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Thank you.

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Introduction

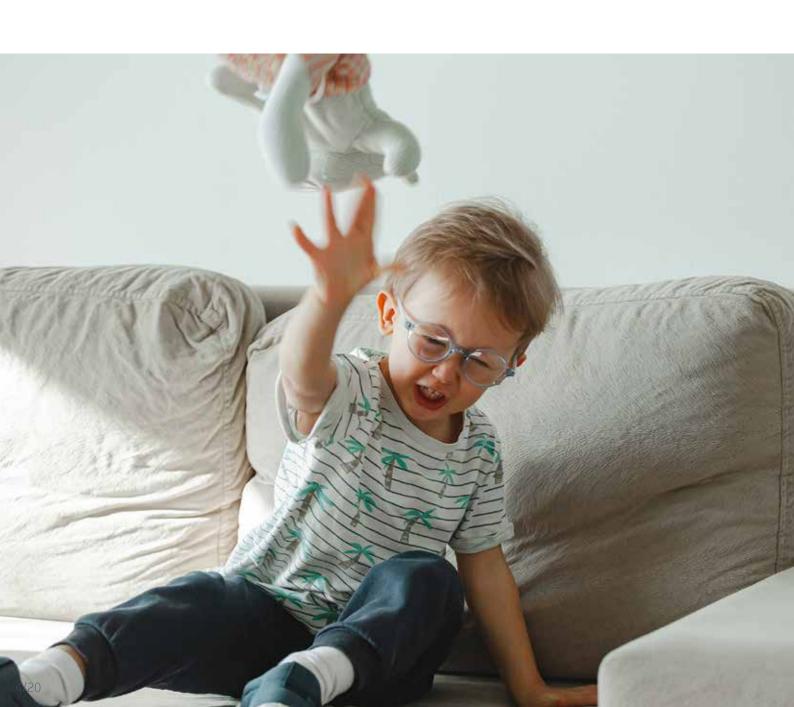
This guide aims to provide information about emotional outbursts for parents of children with intellectual disability.

Part I provides a general overview of what emotional outbursts are and how they come about.

Part 2 outlines the overall characteristics of emotional outbursts and their relationship with

specific neurodevelopmental or psychiatric conditions.

Part 3 summarises strategies that may help in reducing and managing the impact of emotional outbursts.



Part I

What are emotional outbursts?

Emotional outbursts are patterns of behaviour involving strong feelings which are disproportionate to the cause. They may occur suddenly when your child feels overwhelmed by their emotions or by what is happening around them.

A person experiencing an outburst may feel distressed and find it hard to calm themselves or be calmed by others. Outbursts can include several behaviours, which can range from crying or screaming, to physical aggression or self-injury.

Are emotional outbursts common?

In typically developing children, emotional outbursts are common, peaking at around age two and a half to three years, and rapidly decreasing by around 6 years old. As such, it is not unusual for your child to be having outbursts around this stage of their life. If they are still having frequent outbursts a few years after they start school, this is a sign that there may be a problem.

Showing continued outbursts beyond early childhood can sometimes be common in children who have a neurodevelopmental condition. It can also be common in those who have experienced trauma, whether or not they have a neurodevelopmental disorder.

People with intellectual disabilities can show higher levels of challenging behaviours, which commonly includes emotional outbursts.

Prevalence of outbursts can vary between conditions, but they are particularly common in people with Lowe, Prader—Willi and Smith-Magenis syndromes, which are neurodevelopmental conditions with a known genetic cause.

Why do emotional outbursts happen?

