

The background of the entire page is a dense, overlapping field of various pills and tablets. Most are light blue, but there are several distinct colors: a bright green pill in the top left, an orange pill in the top right, a red pill on the left side, a yellow pill in the bottom center, a pink pill in the bottom right, and a purple pill in the bottom left. The pills vary in shape, including circles, ovals, and capsules, and some have visible score lines.

BEHAVIOUR SUPPORT AND THE USE OF MEDICATION

A guide for practitioners

Acknowledgements

We extend thanks to the people who took part in focus groups and interviews to inform this guide, as well as to the project's Reference Group members who provided input, advice and direction to the research process and guide.

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Contents

- About the 'Behaviour Support and use of Medication' guide 4
- What is in the guide? 7
- Understanding challenging behaviour 8**
 - Defining challenging behaviour in person/environment context . . . 9
 - Figure 1: Person/environment context of challenging behaviour* . . 10
 - Responding to challenging behaviour – best practice. 11
 - Recap: Understanding challenging behaviour* 12
 - Josh: Challenging behaviour in person/environment context* 13
 - Figure 2: Understanding Josh's challenging behaviour* 14
 - A Positive Behaviour Support response for Josh 15
- Understanding medication for managing challenging behaviour . . 16**
 - What are the medications in question? 17
 - Considerations in prescribing medication. 18
 - Importance of prescribing medication for mental illness 19
 - Threshold and risks of prescribing medication
for challenging behaviour 20
 - Using medication as one part of Positive Behaviour Support 24
 - Recap: Understanding medication for managing
challenging behaviour* 25
 - Josh: Considering medication* 26
- Resources about the role of Behaviour Support Practitioners . . 28**
 - Figure 3: Roles of different people when exploring and stopping
the use of medication for challenging behaviour* 29
 - Exploring the use of medication for challenging behaviour. 29
 - Informing decisions about medication 30
 - Integrating medication with Positive Behaviour Support 32
 - Figure 4: Positive behaviour support process* 33
 - Preparing information for the prescribing health professional 34
 - Considering safety when medication is used. 36
 - Helping others understand their roles and responsibilities 37
 - Josh: Preparing for the physician appointment* 39
- Evidence base 41**
 - Other resources 42

About the 'Behaviour Support and use of Medication' guide

Context and scope of the guide

This guide is about the use of medication for the purpose of addressing challenging behaviour among people with a disability. Challenging behaviour is behaviour that is persistent and resistant to change, does not meet the expectations of the society or environment in which it occurs and which has a negative influence on the safety and quality of life of the person and others around them.

The use of medication to manage challenging behaviour has potentially severe implications for the health, wellbeing and rights of people with disability. There is also little evidence to support its use to manage behaviour. Despite the risks and lack of evidence, medication is however often mis-used, over-used or used for too long as a form of behaviour management. Its mis-use commonly occurs over both short and long periods of time.

This guide has been developed in response to concerns that there are limited resources setting out the evidence, context and principles in regard to behaviour support and the use of medication. The guide aims to provide some clarity in this area, by exploring issues in the use of medication within the context of best practice in behaviour support, with particular attention to the role of a Behaviour Support Practitioner.

The material presented in this guide has been developed based on the following evidence:

- » a literature review of evidence-based approaches in the use of medication for behaviour support;
- » interviews with health professionals responsible for prescribing medication;
- » focus groups with personnel working in or advising the disability sector, including direct support workers and managers, Behaviour Support Practitioners and people involved in regulating and monitoring disability services; and
- » advice from a Project Reference Group and a Guide Test Group.

Terminology

The language used to refer to challenging behaviour varies across Australia and internationally. The term 'challenging behaviour' is the predominant term used in peer-reviewed literature to refer to behaviours that place a person with disability and/or others at risk of harm. Other terms are however used as well. 'Behaviours of concern' is another term commonly used in Australia. 'Challenging behaviour' has been used in this guide given the wide understanding of the term nationally and internationally.

Policy context

In Australia, the use of medication for challenging behaviour is considered *chemical restraint*, which is a regulated restrictive practice. Such practices have explicit requirements of service providers and Behaviour Support Practitioners in the delivery of behaviour support. Further information regarding these requirements can be found at www.ndiscommission.gov.au. Chemical restraint and restrictive practices are also explained later in this guide.

Purpose

This guide is intended to provide an introduction to the evidence, context and principles for Behaviour Support Practitioners and others to take into account when responsibly considering the use of medication for managing the challenging behaviour of a person with disability. It is not intended to present detailed instructions for decision-making on when or when not to use medication for this purpose. Rather it aims to develop an understanding of the factors to consider when making the decision to explore and/or stop use of the medication for this purpose.

The guide may be used to inform Behaviour Support Practitioners and others. It is suitable for use as a training resource and/or a practice reference guide.

Person-centred approach

This guide uses a person-centred approach. The person-centred approach recognises that the use of medication should always be done with the quality of life of the person with disability as the central concern. Reflecting the person-centred approach, the guide highlights that use of medication to address challenging behaviour should always be integrated with Positive Behaviour Support and so prefaced by the question of whether there are ways to build on the person's strengths and skills and/or modify the environment that may be influencing or causing their behaviour, instead of relying on ongoing medication.

Audience

The guide is for providers, practitioners and others who have a role in providing behaviour support.

- » **Behaviour Support Practitioners** may use the guide to understand (a) their role in the process of deciding whether or not to explore and/or stop the use of medication for managing challenging behaviour and (b) considerations in delivering behaviour support services.
- » **Other providers and practitioners** often provide support and information in the process of deciding whether or not to explore and/or stop the use of medication for managing challenging behaviour. They may also benefit from the information in the guide to inform their understanding of this process.
 - **Prescribing health professionals** may use the guide to inform their collaboration with Behaviour Support Practitioners and others, as they consider whether or not a prescription of medication is appropriate and consider when to stop the medication.
 - **Direct support workers, key workers, case managers** and **allied health clinicians** may use the guide to understand the principles important in the decisions about whether to explore and/or stop the use of medication for managing challenging behaviour.
- » **People with disability** and their **personal supporters** (e.g. family, friends and personal representatives) may also find the guide content useful in understanding how and why medication may or may not be used.

