UNDERSTANDING YOUR CHILD'S BEHAVIOUR

INFORMATION FOR PARENTS OF DISABLED CHILDREN

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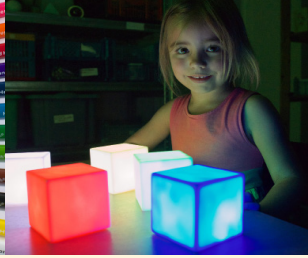

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INTRODUCTION

This guide is for parents who have a child with additional needs and who are worried about their child's behaviour. You may be concerned because your child is beginning to develop some behaviour that challenges you, or already has behaviour that challenges. They may have a recognised condition, be in the process of getting a diagnosis, or you may be wondering if they have additional needs.

Whatever the case, there are ways you can help your child and a number of people and organisations who can support you. In this guide, we offer suggestions that may help, explain who else can help and how, and where you and your child can get support.

This guide was written by Sheila Davies and Rosie Noble.

Thank you to the following parents for their invaluable advice:
Carol Harknett, Adele Meader, Lyn Brown, and Sharon Smith.

1 WHY CHILDREN BEHAVE IN CERTAIN WAYS

All children are different and there is no single answer to any of the difficulties or problems that are happening. There are often complex reasons behind a child's behaviour and it is essential to try to understand what the reasons are. Disabled children may be more likely to display behaviour that challenges than non-disabled children because it is their way of communicating they are distressed or unhappy when they have no other way to show it.

Parents can feel under a lot of pressure to 'solve' behaviour problems and are naturally very worried about the best approach to take. Parents can feel very alone and it can be a relief to discover that other parents are facing the same issues.

BEHAVIOUR AS A FORM OF COMMUNICATION

All behaviours are a form of communication. The challenge for parents is to work out what your child is trying to tell you through their actions, so you can look for ways to prevent them becoming distressed as well as help them find other, more acceptable, ways to communicate their needs.

For example, your child may be trying to express one or more of the following:

- **Frustration:** they can't do something or can't tell you what they want.
- **Fear:** they are frightened of something.
- **Strong feelings:** they are unhappy or angry about something.
- **Hyperactivity:** they have excess energy and cannot seem to burn it off
- **Discomfort:** they are in pain and can't tell you.
- **Attention:** they have learnt they get your attention by behaving in a certain way, and carry on using that behaviour to get your attention.

- **Lack of understanding:** if your child has limited understanding, they may not know what is expected. They may need time to work out what you mean and so don't respond to an instruction when you expect them to.
- **Boredom:** they have had enough of a particular game/food/situation.

BEHAVIOUR MAY BE LINKED TO A MEDICAL CONDITION

Some behaviour that challenges is more likely in children with particular medical conditions or disabilities. For example, there are some conditions which are associated with different behaviours: a child with Phenylketonuria (PKU) is more likely to show aggression or self-harm. Some genetic conditions result in a tendency to be obsessive, anxious, over eat or sleep badly. If you have a diagnosis for your child and know the name of their condition, you may want to find out more about the condition and whether there are strategies to help with behaviours. See our A-Z directory at **contact.org.uk/medicalinformation**

Some examples:

- **Children with attention deficit hyperactivity disorder** (ADHD) find it very hard to stay still or concentrate for long periods of time.
- **Children with an autism spectrum condition** (ASC) may become unsettled by changes in their routine, causing them to become upset or anxious. They can also react strongly to their environment, for example they may not like being in crowds, or in a room where there is a lot of noise.
- **Some children who have sensory impairments** may be over- or under-stimulated by sounds, sights smells and noise. They may also have difficulty processing or making sense of sensory experiences in the environment. This can affect the way they behave: for example if they have hearing or sight problems.

- **Some children have physical disabilities** that mean they are unable to speak. These children need alternative ways to communicate their needs. See 'Setting the scene for good behaviour' on page 11).
- **Some behaviour is classified by professionals as an 'emotional and behavioural' difficulty.** Signs of this include low self-esteem, difficulty making friends, being tearful, withdrawn or not wanting to go to school. If your child is having difficulties at school see page 57 for how the school can help.
- Children with specific learning difficulties or speech and language difficulties may find learning at school difficult without good support. If support is lacking, a child's behaviour may change or become challenging.

SENSORY ISSUES

The National Autistic Society

Has a useful section on their website which explains how our senses work. It describes what to do if a child is under- or over-sensitive to any of the seven senses (sight, sound, touch, taste, smell, balance and body awareness). Parents of any child with additional needs, not only children with autism, may find it helpful.
autism.org.uk

Fledglings

Fledglings is Contact's not-for-profit shop. It has sensory equipment and learning resources to help children with sensory processing difficulties, for example ear defenders, chewy tubes and much more.
fledglings.org.uk

2 SETTING THE SCENE FOR GOOD BEHAVIOUR

There are some general rules that will help you manage your child's day-to-day behaviour. These rules are particularly important for disabled children, who may be struggling to make sense of a very confusing world.

THINK ABOUT HOW YOU COMMUNICATE

Your tone of voice, warmth, posture, eye contact, and facial expression all speak volumes about your own feelings, and will affect how your child responds to you. If our words don't match our facial expression, people tend to believe the expression they see, not the words they hear.

Research has shown how powerful non-verbal cues are:

7% of a message is understood from the spoken word

38% of a message is understood from the tone of voice

55% of a message is understood from the facial expression.

So you can see how powerful these non-verbal cues are. If you appear calm and reassuring, your child is more likely to remain, or become, calm and feel less anxious. It also helps to keep language simple, and give clear consistent messages to your child.

CHOOSE WHAT WORKS FOR YOUR CHILD

There are different ways to help your child learn to communicate their needs, and make sense of what is going to happen throughout the day:

- ***You can use pictures and photos to explain what is going to happen if they have limited understanding or are non-verbal.***
- ***You can show your child objects (for example, a nappy if you are going to change them) before commencing the next step of your routine.***
- ***You can demonstrate the routines visually (for example, if you are going out, show your child your coat and point to the door).***
- ***Try to break down your sentences into single words and keep them simple.***
- ***Many parent carers find they can help their child to understand and communicate using signs for basic needs, such as sleep, hunger and thirst.***

You can also learn to communicate by using picture exchange communication system (PECS) symbols, by signing, learning Makaton (a mixture of signing and symbols), by showing photographs or other familiar pictures or objects. You can find out how to get more information about this and signing using Makaton in the Resources section on page 71.

A social story describes a situation and possible sequence of events to a child to prepare them for what is likely to happen (see page 71). There are also picture books for children to help prepare them for new experiences, such as going to school, travelling on a plane, moving house, visiting the dentist or hospital and so on (see page 71).

You can get help to find the best communication system for your child by speaking to professionals such as Portage workers (for pre-school children) and speech and language therapists. You may be entitled to aids and equipment to help your child communicate, like voice recognition or eye-tracking systems, through the occupational therapy service.

GIVE CHOICES WHEN POSSIBLE

Giving certain choices to children and young people helps them feel more in control. It helps them to feel that their views are being taken into account. This leads to less frustration and can improve their behaviour. For example, you could show two items or pictures to children who are non-verbal and teach them to point to or indicate their preferred choice, or you can ask a child or young person for their opinion on the choices available.

GIVE ENOUGH TIME

It is important that children and young people have time to respond to choices or requests. Give them plenty of time to think about what's being asked before expecting a response. Some children and young people with additional needs take more time to process information and respond. This means that they may need things repeated slowly several times to help them understand what you want them to do.

ESTABLISH DAILY ROUTINES

Children cope more easily if they understand in advance what is going to happen. Carrying out tasks in the same way, or at the same time every day helps give children a sense of security, and become familiar with what is expected of them. Children with severe learning and communication difficulties can start to respond more positively and appropriately as they develop this understanding. You can set up routines for:

- ***morning (wash, breakfast, get dressed, brush teeth)***
- ***after school (change clothes, lunch boxes/bags away, after school snack, homework, play, TV)***
- ***dinner time (wash hands, help set table/get dinner ready, clear table)***
- ***bed time (relaxation time, warm milky drink, bath time, story time, settle in bed).***

Every family will have their own preferred ways of doing things. If there are therapeutic or educational activities you carry out at home with your child, you can incorporate these into the routine.

