



ADVOCACY



POLICY



COMMUNITY

DEVELOPMENTAL DISABILITY *wa*

What is your child's Challenging Behaviour trying to tell you?

A GUIDE FOR FAMILIES





What is your child's Challenging Behaviour trying to tell you?

A GUIDE FOR FAMILIES

This resource was inspired by Contact a Family – United Kingdom www.cafamily.org.uk
and funded by the Disability Services Commission.

February 2017

Developed in consultation with:





“I have yet to meet a child who enjoys misbehaving. Rather, I see a child who is working to communicate a message about an unmet need in increasingly desperate and extreme ways”.

Dr Vanessa Lapointe
Registered Psychologist

Contents

Introduction	6
Understanding behaviour.....	7
Setting the scene for good behaviour	9
Recognising behaviour triggers	12
Dealing with behaviour issues.....	16
When is behaviour ‘challenging’?.....	22
The teenage years	24
Your child and the law	27
Sources of outside help.....	30
Useful organisations.....	32
Tom’s Story – My Challenging Behaviour	35
About Developmental Disability WA.....	39



Introduction

This guide is for parents, family members and carers who are worried about their child's/ family member's behaviour. For the sake of readability we will refer to 'parents' and the child as 'your child' throughout the resource.

Your child may be beginning to develop some behaviour that challenges you, or may already have behaviour that challenges. They may have a recognised disability, be in the process of getting a diagnosis or you may be wondering if they have additional needs.

Whatever the case, 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 feel the same. All children are different and there is no single answer to any of the difficulties or problems you may face. There are often complex reasons behind a child's behaviour and it is rarely anyone's 'fault'.

Fortunately, there are ways you can help your child and a number of people and organisations who can help. 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.

Understanding behaviour

It is not always easy to spot a behaviour that will challenge us during its early stages. We all engage in behaviour that challenges others at times, it's part of being human. Many young children naturally have tantrums and some teenagers may demonstrate other behaviours like ignoring their parents. However behaviour can become challenging when it is harmful to the child or other people, it interferes with the child being able to engage in life experiences and when it persists and is severe. When behaviour is particularly difficult to change or manage, it may be called 'behaviour that challenges', or 'challenging behaviour' (see 'When is behaviour challenging?' on page 22).



IMPORTANT

"It is helpful to remember that all behaviours are a means of communication for your child.....**they are to trying to tell you something**".

The challenge for you as a parent is to work out what your child is trying to tell you through their actions. What do these actions tell you about their needs and what's happening for them? With this knowledge you can better work out how to help your child meet their needs, including finding ways to help them use other, more acceptable, ways to communicate.

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; they dislike or are unhappy about a situation.
- **anxiety:** they are feeling confused, worried, stressed, unable to think well
- **hyperactivity:** they have excess energy and cannot seem to burn it off
- **discomfort:** they are in pain and can't tell you
- **attention:** they are making attempts to meet their need for attention, attachment and interaction by behaving in a certain way. They are wanting engagement with you.
- **difficulty with understanding:** if your child has difficulties with 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. They might not know what is happening around them or retain information that you have given them.
- **difficulty processing or making sense of sensory experiences in the environment:** for example, certain touch, noise and lights may stress your child. Some children may have hyper or hypo-sensitivities to certain stimuli in an environment.
- **seeking sensory input and/or experiences.**

SOME BEHAVIOUR THAT CHALLENGES IS MORE LIKELY IN CHILDREN WITH PARTICULAR MEDICAL CONDITIONS OR DISABILITIES. FOR EXAMPLE:

- children with attention deficit hyperactivity disorder (ADHD) may find it very hard to stay still or concentrate for long periods of time.
- children with an autism spectrum condition (ASX) 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.
- some children who have sensory impairments may be over or under stimulated by sounds, sights, smells and noise. This can significantly affect the way they behave.
- some children have a disability that impacts on their ability to speak. These children need alternative ways to communicate their needs. See ‘Setting the scene for good behaviour’ on page 9.
- some behaviours are common for particular genetic conditions. The way a child with that condition processes information and experiences their environment can lead to the possibility of certain behaviours e.g. obsessive behaviour, anxiety, over eating, poor sleeping or self-harm. If your child has a genetic condition, you may want to find out more about the condition and whether there are strategies to meet the specific needs of your child.
- some behaviour is classified by professionals as an ‘emotional and behavioural’ difficulty. Signs of this include low self-esteem, difficulty making friends, being tearful, quick to anger or not wanting to go to school.
- children with specific learning difficulties (eg reading or writing) or speech and language difficulties may find learning at school difficult and stressful without good support. If appropriate support is lacking, a child’s behaviour may change or become challenging.

UNMET NEEDS – CHALLENGING BEHAVIOUR CAN ALSO BE DESCRIBED AS A REACTION TO NOT HAVING OUR NEEDS MET. WE ALL HAVE NEEDS TO A GREATER OR LESSER EXTENT AND THESE INCLUDE:

Security	Peace	Value	Citizenship
Routine	Health	Fun	Expression
Quiet	Respect	Participation	Communication
Stimulation	Attention	Structure	Freedom
Love	Reassurance	Predictability	Choice
Affection	Appreciation	Stability	Feeling
Friendship	Understanding	Intimacy	Safe/Safety
Tranquillity	Variety	Identity	

Setting the scene for good behaviour

All children will communicate their needs and respond to situations differently. But there are some general principles that will help you manage your child's day-to-day behaviour. These principles are particularly important for children with disability, who may be struggling to make sense of a very confusing world.

They need a sense of predictability and structure

Most children cope more easily if they know in advance what is going to happen. Carrying out tasks in the same way or at the same time, every day helps children become familiar with what is expected of them. Children with more complex learning and communication difficulties may need more support to understand what is happening and to anticipate what is about to happen. Using visual information like pictures and symbols can help children process what is happening now and what will happen in the future. Knowing what is happening helps children feel in control, safe and secure. This does not mean routines are controlling, just that children need support to anticipate what is happening.

Routines can also be used to set up clear boundaries and acceptable behaviour, which can be reinforced with rewards (see 'Rewards' on page 10). For 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. For routines to work, it's important that everyone involved with your child follows the same routines, so let others know what you are doing and why.

Building communication

Children who try to communicate their needs and thoughts but are unable to, can be deeply frustrated. This may mean their frustration is acted out as behaviour that challenges or they need to use behaviour as the only real effective way to tell others what's happening for them.



IMPORTANT

Sometimes using a behaviour that challenges us, is the only way a child or young person can get a person to listen to them, or they just simply don't know another way to tell you what they need.

