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A Framework for the use of Non Pharmaceutical Approaches to Reducing Restrictive Practices in Wales

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Contents

1. Background

Learning disability definition

This framework utilises the Department of Health and Social Care (DHSC) definition of a learning disability:

"**a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood** ".

DHSC distinguishes a learning disability from a learning difficulty, as follows:

"**learning disability is different to a learning difficulty, which is a reduced intellectual ability for a specific form of learning and includes conditions such as dyslexia (reading), dyspraxia (affecting physical co-ordination) and attention deficit hyperactivity disorder (ADHD)**".

Department of Health and Social Care (2001)

As such this Framework is not focused on people with a learning difficulty per say, other than some people with a learning disability may also experience some of the above learning difficulties. Further, this framework does not cover other neurological disorders that occur after the age of 18 years of age (although people with learning disabilities may experience these too).

Further information about what a learning disability is is available from Mencap

https://www.mencap.org.uk/learning-disability-explained/what-learning-disability

Why medications are given to children and adults with learning disabilities

Adults and children with learning disabilities occasionally behave in ways that are harmful to themselves or others. This can happen when they cannot tell others what they need in ways that are effective and that most people can understand. This form of communicating distress is sometimes referred to by professionals as 'behaviours that challenge' or 'behaviours of concern' (the term we shall use throughout this document is 'behaviours of concern'). Behaviours of concern do not occur because people with learning disabilities 'just feel like it,' it is because their needs are not being met and it is the only way they can draw our attention to that. The behaviour is usually a way of communicating needs and wishes, rather than just a symptom of mental illness or part of someone's disability.

Many adults and children with learning disabilities in Wales and elsewhere are being given medication when they present with behaviours of concern, but do not have a mental or physical illness. The medication is likely to have been prescribed by a medical professional or in some cases is bought over the counter in a pharmacy.

Jargon buster

Psychotropic medicine

a group of drugs to treat a variety of conditions. These include antidepressants, antianxiety medications, antipsychotics, and stimulants.

Restrictive practices

"a wide range of activities that stop individuals from doing things that they want to do or encourages them to do things that they don't want to do. They can be very obvious or very subtle." (Social Care Wales, 2022).

Chemical restraint

"the use of medication to make someone do something they don't want to do or prevent someone from doing something they want to do." (Restraint Reduction Network, 2022).

In 2015, Public Health England (PHE) and Clinical Practice Research Datalink (CPRD) have estimated that every day approximately **30,000** to **35,000** adults with a learning disability are taking psychotropic medicines, when they do not have the health conditions the medicines are for. This does not include children and young people who also have them prescribed.

The medication is often given because it has a sedative effect on the person. Although this may provide an immediate solution to manage a person's distress, it does not help us identify the reason why the behaviour of concern was happening, even if the person is calmer after taking it. This can be dangerous – for example if the reason for the behaviour of concern was pain. The person may be calmer, but the origin of the pain might go unexplored. Therefore, a medical treatment is being given to resolve a non medical issue.

In this context, giving sedative medication as custom and practice becomes a restrictive practice and potentially, even a breach of the human rights act. This is sometimes called chemical restraint and can go on for many years where medications for people with learning disabilities continue without review. All medications should be reviewed regularly.

For more information about different types of restrictive practices, including chemical restraint follow this link to watch an animation by the Welsh Government.

https://www.youtube.com/watch?v=T7el4WZCaYI

Jargon buster

Interventions

actions that are designed to bring about change in, or for, people. This may include changes in feelings, emotions or behaviours, e.g., psychosocial interventions are non pharmaceutical (medical), they use psychological, social and environmental factors to improve people's quality of life.

Framework

refers to a set of ideas that can be used to support decision making or to work through problems.

Approaches

a way of dealing with a specific situation, problem or addressing a need.

Physical restraint

using your body to make someone do something they don't want to do, or stopping someone doing something they want to do.

Restraint Reduction Network 2023 RRN 8 types of restraint (A4) UPDATED (restraintreductionnetwork.org)

Why we must consider non pharmaceutical interventions

Medications have side effects

Adults and children with learning disabilities are proportionally more likely to have restrictive practices used on them; this includes physical restraint, chemical restraint, and seclusion.

