



Making it happen: Positively managing risk for children and adults with severe learning difficulties

This information sheet may be useful for families who are:

- Supporting a family member with a severe learning disability whose behaviour challenges.
- Looking to understand what should be considered and who should be involved when making decisions about trying activities or attending events.



All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: [Feedback form](#)

Introduction

This information sheet is aimed at family carers, schools, colleges and adult support services. It sets out what should be taken into account and who should be involved when making decisions about starting activities or joining in events for children and adults with severe learning disabilities who may display behaviour that challenges.



Key Principles

- People should not be prevented from taking part in activities, attending school or services simply because they have complex support needs or display challenging behaviour.
- Risk management is a process to identify potential risks.
- Positive risk taking involves identifying how risks can be eliminated, minimised, mitigated and managed to ENABLE the person to take part safely wherever possible.
- The focus should always be to choose the least restrictive option that successfully mitigates risks and keeps the person and others safe.

What is risk?

There are risks in everything we all do and we all negotiate these risks all day every day without thinking about it very much. Risks can be high, low, or negligible, both in terms of likelihood (how probable it is) and in terms of impact (the effect it will have). Risks are mostly managed routinely (for example holding onto the handrail while walking up the stairs) but even high risks can be managed safely (for example- skydiving is high risk in terms of potential impact if something goes wrong, but the safety measures are stringent, so the likelihood of something going wrong is very low).

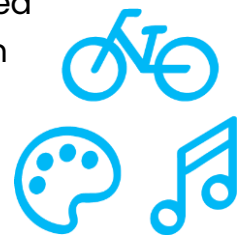


How to positively manage risk

We have summarised below the steps to follow to help enable activities to happen safely.

The positive management of risk involves a number of steps:

- Clearly specify the activity that needs to be assessed and the risks that need to be managed (one activity may have several potential risks– it is important to consider them all).
- Clarify the risks of engaging in the activity as currently planned. It is useful to estimate both the likelihood and the potential impact of these risks.
- Similarly, clarify the risks of not engaging in the activity. It is easy to forget this as the risks may be less concrete and more long-term.
- Completing a matrix that rates likelihood (e.g., unlikely, possible, likely) and the severity of impact (e.g., minimal, some, severe) is one useful way of assessing risk. Please see **appendix 4** for a blank grid you can fill in when assessing and managing risk.
- Identify how each specific risk (especially those that are likely and/or severe) can be mitigated or managed. Often there is more than one way of mitigating risk, and the different options might be weighed in terms of restrictiveness and/or preference.
- Throughout the process and especially in its latter stages (when activities have been specified, risks have been identified and mapped, strategies for managing risks have been laid out) key stakeholders should be involved. This should include, as much as possible, the person with a severe learning disability and should also include family members and others involved in their support. The aim should be to reach an agreement about the way forward, with everyone sharing their input, experience and solutions.
- At the conclusion of the process a decision needs to be made. In most cases this will mean that an activity continues or begins and follows an identified procedure to mitigate risk. If there is agreement that the risks of the activity cannot be managed, alternative activities that meet as many as possible of the original activity's goals should be considered.



Risk assessment is not a one-off process. The decision should be regularly reviewed to see if an activity can take place if the situation changes.

Legal Framework

The following Acts are relevant:

- [Children and Families Act 2014](#)
- [Care Act 2014](#)
- [Equality Act 2010](#)
- [Mental Capacity Act 2005](#)

The key legal duties to bear in mind are that:

- Children should be supported to facilitate their development and supported to achieve the best educational and other outcomes.
- There is a duty to promote the wellbeing of adults.
- There is a duty to make Reasonable Adjustments to ensure disabled people are not disadvantaged; and,
- People should be supported to make and communicate decisions for themselves where they are able; where they lack the capacity to do so, there is a duty to work out what is in their best interests.

What to do if you disagree with how risk is managed

If you think that the decision is risk adverse or the risks of the person not taking part in an activity or not seeing their family have not been properly considered, you can:

- Speak to the decision maker about your concerns. Ask if an individualised risk assessment has taken place. If not, request this.
- Ask for a copy of the risk assessment and check it contains information about:
 - The specific risks
 - The impact of the risk
 - The likelihood of the risk
- It may be that after you read the risk assessment you agree with the decision maker. If you do not agree with the risk assessment try to identify information that you think is



missing or incorrect and speak to the decision maker about your concerns

- If they do not take your concerns on board you may wish to put your concerns in writing, make a formal complaint or seek independent advice.

Please see Appendix 1 –3 for examples of how to assess and manage risk.

Appendix 1 – Risk matrix template

Appendix 2 – Assessing and managing risk when visiting a playground (during the pandemic).

Appendix 3 – Assessing and managing the risks around visits from family.