It is vital to have two-way communication with your child. It's important to find a way to communicate with them and for them to have a way to communicate with you. Often children use a behaviour that can be challenging simply because they want to interact with you. All children have a need for strong attachments and relationships and will sometimes use behaviour to engage and interact with you, even if it is in a negative way. It is also important to find a way to give information and talk about your daily routines to help them understand what it is that's happening and their ability to have some choice and control. If your child has complex communication needs there are ways of communicating that you can try. This may include:

- Using simple language; for example one-step instructions, or key words.
- Giving children time to understand and process what you've said or signed and repeating key instructions is important.
- Remember the power of your own non-verbal language/behaviour. Your tone of voice, warmth, posture, stance, positioning, eye contact and facial expression all speak volumes about your own feelings and will affect how your child responds to you.
- You can also support communication by capitalising on their natural visual skills such as using picture communication symbols, by signing, using gesture, by showing photographs or other familiar pictures or objects and through telling social stories. For example, show your child their coat to let them know it's time to go out, or using a range of picture symbols to have a chat about what they like about an activity.

You can get help to find the best communication system for your child by speaking to other parents, speech pathologists, teachers or other professionals with experience in supporting children with complex communication needs. See 'Sources of outside help' on page 30 for more information.

Play and exercise

Research has shown exercise is very effective in relieving stress, getting rid of frustrations and generally having a positive effect on behaviour. Trampolining in a safe garden 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 such as gross motor activities. Many local government recreational centres can adapt their mainstream activities to suit the needs of children with disability. If your child has very limited mobility/understanding or is very unwell you may need to seek advice about which activities they would be best suited to. There are a range of organisations in WA who organise more specialised activities for children with disability eg. Riding for the Disabled Assoc., Disabled Surfers Assoc., WA Disabled Sports Assoc.



CONTACT US

For more information on both mainstream and specialised organisations in your area contact Inclusion WA on 9201 8900.

Rewards

If you make a point of highlighting or praising appropriate behaviours throughout the day, you can reinforce and increase those behaviours. If you are thinking of using a reward system, it might be helpful to discuss it with the professionals involved with your child. It's important that the reward system you choose to use is appropriate for your child and takes into account any medical or other condition that may be causing the behaviour that challenges. For example, Prader-Willi syndrome can cause children to over-eat and so offering food as a reward could



make the situation worse. Offering a reward for a behaviour they can't control can also be problematic. For example night time bedwetting is not controlled by rewards. Positive examples of rewards may be specific verbal praise and attention, favourite activities, toys and tokens. Make it clear which good behaviour you are rewarding and what the reward will be. **For rewards to really work, you have to be sure your child wants and values that particular reward.** We all like to gain approval and receive something nice for doing something positively and trying our hardest. Start with small, achievable goals and gradually build up to expecting more.



A NOTE OF CAUTION:

Just giving rewards however might not help a child, especially if they don't know what else they could do in place of the behaviour or if there are other underlying difficulties they are experiencing which makes it difficult for them to adapt their behaviour. Children who may experience challenging behaviour need your help not just your praise. Often it is best to better understand what behaviour may be telling us about your child's needs. This can lead to thinking about how you support your child to prevent the behaviour occurring in the first place, which may or may not involve using rewards.

Recognising behaviour triggers

In some situations, children become anxious or distressed, which can trigger behaviour that challenges. You may know these triggers, or at times you may be baffled and caught off guard. It can take time and practice to work out the triggers but it's important you do, so you can find ways to support your child to feel less anxious and distressed. If your child does start to display behaviour that indicates they are anxious or distressed, try to work out the cause and address it. Children who can't speak can find it very difficult to identify and let you know what is upsetting them. For children who can speak, they may still find it difficult to identify and say what is bothering them. Children with more complex communication needs are likely to find it even harder to both understand and communicate their feelings. Your child may have very particular likes or dislikes, or may feel overwhelmed or even bored.

QUESTIONS YOU MIGHT CONSIDER INCLUDE:

- do they understand what they are being asked to do?
- do they understand the task asked of them or are the steps clear?
- are they familiar with the person working with them? Are other people spending time with them, chatting and developing relationships? Are the interactions between them and others positive and enjoyable?
- are they hungry or thirsty?
- are they in pain?
- are they tired?
- is the situation too noisy for them?
- are they too hot or too cold? Are they getting the physical activity they need across the day?
- are they finding change too difficult to cope with?

Devising strategies that remove or reduce the effect of triggers

If a behaviour keeps happening and you are unsure about the triggers, it can be helpful to keep a diary, or a behaviour chart, to try to learn more about it.

A GOOD EXAMPLE IS AN ABC CHART:

- **A** stands for antecedents – the things that lead up to the behaviour. For example, where people are, what is happening, who is there, what the time is, what people are saying.
- **B** stands for behaviour – what the child is actually doing, what the behaviour looks like.
- **C** stands for consequences – what happens in response to the child's behaviour. What do other people do and say? What does the child do?



Sometimes it can be how we respond to a behaviour that can encourage or discourage (whether you mean to or not) the behaviour from recurring. **Remember** your child may be 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 helps to get other people to meet their need for interaction and connection. **Using an ABC chart or a diary may help you identify and manage triggers** (see figure 1 and 2 on next pages). Sometimes an ABC chart is simply useful to get an idea about the purpose of a behaviour, how the behaviour helps the child meet an underlying need. It can help you to be curious about what could be happening for your child and what support they might need to get their needs met.

What if you can't manage a trigger?

It won't always be possible or appropriate to avoid certain triggers. For example, your child loves going out for walks in the park but is really frightened of dogs and runs out of the park onto the road, or screams or hits you if a dog approaches. You will need strategies to reassure your child, gain their trust in these situations and help them learn to cope with their anxiety or stress. It is likely that you will learn what works best. For example, you may help your child to learn strategies to reassure themselves about the safety of dogs, or you might 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 manage triggers in your routine. Learning from other parents through local support groups can also be useful. Developmental Disability WA may be able to help you to find a parent support group in your area.

ABC Charts

By completing an ABC chart, it might give you some clues as to some of the underlying reasons for the behaviour and therefore what support your child may need, for example:

Figure 1:

Date and time	Antecedents	Behaviour	Consequences	Other comments
10/6/16 5.30pm Child has been playing alone while parent gets dinner ready.	I was cooking dinner and my son was in the lounge near me. He kept making noises which were getting louder and louder. His younger sister came in the lounge.	He hit and scratched his sister.	I ran in the room and yelled at him. I took my daughter with me to the kitchen	I feel exhausted. I can't leave him alone or he will hurt his sister

Possible unmet needs

It seems to happen mainly when he is not engaged with me or when I've been busy for a while. I think he's hitting his sister to get my attention and get me to come back and be with him.

Behaviour	Strategy
Hitting sister when I am engaged in something else.	<p>Ensure his need for interaction and engagement is met across the day. Don't leave him for long periods of time on his own</p> <p>Keep talking with him whilst I am busy</p> <p>Involve him in daily tasks if possible</p> <p>Help him engage in an activity that he enjoys when I am busy that is nearby or in my line of sight.</p>

Figure 2:

Date and time	Antecedents	Behaviour	Consequences	Other comments
10/6/16 8am Child is seven years old and has Autism.	He was sitting on the lounge watching his TV show. I turned it off and asked him to get dressed. I gave him his clothes	He tipped over his tray of toys next to him and started hitting his head	I put him in his room until he calmed down. Then I got him dressed in his room. He was still hitting his head though and was really worked up.	It happens most days when I try to get him to do something

Possible unmet needs

It seems to happen mainly when I ask him to stop doing something and do something else. Maybe the change in activities causes him some confusion or maybe he thinks I'm taking his enjoyable activities away.

