

# **Self-Injurious Behaviour**

Guidelines and resources to help support children and young people with special educational needs and disabilities who show self-injurious behaviours.

August 2016

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## Introduction

This resource pack has been developed to support families and organisations such as schools in understanding how to support children and young people with special educational needs and disabilities who show self-injurious behaviours. It should be read in conjunction with the self-harm resources accessible on the Buckinghamshire County Council website, ([http://www.buckscc.gov.uk/media/2722236/29665-NHS-Bucks-Self-Harm-Pack\\_v17.pdf](http://www.buckscc.gov.uk/media/2722236/29665-NHS-Bucks-Self-Harm-Pack_v17.pdf)), which were developed to support children and young people in mainstream settings who self-harm.

The pack has been developed in recognition that the function of self-injurious behaviours shown by children and young people with special educational needs or a learning disability may be different to the function of self-harming behaviours shown by young people without these additional needs. As a result the approaches used to support children and young people with special educational needs and disabilities who show self-injurious behaviour will also be different. It is important to highlight that for young people with a mild learning disability it may be more appropriate to use the guidance for supporting children and young people who show self-harming behaviour or a combination of the two.

When using either or both, of the guidance documents it is important that a child/young person centred approach is always taken to ensure that the support provided is tailored to the needs of the individual child/young person.

This guidance provides information, good practice guidelines and sign posting so that organisations and families feel more able to offer appropriate support to children and young people with special educational needs and disabilities, as well as knowing how to access help and advice when needed. It is not a definitive guide and does not replace any official guidance issued by professional bodies or government policy, but aims to provide a clear and straightforward starting point for easy reference.

This resource pack aims to ensure that everyone working with and caring for children and young people with special educational needs and disabilities (SEND) can:

- Better understand self-injurious behaviours
- Know how to carry out a functional analysis of these behaviours
- Know what to do if a child or young person shows self-injurious behaviours
- Identify where to access additional support and advice

Self-injurious behaviours are shown by many children and young people with special educational needs and disabilities. These children are extremely vulnerable and therefore need particular consideration. Self-injurious behaviour (SIB) is the term usually used to describe behaviours that cause people who have special educational needs and disabilities to physically harm themselves.

Self-injurious behaviours can be difficult to understand and a challenge for everyone involved. For some children and young people, it happens every day, for others it happens infrequently. Studies show that between 3-12% of children with learning disabilities living in

the community show self-injurious behaviours, with the highest rates in teenagers ([http://www.challengingbehaviour.org.uk/learning-disability-files/11\\_SIB.pdf](http://www.challengingbehaviour.org.uk/learning-disability-files/11_SIB.pdf)). Researchers looking at lifetime prevalence in those with ASD suggest that approximately 50% engage in some form of Self Injurious Behaviour (SIB), even if just at one specific period of their life span.<sup>1</sup>

## What are self-injurious behaviours?

Self-injurious behaviours can be described as “Any behaviour, initiated by the individual, which directly results in physical harm to that individual. Physical harm will be considered to include bruising, laceration, bleeding, bone fractures and breakages and other tissue damage”. (Murphy and Wilson, 1985)

For children and young people with special educational needs and disabilities the functions behind the self-injurious behaviours can be varied and multi factorial. It is crucial to fully understand these functions to guide the development of appropriate and person centred positive behavioural support interventions. The team around the child needs to work collaboratively to assess and deliver support to the young person, as well as developing a shared understanding about the self-injurious behaviours amongst the team. The development of positive behaviour support interventions should include the young person wherever possible.

Examples of self-injurious behaviours include:

- hitting self
- banging head or other parts of the body on hard surfaces
- biting self
- eating too little/too much
- eye poking
- Pica (eating inedible items)
- pulling nails, hair
- ripping, tearing, picking skin

## Causes and Triggers of self-injurious behaviours

Any assessment of self-injurious behaviours should begin with a consideration of the possible triggers of such behaviour. The causes/triggers of self-injurious behaviours can relate to internal factors and/or external factors. When considering triggers it is important to not only look at the immediate triggers, but recognise that past triggers or an accumulation of many triggers over time may well result in the young person showing self-injurious behaviour.

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<sup>1</sup> Minshawi NF, Hurwitz S, Fodstad JC, Biebl S, Morriss DH, McDougale CJ. The association between self-injurious behaviors and autism spectrum disorders. *Psychology Research and Behavior Management*. 2014;7:125-136. doi:10.2147/PRBM.S44635.

**Internal factors include:**

- Pain
- Stress and anxiety
- Illness or chronic underlying condition
- Fatigue
- Difficulties understanding what is happening
- Difficulties communicating effectively
- Basic needs not being met e.g. cold, hot, hungry
- Sensory overload or under stimulation
- Emotional distress and/or mental health needs
- Need for interaction
- Part of an underlying condition (behaviour phenotype) for example Prader Willi Syndrome, Cornelia de Lange
- Sensory impairments
- Stereotypies e.g. repetitive behaviour
- Lack of personal control over ones' life

**External factors include:**

- Environmental influences e.g. noise, light, too many people
- Changes: to daily routines, staff, food, living arrangements, classroom
- Other people's reactions
- Restrictive practise
- Lack of communication to the young person about what is happening
- Poor communication with the young person – not using communication methods that they understand e.g. signing, symbols
- Communication system that the child uses is not available to them
- Unreasonable expectations of the child
- Abuse (physical, neglect, sexual, emotional)

The purpose or function of self- injurious behaviours can be complex and need to be analysed carefully. A functional analysis of the behaviours needs to be carried out to identify any possible triggers and the purpose or function of each behaviour. It is important that any positive behaviour support is focused on reducing or managing risks and where possible encouraging more positive behaviours.

Please refer to Appendix 6 for some examples of Functional Analysis/Assessment and Positive Behaviour Support Tools

One of the most immediate actions required, particularly if the self-injurious behaviours are infrequent or have a sudden onset or, is to check if the child or young person is physically unwell and/or in pain, for example do they have ear ache, or toothache? The difficulties children and young people with SEND often have in communicating pain and discomfort means that such health conditions can go undetected and if left untreated, young people can engage in self injurious behaviours in an attempt to relieve the pain.

Thus, it is really important that people familiar to the child or young person are alert to health problems in children and young people with SEND so they can be quickly treated. Any changes in mood, sleeping, eating, sociability, facial expression, activity, posture or vocal sounds are enough to consider a consultation with a GP.

Although rare, some children and young people with genetic syndromes (e.g. Smith-Magenis, Prader-Willi and Cornelia de Lange) may have heightened pain thresholds. As a result they may not feel the immediate pain associated with self-injury, therefore experiencing fewer costs associated with injuring themselves. In these cases it is recommended that specialist assessment is sought in order to provide the most appropriate support for these children and young people.

If clear triggers for the self-injurious behaviour can be identified, rather than physically intervening to stop a self-injurious behaviours, it is important to try and eliminate or change the internal or external factors that could be triggering the behaviour e.g. turn lights off, reduce or increase stimulation, maximise the young person's opportunities to communicate their needs and wants etc.

## **What keeps Self-injurious behaviours going?**

Self-injurious behaviours have often developed over a long period of time, are difficult to understand, resistant to change and cause an emotional reaction in the team around the child which can also be difficult to manage.

There is very good scientific evidence for operant learning theory accounts of self-injurious behaviours, which suggest that self-injury is a learned behaviour that develops due to positive or negative reinforcement from others or stimulation that happens after the behaviour.

Positive reinforcement describes the presentation of something rewarding, for example being comforted or held by someone, following self-injurious behaviours. Over time and with this experience of positive reinforcement, children associate self-injurious behaviours with a reward, and thus self-injurious behaviours are maintained because the behaviour leads to a reward.

Negative reinforcement (commonly confused with punishment but it is very different) involves the removal of something unpleasant following self-injurious behaviours, for example a demand to carry out a task stops, so that the child learns that self-injurious behaviours can lead to unpleasant things stopping or being removed. Different children will find different things unpleasant or rewarding, but there are commonalities across children with special educational needs and disabilities.

There are a number of ways that operant learning is thought to lead to the development of self-injurious behaviour and can also lead to an increase in frequency or intensity of these behaviours over a period of time. The main ways are thought to be through:

**a) Sensory stimulation**

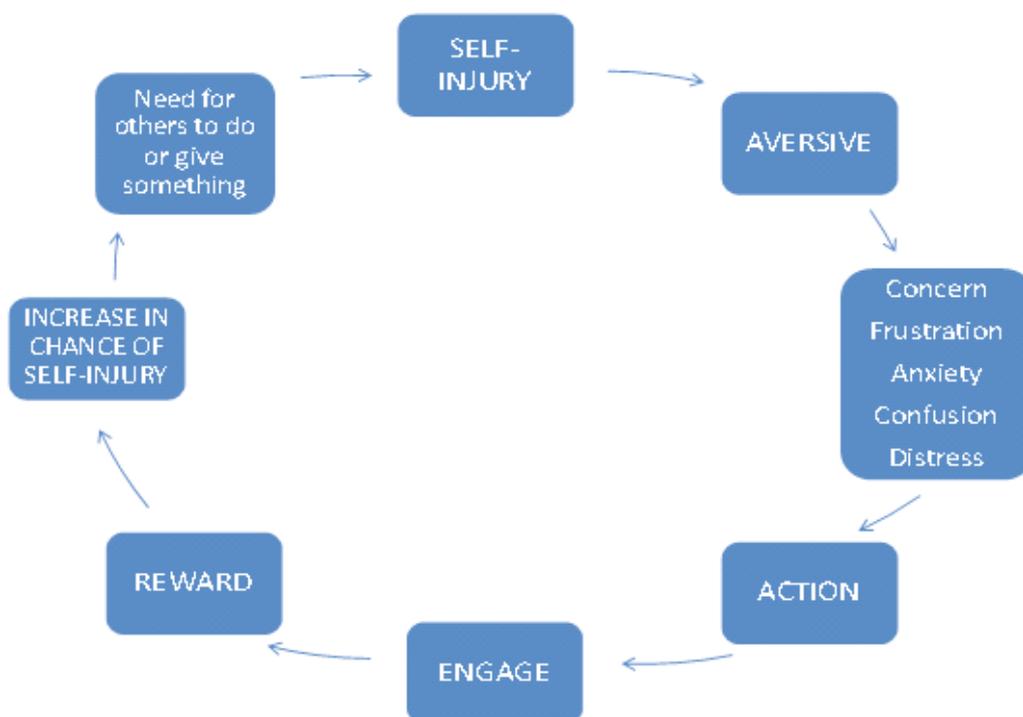
The physical stimulation provided by self-injurious behaviours might be perceived as pleasurable by a child and thus the behaviour is more likely to occur again through positive reinforcement.

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

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

**c) Mutual reinforcement**

The diagram below provides a useful way of conceptualising how the interaction between the young person and the person supporting them can impact the maintenance of self-injurious behaviours.



*Figure 1 Social reinforcement of self-injurious behaviour*

The release of endorphins can continue even after the distressing incident is over resulting in a cycle of behaviour that needs careful management. It needs to be accepted that sometimes self-injurious behaviour cannot be prevented but in these cases the risks need to be effectively managed.

## **Self-Injurious Behaviour and Peer Groups**

It is important to remember that this document is designed to provide guidance to support children and young people with a broad range of special educational needs and learning disabilities. For some of these young people it will be important to consider the interactions with and impact on their peer group around self-injurious behaviours.

It is important for all children young people, to foster an environment in which they are encouraged according to their level of ability to let you know if one of their peer group is in trouble, upset or shows signs of self-injurious or self-harming behaviour. Friends can worry about betraying confidence, so they need to know that self-injurious and self-harming behaviours can be dangerous to life, and by seeking help and advice for their friend they are taking a responsible step. If appropriate the peer group of a child or young person who shows self-injurious behaviour may value the opportunity to talk to an adult, either individually or in a small group.

When a child or young person is displaying self-injurious or self-harming behaviour, it is important to be vigilant in case their close contacts are also showing these behaviours. Occasionally, settings that support children and young people with mild learning disabilities or autism without an associated learning disability discover that a number of students in the same peer group are showing these behaviours; this is known as 'Contagion'. Self-injurious behaviours can become an acceptable way of dealing with stress within a peer group and may increase peer identity. This can cause considerable anxiety within a setting. Each individual within a group may have different reasons for their behaviour and should be offered individualised support following a detailed functional analysis.

