CHAPTER 9

Supporting People with Complex and Challenging Behaviour

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Different words have been used to describe the behaviour of people with disabilities that falls outside expected social norms and is harmful to themselves or others. These include behaviours of concern, behaviours of resistance, challenging behaviour, and abnormal behaviour. This chapter uses the term challenging behaviour, as it is most commonly found in the literature, while recognising that behaviours of concern is preferred in some Australian contexts.

Challenging behaviour is more common among people with intellectual disabilities than other groups of people with disability. As many as 18% of adults with intellectual disabilities display some form of challenging behaviour (Bowring et al., 2017). The extent of the challenging behaviour and the negative impact it has on quality of life highlight the

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importance of designing services and developing practice skills to provide quality support to this group. This chapter defines and considers different types of challenging behaviour, the impact of the behaviour itself and how others respond to it, and its underlying causes. The chapter uses case examples to illustrate good practice. The examples are based on our practice experience and do not represent any one individual. The last part of the chapter reviews evidence-based strategies to support people with challenging behaviour to have a good quality of life.

The Impact of Challenging Behaviour on Quality of Life

Challenging behaviour is often seen as a person's way of communicating about their environment or situation. It may also be a symptom of an underlying health problem or genetic condition. Labelling behaviour as challenging can have lasting consequences for the way people are perceived by staff or services and should not be done lightly. Definitions of challenging behaviour convey a sense of its severity and seriousness:

> Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities. (Emerson, 2001)

There are three categories of behaviour under this broad umbrella: stereotyped, aggressive destructive, and self-injurious.

- **Stereotypy behaviours** are the most common. These are repetitive movements or sounds, such as pacing, rocking, flicking, finger tapping, hand flapping, repetitive sounds or words, and walking in circles. While small amounts of each on its own might be harmless, when behaviours such as this reach high frequency and intensity they can severely impact a person's engagement in activities and relationships.
- **Aggressive destructive behaviours** are directed towards people or property. They include things like verbal abuse, physical violence, breaking or destroying furniture, bullying, screaming, sexually harmful behaviours, and faeces smearing.

- **Self-injurious behaviours** are intentional and often repetitive activities that cause injury or harm. They include self-biting, skin picking and scratching, consuming dangerous or non-food items, self-induced vomiting, or head-banging. This behaviour causes short-term pain and injury or permanent damage which can include physical disfigurement, vision impairment, or brain damage.

Challenging behaviour negatively impacts a person's quality of life, both as direct harm from the behaviour itself and indirectly through the response of service systems to the person and their behaviour. Harm resulting from the response of service systems means that much of the negative impact can be reduced by providing quality services and specialist interventions.

Denial of Human Rights

A frequent response by services to people with challenging behaviour is restraint or seclusion to restrict a person's autonomy or freedom of movement. Known in some service systems as restrictive practices, such actions may be sanctioned and regulated by bodies like the Australian NDIS Quality and Safeguards Commission. This Commission, for example, defines and regulates five types of restrictive practices. These are as follows: chemical restraint, mechanical restraint, physical restraint, environmental restraint, and seclusion (NDIS Quality and Safeguards Commission, 2020). The use of restrictive practices often compounds the negative impact of challenging behaviour and results in further psychological distress, loss of dignity, and autonomy and social inclusion. For example, chemical restraint that involves the use of medication usually prescribed for mental health conditions, to calm or sedate a person, can lead to psychological, neurological, or physical harm. However, it may also go unnoticed and unregulated, as this example illustrates:

> Jing finds noisy and unpredictable environments difficult. Every Sunday, the staff support the other people who live in her group home to host a dinner for their friends and family. Sometimes, the dinner overwhelms Jing and she calls people names, pushes them away, and slams doors as she goes to her room. Although Jing was not diagnosed with anxiety, when this behaviour started many years ago, her doctor prescribed anti-anxiety medication to be given to her by staff when the behaviour occurred.

