3 main forms of FBA;
- **Direct assessment** (direct observation of problem behaviours occurring in natural environment)
- **Indirect assessment** (obtain information on environmental variables for e.g., through interviewing caregiver, staff, teacher)
- **Experimental Functional Analysis** (direct manipulation of environmental variables and consequences in order to test hypotheses about the function of problem behaviours directly)



Behavioural Treatment of SIB

- Antecedent- Based Intervention Strategies
- Reinforcement Based Intervention
- Extinction Based Intervention



Antecedent-Based Intervention Strategies

- By understanding patterns of environmental events preceding SIB, illuminated through the FBA, antecedent-based interventions can be put in place to **alter the environment** to reduce the future likelihood that the problem behaviour will occur.
- Following methods outlined (Minshawi et al., 2014);
- **Create enriched environment-** Implementation of an enriched environment has been shown to decrease the rate of SIB, as well as the presence of negative affect, in an individual with ID and mood disorder (Lindauer et al. 1999). For example placing the individual in a setting where they have continuous access to highly preferred items.
- **Alteration of schedule/activities-** transitions between activities are often times problematic for individuals with ASD and can lead to SIB and other problem behaviours (Sterling-Turner and Jordan 2007). In order to reduce the potential stress associated with transitions, providing supports like structured schedules and presenting these schedules visually (e.g., in a written or pictorial format) can be useful (Dooley et al. 2001; Lequia et al. 2012).
- Escapism/avoidance of demands one of the primary functions of SIB- antecedent interventions can be highly effective in these circumstances via altering the way in which demands are presented. This approach is most substantial where SIB is maintained by automatic or sensory reinforcement (Vollmer et al. 1994; Smith 2011).

Reinforcement Based Intervention

- Reinforcement, referring to stimuli that are provided to encourage desirable behaviour and thereby reduce incidents of SIB
- **Positive reinforcement** entails giving attention, rewards or some other stimuli to the individual with ASD after he or she has engaged in appropriate behaviour, in order to strengthen that behaviour. (e.g., giving praise or a reward to individual for using emotion card when distressed rather than using SIB)
- **Negative reinforcement** entails removing negative stimuli to increase the presence of desirable behaviour. For example, providing the individual with a break from work and offering to do an activity of their choice like playing a game.
- **Differential reinforcement** of other or alternative behaviours reinforces appropriate activities. Can be combined with extinction-based strategies to replace inappropriate behaviour with an acceptable behaviour that serves the same function (Vollmer et al. 1993). (e.g., identify alternative reinforcer option such as rubbing ice cube onto skin or pinching elastic band on wrist).
- These reinforcement based strategies are particularly effective when SIB is maintained by social interaction/attention (Lindberg et al. 2003).

Extinction Based Intervention

- **Extinction** is the withdrawal of a reinforcer in order to bring an end to SIB.
- For example, if the SIB is maintained by social attention, then when using extinction the caregiver would purposefully ignore any incident of SIB; this is called **planned ignoring**.
- Over time, when the SIB is no longer receiving attention the behaviour will cease to occur.
- A related strategy called **escape extinction** is used when SIB is maintained by escaping from demands. Instead of allowing the individual to avoid or terminate demands with SIB, demands are continued through the episode of SIB or the individual is returned to the demands immediately following.
- By ending the functional usefulness of the SIB (i.e. the individual no longer gets what they want when SIB is performed), the SIB is reduced over time (Iwata et al. 1990a; Magee and Ellis 2000).
- This would be an **inappropriate approach** to use if the individual could be severely injured if allowed to engage in SIB.

Is it always just behavioural?


There may be more to the underlying cause of SIB than behavioral interventions alone can explain. In fact, the reduction of SIB may be best **addressed by a multidisciplinary treatment team** designed to look at the complete context of SIB. Members of the team could conduct a comprehensive physical evaluation/examination and consider if pharmacological treatment may be indicated.




Oliver & Richards (2010)

- The studies reviewed suggest that methods of assessment such as functional analysis and the applied behaviour analytic approach more generally are considered as the assessments and interventions of choice.
- This view has been adopted in the relentless stream of policy documents and guidelines that are issued regularly. It is sobering then to consider the results of two empirical studies of clinical practice.
- The first showed that of 205 practitioners the majority used descriptive methods of functional analysis only. Additionally, whilst 67% of respondents indicated that they thought functional analysis was useful, **only 37% used the results to inform interventions** (Roscoe et al., 2015) .
- This finding is consistent with audits of positive behavioural support packages that frequently cite applied behaviour analysis as informing intervention but **rarely implement it in practice.**

2. Positive Behaviour Support Plans



POSITIVE BEHAVIOURAL SUPPORT PLAN



STAFF ONLY VERSION

NAME:	DATE OF BIRTH:
NHS NUMBER:	DATE PLAN CREATED:
MHA STATUS:	DATE PLAN REVISED:

Introduction

Formulation

1.