If your setting is concerned about contagion it is advisable to contact Buckinghamshire CAMHS to discuss the situation in more detail.

All settings should consider ways of supporting young people who may be witnessing self-injurious behaviours from their peers. Supporting other young people should be central to any post incident support and again should be tailored to meet the needs of the individual children/young people involved. The use of social stories or the Blob Tree <http://www.blobtree.com/> may be useful resources to help explain emotions, see appendix 8

## **Supporting children and young people who show self-injurious behaviours**

### **Preventing Self-Injurious Behaviours**

Promoting resilience across a whole setting is an effective way to prevent mental illness, and reduce the likelihood of children and young people adopting risky coping strategies such as self-injurious behaviours. Resilience programmes involve the building and strengthening of problem-solving skills, social skills and coping skills that are adaptive and useful in the settings such as schools and residential care and also for life in general. Settings should create a supportive environment which focuses on building resilience and

encouraging healthy relationships. An effective anti-bullying and inclusion policy is an important aspect of this.

The Public Health Team at Buckinghamshire County Council has funded a number of schools in Buckinghamshire to deliver the FRIENDS programme. This programme has also been shown to positively impact upon pupil attainment and attendance.

The FRIENDS resources have been adapted for children with SEND – there is a manual and workbook available, entitled ‘Special Friends’. The link below is to a project that has adapted the programme for children with special educational needs and learning disabilities.

<http://www.learningdisabilities.org.uk/our-work/health-well-being/friends-for-life/>

For younger children, Buckinghamshire Public Health Team promotes the use of Zippy’s Friends programme which also focuses on building resilience and is structured around an ongoing story, which has proved very popular in Buckinghamshire schools.

If you would like to find out more about promoting resilience in your setting, or introducing the FRIENDS programme please contact the Public Health Team. [publichealth@buckscc.gov.uk](mailto:publichealth@buckscc.gov.uk)

## **Whole system approaches to supporting children and young people who show self-injurious behaviours**

A recent report<sup>2</sup> has shown that people with learning disabilities who show self-injurious behaviours find some of the same support strategies helpful as those without these additional needs, according to their level of ability. For example;

- having someone to talk to/ listen to them
- sensitivity
- practical support such as cleaning wounds
- help to change their way of thinking not their behaviour
- knowing that they are not alone and having support from other people that have shown self-injurious behaviour

Settings such as schools are therefore paramount in the self-injurious behaviour support pathway and they need to consider whole system processes which support staff and families as well as the child or young person and their peer group.

### **Good Practice Policies and Procedures**

- Staff training in self-injurious behaviour
- Safeguarding Policy & procedure (consider self-injurious behaviour in the context of safeguarding)
- Anti-bullying Policy
- Self-Injurious Behaviour Policy
- Promotion of wellbeing, resilience and coping strategies

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<sup>2</sup> Hidden pain- self injury and people with learning disabilities

- Use your Schools CAMHs Link Worker for advice, information, support and referral to CAMHs where appropriate
- Educate friends to be good friends by reporting concerns
- Ensure person centred approaches including developing an individual Positive Behaviour Support Plan, My Likes and Dislikes etc
- Train staff in undertaking a functional analysis
- Have information leaflets available for those that self-injure, friends and families
- Have information available about support agencies

### **Staff reactions to self-injurious behaviours:**

Children and young people who are able to talk about their self-injurious behaviours, often report prejudice from all sectors of society about the understanding of self-injurious behaviour. Below are some commonly held views and children and young people's responses to them:

<b>Societal View</b>	<b>Child/Young person response</b>
All people who show self-injurious behaviours are suicidal	No. This is only true for a small number. For most, it is internal factors such as pain, stress, illness, sensory impairment, difficult communicating, emotional release or external factors such as changes to routine or other people's reactions, abuse (see Causes and Triggers section for full list)
Self-injurious behaviours are attention seeking	No. Some children and young people go to great lengths to hide their self-injurious behaviours - for others they are trying to communicate a need. All self-injurious behaviours have a function for the individual that requires careful assessment.
They must like the pain	No, it is not about pain it is about expressing a need or about coping with the situation. Pain can maintain or exacerbate self-injurious behaviour.
Self-injurious behaviour is a young person's issue	No. Self-injurious behaviour can happen in younger children and adults as well as young people.
Young people with learning disabilities have a high pain threshold.	No. There is no evidence for this. Self-injurious behaviours can result in the production of high levels of adrenalin which can inhibit the immediate experience of pain in some individuals. Self-Injurious behaviours may also be related to sensory processing.
People who show self-injurious behaviours can stop easily if they want to	No. They can only stop if their need is met in the correct way or they are able to find a better way of coping
Self-injurious behaviour is the problem, if we stop this then the person will be fine	No. Self-injury is not really the problem and may be seen as a solution to problem that

## **Support for staff**

It is important to recognise the potential ongoing impact on staff of supporting children and young people who show self-injurious behaviours, and make time to support all staff, allowing them to have an opportunity to discuss the impact the self-injurious behaviour has on them personally. Staff may experience a range of feelings in response to self-injurious behaviour in a child or young person (e.g. sadness, shock, disbelief, guilt, helplessness, disgust or rejection), BILD have produced an easy guide for debriefing staff and tools such as “Daisy” can be a useful way to prepare and/or summarise feelings proactively thinking and reflecting about your own response to the event (Appendix 8).

It is important to consider ways to provide the support and supervision to staff into the busy school day which may require the use of creative ways of incorporating this, suggestions include 1:1 debrief after the students/pupils have left school.

It is also essential that staff are trained regularly in understanding self-injurious behaviour and how to positively support children and young people who show these behaviours.

## **Support for parents/carers**

It is also important to remember that parents/carers of children and young people who show self injurious behaviour are often required to support these behaviours with relatively little formal training, information or access to support. Siblings and wider family members may also be affected by these behaviours.

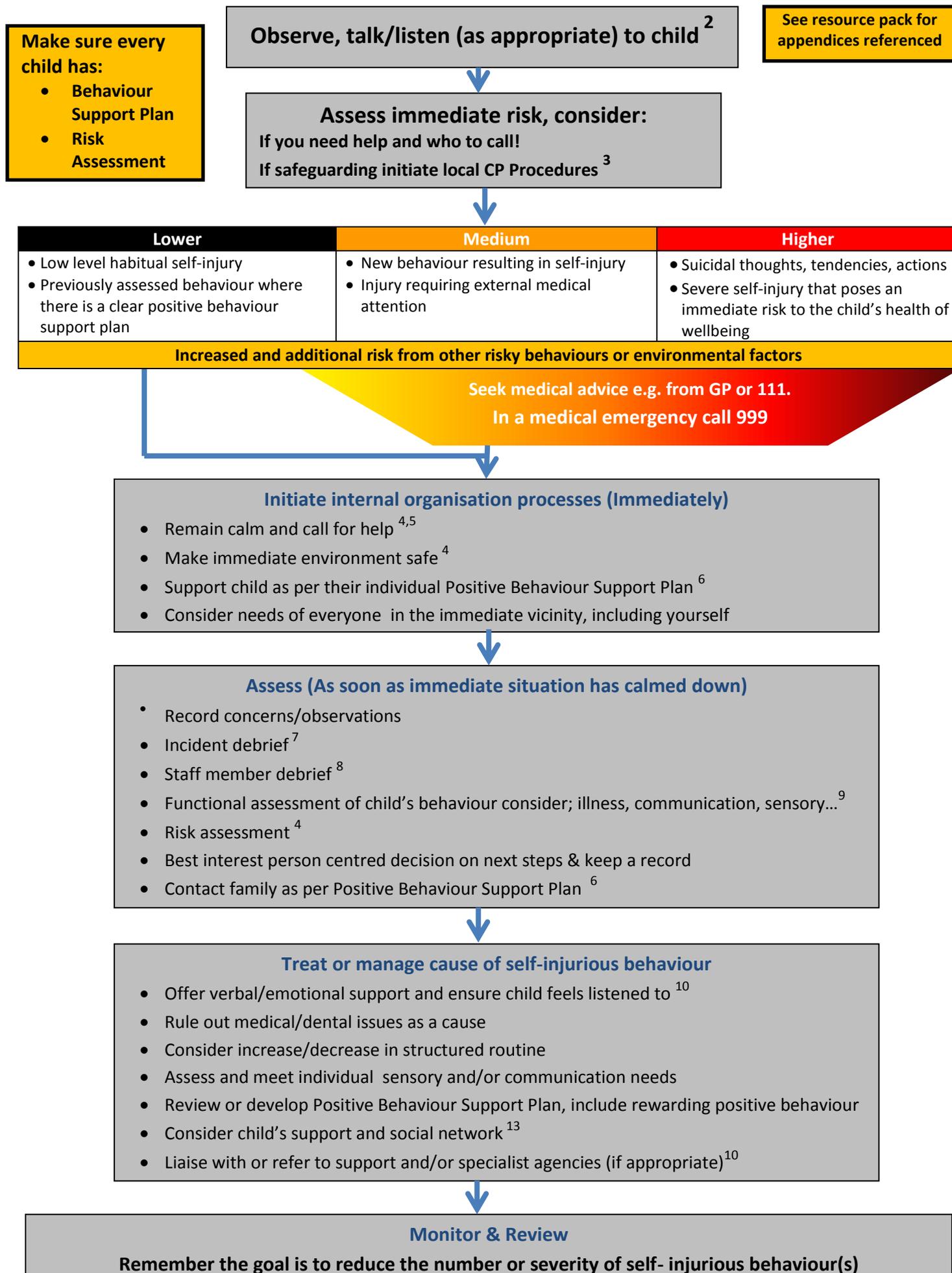
Families may be offered support through school, social care, CAMHS or other professions working with the child/young person.

It is important to involve parents/carers at every stage of the planning and support process and to maintain open lines of communication.

National resources and support can be accessed through The Challenging Behaviour Foundation <http://www.challengingbehaviour.org.uk/> and Self Injury Support [www.selfinjurysupport.org.uk](http://www.selfinjurysupport.org.uk).

# Appendices

## Appendix 1 – Managing self-injurious behaviour in children with SEND



**This guidance is written in the following context: This guidance was written after careful consideration of the evidence available including but not exclusively NICE, SIGN, EBM data and NHS Evidence. Professionals are expected to take it into account when exercising their judgement. The guidance does not, however, override the individual responsibility of professionals to make decisions appropriate to the circumstances of the individual**

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## Appendix 2- Do's and Don'ts- Quick Guide to Managing Self-injurious Behaviour

DO	DON'T
<p><b>Do Call for Help-</b> don't try and deal with it on your own as you may need to move the person</p> <p><b>Do Stay Calm-</b> Staying calm will help you to work out what to do next- is the child still in immediate danger? Do they need urgent medical attention? Staying calm also prevents your reaction from influencing future self-injurious behaviours (see page 5)</p>	<p><b>Don't Panic-</b> unfortunately self-injurious behaviour is common in children with SEND.</p> <p><b>Don't be too hard on yourself</b> – it can be difficult to know how to respond. Try to be aware of the impact of your own emotional response on the young person.</p>
<p><b>Do Listen-</b> People with disabilities have told us that they want to feel listened to (in the same way that those without a disability that self-harm want to feel listened to!)</p>	<p><b>Don't be judgemental-</b> keep an open mind about the behaviour and don't refer to it as 'copycat' or 'attention seeking'</p>
<p><b>Do Observe-</b> A child may say that everything is okay but their behaviour may suggest otherwise. Remember also that many children with SEND are non-verbal or have social or communication difficulties so it's important to observe all cues e.g. body language, facial expression and body control</p>	<p><b>Don't send them away!</b> Try and understand the reason for the behaviour (Functional Assessment) and offer alternative ways of coping and signposting to the right support. This will include signposting parents and staff as well as the young person if appropriate. If the young person has disclosed their behaviour to you It is important to make time for them.</p>
<p><b>Do include the child, parent/carer and staff team in your Concerns</b> - escalate your concerns where appropriate with those both within your organisation and outside of it, consider other agencies that may be involved</p>	<p><b>Don't exclude the child, parent or carer-</b> ensure that whatever actions you take they are person centred and have the best interest of the child at heart</p>
<p><b>Do Think-</b> carefully before you act- what is in the best interests of the child or young person</p>	<p><b>Don't leave the child or young person unsupervised-</b> It may be appropriate to leave the room but you should stay where you can see the child.</p>
<p><b>Do Consider Support Agencies-</b> In addition to statutory services such as CAMHS there are a range of support agencies that can help (see Appendix 10– useful resources) Consider asking for advice or making a referral</p>	<p><b>Don't assume each episode of self-injurious behaviour has the same cause!</b> You need to consider whether anything different could be causing the behaviour</p>
<p><b>Do ensure your organisation has appropriate procedures in place.</b> These should cover what to do if a child self-injures, functional analysis, positive behaviour management, self-management support and be supported by adequate training</p>	<p><b>Don't form a self-injurious behaviour self-help group or equivalent-</b> as this can encourage unhelpful copycat behaviours</p>

## Appendix 3: Buckinghamshire Safeguarding Procedures

The Buckinghamshire Multi-Agency Safeguarding Hub (MASH)/ First Response Team are responsible for dealing with child protection/safeguarding concerns.