Appendix 4 – Assessing and managing the risk of resuming visits to the gym after a break

Further information

[Homepage for the Challenging Behaviour Foundation](#) – information about Positive Behaviour Support and a range of topics associated with challenging behaviour. Aimed at anyone who provides unpaid support to a child, young person, or adult with a severe learning disability.

[Learning Disability Helpline | Mencap](#) – the learning disability helpline offers advice and support for people with a learning disability, their families, and carers.

[\(IPSEA\) Independent Provider of Special Education Advice](#) – advice regarding any educational issue that is the result of a child’s special educational needs or disability. Includes advice on Covid-19 school re-openings and exclusions.

Special Educational Needs and Disabilities Information Advice and Support Services (SENDIASS) – offer information, advice and support for parents and carers of children and young people with special educational needs and disabilities. This service is also available to young people themselves.

To find your local service click [here](#)

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The Challenging Behaviour Foundation

We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email info@theCBF.org.uk, or visit our website: www.challengingbehaviour.org.uk

If you have found this information useful, please consider making a donation. You can show your support at www.challengingbehaviour.org.uk/support-us. Make a £5 donation by texting CBFDN05 to 70085 Or email us to get involved at support_us@theCBF.org.uk



Appendix 1

Complete the table below to help assess risk of engaging in a particular activity.

Activity:.....

	Likelihood	Very unlikely	Unlikely	Possible	Likely	Very likely
Severity of impact						
Minimal impact						

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Some impact						
Significant						

Very severe						
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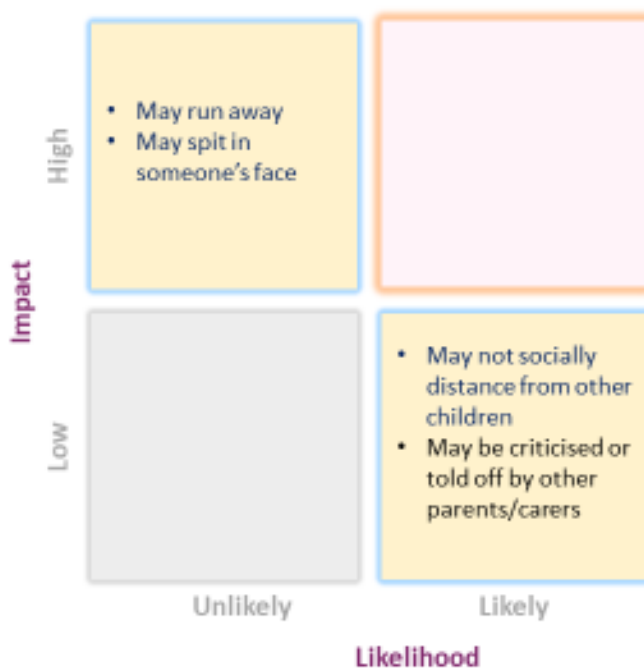


Appendix 2 – assessing and managing risks when visiting a playground (during the pandemic).

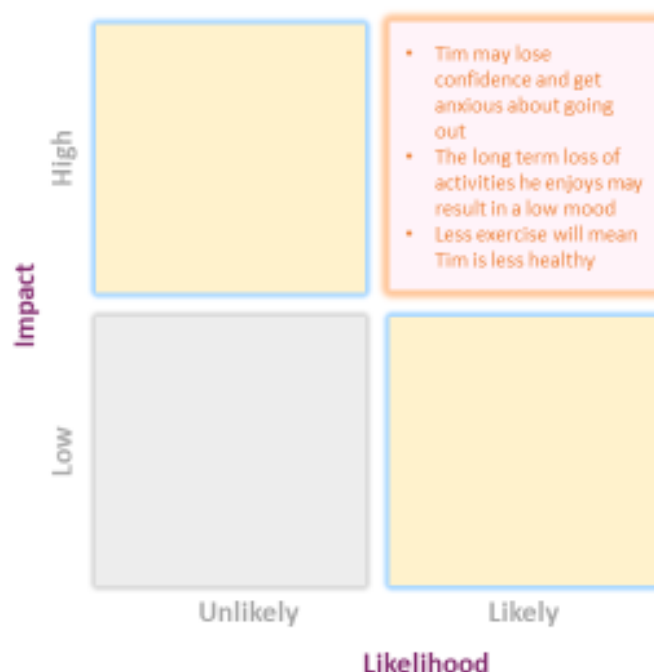
Step 1: Clearly specify the activity whose risks are to be assessed and managed.

Activity: Tim resuming weekly visits to the play park (a park within walking distance of Tim's home with play equipment he enjoys)

Step 2: Clarify the risks of engaging in the activity as currently planned. It is useful to estimate both the likelihood and the potential impact of these risks. A matrix setting out these risks can be found below:



Step 3: Clarify the risks of not engaging in the activity. It's easy to forget this as the risks may be less concrete and more long-term.