> Jing has recently had a new doctor who reviewed her medication. He is concerned that the anti-anxiety medication is causing a range of health concerns, including drowsiness and frequent upset stomachs. Jing has regularly missed work on Mondays due to being tired and unwell. Jing's staff were unaware of the side effects of the medication given to her most Sundays or that the practice was a chemical restraint.

Despite the regulation of restrictive practice, there is little data about its use. Dated figures from the UK suggest that up to 50% of people with intellectual disabilities in group homes are subjected to restraint or seclusion (Deveau & McGill, 2009). Longitudinal data from the Australian state of Victoria suggests that restrictive practices are often used long term and show that 74% of a sample of 1180 people with intellectual disabilities were subjected to restrictive practices for three or more years (Leif et al., 2023). Available national data about the number of times restrictive practices are used does not help to understand how many people are affected. Nevertheless, the figure of 688,163 incidents of unauthorised use of restrictive practices in the first six months of 2022 in Australia does indicate widespread use and raises questions about the effectiveness of the regulatory system (NDIS Quality and Safeguards Commission, 2022).

Regardless of compliance with regulations, using restrictive practices interferes with a person's human rights. Decisions about the use of such practices should reflect complex judgements that balance rights against each other, such as the right to freedom of movement against the right to be safe and free from harm (see Chap. 11).

Staff or service system responses to people with challenging behaviour, although not categorised as restrictive practices, may also limit a person's exercise of choice or restrict their social inclusion. In this example, people in Kenny's life made decisions that meant the loss of employment and relationships:

> Kenny is a young man with intellectual disability as the result of the genetic condition, Fragile X Syndrome. He does not sleep well at night. When he is awake he repetitively bites the skin on his arms. This behaviour has happened for many years, and interventions have not been successful. Kenny has many scars on his arms which have started to limit how much he can bend and straighten his elbows. He used to work at a supermarket stocking the shelves. He enjoyed his job, was a well-liked member of the staff and lots of people used to pop by to say hi. Last year, Kenny's manager suggested he find a less physically demanding job. Kenny has not found another job and has lost contact with his previous colleagues.

Stereotyping

People labelled as having challenging behaviour are often stereotyped. This impacts their opportunities to participate in daily activities and in the way staff regard them. Staff may hear about a person's behaviour before their other characteristics, refer to a person as 'having behaviours' or temper tantrums, use labels such as 'grabber', or collectively refer to people as living in 'a challenging behaviour house'. Labels such as these stereotype the person as dangerous, frightening, childlike, or annoying and influence how support is provided. For example, if a staff member hears a person is violent with sharp objects, they might decide not to support them to cook, without being aware of strategies in place to support safe cooking experiences.

Disruption to Staff Relationships

The presence of challenging behaviour can disrupt the continuity of relationships between staff and the people they support. Supporting a person who frequently hurts themselves is emotionally distressing for staff. Staff who support people with aggressive behaviours may fear for their safety or experience physical harm. The emotional demands of working with people with challenging behaviours can lead to increased absences from work, lower job satisfaction, sudden resignations, and decreased quality of support. This example considers the situation of a female worker supporting adults with physically and verbally aggressive behaviour:

> Toni has worked at the same group home for several years. Two residents have regular episodes of aggressive challenging behaviour, involving throwing objects and standing over and yelling at staff. Toni has been hit by objects and bruised. All incidents are reported, and some emotional support is provided, but Toni feels that little is done to improve the situation. Toni is pregnant and is worried about her baby's well-being. She has taken a week off and is considering resigning from her role.

Reasons for Challenging Behaviour

Understanding the reasons behind a person's challenging behaviour helps select the best support strategies. The features associated with higher rates of challenging behaviour give some insights into potential causes. These include more severe levels of intellectual disability, specific genetic syndromes such as Fragile X, neurological diagnoses such as Autism or

epilepsy, poor physical health, sensory impairments, boredom, and long periods of disengagement (Bowring et al., 2017). Challenging behaviour is unlikely to stem from a single factor but from an interplay of factors. Some of these are fixed and intrinsic to individuals (such as specific syndromes) while others are transient and associated with the quality of the support a person receives (such as the person's level of disengagement). This means some features can potentially be changed whilst others cannot (see, for example, Emerson, 2001) (Table 9.1).