You can use resources like pictures and schedules to help reinforce daily routines, and social stories to help prepare your child for any changes in routine.

Emphasise desirable behaviour, by giving lots of praise when your child follows the desired routine.

AN EXAMPLE

If your child won't sit at the table and eat a meal, you can try to establish firm meal-time routines and reward them for cooperating. You might find it helpful to break this down into small steps, such as getting your child to:

- ***sit on a chair***
- ***sit at the table***
- ***wait for food***
- ***eat the food***
- ***get down from the table.***

Each step is then rewarded with praise. Each mealtime should follow the same pattern whether at home, school, or visiting family members.

BE CONSISTENT

For routines to work, it's important that everyone involved with your child follows the same routines, so let them know what you are doing and why. It is also essential that everyone working with the child knows:

- ***how your child communicates, and***
- ***uses the same systems.***

It is particularly important to have good communication between home and other settings, such as nursery, school or childcare, and if parents are sharing parenting but living apart. Otherwise any routine you try and put in place is unlikely to work.

PLAY AND EXERCISE

Research has shown exercise is very effective in relieving stress and getting rid of frustrations, and that as fun increases, difficult behaviours reduce. It can also have a positive effect on behaviour generally.

A walk to the park each day, trampolining or swimming can work wonders in using up a child's excess energy. Exercise can also be very helpful for children with sensory processing difficulties. Most local authorities have sports, play classes, and clubs for disabled children.

Our website has lots of information about accessing Holidays, play and leisure.

Our not-for-profit shop **Fledglings** has equipment to help children play indoors and out, including continence swimwear products and Radar keys for 8,000 disabled access toilets around the country.

Living Made Easy is a website that can also help you find play equipment.

REWARD GOOD BEHAVIOUR

Sometimes parents inadvertently reinforce bad hehaviour. For example, if a child learns that by throwing a tantrum they get their own way, they will continue throwing tantrums. It is more helpful to reward a child's good behaviour, so they are more likely to repeat that behaviour.

If good behaviour is rewarded, then it is more likely to be repeated. A reward can be anything a child finds pleasant, such as praise, kisses and cuddles, attention, favourite activities, toys and stickers. Make it clear which good behaviour you are rewarding, and what the reward is.

GIVE PRAISE IN DIFFERENT WAYS

Praise can be a wonderful motivator for children. It helps them understand they are loved, cared for, and have value. Kisses, cuddles, and high fives (if your child tolerates them), thumbs ups, or clapping are great ways to show your child you're happy with what they're doing.

"My son doesn't like being touched and is non-verbal. I clap and cheer every time he goes to the toilet, so he can hear, and see from my expression, that I'm pleased with him without having to use words, which he can't understand anyway."

REWARD SYSTEMS

For rewards to work, you have to be sure your child really wants and values that particular reward.

Star charts are one way of rewarding good behaviour which some children respond to. Make a chart (preferably with your child if that is appropriate) showing all the days of the week, place it in the home where everyone can see it, and show it to people who visit. Each day your child is given a goal and they achieve it they are given a star or other sticker that will motivate them (Peppa Pig/Star Wars).

At first start with simple goals, (for example, going to their bedroom when asked) and gradually set more demanding ones (for example, staying in bed once you have left the room). Once your child has a set number of stickers, reward them with an activity they enjoy, for example a trip to the cinema or park.

Younger children and those with learning disabilities need rewards immediately to have an impact. These do not have to be big events or cost money. They might choose a programme to watch on TV or an activity they enjoy as a reward. Show them this on their star chart.

If you are thinking of using a reward system, it might be helpful to discuss it with the professionals involved with your child. It is also important that any reward system you choose to use is appropriate for your child. For example, Prader-Willi syndrome can cause children to over-eat so offering food as a reward would make their over-eating worse.

RECOGNISE TRIGGERS, FIND STRATEGIES

You may know what upsets your child, or at times you may be baffled and caught off guard. If baffled, questions you might consider include:

- ***Do they understand what they are being asked to do?***
- ***Is the task you want them to do too difficult?***
- ***Are they familiar with the person working with them?***
- ***Are they hungry?***
- ***Are they thirsty?***
- ***Are they in pain?***
- ***Are they tired?***
- ***Is the situation too noisy for them?***
- ***Are they too hot or too cold?***
- ***Are they finding change too difficult to cope with?***
- ***Are new shoes/clothes or clothes labels irritating them?***
- ***Are they bored?***

It can take time and practice to work out the triggers for your child but it's important you do, so you can find ways to deal with it.

BEHAVIOUR CHARTS

If a behaviour keeps happening and you are unsure about the triggers, it can be helpful to keep a diary, or behaviour chart, to help you identify and remove triggers. A good example is an ABC chart:

A stands for antecedents

The situation leading up to the behaviour. For example, where people are, what is happening, who is there, what the time is.

B stands for behaviour

What the child is actually doing.

C stands for consequences

What happens in response to the child's behaviour. It's these consequences that can encourage or discourage (whether you mean to or not) the behaviour from recurring.

HOW TO CREATE AN ABC CHART

On a piece of paper draw a box with five rows down with the date and time, antecedents, behaviour, consequences, and a column for other comments. You can then fill it in. For example:

Date and time	10/9/17 5.30pm Child is four years of age. He does not understand complicated verbal requests and displays difficult behaviour.
Antecedents (situation)	I ask my child to stop playing, come to the table and eat his dinner. I explain that it is his favourite meal. He ignores me. I pick him up and bring him to the table.
Behaviour	He hits and kicks me and screams. He moves from the chair to the floor under the table.
Consequences (your response to the behaviour)	I tell him off and try to get him to sit up, but he won't move from the floor.
Other comments	I feel exasperated. I have gone to all the trouble of cooking beef, as it is his favourite, to encourage him to cooperate. I realise that he may not have understood what I was asking him to do when I asked him to stop playing and eat.

Now draw a box with two columns, marked behaviour and strategy. Look at the antecedent (situation) again. In this example, the child was playing and probably enjoying himself, so did not want to stop. As a parent, you can use visual cues like a sand timer, or a countdown, to let them know in advance what is going to happen. You may find strategies such as stressing key words, using fewer words and more visual cues, pictures or signs can also help.

Once you have filled in the ABC chart, you then may be able to devise a strategy to remove the trigger. Remember, the consequences can encourage or discourage behaviours from recurring, whether you mean them to or not.

Behaviour	My child won't come to the table to eat and has a tantrum when I pick him up. When he senses I am cross, he lashes out and cries.
Strategy	Give your child prior warning that the request is coming. Use a sand timer to show them the time remaining to play. Speak in simple and brief sentences, using key words: 'Dinner is on the table', 'Dinner.' Give your child time to process the request. Repeat the command calmly if they do not respond the first time.

EXAMPLE ABC CHART

Date and time	10/10/17 3pm. Child is seven years old and has learning difficulties.
Antecedents (situation)	My seven year old was watching Teletubbies, which is her favourite TV programme. Her brother came in from school and changed the TV channel.
Behaviour	She screamed and hit and kicked me. Continued to scream.
Consequences (your response to the behaviour)	Brother told off by me. She got her programme back. She stopped screaming but still lashed out at her brother if he came near her.
Other comments	It did not feel fair or right on either child. Her brother is only five years old.

Behaviour	My child loves Teletubbies and screams and tantrums if she cannot watch the entire episode.
Strategy	Set up a daily routine for when she can watch Teletubbies without interruption and an equal daily routine for her brother's favourite programme. Use a visual cue such as a sand timer so that each child knows that when the sand has run through, the television programme will change.

REMEMBER

Your child is trying to tell you something with their behaviour. For example, they may be screaming because they cannot bear the door being shut and they have no words to say this. Your child's behaviour may be serving a purpose, for example, they are screaming because it gets your attention. If their challenging behaviour gets your attention, they will do it again.