The box in the top right of the grid is outcomes which are both highly likely and have a high impact.

Step 4: Identify how each identified risk (especially those that are likely and/or severe) can be mitigated or managed. Often there is more than one way of mitigating specific risks and the different options might be weighed in terms of restrictiveness and/or preference

Managing risks associated with taking Tim to the play park:

Risk	Likelihood	Severity of impact	Options for how to manage or mitigate this risk
May be criticised or told off	High	High (Likely to result in anxiety or behaviours	<ul style="list-style-type: none"> Use a "Be Kind" CBF badge explaining that Tim has a severe learning disability

by other parents		that challenge)	<ul style="list-style-type: none"> • One support worker to explain what it says on Tim's badge if needed to other parents/carers in the playground • Only use the playground in bad weather when it is emptier
May not be socially distant from other children	High	Low (children are at low risk from Covid 19, especially when outdoors)	<ul style="list-style-type: none"> • Use a "Be Kind" CBF badge explaining that Tim has a severe learning disability • Do some work with Tim to teach a sign for "apart" to help him learn to avoid going too near to or touching strangers • Support workers to use distraction/encouragement to play on less busy play equipment • Only use the playground in bad weather when it is emptier
May spit in someone's face	Low (has only ever happened when Tim is extremely stressed)	High (Could have a negative impact on someone else and a long term impact on how Tim is perceived)	<ul style="list-style-type: none"> • Support workers to allow Tim freedom to do his favourite activities (even if he will get sandy etc) • Support workers to actively facilitate the experience so it will be enjoyable for Tim • Support workers to monitor Tim's mood to ensure he is enjoying the playpark

			<ul style="list-style-type: none"> • Support workers to discreetly monitor Tim's interactions with others to ensure he is enjoying the playpark & intervene to distract if required • Support workers to avoid any known triggers of stress eg large dogs • Support workers to check other children are not bullying/insulting Tim
May run away	Low (has only ever run away from activities where he feels restricted e.g. school)	High (Tim has no road sense so could put himself in danger if he absconded)	<ul style="list-style-type: none"> • Support workers to allow Tim freedom to do his favourite activities (even if he will get sandy etc) • Support workers to actively facilitate the experience so it will be enjoyable for Tim • Support workers to monitor Tim's mood to ensure he is enjoying the playpark • Support workers to avoid any known triggers of stress e.g. large dogs • Support workers to check other children are not bullying/insulting Tim • Support workers to remain arm in arm with Tim alongside the road on the way to the playpark • Support workers to remain arm in arm with

			Tim at all times whilst in the playpark
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Step 5: Involve key people. Throughout the process and especially in its latter stages (when activities have been specified, risks have been identified and mapped, strategies for managing risks have been laid out) key stakeholders should be involved. This should include, as much as possible, the person with a severe learning disability and should also include family members and others involved in their support. The aim should be to reach a consensus about the way forward

Who has been involved in discussions about Tim going to the play park?

Tim

Tim's mum, dad, sister and grandma.

Tim's support workers.

Tim's social worker.

Step 6. Weighing up risks and making a decision.

Everyone agreed that Tim should resume his weekly visits to the play park as the risks of not going are likely to have a much more severe impact on Tim's wellbeing in both the short and long term.

Visits will usually be on a Wednesday afternoon when two support workers are present to take Tim. There may be an additional visit at the weekend with two or more family members.

All the mitigations in the table will be used except for those in red which were agreed to be too restrictive.

Remaining arm in arm with Tim at all times while at the park would restrict his freedom to do his favourite activities and to choose what to play on. Although the impact of spitting or running away would be high, Tim has never exhibited these behaviours in the playpark before as both are associated with stress and it is a place where he feels happy and at ease. There would be warning signs if Tim was getting stressed and so support

workers could distract Tim onto another activity, away from the source of stress, or calm him down with a favourite snack to avoid these behaviours.

It was agreed that it would be disproportionately unfair on Tim for him to only enjoy the playpark in bad weather. He is not the only child unlikely to socially distance at the playpark and as far as we know the risks of transmission to children when playing in the open air are very low. Of course, if Tim were to display any covid 19 symptoms he would remain home and his family would order a test, consistent with everyone else.

2.

In this case the risks of not going to the park are much greater for Tim than the risks involved in going to the park.

Outcome

Tim has been hugely enjoying his weekly visits to the playpark. All problems encountered have been due to other people using the park, rather than any issues with Tim's behaviour.

Tim has been making great progress with learning "apart" which the family have been practicing daily. Tim doesn't usually manage to stay very much apart from other children (he is not the only one) but there have only been two occasions when parents at the playpark have expressed concerns to his support workers. They showed the CBF card, but also communicated "apart" to remind Tim.