Links with other guides

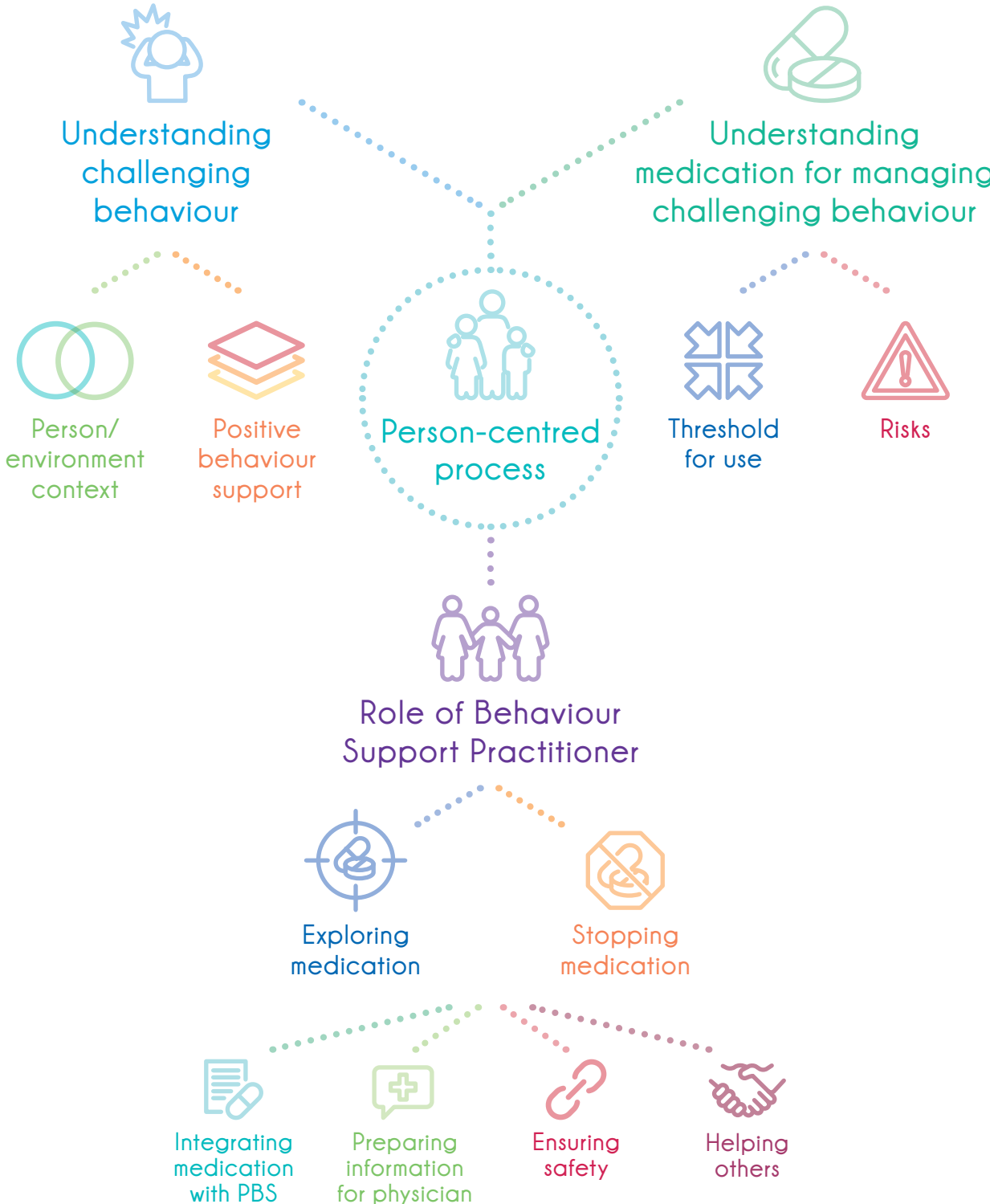
This guide is part of a series developed by the Intellectual Disability Behaviour Support Program, UNSW Sydney, to target better support, planning and practice with people with disability who have complex support needs. The other guides in the series are:

- » Doing an effective case review with a person with disability – a person-centred approach
- » Understanding behaviour support practice guide: Young children (0–8 years) with developmental delay and disability
- » Understanding behaviour support practice guide: Children and young people (9–18 years) with disability
- » Being a planner with a person with disability and complex support needs: Planning resource kit
- » Living the life I want: A guide to help with planning
- » No more waiting: A guide for organisations to plan with Aboriginal people with disability

We encourage providers and practitioners using this guide to consider how these other resources may also be useful to their practice in supporting and planning with people with disability and their families, or in supporting them with areas such as person-centred practice and behaviour support. The guides can be found at: arts.unsw.edu.au/idbs/resources

What is in the guide?

This is a visual representation of the content of the guide. The guide first explains how challenging behaviour is a response to a person/environment interaction, with Positive Behaviour Support the best practice approach to managing it. The guide then goes on to outline issues in the use of medication for managing challenging behaviour. It explains what the medication in question is, the risks of using it as a way of managing challenging behaviour and the threshold for its use for this purpose. The guide ends by outlining the role of a Behaviour Support Practitioner when informing the decision to explore and/or stop use of medication.





Understanding challenging behaviour

Understanding the context for using medication for behaviour support requires understanding challenging behaviour, including how it is defined and emerges, and best practice approaches for managing it.

The following sections address:

-  Defining challenging behaviour in person/environment context
-  Best practice approaches for responding to challenging behaviour

Defining challenging behaviour in person/environment context

All people live within the context of the environment around them, which includes other people and a range of settings or locations. People experience their environment through a range of interactions and relations, which continually change. Particular skills are required to communicate and interact in each part of their environment over time, especially as changes occur.

Some people with disability experience impairments that affect their communication and interactions. It is important that they are provided with the right support to assist them to communicate and/or manage as they navigate the environment around them over time, and that the support is offered in a strengths-based manner.

When people with disability are not provided with the right support to navigate their environment, it may result in them behaving in ways that are challenging to the expectations of the people, settings and locations around them. Such behaviour may involve acts that are considered detrimental to the quality of life of the person or others, dangerous to the physical safety of the person or others or that are seen as disruptive to what is happening around the person. Sometimes the label of **‘challenging behaviour’** is used. A behaviour or set of behaviours is labelled as challenging when they do not fit with what the environment or society around a person expects. To the person however, their behaviour is not necessarily ‘negative’ or ‘challenging’ – it is just their response to their bio-psychosocial environment or to a specific situation they find themselves in.

Challenging behaviour is defined in different ways in different contexts. For the purpose of this guide, challenging behaviour is understood to be behaviour that is a person’s response to their bio-psychosocial environment. It is behaviour that is seen as:

- » Persistent and resistant to change
- » Inappropriate to the context in which it occurs
- » A negative influence on the person’s and other people’s physical, emotional or social safety and/or a risk to their quality of life.

Figure 1: Person/environment context of challenging behaviour

The person/environment context of challenging behaviour is depicted in the diagram below, with some examples of personal and environmental factors that may interact to influence challenging behaviour.



Who is seen as having challenging behaviour?

People with disability who are considered to have challenging behaviour commonly have specific diagnostic labels, including intellectual disability, cognitive disability and autism spectrum disorder. Challenging behaviour is also one factor that is often involved in an assessment of a person as having complex support needs.

Responding to challenging behaviour – best practice

Best practice in managing challenging behaviour is based on understanding the person within their environment. It focuses on equipping or supporting the person to better communicate and manage in their environment and/or on changing the environment itself to make communication and interaction easier for the person.

Addressing the person's environment in this way is the premise of **Positive Behaviour Support**.

What is Positive Behaviour Support?

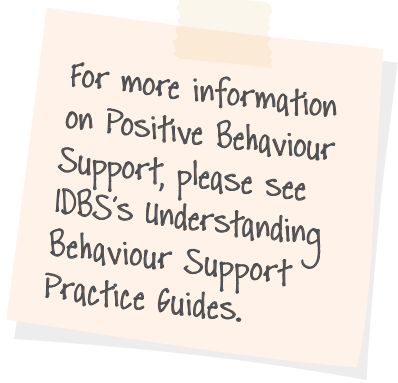
Positive Behaviour Support is currently best practice in supporting people with disability who have challenging behaviour.

The key elements of Positive Behaviour Support are:

- » Taking a proactive approach;
- » Identifying the person's strengths and areas for skill development;
- » Identifying changes to the person's everyday natural environments to support positive behaviour.

Positive Behaviour Support focuses on understanding the purpose that the challenging behaviour is serving for the person within their current environment and finding another way to address that purpose, including through developing new skills or Positive Behaviour Support strategies – this is the focus of an assessment conducted by a Behaviour Support Practitioner and is sometimes also called **applied behaviour analysis**. The results of the assessment are included in a Positive Behaviour Support Plan.

Overall, the aim of Positive Behaviour Support is to re-shape or re-structure the person's environment, to improve their quality of life and that of the people around them. It aims to increase positive behaviours and communication, rather than punish current behaviour.



For more information on Positive Behaviour Support, please see IDBS's Understanding Behaviour Support Practice Guides.



Recap: Understanding challenging behaviour

Challenging behaviour:

- » Is behaviour that is seen as:
 - Persistent and resistant to change
 - Inappropriate to the context in which it occurs
 - A negative influence on the person's and other people's safety and quality of life.
- » Occurs in the context of a person/environment interaction
- » Is best managed through Positive Behaviour Support that focuses on the following areas and is documented in a Positive Behaviour Support Plan:
 - Taking a proactive approach
 - Identifying the person's strengths and areas for skill development, including through developing new skills or Positive Behaviour Support strategies
 - Identifying changes to the person's everyday natural environments to support positive behaviour.

Josh: Challenging behaviour in person/environment context

The example of Josh's experience is used to show how challenging behaviour occurs in a person/environment context and to highlight how Positive Behaviour Support might be used to respond.