Behaviour	Strategy
Hitting his head and getting upset when I ask him to get dressed	<p>Show him through pictures what the routine will be to get ready in the morning.</p> <p>Show him the pictures of the routine at each change of activity</p> <p>Give him warning that an activity will end soon</p> <p>Show him that his preferred activity will happen again and when</p> <p>Use a visual timer so they can predict when one activity will end and another will begin.</p>

Dealing with behaviour issues

You may have to wait to get outside help to deal with your child's behaviour. The first step would be to talk to your doctor or another professional involved in your child's care, who can make the appropriate referrals to other specialists. Remember, getting advice from support organisations and other parents can be invaluable during this time. Assessments by professionals and referrals to services can take some time, so try to access all the support you can while you are waiting. In the meantime, there are useful techniques you can try yourself. First of all, decide which behaviour you want to focus on if your child has several worrying ones. For some parents, this means deciding which behaviours you can live with and which ones you must tackle because they are dangerous or harmful for your child and others. There is no single solution for dealing with behaviour that challenges and not everything can be solved at once. There are some common approaches you can try, which may have some effect:

Focus on prevention

Remember that all behaviour is a way of your child telling you about their needs. Everyone is unique and will have different needs based on the physical and emotional aspects of their environment. At times in our lives, we might experience gaps in our needs, particularly when the people around us change and our environment changes. Sometimes our unique needs just mean that we might find it difficult to cope with what's happening around us. For example: your child might find it difficult to understand what's expected of them by just listening to what you are saying. They might have difficulties with processing and retaining verbal information, especially if they are already stressed. The best way to manage challenging behaviour is to try and prevent it from happening in the first place. To do this, you need to understand what your child's needs are and what triggers a gap in these needs. If you can support your child by addressing their needs, then your child will not experience having to use a behaviour that challenges to get their needs met. If you only focus on managing a behaviour once it has occurred, it is difficult for your child to change their behaviour as we haven't addressed what's caused them to be stressed or to have a gap in their needs. The reason for the behaviour stays the same.

Rule out any medical or dental problems

It is important to rule out any underlying health issues with your child's GP or specialist/s which cause pain and your child cannot tell you about eg. toothache, earache, constipation.



NEED HELP?

If you find it difficult to take your child to the dentist, you may be eligible to attend the Special Needs Dental Clinic in North Perth. Ph: 9201 9889.

Focus on trying to understand the behaviour

Once you've done some thinking about what happens at the time of a behaviour occurring, start to think about what the behaviour might be telling you about their needs. Is the behaviour a reaction to being confused, stressed or anxious? Sometimes stress and anxiety is hard to understand, especially if it presents as being 'bad behaviour'.

ASK YOURSELF WHAT MIGHT BE INFLUENCING YOUR CHILD TO EXPERIENCE THIS CONFUSION, STRESS, ANXIETY:

- Difficulty processing information?
- Difficulty anticipating what will happen?
- Unable to meet their sensory needs? Sensory triggers eg. noise can be overwhelming
- Pain or other health problems?
- Difficulty concentrating?
- There's been a gap in people connecting socially with them?
- They want to tell you something but can't?

Place your energy into helping your child meet their needs

If you can spend your energy and time supporting your child to meet their needs then you can more likely prevent a behaviour from happening in the first place. This might mean changing what other people do around him or her or helping your child develop some new skills. Meeting a child's needs across the day is a preventative strategy to challenging behaviours rather than just in response to a behaviour occurring.

IT'S ABOUT PUTTING THE ENERGY INTO WHEN THE BEHAVIOUR IS NOT OCCURRING SO THAT WE CAN KEEP A GOOD THING GOING. THAT IS POSITIVELY REINFORCING POSITIVE BEHAVIOURS. TO DO THIS, YOU CAN:

Reduce the child's anxiety and distress: focus on how you can reduce your child's stress, confusion and anxiety. Remember that your child's ability to learn something new and do something different can only happen **when their brain is calm.**

Adapt the environment: what needs to change in the physical environment and what people need to do to better support the child? For example; if your child is seeking engagement from others through their behaviour, how can other people ensure they spend quality time regularly with them to meet their need for social interaction. If your child has difficulty processing information, picture symbols can be used to help follow and retain information about what is happening and what is going to happen.

Teaching skills: By putting supports in place, you can teach your child new skills to help them meet their needs. For example: the introduction of a visual communication system might help your child both understand the language being used around them and to learn a way of being able to say what they want and are thinking. You can help your child recognise their signs of stress and help them find ways they can calm themselves in situations that are stressful.



Respond well when they are behaving in challenging ways

When a parent models calm behaviours in challenging situations the child is less likely to escalate their behaviour than if the parent were to react in an alarmed way. Ways to respond well include:

- 1. Stay neutral:** Keep your responses to a minimum by limiting verbal comments, facial expressions and other displays of emotion when the behaviour is occurring as these may further escalate a child's distress. Try to speak calmly and clearly (using just key words and phrases) and keep your facial expression neutral.
- 2. Focus on the behaviour not the person:** It is important for your child's self-esteem that they know you want to change their behaviour, not them and who they are. Otherwise they may be unhappy and this is likely to affect their behaviour and may make things worse.
- 3. 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...". If we focus on what not to do, this is what they will hear and focus on that behaviour. If we focus on what to do instead of the behaviour, this is what they will hear. It also teaches them the skills of what they could be doing instead of the behaviour. Sometimes we expect children to stop doing something but we haven't taught them what to do instead. Children can find it very hard to interpret 'no' messages. If you can re-direct your child into good behaviour, reward them at once, for example with your undivided attention, a hug or specific praise.
- 4. Be consistent:** Tell everyone involved with your child about your strategy for this challenging behaviour so that everyone is working on it in the same way. Children get very confused if adults use different strategies. It can be helpful to agree on a written behaviour support plan, with strategies that work, for all involved with your child, particularly if they go to a day centre, have a support worker or other support option. If you are having a short break, give this plan to everyone who looks after your child in your absence, such as family, friends or other carers.
- 5. Help your child regulate their emotions:** Children need help to recognise, understand and then manage their emotions. This takes some time and relies on the adults around them to learn these skills. If a child can do this then they are better able to cope with difficult emotions and do something positive about them.

SOME EMOTIONAL REGULATION STRATEGIES TO TRY INCLUDE:

Acknowledge: first connect with your child's emotions. Help them name what they are feeling and what the trigger was by acknowledging what they are experiencing. For example:

“you're really mad that your sister took your books”.

“it looks like you're feeling.....”

“It sounds as though you feltwhen.....”

Engage the thinking brain: once you've helped your child to connect to their emotions, help them use the thinking part of the brain. Help them think of ways to address the problem. For example: “what could you say to her to ask for them back?” Help your child understand the perspectives of others. For example “I wonder why she needed to take them?” “What are some things you can do to make yourself feel better when you feel.....?”