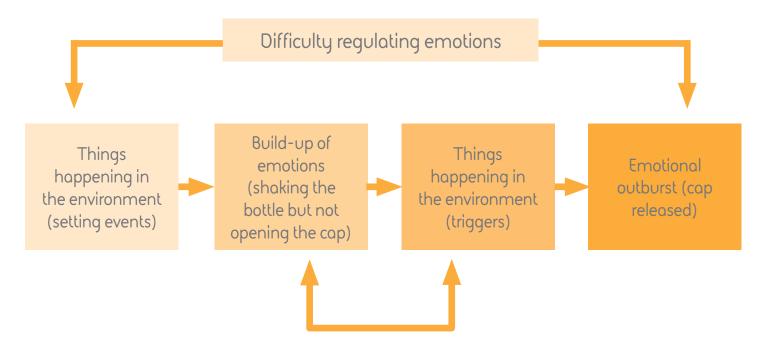
Emotional outbursts are linked to emotion regulation. This is the ability to influence what emotions we have, when we have them, and how we express and experience them. For example, when we stop ourselves from laughing in an inappropriate context or put on a smile when we don't feel like it, we are regulating our emotions in different ways. Emotional challenges such as anxiety or depression can be linked to difficulties with emotion regulation. Furthermore, the journey from childhood through to adulthood is an extremely dynamic time, which can make it even more difficult to regulate our emotions. Therefore, if your child is experiencing emotional outbursts, this might mean that they are struggling to regulate their emotions or regulating them in ways that are not effective.

Outbursts are typically triggered by what is happening around the person, for example, if your child's routine has been changed or if they feel uncomfortable in a situation. However, not every child will experience outbursts in the same way. Outbursts might occur in response to different environmental triggers, or without any environmental trigger. It is important to remember that, in some situations when your child is overwhelmed, they may not have control over whether an outburst occurs. Outbursts cannot always be explained solely by the diagnoses a person has, so identifying what triggers your child's outbursts is a positive step towards implementing strategies that can prevent them.

How do emotional outbursts build up?

It can be helpful to think about the process that leads to outbursts by using the analogy of a bottle

of fizzy drink. Each time something happens in the environment that is difficult for your child to cope with, think of it as the bottle being shaken. As these events happen, you may find that your child becomes increasingly anxious, so they become less and less able to cope with what is happening around them. Eventually, a trigger in the environment may cause the lid to come off and an outburst occurs.



It is important to remember that triggers can vary, and they may be small and insignificant things from our point of view. However, these triggers may in fact be very important to your child, so outbursts can occur because of these things, with or without any prior build-up. For example, some parents have reported that outbursts can be triggered by other family members arriving at the home unexpectedly, or the internet not working for a few minutes². Examples like these might seem trivial to some, but a range of things that have happened in the previous days or weeks (shaking the bottle of fizzy drink) have meant that the trigger has resulted in an outburst (taking the cap off the bottle).

How can anxiety around emotional outbursts be reduced?

Outbursts are usually tolerated in young children, but when they are happening to older children and adolescents, it can cause disorder or embarrassment in public places. Caregivers and children might avoid certain situations, trying to minimise the likelihood of an outburst occurring and the disruptions that they can cause.

This can result in everyone feeling isolated from wider family and friends and can actually increase the likelihood of an outburst occurring when families are eventually faced with the situation that has been avoided. This is because when we avoid certain things, the level of anxiety experienced over time will increase because we have not faced the situation and seen that nothing bad is going to happen. Therefore, by avoiding potentially upsetting situations, you may increase the anxiety around them and increase the likelihood of an outburst occurring, which in turn might make you want to avoid the situation even more!

To overcome this cycle, communicating with your child can be useful. Communication is especially important as it can help you and your child to anticipate and minimise any triggers. For example, some parents and caregivers find it helpful to explain what is going to happen to their child before they are going out or going to engage

with new people, if this is something which might trigger an outburst. Therefore, if this approach matches the level of your child's ability, it might help both you and your child to explain what is going to happen through pictures or drawings of the new environment or people that they might see. This can help your child to feel prepared for the situation and it may reduce the likelihood of an outburst happening³.

Part 2

Emotional outbursts can vary between people in terms of a range of factors (**Table 1**). This part of the guide provides an overview of how these factors are related to specific diagnoses, how they can be measured, and how these factors can affect the impact of emotional outbursts on everyday life.

Table 1. Important factors of emotional outbursts.

Factor	Example
How often do outbursts happen?	Multiple times a day
How long do outbursts last?	30-60 minutes
How long does it take for a person to recover from an outburst?	Over a day
What behaviours happen before outbursts?	Repetitive questioning
What behaviours happen during outbursts?	Screaming and kicking
What behaviours happen after outbursts?	Appearing withdrawn
What situations lead to outbursts?	Changes in routine

How are different diagnoses related to emotional outbursts?