About Josh

Josh is a young man, aged 18, with an intellectual disability and a history of some mental health issues, including anxiety. He has lived in various out-of-home care arrangements since he was a small child, and has little contact with his family. He has an appointed Guardian.

Events leading to Josh's challenging behaviour

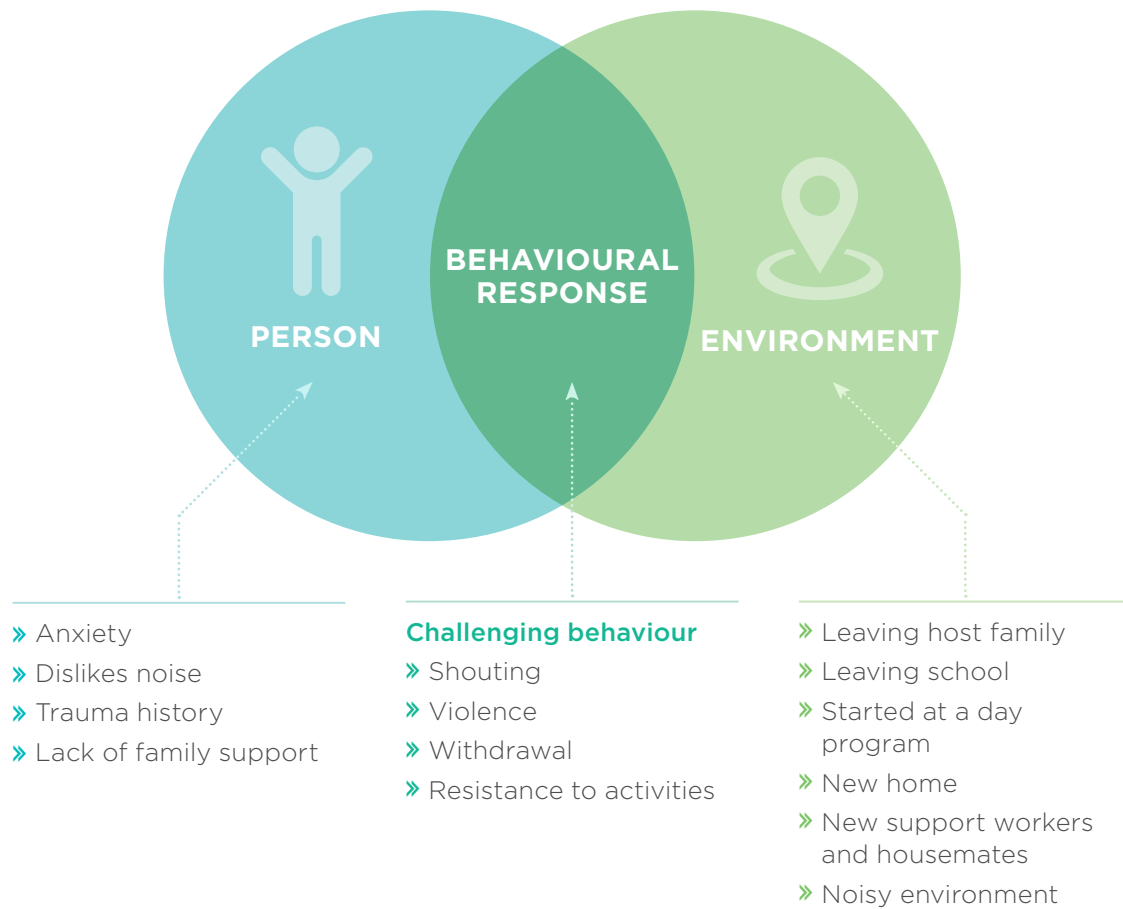


The last 12 months have been a time of many changes for Josh. He turned 18, finished school and started at a day program. He also moved from the out-of-care placement he had been living in with a host family for the last several years and into a house he shares with three other young men who are a similar age to him.

Now living in his new home, a team of disability support workers from a service provider organisation support Josh and his housemates. While Josh's housemates are a similar age to him, they don't tend to spend much time together socially, and there is only one lounge room area. Josh says that it is too noisy and spends a lot of time in his room. Lately he has appeared anxious almost all the time, and has been refusing to leave his room. He becomes upset and shouts at the support workers then they try to get him to join his housemates. On several occasions he has made moves to lash out at the support workers when they have tried to make him come out of his room and he once tried to strike a housemate who was making noise in the lounge room. He doesn't play video games anymore, something he used to enjoy. His personal hygiene has deteriorated and he is often reluctant and sometimes refuses to attend his day program.

The support workers are worried about Josh. They have only known him for a few months, but from all reports he was happy going to school last year, and challenging behaviour was not noted in the records they received when Josh moved in. Some notes indicated that Josh had a 'trauma history', but didn't give any details. There was also reference to a Positive Behaviour Support Plan that his school had put in place a few years ago, but there wasn't one when he moved in. They are unaware of whether Josh is having similar difficulty in his new day program.


Figure 2: Understanding Josh's challenging behaviour





A Positive Behaviour Support response for Josh





The support workers discussed the situation at their team meeting and afterwards consulted with Josh's Guardian. Having met with Josh's GP and ruled out any health and medical reasons for the behaviour, they agreed that they would seek a referral for a Behaviour Support Practitioner to conduct an assessment to understand the reasons for Josh's behaviour.

 As part of the assessment, the Behaviour Support Practitioner met with Josh and his support workers. Josh told her that he missed all the people he used to have around him and that too much noise made him feel worried and jumpy. The support workers said that they were worried about Josh's wellbeing, as well as the wellbeing of their own support worker team and of the other people in the house. After listening to what Josh and his support workers had to say, the Behaviour Support Practitioner considered the following questions as part of her assessment:

 What has been the impact on Josh of leaving both school and his host family at the same time? How might the impact of these changes be addressed for Josh?

 What has been the impact for Josh of moving into a new home, with new housemates and support workers? Does the set up of the house suit Josh? Is it too noisy? Does he have privacy? What might be changed to make the arrangements work better for him?

 A 'trauma history' and a history of an anxiety disorder were mentioned in Josh's notes. What does this mean for Josh? How might Josh's trauma history and anxiety be contributing to the difficulties he is now experiencing? What more can be found out about this?

 What is happening for Josh in other settings? How, for example, is he managing at his new day program? Is there anything happening there that might be contributing to his behaviour?

The Behaviour Support Practitioner made a range of recommendations for environmental changes and Positive Behaviour Support strategies in her assessment. She recommended that the support workers might help Josh investigate if he could better keep in touch with his host family or visit friends he used to have at school. She also recommended that there might be a space in the house that could be re-arranged to create a 'chill out zone' for Josh, where he could have some time and space to himself, listen to music through earphones and play video games. Josh could then be encouraged to actively go to this space as a Positive Behaviour Support strategy for managing his anxiety about noise in the lounge room. The Behaviour Support Practitioner documented these recommendations into a Positive Behaviour Support Plan, and recommended implementing the plan for a set time period to see if it helped. She also said the support workers should follow up with the day program provider to see what they could find out about Josh's experience there. The Behaviour Support Practitioner said that if the Positive Behaviour Support Plan didn't bring about any positive changes and Josh's behaviour continued or escalated, then further action might be required.









Understanding medication for managing challenging behaviour

While best practice is to use Positive Behaviour Support, medication is also often used for the purpose of managing challenging behaviour. Medication for this purpose is however often mis-used, over-used or used for too long. Its use is only considered appropriate in rare instances.

There are currently limited resources explaining the evidence, context and principles to take into account when responsibly considering the use of medication for managing challenging behaviour. This section aims to provide some further guidance in this area.

The following sections address:

-  Defining the medication in question
-  Considerations in prescribing medication
-  Importance of prescribing medication for mental illness
-  Threshold and risks of prescribing medication for challenging behaviour
- 
-  Using medication as one part of Positive Behaviour Support

What are the medications in question?

A range of medications are sometimes used to manage challenging behaviour. Some are commonly referred to as anti-depressants, anti-psychotics, sedatives (anxiolytics) or mood stabilisers. Some are prescribed on a long-term basis, whereas others are on a PRN (as needed) basis.