Target Behaviours	Triggers	Early warning signs
•	<i>Fast Triggers</i> <ul style="list-style-type: none"> • <i>Slow Triggers</i> <ul style="list-style-type: none"> • 	•

Proactive (long term rehabilitative strategies)

-

Secondary prevention (when behaviour starts)

Name:
NHS NUMBER:

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Reactive strategies (managing the behaviour)

-

Recovery phase (after the behaviour)

Staff Name	Signature	Date

Name:
NHS NUMBER:

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Visual Positive Behaviour Support Plan

Devised by Julia Large (Counselling Psychologist)

VPBS ex/n/1/1/1


Visual Positive Behaviour Support

Future Goals


VPBS ex/n/1/1/1

My risk behaviours: 

VPBS ex/n/1/1/1

Triggers to my risk behaviours: 

VPBS ex/n/1/1/1

My exits – what I can do to manage my risk behaviours: 

VPBS ex/n/1/1/1

What staff can do to support me in managing my risk behaviours:

Low 



Medium  



High   



3. Other Modes of Therapy- Dialectical Behaviour Therapy

- Dialectical behaviour therapy (DBT) (Linehan, 1993) has assembled a large body of evidence in the treatment of Emotional Dysregulation (ED) associated with self-harm and suicidal behaviours in borderline personality disorder (BPD) (Linehan et al., 2006; Panos et al., 2014).
- DBT is a third-wave CBT that combines acceptance-based techniques, including mindfulness training, and strategies from traditional CBT, including problem-solving, behavioral analysis, contingency management, and skills training techniques (Linehan, 1993).



Dialectical Behaviour Therapy cont.

- Research on Dialectical Behaviour Therapy (DBT) for patients who self-injure has been encouraging.
- When compared to treatment as usual in the community, DBT appears to produce better improvements in frequency of self-injury, hospitalizations, and many other outcome variables (Linehan, 2000; Robins & Chapman, 2004).
- However, few studies have compared DBT to more rigorous control conditions involving manualized treatments or treatment by experts (Robins & Chapman, 2004; but see Linehan et al., 2006), and many patients treated with DBT continue to self-injure even if less frequently.
- Understanding the functions of self-injury, could greatly improve prevention and treatment.

Bemmouna et al. (2021)

- **Feasibility, acceptability and preliminary efficacy of dialectical behaviour therapy for autistic adults without intellectual disability: a mixed methods study.**
- Results
- DBT was feasible and highly acceptable to participants
- Results suggest that DBT might effectively reduce emotional dysregulation (ED) in autistic adults exhibiting self-harm and/or suicidal behaviours, as reflected by the significant decrease in the Difficulties in Emotion Regulation Scale total scores post-treatment and at follow-up.
- The data collected on DBT diary cards showed that the majority of the participants with self-harm ceased these behaviours for at least 3 months up to the post-treatment measure, and this was maintained in half of them at follow-up.
- Overall, the significant improvement in self-reported ED was consistent with the clinical observations and with findings relative to DBT in several disorders (Panos et al., 2014; DeCou et al., 2019).

Bemmouna et al. (2021) cont.

- Limitations
- Small sample size- does not allow generalising to the target population
- No control group- does not provide definite evidence that improvements were due to DBT
- Dropout during study due to COVID- could have altered outcomes
- Sample was homogenous (white Europeans)- to establish whether DBT is pertinent to autistic population irrespective of ethnicity future research should consider diverse samples
- Measures were self-reported- problematic as autistic individuals might present with high levels of alexithymia (i.e., interfere with their ability to accurately identify their emotional states)

Further findings surrounding use of DBT

- Ashworth et al. (2017). Findings demonstrated an effect upon some secondary treatment targets (namely an increase in use of mindfulness techniques and adaptive coping strategies) but no overall reduction of the primary treatment target of emotional management or associated emotional and psychological problems.
- McNair et al. (2017). Findings indicated that DBT and DBT-skills groups can be adapted for people with ID, but further high-quality research is needed in order to make conclusions about efficacy and effectiveness.
- Morrissey & Ingamells (2011). Preliminary outcomes with six patients who were treated over a period of 18 months with group skills and individual therapy in 2004–2005 were promising (Ingamells & Lascelles, 2005, unpublished). In terms of self report measures, significant reductions were found on Global Severity of Distress Scale of the Brief Symptoms Inventory. Compared to a waiting list control group (n = 5), the treated group were more likely to be moved on to conditions of lower security in the 12 months following treatment (four out of six, compared with one out of five), suggesting that their risk was perceived to have been reduced by assessing clinical teams.
- Sakdalan et al. (2010). The study result showed improvement across all measures. A decrease in the level of risks, increase in relative strengths and general improvement in overall functioning were found significant. The results were promising particularly as a stand-alone adapted DBT group skills training programme for this client group.

So is DBT effective?

The evidence remains **uncertain** about the effects of dialectical behaviour therapy (DBT) within this population.



Findings regarding other modes of Therapy

- Treatments for self-harm in adults (Witt et al., 2021)
- For adults, there may be **positive effects** of psychological therapy based on **CBT approaches** on repetition of self-harm (at six and 12-month follow-up assessments) and there are **positive effects of Mentalisation-Based Therapy (MBT)**(Singh et al. 2006). **Emotion regulation psychotherapy** probably also has benefits.
- However, psychodynamic psychotherapy, case management, brief emergency department-based interventions, remote contact interventions, and other mixed interventions may **have little to no benefit** in terms of reducing repetition of self-harm.
- The evidence is **uncertain** about the **potential benefits and harms of antidepressants, antipsychotics, mood stabilisers, or natural products** in preventing repetition of self-harm in adults.

Summary

Summary

- Provided an overview of the literature surrounding self-harming behaviours in people with intellectual and developmental disabilities.
- Understood the different definitions and terminologies used to explain self-harming behaviours
- Reviewed the functions of why people with ID/DD may self-harm
- Examined different psychological interventions that can be used to treat self-harming behaviours within this population group, using evidence based research
- Behavioural therapy appears to be the most supported in the literature and there remains uncertainty around the efficacy of DBT
- Other modes of therapy have shown positive results, however further research is required specific to ID/DD.

The End

Thank you for listening



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