Redirect: sometimes when a child is experiencing big emotions it can be helpful to redirect their focus onto something else. This can help their brain shift focus and therefore help them calm down. For example: “hey I would love your help making a cake”, “would you like to come and be my special helper?”

Sensory needs: it is helpful to understand what sensory needs your child has to help them feel calm. Some children need a lot of movement, others need certain types of touch and others are sensitive to the type and amount of noise around them. If we can meet a child's sensory needs, they will be less stressed and better able to manage their emotions. Take some time to observe and think about what your child might react to or be seeking from their sensory experiences. Some families choose to access an occupational therapist to complete a sensory profile for their child to help identify their child's sensory preferences. This can be useful in developing a 'sensory diet' to help fulfil your child's sensory needs.

Give space or lean in: what helps your child calm down? Some children like to have some space as they feel overwhelmed with people around them when upset, whilst other children calm down with the comfort and support of others.

You might also need some space for yourself to regulate your own emotions so you can continue to respond positively and helpfully to your child. To do this, you could:

Pause, breathe: pausing and taking at least 6 deep breathes helps calm our brain as well as our physical feelings. It helps us calm down our own big emotions. Practice deep, mindful breathing by inhaling and counting to three and then exhaling.

Take yourself away from the situation: you might need to temporarily take yourself away from the situation to be able to calm your emotions and your thoughts before you respond to your child. You can't help your child manage their emotions if you are upset yourself. You might need to ask someone else to look after to your child temporarily. If your child is safe and not at risk of harm step outside or into your bedroom/bathroom for a few moments before retuning to calmly speak to them.

Build in positive experiences for your child

The more positive experiences you have with your child, the more they will try to engage in behaviour to keep these experiences going. Similarly, if you make a point of praising and rewarding appropriate behaviours whenever possible, you will reinforce and increase good behaviour. Often your undivided attention and having fun together is the best reward. Reading a story together, playing a favourite game (online, board game, cards) and cooking are all positive ways to engage.

Top tips for managing behaviour

WHEN DIFFICULT BEHAVIOURS OCCUR, IT IS GENERALLY HELPFUL TO:

- take time, stay calm and neutral
- give reassurance in a way your child is able to understand
- be supportive, caring and listen
- keep language simple and give clear messages to your child about what you want them to do or show your child how they can engage in a more appropriate behaviour
- remove other adults and children from the situation if required
- look and sound confident – even if you're not feeling it
- intervene quickly, try diverting or distracting your child.

IT IS LESS HELPFUL TO:

- look angry or upset
- lose your temper
- intimidate
- talk a lot, quickly or shout
- confuse your child
- have other people chip in
- re-ignite the situation
- be negative, saying 'naughty', 'bad', 'no' or 'don't'
- threaten punishments, particularly ones you are unlikely to be able to follow through on.



IMPORTANT: PUNISHMENT RARELY WORKS

Using strategies like '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. Similarly punishment does not change the reason the child had a need to use the behaviour in the first place. It doesn't address the problem. Remember that your child's behaviour is communicating an unmet need. There are rarely overnight miracles so remind yourself to be patient. Don't worry if things get worse before they get better. Your child will take time to adjust to your new strategies and learning new ways of getting their needs met.



Look after yourself

None of this is easy, especially when you are tired. We all need time to relax and take care of ourselves. 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 for themselves. It maybe as simple as having a bath in peace, reading a book or seeing a friend. Without taking a break from caring, your health can suffer. If you are a sole parent or you do not feel that you can ask family or friends to help out, contact one of the organisations below and ask about a short break.



NEED HELP?

Carers WA Ph: 1300 337 377

Commonwealth Respite & Carelink Centre Ph: 1800 052 222

Local Coordinator - Disability Services Commision

The break could happen in a number of ways:

- A support worker assists your child to attend a social or sporting activity.
- The family stays home while your child stays with another host family or goes to a residential home for a short while eg Red Cross Lady Lawley Cottage Ph: 9318 2160.
- It may be that a support worker could come into your home to look after your child while the rest of the family goes for a holiday.

If you are concerned about your other children, further information about supporting them is available from Siblings Australia www.siblingsaustralia.org.au If you are supporting an adult brother or sister you can contact Sibswest www.sibswest.com.au or Carers WA for young Carers under the age of 25 years.

The Association for Children's resource 'Growing Together' recognises the unique experiences of siblings of children with a disability and offers parents information and strategies to support them <http://acd.org.au/growing-together-resource/>

Minimising risks

It is important to find ways to reduce the risk of children hurting themselves and to help them feel as safe and calm as possible. Understanding your child's needs, including sensory, communication and interaction needs and structuring their environment to meet these need, as much as practical, is often the best way of mitigating risk. It is sometimes also necessary to build in practical environmental safeguards in addition to these supports.

Simple ideas might include using locks on the fridge and cupboard doors, cooker guards, wall-mounted televisions and electric plug socket covers. The Independent Living Centre can give advice and information on what is available and can keep your child safe and comfortable, yet not be too restrictive, see page 33.

Having said this, the use of locks and restrictions does need to be carefully thought out. Perhaps ask yourself "Is this a reasonable and regular strategy that most families would use?" If you find yourself using a strategy that limits your child's movements, limits acceptable choice and might make them feel bad, it might be useful to discuss this with a professional person or other family support people. Together, you might be able to find other ways you can more positively support your child. See 'Restrictive practices – What are your rights? An information guide for people with intellectual disability' available online from www.disability.wa.gov.au or hard copies from Developmental Disability WA.

When is behaviour 'challenging'?

In some cases, children develop behaviour that is persistent and really impacts on family life and their relationships with others. The behaviour may not only be a risk to the child, but also people around them and prevent them accessing ordinary community facilities like schools, restaurants, leisure centres, cinemas or daycare centres. Often, behaviour that challenges can be associated with a severe learning difficulty and can lead to aggression, self-injury or disruptive and destructive behaviours. Some children may also have other inappropriate reactions to situations eg. they may laugh when someone is hurt, swear at strangers in public or cry a lot for unexplained reasons. On the extreme end of the scale, some children may have regular or lengthy sessions of screaming, kicking, hair pulling, self-harming or damaging clothes or property. It's really important to seek outside help rather than battle on your own. As a starting point you may find it helpful to discuss this with your GP, paediatrician or Local Coordinator. They might refer you to a specialist such as a child psychiatrist or clinical psychologist.

Medical professionals should consider your child's initial diagnosis, as some behaviours are associated with particular disabilities (for example, hand biting is common in children with Fragile X syndrome). Sleep issues, incontinence, problems with feeding/eating, self-harming, emotional problems may be associated with your child's diagnosed disability, but could be due another underlying medical or mental health issue. This is why different health professionals may need to be involved in helping you identify what is influencing your child's need to engage in a behaviour that is challenging and what you can do to support your child.

