

I am trying to tell you something!

Supporting adults who can
behave in challenging ways



A GUIDE FOR FAMILIES

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Developmental Disability WA



DDWA Inc



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About Developmental Disability WA

DDWA is a not for profit organisation that has been the lead disability advocacy organisation in WA for more than 30 years supporting 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 and human rights
- communication
- access and disability services
- health
- housing and accommodation
- social and recreation
- individual rights
- relationships and family
- behaviour

DDWA works in three main ways:



- To support people with developmental disabilities and their families to have a strong voice and seek change where needed.
- To influence government and other decision makers to make positive and lasting change.



- To build the expectations and capacity of people with developmental disability and their families.
- To inform people and families about their rights, choices and options to equitable services and supports.



- To support people with developmental disabilities and their families to live their everyday lives.
- To partner with others to develop more connected and inclusive communities.



About Side by Side

What is Side by Side?

Developmental Disability WA, have co-designed this peer partner program with families. The focus of Side by Side is family members whose loved ones experience challenging behaviour. This is because they are some of the most isolated and vulnerable people in the community. The aim of the program is to build; strength, resilience, and hope through relationships; and to provide information, education, skill development and to share experiences.

What makes Side by Side work?

- Ideas you can share with other people
- Freedom to be real and honest
- Belonging to a community of families in a similar position
- Peers who understand what it's like to live with challenging behaviour
- Hope from hearing other people's success stories
- Knowledge and confidence.

To find out more call **08 9420 7203** or go to **www.ddwa.org.au/behaviour-support-side-by-side**

Acknowledgements

We wish to thank the lead authors of this resource book, Debbie Lobb and Jaquie Mills for their commitment to supporting families who live with challenging behaviour and the families who provided valuable insight and experience to share with other families.



Government of Western Australia
Department of Communities

This project is an NDIS Information, Linkages and Capacity Building (ILC) initiative. For more ILC events and resources please visit www.disability.wa.gov.au/wa-ndis/wa-ndis/information-linkages-and-capacity-building/resources

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Understanding behaviour

Behaviour is part of being human

Sometimes in our ongoing care for a loved one with disability there are times that they engage in actions or behaviour that we find difficult. These difficulties could be in our ability to care for them, support them to have a good life, or concern around potential harm to themselves or others. Whilst this concern is real, it's important to first take some time to think about behaviour itself.

Behaviour is part of being human. It's a part of everyday life.

Do any of us live a life where we never engage in behaviour that challenges other people? How many of us get to a point where we yell, bang doors, walk out, ignore others, say hurtful things and sometimes even throw things, hit things, or break things? We can all get to the point where aspects of our daily lives influence us to feel stressed, upset, angry, anxious, sad or confused. When we experience these emotions and states of mind, we often can't help the way we react or the way we think. We might behave in ways that we would not have if we were feeling good.

When we are having a bad week and everything is going wrong, such as; the person you were hoping to see cancelled, you worked long hours, the house work is piling up, no one seemed to care about helping you, you had a migraine; and then a family member finds fault in something you have done, you might react by yelling at them or perhaps even throwing something and feeling angry. If the migraine continues along with the workload, you might even find yourself yelling or getting angry more often than usual.

People are more than their behaviour. When we are stressed, people might ask us what is wrong, or at least think about what might be going on for us. Are we tired, stressed, worried? It is unlikely our loved ones will recommend us having a behaviour program for the purpose of stopping our behaviour once and for all. It is a challenge for anyone to try and live a life where they don't ever react in a negative way due to stress or other emotions. Sure, our behaviour might be a problem at the time, but without the stressors in our lives we wouldn't resort to expressing our frustration in ways which might upset others.

How we all react may be different. We all have different thresholds of how stressors in our lives influence us, and different aspects of our lives which mount up to cause stress. What are those stressors for you? Imagine what it might be like to have limited control over things happening around you, and the influence this would have on your stress levels for example; being in a situation where you don't know what's happening, you don't understand what others are talking about, you don't have a say in what you will do, or things happen that you didn't expect. When exposed to these things over time, you can become very tense and anxious. Small things can then really upset you or trigger you to react.

When is behaviour a problem?

What are we really talking about when we use the word behaviour?

Everything we do is behaviour and most of everything we do has an underlying message or reason.

We know that what people **do**, is one way of indicating what might be happening for the person from within. This is something we want to really listen to rather than stop. These clues help us to know what people might be experiencing.

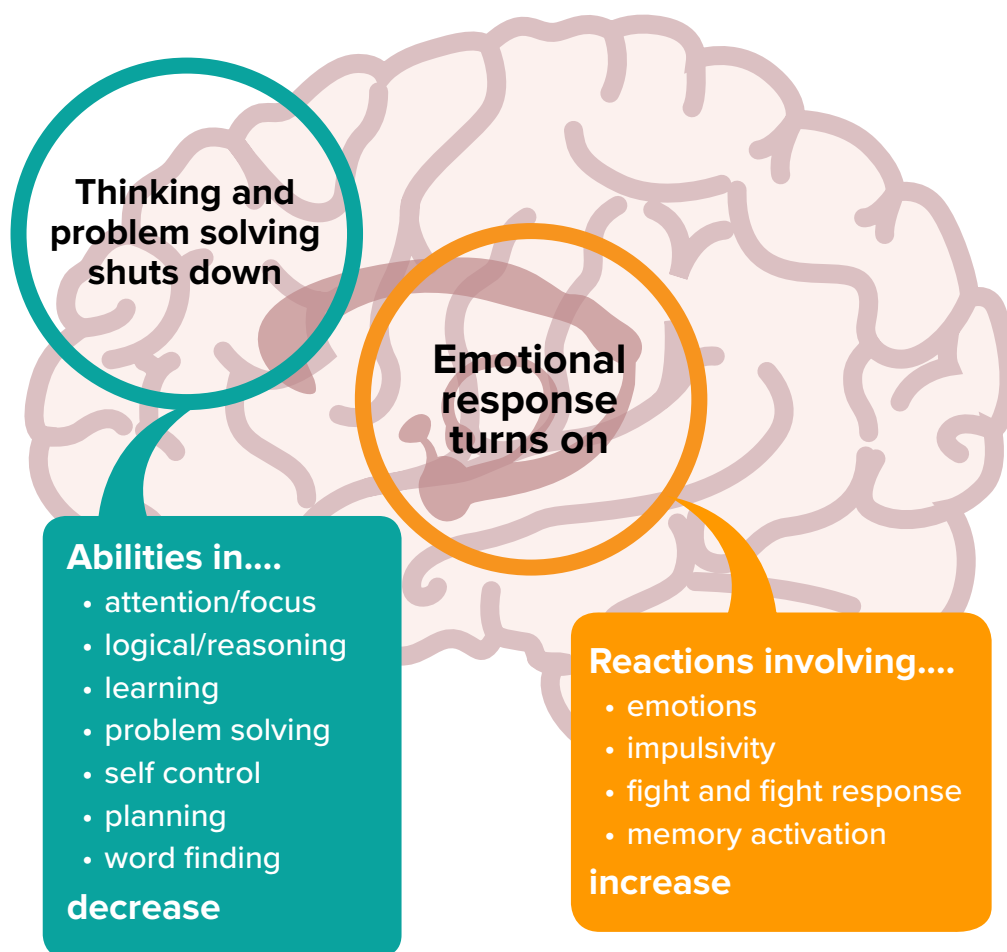
There may be times though, that a person engages in a certain behaviour or behaviours that impacts on their relationships, or causes harm to themselves or others. This might be of concern because we want to help the person to have a good life, one in which they feel happy, valued and content - a life rich in relationships.

Regardless of the impact of behaviour, our response should always be the same, that is to try to find out what is going on for them which has led to them feeling stressed/upset and reacting in this way. We need to take the time to try and understand the behaviour from within. How does the person experience their life? What is unique about how the person perceives the world and what happens around them to result in gaps in their needs being met? Only by doing this can we address the reasons for the behaviour, which will hopefully lead to a reduced need to engage in the behaviour at all.

Sometimes we can't help the way we react

We used to think that behaviour was something you could fix and stop. We now know that behaviour is a result of what we are experiencing. It is an indication, a message about what is going on for us. We might be sad, fearful, anxious, stressed or in pain. Our actions are the result of what we are experiencing, and more often than not, we are experiencing high levels of stress when we react in challenging ways. It is important to understand the changes that happen in our brain when we are experiencing strong emotions and states like stress, distress, worry and sadness. Think about a situation where you might have experienced strong emotions. During these times, the brain redirects its energy away from the 'thinking parts' to the 'emotion parts'. As a result, it is hard and sometimes impossible to activate the parts of the brain which allow for problem solving, logical thinking and clear thinking.

We react in a way that makes sense in the situation for the purpose of helping and protecting ourselves. For some people, we react in the only way we know how. It is important to mention that these actions of the brain are not under our full control. Our brain reacts to the chemicals released in response to how our needs are being met. For some people, living a life with limited control, poor relationships and a lack of predictability, can lead to a lot of stress related chemicals being released in their brain. These chemicals then activate the 'emotion parts' of our brain which in turn reduces the activation of the 'thinking part' of the brain. Can you imagine how hard it is to control and change your behaviour if the brain has to work very hard to even activate the parts of the brain to problem solve and learn new skills?



SEBASTIAN

Sebastian is a young man who lives in his own home with the support of others. He has unique ways of communicating mainly through body language, facial expressions, vocalisations, and the use of visual communication systems. He has a strong desire for food and has mobility difficulties. On one occasion, Sebastian was shopping with his support worker when she noticed he had disappeared. On looking for him, she found him in the nearby bakery pulling food off the shelves and eating them. There was food everywhere, along with other items strewn across the store.

The bakery staff were understandably very distressed and tried to remove him from the store. Sebastian dropped to the floor and would not move. He proceeded to yell, push people away and kick at those who came near him. Eventually after some time, the support worker was able to physically assist Sebastian to stand and go to a park to calm down. He used the sign for 'd**khead' a number of times when his support worker was talking to him.