Behavioural phenotypes are patterns of behaviour associated with other characteristics and specific genetic syndromes. For example, people with Fragile X syndrome are likely to have stereotypic and self-injurious behaviours (Langthorne & McGill, 2012), and people with Prader-Willi Syndrome to ask repetitive questions and have outbursts of temper (Oliver et al., 2009). The biological predisposition for such behaviours cannot be changed, but knowing if a person has a diagnosed syndrome is important for deciding which support strategies will likely be most effective in supporting a good quality of life.

Untreated physical and mental health conditions, which are common among people with intellectual disabilities due to difficulties of diagnosis or access to health care, may be the underlying cause of challenging behaviour. These may include pain, hormonal changes, reflux, medication side effects, constipation, sleep disturbances, dementia, or deterioration in hearing or eyesight. A sudden change in behaviour such as that described in this example indicates that the cause may be a health condition or pain:

> Daniel has a profound intellectual disability and is non-verbal. He started slapping his cheek after meals. This was new behaviour and staff thoroughly

Table 9.1 Intrinsic and extrinsic reasons for challenging behaviour

Intrinsic *Biological and psychological*	*Extrinsic* *Social and environmental*
• Behavioural phenotypes (see explanation below)	• High sensory demands
• Physical or mental health conditions	• Limited support for engagement
• Pain	• Inappropriate service design
• Vision or hearing loss	• Restricted rights
• Sleep patterns	• Lack of support for communication
• Menstruation	
• Neurological conditions	
• Adverse life events and psychological trauma	
Some can be changed	**Can be changed**

checked his mouth and gums during his oral health routine and did not notice any injuries. They booked a review with his dentist who found a piece of tooth missing from the back of Daniel's molars, exposing the nerve. Once the tooth was repaired, the behaviour ceased.

Environmental demands, such as high levels of noise or other forms of sensory stimulation, are difficult for some people to tolerate and can lead to learned stereotypic behaviours as a coping mechanism. An example of this is repeating the same sound over and over while walking through a shopping centre as a way of reducing the sensory overload of a busy and loud environment. Although this type of behaviour may not always be harmful, it may limit the activities a person can do or who they can be with.

Disengagement and boredom are also reasons for challenging behaviours. People with intellectual disabilities who live in supported accommodation with 24 hour staff support are at much higher risk of challenging behaviour as they may not get the type of staff support they need to be engaged in meaningful activities and social interactions. Services may not equip staff with the opportunities and support they need to learn the skills to create regular routines, communicate choices, offer opportunities, and provide the individualised support that some people require to be engaged. The absence of skilled support has a greater negative impact on people with more severe intellectual disabilities who find it hard to engage by themselves and whose communication difficulties make it difficult to seek out support in the way those with milder intellectual disabilities may. Indeed, in some instances, a person may learn challenging behaviour through the repeated and similar responses of others to their attempts to be engaged. For example:

Elly stopped attending her day program during the COVID-19 pandemic and has not returned due to staffing shortages. She is at home all day with limited planned activities and the staff are busy with administrative work and attending to house chores. They notice that Elly has started picking apart the lounge chair's stitching. When they see this happen, they sit with her, and talk about what is happening around the house. Over time, more and more furniture is damaged. The staff continue checking in with Elly, trying to distract her when they see her damaging the furniture.

In this example, staff reinforced Elly's behaviours by delivering positive outcomes in the form of social interaction.

Some causes of challenging behaviour are related to emotional or psychological development. People with intellectual disabilities are more

likely to have experienced disrupted relationships with primary carers, maltreatment, or traumatic incidents in childhood than their non-disabled peers (Clegg & Lansdall-Welfare, 2022). If left unresolved such experiences may manifest in adulthood as challenging behaviours. For example, a person with unresolved emotional issues from childhood may become excessively attached to one staff member leading to aggressive behaviour when the staff member's attention must be shared with others or when they are leaving at the end of their shift.