WHAT IF YOU CAN'T REMOVE A TRIGGER?

It won't always be possible to avoid certain triggers. For example, your child loves going out for walks in the park, but is frightened of dogs and runs out of the park into the road, or screams or attacks you if a dog approaches.

You will need strategies to reassure your child and gain their trust in these situations. It is likely that you will learn what works best. You may find a simple phrase to reassure your child, you may offer to hold their hand as a dog approaches, in some situations you may ask the owner to put the dog on a lead until you have passed. You may learn that telling a particular story, using a favourite toy, or singing a favourite song will help to calm your child.

Professionals and other parents may be able to offer suggestions of ways to remove triggers from your routine. Learning from other parents through local support groups or linking services can also be useful.

3 RESPONDING TO BEHAVIOUR THAT CHALLENGES

Behaviour becomes an issue when it starts to have a detrimental effect for the child, the parent, or the child's family. All children can become cross and behave in ways not considered appropriate, but many will respond to strategies put in place by parents. Children with additional needs may not be able to respond in the same way, and behaviour that causes problems may escalate and become persistent.

Examples of persistent behaviour in young children that families might find problematic are:

- ***frequent screaming and tantrums***
- ***kicking and hitting parents and siblings***
- ***breaking things***
- ***biting people and objects***
- ***not sleeping***
- ***feeding problems***
- ***smearing faeces, urinating in odd places.***

It is important to tackle issues with your child's behaviour early on. If you notice certain behaviours getting more frequent, occurring over longer periods of time and becoming unmanageable, you can look at strategies to help manage them.

First rule out any medical or dental problems: the cause of your child's behaviour may be because they are in pain or discomfort, and are not able to communicate this. So, for example, check whether they are constipated, and visit the doctor as this can be a cause of discomfort. Urinary tract infections and ear ache are common in children and painful.

Prioritise: if your child has several worrying behaviours, decide which one you want to focus on first. Tackling one at a time will avoid confusing them (and you). For some parents, this means deciding which behaviours you can live with, and which ones you must tackle because they are dangerous for your child and others.

Focus on changing the behaviour: it's important for your child's self-esteem that they know you want to change their behaviour, not them and who they are. Otherwise they will be unhappy, which is likely to affect their behaviour, and may make things worse. Remember, if you are introducing new responses to behaviour then initially things may get worse before they get better!

Be positive: state, or show how or what you would like your child to do in a positive way, for example, "Please do..." rather than "Do not do...". Children can find it very hard to interpret 'no' messages. Just saying "Stop," can be more effective. If you can re-direct your child into good behaviour reward them at once, for example with a hug or praise.

Stay neutral: if your child is displaying difficult behaviour, keep your responses to a minimum by limiting verbal comments, facial expressions, and other displays of emotion, as these may encourage the child to behave in this way. Try to speak calmly and clearly (using just key words and phrases) and keep your facial expression neutral.

PUNISHMENT IS NOT A STRATEGY

Punishment – for example using 'time out' for a child who can't understand its meaning – rarely works, because many children do not see the connection between what they did and the punishment that follows it. And for some children what is deemed a punishment may actually be seen as a reward. For example being kept in at break time with the teacher when it's cold could be seen as a treat, and the child will also have one-to-one attention.

There are rarely overnight miracles, so remind yourself to be patient.

TOP TIPS FOR MANAGING BEHAVIOUR

- **Take time,** stay calm and neutral.
- **Give reassurance** in a way your child is able to understand.
- **Make yourself appear less threatening,** for example by sitting down.
- **Keep language simple,** give clear messages or demonstrate or show a visual cue card to indicate the behaviour you want.
- **Remove other adults** and children from the situation.
- **Look and sound confident** – even if you're not feeling it.
- **Intervene quickly,** try diverting or distracting your child.
- **Give choices** where appropriate. Children and young people naturally want to have some control over their lives – allow them to feel that they do.

It is less helpful to:

- ***Look angry or upset.***
- ***Lose your temper.***
- ***Intimidate.***
- ***Talk a lot.***
- ***Confuse your child.***
- ***Have other people chip in.***
- ***Look nervous.***
- ***Do nothing.***
- ***Re-ignite the situation.***
- ***Be negative, saying 'naughty', 'bad', 'no' or 'don't'.***
- ***Threaten punishments, particularly ones you are unlikely to be able to see through.***

All children are different – there's no one answer that fits all.

MINIMISING RISKS

It is important to reduce the risk of children hurting themselves, and to make them as comfortable as possible. Simple ideas include using locks on fridge and cupboard doors, cooker guards, wall-mounted televisions, and electric plug socket covers.

It might be helpful to have more specialist aids and furniture for around the house. For example, robust bedding that is easy to wash, alarm devices to prevent the bath flooding, wardrobes and cupboards which can be fixed to walls, clothing to suit someone's likes and dislikes of fabrics or behaviours, and abilities of dressing/undressing.

Contact's not-for-profit shop **Fledglings**, **The Challenging Behaviour Foundation** and **Living Made Easy** can advise on what is available and where to find aids, equipment and clothing to keep your child safe and comfortable. See Useful Organisations.

TACTICS THAT MIGHT HELP

- **Distract your child:** this works especially well with toddlers, or children who tend to focus on one item or activity at a time, who can easily be led on to something else.
- **Remove your child:** some children become so overwhelmed they need be taken to a new setting before they will calm down. If this is the case, even taking them to a different room in the house or stepping outside the supermarket can help.
- **Ignore your child:** some behaviour is a way for the child to gain your attention. Simply ignoring this type of behaviour may help to defuse it. Once your child is calmer, redirect them to a positive activity.
- **Praise your child when they stop:** once your child has calmed down and is behaving appropriately, pay attention to them again and praise them for stopping. If you reward the new behaviour like this, your child is more likely to stay calm and learn that positive behaviour gets positive attention.
- **Provide sensory stimulation:** if your child is looking for sensory stimulation, provide it in other ways, by for example pinching play-dough, clapping hands, singing a clapping song/rhyme, kicking a football, using a punch bag, going on a swing, and so on.
- **Be calm and redirect:** straight after the undesirable behaviour, using a calm voice without showing emotion, direct them to another activity telling them what to do, rather than what not to do.
- **Be consistent:** tell everyone involved about your strategy for the behaviour problem so that everyone is working on it in the same way. Children get very confused if handled differently. It may be helpful to agree a written behaviour plan with strategies that work for all involved with your child, particularly if they go to day centres, have a support worker, or short break support. Give this plan to everyone who looks after your child in your absence, such as friends, family or other carers while you are having a short break.

4 MANAGING SPECIFIC ISSUES

This section looks at particular examples of behaviour, and offers ideas on how you can work out the cause and find solutions. It is a good idea to involve any practitioners working with your child.

TANTRUMS

Many children have tantrums between the ages of one and four years. This is often because they want to do things for themselves, and get very angry and upset if they cannot do what they want or are stopped by their parent carer. Sometimes, tantrums happen in public because the child wants something they cannot have, or they are very tired or hungry. Tantrums usually stop by the time the child starts school, because by then they have more language and social skills.

Children with additional needs can have tantrums for the same reasons as other children. However, some with specific impairments or difficulties can become overwhelmed more easily, and have fewer coping skills, less language, and not as much patience. This can make temper tantrums more likely. Parents might find this embarrassing, especially when the child has tantrums in public places, such as in the supermarket or on the bus.

You may know what triggers your child and generally avoid them. However, you might get caught out by an unexpected trigger. If you are not sure about your child's tantrum triggers, keep an ABC chart to help you identify them (see page 19).

WHAT YOU CAN DO

Distract your child: this works especially well with toddlers or children who tend to focus on one item or activity at a time and can easily be led on to something else.

Remove your child: some children become so overwhelmed they need be taken to a new setting before they will calm down. If this is the case, even taking them to a different room in the house or stepping outside the supermarket can help. If necessary abandon your shopping!