What was it that the bakery staff saw? It is likely they saw a young man with a disability who purposefully rampaged through their store, taking items, eating them and was out of control. They understandably directed the support worker to never bring him back. When support workers met and talked about the incident later, they “could” have focused on how they needed to:

- Reduce the likelihood of Sebastian being near a bakery again
- Develop a behaviour program to teach him not to take food
- Implement a consequence for his ‘behaviour’
- Reduce his access to cakes to reduce his desire to take them

Instead, his support team took time to think about what Sebastian may have been experiencing during the bakery incident. They realised that it looked like Sebastian:

- Could not control his impulsivity around the food items
- Was distressed and could not control his actions
- Was very confused
- Didn’t seem to be able to comprehend what the support worker was saying
- Didn’t know what to do and looked frozen, unable to move from the bakery
- Needed to get to the end of his distress before he could think again and move out of the store

On reflection they realised he was calling himself a ‘d**khead’ and the staff felt a great amount of empathy for Sebastian. How hard it must have been for him during that incident.



Our behaviour is influenced by our needs

In order to feel good about ourselves and to feel calm, happy and in control, we all have common underlying needs. These needs are not something we choose, they are needs we are born with.

Some of these needs are to:

- have meaningful relationships and close attachments to others
- belong
- feel in control
- feel safe
- do things we enjoy
- understand what is happening and for life to be predictable
- feel valued and good about ourselves
- be able to interact with others

Even though everyone thinks differently and has different physical needs, these underlying needs never change. It is what happens in our interactions with others and with the environment that results in how our needs are met. Sometimes there might be an imbalance in accessing what we need to understand the world, or to feel good, that results in emotive experiences or confusion.



People are more than their behaviour.
We have to understand the world through their eyes.

What makes the person tick? What are their underlying needs? How does the environment and people around them help them meet their needs?

SARAH

Sarah is a young woman, who with the help of her planner has moved into a unit of her own. She spent a lot of time participating in person-centred planning, identifying that her goal was to live independently. At first, Sarah appeared to like living on her own. However, after a short period of time, she started to cut herself, take overdoses of paracetamol and present to the emergency department of her local hospital. There was significant concern whether Sarah had developed a mental health condition. Sarah was not aware why she was harming herself and continued to want to live in her own home.

Sarah's support network took some time to think about what was happening for her. They realised that the move had resulted in significant gaps in her underlying needs.

As a result of Sarah moving:

- Her contact with people had reduced and therefore her need to interact was not being met
- Her routine had changed, leading to confusion and lack of predictability
- She was experiencing a significantly increased need to process information, problem solve and plan without any supports

Many people who don't have a disability also discover that they do not like living on their own, or that it takes time to adjust. Gaps in the above needs can often affect our physical health as well as mental health. Loneliness and lack of predictability are known to be key factors which lead to depression and anxiety.

Does Sarah need to move in with other people? Not necessarily, but she does need help to embed some supports and to plan her daily routines to meet her underlying human needs.



Is behaviour part of having a disability?

Behaviour is not a result of having a disability

Unfortunately, it is sometimes believed that having a disability is a direct cause for the presence of behaviour that can challenge us. However, everyone can behave in ways that challenge others. We all have the same underlying needs, whether we have a disability or not.

Having a particular type of disability does not necessarily mean that you will engage in certain behaviours.

To really understand behaviour, we need to shift the focus away from the disability and to the person.

What do you think you might experience if:

- You didn't have a way to tell people what was wrong or what you needed?
- You couldn't choose who you saw today or what you wanted to do?
- You had to wait for all your meals and then didn't get to choose what you ate?
- You hadn't seen your friends for a while and didn't know when they might come again?
- You have been feeling unwell and haven't been able to tell other people how you are feeling?
- The people around you are so focused on what you have to do all day long, that they don't spend any time just chatting with you, or worse still, don't talk to you hardly at all?

We all need to have choice and control in our lives; to have meaningful relationships and to understand the information around us. We need to be able to predict what's happening and to interact with others. The needs of people with disability are no different to people without a disability. The problem often lies in a person's ability to meet their own needs.

There is no doubt that having a disability might result in the person having unique ways of thinking, processing information, communicating, and experiencing physical needs. If we strive to understand these qualities and develop supports to meet these needs, the person is unlikely to experience gaps in their needs being met, thus preventing the need to engage in challenging behaviour.

Whilst having a particular disability does not determine behaviour, it is helpful to learn about some of the unique ways people with certain disabilities might process information and experience the world. This knowledge can lead to a better understanding about where the gaps in their needs might be. For example:

- People with autism can have particular ways of making sense of information and of relationships. They can find it difficult to predict information and to filter the information they receive. As a result, they might experience stress and anxiety from needing to constantly process the confusing information around them. Things like changes in routine or information which is presented in ways they find hard to process can often contribute to this stress.

- People with an acquired brain injury are likely to experience difficulties with memory, impulse control and making sense of relationships because of impaired neural pathways. Not having information presented in a way that helps with memory, recall and understanding context can lead to confusion, anxiety and altered emotional control.

There are many other disabilities which when understood, can help us to get to know what a person may be experiencing. These include; Down syndrome, Prader Willi, Angelman syndrome and Rett syndrome to name a few. Whilst some people have similar behaviours (for example people with Angelman often pull hair, or people with Prader Willi may have a food compulsion), it's not necessarily the disability causing the behaviour.

Many people with disability have difficulty expressing themselves and understanding language. This can make it more likely for them to experience significant difficulties in communicating such as; telling people what they think, finding ways to connect and interact with others, and understanding language and information. Over time, they might develop ways to communicate in the only way they can, including using behaviour that other people might find challenging.

Whilst having certain disabilities can mean that people have a tendency to behave in certain ways, we must be careful to not write off the behaviour as being just part of the diagnosis. The behaviour is an expression of an unmet need.

SEBASTIAN'S STORY CONTINUED....

Sebastian didn't react the way he did in the bakery because he has Angelman syndrome (and therefore it's a given that he will always react like this around food), Sebastian reacted because he experiences difficulties in being able to:

- Control his impulsivity around food
- Anticipate when things might happen
- Plan and predict information

Would the scenario have been different if supports were in place to help Sebastian meet his needs in the above areas in ways which relate to how he experiences the world?

Having a disability might impact on quality of life

Unfortunately, having a disability can often lead to a poorer quality of life. Living with communication difficulties, struggling to make sense of what is happening around you, and lacking control over life choices places people at risk of not leading a life that is enjoyable and meaningful.

Due to the impact of underlying needs not being understood or met, people with disability often experience:

- Isolation and loneliness
- Social adversity and stigma
- Communication breakdown
- Lack of a meaningful occupation and valued roles
- Lack of friendships and meaningful relationships
- Physical inactivity and dietary issues
- Pain and other health related issues
- Overmedication

It is well known that people with disability are at a significantly greater risk of trauma and abuse. The experience of powerlessness alone can be extremely traumatic and over time can result in long lasting impacts on wellbeing, functioning and behaviour. It is no wonder that people with disability also experience much higher rates of anxiety, depression and other mental health concerns. Not only can their world be highly unpredictable and confusing, it can also be one where they have limited control over what happens and the relationships they form.

With the above common experiences, who wouldn't find it hard to *not* react in challenging ways! Unfortunately, when people do engage in behaviour that challenges, this can lead to further isolation and loss of relationships as well as reduced access to meaningful engagement and social adversity.

Instead of seeing the person as a person and trying to understand the behaviour, we tend to make life even harder and even less enjoyable for them.

OSCAR

Oscar is an engaging young man who really enjoys the company of others. He lived in a group home where the staff were becoming increasingly concerned about his behaviour. Oscar would ask questions continually, leading to staff trying to avoid him and redirect his conversations. He started to appear angry at staff, often calling them names and accusing them of lying to him. Oscar also started to hit out at staff and damage property such as breaking windows in the house. Staff became fearful of taking Oscar out, so he stopped going out into the community. Soon after, staff would leave him on his own on one side of the unit with a locked door separating them. When they approached Oscar to engage with him, he was often found to have defecated on the floor. Unfortunately, Oscar developed a reputation as being a person with significant challenging behaviours and difficult to support, making his accommodation options limited.

If we look past Oscar's behaviours, it is possible to guess what he might have been experiencing, such as:

- Difficulty understanding and predicting his routines
- Difficulty making sense of and recalling information
- Difficulty engaging with people using the communication skills he had
- Loneliness and isolation due to limited opportunities to engage in valued roles and community life

Unfortunately, Oscar was being punished for experiencing universal needs. Imagine experiencing these needs and people reacting by taking things away, and making life even more confusing and isolating?



A new way of thinking about behaviour

Understanding universal needs

There has been a significant shift in the approach to behaviour support, one which now sees the person and their quality of life, rather than the behaviour alone.

We used to spend a lot of time analysing the behaviour itself, trying strategies to modify it, and trying to motivate the person not to engage in it. The fundamental issue with this approach however, is that it fails to really look at the underlying reasons or the experiences of the person which have led to the need to engage in the behaviour. We now realise that often people cannot control their behaviour, and so our focus is not on reducing their behaviour but reducing the experiences of stress, anxiety and dysregulation.

So, what can we do now that we know our wellbeing is influenced by our underlying needs, and that when these needs are not met, this can lead to behaviour that can be challenging?

Before we start to look at the behaviour and try to modify it, we need to take the time to first look at how well the person's universal needs are being met. Let's think about the effect of the following factors on; regulation, stress and anxiety.

Belonging and relationships

At the core of our existence is the need to form attachments with others and to feel like we belong. This drive is at the centre of everything we do at an unconscious level. Imagine how difficult it would be to meet this underlying need if you have communication difficulties or you have no control over the relationships in your life.

Is the person supported by other people who the person likes and chooses to spend time with?

- Does the person have people in their life they regard as friends?
- Does the person have regular connection with family which they can control?
- Does the person have the opportunity to develop meaningful and intimate relationships?
- Does the person have active involvement in the community as a valued community member?