Children with different diagnoses can share many similarities in their emotional outbursts, but there are some patterns of outbursts that can be particularly common in people with some genetic syndromes or other diagnoses. This section gives an overview of the patterns of emotional outbursts found in published research for people with Lowe syndrome, Prader-Willi syndrome, Smith-Magenis syndrome, or autism. There may be other patterns of emotional outbursts related to the above diagnoses and other diagnoses, which have not yet been researched.

Lowe syndrome

People with Lowe syndrome tend to experience emotional outbursts at home. Physical aggression

towards others and/or objects might be common behaviours during outbursts experienced by people with Lowe syndrome. A common trigger for people with Lowe syndrome seems to be related to frustrations around being prevented from reaching a particular goal (e.g., a child is playing in the garden, but it then starts raining)⁴.

Proder-Willi syndrome

Emotional outbursts experienced by people with Prader-Willi syndrome can often be related to frustrations about not being able to reach a particular goal. People with Prader-Willi syndrome may find it more difficult to switch between tasks, so unexpected changes to routines or expectations can be a common trigger for emotional outbursts. Being unable to access food can also be a trigger for people with Prader-Willi syndrome^{5,6}.

Smith-Magenis syndrome

Some emotional outbursts experienced by people with Smith-Magenis syndrome may occur when the person is receiving less attention from the adults around them than they would like (e.g., a parent, carer, or teacher)⁷. Some emotional outbursts may be linked to sleep problems that are commonly experienced by people with Smith-Magenis syndrome⁸.

Autism

Unlike genetic syndromes, there is no single cause for autism. A diagnosis of autism is based on the behaviour of a person. People with an autism diagnosis may be more likely to experience emotional outbursts (also commonly called "meltdowns") that are related to sensory sensitivities (e.g., loud or sudden sounds). People who are autistic might prefer a rigid routine and find unexpected changes in their routine or expectations difficult to manage^{3,9}.

Attention deficit hyperactivity disorder (ADHD)

Similar to autism, there is no single genetic cause for ADHD and the diagnosis is based on how a person behaves. ADHD can commonly occur alongside other conditions, including autism, which can increase the severity of emotional outbursts¹⁰. This may be related to additional differences in how people with ADHD process their thoughts and feelings, but the link is currently unclear.

Other co-occurring conditions

Having frequent and severe emotional outbursts can be related to a number of different behavioural conditions, such as conduct disorder, disruptive mood dysregulation disorder, intermittent explosive disorder, and oppositional defiant disorder. Although these diagnoses do not directly explain why a person experiences emotional outbursts, it may be important to bear in mind that emotional outbursts can be related to these conditions, to make sure that a person experiencing emotional outbursts has access to

the most appropriate forms of support.

How are emotional outbursts measured?

Emotional outbursts can be measured in many different ways, but there is currently no standard approach. Measuring outbursts in more detail may help families identify patterns related to the outbursts, which may require different types or levels of support. These patterns may include the types of situations that commonly lead to outbursts or the behaviours that happen before, during, or after outbursts. Most methods rely on parents to report details of past outbursts, which can be in the form of a questionnaire (e.g., the Emotional Outburst Questionnaire), an interview⁵, or a behaviour diary¹¹. Other methods may involve a researcher or clinician observing outbursts in different situations.

How do emotional outbursts impact daily life?

Emotional outbursts can affect people and their families in different ways and to different extents. The severity of outbursts can depend on the different factors related to outbursts. Some people may show self-injury or aggressive behaviours, which can put the safety of themselves and others at risk. Outbursts can disrupt learning in the classroom and affect peer relationships for the person experiencing outbursts9. Families can also feel isolated from their friends and extended family, who might be less aware of why emotional outbursts happen and how people experiencing them can be supported. These different factors can have a significant impact on the mental wellbeing of people who experience emotional outbursts and their families3. Therefore, it is important to identify effective ways to manage emotional outbursts to limit the impact that they may have on daily life. This process is discussed in more detail in Part 3 of this guide.