Supporting People with Challenging Behaviour

For some people challenging behaviour is caused or exacerbated by the poor quality of services or other aspects of their environment. Ensuring receipt of good quality services and support is therefore a fundamental part of any intervention. This may be sufficient to reduce or prevent challenging behaviour.

Health-related causes can be minimised through timely attention to behaviour changes and preventative health care, such as annual health assessments and regular reviews by a person's general practitioner and other healthcare team members. Maintaining records of health assessments, recommendations, and follow-up are important points of reference to track changes that occur over time: for example, tracking menstrual cycles to determine the onset of menopause or regular cognitive screening as a person ages to identify slow decline that might indicate dementia.

Reasons for challenging behaviour related to sensory overload can be minimised by supporting choice about the types of places a person visits or the timing (going to shopping strips rather than large centres, or visiting early or late in the day when there may be less noise or people) or adjusting a person's home environment to suit their tolerance levels for noise or using equipment such as ear plugs or headphones to minimise the sensory load they experience.

Staff's use of Active Support as a way of working is one very clear strategy likely to diminish disengagement and learned behaviour such as Elly displayed. It is likely however that a combination of preventative actions by a person's everyday services and specialist intervention may be necessary to support a person with challenging behaviour to have a good quality of life.

Behavioural Strategies

Most specialist interventions for people with challenging behaviour are behavioural and apply principles from behavioural psychology. They use comprehensive functional assessment to understand the meaning of behaviour and develop multi-element support plans. Techniques such as Applied Behavioural Analysis (ABA) aim to understand and manipulate the antecedents of behaviour (what happened immediately before the behaviour), the behaviour itself, and the consequences of behaviour (what happened directly after).

Since the 1990s, the aims of interventions widened, to improving a person's quality of life rather than simply reducing challenging behaviour. This recognised that for some people the multiple or underlying genetic causes of people's challenging behaviour meant it was unlikely to reduce and that supporting social participation could not only improve quality of life but also reduce challenging behaviour (Bigby, 2012). Positive Behaviour Support (PBS) has become the dominant approach in both Australia and the UK. PBS is a whole of system, multi-component approach, that aims to understand the reasons for challenging behaviour and create change both at the individual level through expanding a person's repertoire of behaviour and in a person's social, environmental, or support system through redesign. PBS has twelve components which, as Table 9.2 shows, fall into three distinct types: rights and values, theory and evidence base, and process and strategy.

Creating a high-quality service environment, as well as individual assessment and support plans, is central to the processes and strategies of PBS. The next section turns to a consideration of assessment and support plans.

Assessing Behaviour and Developing a Behaviour Support Plan

Developing a behaviour support plan uses processes similar to those described in Chap. 10 for other types of plans. However, in this case the lead is taken by someone with expert knowledge about behaviour support. In some countries, this may be a person with recognised qualifications in behaviour support or a psychologist with specialist training. In Australia, the lead person is likely to be known as a behaviour support practitioner, who might have a professional background in psychology, allied health,

Table 9.2 Components of a PBS framework (Gore et al., 2022, p. 13)

Rights and Values: A focus on rights and good lives	1. Person-centred foundation 2. Constructional approaches and self-determination 3. Partnership working and support for key people 4. Elimination of aversive, restrictive, and abusive practices
Theory and Evidence Base: Ways to understand behaviour, needs, and experience	5. A biopsychosocial model of behaviours that challenge 6. Behavioural approaches to learning, experience, and interaction 7. Multi-profession and cross-discipline approaches
Process and Strategy: A systematic approach to high quality support	8. Evidence informed decisions 9. High quality care and support environments 10. Bespoke assessment 11. Multi-component, personalised support plans 12. Implementation, monitoring, and evaluation

education, or nursing or have no formal qualifications but is recognised as having relevant skills and experience.