Bringing together key partners and forging stronger links with other agencies enables information to be shared quickly and effectively and better informed decisions to be made by social care. This approach will assist in identifying risk at an earlier stage and result in appropriate early intervention in order to safeguard both vulnerable children and adults.

Referrals to MASH/First Response are assessed to check the seriousness and urgency of the concerns and to establish if children's social care need to be involved. This may be in the form of support for a child (Section 17 of the Children Act 1989) or where there are child protection issues (Section 47 of the Children Act 1989)

Where concerns do not need intervention from Children's Social Care families or professionals may be directed for help or provision to universal services and/or other specialist services.

MASH/First Response also provide advice and consultation to family members or to professionals where there is concern for a child.

### MASH/First Response Contact details

Call: 0845 4600001 or 01296 383962

Email: [secure-cypfirstresponse@buckscc.gcsx.gov.uk](mailto:secure-cypfirstresponse@buckscc.gcsx.gov.uk)

Fax: 01296 382207

Website: <http://www.buckscc.gov.uk/social-care/children-and-families/child-protection-and-safeguarding/>



### Buckinghamshire Safeguarding Policies and Procedures

For a copy of all Buckinghamshire safeguarding policies and procedures see:

<http://www.bucks-lscb.org.uk/bscb-procedures/>

## Appendix 4: Dynamic Risk Assessment



Shared by kind permission of Kite Ridge School, Bucks

### Proforma for assessing and managing foreseeable risk for challenging students

Name of Pupil: F

Name of Keyworkers:

Transport and driver:

Identification of Risk	
Describe foreseeable risk	F can become anxious and will seek aggressive confrontation towards staff and students. F will hit, slap, bite, kick, pull hair, head butt, throws objects with force and accuracy.
Is risk potential or actual?	Actual
Who is affected by risk?	Staff, students and F
Assessment of Risk	
In which situations does the risk usually occur?	When F has been redirected away from inappropriate behaviour, when he has been asked to do something he doesn't want to, wish denial, over stimulation, too much verbal/interaction.
How likely is it that the risk will arise?	Extremely likely
If risk arises who is likely to be injured/hurt?	Staff, students and F
What types of injuries or harm is likely?	Severe
How serious are the adverse outcomes?	Extremely serious

Assessment completed by:

Signed:

Date:

<b>Risk Reduction Option</b>			
<b><u>Measures</u></b>	<b><u>Possible options</u></b>	<b><u>Benefits</u></b>	<b><u>Drawbacks</u></b>
<b>Proactive measure to prevent risk</b>	<b>Clear room, therabands, deep pressure, regular breaks, short work tasks, step back, PPE</b>	<b>Supports sensory needs</b>	<b>None</b>
<b>Early interventions to manage risk</b>	<b>Distraction, planned ignoring, change of environment, change of face, reduction of demand, alternative communication method, space and time</b>	<b>De-escalation</b>	<b>None</b>
<b>Reactive interventions to respond to adverse outcomes</b>	<b>Restrictive intervention – double elbow, figure of four, half shield, back or front ground recovery</b>	<b>Stops violent action</b>	<b>Does not appear to calm F. Use only for a short period of time. Due to severity of head butts it is appropriate for taller members of staff to swap in when escorting F restrictively</b>
<b>Agreed Support Plan &amp; School Risk Management Strategy</b>			
<b><u>Focus of Measures</u></b>	<b><u>Measures employed</u></b>	<b><u>Level of risk</u></b>	

<b>Proactive measure to prevent risk</b>	<b>Clear room, therabands, deep pressure, regular breaks, short work tasks, step back, PPE</b>	<b>High</b>
<b>Early interventions to manage risk</b>	<b>Distraction, planned ignoring, change of environment, change of face, reduction of demand, alternative communication method, space and time</b>	<b>High</b>
<b>Reactive interventions to respond to adverse outcomes</b>	<b>Restrictive physical intervention – double elbow, figure of four, half shield, full shield, back or front ground recovery</b>	<b>High</b>

**Agreed by**

**Signed:** \_\_\_\_\_ **(Parent/guardian)**

\_\_\_\_\_ **(Keyworker)**

\_\_\_\_\_ **(Head of Unit)**

\_\_\_\_\_ **(others)**

**Communication of Support Plan & School Risk Management Strategy**

<b>Plans shared with:</b>	<b>Communication Method</b>	<b>Date Agreed</b>
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**Parents**

**Written**

**Social Services**

**Staff Training Issues**

<b>Identified training needs</b>	<b>Training Provided</b>	<b>Date completed</b>
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# Risk Assessment Form

Effective Date:

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<b>Risk Assessment Title</b>	
<b>Reference Number and Date</b>	
<b>Name of Service</b>	
<b>Summary</b> Briefly summarise what this risk assessment is about.	
<b>Benefits</b> If this is for someone we support, what are the benefits of this task/activity?	
<b>List of related documents</b>	

<b>Involvement</b> *You must involve people you support as much as you can. How will you involve them in completing this risk assessment?	
<b>Interested Parties</b> Who else will you involve in this risk assessment? For example; circle of support, care manager.	
* Maximum involvement is required by the Mental Capacity Act. For further information on person centred decision making, refer to the Person Centred Planning Guide.	

		Severity The worst harm you'd reasonably expect		
		Minor Up to 3 days off work	Serious Can't work or do normal activities for over 3 days.	Major Permanent injury, illness or death.
Likelihood of the worst reasonable harm happening.	Highly Unlikely	Risk Ratings		
		Trivial	Low	Medium
	May Happen	Low	Medium	High
	Likely	Medium	High	Intolerable

What are the hazards?	Who might be harmed and how?	What are you already doing?	What's the risk?	What extra action is necessary?	Action by who?	By When?	What's the new risk?	Action Done (v)
First Hazard			Severity				Severity	
			Likelihood				Likelihood	
			Risk Rating				Risk Rating	
Next Hazard			Severity				Severity	
			Likelihood				Likelihood	
			Risk Rating				Risk Rating	
Next Hazard			Severity				Severity	
			Likelihood				Likelihood	
			Risk Rating				Risk Rating	

What are the hazards?	Who might be harmed and how?	What are you already doing?	What's the risk?	What extra action is necessary?	Action by who?	By When?	What's the new risk?	Action Done (✓)
Next Hazard			Severity				Severity	
			Likelihood				Likelihood	
			Risk Rating				Risk Rating	
Next Hazard			Severity				Severity	
			Likelihood				Likelihood	
			Risk Rating				Risk Rating	
Next Hazard			Severity				Severity	
			Likelihood				Likelihood	
			Risk Rating				Risk Rating	

If there are more than six hazards in this risk assessment, attach another copy of this page.

Frontline Manager Quality Check:	Yes	No	Comments. If 'No', please explain in this column.
<b>Is the risk assessment of adequate quality?</b> (Clear English, enough detail, avoids ambiguous words and phrases, uses committed words like 'will' rather than 'should')	<input type="checkbox"/>	<input type="checkbox"/>	
<b>Does it include all significant hazards</b> (Rather than lumping all hazards together on one line?)	<input type="checkbox"/>	<input type="checkbox"/>	
<b>Were you able to involve interested parties enough?</b> (Such as families, advocates, care managers – especially if there are controversial decisions)	<input type="checkbox"/>	<input type="checkbox"/>	
<b>Do you agree with all the actions and guidelines?</b>	<input type="checkbox"/>	<input type="checkbox"/>	
<b>Are actions and guidelines based on the <i>hierarchy of controls</i>?</b> (Trying to avoid the hazard first, then considering safe place controls and then safe people controls as a last resort)	<input type="checkbox"/>	<input type="checkbox"/>	
<b>Have risks been reduced to the lowest level reasonably practicable?</b>	<input type="checkbox"/>	<input type="checkbox"/>	
<b>Were you able to explain this risk assessment to all staff at risk?</b>	<input type="checkbox"/>	<input type="checkbox"/>	
<b>If this risk assessment concerns a person you support, does it encourage them to take risks in a controlled way?</b> (Being innovative and finding less risky ways to enable?)	<input type="checkbox"/>	<input type="checkbox"/>	
<b>Were you able to explain the actions to the person(s) you support?</b>	<input type="checkbox"/>	<input type="checkbox"/>	
<b>Were you able to give them opportunity to appeal against the actions?</b>	<input type="checkbox"/>	<input type="checkbox"/>	
<b>Is the person able to consent to <u>all</u> actions in this risk assessment?</b> If 'No', do these actions amount to a 'Significant Decision' under the Mental Capacity Act? If so, have you evidenced that the actions are in the person's best interests? And where is this documented?	<input type="checkbox"/>	<input type="checkbox"/>	
<b>If this risk assessment refers to related documents, have you updated these documents in the light of any new actions?"</b>	<input type="checkbox"/>	<input type="checkbox"/>	
<b>Have you received risk assessment training in the last three years</b>	<input type="checkbox"/>	<input type="checkbox"/>	

Person(s) who uses the service		
Name(s):	Yes	No
<b>Do you agree with this risk assessment?</b> If 'No': attach comments, use complaints procedure or ask staff to do so.	<input type="checkbox"/>	<input type="checkbox"/>

People who completed this risk assessment		
Name	Signature / Initials	Date Signed

Management Declaration			
	Name	Signature	Date Signed
<b>Frontline Manager</b> I have made sure this form is completed fully and I will do my utmost to ensure any actions are carried out.			
<b>Area Manager</b> If you checked this risk assessment as part of your auditing or line management, please sign here.			