Part 3

Currently, there are few formal interventions that specifically help with emotional outbursts. However, identifying the situations that can lead to emotional outbursts can help us understand the reasons for the outbursts.

This process can be a key step in preventing and managing outbursts by addressing any difficulties that your child may be facing. You may find that the emotional outbursts experienced by your child are related to multiple reasons, which may require different strategies to manage. In this section, the strategies for managing outbursts are divided into three categories:

- What can be done to prevent emotional outbursts?
- What can be done during emotional outbursts?
- What can be done when calming down from emotional outbursts?

What can be done to prevent emotional outbursts?

Identifying situations that cause emotional outbursts

Keeping a behaviour diary can help you find patterns in the situations that are related to your child's emotional outbursts. You can make a note of the trigger (e.g., a sudden loud noise), where it happened and who your child was with (e.g., in the park with family), and what else had been going on prior to the outburst (e.g., a bad night's sleep).

Doing this may help you identify situations that consistently lead to emotional outbursts for your child. You may find that some outbursts always happen in response to certain triggers, whereas other outbursts may have no clear pattern in terms of triggers, but may instead be linked to

certain places, people, or events that happened earlier.

Identifying reasons for emotional outbursts

Your child may feel overwhelmed in different situations for various reasons. You might find that understanding what makes a situation difficult for your child to cope with helps your ability to identify and prepare for these types of situations.

Some of these difficulties (e.g. sleep problems) could be addressed directly with interventions, which might then help to reduce the outbursts experienced by your child. **Table 2** on page 10 lists some of the common reasons related to emotional outbursts.

Table 2. Common reasons and situations related to emotional outbursts.

Reason	Examples of common situations
Cognitive inflexibility	Changes in plan or routine
Pain and discomfort	Out of the blue
Sleep	Tired
Sensory sensitivity	Loud or sudden noises Crowded areas
Safe environment	At home With close family members
Unsafe environment	In public With people other than close family members
Learned behaviour	Being asked to do something Being refused or unable to get something
Communication	Wanting or needing something to start, stop or pause Not understanding someone else

Cognitive inflexibility

If you find that your child experiences outbursts when there are changes in their plans or routines, this may be due to difficulties in being able to think flexibly and switch their attention between tasks. Children who struggle with changes may prefer a rigid routine, but gradually introducing some flexibility may help to build up their tolerance for unpredictable changes. For more information, please see Cognitive Difference: Inflexibility and Impulsivity - A Guide for Parents (https://cerebra.org.uk/download/cognitive-difference-cognitive-inflexibility-and-impulsivity/).

Pain and discomfort

If your child is experiencing pain or discomfort, they may be less able to control and express their feelings as effectively across situations. Outbursts may be a way for a person to communicate their pain or discomfort if the person has difficulties communicating with others. You may find that outbursts related to pain or discomfort can happen out of the blue or there may not be a clear pattern of situations related to these outbursts. Some parents have also noticed that their children's diet has an effect on outbursts, which might be related to feelings of pain or discomfort. For more information, please see Pain - A Guide for Parents (https://cerebra.org.uk/download/pain-a-guide-for-parents/).

Sleep

Parents often notice that their children are more likely to experience outbursts if they feel tired, which can be linked to sleep problems. You may find that when your child is tired, they may struggle with situations that they could normally cope with. Similar to when experiencing pain or discomfort, your child may be less able to control

or express their feelings when they feel tired. For more information, please see Sleep - A Guide for Parents (https://cerebra.org.uk/download/sleep-a-guide-for-parents/).

Sensory sensitivity

It is important to be aware of any sensory sensitivities your child may have, as too much sensory stimulation can directly trigger outbursts. Your child may also find it more difficult to cope with other demands when there is too much sensory stimulation. For example, if your child is hyperreactive to sounds, a sudden noise may trigger an outburst. However, if your child is in a noisy place (e.g., in a supermarket), they may not experience an outburst until they are faced with tasks or demands that they are normally fine with (e.g., being asked what kind of cereal they would like). For more information, please see Sensory Processing - A Guide for Parents (https://cerebra.org.uk/download/sensoryprocessing/).