All are medications that affect how people think and feel. They are medications that have an impact on:

- » How people perceive what is happening around them
- » The mood people are in – for example, whether they feel happy, sad, calm or angry
- » The feelings that people have about what is happening to them
- » The types of actions people take as a response to how they feel
- » How sexually aroused people are

These medications are usually used as a component in the treatment of mental illness. They should not be used as the primary response to a bio-psychosocial issue – that is, to treat an individual's biological or psychological response to what is chiefly an environmental problem.

The box below includes a list of relevant medications.

Relevant medications

Category of medication	Key active ingredient	Commonly prescribed for
Anti-depressants	Serotonin uptake inhibitors (SSRIs)	Depression
Anxiolytics	Benzodiazepine	Anxiety
Mood stabilisers	Lithium	Bi-polar disorder
Anti-psychotics	Risperidone	Psychosis
Psycho-stimulants	Methylphenidate	Attention Deficit Hyperactive Disorder (ADHD)



Considerations in prescribing medication

The medications listed on the previous page are always prescribed by a health professional, often a general practitioner, psychiatrist or paediatrician. Just because a person with disability has an appointment with a prescribing health professional does not mean that medication will necessarily be prescribed. The health professional may or may not agree with that the medication is warranted, and will often have alternate recommendations for addressing challenging behaviour.

To prescribe such medication, the prescribing health professional needs to¹:

- » Complete a thorough diagnostic assessment
- » Be confident that the use of the medication is appropriate:
 1. The medication is used to address only:
 - A confirmed diagnosis of a mental illness.
 - Challenging behaviour that is severe and non-responsive to Positive Behaviour Support alone.
 2. The medication is not used to address a bio-psychosocial response to an issue which is chiefly environmental – in this case, Positive Behaviour Support and/or environmental changes should be made first.
 3. The medication is not used to address a behavioural response to symptoms of a physical health condition (e.g. epilepsy, conditions causing pain) – in this case, the physical health condition should be addressed first.
- » Be confident that the medication will not have an ill-effect on any co-occurring health conditions the person may have or adversely interact with other medications they may take.
- » Be confident that the benefits of using the medication will outweigh the impact of any harmful side-effects.
- » Be confident that the medication is prescribed as part of an overall care and support strategy, which includes ongoing assessment and monitoring of the extent and impact of side-effects and is agreed to by the person and/or their family or carers.
- » If used for challenging behaviour, include a plan for when the medication's use will be stopped, based on improved behaviour. The intention should be for the medication to only be temporary or short-term.

'That's really the hardest thing, to be called upon constantly to prescribe for psychosocial reasons.'

Prescribing health professional

'Medication exists in a context and the context has to be right, [otherwise it's] medication for environmental problems.'

Prescribing health professional

¹ Adapted from Trollor et al., 2016.



Importance of prescribing medication for mental illness

The primary purpose of prescribing the medications discussed in this guide is to address a confirmed diagnosis of a mental illness. Relevant conditions include depression, anxiety and psychosis.

These medications may be prescribed to anyone who has a confirmed diagnosis of mental illness, irrespective of disability. **People with intellectual disability have a 2.5 times higher likelihood of having a mental illness or mental health condition compared to the general population².** For this reason, they are commonly prescribed the medications discussed here.

Where a person with intellectual disability has a mental illness or mental health condition, it is important that they have access to appropriate treatments, including medication. Their right to seek treatment for mental health and other health conditions is supported by both the *United Nations Universal Declaration of Human Rights* (UDHR) and the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD).

'Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including... medical care' (UDHR, Article 25).

'States Parties recognise that persons with disabilities have the right to enjoyment of the highest attainable standard of health without discrimination on the basis of disability... In particular States Parties shall provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons' (CRPD, Article 25).

Despite having a higher likelihood of having a mental illness or mental health condition than the general population, appropriate services and supports are not always available to assess the mental health of people with intellectual disability or to determine the presence or absence of a mental illness.

In addition, it can sometimes be difficult to distinguish between challenging behaviour and mental illness for some people with disability.

These situations present many challenges to health professionals who prescribe medication. Accordingly, it is important that appropriate specialist support is sourced to thoroughly assess the mental health of people with intellectual disability, especially when issues regarding challenging behaviour and the use of medication are under consideration.

² Trollor et al., 2016.



Threshold and risks of prescribing medication for challenging behaviour



The threshold for prescribing medication for managing challenging behaviour is that the challenging behaviour is severe and non-responsive to Positive Behaviour Support alone. In this respect, medication should only be used for challenging behaviour in rare instances.

The threshold means that:

- » Medication should not be prescribed lightly for managing challenging behaviour, nor should it be the first response. Positive Behaviour Support strategies should be explored and exhausted before medication is considered.
- » Medication should not be the first response when initial Positive Behaviour Support strategies do not work. There may be a range of reasons why they have not worked, including that the strategies do not sufficiently address the reason for the behaviour or that they have not been consistently implemented. Trialling other options and ruling out other reasons that the strategies have not worked are important before considering the use of medication.
- » The exploration of Positive Behaviour Support strategies needs to balance allowing enough time to thoroughly establish that the Positive Behaviour Support strategies have not worked, while also ensuring that undue harm is not caused for the person in the meantime.
- » Where it is prescribed, medication should not be a permanent solution – it should be temporary and short-term, with a plan in place to stop its use when the person's behaviour improves.

Despite this threshold, misuse/over-use of medication to address challenging behaviour is common and well documented³. A recent international meta-analysis found that 30–40% of people with intellectual disability living in institutional care and 10–20% of those living in community settings receive the types of medication sometimes used to address challenging behaviour⁴. Estimates vary, with some estimating that the medications could be misused in around 20% of cases, but others estimating that this occurs in as much of 85% of such cases⁵.

³ Tsiouris et al., 2013, Bamidele and Hall, 2013, Paton et al., 2011, Deb et al., 2009, Tsiouris, 2010, Trollor et al., 2016.

⁴ Bhaumik et al., 2015. ⁵ Deb et al., 2015.



Misuse and over-use of medication for managing challenging behaviour is a problem for several reasons, including:

- » A limited evidence base for its effectiveness in reducing challenging behaviour
- » The risk of side-effects
- » The status of medication for managing challenging behaviour as a restrictive practice
- » Poor monitoring practices that can lead to risks for wellbeing



Limited evidence base

The majority of research into the use of medication for challenging behaviour has found that there is insufficient/inconsistent evidence to confirm its effectiveness for reducing this type of behaviour⁶.

Without a threshold of evidence, there is little to support using medication to address challenging behaviour.

- » A systematic review found a lack of rigorous evidence to support the use of medication to manage challenging behaviour in people with intellectual disability⁷.
- » Another review found that 'with the possible exception of risperidone, there is no reliable evidence that antidepressant, neuroleptic or anticonvulsant drugs are effective treatments' for aggression⁸.
- » A randomised control trial found no significant difference in the effects of the medications and a placebo used to manage challenging behaviour, and in fact found that the placebo had the largest impact on the reduction of the behaviour⁹.

⁶ Brylewski and Duggan, 2004, Griffiths et al., 2012, Matson and Neal, 2009, Nøttestad and Linaker, 2003, Raghavan and Patel, 2010, Tsiouris, 2010, Willner, 2015, Heyvaert et al., 2012, Tyrer et al., 2008, Trollor et al., 2016.

⁷ Brylewski and Duggan, 2004. ⁸ Willner, 2015:82. ⁹ Tyrer et al., 2008.

Side-effects

The medications commonly used to address challenging behaviour are associated with side-effects with severe health consequences, including weight gain/obesity, increased likelihood of seizures, raised blood pressure/hypertension and cognitive, breathing and swallowing problems, as well as sleeping problems, fatigue, depression, gastro-intestinal problems, memory impairment and diabetes¹⁰.

The potential health implications of these side-effects make it preferable to avoid prescription of such medication for challenging behaviour wherever possible, especially where modifications can be made instead to a person's environment using Positive Behaviour Support.