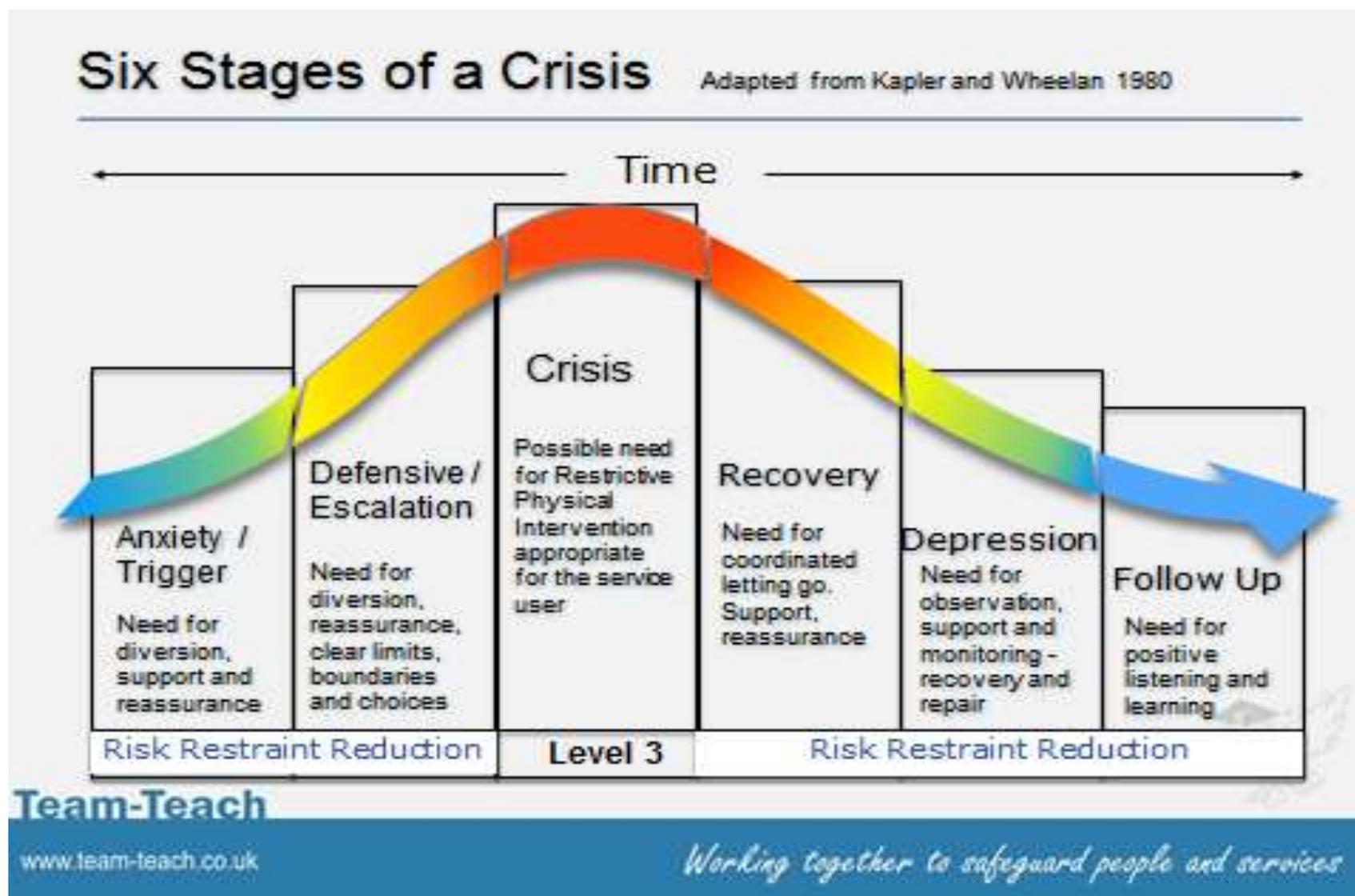
Minor Review		
If you review this risk assessment and it only needs small changes, summarise and sign here		
<b>Summary of changes:</b>  <div style="border: 1px solid black; height: 100px; width: 100%;"></div>		
Name	Signatures	Date Signed

Staff Team Declaration		
I understand this risk assessment and agree to follow its guidelines		
Name	Signature/Initials	Date Signed

Date for Next Review

## Appendix 5: Stages of a Crisis

Use this chart to understand stages of a crisis



## Appendix 6 Functional Assessment and Functional Analysis

### Good Practice Guidelines: Functional Assessment and Developing Positive Behaviour Support Plans (PBSPs)

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#### Key Points

- All PBSPs must be based on evidence captured through a functional assessment of the meaning behind the behaviour.
- A PBSP will be an extension of a good person-centred plan and so it can make sense for this to be one document.
- The assessment should consider all possible reasons for the behaviours of concern and further support should be sought where necessary, for example to investigate potential pain / health needs / sleeping difficulties.
- The child or adult should be supported to be involved in producing and understanding their own PBSP, for example through the development of an easy read version.
- The availability of an independent advocate to support this involvement should be encouraged
- As with person centred support plans, all PBSPs must include engagement in interesting and meaningful activities and teaching of skills which include opportunities for increasing choice and control, contribution and a sense of achievement.
- All PBSPs must include non-restrictive / first resort reactive strategies.

#### Functional Assessment

Functional assessment is a structured process for understanding the meaning behind a behaviour of concern. The flow chart over the page guides you through the stages of functional assessment, starting with person-centred planning, and provides information on who can help you at each stage.

The key stages are described in more detail in the text that follows.

## Functional Analysis Process Flow Chart

**PREVENTION** – all children should have a **PERSON-CENTRED PLAN** and person centred reviews leading to clear Outcomes including ‘a life that makes sense to me’ and ‘increases well-being’.

**EARLY IDENTIFICATION** – All staff should have an awareness of risk factors (e.g. mental health diagnosis, loss, changes to environment, previous or possible triggers) and observe, record and report behavioural changes. (see below)

**INITIAL FUNCTIONAL ASSESSMENT AND PBS PLAN** – Carried out by trained staff to consider all current, past, personal and environmental factors, carry out a brief functional assessment e.g. Motivational Assessment Scale , and formulate and implement a PBSP

**ADDITIONAL SPECIALIST SUPPORT** is sought by the team as needed e.g. referrals to investigate potential co-existing mental, or physical health conditions including sleep problems. See Health Notice board for support to achieve this.

**IN-DEPTH FUNCTIONAL ASSESSMENT** - If the PBSP is not effective, or needs are more complex, prompt and co-ordinated access to a more in-depth should be arranged. This assessment will need to be undertaken by a qualified Behaviour Analyst, or other professionals e.g. S&LT. A full multidisciplinary assessment will involve interviews with the child and their circle of support, direct observations, data collection and a review of case notes. A tool appropriate to the person’s needs like the ‘Behaviour Assessment Guide’ (IABA) guides the process.

## **Early Identification - Observing, Recording and Reporting Behaviours of Concern**

- All staff play a crucial role in observing, recording and reporting concerns and changes.
- The data you record should be objective – be very specific about what actually happened, when, where and for how long.
- If you are recording your opinions, perceptions or ideas make it clear that this is opinion and not fact.
- Report your concerns, with supporting evidence if you can, to someone who can help plan the next steps, e.g. your manager, a PBS Coach, or the person's Key Worker.

## **Risk factors including health needs**

Some conditions may increase the risk of behaviours of concern occurring, for example:

- Seizures
- Sleep disturbance
- Mental health problems- known, or new
- The loss of an important person for example may be a trigger for depression even if the person does not appear to register the loss in the way you might expect
- Infectious or pain related disorders e.g. constipation, indigestion, urinary infections, joint pain etc.
- Eyesight problems
- The onset of dementia which can occur much younger in some people with learning disabilities
- Anxiety as a result of a significant life change such as. a move, or change in staff.
- Communication difficulties
- Low levels of interaction
- Lack of stimulating activities
- Part of an underlying condition (behaviour phenotype) for example Prader Willi Syndrome, Cornelia de Lange

People with special educational needs and disabilities (SEND) can experience barrier to accessing health care, for example they may find it harder to communicate that they are in pain, or may find medical appointments overwhelming. As a result, people with SEND are more likely to have unmet or undiagnosed health needs.

Every person with SEND is entitled to general support from their GP and more often than not will have specialist health e.g. a paediatrician involved in their care. It is important to work in a coordinated way with other professionals such as health to ensure that a team around the child is developed.

## **Daily recording**

Each organisation should have systems for staff to record their observations at the end of a shift. This may be a daily log, a learning log, 4+2 questions (see PCA Noticeboard), or a diary of some sort. Staff should record their observations of things which work well as well as any observations of responses to situations, or activities, changes to behaviour, or concerns. The child should be involved in these evaluations. Can they indicate whether they liked, or

disliked the activity by choosing between two symbols, or tell you what is was about something that made them feel good, or not good?

### Keeping track of low level behaviours of concern: ABC Charts

ABC charts are one simple way of tracking a concern to find out more about it. Each time the concerning behaviour occurs record:

Date, time, persons present, location.	Antecedents of behaviour: What happened before the behaviour occurred?	Behaviour: a record of the behaviour and of any variation in frequency and severity, in different settings	Consequences of the Behaviour: possible reinforcers –positive or negative. (What makes it more or less likely.)

### Keeping track of low level behaviours of concern: Monitoring Forms

You may be asked to keep track of behaviours on quick recording sheet, for example by recording all incidences of a behaviour on a blank timetable using codes.

- B. Biting hand
- S. Slapping arm
- N. No self-harming behaviours

	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
7-8am	N	N	S	N			
8-9am	B	N	N				
9-10am	B	N	B				

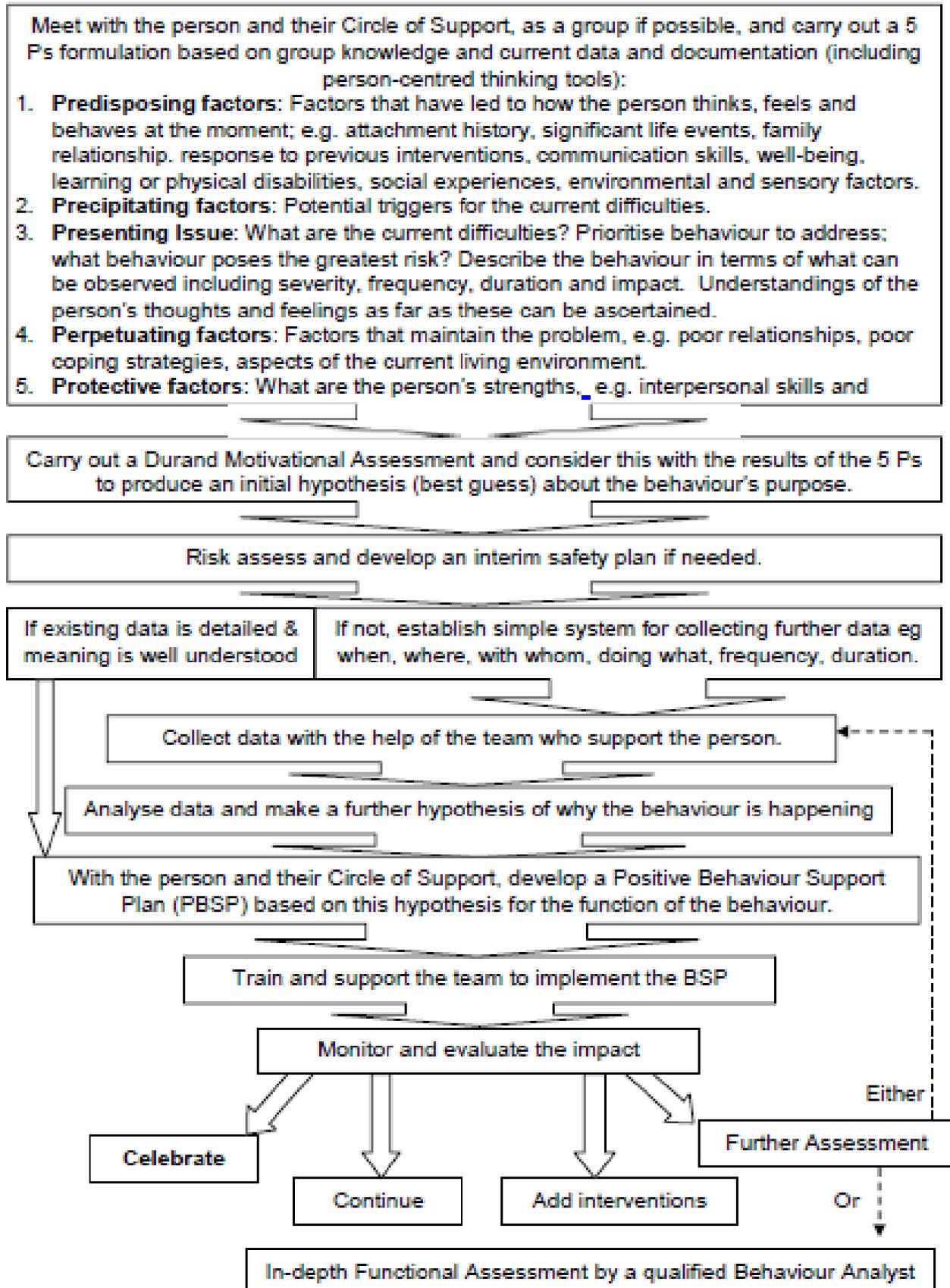
### Reporting High Level Incidents of Behaviours of Concern

High level incidents of behaviour and concern should be reported on an Incident Form and then recorded in the most appropriate place.