Safe environment

Some families tell us that their children experience outbursts only when at home or with close family members, which may be because they feel safer in these situations. If you notice that your child mostly experiences outbursts when they feel safe, they may be hiding or camouflaging how they feel in situations where they are struggling (e.g., at school). When your child returns to a place where they can feel safe again, they may be less able to cope with tasks or demands due to all of their bottled-up feelings, so they may be more likely to experience outbursts. Therefore, it may be helpful to work with the people who are responsible for your child in those other environments to find out what may be causing these negative feelings for your child and what can be done to help.

Unsafe environment

If you notice that your child experiences outbursts outside of the home or with people who are less familiar, they may be struggling because these situations feel less safe. If your child feels less safe in these situations, they may feel more anxious and be less able to effectively control and express their feelings.

Learned behaviour

You might find that in some situations, your child experiences outbursts that stop if the trigger is removed. Common examples of these situations could include being asked to do something, being refused or unable to get something, or someone moving away from your child. Although outbursts in these situations may have started because of other reasons, these outbursts could be unintentionally rewarded by how other people respond, so that outbursts become associated with these triggers being stopped or removed. As this form of learning can have an important role in shaping every behaviour, this process has been covered in a previous resource concerning self-injurious behaviour; for more information, please see Research Summary - Self-injurious Behaviour in Children with an Intellectual Disability (https://cerebra.org.uk/wp-content/ uploads/2020/01/Self-injurious-behaviour-2019-low-res.pdf).

Communication

If your child has difficulties with communication, emotional outbursts may happen in situations where they find it hard to understand or communicate with others. For more information, please see Communication with Children with Severe or Profound Intellectual Disabilities - A Guide for Parents (https://cerebra.org.uk/download/communication-with-children-with-severe-or-profound-intellectual-disabilities/) and Information Sheet - Communication and Challenging Behaviour (https://www.challengingbehaviour.org.uk/understanding-behaviour/communication-sheet.html).

Using calming strategies

If your child has access to strategies that can reduce their distress or anxiety, they may be more able to cope with some situations. Selfcalming strategies can vary from person to person, but examples can include breathing exercises, physical activity, or sensory stimulation (e.g., listening to calming music). You may find that your child needs to be prompted or supported in using these strategies, but they may learn to use these strategies on their own with practice. There may also be strategies that you could use to help calm your child, such as diverting their attention away from the situation or using humour to distract them. For more information, please see Anxiety - A Guide for Parents (https://cerebra.org.uk/download/anxiety-guide-a-guide-for-parents/).

Helping your child recognise their emotions

If your child can identify when they feel distressed or anxious, they may be more able to use a selfcalming strategy before their feelings escalate into an emotional outburst. Similarly, if your child can communicate how they feel (e.g., verbally, or by pointing to a picture card associated with distress), you or the people around your child may be more able to help them use a calming strategy. Some children may find psychological therapy, such as cognitive behavioural therapy, helpful in finding ways to think and feel differently in situations that would otherwise distress them. A Clinical Psychologist may be able to help by adapting the therapy, so that it is more suitable for your child. For more information, please see Anxiety - A Guide for Parents (https://cerebra. org.uk/download/anxiety-guide-a-guide-forparents/).

What can be done during emotional outbursts?

As an emotional outburst escalates, you may find that it becomes increasingly difficult to help your child calm themselves. During the outburst, it may help for you to appear calm and create a calm environment around your child, which may help them de-escalate from their outburst. In these situations, one of the priorities is to make sure that your child and the people around them are safe. For example, you may need to remove

other people or objects from the environment to reduce the risk of harm to your child or the people around them. In some situations, restrictive strategies, such as physical restraint may be required to ensure that your child does not harm themselves or others. However, it is critical that restrictive strategies are only used as a last resort and with appropriate training, so non-restrictive strategies should be used whenever possible. For more information, please see Information Sheet - Positive Behaviour Support Planning https://www.challengingbehaviour.org.uk/information-and-guidance/positive-behaviour-support/pbs-an-information-pack-for-family-carers/.