- » A further complication is that side-effects may be difficult to diagnose in people with intellectual disability. Side-effects may manifest as irritability or agitation, which may be misinterpreted as additional challenging behaviour. This can result in potentially harmful increased dosages of the medication, rather than its cessation¹¹. Furthermore, self-report of adverse effects is unlikely among people with intellectual disability, also making it hard to be sure of the extent of side-effects¹².
- » Several studies have raised ethical concerns regarding the prescription of medication to people with intellectual disability who may not fully comprehend the potential side-effects¹³.

Restrictive practices

The use of medication for challenging behaviour is considered a 'restrictive practice'. A restrictive practice is 'any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with disability, with the primary purpose of protecting the person or others from harm'¹⁴. Restrictive practices are infringements on the rights of people with disability, and the legality of their use has been questioned¹⁵.

As it is a restrictive practice, using medication to address challenging behaviour should be avoided wherever possible to maintain the rights of people with disability.

- » There are different types of restrictive practices – medication for challenging behaviour falls under the category of 'chemical restraint'¹⁶. Chemical restraint is a regulated restrictive practice in Australia. This means that there are specific requirements for Behaviour Support Practitioners and other service providers when it is used, and its use is monitored by the NDIS Quality and Safeguards Commission. Further information regarding these requirements can be found at www.ndiscommission.gov.au.
- » The rights infringement to people with intellectual disability from restrictive practices is considered particularly problematic given the enhanced vulnerability of this group¹⁷.

¹⁰ Trollor et al., 2016, Griffiths et al., 2012, Scheifes et al., 2016.

¹¹ Raghavan and Patel, 2010, Scheifes et al., 2016, Flood and Henman, 2016.

¹² Chandler et al., 2014. ¹³ Sheehan et al., 2015, Raghavan and Patel, 2010, Chandler et al., 2014.

¹⁴ Department of Social Services, 2014. ¹⁵ Victorian Law Reform Commission, 2003, Carter, 2006.

¹⁶ Department of Social Services, 2014. ¹⁷ Chandler et al., 2014.



Poor monitoring

The use of medication for challenging behaviour often happens in ways that are 'unseen, unsupervised and unmonitored'¹⁸. Poor monitoring of the use of medication for this purpose leads to risks, including adverse side-effects remaining unnoticed, dosages being prescribed that are higher than recommended, multi-prescribing (where the interactions between different medications are unknown and/or not monitored) and to the medication staying in place longer than appropriate. It may also give false reassurance that the behaviour is being addressed, without confirming that the medication is having the intended effect. This can delay access to other more appropriate and effective treatments.

Each of these effects of poor monitoring can have severe health consequences, and so are further reasons to avoid using medication to manage challenging behaviour.

- » Multiple studies have revealed a lack of effective monitoring of both physical and psychological side effects of the medication¹⁹.
- » Research has found that dosages of antipsychotics prescribed to people with challenging behaviour are often higher than what is recommended²⁰.
- » A high number of people with intellectual disability who die in residential care receive multiple medications as their primary behaviour support strategy²¹.

¹⁸ Chandler et al., 2014:2. ¹⁹ Bhaumik et al., 2015, Raghavan and Patel, 2010.

²⁰ Deb et al., 2015, Valdovinos et al., 2016, Trollor et al., 2016. ²¹ Ombudsman NSW, 2015.



Using medication as one part of Positive Behaviour Support

Where the challenging behaviour is considered by a prescribing health professional to meet the threshold to warrant use of medication, the medication should still be prescribed as only ever one part of a broader behaviour support strategy and with the intention that Positive Behaviour Support strategies will replace its use over time.

The medication should always be complementary to Positive Behaviour Support, not instead of it. It may be used, for example, to help stabilise the person's behaviour while they are supported, through Positive Behaviour Support, to learn new ways to communicate and interact within their environment. In this respect, the medication should not be a permanent arrangement and once new Positive Behaviour Support strategies are learnt, the medication should be reduced or stopped.

Very often, however, people with intellectual disability are prescribed medication without an appropriate Positive Behaviour Support Plan in place, which can lead to it being inappropriately prescribed, unmonitored and/or kept in place longer than is appropriate. This is a concern. The next section of the guide provides some resources to show how the use of medication should be integrated into a broader Positive Behaviour Support strategy. It outlines the role of a Behaviour Support Practitioner in exploring and stopping the use of the medication, as well as others with whom Behaviour Support Practitioners interact.

'We're seeing people that are prescribed way too many medications with no [Positive] Behaviour Support Plan in place.'

Behaviour Support Practitioner

'So, you've got people on long-term... medication... [but] there's a lack of examination of the [Positive] Behaviour Support Plans that are linked and relevant to that.'

Behaviour Support Practitioner

'There also needs to be connection between the delivery of behaviour support services to address behaviour and the connection with an additional therapeutic approach by a psychiatrist or physician to address the same behaviour through an alternative way. We've not been good at connecting those two approaches and making sure those two practices work together.'

Behaviour Support Practitioner

²² Trollor et al., 2016.



Recap: Understanding medication for managing challenging behaviour

The medications discussed here:

- » Affect how people think and feel.
- » Should always be prescribed by a health professional, often a general practitioner, psychiatrist or paediatrician.
- » Should only be used to address:
 - A confirmed diagnosis of a mental illness.
 - Challenging behaviour, that is severe and non-responsive to Positive Behaviour Support alone.
- » Should only be used for managing challenging behaviour in rare instances
- » Should, where possible, be avoided as a way of managing challenging behaviour due to:
 - A limited evidence base for its effectiveness in reducing challenging behaviour
 - The risk of side-effects
 - The status of medication for challenging behaviour as a restrictive practice
 - Poor monitoring practices that can lead to risks for wellbeing
- » When used for challenging behaviour, should always be complementary to and integrated with Positive Behaviour Support, not instead of it.
- » Should be stopped when Positive Behaviour Support strategies lead to improvements in behaviour.

Josh: Considering medication



Josh's support workers took Josh to his GP to ensure that his current behaviour was not associated with a mental or physical health condition. Given concerns about Josh's anxiety, the GP referred him to a psychologist for a mental health assessment. The psychologist determined that Josh's behaviour and emotions did not relate to a mental health disorder.

The time period for implementing Josh's Positive Behaviour Support Plan progressed. Josh's support workers arranged the 'chill out zone' in the house, and they encouraged Josh to relax there when the noise in the lounge room was too much. It took some time, but they also managed to arrange some opportunities for Josh to see his school friends and host family.



Even though these environmental changes and Positive Behaviour Support strategies were in place, Josh was increasingly distressed and unsettled. He didn't always go to the 'chill out zone' when it was noisy in the lounge room, and often when he came home from his visits with his school friends and host family he was even more upset than before. He frequently tried to, and sometimes succeeded at, hitting support workers, and he began to throw items at his housemates and to hit himself on the side of the head when he was most stressed.



The support workers asked the Behaviour Support Practitioner what should be done. She recommended some additional Positive Behaviour Support strategies. One strategy was that a support worker should meet and go for a walk with Josh before he came home from a visit with his host family or school friends, to talk about the visit and practice feeling calm before returning home. She also recommended that the visits could be timed so that Josh returned home when his housemates were out, so that he didn't re-enter the bustle of the house at once.



The support workers consistently implemented all of the Behaviour Support Practitioner's strategies. They also continued to encourage Josh to use the 'chill out zone', especially as a place to go when already feeling anxious. However, despite their consistent implementation of the strategies, Josh continued to be very unsettled. On one occasion, he remained agitated for eleven hours after a visit with his host family, right throughout the night. Despite the support workers following all the recommended strategies, Josh would not calm down - he hit another resident, pushed a support worker into a wall and blackened his own eye.



The support workers contacted the Behaviour Support Practitioner the next morning. She said that Josh's challenging behaviour appeared less responsive to the Positive Behaviour Support strategies than everyone had hoped. She wondered aloud whether treating Josh's emotional distress might assist alongside the Positive Behaviour Support Plan, and whether an option for PRN medication should be explored. She suggested an appointment with a health professional to investigate whether some medication to help Josh manage his emotions might be an option. She was careful to emphasise that the medication would not be *instead* of his Positive Behaviour Support Plan, but would rather *complement* it, allowing additional support to help Josh learn to use the Positive Behaviour Support strategies when he was most anxious and stressed. She also suggested that Josh might talk with a psychologist to learn some basic relaxation and mindfulness exercises as well, and that over time that might help the PRN medication to be no longer needed.