Social interaction and engagement

It is a common misperception that just being supported by other people is enough to meet our need for meaningful relationships. We often fail to realise that it is the quality of the actual interaction that meets our underlying need for social connection. We are social beings and as such our brain drives us to connect with others. Take some time to look at what the interaction patterns look like for people with disability. Often interactions are one-sided, being very directive and laden with questions. When this happens it can lead to significant stress and anxiety. People need social interaction, including chatting, comments, joking and general conversation. How would you feel towards someone who mainly told you what to do all day and asked an overload of questions?

Take some time to observe what social interaction looks like for the person you support.

- Do interactions contain mainly questions and instructions?
- Do people engage in a more conversational style of interaction? For example, lots of comments and taking the time to just chat?
- Do people interact with the person often and regularly across the day?
- Are opportunities for interaction frequent regardless of the verbal skills of the person?
- If the person has access to communication supports like pictures, are they designed in such a way to support conversation and social interaction, and not just for choice making or to tell them what to do?

Control and predictability

Just as important as belonging is the need for predictability.

To function well, our brain strives to make sense of information and needs information to be predictable.

We need to feel in control and to have access to information to be able to predict what is happening now, next and into the future. We also need enough information about the context we are in to be able to filter and make sense of how to respond. People with disability may have greater difficulty with processing information around them and predicting what will happen. This can be compounded by difficulties with memory and understanding language. Take for example, someone with autism who struggles to focus on the information they hear, and to filter what the most important information is to focus on, as well as the context needed to make sense of the situation.

- Are there supports in place to help the person predict and anticipate what is happening today, this week and into the future?
- Are there supports in place to help the person know and understand changes to the routine?
- Are there supports in place to help the person follow, process and recall information, particularly verbal information?
- Are there supports in place to help the person know the details of what will happen so that they can have some control over the situation?

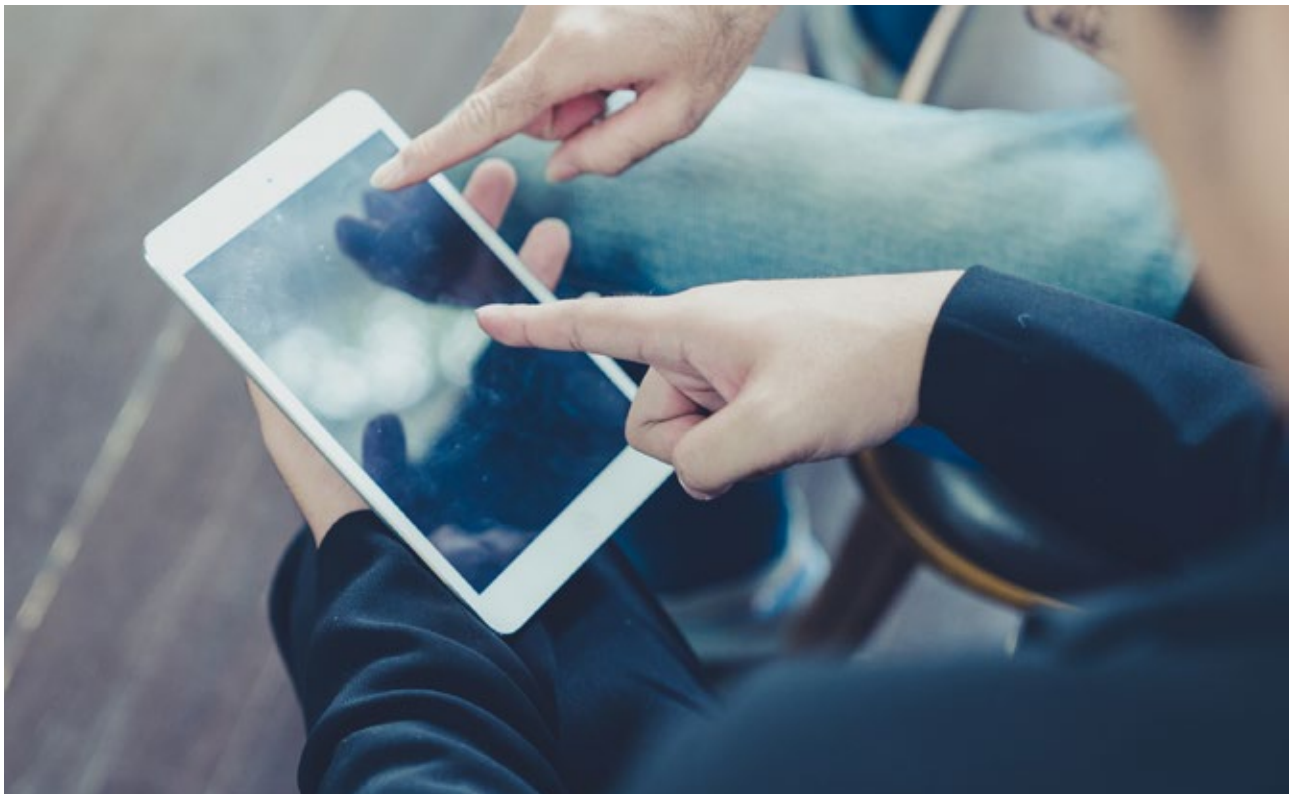
Communication

People with disability are often subjected to tireless attempts to teach them to ask for things, make choices and to label things in their lives. What people with disability need is the opportunity to communicate for the purpose of maintaining relationships. Relationships and connection are the essential drive for communication for all people. People with disability are no different.

The need to communicate our thoughts and to connect with others is one of the primary underlying reasons for the presence of challenging behaviour.

We need to consider how well a person is supported by the people around them to develop communication skills and understand language.

- Does the person have access to communication supports that both the person and their communication partner use together to engage in two-way interaction?
- Do these communication supports include vocabulary/words in both a verbal and visual format?
- Do the communication supports include enough vocabulary/words for the person to have access to whatever they might want to say at a time they want to say it?
- Are the communication supports used by all those interacting with the person and actively modelled across all interactions (just like we use verbal words) for the person to continue to learn?



Sensory

We all have different ways that we react to and interact with our environment. All people have sensory needs and these will be unique to each one of us. Some people will be sensitive to noise, some to certain types of touch, some to light etc. We need to be mindful of the way a person might respond to their sensory environment. How do we understand the person's sensory needs and how can we support them to access their needs from their routine and environment? We don't want to avoid sensory experiences, instead we just need to be aware of potential influences and help the person to manage the sensory input.

"My adult son can now tell us what his needs are when he is escalating due to sensory processing issues. He can ask for what he needs whether it is some deep pressure, his sensory brush or his straw to chew on"

"I can't believe the difference having a range of sensory strategies can make."

People with disability can have difficulties with sensory processing which can then affect their behaviour. Unmet needs can also intensify difficulties with sensory needs. This means that people can misinterpret everyday sensory information, such as touch, sound and movement. They may feel overwhelmed by sensory information and may seek out or try to avoid certain experiences.

Sometimes differences in sensory processing is called Sensory Processing Disorder (SPD). People with SPD can experience their world as either 'hypersensitive' (over reactive, sensory avoidance) or 'hyposensitive' (under reactive, sensory seeker). They may also present with motor skill problems or react with strong emotional behaviours and experience what can be described as 'melt downs'.

Exploring the person's sensory experiences can be an important part of working out any unmet needs which are affecting their behaviour. It's important to know that sensory needs are unlikely to be the only reasons and other needs should be explored as well. It may be helpful to think about the following questions:

- Have sensory preferences been identified?
- Are sensory preferences built in to the daily routine and adaptations made if required?
- Does the person have regular calming and self-regulation supports in place?
- Are visual supports in place and regularly referred to help the person identify their emotional regulation levels and strategies to help?

*Information in this section referenced from Sensory Processing Disorder Australia
www.spdaustralia.com.au/about-sensory-processing-disorder

Health

Health problems and pain are commonly experienced by people with complex communication needs, but are also experienced by people who are very capable of communicating with others. When we have ongoing pain or health issues, it can make us more agitated and affect our ability to cope. During these times, it might not take much for us to react negatively to others and we may not always take the time to try and explain what we are feeling. Sometimes we can't even recognise what we are feeling.

"There have been times where the sole focus has been on a behaviour, with much energy put in to stopping it- when the person was very unwell or in pain"

Thinking about the following can be helpful when we are trying to understand someone's behaviour:

- Do they drink enough water?
- Is the person getting enough sleep?
- Could they have dental pain?
- Are there signs of pain or other health issues?
- Has there been a change in toilet routines eg are they constipated?
- Are there changes in the amount of food eaten?

Sometimes when behaviours are worse at night, this can be a sign that the person is experiencing physical discomfort. If it is possible that the cause of behaviour might be pain or illness, it is very important to seek medical advice.

MICHAEL

Michael was a 58 year old man who was blind and had an intellectual disability. He was very particular with how he liked to spend his day, disliking changes to his routine on most occasions. Michael loved spending time engaging in conversation with friends, family and carers and used unique ways to communicate which relied on people knowing him well. When his predictability and interaction needs were not met, he often became distressed which presented as hitting out at others, screaming and moving around a lot in his wheelchair. Michael's behaviours started to increase and his health started to deteriorate and he eventually passed away surrounded by those who loved and cared for him. Just prior to his passing, he was found to have a large colorectal cancer. This had been undiagnosed for some time.

Sexuality

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

“I didn’t realise that my son just needed time to learn that masturbation needs to take place in private. Overall it took 6 months of his housemates consistently reminding him to go to a private place. At times it felt hopeless but we got there in the end and now he is appropriate 100% of the time.”

Sexuality is a sensitive area for most families. Educating young people 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. How to do this can be tricky and it might be that you need support to learn how to talk to your son or daughter about sexuality, or to find the right people to do it.

There are many reasons for challenging or inappropriate behaviour such as masturbating in public including; pleasure, not knowing social rules or norms, anxiety, boredom, or seeking engagement with others.

It is helpful to consider why someone is behaving in this way in order to address the cause, not just the behaviour.