In the school setting, behaviour can often be misunderstood as being rude, disruptive, uncooperative or aggressive towards staff and other pupils. You will need to speak to your child's teacher and the school psychologist. The school can contact SEND (School of Special Education Needs: Disability) for further support.

Sleep problems

Many children have difficulties around sleep and bedtime. These are common in all children, and especially children with learning difficulties, vision impairment or those on the Autism Downs spectrum. For example, the child may not settle in bed until late, get up in the night, refuse to sleep in their own bed, refuse to sleep alone, make noise which wakes up the household or wake up very early. These issues may not seem urgent at first, but long periods of poor sleep can mean you and your child are sleep deprived which can have a significant impact on your ability to cope, think and manage stress. Sleep deprivation may also lead to your child being more inattentive and/or irritable. It is important to speak to your GP to check that your child does not have any medical reason for poor sleep quality eg tonsils, adenoids.



NEED HELP?

Ngala provides advice on general sleep issues for young children Ph: 9368 9368
Country callers 1800 111 546.

The Ability Centre has sleep specialists who assist with general sleep issues and can refer you to a psychologist if there are deeper underlying issues. Ph: 9443 0211

Smearing faeces and urinating

Some children and young people may smear faeces or urinate in inappropriate places. There can be various reasons for this including underlying medical, cognitive, social or sensory reasons (they are meeting a sensory need by performing this action). This behaviour can be very hard to deal with because of the smell, extra washing, disinfecting and expense of replacing ruined carpets, wallpaper and bedding. You may become exhausted and anxious about the behaviour and the endless explanations you may feel you have to make to other people, so it is important to seek professional help. You may find the behaviour socially limiting therefore leading to a sense of isolation. Sometimes it is difficult to work out the underlying reasons for this type of behaviour. Professional support can help you understand the reasons.



NEED HELP?

PEBBLES is a continence management service for children and young people. Contact PEBBLES for a continence assessment and to find out how to deal with smearing and urinating issues Ph: 1300 865 401.

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:

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

You can try to address the behaviour by working out what is causing the episodes, but you will quite likely need to seek professional help if your child is showing these types of behaviours frequently, intensively or dangerously.

The teenage years

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

School transition

Many children who have transferred from primary to secondary education will have appropriate, on-going support in place, however some children who have had good support in primary school may struggle in a large secondary school. They can feel overwhelmed by the size of the school, the numbers of pupils, different teachers and unfamiliar routines. Children become more conscious of their peers' independence and the fact that they cannot keep up or are not allowed similar freedoms. They may feel they are 'different or isolated/not included and lose confidence in themselves. Parents sometimes comment that their children's behaviour and their mental health gets worse when moving from primary to secondary school. You may find yourself despairing of teachers who fail to see your child's difficulties and feel they blame them unfairly for 'day dreaming' or for being aggressive and getting into fights. Behaviour that becomes more challenging may also coincide with your child growing bigger and stronger as they get older. Despite this, children and young people can be well supported in secondary school (whether mainstream or in a specialist environment) and settle well. It's important that you prepare the way as much as possible and this may mean that your child needs a greater level of supports to meet their needs during this transition time. Remember there are laws in place to help protect children with disability from being seen as simply naughty or deliberately disruptive. Their behaviour difficulties may arise because of their unique and unmet needs and so if you feel your child is not receiving appropriate support, ask to speak to the person at your



child's school responsible for supporting children with disability. Your child has the right to have their needs for support properly met and their school has a responsibility to work with you to ensure your child's educational, social and emotional outcomes are achieved.



NEED HELP?

If you feel your child's needs are not being met and you have tried to resolve the situation with the school Principal, you can ask the school to consult with SEND (School of Special Education Needs: Disability), contact Developmental Disability WA Ph: 9420 7230 or the Coordinator of Regional Operations at the Regional Education office. Numbers are listed in the phone directory under Dept. of Education.

Sexuality and inappropriate sexual behaviour

Parents of young people with disability generally accept that their children will naturally develop sexual awareness and feelings like other teenagers, however they also worry about their extra vulnerability. Some young people with a disability find it hard to know where and how they can express their sexuality and when it is inappropriate.

Sexuality is a sensitive area for most parents. Educating children about relationships and sexuality will help them to feel good about themselves and their bodies, to get on well with others, to protect themselves and to feel safer in navigating their world.

There are many reasons for challenging or inappropriate behaviour such as masturbating in public: pleasure (not comprehending social rules or norms), anxiety, boredom and seeking attention are just a few. It is useful to consider why your child is behaving in this way, so you can address the cause, not just the behaviour.

Parents may feel embarrassed and upset, or worried about the serious consequences of the behaviour. However, it is important to remain calm, to re-focus or distract the child and not reinforce the unacceptable behaviour. The most important thing to do is to provide your child with lots of attention and positive responses when they are behaving well and appropriately.

So what else can parents do?

- Teach your child about public and private places, body parts, behaviour and touch as well as private talk (ie. who it is ok to talk to about private things);
- Model appropriate public and private behaviour within your own family;
- Teach your child the correct anatomical names for private body parts so they can communicate with doctors or teachers and others if needs be;
- Prepare your child for puberty and the changes they will experience in a way they will understand;
- Prepare girls for menstruation and managing hygiene;
- Explain that masturbation is normal and pleasurable, but only done in private (ie in their bathroom or bedroom, with the door and curtains shut and when they are by themselves);
- Talk about your child's different relationships and different interests as they grow up;
- Teach your child about internet safety; and
- Seek advice and support if you are concerned or not sure of how to respond to your child's needs.



NEED HELP?

SECCA produce information and materials for young people around issues of sexuality, disability and relationships and run workshops on puberty and adolescence.

Ph: 9420 7226 or www.secca.org.au

People First programme

Ph: 9227 6414 or www.peoplefirstprogramme.com.au

Emotions and mental health

Sometimes you or the professionals working with your child, may notice other emotional and behavioural changes to the extent you may be concerned about your child's mental health. If you are worried, contact your GP, consultant paediatrician or child health professional to talk about it. They may suggest a referral to your local Child and Adolescent Mental Health Services (CAMHS) 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 may lead to an intervention plan to help you and your child manage their mental health and unmet needs. Some mainstream secondary schools are also able to provide a school counsellor to support your teen or you can contact the following services:



NEED HELP?

Beyond Blue Youth 1300 22 4636

Headspace <http://headspace.org.au/headspace-centres/> 11 centres in WA

Reach Out <https://about.au.reachout.com/what-we-do/>

Your child and the law

Sometimes, a young person with behaviour that challenges may come into contact with the police. If your child has a specific learning disability, sharing information with the police about their particular difficulties and needs (communication especially) is important. It may be useful for a young person with communication difficulties to carry an information card to explain their situation. Some young 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 Policing Team www.police.wa.gov.au/Contact-Us/LPT, enter your postcode to find your local team. If your child does get into trouble with the police, it is useful for you to know their rights.

Children under ten years

can't usually be held legally responsible for a crime. If your child is under the age of ten and has committed an offence, it is important to seek outside help. There are local disability advocacy services and community legal centres that offer advocacy services and advice about legal rights.



NEED HELP?