### Getting to Know You (GTKY)

- Before providing support to new children a thorough Getting to Know You process is essential.
- NICE Guidelines require early intervention and initial functional assessments to support people with SEND, so these documents should already exist for anyone who is known to have previously exhibited behaviours of concern.
- Before the child starts attending your organisation an Initial Functional Assessment and formulation of the initial PBSP based on the framework in the following section should be carried out.

## Initial Functional Assessment and Formulation of PBSP- Process Flow Chart



Adapted from: John Clements, BILD PBS Coaches materials, the '5 Ps model' & NICE '15.

## The Motivational Assessment Scale by Durand and Crimmins (1992)

<http://www.txautism.net/assets/uploads/docs/MAS-ed-KS-AK.pdf>

### Positive Behaviour Support Plan (PBSP) Quality Checklist

1. Checklist for a good person centred plan is all achieved. To avoid repetition it can be best to create one plan for the person. A plan does not have to be called a PBSP to be one!
2. Developed with the person with and the people who support them, including their family where possible.
3. The plan is based on a shared understanding of the meaning behind the behaviours based on an appropriate functional assessment process (see previous sections). Sensory interventions e.g. sensory rooms are only implemented following a sensory profile assessment.
4. The plan contains proactive strategies including at least one strategy in each category, unless there is a good reason not to include certain categories of strategy:
  - 4.1 Preventative strategies e.g. Removal or reduction of triggers. Introduction of a schedule or reinforcement e.g. a reward system for making a more positive choice.
  - 4.2 Environmental strategies e.g. adaptations to environment or routine (including long term strategies e.g. moving to a new service), staff learning to communicate using the person's preferred method.
  - 4.3 Strategies to increase the person's well-being e.g. increased purposeful activities, teaching skills to increase choice and control.
  - 4.4 Strategies to promote active engagement through structured and personalised daily activities
  - 4.5 Strategies to help them develop another behaviour that fulfils the same function by developing a new skill (for example, improved communication, emotional regulation or social interaction).
  - 4.6 Strategies to increase coping and tolerance over time e.g. anger management programme or gradual and controlled re-introduction of triggers.
5. The plan contains reactive strategies:
  - 5.1 De-escalation strategies to calm the person when they begin to show early signs of distress. A checklist is a good way of quickly showing which de-escalation techniques are known to work, or not work for the person. This can be broken down into different behaviours if responses are different. See examples in sample plans. De-escalation strategies include:
    - individual relaxation techniques
    - humour
    - simple listening
    - active listening – acknowledge how they might be feeling
    - distraction and diversion with activities, topics, or items they find enjoyable and rewarding
    - offering a choice
    - re-direction to programme
    - stimulus change – remove trigger

- agree to what they want
- allow take up time
- verbal advice and support
- reminder of successes
- reassurance
- apologise
- supportive touch
- social stories
- give space / step away
- change of staff member
- remove audience

5.2. If the plan contains restrictive strategies these have been authorised in line with the Good Practice Guidelines: Authorisation and Reduction of Restrictive Practices.

5.3. The reactive plan is comprehensive and staff are confident it.

### **Enabling Environments**

Enabling environmental adaptations to meet communication, sensory and physical needs should be evaluated and planned for through both the person's plan and the associated service plan. These may include:

- Developing low arousal environments where this is functionally appropriate (i.e. when sensory overload, or high anxiety have been identified).
- Developing total communication environments so children who communicate primarily through means other than verbal communication can access the resources they need to do this at all times.
- Planning for significant changes to environments to enable people to live in more socially valued homes, to maximise opportunities to connect people positively to their local community, to have enough space away from others, or to have safe access to the things the rest of us do as part of our daily lives (e.g. cooking our own meals).

### **Implementation of PBSPs**

- Staff will need to be taught the skills and systems for teaching any skills including in the PBSP.

# Positive Behaviour Support

...and why it should be included in service specifications.

1. Behaviour that challenges services
2. Positive Behaviour Support
3. Service Specifications

## Behaviour that challenges services

If people with learning disabilities do these things, their support staff can find it very hard to know to how to help.



Shouting



Hitting



Kicking



Biting



Not joining in



Hurting themselves

**Some reasons why people do these things:**



**Pain or  
feeling unwell**



**Unhappiness**



**Loud noise**



**They do not like  
certain people**



**People don't understand  
their communication**



**Being told to do  
things they don't  
want to do**



**Genetics  
(the type of learning  
disability a person has)**

## Positive Behaviour Support

- **Positive** - good, helpful, respectful, hopeful
- **Behaviour** - the things that people do and say
- **Support** - help that people get with everyday things

**It means trying to:**



Understand why a person behaves the way they do.



Look at things like where they live and how they are supported.



Find ways to prevent the behaviour from happening.



Find good ways to deal with the behaviour when it does happen.



Avoid the use of punishments to change a person's behaviour.

## Service Specifications



- **Service:** A residential home, assessment centre or organisation giving people care in their own homes.
- **Specifications:** A list of things that organisations promise to do, in order to give people good quality care.

Positive Behaviour Support has been proved to work. This means it has been tried with lots of people already, and it has helped them and their support staff.

**The specifications could include things like:**



- Everyone whose behaviour challenges services must have a Positive Behaviour Support plan.
- This plan must be based on information about everything in the person's life that could affect their behaviour.



- People with learning disabilities and their families must be involved in creating Positive Behaviour Support plans.



- Organisations must work with people in person-centred ways.
- Staff must learn about Positive Behaviour Support.

**Written by**

**Peter McGill – Tizard Centre**

**Easy Read version by Clare Tarling, People First Dorset.**





### Individual Behaviour Support and Risk Reduction Plan

Pupils name: J February 2015 D.O.B: 9/11/97		Date: 4 Renewal date: Sept 2015
<b>Known motivators interests and activities</b> Things J likes to do:	<b>Activities that J does not like to do:</b>	
Bean bag Drawing/colouring	Swimming Group lessons	
<b>Internal and medical factors that may influence the way J feels and behaves</b>		
Pain; sore mouth, period pain, thrush, sore from pulling finger nails, can lead to self-harm Temperature regulation: overheating can lead to self-harm		
<b>Any additional information that may influence the way J thinks, behaves or communicates</b>		
J communicates by smiling, pointing and vocalising		
<b>Slow triggers:</b> these may increase the risk and contribute to the occurrence of challenging behaviour but may not necessarily result in challenging behaviour in isolation.		
Frustration, feeling under pressure The sight of blood Too many people in her room or personal space Giving closed task instructions e.g. Over enthusiastic or high levels of praise Communication around food at lunch time Too many prompts to attend group activities Too much verbal interaction and people entering her personal space Saying 'no'		

**Fast triggers:** events that take place just before challenging behaviour occurs and have an immediate effect

Change of timetable while J is in the room

Pain

Too much noise in vicinity

Unfamiliar staff

Demands in general

Change to expected routine

Transitioning

Eating salty or bitter foods if she has a sore mouth

### **High risk situations/activities**

Accessing the community

Transport

Unexpected demands or activities

Unexpected visitors

Fire drill

Busy environment

no space to exit safely

**Proactive Strategies:** What do we need to do on a daily basis to enable J to maintain positive behaviour? Include J's personal preferences e.g. in relation to environment, interaction and communication.

- Visual timetable – symbols
- PECs – to choose activities or indicate wellbeing
- Makaton
- Social stories
- Transition; take up time
- Proprioceptive techniques; Massage and deep pressure
- Mirroring body language
- Personal space
- Minimal use of verbal language
- Clear, safe exitway
- Positive opt out; classroom PEC to leave activity
- Sanctuary to withdraw to
- Low arousal environment

**Praise points:** Three opportunities to positively reinforce appropriate behaviour

**Topography of challenging behaviour:** describe what the behaviour looks/sounds like

Self-harming

- Biting hands, knees
- Picking at mouth
- Pulling at finger nails
- Banging head on wall

High pitch vocalisation

Pulling hair of others

**Early warning signs:** What are the signs that J behaviour/anxiety is escalating

Self-harming

Very vocal

Staring at learning mentor

Covering ears

Rocking

Stripping

**Early intervention strategies and responses:** highlight and then describe the implementation of effective de-escalation, diversion, diffusion strategies that support J to remain calm.

**Verbal support** Humour **Contingent touch** Negotiation Calm body language and communication Informed of desired behaviours

**Fresh face** **Removal of audience** Change of task/activity Change of environment Distraction (key word/like/object/job/etc) Reminded of rules and consequences **Given choices** Reward system Planned ignoring Positive directive cards Other (please specify):

**Given choice:** avoid open choices, offer options from choice of 2 .....

**Fresh face:**

**Removal of audience:** visitor or learning mentor to leave the room

**Contingent touch:** foot or hand massage

**Verbal support:** use less language, keep language simple, use a calm intonation e.g. 'It's ok J' or 'J trousers', avoid negative language

**Crisis behaviour:** describe what behaviour J may display when in crisis

Intense vocalisation

- Screaming
- Crying

Intense self-harming behaviour

- Biting hands, knees, pulling at mouth
- Bang head on wall
- 

Stripping

Pulling hair of learning mentor or person nearby

Biting learning mentor

Run back to sanctuary

**Reactive intervention and responses:** describe the strategies that will keep J safe when in crisis

Leave room and allow time and space

Change of face

Restrictive intervention; team teach physical techniques are used to maintain safety and prevent serious self-injury or injury to others

- Steer away
- Seated single elbow
- Hair response
- Back ground recovery in incidents presenting extreme risk

**Post incident support:** describe the supportive strategies that enable J to recover and re-engage in activities

Observe and monitor

Give plenty of time to calm

Minimal interaction

Positive but not sustained gestural support and facial expression; smile, thumbs up,

**De-brief:** describe the de-brief procedures that will support J to evaluate and change behaviour

Social stories are used proactively to support J to respond appropriately in situations that she may find challenging. De-brief post incident can reinstate negative feelings and return J to crisis.

### Recording and Reporting

**School:** Follow school procedures for recording and reporting of serious incidents

**Parents:** inform parents by letter, phone call or diary

**Other:**

### Strategies that have been SUCCESSFUL in the past

Change of face

Planned ignoring

Leaving room

Allowing time to calm

Massage

### Strategies that have NOT been successful in the past and should NOT be used

Saying 'no'

Too much verbal communication or complicated language

Intruding in J's personal space when she is anxious



# Disability

## Distress Assessment Tool



Please take some time to think about and observe the individual under your care, especially their appearance and behaviours when they are both content and distressed. Use these pages to document these.

We have listed words in each section to help you to describe the signs and behaviours. You can circle the word or words that best describe the signs and behaviours when they are content and when they are distressed.

Your descriptions will provide you with a clearer picture of their 'language' of distress.