- Has the person had the opportunity to engage in education about relationships and sexuality?
- Do support people model and explain the difference between public and private behaviours?
- Do support people teach the correct anatomical names for private body parts so the person can communicate with doctors or others if need be?
- Are the person’s sensory needs and experiences considered when understanding the needs underlying their actions?

You may want to consider seeking advice and support if you are concerned or not sure of how to respond to your son or daughter around these areas.

* SECCA is a non-profit organisation designed to support people with disability, in their efforts to learn about human relationships, sexuality and sexual health.

Contact: **08 9420 7226** or **www.secca.org.au**

Addressing quality of life

We all have universal needs that help us remain regulated and feel connected and in control. Once supports are in place to ensure the person's processing, communication and relationship needs are met, we also need to look more broadly at their overall quality of life.

We think of quality of life as being two things:

1. The essential needs for human life (food, shelter, warmth etc.)
2. The needs all humans have to express themselves as a unique person.

A person can appear to have their essential needs met but still not seem happy or at peace. Happiness or quality of life is achieved for all people when they can find ways to express who they are as a unique person. It's about respecting a person's adulthood or unique likes and preferences. It's about really supporting a person to meet their need for:

- Purpose, valued roles and achievement
- Employment, education, citizenship
- Financial security
- Independence and self-determination
- Relationships and community connection

It's about having a reason to get up in the morning!

Being respected as an adult, regardless of any level of intellectual disability, is critical to having 'Quality of Life'. This respect recognises that age and life experience has provided you with the time and opportunity to form preferences and to understand what you do and don't like. Just because a person has a disability does not mean they do not have a desire to be in control over guiding the pathway of their life.

All people can make choices and must be assumed to be able to make choices. If a person's situation has choice removed or real choices are limited, their reaction is a natural human reaction to loss of power. For some, this reaction may be withdrawal and for others it may be more dynamic expressions of frustration. This doesn't mean they have to have choice over everything in their life, especially in areas of risk, but it does mean that people need as much choice as possible during the course of their day. Generally the more choices people with disability are supported to make, the greater their capacity to engage in more complex decisions over time.

Mental Age Theory, which says things like 'they are a 10 year old in a 25 year old body', just doesn't hold up anymore. You can't write off a person's whole experience of life as an adult by saying they are just a child. People with disability struggle with the complexities of life just like anybody else and they can have greater maturity and wisdom as a result, not necessarily less.

Being able to make decisions about your own life is very important for people with disability. Sometimes people think this isn't possible, however the *Law states that all people are regarded as having capacity to make decisions unless there is good evidence that a person cannot. Unfortunately, not many people with disability are provided with enough communication or *supported decision-making tools to help them to actively express their desires and decisions. Is the person engaged in decision making around:

- Relationships – who they see, when and what for?
- Where to live and who to live with?
- Who they want to support them?
- Daily choices like the routine, household tasks, leisure?

* Guardianship law says that a person is presumed to have the capacity to make their own decisions unless there is strong evidence to say that they can't. (Guardianship and Administration Act 1990)

*You can find more information on supported decision-making here:

www.waindividualisedservices.org.au/resources/supported-decision-making

Sometimes we can use the person's behaviour as a guide to understanding the decisions they might want to make. For example, if the person is sharing a house with another person they clearly don't like or feel safe with, their behaviour might express their preference to not live with that person. Similarly, if their behaviour is challenging with specific support workers, it might be that they are not who the person wants to have on their team.

'I didn't realise until somebody pulled me up on it, how often I was talking about private things like toileting and her behaviour in front of her and other people and how much this was a trigger for some of her behaviours. We had not thought to give her the respect we give our other children. It's really important to understand that people with disability need to be respected just as much as anyone else'

Having respect for people as an adult also plays out in ways other than self-determination and supporting their happiness. Consider how people communicate around them, and if they engage in a way that respects their value.

For example:

- Does the doctor talk directly to the person during a consult?
- Do people address the person directly when making appointments?
- Is the person engaged in planning what their week will look like rather than just being told?
- Is the person spoken to respectfully as an adult?
- Do people talk about the person in front of them, or do they discuss private matters openly where other people can hear?

Building supports to meet needs

Importance of support planning

Just as our understanding of behaviour has changed, so has our understanding of the role of support planning. There used to be a lot of focus on teaching the person to stop the behaviour. The focus was on what the behaviour looked like and what we needed to do to influence the person to stop using the behaviour. Thankfully, for both the person and ourselves, this has now changed.

By focusing on the person's needs, we are in effect focusing on preventing the need to engage in behaviour that can be challenging.

Considering what we have already talked about, more successful and person-centred support plans now focus on:

- Who is the person - what makes them cool, nice to be around, a character, what are their strengths?
- What are their interests and what matters to them?
- What is the person's history and how does that impact on how they think about the world and relationships?
- What is unique about how they;
 - process information
 - communicate
 - perceive relationships
 - learn new skills
- What supports need to be embedded in the person's environment and interactions to meet their underlying needs for;
 - predictability
 - information processing
 - choice and control
 - communication
 - social engagement
- What are their dreams, goals, and choices both now and into the future?

The focus is not on the behaviour but on how we understand who this person is and what their needs are.

Effective support planning builds empathy, awareness and a shared understanding of the person's needs. Once we know these needs, it's amazing to see the creative ideas people come up with to find ways to meet them.

SEBASTIAN CONTINUED...

Sebastian was fascinated by technology of all kinds. It had become impossible to take him out as he would seek and find DVD players, stereos and computers and try to take them apart. He would plan to escape from his house and break into people's cars if they were left unlocked to try to steal their car radios. When the people in Sebastian's life got together to talk about his interests and strengths, instead of seeing this behaviour as a problem they looked at it as a strength - as an interest, something he is highly motivated to do and something which could be of value. Somebody had the idea for Sebastian to do volunteer work at a computer recycling place and this idea worked out really well. Sebastian enjoyed taking computers apart to be recycled and was valued for his work. This decreased his need to seek out and break technology at other times.

Support planning is about the skills that we need to learn and to use. The aim is to work out how to create an environment that helps the person to meet their needs, learn new skills which have value to them, and have many things they like in their life. It also means minimising things the person doesn't like or enjoy.

Some questions to think about:

- How well do we know the person and the things they like and don't like?
- How does the person communicate likes, dislikes and when something is wrong?
- How well do support staff know how to use scheduling tools to help the person process what is happening now and into the future?
- How are visual supports used to help explain the steps of a task so the person can better anticipate and process?
- How tuned in are supporters to how their own behaviour and emotional regulation affects the person?

"It wasn't until we attended the 'Is There a Better Way?' workshops about behaviour, that we realised how his supporters were feeling and behaving contributes to his behaviour. If we are in a bad mood, or highly anxious, or just not in tune with how he's feeling, we can be the trigger to him feeling really bad and resorting to using challenging behaviours."

"Is There a Better Way?" workshop program is for families and their supporters to use a 'Positive Behaviour Support' approach when responding to people with disability whose behaviour can cause stress or concern.

For more information contact Developmental Disability WA **08 9420 7203**.

Support planning across the years

As an adult, it is normal that our needs change across the years, as do our experiences and what is important to us. The needs of a young child are vastly different to a person navigating the relationships and choice and control needs of being a teenager. Similarly, a young adult will have changing desires and interests from one year to another. When engaging in support planning for people with disability, we need to continue our focus on how to support their processing, communication and choice and control needs, but in the context of changing interests, relationships and desires.

People with disability can be subjected to a lot of support plans and documentation in our attempt to ‘help’. When developing support plans we need to be mindful of some common issues that may arise. These include:

Disability vs typical needs

Sometimes we get so caught up trying to solve or fix something that we lose sight of what is ‘typical’ for that age. It is normal for a young adult to look towards peers as their main source of relationship needs, so how do we make sense of their behaviour in the context of limited social relationships which are mainly family or paid supports? It is typical for a young adult to experience significant changes in their hormones and exploration in understanding sexuality. Why then do we sometimes view people with disability as having ‘sexualised behaviour’ or ‘abnormal sexual desires’ when it is a normal part of physical and cognitive changes they are trying to navigate themselves. The unconscious need isn’t something they can change or the problem, but rather an inability to get their needs met.

Sole focus on lifestyle planning

Many plans focus mainly on what the person’s day might look like and what their interests might be. This is certainly an important aspect of planning, but if it stops here, then so much can be missed.

JOHN CONTINUED...

John’s support workers knew that John liked to go walking and swimming, and that he usually spent his day engaging in certain activities. However, John was often highly agitated and stressed. He couldn’t understand what was happening next in his day, who was coming to support him each day, and was finding it difficult to remember information from one day to the next. John’s support plan didn’t focus on: the knowledge support workers needed to understand how he processes information, how to use supports to help John understand his world, or how to engage John in his interests and to have access communication.

Plans that don't show how to use supports

How do we really know how to support a person and to use supports in a consistent way? A lot of plans detail what the person needs but don't really capture how to do it. It is difficult, if not impossible, to capture the quality of engagement like facial expression, what to say and how to say it, in a written plan.

How many of the people that we know with a disability, have lengthy written support plans? Let's be realistic, many people don't read a support plan that is too long or too technical. Plans need to be matched to the needs of the person reading and using it. They should be clearly articulated and easily understood. Support plans do not always have to be a written document, they could be presented visually such as a video or in images.

Plans that are not constantly reviewed

Support plans should evolve and change as the person's needs and choices change. It is helpful to have a way of updating support plans to include support workers' input. Support workers can be valuable partners in creating and updating support plans, for example by making a video or taking photos of successful ways they have discovered to support the person.

Support planning across the range of emotional experiences

Probably the most common reason why a plan doesn't work
is when we think about them as a one stop shop.

Often a person with a disability, or their family and carers are given a 'thirty- plus' page 'positive behaviour plan' which tries to outline the person's needs and their behaviour. These plans are not always read or made accessible to family members, and when they are, it is difficult to know where to start or which part to focus on. Similarly, plans are often developed around the behaviour itself and how the behaviour can be controlled. People need support, not only when they engage in behaviour, but at all times of different emotional states. Recognising that our support needs will be different according to what we are experiencing, is the first step towards creating effective support plans.