The assessment and planning process should be collaborative, involving the person, their family or significant others, staff from their various service providers, and professionals involved in the person's life. A functional behaviour assessment is undertaken to understand the behaviour, its underlying cause, where it occurs, with whom, and what happens before (antecedents) and after it (consequences). This may draw on existing reports or new medical, dental, or allied health assessments to rule out medical or psychiatric causes for the behaviour. Background information about the person should be collected by reviewing reports and interviews with the person and key people in their life. It should include information about the person's strengths, support needs, their social relationships, and the services they access. Direct observation of the person's behaviour should also be conducted in the various settings where challenging behaviour occurs. Information is analysed to formulate a theory about the causes of behaviour, which then forms the basis for the development of strategies to prevent or reduce the behaviour.

During the assessment or intervention planning stage, reports may be sought from professionals with knowledge about specific types of intervention strategies. For example, speech pathologists can provide advice about effective and appropriate ways to improve communication, and occupational therapists can suggest how to adapt the physical or sensory environment or propose the use of adaptive equipment.

A behaviour support plan should include three types of strategies: preventative, proactive, and reactive.

- **Preventative** strategies aim to reduce or eliminate challenging behaviours. They include the types of actions discussed earlier: preventative health care, reduction of the sensory load of a person's environment, training and leadership for staff to implement Active Support to reduce disengagement and support participation in meaningful activities and social interactions, or specific psychological intervention techniques such as cognitive behaviour therapy.
- **Proactive** strategies are activated when a person becomes distressed, or something is happening, which could trigger behaviours. The aim is to intervene early to remove the trigger or provide the person with something they enjoy. Strategies may involve moving the person or others to another environment, calming, distracting, or re-directing the person. Remaining calm is essential to ensure the situation does not escalate.
- **Reactive** strategies are a last resort when other strategies fail to avoid challenging behaviours. They are used to gain control of the situation, cease the behaviour, and ensure the safety of all involved. Reactive strategies are often restrictive practices, such as physical or environmental restraints. They must be the least restrictive option available and used for the shortest time possible. Plans must also include strategies to fade out or reduce the use of restrictive practices.

Strategies must be practical and understandable to the staff responsible for implementing them, and plans must identify the people responsible for oversight and review. Where necessary plans must include details about the training and ongoing support available for staff implementing them and include ongoing data collection to inform a continuous cycle of review.

Psychodynamic Approaches

Some causes of challenging behaviour are related to separation or trauma in early childhood. If this is the case, alternatives to behavioural theories to inform specialist interventions are relevant. Psychodynamic interventions recognise the "untapped potential for development and growth in the emotional lives of people with intellectual disabilities that has the possibility to redress non-optimal life-histories and reduce distressed and distressing behaviour" (Clegg & Lansdall-Welfare, 2022, p. 6). These interventions aim to support staff connection with, and the co-regulation of, the emotional worlds of distressed people through careful "use of words, tone of voice, facial expressions, or body language that steadies the person who struggles to harness their chaotic emotions" (Clegg & Lansdall-Welfare, 2022, p. 6). For example, services in the Netherlands use a practice known as Triple C (Tournier et al., 2020). The Cs represent Client (the person with an intellectual disability), Coach (the support worker), and Competence (the activity which the client and coach perform together). This practice emphasises relationships, unconditional support to improve a person's attachments and relationships with support staff, to provide a secure base for joint activities. Several other practice tools to support practice-based or emotional co-regulation are described in detail by Clegg and Lansdall-Welfare (2022). There are, however, few professionals with this type of practice expertise in Australia with the consequence that behavioural interventions dominate practice.

Examples of Supporting People with Challenging Behaviour

The two examples below illustrate the service context and evidence-based practices, relationships, training, supervision, support, and teamwork, that may be involved in implementing a behaviour support plan and supporting a person with challenging behaviours to have a good life.