Sussex St Community Law Service Ph: 6253 9500

Developmental Disability WA Ph: 94207203,

People with Disability WA Ph: 9485 8900 or 1800 193 331

Mental Health Law Centre WA Ph: 9328 8012 or 1800 620 285

Children aged over ten

can be held responsible for a crime if it can be proved they were aware that their actions were wrong. Parents must be informed if a child has been arrested and the parent or another 'responsible adult' (eg. a social worker) must be present if they are questioned. Children have the same right to legal representation as adults. If your child is arrested, it is important that you make their legal advisor aware of any disability or illness and what this means for the child, for example, any link with behaviour that challenges, and the degree to which they can understand what is being communicated to them.

Under the WA Criminal Law (Mentally Impaired Accused) Act 1996 children over ten who have committed an offence can be found by a Court to be not mentally fit to stand trial for an offence if they are:

- unable to understand the nature of the charge;
- unable to understand the requirement to plead to the charge or the effect of a plea;

- unable to understand the purpose of a trial;
- unable to understand or exercise the right to challenge jurors;
- unable to follow the course of the trial;
- unable to understand the substantial effect of evidence presented by the prosecution in the trial; or
- unable to properly defend the charge.

Being found to be not mentally fit to stand trial for an offence can have significant consequences, and it is important that you consult with your legal advisor about the implications. For further information you can also contact one of the disability advocacy services or community legal centres listed above.

Getting support

It is important to tackle issues with your child's behaviour early. If you notice certain behaviours getting more frequent, occurring over longer periods of time and becoming unmanageable, look at how you might better understand the reasons for the behaviour and what you might be able to do to address these reasons and/or needs of your child.

If your child has a specific diagnosis, there are many support groups that can usually offer tips and strategies to prevent or manage behaviours that challenge. Many parents say the best advice comes from other parents they meet with similar challenges. To get in touch with disability specific support organisations and groups, contact:



NEED HELP?

Connect Groups Ph: 9228 4488 www.connectgroups.org.au/
 Developmental Disability WA Ph: 9430 7203

Help at school, preschool or kindy

If you're concerned about your child's behaviour, it's helpful to know that schools and early years' settings have legal obligations to support children who have difficulty learning, and to treat children with disability fairly. Behaviour and discipline policies should take into account a child's disability and educational needs. Laws are in place to help protect children with disabilities. Behaviour that challenges may arise because of a lack of reasonable adjustments to accommodate their disability or their unique needs. School staff should receive adequate disability training so they can recognise and respond to their needs. Depending on the age of your child, you can talk to your child health nurse, your child's teacher or the special educational needs coordinator. Tell them what your concerns are, giving examples to illustrate your concerns and ask what support can be put in place. The school should work with you to ensure your child's needs are met. For more information see '**Personalised Learning Support Plans – A Guide for Families**', produced by Developmental Disability WA – www.ddc.org.au/rise

What are multi-disciplinary teams?

These are teams which include health professionals with specialist knowledge and expertise. Different specialists can help to bring together ideas about what could be influencing your child to need to engage in behaviour that is challenging. Examples of multi-disciplinary teams include child development teams (CDCs), Child and adolescent mental health services (CAMHS) and Disability Support Teams e.g. Disability Services Commission, Early Years and Behaviour Support teams and DSC approved Therapy Providers.



NEED HELP?

Autism Association of WA Therapy and Clinical Services Ph: 9489 8900.

Ability Centre Psychologist Ph: 9443 0211

Rocky Bay Clinical Services Ph: 9283 5111

Therapy Focus Clinical Services Ph: 1300 135 373

Visibility Psychologist Ph: 1800 847 466

Teams like these specialise in working with children with disabilities or where there are concerns about a child's development. A child development team usually include a paediatrician, physiotherapist, occupational therapist, speech pathologist and clinical psychologist. They also work with child and adolescent psychiatrists, psychologists and paediatricians. Child and adolescent mental health services (CAMHS) teams promote the mental health and psychological wellbeing of children and young people.

If you feel your child's support needs are not being met by a health or disability service provider you can contact the Health and Disability Services Complaints Office (HaDSCO) www.hadsco.wa.gov.au Ph: 6551 7600 or country callers 1800 813 583.



Positive Behaviour Support

Throughout this resource we have been talking about the need to understand behaviour before we can hope to change it. Advances in our knowledge and approaches to behaviour support have highlighted some common aspects of supporting behaviour change and these aspects include:

- Understand that behaviour is a way communicating something
- Often behaviour that challenges is a way of telling us about the person's unmet needs
- There might be many environmental and personal factors which influence the person having unmet needs
- Our goal is to support the person to reduce the need to engage in behaviour more than to just stop it. Most effort is put into preventing behaviour.
- Our ultimate goal is to truly understand the needs of the person and to improve their quality of life.

These approaches underlie a behavioural focus called Positive Behaviour Support (PBS). Positive Behaviour Support can support families to better understand the reasons for behaviour resulting in identifying strategies to address these reasons as well as strategies to support the child and others when behaviour occurs. When seeking the support of professionals, it might be useful to ask what their model of behaviour support is and whether their approach will help you understand behaviour as well as knowing how to respond to it.

Sources of outside help

In this section, is a list of the people, organisations and resources that exist to help parents and family members cope with behaviour that challenges. There are a large number of professionals and other sources of support that can be involved in helping you and your child.

Support groups

They may be local (covering a certain area or region), national or even international. They may be a generic (for all parents of children with any additional need), or condition groups (for example, for parents of a child with ADHD or Fragile X syndrome). Support groups offer different services according to their size. Even if you do not meet a parent of a child with the same needs as your child, you may still find it helpful to share experiences with other parents. Condition support groups will be able to give you information on the condition and how it might affect your child. They may also be able to link you with other parents of children with the same condition as your child.

Parents

Often parents find the best advice that they get is from other parents who may have gone through, or are currently going through, similar experiences to their own. You can link with other parents through parent support groups. To find a local group, contact:



NEED HELP?

Contact Carers WA Ph: 1300 337 377

Developmental Disability WA Ph: 9420 7203

Professionals

The assessment of and advice about the successful management of behaviour that challenges, often needs a multi-disciplinary approach. Positive Behaviour Support is underpinned with a comprehensive look at the functional needs of a child in many areas of their life. In this guide, we have made reference to several different professionals and services who can help with you better understand and respond to your child's behaviour including:

- **Clinical psychologist:** who will consider a child's behaviour, assess its causes and discuss practical strategies you can use.
- **Community psychiatric nurse:** a children's nurse from CAMHS who provides support around mental health conditions and behaviour support options.
- **Educational school psychologist:** children can be referred by their parents, a health professional or school to an educational psychologist to look at setting up strategies to support positive behaviour.
- **GP:** your child's General Practitioner or family doctor may be able to give some useful advice, but may also want to refer you on to a professional or community team with more specialist knowledge.
- **Child Health Nurse:** are likely to have had face-to-face contact with you and your child and will have experience and expertise in the management of common problems in childhood. Child Health Nurses can also work with other agencies to contribute to support for your child.
- **Occupational therapists:** Can provide advice on and assistance with practical issues for children whose challenging behaviour may be linked to the need for support in developing physical coordination, fine motor skills, activities of daily living, independence and strategies for more effective sensory processing.
- **Paediatrician:** a child's paediatrician may offer advice on how to deal with behaviour that challenges or refer your child to any of the other professionals in this guide.
- **Paediatric nurse:** often come across different behaviours in their working with children who are sick or have a disability. They can have a wide range of knowledge and suggestions to support you and your child.
- **Physiotherapist:** can assist children who experience limitations in their mobility, which may contribute to their frustration and behaviour.
- **Psychiatrist:** may be able to support children whose behaviour is linked with mental health conditions.