Ignore your child: some behaviour is a way for the child to gain your attention. Simply ignoring this type of behaviour may help to defuse it. Once your child is calmer, it may be helpful to redirect them to a positive activity.

Praise your child when they stop: once your child has calmed down and is behaving appropriately, pay attention to them again, and praise them for stopping. If you reward the new behaviour like this, your child is more likely to stay calm and learn that positive behaviour gets positive attention.

Ask for advice and support: if the tantrums are getting worse, ask your health visitor for advice and local help.

HITTING, KICKING AND PINCHING

All small children can feel very frustrated at not being able to communicate their needs and wishes. They may occasionally hit other children because they are jealous, or because they don't want to share their toys. With help from parents, they learn to deal with their anger and frustration in more acceptable ways.

Children with additional needs can sometimes become more easily frustrated or angry with other children. They may not be as quick as their peers in developing social skills.

Typical frustrations are:

- ***difficulty waiting for something because they do not understand time concepts***
- ***disliking a change in routine***
- ***being upset if familiar staff or care workers leave***
- ***being hypersensitive or having sensory overload. Some children with additional needs can be very sensitive to one or more of the following: loud noises, colours and patterns; particular smells; the feel of certain materials; being hot or cold; visiting a strange place; being among lots of people***
- ***wanting more sensory stimulation***
- ***not wanting to do something.***

They may express these frustrations through hitting, pinching or kicking other children and adults. If you are not clear what the cause is, try keeping an ABC chart or a behaviour diary. See page 19.

WHAT YOU CAN DO

Provide sensory stimulation: if your child is looking for sensory stimulation provide it in other ways by, for example, pinching play-dough, clapping hands, singing a clapping song/rhyme, kicking a football, using a punch bag, going on a swing, and so on.

Use rewards: reward your child for doing something you want them to do. Tell them why you are rewarding them. Make sure the reward is something that they like, and give the reward straight away where possible.

Be calm and redirect: straight after the undesirable behaviour, using a calm voice without showing emotion, direct them to another activity telling them what to do, rather than what not to do.

If your child is upset by changes of routine or unfamiliar people, you may wish to use visual aids to support their understanding. You should try to use these visual cues daily, and refer to them regularly throughout the day.

BITING

Biting is a common behaviour in children between the ages of 14 months and two-and-a half years. It mostly occurs in very young children who have little language, and it tends to stop as language develops. Small children may also bite because of hunger, teething, anger, or boredom. They may not have enough access to favourite toys or may be reacting to a transition, such as giving up a dummy or having a new sister or brother. Biting may persist in children who have additional needs for various reasons:

- ***it is a powerful way of telling people something is not right if the child lacks communication skills***
- ***children in this situation can feel overwhelming frustration or distress and biting is a way of expressing this***
- ***some children, such as those on the autistic spectrum, experience sensory processing difficulties. Biting stimulates the part of their nervous system that helps them know what their body is doing***
- ***putting objects in their mouths to explore their size, shape and texture is a normal part of child development. Some children with additional needs may go through this phase later or longer – for example, you might find this if your child has a visual impairment, or takes longer with their development.***

WHAT YOU CAN DO

First, you should rule out any medical or dental reasons, such as toothache. If there is no medical reason, you need to work out the cause of the biting. The ABC chart or a behaviour diary (see page 19) is a good way to identify causes. Possible solutions could include:

Helping your child to express their feelings: if your child is biting because of frustration, your strategy could be to find different ways to help them express their feelings. For example, if the problem is lack of ability to communicate, provide pictures and symbols that they can use to convey their feelings.

Offering more sensory input:
if your child needs more sensory input, consider offering more crunchy snacks, such as apples, carrots, crackers, and dried fruit. You could keep a bag of chewy things ready as needed.

Objects for chewing: you could offer teething rings to chew on or 'chewy tubes', which are cylindrical pieces of safe, non-toxic rubber. Studies have shown that chewy tubes provide a focusing and calming function and release stress.

Immediate responses: straight after the undesirable behaviour, say in a calm voice without showing emotion, "Stop pinching/slapping/kicking," and then direct them to another activity.

Contact's not-for-profit shop **Fledglings** has sensory equipment for children, for example chewy tubes, tangles and more.

SMEARING

Some children and young people handle and smear their poo. There can be various reasons for this:

- ***it could be that the child has learning difficulties and has simply not understood the process of wiping with paper properly***
- ***others enjoy the feel of the texture of the faeces***
- ***some will use smearing as a way of getting attention, or because they have learnt they are rewarded for such behaviour by being given a nice warm bath***
- ***some children and young people can also behave in this way because they are extremely upset and agitated.***

WHAT YOU CAN DO

Look for behaviour patterns: if your child smears, try to see if there is a pattern to their behaviour, as it might help you understand why they are doing it. If it started suddenly, the smearing might be in response to something upsetting that's happening to them. Try using a behaviour diary or ABC chart (see page 19).

Stay neutral: try to react to the behaviour as neutrally as possible, with no eye contact and very little conversation.

Provide alternative activities: if your child enjoys the sensation of smearing, provide an alternative, such as play-dough, or cornflour and water.

Use specialist clothing: dress your child in clothes such as dungarees or large-size babygrows that restrict access to faeces.

Information about where you can buy these can be found by contacting **Living Made Easy**.

SLEEP PROBLEMS

Small children can usually sleep through the night by the age of one unless they are disturbed by teething or illness. Children with additional needs may have persistent difficulties with sleeping. They may be over-active, anxious, physically uncomfortable or have a neurological condition, such as cerebral palsy or epilepsy, which makes it more difficult to relax. Young people who have additional needs can also experience sleep difficulties.

WHAT YOU CAN DO

Regular and calming bedtime routines are essential. You may find it useful to keep a sleep diary. This might contain:

- ***the time your child went to sleep, the number of times they woke and for how long they stayed awake each time during the night***
- ***the number and length of naps during the day, to see if these should be cut down***
- ***the way you prepare your child for bed to see if changes made to their sleep routine would help***
- ***the medication your child is on, and the times at which they take it, as medication can affect your child's sleep patterns.***

Our guide ***Helping your child sleep*** has practical ideas and solutions for sleep issues. Download it or contact our helpline for your free copy on **0808 808 3555**

Contact's not-for-profit shop **Fledglings** has products for bedtime, including waterproof duvets and pillows and weighted blankets.

EATING AND MEALTIMES

Mealtimes can be more challenging for parents of children with additional needs, and problems can continue into adulthood. They may display other types of behaviour. For example, some children and young people with additional needs:

- ***are hyperactive and find it impossible to sit still for a few moments at a time***
- ***are obsessed by a particular activity and have a tantrum if stopped in order to have a meal***
- ***cannot bear particular food textures or the feel of cutlery***
- ***would like their food presented in very particular ways***
- ***may be obsessive about food and overeat, leading to weight problems***
- ***grab food from other people's plates.***

WHAT YOU CAN DO

Try to establish regular routines for meal times. Sit down as a family at a table for meals so your child gets into a routine. If this is not possible, try to ensure that your child is sitting with at least one other person, rather than on their own.

Don't force your child to eat. If your child won't eat, it is possible that they are overwhelmed by the amounts you are giving them. Try offering a little bit of food on the plate at a time. If your child will only eat one or two kinds of foods, seek advice from an eating specialist.

Read our free guide to ***Feeding and Eating*** or contact our helpline on **0808 808 3555** **helpline@contact.org.uk**

Contact's not-for-profit shop **Fledglings** also has solutions for eating and drinking, including adapted cutlery and plates.

TOILET-TRAINING

This can be more difficult for parents if a child has additional needs. Most children are ready to be toilet trained around the age of two, but some children with additional needs will not be ready until they are older.

WHAT YOU CAN DO

Wait until there are signs that your child is ready to use the potty or toilet, such as awareness of passing urine or having a bowel movement. Try to find ways so your child can communicate to you when they need to use the toilet.

If they are unable to speak try using Makaton, a picture, or an object such as a toilet roll to show that they need to go to the toilet.