### COMMUNICATION LEVEL \*

This individual is unable to show likes or dislikes	Level 0
This individual is able to show that they like or don't like something	Level 1
This individual is able to show that they want more, or have had enough of something	Level 2
This individual is able to show anticipation for their like or dislike of something	Level 3
This individual is able to communicate detail, qualify, specify and/or indicate opinions	Level 4

\* This is adapted from the *Edinburgh Curriculum for Children and Adults with Profound Multiple Learning Difficulty* (Jones, 1994, National Postage Association)

### FACIAL SIGNS

#### Appearance

What to do	Appearance when content	Appearance when distressed
(Ring) the words that best fit the facial appearance. Add your words if you want.	Passive    Laugh    Smile    Frown Grimace    Startled	Passive    Laugh    Smile    Frown Grimace    Startled
	In your own words:	In your own words:

#### Jaw or tongue movement

What to do	Movement when content	Movement when distressed
(Ring) the words that best fit the jaw or tongue movement. Add your words if you want.	Relaxed    Drooping    Grinding Biting    Rigid    Shaking	Relaxed    Drooping    Grinding Biting    Rigid    Shaking
	In your own words:	In your own words:

#### Appearance of eyes

What to do	Appearance when content	Appearance when distressed
(Ring) the words that best fit the appearance of the eyes. Add your words if you want.	Good eye contact    Little eye contact Avoiding eye contact    Closed eyes	Good eye contact    Little eye contact Avoiding eye contact    Closed eyes
	Staring    Sleepy eyes	Staring    Sleepy eyes
	'Smiling'    Winking    Vacant	'Smiling'    Winking    Vacant
	Tears    Dilated pupils	Tears    Dilated pupils
	In your own words:	In your own words:

### BODY OBSERVATIONS: SKIN APPEARANCE

What to do	Appearance when content	Appearance when distressed
(Ring) the words that best fit the describe the appearance of the skin. Add your words if you want.	Normal    Pale    Flushed Sweaty    Clammy	Normal    Pale    Flushed Sweaty    Clammy
	In your own words:	In your own words:

**VOCAL SOUNDS** (NB. The sounds that a person makes are not always linked to their feelings)

What to do	Sounds when content	Sounds when distressed
<p><b>(Ring)</b> the words that best describe the sounds</p> <p>Write down commonly used sounds (write it as it sounds; 'tizz', 'eeow', 'teletetele');</p> <p>.....</p> <p>.....</p> <p>.....</p>	<p>Volume: high medium low</p> <p>Pitch: high medium low</p> <p>Duration: short Intermittent long</p> <p>Description of sound / vocalisation: Cry out Wail Scream laugh</p> <p>Groan / moan shout Gurgle</p> <p>In your own words:</p>	<p>Volume: high medium low</p> <p>Pitch: high medium low</p> <p>Duration: short Intermittent long</p> <p>Description of sound / vocalisation: Cry out Wail Scream laugh</p> <p>Groan / moan shout Gurgle</p> <p>In your own words:</p>

**SPEECH**

What to do	Words when content	Words when distressed
<p>Write down commonly used words and phrases. If no words are spoken, write NONE</p>		
<p><b>(Ring)</b> the words which best describe the speech</p>	<p>Clear Stutters Slurred Unclear</p> <p>Muttering Fast Slow</p> <p>Loud Soft Whisper</p> <p>Other, eg. swearing:</p>	<p>Clear Stutters Slurred Unclear</p> <p>Muttering Fast Slow</p> <p>Loud Soft Whisper</p> <p>Other, eg. swearing:</p>

**HABITS & MANNERISMS**

What to do	Habits and mannerisms when content	Habits and mannerisms when distressed
<p>Write down the habits or mannerisms, eg. "Rocks when sitting"</p>		
<p>Write down any special comforters, possessions or toys this person prefers.</p>		
<p>Please <b>(Ring)</b> the statements which best describe how comfortable this person is with other people being physically close by</p>	<p>Close with strangers</p> <p>Close only if known</p> <p>No one allowed close</p> <p>Withdraws if touched</p>	<p>Close with strangers</p> <p>Close only if known</p> <p>No one allowed close</p> <p>Withdraws if touched</p>

**BODY POSTURE**

What to do	Posture when content	Posture when distressed
<p><b>(Ring)</b> the words that best describe how this person sits and stands.</p>	<p>Normal Rigid Floppy</p> <p>Jerky Slumped Restless</p> <p>Tense Still Able to adjust position</p> <p>Leans to side Poor head control</p> <p>Way of walking: Normal / Abnormal</p> <p>Other:</p>	<p>Normal Rigid Floppy</p> <p>Jerky Slumped Restless</p> <p>Tense Still Able to adjust position</p> <p>Leans to side Poor head control</p> <p>Way of walking: Normal / Abnormal</p> <p>Other:</p>

**BODY OBSERVATIONS: OTHER**

What to do	Observations when content	Observations when distressed
<p>Describe the pulse, breathing, sleep, appetite and usual eating pattern, eg. eats very quickly, takes a long time with main course, eats puddings quickly, "picky".</p>	<p>Pulse:</p> <p>Breathing:</p> <p>Sleep:</p> <p>Appetite:</p> <p>Eating pattern:</p>	<p>Pulse:</p> <p>Breathing:</p> <p>Sleep:</p> <p>Appetite:</p> <p>Eating pattern:</p>

## Information and Instructions

### DisDAT is

intended to help identify distress cues in individuals who have severely limited communication.

designed to describe an individual's usual content cues, thus enabling distress cues to be identified more clearly.

**NOT a scoring tool.** It documents what many carers have done instinctively for many years thus providing a record against which subtle changes can be compared.

**Only the first step.** Once distress has been identified the usual clinical decisions have to be made by professionals.

**Meant to help you and the individual in your care.** It gives you more confidence in the observation skills you already have, which in turn will give you more confidence when meeting other carers.

### When to use DisDAT

**When the carer believes the individual is NOT distressed**

The use of DisDAT is optional, but it can be used as a  
- baseline assessment document  
- transfer document for other carers.

**When the carer believes the individual IS distressed**

If DisDAT has already been completed it can be used to compare the present signs and behaviours with previous observations documented on DisDAT. It then serves as a baseline to monitor change.

If DisDAT has not been completed:

- When the person is well known DisDAT can be used to document previous content signs and behaviours and compare these with the current observations
- When the person is new to a carer, or the distress is new, DisDAT can be used document the present signs and behaviours to act a baseline to monitor change.

### How to use DisDAT

- Observe the individual** when content and when distressed- document this on the inside pages. Anyone who cares for them can do this.
- Observe the context** in which distress is occurring.
- Use the clinical decision distress checklist** on this page to assess the possible cause.
- Treat or manage** the likeliest cause of the distress.
- The monitoring sheet** is a separate sheet, which will help if you want to observe a pattern of distress or see how the distress changes over time. It's use is optional. There are three types to choose from the website- use whichever suits you best.
- The goal** is a reduction the number or severity of distress signs and behaviours.

### Remember

- Most information comes from several carers together.
- The assessment form need not be completed all at once and may take a period of time.
- Reassessment is essential as the needs may change due to improvement or deterioration.
- Distress can be emotional, physical or psychological. What is a minor issue for one person can be major to another.
- If signs are recognised early then suitable interventions can be put in place to avoid a crisis.

### Clinical decision distress checklist

Use this to help decide the cause of the distress

#### Is the new sign or behaviour?

- Repeated rapidly?**  
Consider pleuritic pain (in time with breathing)  
Consider colic (comes and goes every few minutes)  
Consider: repetitive movement due to boredom or fear.
- Associated with breathing?**  
Consider: infection, COPD, pleural effusion, tumour
- Worsened or precipitated by movement?**  
Consider: movement-related pains
- Related to eating?**  
Consider: food refusal through illness, fear or depression  
Consider: food refusal because of swallowing problems  
Consider: upper GI problems (oral hygiene, peptic ulcer, dyspepsia) or abdominal problems.
- Related to a specific situation?**  
Consider: frightening or painful situations.
- Associated with vomiting?**  
Consider: causes of nausea and vomiting.
- Associated with elimination (urine or faecal)?**  
Consider: urinary problems (infection, retention)  
Consider: GI problems (diarrhoea, constipation)
- Present in a normally comfortable position or situation?**  
Consider: anxiety, depression, pains at rest (eg. colic, neuralgia), infection, nausea.

If you require any help or further information regarding DisDAT please contact:  
Lynn Gibson 01670 394 260  
Dorothy Matthews 01670 394 808  
Dr. Claud Regnard 0191 285 0063 or e-mail on [claudregnard@stoswaldsuk.org](mailto:claudregnard@stoswaldsuk.org)

For more information see  
[www.disdat.co.uk](http://www.disdat.co.uk)

### Further reading

Regnard C, Matthews D, Gibson L, Clarke C, Watson B. Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing*, 2003, 9(3): 173-6.

Regnard C, Reynolds J, Watson B, Matthews D, Gibson L, Clarke C. Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *J Intellect Disability Res*. 2007; 61(4): 277-292.

**Distress may be hidden,  
but it is never silent**

### **Behaviour Monitoring Chart**

<b>Date and Time</b>	<b>What was happening immediately before? i.e. what was the trigger? What was the student doing at the time?</b>	<b>What happened during the incident? Name all involved and those who were in the vicinity even if not directly involved.</b>	<b>How was the situation resolved? What happened afterwards? What methods were successful in calming the student?</b>	<b>Initials of person completing this form.</b>

## Appendix 7- Incident Debrief



Shared by kind permission of MacIntyre Registered Charity No. 250840

### Incident Debrief Form

**Name of member of staff**.....

**Name of debriefer**.....

**Date**.....

This form is intended as a prompt for debrief discussion following an incident. It is not prescriptive and you should use your judgement in holding the conversation, and be guided by the person you are debriefing. See BILD document "Easy guide; Debriefing for Workers" for more information.

Some sample questions that might be useful in supporting the person to reflect on what has happened:

What happened today?

What went well and what did not go well today?

What do you think could have been done differently?  
By you, by a colleague, by MacIntyre?

What would you do differently next time?

How do you feel about what happened?

What do you think you need from MacIntyre right now?

What do you think MacIntyre can do to improve things for next time?

- Agree follow-up actions:
- Offer advice and contact details for Health Assured
  - Further discussion in a day or two?
  - Work alongside someone for a period of time? etc?
  - Any other supportive measures?
- Book additional supervision?  
Review training/risk assessment/rota

Anything else to add?

Signed (member of staff):	Dated:
Signed (debriefer):	Dated:

## Staff Debrief

### The Daisy Model

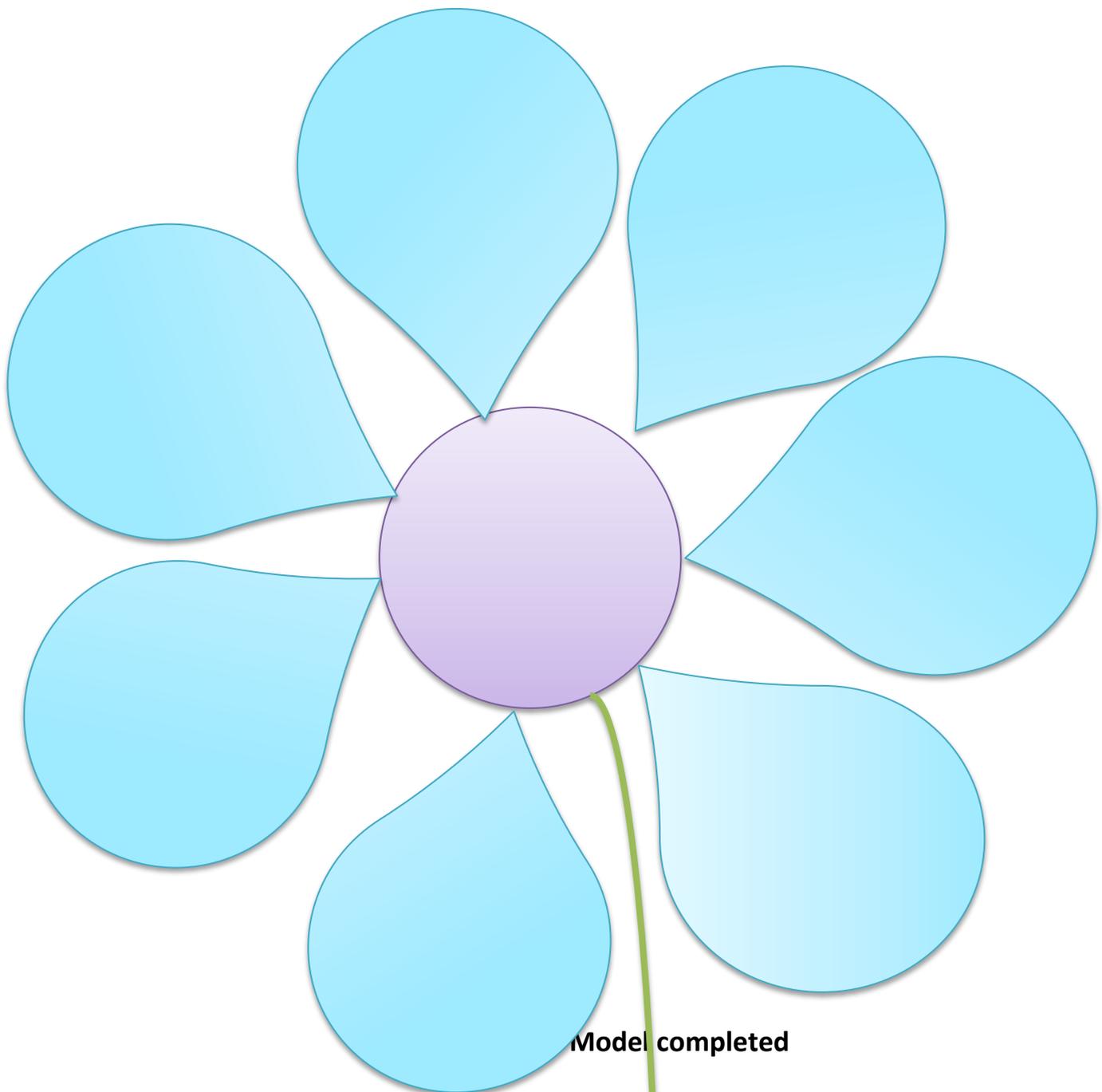
Date:

Incident (brief overview):

Staff involved:

Initials of person/ child concerning:

*\*Use the inside of the petals to note you worries, thoughts or concerns prior to the meeting, discussion or incident, using the outside of the petals to reflect on thoughts after the event\**



Model completed

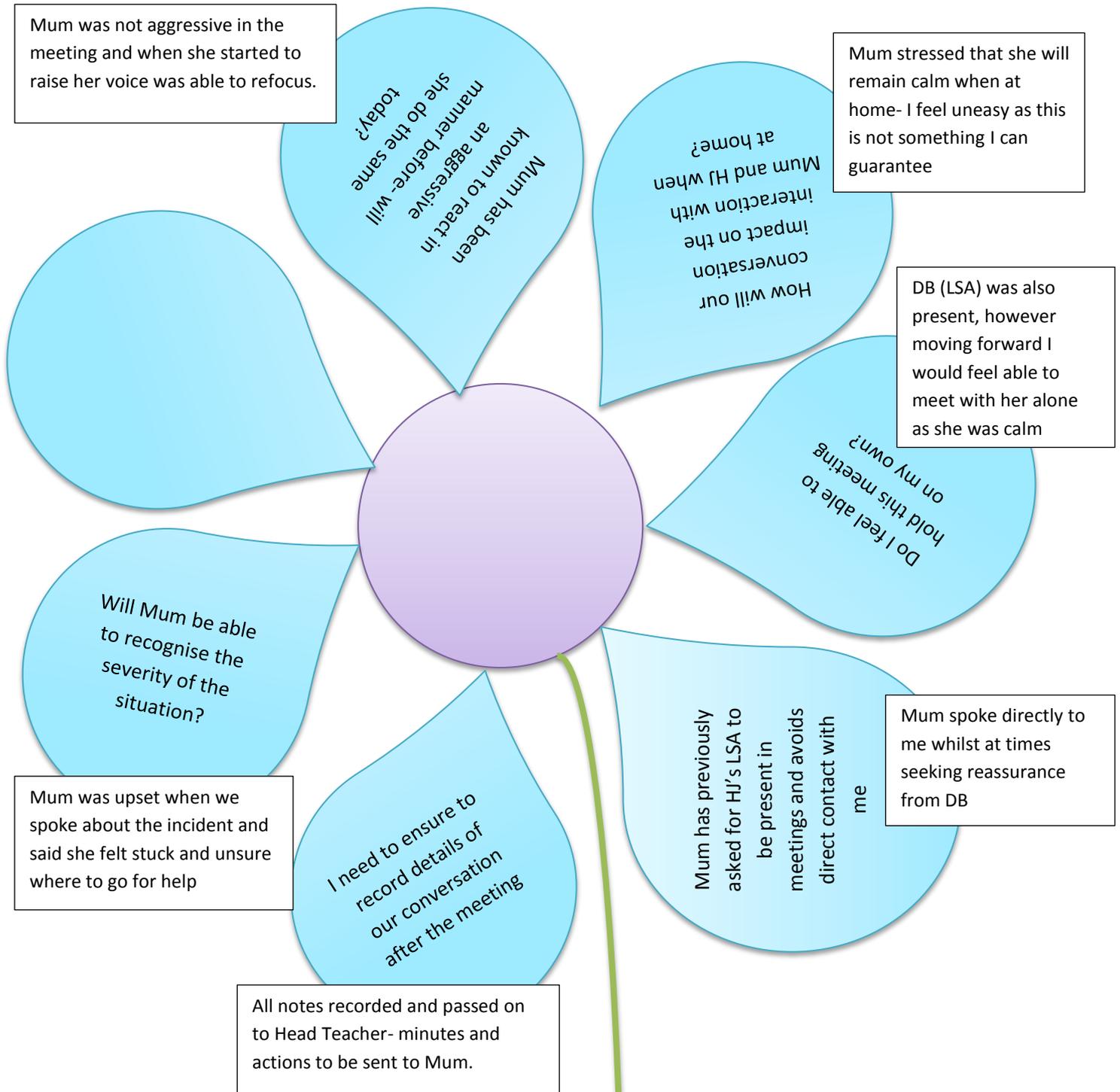
**Date:** 1/1/16

**Incident (brief overview):** Difficult conversation with parent regarding their child's (HJ's) behaviours at school- serious incident involving another child

**Staff involved:** SM and DB

**Initials of person/ child concerning:** HJ

*\*Use the inside of the petals to note your worries, thoughts or concerns prior to the meeting, discussion or incident, using the outside of the petals to reflect on thoughts after the event\**



## Appendix 8- Support for Self-Injury

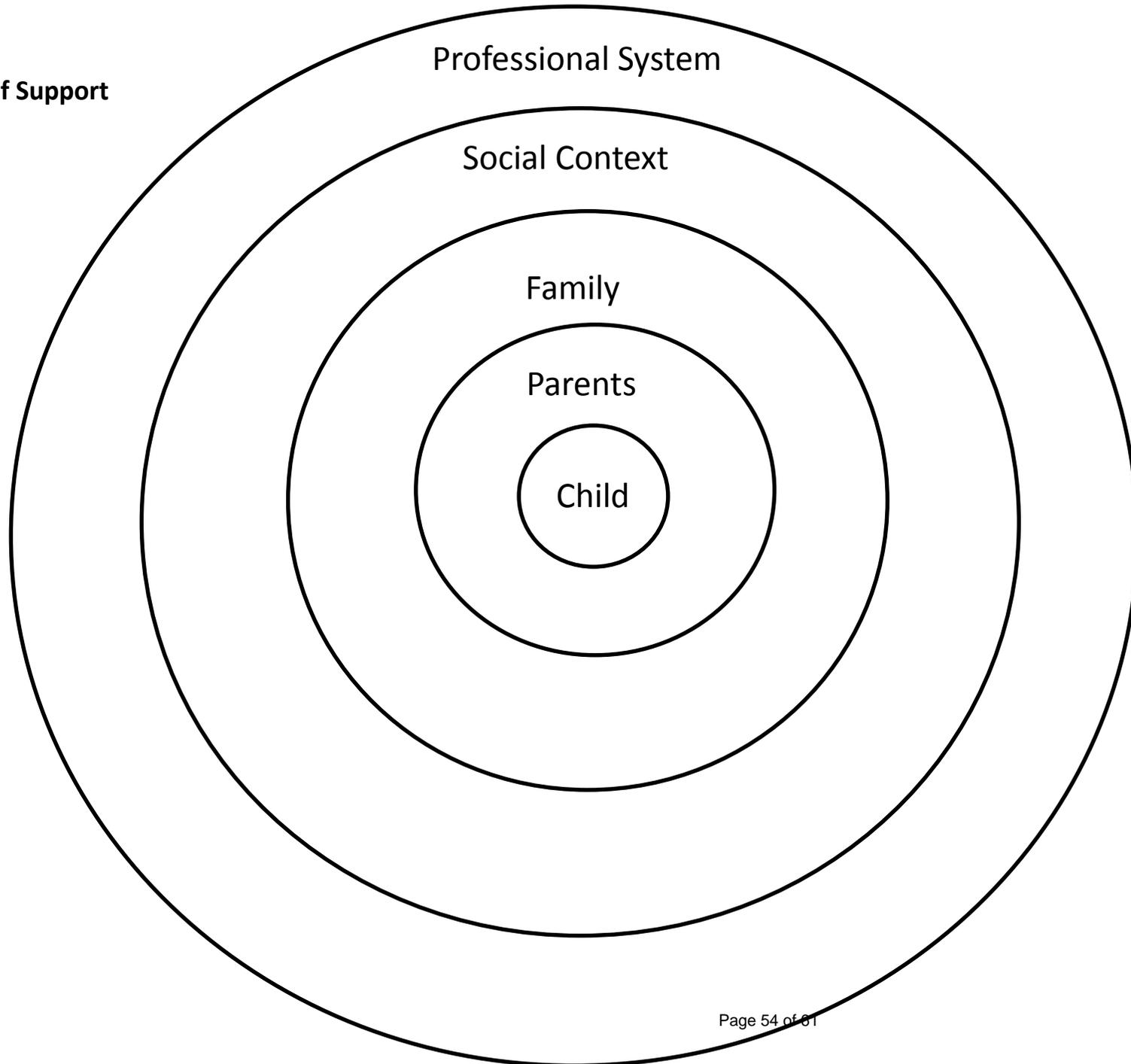
Access Guided workbook- available for free for people with learning Disabilities from [Self injury support](#)

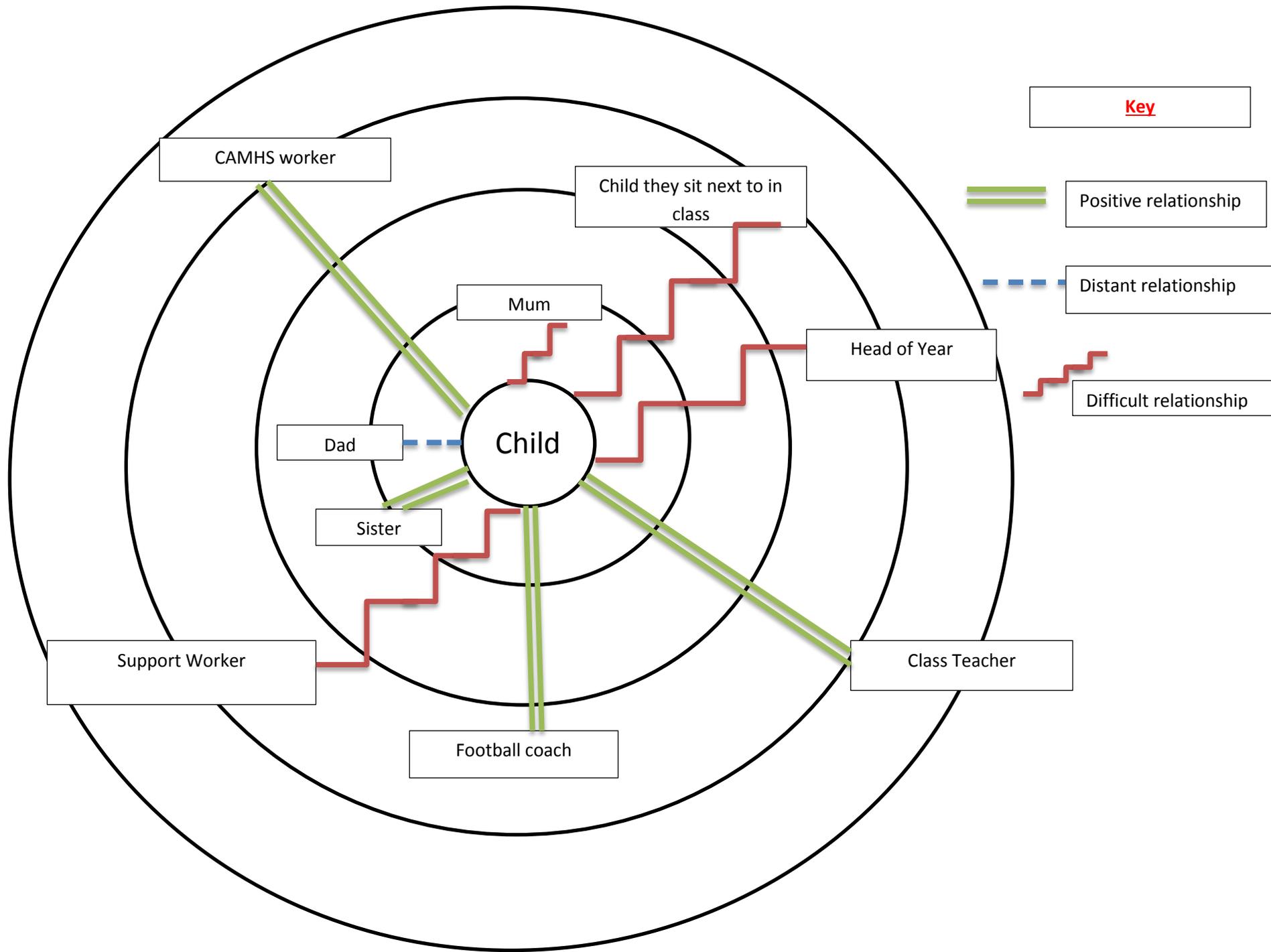
Distractions that can help [leaflet](#) from NHSN.co.uk