- **School counsellor:** a qualified counsellor employed by a school so that children experiencing difficulties can discuss their concerns.
- **Special educational needs coordinator:** a member of staff in an early years setting or school, who is responsible for coordinating special educational needs provision in mainstream schools.
- **Speech pathologist:** support the development of expressive and receptive language and/or utilise AAC (Augmentive and Alternative Communication) devices in order to reduce or limit communication frustrations leading to behavioural challenges.
- **Social workers:** can provide counselling around supporting your child as well as some practical support in accessing respite and support services.

Useful organisations

Family/Carers' organisations

Kalparrin Ph: 9340 8094 www.kalparrin.org.au

Kalparrin helps families of children with special needs to carry the load by offering practical and emotional support. Their Family Support Officers are based at the Perth Children's Hospital and can help families navigate complex health systems and connect to services, organisations and other families in similar situations who can assist them. Kalparrin also runs a range of programs and social events which provide support for mothers, fathers, siblings, grandparents and carers.

Carers WA Ph: 1300 337 377 www.carerswa.asn.au

Carers WA provides quality information, advice and support services, including counselling, social support, in home supports, education and training, information and advocacy. They are based in Perth but provide services across the State.

Communication

Independent Living Centre WA - ILC Tech Team

Ph: 1300 885 886 www.ilc.com.au

ILC Tech Speech Pathologists have experience in the specialist area of augmentative and alternative communication (AAC), which includes information, assessment, prescription, therapy, training and support for people of all ages with complex communication needs who may require visual supports, communication boards/ books/ PODD, and high tech communication devices/ apps.

Key Word Sign WA

www.facebook.com/kswa or keywordsignwa@gmail.com

Promotes the use of Key Word Sign across WA for the benefit of people with communication difficulties.

Continence

PEBBLES Continence Management Service
Ph:1300 865 401 www.therapyfocus.org.au

PEBBLES is a state-wide program dealing with toilet training, daytime wetting, bed wetting, constipation and soiling in children and young people with special needs. PEBBLES provides services to children aged 0 -16+ years (Note: Bedwetting service age group eligibility is 6 – 16 years). The PEBBLES team consists of continence nurses, physiotherapists, occupational therapists as well as a dietician and a psychologist.

Equipment

Independent Living Centre WA Ph: 1300 885 886 www.ilc.com.au

State-wide service, with centres in Nedlands and Cockburn. ILC's occupational therapists can provide free information and advice to help people choose and access the most appropriate equipment, to support greater independence and improved wellbeing. To complement this service and to provide more comprehensive support, the ILC can provide additional services in the home and community, including assessment, prescription, training and support to use assistive equipment that will enable people to better manage in the home, school, work or wider community. Fees may apply for these services.

Noah's Ark WA Ph: 9328 1598 www.noahsarkwa.org.au

The Noah's Ark Toy Library for children with disability and additional needs, provides resources and information to help families and agencies promote children's development through play. Memberships are available.

Sexuality and Relationships

SECCA Ability | Relationships | Sexuality Ph: 9420 7226 www.secca.org.au

SECCA provides education, counselling and consultancy on sexuality and relationships for children and adults with disabilities and those who care for them. Secca's staff are specialists in the area of sexuality education, and psychotherapists work with individuals and families on a wide range of relationship and sexuality issues. Secca offers regular training in disability and sexuality, boundary setting and protective behaviours, and internet safety, as well as customised training for organisations who support people with disabilities. Secca also has an extensive library of resources available to members.

People 1st Programme Ph: 9227 6414 www.people1stprogramme.com.au

Siblings

Sibswest (for adult siblings) www.sibswest.com.au

Siblings Australia - www.siblingsaustralia.org.au



My challenging behaviour – Tom’s story

My First Primary School Experience

School was a difficult time for me. I was a bubbly, intelligent and outgoing boy, who happened to be the first severely disabled boy in a school that didn’t realise my potential. This gave me feelings of deep anger and sadness, which often resulted in me crying, shouting and spitting. Because of my disability, I wasn’t treated like the other students. I had to spend a portion of the day doing therapy in class while lessons were going on. I often had to miss school for extended periods for various doctors’ appointments.

The school didn’t have the funding and resources to tap into my full potential and that resulted in me feeling isolated and not being able to enjoy my time in school. I was also made to use a complicated communication system that was frustrating and degrading, given that I could communicate quite easily without any assistive technology. At times I was included (assembly, sports day etc), however when something occurred that upset me, I would be removed from the event and taken back to class. All this did was further fuel that feeling of a sense of inadequacy because I could not behave in the ‘correct’ manner.

I was often subjected to sensory overload such as too much noise. Once during a science show, something exploded that resulted in me screaming and crying out loudly. The teacher took me away and instead of being comforted, I was told off for reacting in a way that was deemed inappropriate and for being a nuisance.

I developed some unexplainable phobias as a child, one such phobia was that of puppets. I would freeze (verbally and physically) in shock when I came face to face with puppets. Even though this had been explained to the school, we were all taken on a school outing to a puppet show. Once again, I was accused of behaving badly.

My behaviour was made worse, because I often didn’t sleep through the night. This information was shared with the school; however, I would still be reprimanded for behaving badly or inappropriately.

More time was spent on documenting my behaviour and my therapy outcomes than focusing on social inclusion. Attending the after school programme was very difficult for me emotionally, because I was in a situation where fellow schoolmates were doing things I wanted to do, like playing basketball, swimming, or working on art projects. The mere fact that I couldn’t do what they were doing, made me further isolated socially, and left me feeling depressed. I was often in the same room, but I felt distant from others and my disability became an obstacle to my ability to enjoy what I was experiencing. This resulted in bad behaviours, such as being very moody, acting out, not wanting to be included and crying until it was time to go home.

Next Primary School

I was the first disabled student to attend this school and the first year was a period of uncertainty. Teachers did not know how to teach me and at first most of them underestimated my capabilities and aptitude to learn. Although the teacher’s assistant was very pleasant she was rather ineffective and unhelpful. As a result, for the first year I was not fully integrated into the classroom and my classmates were unable to get to know me for who I was, instead

all they saw was an alien. I felt intimidated, lacked a sense of belonging and I was emotionally unstable because of all the changes that were occurring. Furthermore, the uncertainty of my fate in the school made me very reluctant to participate in school activities. I was often moody and didn't want to go to school. I was often feeling depressed and I remember not wanting to get out bed in the mornings, telling my mum that I was sick, when in fact I was just extremely nervous and anxious about school and constantly living in a state of panic. All these negative feelings in turn contributed to my behavioural issues in school.