All medications carry a risk of side effects. Sometimes these side effects are related to being given in high doses, for a long time, or if people are given medication for the wrong reasons. This can cause more problems for the person, result in long term health problems and contribute to a poor quality of life (making it more likely that behaviours of concern keep going or new ones develop).

Medication side effects

> All I wanted to do was sleep, I wouldn't do any personal care. I wouldn't do any hygiene or nothing. I just wanted to stay in bed because I was so sedated and so depressed.
>
> (Learning disability forum attendee)

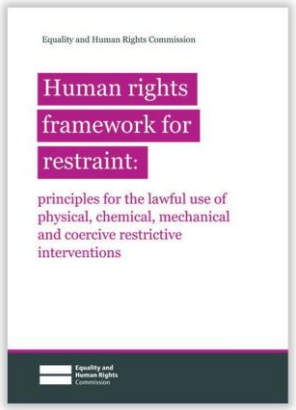
> I would really want to be looking at more targeted medication because we just got risperidone because that's, you know, that's what you give aggressive people who have autism.
>
> And that really bugged me because it has nasty side effects too.
>
> (Family forum attendee)

> And it worries me because lorazepam can have quite quick side effects. And you're not supposed to use it for a long time. So I did have concerns about that.
>
> (Family forum attendee)

The side effects might include:

- putting on weight;
- feeling tired/groggy/drowsy;
- changes in mood;
- distorted perceptions;
- anxiety;
- constipation.

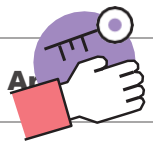
Restrictive practices breach human rights



The use of all restrictive practices, including restraint, should be in line with the principles described in the Human Rights Framework for Restraint produced by the Equality and Human Rights Commission (EHRC, 2019). The Welsh Government is clear that the use of restrictive practices should be within the context of the European Convention on Human Rights and in line with the principles described in the Human Rights Framework for Restraint produced by the Equality and Human Rights Commission. The approach set out in this framework seeks to promote the rights and principles set out in the United Nations Convention on the Rights of the Child (UNCRC), United Nations Principles for Older Persons and the United Nations Convention on the Rights of Persons with Disabilities.

If medication restricts a person's freedom to move or act, whether intentional or not, then human rights principles must be applied.

If medication is used unnecessarily the following human rights could be breached: 3, 8 and 14 of the European Convention on Human Rights (ECHR).

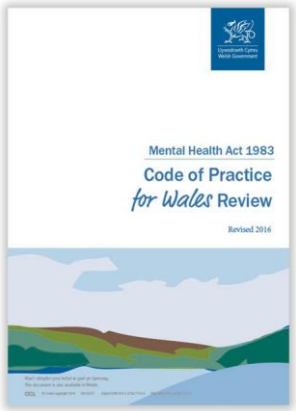


	Potential breach
Article 3 (prohibition on torture, inhuman and degrading treatment).	It could be argued that side effects of the medication are harmful when less harmful and more dignified evidence based interventions could be used.
Article 8 (respect for autonomy, physical and psychological integrity).	Medication is being used to force someone into compliance or stop them from doing something they want to do.
Article 14 (non discrimination).	Anti psychotic medication is used disproportionally on people with learning disabilities for a non medical reason (eg to reduce staff support requirements for the person).

There are also national legal frameworks governing the use of restrictive practices.

There is national guidance in Wales on reducing restrictive practices in childcare, education, health and social care settings. This guidance tells us that restrictive practices should only ever be used as a last resort and should only be used where there is a real possibility of harm to the individual or to others. The Welsh Government is clear that the focus of all policy and practice should be on the reduction of restrictive practices as part of person centred planning. The principle of least restrictive method applies. That means the least restrictive method should be used and only applied for the minimum amount of time. They should only be used if absolutely necessary (if there is a genuine belief that harm is likely to occur to the individual or others if it is not used, and if other less restrictive methods have been tried and have failed).