Reviews: It will be reviewed by all stakeholders weekly to begin with, particularly as support workers have found the experience stressful, with extra covid restrictions and other people's judgements, even though they fully agree and can see the benefits for Tim. It helps to reflect on how things went and what could be done differently or better. Once everyone is used to the arrangement it will be reviewed monthly, unless rules change again.

Appendix 3 – Family visits

Maintaining contact with family and loved ones is important for everyone and people living in care homes often need support to process and enjoy visits from their family.

Family carers report that sometimes their visits are restricted – with reasons given that after the visits the person is distressed.

It is natural to feel sad or dysregulated when saying good bye to the people we love and for people with severe learning disabilities with limited verbal communication, the only way they have to communicate this upset may be through their behaviour.

These risks should be identified so support can be in place:

Risk	Likelihood	Severity of impact	Options for how to manage or mitigate this risk
P may become upset during the family visit	Low	High (Likely to result in anxiety or behaviours that challenge)	<ul style="list-style-type: none">• Mark family visits on the calendar and prepare P in advance• Think about the timing of the visits• Staff to have a positive attitude to family visits• Have a planned activity that P enjoys doing with her family• Staff to support P's family as required
The visit may be cut short due to other commitments or P's family may wish to stay longer than usual	Low	High (Likely to result in anxiety or behaviours that challenge)	<ul style="list-style-type: none">• P's family and keyworker to plan the length of visits in advance• Any changes are to be communicated as far in advance as possible and all staff are made aware

			<ul style="list-style-type: none"> • Use a sand timer or other appropriate visual cue as an object of reference so P knows the visit is coming to an end •
P may become upset when her family leave	High	High (Likely to result in anxiety or behaviours that challenge)	<ul style="list-style-type: none"> • Use visual supports to prepare P for the end of her family's visit (e.g. sand timer) • Plan an engaging activity or preferred snack for immediately after P's family's departure • Support P to look at the calendar to see when her family will next visit • Plan low demand but engaging activities for the evening following the family visit

In the example above P is unlikely to become upset when her family are around because she enjoys their visits. However, preparing P for her families visits using visual supports and planning activities in advance so P knows what to expect helps reduce the risk further. P is happy to stay at home or go out with her family as long as she knows what she is doing in advance.

P may become upset if the length of the visit is not what she expects. The likelihood of this is low because P's family and staff agree that P likes routine and 1pm until 5pm on a Saturday is the best time for her. If there is an unexpected change everyone is made aware and a sand timer is used because P knows that this means the visit is soon to end.

P does often become upset when her family leave and the impact of this can be severe as P is likely to display behaviours that challenge when her family leave if not supported well.

Staff and P's family have agreed that using a 10-minute sand timer as an object of reference helps P to know when to start to say goodbye and when her family will leave her house.

Staff have P's favourite snack ready and direct her to this when she has finished saying goodbye.

When P has finished her snack staff help her to mark her families next visit on the calendar, pointing out other activities that will happen before the next visit.

Staff keep P engaged in activities that she enjoys for the rest of the day, being mindful not to place too many demands on her. They use the proactive strategies in P's PBS plan if she shows signs of becoming distressed.

Appendix 4 Returning to an activity after an absence (e.g. illness)

When returning to a familiar activity use the existing support plan as a starting point.

The support plan will need to be updated to take into account any issues relating to the person's ill health.

One way to do this, is to arrange a visit to the gym, without your relative, with the opportunity of a walk through with a member of staff.

Take the support plan with you so you can go through it step by step identifying any changes, which may include, for example:

- Having to book a session
- Arriving and leaving promptly
- Gelling hands before, during and after a gym session
- Wiping down equipment before and after use
- Adjusting gym activities as a result of the person's ill health and need to gradually build up to previous levels of activity
- Following a one way system
- Music in the gym being played at a lower volume
- Taking photos/ short film clips that can be used to familiarise your relative with returning to the gym and any changes since they last went

Solutions to managing the above changes, could include:

- Booking a quiet time for the first couple of sessions back
- Using visual supports such as photographs/ short video clips of one way markers, social stories to explain why equipment has to be wiped down before and after use and a schedule showing what time to arrive and leave.

Familiarising your relative with these changes will be beneficial for other activities which are likely to have the same guidelines in place.

You can help your relative prepare for returning to the gym by:

- Developing a social story

- Sharing photographs of former times at the gym
- Choosing a time to go when the person is feeling well and keen
- Session plans should always be continuously updated. It may take a couple of goes before you get the plan exactly right.

Don't be afraid to ask for help from gym staff or professionals involved in your relative's support, e.g. speech and language therapist to write a social story, provide visual supports.