Joe

Joe is a young man with Prader-Willi Syndrome and moderate intellectual disability who lives in a group home with three other young men with intellectual disabilities. His housemates have similar support needs to Joe but none have challenging behaviour. Joe attends a community access

programme. As part of his syndrome, Joe asks many repetitive questions and finds it difficult when things do not go how he would like. If the staff answer "no" to one of his questions, he argues with them. Occasionally, this escalates, and Joe slams doors and throws items within his reach. As part of his diagnosis of Prader-Willi syndrome, Joe has a range of health needs that require ongoing monitoring and review.

Services and Evidence-Based Practice

Joe uses accommodation and community access services and has a behaviour support practitioner. He also uses mainstream services, for example, a general practitioner and a dentist. For people like Joe living in supported accommodation it is not always clear who leads the coordination of their services and collaboration among staff. It may be a support coordinator or, in the case of Joe, the manager of his accommodation service.

The design of the group home reflects research that homes should be small with no more than six people and dispersed in the community (Bould et al., 2019). Attention has been given to knowledge about the compatibility of people living together, in that they should have similar support needs and people with challenging behaviour should not be grouped together. The organisations that manage Joe's group home and community access programme mandate Active Support (see Chap. 7) as the expected staff practice and it is embedded into organisational policies and procedures. Staff's use of Active Support to support Joe means he engages in meaningful activities and social interaction at home and in the community and exercises choice and control throughout the day. He is not disengaged for long periods and staff provide the right amount of the right type of assistance to enable him to successfully participate in household and leisure activities. Joe interacts with staff and people he encounters when he is out in the community (see Chap. 4). When people have choice and control over their lives and are engaged they are less likely to use challenging behaviours to express their needs (Ockenden et al., 2014). Knowing the person and understanding communication will ensure Joe's preferences are understood by staff and he understands the activities offered to him, which are important for good Active Support practice.

The organisation that manages Joe's group home keeps detailed records about his health needs, which are compiled into a one-page summary accessible to all staff. One staff member is his key worker: they are responsible for supporting him to attend medical appointments, interact with

health professionals, understand their advice, share health information with other staff, and ensure all actions from appointments are followed up.

Relationships

As part of Active Support practices staff interact with Joe in a warm and friendly manner, treating him with respect and dignity. All the staff play an important role in his life, and he has a strong relationship with his key worker. These relationships, and the nomination of a key worker, accord with evidence that challenging behaviour is reduced when a central staff member is involved and there are positive interactions with all staff (Olivier-Pijpers et al., 2020).

It is not uncommon for people like Joe to develop close bonds with support workers. Aware that the turnover of staff can be distressing when staff leave, Joe's services aim to extend his social connections beyond staff. The community access programme he participates in supports him to attend several classes at a local recreation centre. One of the aims of the community access programme is that Joe will become known and recognised by other users of the centre and may begin to form friendships. Staff at the group home are aware of this strategy and support Joe to interact when he sees people from the centre in other contexts. Staff from his group home also support Joe once a week to use Zoom on his iPad to catch up with his brother who lives interstate.

Staff Training and Supervision

Joe's service providers are responsible for ensuring staff are competent and have the knowledge and skills to provide high-quality and consistent support to Joe. They have accessible and practical policies and procedures, an induction programme, training, clear reporting lines, supervision, and access to debriefing.

Reflecting evidence about effective Active Support training they ensure that staff have a practical hands-on component and theory components delivered in a classroom or online. As part of their induction all staff are given basic knowledge about Prader-Willi syndrome and taught about the procedures in place to support Joe to manage his insatiable appetite and constant need for food which are part of this syndrome.

Staff in the group home and community access programme are supervised by a Frontline Practice leader. Their role is to ensure staff remain

focused on Joe's quality of life, get regular feedback on their practice and coaching to improve it. Frontline Practice leaders model good practice, support staff to work together as a team, and ensure they maximise their time on every shift to support Joe. This accords with evidence that strong Frontline Practice Leadership is associated with good Active Support and reduced challenging behaviours (Olivier-Pijpers et al., 2020).