Read our free guide to ***Potty/Toilet training***. Download it or contact our helpline for a copy on **0808 808 3555**, **helpline@contact.org.uk**

You can find continence aids and equipment for toilet training at Contact's not-for-profit shop **Fledglings**

Scope, **ERIC**, the children's continence charity, and **The National Autistic Society** also provide information and practical tips on toilet training.

SELF-HARMING

Having a child with behaviour that includes self-harm is one of the most difficult and distressing issues parents may have to face. Behaviours can vary, and may include the child:

- ***biting the back of their hand***
- ***picking at areas of their skin***
- ***scratching one particular area on their body a lot***
- ***head banging***
- ***pulling hair out***
- ***eye poking***
- ***sticking objects into ears or nostrils***
- ***eating inappropriate things.***

WHAT YOU CAN DO

It could be that a child's self-harming serves a sensory need. The National Autistic Society has a useful section on their website which explains how our senses work, and our not-for-profit shop Fledglings has resources to help children with sensory needs. See box on page 9 for information on these.

You can try to stop the behaviour by working out what is causing the episodes, but you will almost certainly need to seek help from an expert if your child is showing these types of behaviour frequently, intensively or dangerously.

For children with significant learning disabilities and/or complex needs, there is usually a need for careful, systematic, multi-disciplinary team assessments. You can read more about this in the next section.

TOP TIPS FOR MANAGING BEHAVIOUR

- **Moving from one activity** to another can be very stressful for children with learning disabilities or autism. Use visual timetables and gradual transitions. Counting down slowly and gently from 10 to 1 can help too.
- **Prepare a 'safe' area** your child can retreat to if it's all becoming too much. It could be their bedroom, a corner of the hall, or even underneath the dining table. Ensure that someone will prevent less aware people from stepping in and inadvertently making things worse for your child. A great 'safe' space when you're away from home is sitting in the car outside the house, but make sure an adult is with them all the time.
- **Prevention is the best strategy.** For example, protect them as far as possible from unwanted hugs, kisses and touch from relatives by letting them know your child can't endure them.
- **It isn't bad behaviour, it's overwhelming distress,** probably caused by sensory overload or something in your child's world going horribly wrong for them – and they haven't got the communication skills to explain. Stay calm, keep your voice gentle – sometimes singing helps. Your child needs to see that you're in control and that you understand how upset they are.
- **Lead them away from other people or noise** – or gently but firmly ask everyone else to leave the room. Brief people beforehand.
- **Eye contact** – your child may struggle with this, particularly in the middle of a meltdown or an anxiety attack. When talking focus very slightly away from their eyes. Eye contact can be very intense for children and adults on the autistic spectrum.

- **Distraction can work wonders.** If you can put together a 'Calm Down Box' it can help enormously. Good things to include are things that will encourage deep breathing, which in itself is very calming, like bubbles to blow or whistles.
- **Something to fidget with** like a tangle is great. Putty is good to squeeze all that anger and distress out with. Something to chew on can help too – or even some of your child's favourite sweets.
- **Some children benefit from the noise** being cut out so ear-muffs or ear-plugs might be a good idea to include.
- **If you get it wrong, don't beat yourself up**. Guilt just festers, sucking away energy and resources. Learn not to do guilt, instead think about how to do it right next time.
- **Don't let friends and family criticise your parenting skills.** Everything is a little different in families with disabled children, sometimes you have to make it up as you go along.
- **Life is tough.** If you want to weep and rage and throw things, allow yourself 'wallow' sessions. Set the alarm, and rant and rage for a cathartic half hour.
- **Accept help.**

You can read more on **Yvonne's blog**

5 LOOKING AFTER YOURSELF

None of this is easy, especially when you are tired. Many parents whose children have behaviour issues talk of the frustration and hurt they feel when friends, teachers, health care professionals and others dismiss their child as simply being badly behaved, or imply that their child's behaviour is due to bad parenting. It's all too easy to be affected by other people's criticisms.

DEALING WITH CRITICISM – WHAT PARENTS SAY

"It is ignorance and non-understanding. It depends on the situation, but I would try to talk to the person and explain how it is for my child - in a friendly and smiling way. If we are positive towards other people, they tend to be more positive and accepting towards us."

"Criticism is often more about the other person and their agenda than you. You can choose to accept their negative view of you, or you can think to yourself – that is their issue, that is their world and I don't have to accept it into my world. "

"Don't take it personally, take deep breaths and talk to as many other parents as possible – they "get it."

You will need time to relax and take care of yourself. Parents are often so busy thinking about everyone else that they can find it very hard to set aside time to do something they really enjoy. This might be as simple as having a bath in peace, reading a book or seeing a friend. It sounds strange, but your relationships will benefit if you set some time aside for yourself. This is not an indulgent luxury, but valuable time to recharge your batteries. Let others know when your time is. Without taking a break from caring, your health can suffer.

SUPPORT FROM OTHER PARENT CARERS

Many families find talking to other parent carers very useful and a great emotional comfort. Being involved with a support group means you'll be able to talk to other parent carers in similar situations who can share valuable information, experience and support. Contact and your local Family Information Service can tell you about groups in your area.

The **Early Support Looking After Yourself** guide was developed by Contact as part of the Early Support programme and has lots more tips.

"It's heart-breaking to watch your child suffer. I felt alone and vulnerable. Someone told me about support groups run by other parents, so I started going. I found it really helpful to be able to be able to talk to others who really understood what I was going through, and I gained lots of useful knowledge and coping strategies."

GETTING A BREAK

If your child has severe challenging behaviour, you may be eligible for a regular short break from care. Local authority social services departments (Social work department in Scotland, and Health and Social Services Trust in Northern Ireland) are required by law to provide a range of short breaks for parents of disabled children, including:

- ***overnight care in the family home or elsewhere***
- ***daytime care in the family home or elsewhere***
- ***educational or leisure activities for disabled children and young people outside their homes***
- ***services available to assist carers in the evenings, at weekends and during the school holidays.***

You will need to ask for an assessment from social services to find out if you are eligible for any of these.

If you are not able to access short breaks, you can ask your local Family Information Service about local organisations offering relaxation sessions for carers, as well as activities in the holidays and at weekends for you, your disabled child and any siblings.

Please see our website for more information on short breaks plus how to get other services and support from your local authority.

Parents in Northern Ireland, Scotland and Wales please call our helpline for information about short breaks in your area.

6 WHO CAN HELP

WORKSHOPS/TRAINING COURSES

You may find it helpful to attend a workshop or training course on managing behaviour in children with additional needs. These courses can give you lots of practical hints and tips, increase your confidence, and allow you to meet other parents facing similar challenges.

These are provided by children's services in some areas, but make sure the course is for parents with disabled children which will take into account your child's additional needs, rather than a general parenting class.

Contact, **The National Autistic Society**, **Cerebra** and **Challenging Behaviour Foundation** provide workshops/training in some local areas. Call our helpline on **0808 808 3555** for more information on local courses, or look on your local authority website.

WORKING WITH OTHERS

It is very important to tell everyone involved with your child what might trigger your child to behave in a challenging way, and what strategies work in preventing and minimising this. You might need to share this with relatives, childminders, nursery/school staff and health practitioners.

You might want to make a communication passport, or use the Early Support Our Family resource (see page 70). You will find it useful to share this when meeting people who are going to become responsible for looking after your child.

HEALTH PROFESSIONALS

In some cases, children develop behaviour that is persistent and severe. The behaviour may be a risk to the child or people around them, and prevent them using ordinary community facilities like a leisure centre or day centre. This kind of behaviour can also have a severe impact on family life.

When a difficult behaviour reaches this level of severity, it could be defined as 'behaviour that challenges' or 'challenging behaviour'. Often, behaviour that challenges may be associated with a severe learning difficulty and can lead to aggression, self-injury, or disruptive and destructive behaviours.

It is important to seek outside help if your child's behaviour has become challenging.