The most important aspect of support planning is to understand a person's need and build supports in their life to meet these needs. This in effect is a preventative approach to not experiencing the need to engage in behaviour that can be challenging.

How do we help the person engage in a life that supports them to feel happy, calm, content and valued?

There are times when a person experiences stress as a part of normal life and being human. We may need a plan here which recognises what the signs of stress for the person are, and how we can support them at those times remembering that their processing, communication skills and physical reactions will have changed.

There may also be times when stressors become too great and the person starts to react in ways that place themselves or others at risk or harm. Supporters need a plan here to understand what the person is experiencing at the time and how to best support them to get back to a calm emotional state and regain control over their thoughts and reactions. In these situations, supporters need to know what they can do to help the person, as well as how to help themselves to feel confident and safe.

Seeking support from others

Where to get help

Regardless of how much we know and how many skills we have in supporting someone, there will always be the need to seek support from others to gain and share ideas and to get help. With all aspects of our lives, a shared community of thinking and support can often be better than doing something alone.

There are many services and people available in the disability community that can help us to understand behaviour and shape support strategies. Who you choose to engage to help may impact how the support needs of the person will be navigated. Although there is no 'expert' who has all the answers, seeking the support of professionals or other people can make a big difference.

Who are the experts in the person's life?

Seeking professional support can be highly valuable, however, the approach practitioners use and how they work alongside families is critical for the success of support planning. Support planning needs to recognise who the experts are in developing a way forward.

There are two groups of experts and these are; the person themselves, and the people who support them on an everyday basis. Support planning should first and foremost seek to involve the person in exploring how they experience the world and what their needs are. At times they may need communication or other supports to help engage in discussions, or to find out more information about their thoughts and desires.

The people who support a person in their everyday life are the other main experts in a person's support planning. They can be the ones who know the person best, their unique characteristics and sometimes, their goals.

Without intricate knowledge of really 'knowing the person' and 'knowing the context' that the person lives in, no professional or clinician can be an expert on what to do. Professionals can however bring knowledge and experience to the discussion which can help shape the understanding of what the person's needs may be. A good professional will have expertise in being able to **help others think** about and identify the underlying needs of the person. They might also be able to help to identify support strategies and share knowledge of how to use them.

'One of my best experiences of professional support was from a clinician who approached our relationship like a partnership where we worked out the ways forward together. One of the things she did which changed how I felt about myself as a parent was to film me interacting with my son. We watched the film together and she showed me all the things I was doing really well. It helped me to understand this wasn't my fault, and that I do so many things right.'

Who families seek support from will also likely change as the person and their family's needs change over time.

'Hearing stories from other families has been the most important source of knowledge, wisdom and information I have found. Other families who get it and have been through the same journey often know more than professionals about the kinds of supports and services we need and where to get them.'

Working in partnership

Supporting a person who engages in behaviour that can be challenging can be very isolating and significantly affect the mental and physical health of those around them. It is important to seek support from others and to find ways to re-group, refresh and relax. One way to do this is to include many people who know them well during the planning process and not relying on one 'expert'. A team approach could explore:

- What are our hunches?
- What do we know?
- What are our ideas?
- What would we like to try?

With this knowledge the team can then work towards changing and improving the environment around the person so that their experiences are more matched to what they need to understand the world and to engage with others. When this is the main focus, support plans are often more successful.

The team can also help those who are in a direct support role by thinking about what supporters need to help them cope well, feel happy and confident in their supporting role and continue to improve their skills in embedding supports in the environment. As with all people, when we are stressed we react differently and sometimes not positively. When support people are stressed they might not be in the best position to support the person with a disability to meet their needs. Working in partnership with each other to support everyone in the person's life is very important.



What do you want help to look like?

Throughout this resource we have been talking about the importance of taking the time to understand behaviour first, before we start to think about what might be needed. This approach goes way beyond traditional approaches to ‘behaviour management’ or ‘behaviour modification’. Advances in our knowledge and approaches to behaviour support have highlighted some key aspects of what is useful when trying to support behaviour change. These approaches underpin a behaviour focus called Positive Behaviour Support (PBS). Some fundamental aspects of a PBS approach include:

- Understanding that behaviour is a way of communicating something
- Often behaviour is a way of telling us about the person’s unmet needs
- There might be many environmental, social and personal factors which influence the person having unmet needs
- The goal is to support the person to reduce the need to engage in the behaviour, with the effort being directed into preventing the behaviour
- Focus is on building environments where supports are embedded to meet the person’s needs as well as providing opportunities to learn new skills
- The ultimate goal is to truly understand who the person is, their needs and to improve their quality of life

Positive Behaviour Support can support families and carers to better understand the reasons for behaviour, resulting in identifying strategies to address these reasons as well as strategies to support the person and others when behaviour occurs. PBS seeks to support someone to feel less anxious, less stressed and less dysregulated.

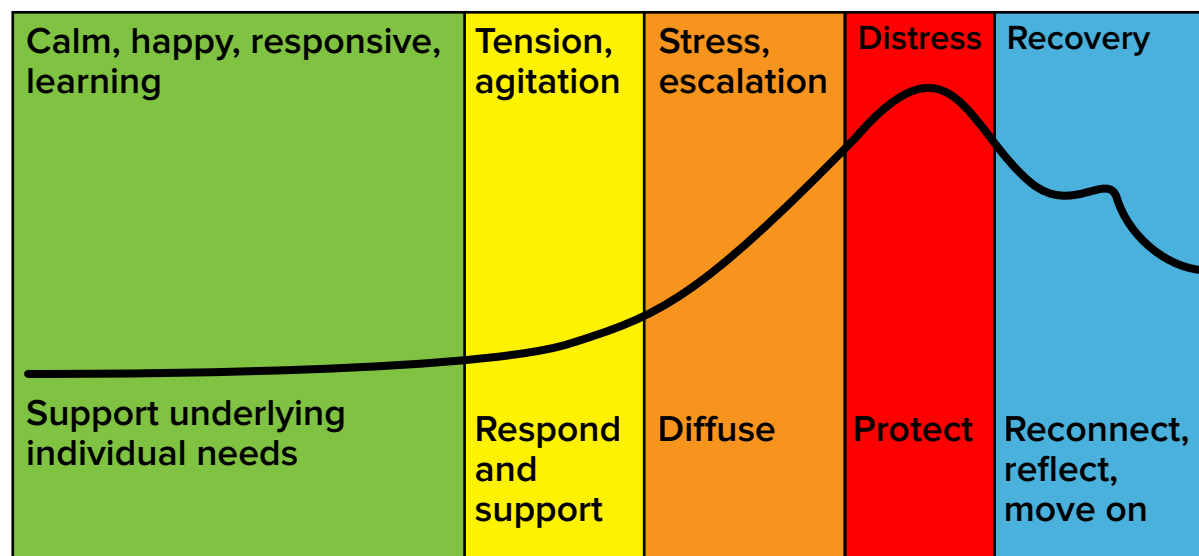
When seeking the support of professionals it might be useful to ask what their model of behaviour support is, and whether their approach will help you understand the needs of the person as well as knowing how to respond to their behaviour.



What about when the behaviour is occurring?

Patterns of escalation

We all experience times where we react in challenging ways. It is how we as humans react to stressors in our life, and is a result of changes to the reactions in our brain. Sometimes this normal pattern of coping and how we react to it is referred to as a behaviour cycle or a crisis cycle. Typically the patterns of behaviour escalation look like this.



**Image from Department of Communities, Disability Services, Personal Safety and Situational Training.*

As you can see from this diagram, the pattern of escalation tells us what a person might be experiencing. It also shows us that how we respond needs to be different at each stage. This cycle is commonly compared to the 'traffic light system'.

Green means go – spend most of your time here building supports and meeting needs to help the person stay happy and emotionally regulated.

Yellow means be attentive – these are early signs that something is wrong and that the person is not coping, or their needs are not being met.

Orange means be alert – the person is experiencing significant stress and possibly anxiety. A lot more attention is required to look at how to support the person. Without support, the person may reach crisis point.

Red means stop and protect – this is not a time to learn new skills or talk it through. The person is distressed and reacting to their emotional, impulsive brain.

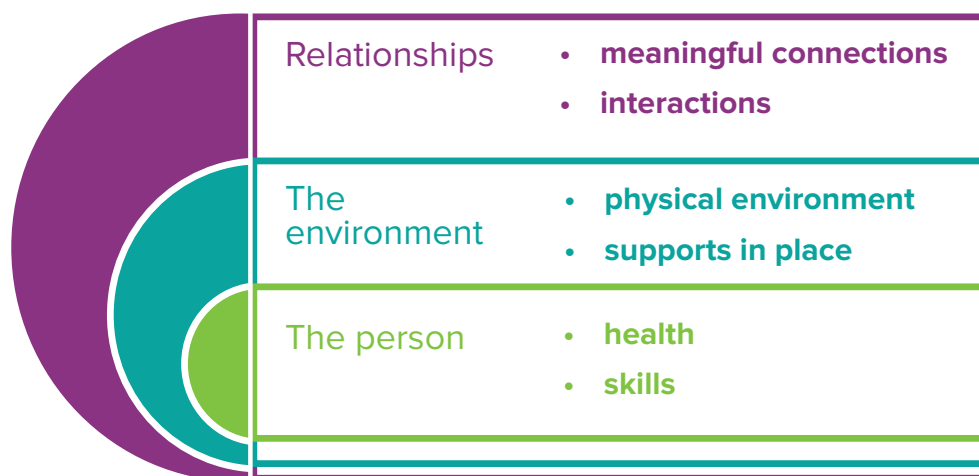
Blue means recover – help the person and others get back to feeling better and reconnect. This stage can at times be a bumpy road.