The Behaviour Support Practitioner consulted with Josh's Key Worker, who then approached Josh's Guardian about this plan, checking that Josh had no health conditions that might make medication a risk, and received their consent to go ahead with a referral for the appointments with the health professional and psychologist. The Behaviour Support Practitioner also spoke to Josh and asked if he'd like to see the doctor to discuss whether a medication might help him to be less emotional or distressed. Josh agreed that this might help and said that he would go to the doctor's appointment and be okay with taking medicine. With these permissions in place, an appointment with the health professional was made.



Resources about the role of Behaviour Support Practitioners

Many people are involved when the potential use of medication for managing challenging behaviour is explored. A Behaviour Support Practitioner has a particular role, which is only one part of the process. Figure 3 shows the roles of different people, and then the following sections describe the role of a Behaviour Support Practitioner in more detail.

The sections on the role of a Behaviour Support Practitioner include information on:



Informing decisions about medication



Decision to introduce medication



Decision to stop medication



Integrating medication with Positive Behaviour Support



Preparing information for the prescribing health professional

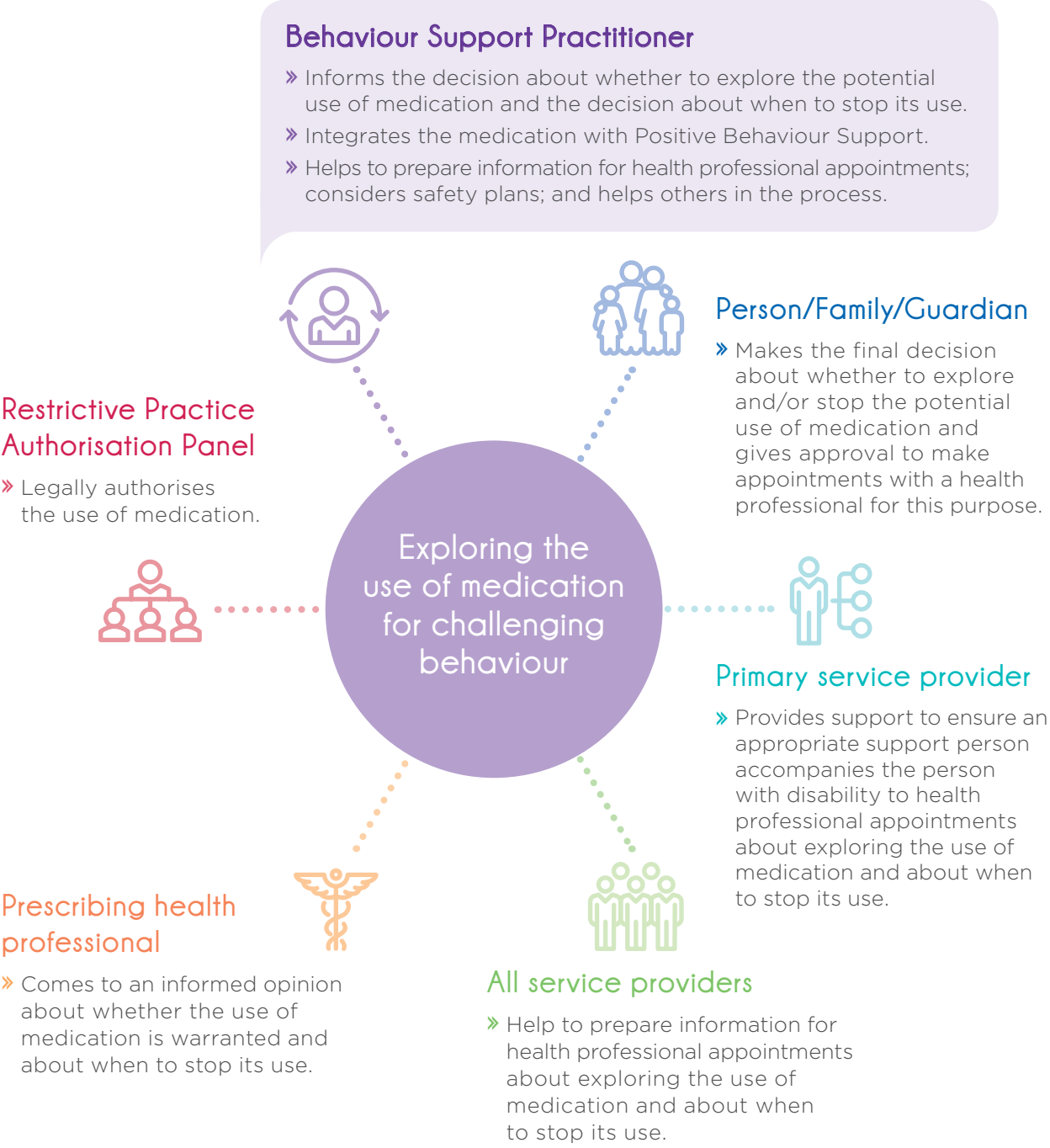


Considering safety when medication is used



Helping others understand their roles and responsibilities

Figure 3: Roles of different people when exploring and stopping the use of medication for challenging behaviour





Informing decisions about medication

A Behaviour Support Practitioner will have a role in informing decisions about using medication for challenging behaviour. This can include two types of decisions.



Decision to introduce medication

While a prescribing health professional will make the final decision about whether or not medication can be used, a Behaviour Support Practitioner has a key role in informing the decision about whether or not the potential use of medication should be explored.

Informing this decision involves ensuring that Positive Behaviour Support strategies have first been thoroughly explored with the person, and that the challenging behaviour is confirmed as being severe and non-responsive to Positive Behaviour Support alone. It also means being confident that medication is not being considered when there is an environmental issue that should be addressed instead. Finally, it involves ensuring that the correct conditions are or can be met to allow for the use of the medication. Relevant conditions are in the checklist on the following page.



Decision to stop medication

A Behaviour Support Practitioner also has a role in informing the decision about when use of medication should be stopped. This is important as the medication should only be temporary and short-term.

Although the prescribing health professional will also make the final decision to stop the medication, a Behaviour Support Practitioner will have a key role in assessing when the person's behaviour has improved and when the person may have, for example, learnt other sufficient Positive Behaviour Support strategies for managing without the medication. A Behaviour Support Practitioner may use the checklist on the following page to see whether the conditions for using the medication are still met. They may also assess improvement in the person's behaviour through implementing repeated cycles of assessment during the Positive Behaviour Support process, as outlined in the following section.

Importantly, many people with disability may already be prescribed medication when a Behaviour Support Practitioner becomes involved in their support, sometimes without proper Positive Behaviour Support processes simultaneously in place. In these instances, it is important for the Behaviour Support Practitioner to inform a decision about whether the medication should be stopped and a more thorough Positive Behaviour Support process initiated instead.

The medication is...

- Consented to**
Does the person and all relevant parties (e.g. Guardian, Person Responsible) consent to use of the medication?
- Linked to the behaviour's function**
Will the medication address the reason for the behaviour and the function it is playing in the person's life? Is there agreement that the medication will address the reason for and function of the behaviour?
- Used after Positive Behaviour Support and environmental adjustments**
Have Positive Behaviour Support strategies been tried and exhausted to replace the behaviour with new skills? Has it been confirmed that there is no environmental issue that should be addressed instead?
- Justified**
Is there a clear reason to use the medication? Is that reason therapeutically, legally and ethically justified and supported by the evidence-base?
- Safe**
Is use of the medication safe for the health and wellbeing of the person and all family members, friends and providers who may be in contact with the person?
- Forward-looking and short-term**
Will the medication support the person to learn new skills for communication and interaction? Will the medication be decreased as those skills are acquired?
- Used in conjunction with a Positive Behaviour Support Plan**
Will the medication work in conjunction with a Positive Behaviour Support Plan?
Is its use integrated into the plan?
- Prescribed**
Is the medication prescribed by a qualified health professional with clear instructions?
- Authorised**
Is the medication authorised by bodies regulating restrictive practices?
- Reviewed**
Are plans in place to regularly review the use of the medication?