What can be done when calming down from emotional outbursts?

As your child de-escalates from their outburst, it may be helpful to maintain a calm environment with low demands, which may help your child recover from the outburst and avoid the risk of reescalation. Other strategies may include checking the physical and mental well-being of your child and the people around them at the time of the outburst. For more information, please see Information Sheet - Positive Behaviour Support Planning (https://www.challengingbehaviour.org.uk/learning-disability-assets/003positivebehavioursupportplanningpart3os l.pdf).

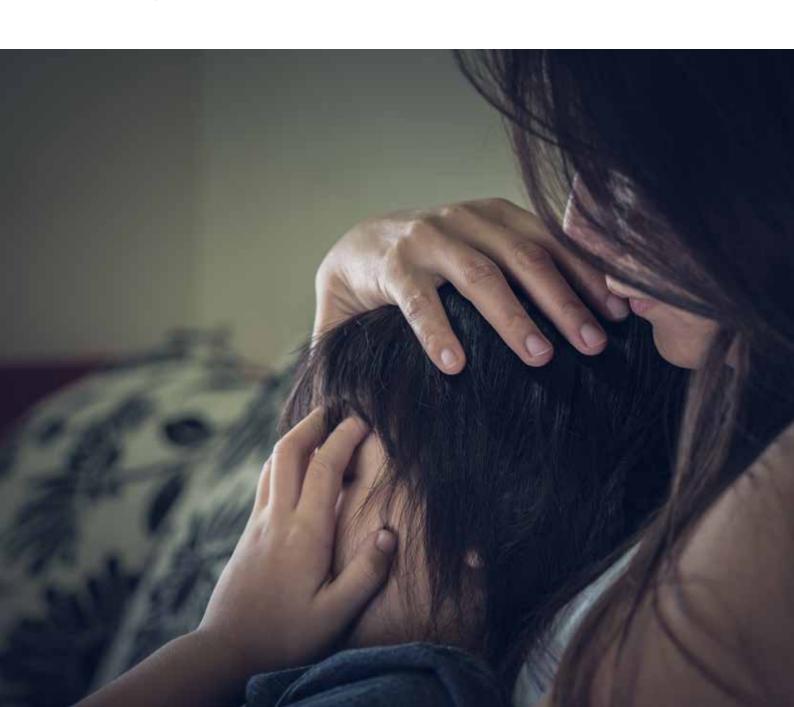
Summary

This guide has provided an overview of emotional outbursts in terms of:

- what they are and how they come about;
- how emotional outbursts can vary between people, be it in duration, how often they occur, when they occur, and what might happen before and after an outburst;
- what approaches can support families in managing and reducing outbursts. It is important to remember that everyone is different and unique, and although individuals with the same syndrome or neurodevelopmental condition could

sometimes experience outbursts in a similar way, the outbursts might happen for different reasons and require different management strategies. Emotional outbursts have a large impact on the daily life of the people experiencing them and their caregivers, and sometimes outbursts might be quite distressing for the people involved.

It is therefore important to identify effective ways to manage outbursts and limit the impact that they might have on daily life.



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Researchers investigated whether a strategy for signalling changes that were about to happen could help people who struggle with changes. A behaviour diary was used by parents and carers to record emotional outbursts.

Resources

- Anxiety A Guide for Parents (https://cerebra.org.uk/download/anxiety-guide-a-guide-for-parents/)
- 2. Cognitive Difference: Inflexibility and Impulsivity A Guide for Parents (https://cerebra.org.uk/download/cognitive-difference-cognitive-inflexibility-and-impulsivity/)
- 3. Communication with Children with Severe or Profound Intellectual Disabilities A Guide for Parents (https://cerebra.org.uk/download/communication-with-children-with-severe-or-profound-intellectual-disabilities/)
- Information Sheet Communication and Challenging Behaviour (https://www. challengingbehaviour.org.uk/understanding-behaviour/communication-sheet.html)
- 5. Information Sheet Positive Behaviour Support Planning (https://www.challengingbehaviour.org.uk/information-and-guidance/positive-behaviour-support/pbs-an-information-pack-forfamily-carers/)
- 6. Pain A Guide for Parents (https://cerebra.org.uk/download/pain-a-guide-for-parents/)
- 7. Research Summary Self-injurious Behaviour in Children with an Intellectual Disability (https://cerebra.org.uk/wp-content/uploads/2020/01/Self-injurious-behaviour-2019-low-res.pdf)
- 8. Sleep A Guide for Parents (https://cerebra.org.uk/download/sleep-a-guide-for-parents/)
- 9. Sensory Processing A Guide for Parents (https://cerebra.org.uk/download/sensory-processing/)