Focus on prevention

Although this section is about how to respond to behaviour when it does occur, it is important to highlight that the most effective approach to addressing challenging behaviour is to prevent it in the first place. Let's put most of our energy into building supports to keep people in the 'green zone'. Here is a summary of the key principles outlined in this booklet:

- Behaviour is a way of communicating something
- Behaviour results from our needs not being met in some way
- More often than not, behaviour which can be seen as challenging results from people with disability experiencing a lower quality of life
- Behaviour is an indicator that we do not, as yet, know enough about how the person experiences and perceives the world

Prevention is about building environments that work towards meeting the person's needs. In general this includes three elements:



Relationships

Positive, supportive relationships are central to our wellbeing. Before a person can learn they need to feel connected, safe and engaged.

It is what other people do and how they interact with the person that makes both environmental supports and the skills of the person possible. Not only is it about the quality of our relationships, it is also how we use supports to create environments that meet people's needs. For example, a 'visual schedule' is for us to share information in a way which helps the person understand and know what is happening. Similarly, people will only learn new skills if modelled by others during natural interactions across their day to day routine.

We need to consider how our own behaviour can affect or meet the person's:

- Need for meaningful connection and belonging
- Need for social interaction
- Sense of worth and value

The environment

How do we create an environment that embeds supports and practices designed for the purpose of meeting the underlying needs of a person? Consider how well the ideas outlined in the section **Building Supports** have been used in the person's life. Before we respond to someone's behaviour, we need to make sure the person is living in an environment where they have:

- Access to communication methods that are matched to their needs and allow for meaningful two-way interaction
- Meaningful engagement with choice and control
- Access to visual and stable supports to understand and process information and language for example; the use of visual schedules/diaries and information about what an activity might look like and what will happen next
- Their sensory needs known, and changes are made to the environment where necessary

The person

At the core of preventing challenging behaviour from occurring, is taking the time to really get to know the person and best understand how they perceive and experience the world.

The first thing to check is the person's health and dental needs to rule out any underlying health issues they may be experiencing such as pain or illness. Next we can look at how to build supports so the person has the opportunity to continuously learn and enhance their skills. It is important that we strive to support a person to have access to ways to meet their own needs, now and into the future.



Look for warning signs

Warning signs are indicators that the person is experiencing some kind of stress. They might be feeling confused, anxious, upset, in pain, worried or show other “unsettled” feelings. These signs not only indicate that the person is not feeling calm and happy, they can also provide us with clues that they might become increasingly agitated and stressed.

Warning signs might be very obvious to us, or at times not so easy to recognise. It is common to hear people say, “but there were no warning signs”. Let’s consider this for a moment and what we know about how our brain reacts to stress. Consider the example on page seven; when the build-up of many aspects of our needs not being met resulted in our overall stress levels increasing until something very small like a comment causes us to react in a not so helpful way. In this example, our behaviour was the result of frustration and stress that had been building up over time, and not solely a reaction to the comment made.

We need to pay attention to signs that the person might be experiencing stress or agitation of some form. This might be obvious in a particular setting or there might be signs across days and weeks.

JOHN

John lives with two other people and is supported by paid carers. John doesn’t have access to a form of communication to help him express his thoughts. During a typical morning, one of John’s supporters was sitting at the dining table having a coffee and chatting with another resident when John walked into the room with another supporter and watched as morning tea was being prepared. Suddenly John turned and quickly hit the seated supporter on the head.

In the moment we might think that there were no immediate warning signs, but if we look beyond the immediate situation we can start to recognise signs of John’s agitation building over the previous week such as:

- Pacing more often
- Up during the night more often
- Vocalising loudly earlier in the morning

We could also consider that John probably lives with high levels of stress and anxiety most of the time given that he has: no effective way to tell others what he wants to say, no supports in place to help him understand what is happening, and limited meaningful activities to engage in across the day. This would make it difficult to identify signs of change in his emotional regulation as he may always be feeling stressed and anxious. This could also mean that John is often in the ‘yellow or orange zone’, meaning he is more reactive and may find it hard to manage his stress.

Some warning signs are easier to identify such as; pacing, a change in vocalisation, an intense gaze, or certain movements. Other signs might not be as obvious to someone who doesn't know the person well. Thinking about warning signs as a team is a helpful approach to identifying indicators or signs that the person needs support, or a particular kind of support. What one person observes might be different to what another person observes.

It can be helpful to record some of your observations about the lead up to incidences of behaviour that concern you or others. This can help to identify what the early warning signs might look like, as well as clues about how the environment and actions of others might have influenced the reactions of the person.

SEBASTIAN- THE STORY CONTINUED....

After the bakery incident, Sebastian's support workers realised that his behaviour had in fact been escalating over time. No one had mentioned it or really noticed as they didn't document the changes or meet to discuss their observations. When the team got together to talk about it, they realised that over the previous weeks Sebastian had been:

- Picking his nails
- Pulling other people's hair
- Throwing things more often at home
- Breaking things more often at home
- Not sleeping well

They realised that there were indicators that some of his needs were not being met and some contributing factors leading up to the incident.

- His water intake had reduced
- They had changed his diet resulting in reduced access to cakes
- His ability to anticipate and be in control of food consumption had reduced
- His lack of sleep had resulted in tiredness therefore impacting his coping ability

As a result the team realised that Sebastian was likely experiencing high levels of stress. His unconscious compulsion for food had increased, and he was confused, tired and on edge. Furthermore, they looked beyond the bakery incident itself, realising that constant stress for Sebastian had resulted from:

- A change in routine, which resulted in reduced access to his favourite activities
- No clear plans for Sebastian to know when he could eat his favourite foods
- No consistent access to music to meet his sensory needs

It was no wonder that Sebastian reacted the way he did when he entered the bakery. He was already stressed from a range of environmental and relationship based changes in his life, and as we know, it is difficult to control our actions when our brain is stressed.

Support early

The earlier we respond to clues about how a person may not be coping, the better we can help them to meet their needs and reduce their stress or agitation. The longer a person has to experience stress, the more factors tend to build up and influence their ability to cope. The more stressed we are, the less we are able to cope with noise, changes, and lack of control. As we have already discussed, the more stressed a person becomes, the less the person is able to activate the parts of the brain for logical thinking and problem solving. The emotional, reactive parts of the brain take over, which can lead to a person losing control over their actions.

By learning from early warning signs of behaviour and other patterns of the person's unique qualities, we can continue to review:

- What do we understand about their needs?
- What supports do we have in place to meet these needs and how are people embedding them?
- What further supports do we need to consider?

SEBASTIAN- WHAT HAPPENED NEXT?

As a result of the team talking about the bakery incident, Sebastian's support workers put in place supports to meet the gaps in his needs.

The team:

- Engaged Sebastian in meal planning, including making a visual plan for when meals will happen across the day, and what he would be eating at those times.
- Made sure that Sebastian knew when his favourite foods such as cake would occur on the menu, and that they occurred with regularity.
- Used visual information to explain what they might do when they next visit the bakery store.
- Looked at his sleep patterns and encouraged consistency in helping him go to bed at a regular time.
- Looked at his schedule and made sure that his interest in trains was part of the activities he engaged in. They also made sure Sebastian had a visual planner to know what his week looked like.
- Made sure his iPod was available at all times for when he chose to use it.

Alongside these supports, the team met with the bakery staff and explained what Sebastian was experiencing during the incident. The bakery staff and support workers then agreed to allow Sebastian back into the store given the supports that were put in place. Sebastian is now able to visit the bakery without incident as his underlying needs are being met therefore resulting in him being more in control of his reactions, rather than the emotional centre of his brain taking control.

Respond in a calm supportive way

It is important to remember that when a person is agitated they need our support not our judgement or punishment. They might be feeling distressed or out of control. We can help the person become calm by remaining calm ourselves, by focussing on what they are experiencing and not the behaviour itself.

The following strategies can help us to respond in a calm way:

Stay neutral

Keep responses to a minimum. Limit verbal comments, facial expressions and other displays of emotion when the behaviour is occurring as these may further escalate a person's distress. Try to speak calmly and clearly using just key words and phrases, and keep facial expressions neutral or supportive and empathic.

Help them to get what they need

Is it possible to assist the person to access something they need or complete a task in a certain way?

Be positive

State or show the person what they can do in the situation instead of focusing on the behaviour. When we focus on what “not to do”, this is what the person will hear and focus on, but when we focus on what “to do”, this is what they will focus on instead. This helps someone to learn what they could be doing instead of focusing on the behaviour. For example, instead of saying “stop running”, we might say “walk with me”. Sometimes we expect people to stop doing something, but we haven't taught them what to do instead. Remember that our brain can't problem solve when we are distressed. People can also find it difficult to interpret 'no' messages.

Be consistent

Supporting a person in a predictable way when they are distressed can help them to calm down. It can be very confusing if the responses to their distress and anxiety keep changing. It is very important that everyone involved in providing support knows the strategies that are helpful, and that these strategies are captured in a plan that everyone can refer to and understand.

Help the person regulate their emotions

Sometimes people need help to recognise, understand and then manage their emotions. This can take some time and may rely on those around them to learn these skills. If a person can develop self-regulation skills, they are better able to cope with difficult emotions and do something positive about them.

Here are some emotional regulation strategies to try:

Acknowledge - first connect with the person's emotions. Help them name what they are feeling and what the trigger was by acknowledging what they are experiencing.

"You're really sad because you couldn't see your brother today"

"It looks like you're upset right now"

Engage the thinking brain - once you have helped the person to connect to their emotions, help them to use the thinking part of their brain and think of ways to address the problem.

"Your brother must have been busy. He might have had work to do or was helping your parents. Let's make a plan to call him and make another time for him to come here."

Redirect - sometimes when a person 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.

Sensory needs - It is helpful to understand what sensory needs the person has to help them feel calm. If we can meet a person's sensory needs, they might be less stressed and better able to manage their emotions. Take some time to observe and think about what the person might react to or be seeking from their sensory experiences. Some families choose to access an occupational therapist to complete a sensory profile for the person to help identify the person's sensory preferences. This can be useful in developing a 'sensory diet' to help fulfil the person's sensory needs.