You can speak to any professional involved in your child's care – like your GP, health visitor or children's centre or school staff. They should be able to refer your child for more help if necessary. Your child might be referred to a paediatrician, psychiatrist or clinical psychologist.

Medical professionals should consider your child's initial medical diagnosis, as some behaviours are associated with particular medical conditions (for example, hand biting is common in children with Fragile X syndrome).

Sleep problems, incontinence, problems with feeding and eating, self-harming, emotional and behaviour problems may be associated with your child's diagnosed condition, but could be due to another underlying medical or mental health issue.

Other professionals who might get involved in carrying out an assessment of your child include:

- **CLINICAL OR EDUCATIONAL PSYCHOLOGIST**: to look at your child's behaviour, assess its causes, and discuss practical strategies you can use.
- **PAEDIATRIC OR COMMUNITY PSYCHIATRIC NURSE**: who can have a wide range of knowledge, and suggestions to help with specific behaviour.
- **SPEECH AND LANGUAGE THERAPIST**: can offer strategies around communication that may help to improve a child's interpretation of some situations.
- **OCCUPATIONAL THERAPISTS**: can provide advice on practical issues for children whose behaviour that challenges may be linked to a need for support in developing physical coordination and mobility.
- **PHYSIOTHERAPIST**: can help children who require support in the physical aspects of their life and who experience limitations in their mobility, which may be at the centre of their frustration and behaviour problems.
- **SCHOOL COUNSELLOR**: a qualified counsellor employed by a school so that children experiencing difficulties can be referred to them to discuss their concerns.

Assessments by professionals and referrals to services can take some time, so try to access all the support you can while you are waiting.

MULTI-DISCIPLINARY TEAMS

Some children will need input from lots of different professionals working together as a multi-disciplinary team.

These are teams which include different health professionals, each with their own specialist knowledge and expertise. Examples of multi-disciplinary/multi-agency teams include child development teams/centres (CDCs), child and adolescent mental health services (CAMHS), and community learning disabilities teams (CLDTs).

CHILD DEVELOPMENT TEAM/CENTRE (CDC)

This is a healthcare team specialising in working with children with disabilities, or where there are concerns about a child's development. A child development team usually includes paediatricians, physiotherapists, occupational therapists and speech and language therapists. They also work with child and adolescent psychiatrists and psychologists.

CHILD AND ADOLESCENT MENTAL HEALTH SERVICES (CAMHS)

CAMHS teams promote the mental health and psychological wellbeing of children and young people. They include professionals that work in a number of different organisations such as health, education, and social services. The professionals can include occupational therapists, clinical psychologists, psychiatrists, and social workers.

You may have a CAMHS Learning Disability team in your area. These teams specialise in meeting the psychological and emotional needs of children and young people with a learning disability.

COMMUNITY LEARNING DISABILITIES TEAM (CLDT)

Some CLDTs promote what is called a 'lifespan service'. This means they can help plan and arrange care and support for people of any age with learning disabilities and their carers. CLDTs are made up of staff from health and social care. They might include social workers, learning disability nurses, psychiatrists, psychologists, and a range of other therapists.

MULTI-DISCIPLINARY MEETINGS

You, or any professional involved with your child, can ask for a Team Around the Child (TAC) meeting between you and all the professionals involved with the care of your child. This allows communication between social care, healthcare, and education professionals, and ensures everyone can contribute to your child's care plan.

Here are a few tips to help you get the most out of meetings with professionals helping your child:

- **Take a partner, friend or relative** with you if you can – it makes it easier when there are two people listening to the advice.
- **It's helpful if the professional** you are meeting has met your child before. If this has not been possible and you have to take your child with you, then it might be helpful to ask a friend or family member to come along and take your child into a separate room while you discuss any behaviour that's causing concern.
- **Write down all your questions in advance** of the meeting – it is very easy to forget some of the things you are concerned about when face-to-face with the professional.
- **Don't be afraid to ask questions,** especially if you are nervous about some of the advice given, or if you don't understand anything.
- **Make your own notes** if you would like to, and ask for a summary of the advice you receive to be written and sent to you by email or post – whatever suits you best.
- **Keep everyone informed** – ask for copies of minutes or notes to be circulated to all present, and any other relevant people.

SUPPORT GROUPS FOR SPECIFIC CONDITIONS THAT CAN HELP

If your child has a diagnosis of a specific condition, the support group for that condition will almost certainly have information about coping with challenging behaviour common in that condition. This information will have been developed by parents with experience of bringing up a child with the condition in question.

There are more than 400 medical conditions and disabilities listed on our website, with details of support groups where there is one.

Call our freephone helpline to find the support group for your child's condition **0808 808 3555**. They will be happy to send you any information.

Or find a support group in our **A-Z directory of medical information**. If a condition isn't listed on our website, we may still be able to find you information, so please do call.

BENEFITS AND FINANCIAL HELP

Extra financial help available to parents of children with behaviour problems includes Disability Living Allowance, which is payable if your child needs significantly more care or supervision than other children of the same age because they are disabled, and if your child has mobility issues.

We publish a number of guides on money issues, including ***Claiming Disability Living Allowance for Children***. Find out what other financial assistance you may be entitled to.

You can also ask our helpline to check that you are getting all the financial assistance you are entitled to.

7 SCHOOL

EARLY YEARS

Attending nursery or other early years settings provides opportunities for children to play with other children and learn what is acceptable and unacceptable behaviour outside of their own home. As well as helping children to learn and develop, these settings help prepare children for school. They can be especially helpful for children with additional needs.

Early years staff in nurseries, children's centres and other early years settings can support young children to develop social skills. Extra support can be put in place for a child to attend nursery, early years settings and school if they need it. This may involve your child going through an assessment process to see what is needed.

If you think your child needs additional support, it is best to speak to the person responsible for supporting children with additional needs who works at the early years setting or school well before your child is due to start.

Your child has the right to have their needs for support properly met. There are laws in place to help protect disabled children from being seen as simply naughty or deliberately disruptive when their behaviour difficulties may arise because of their condition.

Our website has information about **support your child might receive in the early years**, including factsheets for parents.

If you feel your child is not receiving appropriate support at school, ask to speak to the person responsible for supporting children with additional needs in their nursery or school. Please also see our **education information** or call our Education Advice Service on **0808 808 3555**. Our friendly parent advisers can tell you about support your child may be able to get in school.

MOVING TO SECONDARY SCHOOL

Moving to secondary school is a big change for any child, but if your child has additional needs it can be even more daunting.

Ask well in advance to meet with the person responsible for pupils with additional needs at the secondary school. Discuss how your child will be supported, and how information about them will be shared with other staff in the school. Take information with you about what might trigger behaviour that could be challenging and strategies that minimise this. It might also be helpful to take any letters from health practitioners about your child's condition and support needs.

Discuss with the school what might be difficult for your child and how they will be supported – for example, reading the timetable, finding their way to the next class, or break time.

Children who have had good support in primary school can struggle in a large secondary school. They can feel overwhelmed by the size of the school, the number of pupils and teachers, and unfamiliar routines.

Allow time to prepare your child for the move. It might help to arrange extra visits to the new school to allow your child to become familiar with it. You might want to write a social story to help prepare your child for the change.

If your child doesn't have a current statement of special educational needs or an Education, Health and Care plan, and you think they may benefit from one, speak to the school or talk to your local advice service. It's important that you prepare the way as much as possible.

Visit our website for information about **extra help at school**

The **National Autistic Society** also has ideas on preparing your child for secondary school on its website.

CIRCLE OF FRIENDS

If your child is experiencing difficulties because of their condition or their behaviour towards others, it could be helpful for them to have a circle of friends. The circle should help to improve the inclusion of your child in their mainstream school.

The circle of friends idea works by getting a group of the young person's friends and peers together at their school with the aim of creating a support network for them, and helping them to live life to the full.

In the early stages, an adult teacher/facilitator will probably need to meet with the circle and the 'focus child' to help them with choosing their circle of friends and problem solving.

After the early stages, you and your child and/or their teacher will probably be able to review the amount of help the circle needs on a regular basis.