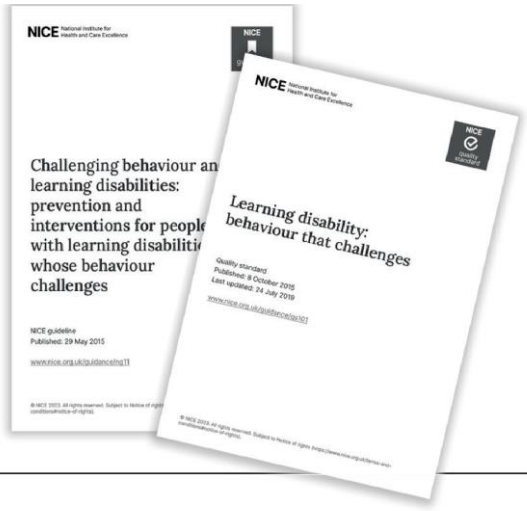
This means that psychotropic medication should only be used as a last resort or for a very temporary period while other approaches are tried.



This is the legislation that sets out guidance for professionals on their responsibilities under the Mental Health Act.

The Code explains how individuals are to be kept as safe as possible and how people in mental health crisis in public places are to be supported and kept safe in the most appropriate place of safety for the least amount of time. Patients and, if appropriate, their families and carers need to be given the information they require to ensure they understand why they are in hospital and the treatment they are being offered or must have. There must be minimum restrictions on a patient's liberty and discharge should be facilitated as soon as possible.

NICE guidance



https://nice.org.uk/guidance/ng11/resources/challenging-behaviour-and-learning-disabilities-prevention-and-interventions-for-people-with-learning-disabilities-whose-behaviour-challenges-pdf-1837266392005

https://www.nice.org.uk/guidance/qs101/resources/learning-disability-behaviour-that-challenges-pdf-75545232605125

National Institute for Clinical Excellence (NICE) has also published guidance in this area:

The NICE view is that:

> People with a learning disability and behaviour that challenges should only receive antipsychotic medication as part of treatment that includes psychosocial interventions.
>
> (NICE, 2019, p.52)

Jargon buster

Psychosocial interventions

non pharmaceutical (medical) interventions and approaches that use psychological, social, and environmental factors to improve people's quality of life.

They state that psychotropic drugs should only be considered for managing behaviour if:

- psychological or other forms of therapy do not help within an agreed time; or
- treatment for a mental or physical health problem has not improved the behaviour; or
- the risk of harm to the person or others is very severe;
- psychotropic drugs are only used in combination with psychological or other therapies.

In quality statement 11, on the use of medication, NICE states:

> Antipsychotics are the most frequently used drugs for people with a learning disability and behaviour that challenges, often in the absence of a diagnosis of a mental health problem. They should be used only if no or limited benefit has been derived from a psychosocial intervention, and treatment for any coexisting mental or physical health problem has not led to a reduction in behaviour that challenges.
>
> Psychosocial interventions are the most commonly reported forms of intervention used for people with a learning disability and behaviour that challenges and should be the first line intervention to address any identified triggers for the behaviour.
>
> (NICE, 2019, p.52)

STOMP

Stopping over medication of people with a learning disability, autism or both

STAMP

Supporting Treatment and Appropriate Medication in Paediatrics

It is possible to reduce medication use

In England two campaigns have highlighted this problem: STOMP − Stopping Over Medication of People and STAMP – Supporting Treatment and Appropriate Medication in Paediatrics. These campaigns have been successful in reducing the numbers of overmedicated people with a learning disability.

While reduction is a very positive outcome, alternative, person centred approaches need to be found, so that people are not at risk of harm or exclusion. While medication use is sometimes helpful and necessary, following the STOMP and STAMP principles can help reduce the burden on quality of life for people given medication in situations where alternatives are equally effective. For example, there is evidence for discharge planning and community services in supporting long term reduction in medication use.


A STOMP-focused evaluation of prescribing practices in one assessment and treatment unit for people with intellectual disabilities

Jon Painter, Wiveca Chio, Liam Black and David Newman

A STOMP-focused evaluation of prescribing practices in one assessment and treatment unit for people with learning disabilities

Duty to make reasonable adjustments

The Equality Act 2010 and Disability Discrimination Act 1995 outline the need to make reasonable adjustments to enable the inclusion of people with disabilities. The public sector also has a proactive obligation to seek out opportunities to support inclusion under the public sector equality duty. Having these types of adaptations in place can be critical to whether or not medication may be considered or can be reduced. The emphasis here is on a society and services that are flexible, aware and adaptive.