Give space or lean in - What helps the person calm down? Some people like to have some space as they feel overwhelmed with people around them when upset, whilst other people 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 the person.

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. This can be helpful for ourselves as well as the person we are supporting.

Give in - It is quite logical to think that by paying attention to a behaviour we might reinforce it and make it more likely to occur in the future. This is a real concern we face, however when we stop and think clearly about what a person is experiencing when they are stressed or distressed, we may realise that they cannot help the way they are reacting most of the time. They may be unable to problem solve or think of different ways to behave. In most cases people don't want to behave in challenging ways. It is often not a choice. When someone is distressed, it is not a time to teach it is a time to help calm the brain and help them to get back to the green zone or at least the yellow zone. To do this we might need to give in, walk away or give them what they need- mostly to feel connected and cared for.

If the person gets very distressed

It would be rare for anybody to live a life where they never ‘lost it’ or behaved in a way that could be perceived as angry, reactive etc. Hopefully it doesn’t happen very often, but when it does it can be quite traumatic for both ourselves and others. After we’ve experienced these intense emotions and reactions, we may sometimes think, “why did I do that?”, “why did I say that?” or “I should know better”. Although we may know better, when we are at crisis point we are no longer actually thinking about our behaviour or what we are doing. We now know that this part of the brain has effectively shut down and our behaviour is “out of our control”.

Like in our own lives, there might be times where despite our best efforts to support someone to meet their needs, something might trigger an intense emotion or reaction. It is important to recognise that when this occurs, it is not a time for learning or trying to de-escalate the situation. Instead, this is a time to provide support for safety.

Consider the following strategies to support safety for the person and safety for those around them:

Do an environmental scan

Do a quick look around the environment. Can you safely stay at a distance from the person? Is there anything they can harm themselves or others with at this time? Do you need to ask people nearby to step back or move away? Do you and the person have a clear exit point from the room?

Talk less

The person may not be able to activate the rational thinking part of the brain or process information easily. Reduce the amount of information they need to process and keep any talking simple and direct.

Keep calm

The same goes for our ability to cope when stressed. We can’t think and respond effectively when we are in an escalated state. Remember, the person isn’t doing this to target you, they are distressed.

Seek help

It is important to seek help if you can, both to help you support the person and for reassurance for yourself.

Stay connected

When distressed, people need our help. It makes sense at times to remove our attention or assistance, but often what people need is support to regulate their emotions. Remaining connected can help calm emotions. Sometimes just your presence and reassurance is all that is needed.

Provide direct prompts for what they can do (if known)

When in a highly dysregulated state people often react in the way they have always done as these behaviours have strong pathways in their brain. The person might need help to know what else they can do to help them get their needs met at this time. For example when escalated, Sarah automatically runs towards a road. Over time Sarah's support staff have coached her to recognise the signs of becoming distressed and prompted her to move to the backyard or sit down when she feels this way. It is important to note that this might not happen overnight, but with consistent support people are able to learn new coping skills.

Have a safety plan

If the person is known to react to certain triggers or the signs of distress are known, it is important for those supporting them to have a safety plan. A safety plan outlines the signs of escalation and the agreed upon support strategies to ride it through safely.

Recognise the need for recovery

After an intense incident the person may remain in a fluctuating emotional state for some time. Therefore, their ability to process what has happened and to gain control of their emotions might be variable. Afterwards, a person can be quite remorseful or emotionally fragile. They can be physically exhausted and tired. This is not a time for rehashing what happened or trying to teach alternative behaviours. This is a time for moving on and helping the person to stay connected, repair the relationship and to move towards calming the brain.



Minimising risks

It is certainly important to reduce the risk of a person hurting themselves or others and to help them feel as safe and calm as possible. Understanding the person's needs including; sensory, communication and interaction needs, and structuring the environment to meet these needs as much as practical, is often the best way of mitigating risk. It is sometimes also necessary to build in environmental safeguards in addition to these supports.

Developing safeguards or risk strategies need careful consideration. Whilst we might think of support strategies with the best of intent to keep someone safe, we need to consider how the strategy impacts on the person's rights, choices, lifestyle and overall wellbeing. If the strategy is considered to restrict a person's movement or rights, the strategy may be considered a 'Restrictive Practice'.

In Western Australia, services provided by Disability Service Organisations are guided by the **Code of Practice for the Elimination of Restrictive Practices*. This document outlines support strategies which may be deemed to be restrictive, and helps organisations work towards finding other ways to meet the safety needs of individuals whilst continuing to also promote their quality of life and rights. The **NDIS Quality and Safeguarding Framework* is a national framework being introduced, which outlines core strategies for reducing and eliminating the use of restrictive practices in the disability service sector.

The key to providing safe and respectful supports for people is to constantly review the needs of the individual and to explore different ways to meet these needs. A first step is to ask ourselves what our life would be like if we had that restriction imposed on us. How would it impact on our wellbeing? It might be useful to discuss possible support strategies with a professional or other people in the person's support network. Together, you might be able to find alternative ways to more positively support the person.

*For an explanation of what Restrictive Practices are, and how to plan to eliminate them, please refer to 'The Code of Practice for the Elimination of Restrictive Practices'. This resource is also available in Plain English and Easy Read from the Government of Western Australia, Department of Community Services - Disability Services website: www.disability.wa.gov.au

*Please also refer to the NDIS website or the NDS (National Disability Services) website for more information regarding the Quality and Safeguarding Framework. www.nds.org.au/news/navigating-the-ndis-quality-and-safeguarding-framework

Your family member and the law

Sometimes a person with a disability may have contact with the police and legal system. Like all people, this can be due to having been offended against or being in a situation where their behaviour may be interpreted as an offence according to the law. Having a disability can often place a person in a position of vulnerability in: understanding their actions, being offended against and interacting with members of the law.

This vulnerability may result from behaviours that may be misunderstood by others in the community, such as:

- Not realising it is inappropriate to touch other people or themselves in public
- Taking something from a shop/property without paying/asking for it
- Talking to children inappropriately

As well as general difficulties with:

- Making decisions and impulsivity
- Understanding consequences
- Coping with change or unexpected events
- Responding to anxiety
- Understanding different social contexts
- Meeting their need for social connectedness

Some parents and carers may also worry that their family member is falling in with the ‘wrong crowd’ and does not grasp the seriousness of the group’s anti-social behaviour.

If you are concerned about your family member, it may be worth contacting your Local Policing Team and letting them know about your family member’s needs. Go to www.police.wa.gov.au/Contact-Us/LPT, enter your postcode to find your local team.

While in the community a person may have their needs or intentions misunderstood by members of the community leading to police intervention. They may have difficulty communicating with the police or understanding what is being asked of them. Given the vulnerability of people with disability, it is vital that people are clear about their rights so they do not end up facing legal issues.

Useful tips

- Educate your family member on what to say and what not to when alone with the police. For example, teach your family member a script such as “I am not going to say anything until my mum gets here”.
- Prepare an information card for your family member to carry around detailing their name, age, address, intellectual disability diagnosis and your contact details.

The police have the power to question your family member, therefore it is important that you know their rights and understand why they are so important. According to the Human Rights Commission, people with intellectual and other learning disabilities may respond in the following ways when dealing with the police:

- May be more prone to suggestibility, and thus leading questions by interviewing officers may be a distinct problem
- May be eager to please a person perceived to be an authority figure thus giving the answers he or she believes are the desired ones rather than the correct ones
- May be anxious or frightened which can impair their ability to think and plan
- May be more likely to respond to questions in a manner they believe is expected of them
- May have poor understanding of questions asked and the implications of the answers given
- May try to hide their disability or answer a question to which they do not know the answer so as not to appear 'dumb or stupid'

Source: (<https://www.humanrights.gov.au/publications/rights-people-disabilities-areas-need-increased-protection-chapter-5-criminal-justice>)

Rights

If your family member is involved with the police they should use their information card to explain their situation when alone. It is useful to know that police have the power to ask questions at any time even if you have not been arrested however:

- Your family member has the right to silence in general, but there are some questions that they must answer or risk committing an offence if they remain silent or lie about which include:
 - name, date of birth, address
 - proof of age
 - the sale, supply or manufacture of illegal drugs/plants, if your family member is asked under a search warrant
- Your family member has the right to have an independent thirdparty e.g. advocacy service present throughout the criminal justice process from an initial police interview through to sentencing. See services in **Need Help** list below.
- The Disability Act protects your family member's privacy or being subjected to restraint or seclusion.
- The Criminal Law (Mentally Impaired Accused) Act 1996 allows mental impairment to be used as defence if your family member is accused of breaking the law. Mental impairment includes mental illness, intellectual disability, dementia and brain injury. Being found to be not mentally fit to stand trial for an offence can have significant consequences so it is important to consult a legal advisor about the implications.

There are supports available across the justice system to help people with disability and their families when interaction with the police occurs. You can contact the police department for support as well as the advocacy and disability legal services listed below.



NEED HELP?

Sussex St Community Law Service	Ph: 08 6253 9500
People with Disability WA	Ph: 08 9485 8900 or 1800 193 331
Mental Health Law Centre WA	Ph: 08 9328 8012 or 1800 620 285
Developmental Disability WA	Ph: 08 9420 7203



Mental health and disability

Likelihood of mental illness

In general, mental health refers to a person's emotional, psychological and social wellbeing. Having good mental health does not just mean that we do not have a mental illness. When a person has good mental health, they are able to experience a range of emotions (positive and negative), cope with daily pressures, have healthy relationships and are involved in something meaningful (e.g. work, volunteering, community involvement).

People with disability experience the same types of mental illness as people without a disability for example; depression, anxiety, bipolar disorder, schizophrenia, personality disorders, eating disorders, drug and alcohol disorders and dementia. However, the risk of experiencing poor mental health is significantly greater.