The very specific strategies in the behaviour support plan developed with Joe and others will be shared with all the staff working with Joe. The behaviour support practitioner will take responsibility for briefing and training staff in its implementation.

Teamwork

Teamwork is critical to the quality of all Joe's support and successfully implementing the behaviour support plan. Joe is included in the team and staff work together with him collaboratively to ensure consistent support. Teamwork among staff in each service is facilitated by their Frontline Practice leaders, and a monthly meeting or conference call between leaders supports consistency and coordination of staff in the different services. This accords with evidence that challenging behaviour is reduced when there is cohesion between the staff team, collaborative input from specialists, such as allied health and medical professionals, supportive colleagues, and the space to make mistakes and learn from them (Olivier-Pijpers et al., 2020).

Sylvie

Sylvie is a young woman with mild intellectual disability, obsessive-compulsive disorder (OCD), epilepsy, and dental disease. She has moved to be closer to her sister and shares a unit with one other woman. She receives daily drop-in support to assist with cleaning, meal preparation, and to attend appointments. She has no regular activities but is interested in finding work with animals, making friends, spending time with her sister, and attending live music gigs.

Her OCD means she showers many times a day. In the past, this has meant she has missed appointments and scheduled activities. Excessive showering results in skin rashes and fungal infections. If staff intervene, she can be verbally and physically aggressive.

Service Delivery

Sylvie uses one service for drop-in support and support coordination. The support coordinator takes the lead and is negotiating a range of additional services, including a general practitioner with experience supporting adults with intellectual disabilities and mental health, a dentist, and a mental health professional to support her to manage the OCD and associated behaviours. Such services will be important to the success of her living situation as evidence shows that unmet medical and behaviour needs are common reasons that community living arrangements fail (Kim & Dymond, 2020). Accessing services to support Sylvie to find employment and social activities are equally important, as engagement will avoid boredom, help improve Sylvie's quality of life, and reduce her behaviours.

Relationships

The support coordinator aims to maintain Sylvie's relationship with her sister and include her as part of Sylvie's support team. Further the support coordinator will support Sylvie to find a service to provide opportunities for her to meet new people with similar interests to her own. The coordinator is also aware that Sylvie's relationship with her flatmate is very important. Advice from the mental health professional who will manage Sylvie's OCD about strategies for reducing excessive use of the shower will be important to avoid putting strain on this relationship.

Training and Supervision

The coordinator has ensured that the drop-in support service has trained staff about Sylvie's support needs and OCD. They have been trained in Active Support and take care not to over support Sylvie with household tasks that she can do alone with some prompting. She has also made the service aware that staff may need supervision and incident debriefing should Sylvie be verbally or physically aggressive. For staff working alone in this type of one-to-one situation, immediate incident debriefing is important to ensure accurate reporting, the well-being of all involved, and any immediate strategies to reduce the risk of another incident. Regular supervision allows staff who work with Sylvie to discuss support for her and opportunities for improvement.

Sylvie has a dated behaviour plan, written when she lived at home with her parents. Her mental health professional will update this plan and will also provide training for Sylvie's support team in implementing new or revised strategies.

Teamwork

As more services are established for Sylvie, training and sharing of information among new staff will become more important. New people will have to quickly get to know Sylvie and understand information about her support needs. The service coordinator will support the flow of information between these services which will help ensure that her team works collaboratively. Sylvie and her sister are critical members of this team, and an essential part of this teamwork is empowering Sylvie to be actively involved in decision-making.