Things turned around for me when a new teacher's assistant came in. The change she brought on highlights the importance of finding a suitable person for the job. She was able to reach out to students in ways that other teachers were unable to. She did a splendid job assisting me in my social and academic participation. For example, she suggested to the teacher that it might do some good if I worked with certain students on some activities, so that members of the class could see that I was more than just the person in a wheelchair who needed supports. She also conducted disability awareness training in class, and that taught my friends how to care for me. She helped to facilitate outings on the weekends for me and my classmates.

The main issue I faced in school was bullying. I was often bullied and picked on by some students, and those experiences caused feelings of anxiety and hatred. It was nice to attend a school where I felt cocooned by half of the class and it was nice to see that when I was being bullied, certain members of the class would come to my defence and try to talk sense to the bullies, which left me free to have fun for the most part. While it was touching to know I could trust some people, the bullying did take a toll on my social and mental health. I often blamed myself for putting my friends at risk of physical and emotional torment because they were sticking up for me. Even though I knew there were people who would stand up for me, I didn't like the idea of friends going to school with the thoughts of having to engage in physical scuffles because of me. There were days when I didn't want to attend school because the bullying was affecting me so much emotionally. I couldn't bear to see my friends constantly having to engage in 'battle' mode, and constantly having one of my friends be the lookout person to make sure I was fine, when they could instead be participating in sports or other activities they enjoyed.

By the final year of primary school, I could actually call all the people in my year group as friends. That realisation was very exciting, and at the same time it was terrifying knowing that it was all going to end soon. In the last month of school, the negative feelings such as depression and anxiety came back because all my friends were going to different schools, and I was going to a high school where I knew no one. It had taken me a long time to feel as a part of the group and the thought of all the changes to come was too much to handle.

The time of transition between primary and high school was very difficult for me and my family. I felt a deep sense of loss, hopelessness and being out of control. These feelings manifested in many bad behaviours at home. I was crying, screaming and telling my mum I didn't know what to do with my life. A behaviour pattern emerged where I was out of emotional and physical control, I used to just cry and say 'why me, this is not fair'. It got to a point where, I would go for walks around the neighbourhood and just start crying. It was a challenging time for my family who had to try and fill the gaps that my friends had left behind.



First High School Experience

I attended a school with a special education centre attached to it, and I was placed in the same class with other people with intellectual disability.

High school was meant to be an exciting time for me. For the first year it was incredibly exciting and empowering because I went to the 2000 Paralympics in Sydney with my class. I was quite heavily involved in the planning and fund raising process and that took up a lot of time, but when I came back from Sydney, things started falling apart.

The school had a special education programme and everyone in my class was expected to follow it. Unlike some students in the class who could read and count, I was unable to read, tell the time or count. The teachers pushed me really hard to get me to do things they expected of me and all that did was make me feel like I lacked intelligence. I ended up pretending that I could do the tasks even though I really couldn't. My feelings of depression and anxiety returned and I even developed suicidal tendencies. It got to the point where I was asking my parents to kill me and I was planning ways to commit suicide. I didn't think I had any future in this world because, I was basically told that if I can't read, do maths or tell time I will not be able to function in society, such as getting a job, manage money, etc. I was made to feel like I wasn't good enough. I even asked my parents questions like 'why did they not get an abortion', or 'why did they let a vegetable live'.

For a period of six years I was totally out of physical and emotional control. I tried to hurt myself on many occasions by biting, punching or hitting my head against the headrest. I was even threatening to hurt my teachers.

These violent and self-destructive behaviours were part of my everyday life, which placed my parents and family in a tricky situation. I used to scream for up to five hours at a time because I was depressed and angry at my school experience.

As a result of the depression I developed from my experiences in high school, I was hospitalised. The teachers in the hospital school actually discovered my potential to do mainstream high school work. The team at the hospital suggested another school for me, however, that only lasted a week because the change from a very close and supportive environment with a teacher's aide to myself, to a big school that was highly academic was too much for me. The teacher's aide there wasn't very welcoming or supportive.

I was home schooled for a while, before I hopped from one school to another. None of which worked out for me and finally my parents and I decided to try post school options. This experience was limiting as I was often doing activities such as watching movies, going to shopping centres, bowling and doing other activities that didn't give me a sense of purpose or challenge me to better myself. In addition, some of the carers were really rude and degrading. They would say things like why would a person like me want to go to Uni or travel and that I would never be able to achieve my ambitions. This in turn caused major feelings of anxiety, helplessness and depression, which resulted in me acting out in challenging ways.

My initial experience when I moved into supported accommodation, was rather positive, however the standard of care went down dramatically and the people I liked left. This resulted in my anxiety and depression coming back and the frequency of my anti-social behaviours increasing. My parents and sister decided that living in a residential facility wasn't doing me any good emotionally or physically so I went home for a while and even then I was still feeling very upset and traumatised.

My friends and family worked hard to build up my confidence. They encouraged me to engage in activities instead of just staying at home and moping around about what a bad person I was, who couldn't even succeed in living independently. Together with the help from another agency, my parents sought out a house for me. My experience at the residential facility left me strong feelings of self-doubt, anxiety and depression and I burst into tears when I saw the house my parents found. I didn't feel like I could try anymore and I sat down with my family and friends and told them I couldn't do it, I didn't want to, I just wanted to stay at home where I was protected, where I could still be independent. They convinced that it was all going to be fine, that I would still be in contact with my loved ones, that I would be protected and that I should give it a try. Although there have been periods where my behaviour was occasionally challenging, through the care and encouragement from my dedicated family, friends and team of support workers, who have and continue to give me a lot of life enriching experiences, I am now studying at University and have found work that gives me a sense of purpose and control over my life, as well as the opportunities to contribute to society.

I am living a happier and fulfilling life, and I no longer behave in challenging ways.



About Developmental Disability WA

DDWA is a not for profit organisation that has been the lead disability advocacy organisation in WA for nearly 30 years and supports people with developmental disability, their families and the organisations that support them. DDWA advocates on a system wide (systemic) basis about issues such as:

- education
- employment
- justice
- disability services
- access, transport
- health
- recreation
- individual rights
- relationships
- housing and accommodation

DDWA also provides information and training for both families and service providers with the aim of ensuring:

families are more informed about issues and how they can better navigate the system, and service providers are supported so they better understand the issues, experiences and perspectives of families.

Ph: 08 9420 7203

Email: ddc@ddc.org.au

Web: www.ddc.org.au



ADVOCACY

POLICY

COMMUNITY

DEVELOPMENTAL DISABILITY *wa*

City West Lotteries House
2 Delhi Street, WEST PERTH WA 6005

phone 08 9420 7203
email ddcwa@ddc.org.au
web www.ddc.org.au
ABN 61 889 503 484