The circle of friends approach has been used successfully for a number of years. Evaluations of this approach have been very positive for both the child at the centre of the circle, whose behaviour has improved and anxiety lessened, and the children supporting them. If your child is in mainstream school, talk to a professional involved in their care, like the SENCO or their form teacher.

Circles of Support is a similar approach to including people in the community, where a group of people meet to help someone achieve their goals in life. You could ask professionals involved in your child's care about putting these approaches in place in the community.

Circle of Friends and **Circles of Support**.

WHO CAN HELP WITH SCHOOL

England: Information Advice and Support Services

Gives advice, information and support to parents and carers whose children have special educational needs. To find your local service, contact the **Information Advice and Support Services Network**

Wales: SNAP Cymru

Charity working throughout Wales giving advice, information and support to families, young people and professionals around additional learning needs and disabilities. They can help with choosing a school, getting support for your child in school and help resolve disputes. They also have an advocacy service for children and young people.

Helpline: 0808 801 0608 **snapcymru.org**

Northern Ireland: SENAC

The Special Educational Needs Advice Centre (SENAC) in Northern Ireland, provides an independent advice, information and advocacy service for parents of children and young people with special educational needs.

Advice Line: (028) 9079 5779 **senac.co.uk**

Scotland: Enquire

Offers independent and impartial advice and information to parents, carers, practitioners, children and young people.

Helpline: 0345 123 2303 **enquire.org.uk**

For more information on your rights and how to get help at school call our Education Advice Service on 0808 808 3555. Our parent advisers can tell you about the help school should be providing at any age.

Something Strange
in Wellington Square

8 GROWING UP

Puberty and teenage years are times of change and adjustment for all children and young people. Parents of disabled children can find it difficult to know what allowances to make for their child's puberty and hormonal changes. But even allowing for hormones, there are some real concerns for many parents during the teen years.

SEXUALITY AND INAPPROPRIATE SEXUAL BEHAVIOUR

This can be a major worry for parents. Parents of disabled young people generally accept that their children will naturally develop sexual awareness and feelings, but they also worry about their extra vulnerability. Some disabled young people find it hard to know where they can express their sexuality, and where it is inappropriate.

Parents, young people and their advocates need access to good information and support. It is important to remember that professionals are often familiar with the sorts of behaviours that can occur, so it should be possible to have honest and open discussions without being embarrassed by the nature of the problem. You may find it helpful to discuss this with your child's school as well.

We have a guide for parents, and a separate guide for young disabled people called ***Growing up, sex and relationships***, available free to download or by calling our helpline on **0808 808 3555**, **helpline@contact.org.uk**

EMOTIONS AND MENTAL HEALTH

Sometimes you, or the professionals working with your child, may notice other emotional and behavioural changes. You may be concerned about your child's mental health. If you are worried about this, contact your GP, consultant paediatrician or child health professional to talk about it. They may suggest a referral to your local CAMHS or a CAMHS learning disability service, for an assessment to understand your child's behaviour, moods and feelings.

The assessment may involve one or more members of the CAMHS team, and will usually involve seeing you as parents, your child, and probably other members of the family. The CAMHS team will usually ask for permission to request reports from your child's school and any other professionals, and services already involved in supporting you and your child. The assessment is likely to lead to an intervention plan to help you and your child manage their mental health and behaviour needs.

Some mainstream secondary schools are able to provide a school counsellor to support emotionally troubled teenagers, and some schools (including special schools for children with significant learning disabilities) have regular outreach clinics and links with community specialist services.

Further information about mental health issues is available from **YoungMinds** and the **Royal College of Psychiatrists**. For information about where to get help locally, speak to your GP, health visitor, or your child's consultant.

IF YOUR CHILD IS IN TROUBLE WITH THE POLICE

Sometimes, a young person with behaviour that challenges may come into contact with the police. Some young disabled people don't realise it's inappropriate to touch a stranger, or may take something from a shop not realising it must be paid for. Perhaps your child's behaviour and intentions have been misunderstood by others.

Some parents worry that their child is falling in with the 'wrong crowd' outside of school and does not grasp the seriousness of the group's anti-social behaviour. If you are worried about this, it may be worth contacting your local youth offending team (YOT). Every local council has one of these teams, who work to prevent young people getting involved in crime or re-offending. They are generally well aware that young people with special educational needs can get into trouble, and they seek ways to prevent this and to help them.

If your child has a particular learning disability or disorder, sharing information with the police about their particular difficulties and needs (communication especially) is important. The National Autistic Society produces information cards which can be carried by a young person with communication difficulties who may not be able to explain their situation.

If your child does get into trouble with the police, it is useful for you to know their rights.

Children under ten: can't usually be held legally responsible for a crime. Social services are responsible for dealing with a young child who has committed an offence. Social services may already be aware of your child's needs and behaviour, and should assess whether the behaviour is a risk, and work closely with you.

If your child is under the age of ten and has committed an offence, it is important to seek outside help. There are local family rights groups that offer advocacy services and advice about legal rights. Call our freephone helpline on **0808 808 3555** and we can tell you where your nearest advice service is.

Children over ten: can be held responsible for a crime if it can be proved they were aware that their actions were wrong. Parent carers must be informed if a child has been arrested, and the parent carer or another appropriate adult must be present if they are questioned.

Children and young people have the same right to a solicitor as adults. If they consult a solicitor, it is important that you make the solicitor and appropriate adult aware of any impairments, additional needs or illness, and what this means for the child. For example, if they have any history of challenging behaviour, and the degree to which they can understand what is being communicated to them.

BRINGING DOWN BRICK WALLS

A PARENT'S STORY BY YVONNE NEWBOLD

Have you ever hit a brick wall with your child's behaviour, where you simply haven't got a clue what to do next, because nothing seems to be working? Do you ever want to sit and cry because you can't see the end of the tunnel?

I remember whole weeks and months when I felt like that, totally despairing and not knowing how to make things better.

When our children have behaviours that challenge us, we have to learn to think outside the box in ways most parents don't have to contemplate. Maybe it's a child who has a violent meltdown all the way between school and bedtime, perhaps screaming, lashing out, hitting, kicking, biting or breaking things. Or a child who simply won't do anything you ask them to, or who has become a school refuser.

Even if it's a relatively good week and there haven't been too many crises, there is still the paperwork mountain to climb, the phone-calls to make and the funding decisions to fight. You crave sleep, you crave a moment you can sit down and relax, but you know that's unlikely to happen.

You're not alone – thousands of us have coped with similar battles behind closed doors where no one can see. Those brick walls too, they do come down, and we do find our way out of those tunnels, even when it seems to take forever to work out how to.

When things are tough and you feel like you're fire-fighting and losing, there are some very simple strategies you can do that can really help you feel that everything is that little bit more doable. Here are some of the ones I used:

- **Don't beat yourself** up and blame yourself. You are doing a fab job, and no one could possibly do it any better than you. Accept that this is how things are for now, and that it is what it is, and that you will cope.
- **Remember that things will always get better.** Whatever brick wall you're facing today, you'll work out better ways of coping with it sooner or later. OK, so by then there might be other brick walls, but this one won't be so insurmountable.
- **Notice how much more resilient and resourceful you are now.** Since the day you started caring for your child, look how far you've come and how much you've learnt. You are getting better at this parenting stuff every single day, and your child is developing and growing too – be proud of both of you.
- **When things are really tough, stay in the moment.** Try to only cope with life in ten minute chunks, one ten minute chunk at a time. It reduces panic, and you can cope with virtually anything for just ten minutes.
- **Stop and breathe,** consciously taking slow deep breaths, all the way down to the pit of your stomach. Deep breaths are calming, they help get oxygen around your body including to your brain, so that you can think more clearly too.
- **Stop actively trying to find** a solution to the current brick wall. Sometimes when we think too hard we chase away any possible ideas that might help. The best answers often arrive when we least expect them, or they will just develop all by themselves and you'll look back and just realise that something simply isn't an issue any more. Things shift, change, develop and evolve, and it won't always be like this.
- **Find some other special needs parents** either online or locally. They 'get it', they can help by pooling ideas of what they've tried in similar situations, they can even help you see the funny side of whatever's going on – and if you can laugh about life you're halfway over that brick wall already.