Reflecting on the Use of Positive Behavioural Support

There are gaps in evidence about the effectiveness of PBS in the context of supported accommodation services (Gore et al., 2022). Some researchers suggest this is because what is regarded as best practice is seldom fully implemented in services. For example, one UK commentator suggested:

> It is relatively rare to find a service that has all of the recommended elements in place in the right amounts and combinations ….
>
> Most people with challenging behaviour still do not receive effective interventions even though adopting a positive behavioural support (PBS) model has been shown to provide them. Instead there continues to be an overreliance on inappropriate medication and restraint, the unethical use of control and punishment and exclusion of people from their own communities. (Jones, 2013, p. 5)

Data from the regulatory body in Australia points to the poor quality of behavioural support plans (NDIS Quality and Safeguards Commission, 2022) and research shows that plans are unlikely to be fully implemented (McGowan et al., 2017). Research also suggests that Australian policies misinterpret PBS as a set of strategies that narrowly concentrate on producing behaviour support plans and reduction of restrictive practices

rather than a systematic approach to improving quality of life (Hayward et al., 2021).

A number of small studies do however suggest the effectiveness of PBS when external specialist behavioural services support accommodation staff teams (Lewis et al., 2021). Notably, in these studies, it is specialist teams that conduct assessments, develop individualised plans, and support accommodation staff with implementation. This suggests that specialist teams may be more effective than the arrangements in Australia where many such teams were disbanded as a result of individualised funding and replaced by sole behaviour support practitioners.

The largest and most rigorous study of PBS in supported accommodation took a 'setting wide' approach (McGill et al., 2018). Its principal aim was improving the quality of care and the support environment (see Table 9.2 Component 9) for people with challenging behaviours, while maintaining support from external behavioural specialists. Expected standards of support were defined, coaching was provided to service managers and staff to enhance their performance, and progress was regularly monitored. From this study, the concept of Capable Environments was developed (McGill et al., 2020). The study sets out the features that should be in place both in terms of the everyday support in a service and in the managing of the organisation to support a good quality of life for people with challenging behaviour. These are summarised in Table 9.3 alongside the evidence-informed practices discussed in this chapter.

This table may be a useful checklist for staff and organisations managing group home services or drop-in support for adults with intellectual disabilities and challenging behaviours.

The major challenge for organisations is to create and sustain the conditions necessary for supporting people with challenging behaviours set out in the Capable Environments framework. This will primarily be through the values of senior and mid-level managers, and organisational structures and processes they put in place. Culture is a key influencing factor on service quality and practice, and establishing a cohesive, respectful, enabling, and motivating organisational culture is a major task for leaders across an organisation. The nature and influence of culture has not been considered in this chapter as it is so significant that it warrants a dedicated chapter (see Chap. 13).

Table 9.3 Evidence-informed practice and services that deliver Capable Environments

Characteristics of Capable Environments (adapted from McGill et al., 2020)	*Evidence-informed practice or service delivery approach*
Everyday support	
• Support for participation in meaningful activity • Personalised routines • Support for communication • Support opportunities for choice • Positive social interactions • Support to establish and/or maintain relationships • Support for more independent functioning • Personal care and health support	• Active Support • Key workers • Shift plans (task of Frontline Practice Leadership) • Teamwork (task of Frontline Practice Leadership) • Staff focus on quality of life (task of Frontline Practice Leadership) • Preventative and attentive health care
Management and organisational context	
• Effective organisation context • Effective management support • Mindful skilled support workers • Provision of consistent and predictable environments • Provision of acceptable physical environment	• Frontline Practice Leadership • Supervision of staff (task of Frontline Practice Leadership) • Observation and feedback to staff (task of Frontline Practice Leadership) • Senior leadership values practice • Organisational structures for training and practice leadership • Small-size homes and not grouping people with challenging behaviours together • Environments reflect sensory preferences

Take Home Messages

- Challenging behaviours substantially reduce the quality of life for people with intellectual disabilities who display them.
- There are many reasons for challenging behaviours. However, some are easier to change than others.
- Challenging behaviours are more common for people with intellectual disabilities who receive accommodation-based support.
- Ensuring high-quality, individualised services and environments can reduce and prevent challenging behaviours.
- Specialist behavioural or psychodynamic interventions may be required for some people with intellectual disabilities and challenging behaviours. Implementing this requires significant collaboration between specialist practitioners and staff in services.

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