Circle of Support – see following sheets and website <http://mhfid.unified.co.uk/content/assets/pdf/resources/a-guide-to-circles-of-support.pdf>

Social stories – example attached shared with kind permission of MacIntyre Registered Charity No. 250840

Circle of Support



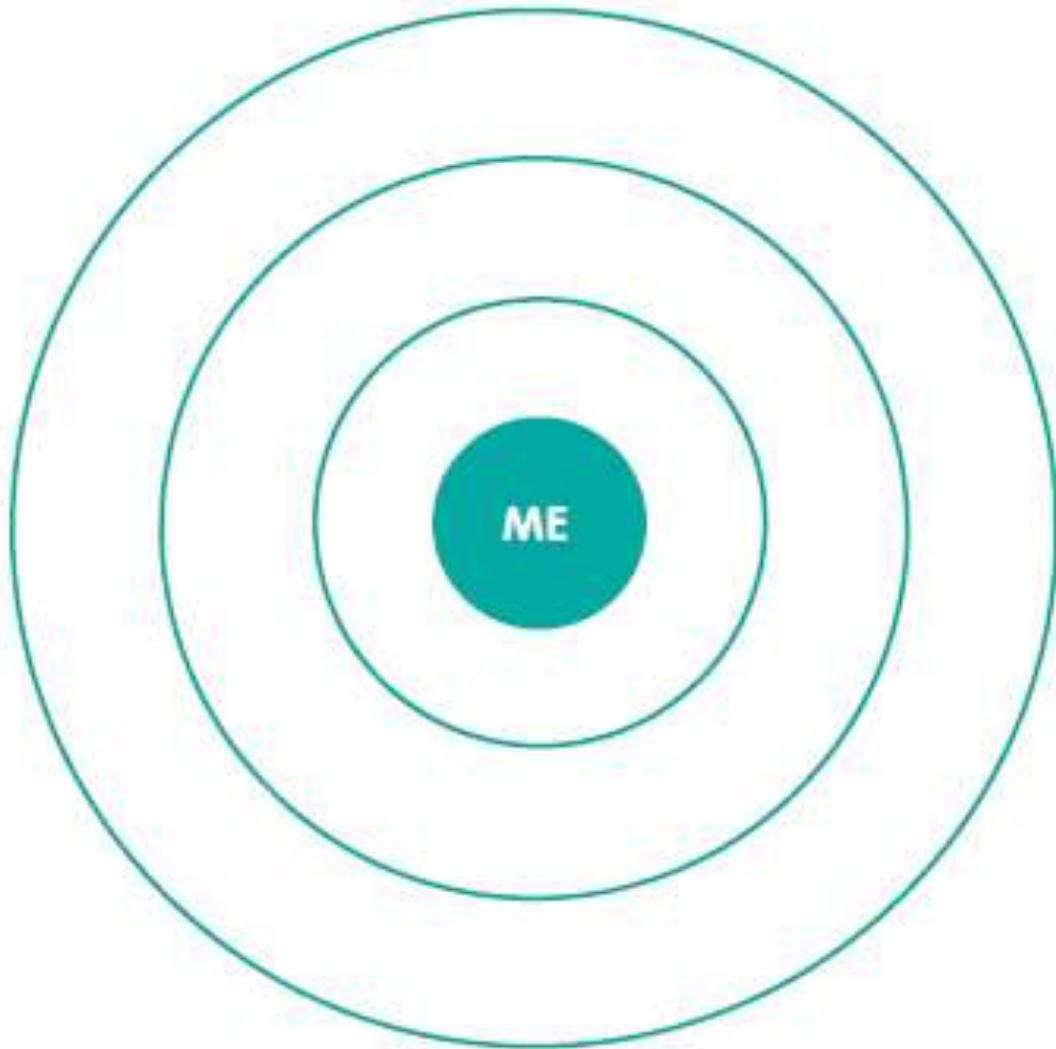


## My Safety Net

There are different types of people in our lives; try to identify some people in each of the groups below that you would feel comfortable talking to:

- 1 Family and close friends
- 2 Friends and people you see every day
- 3 Helpline and professional people you could go to for help

Also, write into the space below the safety net the things that you can do yourself to cope with difficult feelings and keep yourself safe.



Things I can do myself to cope with difficult feelings:

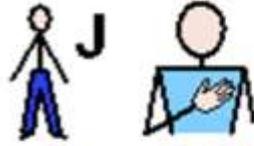
- .....
- .....
- .....
- .....
- .....

Example of social story as part of debrief support for Child and their peers

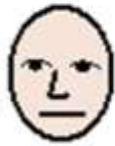
On Friday J hurt Himself



How did this make J feel?



Its ok to feel



When J feels J can go to



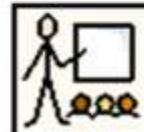
Joanna, Anna, Jenny or Vicky



When J feels J can go to the



sofa or ask to leave the classroom.





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[www.blobtree.com](http://www.blobtree.com)

A licence to use the Blob Tree for £5 can be obtained from  
<http://www.blobtree.com/products/blob-tree>

## Appendix 9 Support Agencies and Further Resources

Organisation	Contact	Website
<b>Local Support</b>		
Buckinghamshire MIND	01296 437328 <a href="mailto:info@bucksmind.org.uk">info@bucksmind.org.uk</a>	<a href="http://www.bucksmind.org.uk">www.bucksmind.org.uk</a>
Bucks Local Offer (Information & support for children with SEND)	01296 383065 <a href="mailto:familyinfo@buckscc.gov.uk">familyinfo@buckscc.gov.uk</a>	<a href="http://www.bucksfamilyinfo.org">www.bucksfamilyinfo.org</a>
Buckinghamshire Public Health (Emotional resilience support-FRIENDS & ZIPPY)	<a href="mailto:publichealth@buckscc.gov.uk">publichealth@buckscc.gov.uk</a>	<a href="http://www.buckscc.gov.uk/healthy-living/public-health">www.buckscc.gov.uk/healthy-living/public-health</a>
CAMHS	01865 901951 <a href="mailto:enquiries@oxfordhealth.nhs.net">enquiries@oxfordhealth.nhs.net</a>	<a href="http://www.oxfordhealth.nhs.uk">www.oxfordhealth.nhs.uk</a>
First Response/MASH - initial referral route for the most appropriate social care response including Family Resilience & Child Protection	0845 4600001 <a href="mailto:cypfirstresponse@bucks.gov.uk">cypfirstresponse@bucks.gov.uk</a>	<a href="http://www.buckscc.gov.uk/social-care/buckinghamshires-multi-agency-safeguarding-hub">www.buckscc.gov.uk/social-care/buckinghamshires-multi-agency-safeguarding-hub</a>
TalkBack	Amersham 01494434448 <a href="mailto:talkback@talkback-uk.com">talkback@talkback-uk.com</a> Aylesbury 01296 434448 <a href="mailto:nclude@talkback-uk.com">nclude@talkback-uk.com</a> Wycombe 01494446358	<a href="http://www.talkback-uk.com">www.talkback-uk.com</a>
Time to Talk local counselling	0845 408 5022 or 07764 210398 <a href="mailto:counselling@timetotalkbucks.org.uk">counselling@timetotalkbucks.org.uk</a>	<a href="http://www.timetotalkbucks.org.uk/">http://www.timetotalkbucks.org.uk/</a>
<b>National Support and Further Resources</b>		
Mind	Mind infoline: 0300 123 3393 email: <a href="mailto:info@mind.org.uk">info@mind.org.uk</a>	<a href="http://www.mind.org.uk">www.mind.org.uk</a>
Mencap	0808 808 1111	<a href="http://www.mencap.org.uk">www.mencap.org.uk</a>
Young Minds	0808 802 5544	<a href="http://www.youngminds.org.uk">www.youngminds.org.uk</a>

## Further Resources

Resource	Details
Action For children SIB guide	<a href="https://www.actionforchildren.org.uk/media/5767/easy_guide_self_injurious_behaviours_and_learning_disability.pdf">https://www.actionforchildren.org.uk/media/5767/easy_guide_self_injurious_behaviours_and_learning_disability.pdf</a>
British Institute of Learning Disability- factsheet on SIB	<a href="http://www.bild.org.uk/information/factsheets">http://www.bild.org.uk/information/factsheets</a>
Challenging Behaviour Foundation <a href="http://www.challengingbehaviour.org.uk">www.challengingbehaviour.org.uk</a>	<a href="http://www.challengingbehaviour.org.uk/understanding-behaviour/self-injurious-behaviour-sheet.html">http://www.challengingbehaviour.org.uk/understanding-behaviour/self-injurious-behaviour-sheet.html</a>
National Autistic Society Information about self-injury	<a href="http://www.autism.org.uk/About/Behaviour/Challenging-behaviour/self-injury">http://www.autism.org.uk/About/Behaviour/Challenging-behaviour/self-injury</a>
Relevant NICE Guidelines Challenging Behaviour Self Harm	<a href="https://www.nice.org.uk/guidance/ng11">https://www.nice.org.uk/guidance/ng11</a> <a href="https://www.nice.org.uk/guidance/cg16">https://www.nice.org.uk/guidance/cg16</a> <a href="https://www.nice.org.uk/guidance/cg133">https://www.nice.org.uk/guidance/cg133</a> <a href="https://www.nice.org.uk/guidance/qs34">https://www.nice.org.uk/guidance/qs34</a>
National Association of Special Schools- <a href="http://www.nassschools.org.uk">www.nassschools.org.uk</a>	<a href="#">E Learning Resource- Making Sense of Mental Health</a>
Mental Health First Aid <a href="https://mhfa.com.au">https://mhfa.com.au</a>	<a href="#">Mental Health First Aid</a> - Manual for additional needs
Children and Young People's Mental Health Coalition-	<a href="#">Resilience &amp; Results</a> <a href="http://www.partnershipforchildren.org.uk">www.partnershipforchildren.org.uk</a>
Foundation for people with a Learning Disability <ul style="list-style-type: none"> <li>• Friends for Life</li> <li>• Person Centred Planning</li> </ul>	<a href="#">FRIENDS for Life - Learning Disabilities</a> <a href="#">Person Centred Planning</a> <a href="http://www.learningdisabilities.org.uk">www.learningdisabilities.org.uk</a>
Partnership for Children- Zippy's friends for children with SEN	<a href="#">Children with Special Needs - Partnership For Children</a> <a href="http://www.partnershipforchildren.org.uk">www.partnershipforchildren.org.uk</a>
Resilience Based approaches to working with children and young people with complex needs	<a href="#">Getting hold of our stuff - boingboing.org.uk</a>
Child Bereavement UK- supporting children with bereavement who have SEND <a href="http://www.childbereavment.org.uk">www.childbereavment.org.uk</a>	<a href="#">Supporting bereaved children and young people with Autistic Spectrum Difficulties (ASD)</a> <a href="#">Children with special educational needs and their grief</a>  Courses and information/Resources
Self Injury Support <a href="http://www.selfinjurysupport.org.uk">www.selfinjurysupport.org.uk</a>	<a href="#">Hidden Pain? Self-injury and people with learning disabilities</a>

## Thanks

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Highworth Combined School

Booker Park School

Stocklake Park School

Children with Disabilities, Buckinghamshire County Council

Family Resilience Service, Bucks County Council

Community Paediatrics, Bucks Healthcare Trust

Stony Dean School,

Buckinghamshire Speech & language Therapy, Oxford Health Foundation Trust

Buckinghamshire Occupational Therapy, Buckinghamshire Healthcare Trust

Deaf CAMHS, Central England

Educational Psychology, Buckinghamshire County Council

Public Health, Buckinghamshire County Council

Chiltern Way Federation