About the authors

Justin Chung

Justin Chung is completing his PhD at the Kate Woodcock Research Group, University of Birmingham. His research focuses on understanding the reasons why children and young people may experience emotional outbursts in different situations and how the individuals experiencing outbursts and those around them may be affected. This work primarily involves families of children and young people with neurodevelopmental conditions and children and young people who have experienced childhood adversity.

Emily Smith

Emily Smith is an MRes Clinical Psychology researcher at the University of Birmingham and she holds an undergraduate degree in Criminology and Psychology from the University of Southampton. Her research focuses on the characterisation of emotion regulation strategies in children and adolescents, including both clinical and subclinical populations, as well as individuals with neurodevelopmental conditions.

Dr Kate Woodcock

Dr Kate Woodcock carried out her PhD research at the School of Psychology, University of Birmingham between 2005 and 2008. She worked as a Cerebra Research fellow at the Cerebra Centre for Neurodevelopmental Disorders from December 2008 until February 2011, before taking up an International Outgoing Marie Curie Fellowship, which she had designed under the European Union's seventh framework programme. The Marie Curie Fellowship took Kate to Beijing, China until March 2013 and then brought her back to the University of Birmingham until February 2014. In March 2014, Kate took up her first lectureship position at the School of Psychology, Queen's University Belfast. In September 2017, Kate returned to the School of Psychology, University of Birmingham to take up a senior lectureship.

About the peer reviewers

Dr Caroline Richards

Dr Caroline Richards, Senior Lecturer in Neurodevelopmental Disorders, is a Clinical Psychologist and researcher at the University of Birmingham. Her research focuses on reducing negative clinical outcomes for children. Caroline will lead a programme of sleep research in the Cerebra Network for Neurodevelopmental Disorders. This research will help us to understand why sleep problems occur in children with rare genetic syndromes and help families to find solutions to these sleep difficulties. Outside of work Caroline enjoys spending time with her family, especially her twin boys, who have helped her to understand the critical importance of sleep.

Dr Hayley Crawford

Dr Hayley Crawford is an Assistant Professor at University of Warwick Medical School. Her research focuses on characterising behavioural difficulties and mental health problems in individuals with neurodevelopmental conditions. As part of the Cerebra Network for Neurodevelopmental Disorders, Hayley will conduct research that improves our understanding of autism and anxiety in children with rare and complex needs.

Dr Jane Waite

Dr Jane Waite is a Clinical Psychologist and Lecturer at Aston University, Jane's research focuses on understanding, assessing and treating mental health problems in individuals with neurodevelopmental conditions. As part of the Cerebra Network for Neurodevelopmental Disorders, Jane will lead a programme of work to better understand mental health in children with rare genetic syndromes and will develop assessment tools and interventions to be used in clinical services.

Dr Jo Moss

Dr Jo Moss is a Lecturer in Developmental Psychology at the University of Surrey. Her research aims to improve our understanding of the social and emotional wellbeing of individuals with neurodevelopmental conditions. In the Cerebra Network for Neurodevelopmental Disorders Jo will lead a programme of research into atypical autism. This work will improve our ability to assess autism and related social-communication difficulties in children with rare genetic syndromes and will support the development of targeted interventions.

The findings of this report are those of the author, not necessarily those of Cerebra.

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Working wonders for children with brain conditions

Postal Address Cerebra

The MacGregor Office Suite
Jolly Tar Lane
Carmarthen
SA3 I 3LW

Tel: 01267 244200

Freephone: 0800 328 1159

www.cerebra.org.uk