USEFUL RESOURCES

Autism Alert Cards

Can be carried by a person with autism and used in situations where they may find communication difficult. Search for 'autism alert card' to find one in your local area

Communication passport

Widely used in home, care, social work, health and education settings. You can read more about them and download templates at:
communicationpassports.org.uk

Circles of Support

An approach to including people in the community to achieve their goals in life. More information about Circles and how they work is at:
circlesnetwork.org.uk

Circle of Friends

An approach to the inclusion of your child in mainstream school. You can find more information about circle of friends from National Autistic Society and Inclusive Solutions:
inclusive-solutions.com

Early Support Family File

Contains information about all the people involved with your child as well as their likes, dislikes, and how they communicate.
councilfordisabledchildren.org.uk

Hospital passports

Some hospitals use passports that you can use to communicate information about behaviour triggers to hospital staff. Mencap also have a hospital passport for children with a learning disability on their website:
mencap.org.uk

Health action plan

These are for young people and adults with learning disabilities, and contain useful information such as the medicine they take, the health practitioners they meet, and what they need to do to stay healthy. For example, when they should have health checks.
councilfordisabledchildren.org.uk

Social stories

Describe a situation and possible sequence of events to a child to prepare them for what is likely to happen next. The National Autistic Society has information on how to write them. Search for 'social stories'.
autism.org.uk

PICTURES

Usborne

Publishes a range of picture books for children to help prepare them for new experiences, such as going to school, travelling on a plane, moving, visiting the dentist or hospital.
usborne.com

Picture Exchange Communication System (PECS)

PECS is a way of using pictures to help children ask for what they want. The central resource for PECS in the UK is Pyramid Educational Consultants UK Ltd. They run PECS courses, and their website has a wealth of information and products.
pecs-unitedkingdom.com
Other picture and symbol websites that are free of charge include:
do2learn.com
symbolworld.org

The Makaton Charity

Signs and symbols to promote understanding and language for children with communication and learning difficulties. The charity runs Makaton courses for parents.
01276 606 760
makaton.org

Books Beyond Words

Produce a series of books and e-Books that use pictures to tell stories. These cover important topics such as love and relationships, health, death and dying, and crime.
booksbeyondwords.co.uk

SPECIALIST EQUIPMENT

Chewy tubes

Pieces of rubber tubing (that are safe, non-toxic, washable and latex-free) that can be sucked or chewed on, and provide good resistance for people who need the sensory input provided by biting. Studies have shown that they appear to provide a calming and focusing function, and act as a release for stress. They can be bought from our not-for-profit Fledglings shop, which also has other useful products, such as harnesses and toys for soothing or stimulating children's senses.
fledglings.org.uk

Sand timer/egg timer

These can be bought online from the Fledglings or popular online stores.
fledglings.org.uk

Safety indoors and outdoors

Products to help to create a safe and stress free environment, and prevent accidents and mishaps at home. Plus, solutions for travelling, days out and holidays.
fledglings.org.uk

Living Made Easy for Children

Website and helpline run by the Disabled Living Foundation who can help you find play and a range of other equipment suitable for disabled children.
livingmadeeasy.org.uk

SEXUALITY

NSPCC

Information on talking to young children about staying safe and explaining appropriate and innapropriate behaviour using PANTS, the underwear rule. Search for it at:
nspcc.org.uk

Books Beyond Words

A series of illustrated booklets with no words (or very few) to help people with learning disabilities to understand health issues, personal relationships or life changes.
booksbeyondwords.co.uk

Talking together … about growing up

by Lorna Scott & Lesley Kerr-Edwards (2010).
An activity-based workbook for parents of children with learning disabilities. With chapters on body parts, the difference between public and private, keeping safe, feelings, growing up, which words to use and so on.
fpa.org.uk

USEFUL ORGANISATIONS

British Psychological Society

Regulatory body for psychologists in the UK. You can search for details of psychologists on their website.
0116 254 9568
bps.org.uk

Challenging Behaviour Foundation

Information and advice for families caring for, or individuals with, severe learning disabilities (both children and adults) who display behaviour that challenges.
Family support line: 0300 666 0126
challengingbehaviour.org.uk

Family Lives

24-hour helpline for all general aspects of parenting.
Helpline 0808 800 2222
familylives.org.uk

The National Autistic Society

Lots of information on behaviour and sensory issues useful to parents of any disabled child, not just those with autism:
autism.org.uk

Royal College of Psychiatrists

The professional body for psychiatrists in the UK. Its website has information leaflets covering many different mental health conditions affecting children, young people, their parents, carers, and professionals supporting them.
rcpsych.ac.uk

FOR YOUNG PEOPLE

YoungMinds

Charity committed to improving emotional wellbeing and mental health of children and young people.
Parents Helpline 0808 802 5544
youngminds.org.uk

Sibs

Charity supporting siblings of disabled children. They have ideas for coping with difficult situations and help brothers and sisters learn about the experiences of other siblings.
sibs.org.uk

Young carers

The Children's Society can put you in touch with help and support for siblings and young carers in your local area.
childrenssociety.org.uk

FOR CARERS

Carers Trust

Has branches of carers centres throughout the UK, providing information, advice and support services, to all carers, including parent carers. They often run support groups, relaxation sessions and other activities for carers. You can find your local carers centre on their website:
carers.org

Carers UK

Provides advice support and information for carers, including short break provision.
Helpline 0808 808 7777
carersuk.org

EQUIPMENT AND CLOTHING

Fledglings

Contact's not-for-profit shop. Toys and products for disabled children.
fledglings.org.uk

Living Made Easy

Advice and information on equipment for children.
Helpline 0300 999 0004
livingmadeeasy.org.uk

POTTY/CONTINENCE ISSUES

Fledglings

Contact's not-for-profit shop Fledglings has aids and equipment for children's continence issues, including swimwear.
0203 319 9772
fledglings.org.uk

ERIC (the children's continence charity)

Charity dealing with bed wetting, daytime wetting, constipation, and soiling in children and young people.
Helpline 0808 169 9949
eric.org.uk

Scope

Information on toilet training and bedwetting on their website.
Helpline 0808 800 3333
scope.org.uk

SEXUAL HEALTH

Brook

Free and confidential sexual health advice and services specifically for young people under 25 years old.
brook.org.uk

SLEEP ISSUES

Cerebra

Resources to help manage sleep issues for children with brain related conditions. Trained phone counsellors can give advice, and sleep practitioners may be able to visit your home or you may be able to go to a sleep clinic near you.
Helpline 0808 328 1159
cerebra.org.uk

The Sleep Charity

Offers training around sleep for parents and professionals.
03303 530 541
thesleepcharity.org.uk

Sleep Scotland

Charity providing support to families of children and young people with additional support needs and severe sleep problems in Scotland.
0131 258 1258
sleepscotland.org

Fledglings

Contact's not-for-profit shop Fledglings has aids and equipment to help children sleep.
fledglings.org.uk

GRANTS

Family Fund

The Family Fund gives grants to families who have severely disabled children up to 17 years of age. See their website for details of criteria.
01904 550 055
familyfund.org.uk

Contact

We have a list of charities which give grants to families with disabled children, including grants to help disabled children access education, and for equipment. We also have an online grants search tool you can use to look up grants you may be eligible for.
0808 808 3555
contact.org.uk/financial-support

GET IN CONTACT

Our helpline advisers can support you with any issue about raising your disabled child: help in the early years, diagnosis, benefits, education and local support.

0808 808 3555

info@contact.org.uk

contact.org.uk

Contact Head Office
209–211 City Road
London EC1V 1JN

We are Contact, the charity for families with disabled children.

We support families with the best possible guidance and information.

We bring families together to support each other.

We help families to campaign, volunteer and fundraise to improve life for themselves and others.

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