More information on making reasonable adjustments can be found here: Reasonable adjustments for people with a learning disability - GOV.UK (www.gov.uk)

Information related to reasonable adjustments can be found here: https://www.gov.uk/rights-disabled-person/education-rights

Useful information for social care supporting reasonable adjustments in health settings is available here: How social care staff can use reasonable adjustments to support the health of people with learning disabilities (publishing.service.gov.uk)

2. The purpose of this framework

The aims of this framework are to:

- **Highlight** the approaches that are being used successfully in Wales and identify best evidence for these, including strengths and limitations.
- **Explain** the key principles of each approach – who they are for and when they might be used.
- **Link** to current policy and guidance.
- **Identify** the existing information and resources available for each approach/intervention.
- **Include** recommendations on how to implement the framework in Wales.

The rationale for this framework will now be set out in relation to relevant policies and laws.

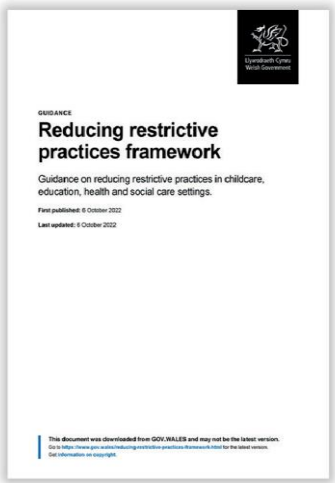
Reducing restrictive practices

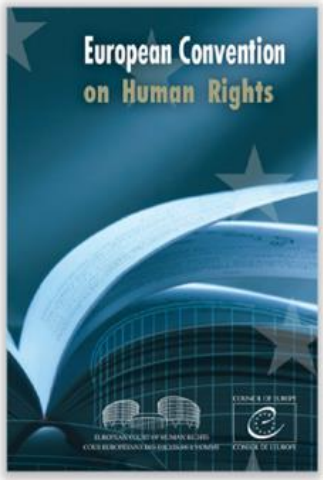
This rights based framework supports the commitment the Welsh Government has made to reduce the use of unnecessary restrictive practices. The Reducing Restrictive Practices Framework (Welsh Government, 2021) tells us that the use of restrictive practices should be within the context of the European Convention on Human Rights) and should be the least restrictive approach. Reducing the use of all restrictive practices is one of the priority actions in the Welsh Government Learning Disability Strategic Action Plan 2022-2026.

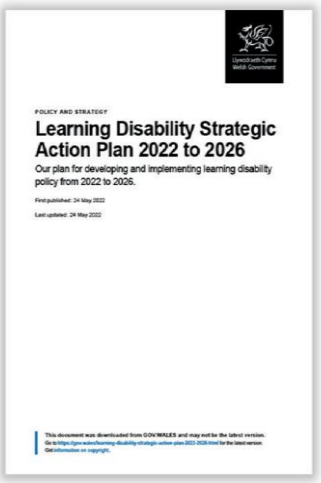
Jargon buster

The European Convention on Human Rights

an international convention to protect human rights and political freedoms.







Empowering people to make decisions about their care and treatment

It is also important to understand the above Reducing Restrictive Practices Framework in the context of the Mental Capacity Act (MCA), 2005. The Mental Capacity Act sets out to protect and empower people who may lack the mental capacity to make decisions about their care and treatment. It covers everyday and more life-changing decisions.

A fundamental principle within the Mental Capacity Act is that when making a decision on someone's behalf this should be in their best interest and the decision or action taken should be the 'least restrictive,' i.e. the option should be the least likely to interfere with their rights and freedoms. Although sometimes what is in someone's best interests may not be the least restrictive option.

The Deprivation of Liberty Safeguards amendment to the Mental Capacity Act ensures that people who cannot consent to their care arrangements are protected if they are deprived of their liberty. Where such arrangements are in place these are assessed to check they are necessary and, in the person's, best interests (SCIE). Frequent use of sedation/medication to control behaviour and regular use of physical restraint to control behaviour are two examples of when such assessments may be applied.

Principles

Social Services and Wellbeing (Wales) Act, 2014. Principles:

Voice and control – putting the individual and their needs, at the centre of their care, and giving them a voice in, and control over reaching the outcomes that help them achieve wellbeing.

Prevention and early intervention – increasing preventative services within the community to minimise the escalation of critical need.