TO USE MEDICATION, THE ANSWER TO ALL QUESTIONS MUST BE 'YES'.



Integrating medication with Positive Behaviour Support

Where the potential use of medication is going to be explored, a Behaviour Support Practitioner will have the responsibility of ensuring that the medication will be a recognised and integrated part of the person's Positive Behaviour Support Plan.

Integrating medication with Positive Behaviour Support means:

- » Understanding which Positive Behaviour Support strategies the medication will complement, so that the medication is only ever **one part** of a broader behaviour support strategy.
- » Making plans for the reduction or removal of the medication once the person's behaviour has improved, including planning and implementing strategies for working towards the goal of stopping the medication.
- » Conducting ongoing assessment, planning, implementation and review of what is happening for the person – using Positive Behaviour Support processes – to understand how the medication and Positive Behaviour Support strategies are working together and when the medication may be stopped. There are more details about this on the following page.

It is necessary for the Behaviour Support Practitioner to think about how the medication will be included, documented and monitored in the person's Positive Behaviour Support Plan prior to the appointment with the prescribing health professional, as the health professional may ask for details about how the medication will be integrated with broader Positive Behaviour Support strategies. Documentation of the plan should be provided by the Behaviour Support Practitioner to the prescribing health professional.

Upskilling others in integrating medication with Positive Behaviour Support

When medication is included in a Positive Behaviour Support Plan, a Behaviour Support Practitioner will need to let the range of people who will be responsible for implementing the plan know about the changes and arrange for any extra training needed to implement the new Positive Behaviour Support Plan. This may include family members, Guardians and other service providers. It is important to ensure that all people who have a role in supporting the person understand the purpose, benefits and risks of the medication, in the context of the broader Positive Behaviour Support strategy.

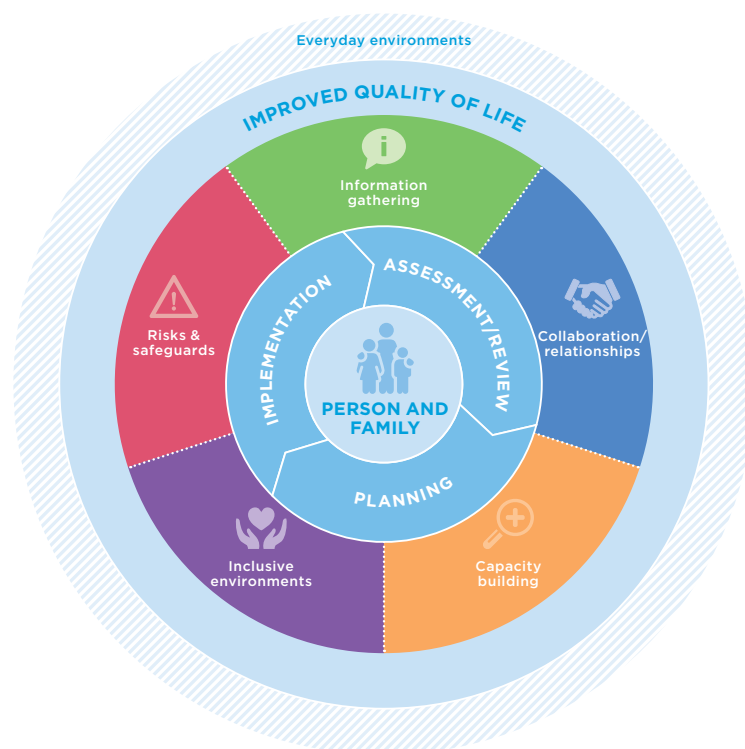
Positive Behaviour Support planning involves an iterative process of repeated cycles of:

- » **Assessment:** Functional behaviour assessment is used to understand why the behaviour is happening.
- » **Planning:** A Positive Behaviour Support Plan is developed to address the behaviour within the context of the person and their family's priorities, goals, values and strengths.
- » **Implementation:** The person, their family and their support team implement the plan.
- » **Review:** The plan is reviewed and ineffective elements of it changed.

This process is represented in Figure 4 and is explained in more detail in IDBS's Understanding Behaviour Support Practice Guides.

To be thoroughly integrated with Positive Behaviour Support, a Behaviour Support Practitioner will need to consider the medication at each stage of this process, and, in particular, plan to use the repeated cycles of assessment, planning, implementation and review as part of the process of assessing when the medication should be stopped.

Figure 4: Positive behaviour support process



Preparing information for the prescribing health professional

A Behaviour Support Practitioner will have a key role in preparing information for the person with disability to take to appointments with the prescribing health professional. These appointments may be for the purpose of either deciding whether the medication is warranted and potentially introducing it, or for the purpose of stopping the medication.

For both types of appointment, the prescribing health professional will want to see summary data about the nature, frequency and severity of the person's challenging behaviour, and information about any trigger events that have prompted the appointment. The health professional needs a thorough understanding of what is happening for the person to ascertain whether or not the use of the medication is or continues to be warranted.

For the information to be useful, it needs to have certain characteristics:

Information is comprehensive but not excessive

'The most important thing for me is the questionnaire that I've sent out and they fill out, because it's concise... Within five minutes, I've got a picture of what's happening.'

Prescribing health professional

'I heard [two psychiatrists talking] a couple of years ago at a symposium. They were up on stage, talking about what not to bring [to an appointment]. [They said,] "Don't bring every file in the house".'

Behaviour Support Practitioner

Information is presented in a tailored and useful way

'You need structured quality data collection... it's much better... if we've got data being collected in some kind of systematic reliable way. If you're relying on incident reports and so on, they're not a good source of data.'

Prescribing health professional

'I really love it when they walk in and a psychologist has done them some ... graphs and said this is their weight change over this particular time or these are the number of incidents over time and that's the trend.'

Prescribing health professional

Information is simple but useful

'I try to keep it really simple. I want to know very simple checklists... those checklists might be as simple as a sleep chart along with the number of episodes and behaviour during the day. Very simple identifiable indicators of whether they're improving or not.'

Prescribing health professional

What topics should the information cover?

Information and records across a range of domains are relevant to the health professional's decision-making about introducing and stopping medication, and should be compiled to either feed into the summary information or be brought to the appointment with the health professional. In collaboration with the person's family and/or other providers and practitioners, a Behaviour Support Practitioner will have a key role in collecting and preparing information about:



Challenging behaviour

- ✓ Presenting issue that prompted medication to be explored
- ✓ Records of current and past challenging behaviour
- ✓ Positive Behaviour Support strategies tried
- ✓ Current Positive Behaviour Support Plan



Medical

- ✓ Medical history, including all diagnosed conditions
- ✓ Medication history, including all known side-effects
- ✓ Webster pack of current medications
- ✓ List of current and past doctors and medical team
- ✓ Physical health, dental, vision, hearing and immunisation records
- ✓ Sleep records



Environmental

- ✓ Information on the person's family, support team and living arrangements
- ✓ Records of communication and daily living skills

This information might be available from a range of sources, including:

- » Medical records
- » Family and carers
- » Support team staff
- » Psychologists
- » Behaviour Support Practitioner records
- » Allied health professionals
- » Guardian (public or appointed)

Information from the Behaviour Support Practitioner

In addition to helping others prepare information, sometimes the Behaviour Support Practitioner will also send information from their own assessment directly to the prescribing health professional. This is important where there are differing views about the use of medication. It is also important for removing reliance on those at the appointment to represent other people's information – especially where the information is complex or may present a conflict of interest.

Considering safety when medication is used

A prescribing health professional may or may not decide that medication is warranted. Where a health professional makes the decision that medication can be used to address a person's challenging behaviour, there are several ways in which the safety of the person will need to be monitored and maintained. These considerations are relevant both to introducing the medication and to considering when it should be stopped.