A person with an intellectual disability is more likely to experience a mental illness than someone without an intellectual disability. In people with an intellectual disability, 4 or 5 in 10 people experienced a mental illness in the past year. That is around 2.5 times the likelihood of people without an intellectual disability. The risk of developing a mental illness increases where the person's disability results in greater gaps in their needs being met.

For more information refer to: Intellectual disability mental health e-Learning free resources for carers, health professionals and disability professionals. www.idhealtheducation.edu.au

Risk factors for mental illness

There are a number of factors that may influence the likelihood of developing a mental illness or affect our overall mental health. **Intellectual Disability and Mental Health eLearning** outline these factors in detail including:

Biological factors

- A person's genes can increase the risk of a mental illness in people with disability.
- Some disabilities are associated with brain changes that can increase the risk of mental illness.
- The presence of vision or hearing difficulties as well as other physical disabilities, can impact on the person's participation as well as their vulnerability.
- Pain and illness are likely to have a greater impact on people with disability. This is due to a reduced ability to describe their physical symptoms and therefore experiencing pain and illness for longer before receiving treatment. Feeling physically unwell and worrying about health can affect mental health.
- Medications and side effects can affect a person's mental health. People with disability are more likely than people without a disability to take medications. They may also be taking a number of different medications.



Source: www.idhealtheeducation.edu.au

Psychological factors

- Low self-esteem or lack of confidence in abilities (feeling “not good enough”) can affect a person’s mental health.
- Some mental illnesses may be linked to poor coping strategies.
- People with disability are more likely to have experienced negative life events (e.g. abuse) but may not have received support.
- Some people with disability have difficulty understanding and labelling their emotions.
- The trauma of living with the stress of unmet needs can lead to psychological impact.
- People with disability may experience difficulties with understanding information and to carry out cognitive skills like planning and problem solving. This can cause significant anxiety and distress.

Past experiences

- People with disability are more vulnerable to bullying, neglect and abuse.
- People with disability may not be able to or have the support to express and manage feelings of grief.
- There is a greater likelihood of experiencing unwanted life changes. Many people with disability lack control over their major life decisions.

Lifestyle factors

- People with disability are more likely to be underweight or obese. This can affect other areas of health and wellbeing.
- Limited amount of exercise. Doing very little exercise can affect mood and make a person feel low in energy.
- Difficulties sleeping can affect mental health.
- People with disability are likely to experience greater effects from using drugs or alcohol. For example, people with intellectual disability may experience greater sedative effects, or if the person has mobility difficulties these could be worsened by drugs and alcohol.

Environmental factors

- Living conditions may have a negative effect on mental health.
- People with disability are more likely to experience financial difficulties.
- Support staff and organisation policies may not support good mental health (for example, if choice and decision making are limited). Including people with disability in service planning and recruitment can help to give a sense of belonging and control.
- Lower socio-economic status (income) is related to a greater risk of mental ill-health.

Social factors

- Being isolated with limited social connections are more likely for a person with a disability.

- Communication difficulties may impact on social connections and relationships.
- Fewer opportunities to have a meaningful job or role, can mean not having a sense of purpose or belonging.
- People with disability are more likely to experience stigma.

Whilst these risk factors are relevant for everyone, having a disability increases the likelihood of the person experiencing these, which can then affect their mental health.

Accessing services for mental health

Whilst it is certainly important to recognise signs of either a change in mental health or sustained issues, we need to consider not only the symptoms, but also how the person's life has contributed to them becoming mentally unwell. Looking at the above factors, we can see how the people we support are likely to live with high levels of anxiety, stress, confusion, isolation and disorientation across their lives.

Accessing the support of mental health professionals, including psychiatrists and psychologists, can be useful to both diagnose and treat mental health concerns. This might involve the use of medication to assist in the management of chemical and neurological processes within the brain. The use of medication however, should never be decided upon without looking first at the person's quality of life, and the continuation of developing supports to lessen the risk factors as described above. Too often people with disability are prescribed large combinations of medications for the purpose of reducing the likelihood of behaviour without addressing the underlying reasons.



Supporting those around the person

Giving self-compassion

Families and supporters, especially parents, can feel many difficult emotions with the stress of living with somebody who is experiencing the need to engage in challenging behaviour. As well as guilt, fear, exhaustion, embarrassment and shame, parents in particular can worry that the behaviour is their own fault. It's important to know that challenging behaviour is experienced by many people around the world and there are many factors that may contribute to the unmet needs that underlie behaviour. Working out which unmet needs are driving behaviour can be complex and parents and supporters need to be gentle on themselves.

Focus on own coping

It can take time to understand and find new ways to respond to behaviours so it's helpful to take a long term approach. This means taking care of your health and your energy levels. An important part of planning to support people experiencing the need to engage in challenging behaviour is planning to support their families. What steps can be taken to help families and supporters have their own needs met, to have enough rest, recreation and social connection? How can people be supported to prioritise their own health and wellbeing needs? Are there plans in place for:

- Free time
- Catching up with friends
- Opportunities to talk things through with a friend, supporter or counsellor
- Exercise
- Spending time with loved ones and other children

Small things can help - like going for a walk, learning how to use deep breathing to manage emotions, having a bath or using essential oils you like. Although these seem like simple things, for some families even small steps like this can be extremely difficult. Self-care might seem like a luxury, but it is essential for both your own wellbeing and your ability to care for others.

Siblings

Siblings can struggle with challenging behaviour, but can also be a source of strength and inspiration. Families often say that explaining the reasons for challenging behaviour to siblings can help as it's important they don't feel that the sibling with a disability is being treated differently and unfairly. It's important to explain that behaviours are not personal - the person is not trying to hurt, annoy or anger others on purpose. Siblings can be insightful partners in finding some ways forward. It is important to ask them what they think. If there are concerns that other children's mental health is suffering, it is important to get support for them.

Sources of outside help

The following is a list of organisations and resources that help families and carers in their supporting role of a person who uses behaviour that is challenging. There are also many other private practitioners whom some families choose to partner with.

Peer groups

If your family member has a specific diagnosis, there are many peer support groups that can offer tips and strategies to prevent or manage behaviours that challenge. Many families say the best advice comes from other families they meet with similar experiences. It's important to find a group that you feel is the right fit for you, and has a positive focus.

They may be local (covering a certain area or region), national or even international. They may be a generic or diagnosis specific group (eg. Autism or Fragile X syndrome). Peer support groups offer different supports according to their size. Even if you do not meet another person with the same needs as your family member, you may still find it helpful to share experiences with other families.

Here are a few support organisations and groups that families can contact for support:

Carers WA	Ph: 1300 227 377	www.carerswa.asn.au
Connect Groups	Ph: 08 9364 6909	www.connectgroups.org.au
Developmental Disability WA (DDWA)	Ph: 08 9420 7203	www.ddwa.org.au

Multi-disciplinary teams

Multi-disciplinary teams include health professionals with specialist knowledge and expertise. Different specialists can help to bring together ideas about what could be influencing your family member's need to engage in behaviour that is challenging. The following are a few support organisations that families can contact for support:

Autism Association of WA- Therapy and Clinical Services	Ph: 08 9489 8900	www.autism.org.au
Ability Centre	Ph: 1300 106 106	www.abilitycentre.com.au
Department of Communities - Individualised Services	Ph: 08 9426 9200	www.disability.wa.gov.au
Rocky Bay Clinical Services	Ph: 08 9383 5111	www.rockybay.org.au
Senses Australia	Ph: 1300 111 881	www.senses.org.au

Therapy Focus	Ph: 1300 135 373	www.therapyfocus.org.au/ comprehensive-therapy
VisAbility	Ph: 1800 847 466	www.visability.com.au
Nulsen	Ph: 08 6253 4700	www.nulsen.com.au/service/ nulsen-therapy-services
Activ	Ph: 08 9387 0555	www.activ.asn.au
Identity WA	Ph: 08 9474 3303	www.identitywa.com.au
Family Support WA	Ph: 08 9206 3400	www.familysupportwa.org.au

If you feel your family member's support needs are not being met by their health or disability service provider, you can contact:

The Health and Disability Services Complaints Office (HaDSCO)	Ph: 08 6551 7600 or country callers 1800 813 583	www.hadsco.wa.gov.au
Health Consumers' Council	Ph: 08 9221 3422 or country callers 1800 620 780	www.hconc.org.au/what-we-do/ advocacy
People with Disabilities WA	Ph: 08 9485 8900	www.pwdwa.org

Professionals

The assessment of, and advice about behaviour support often needs a multi-disciplinary approach. Positive Behaviour Support is underpinned by a comprehensive look at the needs of a person in many areas of their life. In this guide, we have made reference to several different professionals and services who can help families and supporters understand and respond to behaviour. These include:

Clinical Psychologists: can help to understand the underlying reasons for behaviour, mental health concerns and possible practical strategies you can use.

Psychiatrists: may be able to support people whose behaviour is linked with mental health conditions. They can also help with diagnosis of mental health conditions.

General Practitioners: your GP 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.

Speech Pathologists: help to understand the impact of gaps in expressive and receptive language on the need to use behaviour. They can also help you create communication supports to help the person have access to ways to communicate effectively.

Occupational Therapists: can help to understand the arousal levels of people, including how sensory needs impact on self-regulation. They can provide advice on, and assistance with practical issues for people 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.

Physiotherapists: can assist people who experience limitations in their mobility and posture which may contribute to their frustration and experience of pain and behaviour.

Social Workers: can provide counselling around supporting your family member as well as some practical support in accessing respite and support services.

Positive Behaviour Support Clinicians: usually have a background in one or more of the above professions and have experience in working with families in ways outlined in this resource. They might be able to support an understanding of reasons for behaviour, and identify supports that might be useful for the person. Some Behaviour Support Clinicians or Practitioners have significant experience in supporting adults with complex needs such as challenging behaviour, however may not come from an allied health background.

For further information about supporting someone you care about, please contact us, or have a look at the resources on our website: www.ddwa.org.au

DDWA can also provide support coordination and behaviour support through an NDIS plan. For more information please contact us on **08 9420 7203** or ddwa@ddwa.org.au



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Developmental Disability WA



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