Some safety considerations include:

- The medication is always used together with a Positive Behaviour Support Plan.
- The medication is authorised by a Restrictive Practice Authorisation Panel.
- The medication is detailed in the person's current health care plans.
- All members of the person's support team are clear and confident about when and how to administer the medication.
- All service provider organisations the person uses have a medication policy in place.
- There is regular monitoring of the medication and of the person's behaviour.
- There are regular, well-administered case reviews to understand whether there has been a change in the person's behaviour and when the prescribing health professional might be approached about reducing or stopping the medication.
- There is a plan for regular follow up consultation with the prescribing health professional.

These safety considerations will be the responsibility of a range of people across the person with disability's family and support team, including their primary support provider. A Behaviour Support Practitioner will need to identify if the safety mechanisms are in place, and if they are not, then may need to prompt others who hold the responsibility to act further to ensure the person's safety.



Helping others understand their roles and responsibilities

Alongside the role of the Behaviour Support Practitioner, a number of other people will also have roles and responsibilities in the process. It is important that each of these people understand their roles and responsibilities so that everyone involved can work together for the best outcome for the person.

Some information on the roles of different people and how a Behaviour Support Practitioner can assist them includes:

Roles and responsibilities

Considerations for Behaviour Support Practitioners

The prescribing health professional should...

- » Make sure that the person is included in making decisions that affect their health and wellbeing.
- » Come to an informed view about whether the use of medication is warranted and later about when it should be stopped.
- » Explain the purpose of the medications they are prescribing and the risks and benefits in ways that will be accessible to the person, their family and support team, including providing accessible written information about the medication.
- » Advise the person, their family and support team of what information needs to be reported back at subsequent appointments and provide simple ways to feed back this information.
- » Advise the person, their family and the support team of a plan for reducing and stopping the medication when the person's behaviour improves.



How to best help a prescribing health professional be accessible in their approach to the person and their family and support team?

- » Provide the health professional with information about the person's communication
- » Guide the health professional to Easy Read and other accessible resources

The person's family and guardian should...

- » Make sure that the person is included in making decisions that affect their health and wellbeing.
- » Make the overall decision about whether to explore and/or stop the use of medication and, where appropriate and if recommended by the prescribing health professional, provide consent for it to be used/stopped.
- » Implement the Positive Behaviour Support Plan.
- » Provide information to the prescribing health professional.
- » Play a role in monitoring the person's challenging behaviour, including for the purpose of reducing and stopping the medication as the person's behaviour improves.



How to best help families and guardians feel equipped to play a role in monitoring the person's behaviour and in considering the option of medication?

- » Encourage families and support teams to seek information about the medication, for example, consumer medicines information
- » Guide families and support teams to upskilling opportunities for their participation in the person's medical appointments

The primary support provider should...

- » Ensure that only a support person who has an identified role in working with the person attends the appointment with the prescribing health professional. This support person will ensure that the person has the opportunity to ask questions and will also seek family/guardian input.
- » Assist the support person to be well-prepared for the appointment, for example, to feel confident and know what questions to ask.
- » Ensure all support people have the capacity and understand their responsibility to implement the Positive Behaviour Support Plan.
- » Put in place clear strategies and guidelines to effectively implement and monitor the use of the medication.
- » Play a role in monitoring the person's challenging behaviour, including for the purpose of reducing and stopping the medication as the person's behaviour improves.



How to help the primary support provider to select and prepare the best support person?

- » Guide the primary support provider to useful resources
- » Contribute knowledge of the person's support relationships

All service providers, practitioners and service provider organisations working with the person should...

- » Make sure that the person is included in making decisions that affect their health and wellbeing.
- » Ensure all support people have the capacity and understand their responsibility to implement the Positive Behaviour Support Plan.
- » Put in place clear strategies and guidelines to effectively implement and monitor the use of the medication.
- » Play a role in monitoring the person's challenging behaviour, including for the purpose of reducing and stopping the medication as the person's behaviour improves.
- » Have systems to ensure effective practice governance and to look for ways to have less reliance on medication for managing challenging behaviour. This might include:
 - Personalised services.
 - Staff with the right skills.
 - Regular case reviews.
 - Commitment to evidence-informed practice.



How to help providers, practitioners and organisations play their roles?

- » Provide guidance, education and upskilling on Positive Behaviour Support, where required

Josh: Preparing for the physician appointment



With the appointment with the health professional booked in, Josh's Behaviour Support Practitioner started preparing. There were lots of things she had to do:



First, she clarified the reasoning behind exploring the potential use of PRN medication. Using the checklist on the following page, she confirmed that the medication was consented to, linked to the behaviour's function, used only after a range of Positive Behaviour Support options had been tried, justified, safe, forward-looking and planned to be short-term, and used in conjunction with Josh's Positive Behaviour Support Plan. She also knew that, to be used, the medication would need to be appropriately prescribed, authorised and reviewed. She notified Josh's primary service provider organisation that their Restrictive Practices Authorisation Panel would need to authorise the medication if the health professional agreed it was needed.



She did some work on how the medication would be integrated into Josh's Positive Behaviour Support Plan. She printed out an outline of how it would be included to give to the health professional, so that the health professional would understand how it would be used. She made sure the outline showed how the medication would sit within an overall Positive Behaviour Support strategy, emphasising that it would be accompanied by work with a psychologist on relaxation and mindfulness.



She worked with Josh's support workers and Guardian to gather information about Josh's behaviour, support needs and health records, so that it could be provided to the health professional. She asked the support workers to fill in some behaviour recording sheets, and summarised the data so that the health professional would have consistent, clear information about his challenging behaviour. She also asked the support workers to make sure that all records of Josh's daily schedule and recent life changes were up to date and printed in a pack for the health professional.



She started a checklist on her computer to think about what safeguards and monitoring arrangements would need to be in place, if the health professional approved the use of PRN medication. This included plans to review the medication via a regular case review and to keep track of Josh's progress with the psychologist, so that the medication could be stopped when it was no longer needed. She noted who would be responsible for the safeguards, and made a note in her diary to check in with them that they had the required arrangements in place should the medication go ahead.



She checked in with everyone – Josh, his support workers and the manager at their service provider organisation, as well as Josh’s Guardian – to feel confident that everyone knew their role and responsibilities. In particular, she checked with the manager at Josh’s primary service provider that someone who knew Josh well would attend the health professional appointment with him, and was pleased to hear that his Key Worker and Guardian were both planning to attend.

Checklist used by Josh’s Behaviour Support Practitioner:

The medication is...

- Consented to**
Both Josh and his Guardian agreed to the prospect of medication.
- Linked to the behaviour’s function**
The medication is intended to address Josh’s anxiety, to help calm his behaviour.
- Used after Positive Behaviour Support and environmental adjustments**
Other environmental issues have already been addressed and Positive Behaviour Support strategies trialled. It has been assessed that PRN medication might be a helpful complement at the times when Josh is most stressed.
- Justified**
The medication is to address anxiety, a use for which there is an evidence-base in the literature.
- Safe**
Josh has no health conditions that might make use of the medication a risk.
- Forward-looking and short-term**
The medication will help Josh implement his other Positive Behaviour Support strategies when he is most stressed, such as knowing when to go to the ‘chill out zone’. By combining the medication with also seeing a psychologist to learn relaxation and mindfulness, there is also a plan for extending the support around Josh so that over time the PRN medication will hopefully no longer be needed.
- Used in conjunction with a Positive Behaviour Support Plan**
The medication will complement Josh’s Positive Behaviour Support strategies and it is part of Josh’s Positive Behaviour Support Plan.
- Prescribed**
The medication will be prescribed by the health professional with clear instructions.
- Authorised**
The medication will be authorised by the relevant Restrictive Practice Authorisation Panel.
- Reviewed**
Plans are in place for review of Josh’s medication via a regular case review.

Evidence base

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Other resources

3DN Podcasts: *Responsible psychotropic prescribing to people with intellectual disability*: <https://3dn.unsw.edu.au/content/responsible-psychotropic-prescribing-people-intellectual-disability-podcasts>

3DN e-learning modules for family/carers and disability professionals: *Intellectual disability and mental health*: www.idhealtheducation.edu.au

Notes

A series of horizontal dotted lines for taking notes.



For more information and further resources visit:
arts.unsw.edu.au/idbs/resources