Well-being – supporting people to achieve their own well-being and measuring the success of care and support.

Coproduction – encouraging individuals to become more involved in the design and delivery of services.

Improving wellbeing

Furthermore, this framework and the Reducing Restrictive Practices Framework should be considered in light of the Social Services and Wellbeing (Wales) Act, 2014 provides an additional legal framework for improving the wellbeing of people who need care and support, and carers who need support, and for transforming social services in Wales. Both frameworks align with the principles of the Act as shown to the left.

Promoting early intervention and education

Finally, for Education, the Additional Learning Needs (ALN) Act should provide context to supporting children with learning disabilities. The Act creates a unified system for supporting learners from 0 to 25 with Additional Learning Needs (both learning disabilities and learning difficulties). A key focus is on early identification of needs and early intervention, improving planning and delivery of support (putting the learners needs at the centre) and ensuring support to overcome barriers to learning and helping them achieve their potential. Alongside this is an ALN Transformation Programme to support workforce development.

Alongside this, the Additional Learning Needs and Education Tribunal (Wales) Act explains how health services and education must work together to support learners with additional learning needs (ALN) from 0 to 25 years old. A Designated Education Clinical Lead Officer (DECLO) should co-ordinate collaborative working for the health board.

POLICY AND STRATEGY

Learning Disability Strategic Action Plan 2022 to 2026

Our plan for developing and implementing learning disability policy from 2022 to 2026.

First published: 24 May 2022

Last updated: 24 May 2022

Links to further information

Learning Disability Strategic Action Plan

https://socialcare.wales/resources-guidance/information-and-learning-hub/sswbact/overview

Mental Capacity Act

More information about the Mental Capacity Act, assessing capacity and supporting decisions:

https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/

Deprivation of Liberty Safeguards

More information about the Deprivation of Liberty Safeguards and Liberty Protection Safeguards:

https://www.scie.org.uk/mca/dols/at-a-glance/#:~:text=The%20Deprivation%20of%20Liberty%20Safeguards%20(DoLS)%20is%20the%20procedure%20prescribed,keep%20them%20safe%20from%20harm.

https://www.scie.org.uk/mca/lps/latest/

ALN and ALNET

More information about ALN and ALNET:

https://www.rctcbc.gov.uk/EN/Resident/SchoolsandLearning/AccessandInclusiontoEducation/AdditionalLearningNeedsAct/InformationrelatingtoAdditionalLearningNeedsEducationTribunalActALNET.aspx

Designated Education Clinical Lead Officer

More information about the Designated Education Clinical Lead Officer is available here.

https://bcuhb.nhs.wales/services/hospital-services/designated-education-clinical-lead-officer-declo/

Mental Capacity Toolkit

This mental capacity toolkit from Bournemouth University and the Burdett Trust for Nurses has been created to help support health and social care professionals working with individuals whose decision-making capacity is limited, fluctuating, absent or compromised.

https://mentalcapacitytoolkit.co.uk/

Sharing alternative approaches and interventions

Finally, this framework sets out other solutions – alternatives to medication for behaviours of concern – that people have told us work well. We were asked to find out evidence for those alternatives (please refer to: 'What is the evidence?' from p29 onwards).

Proposing alternative approaches and interventions shifts the focus to prevention. **Underpinning this is the idea that if we find out what the person's behaviour is communicating, we can find a person centred way of meeting their needs and sorting out the problems they are experiencing**.

Of course, not everything will work for everyone. The main aim here is to improve the quality of life for the many people with learning disabilities and families whose needs aren't being met. They are often left with medication as the only alternative to turn to as a way of managing everyday problems. Hopefully this framework will help people see that prevention is better than reaction, and that there are more person centred alternatives.

The alternative approaches are presented in a tiered model in the next section.

This framework does not supersede clinical judgement and decision making, current laws or government policy.

3. A tiered approach to prevention

Introduction to the tiered approach

The following tiered approach to prevention is based on consultations and evidence review (see section 4 for more information on how we developed the framework). Framing alternative approaches in a tiered framework in this way, emphasises that everyone needs good support to meet their needs, and at different times, some people will need more intensive support.

A graphic for the tiered approach is presented on the next page with examples provided for each of the three tiers. The graphic should be read starting from tier 1 at the bottom.

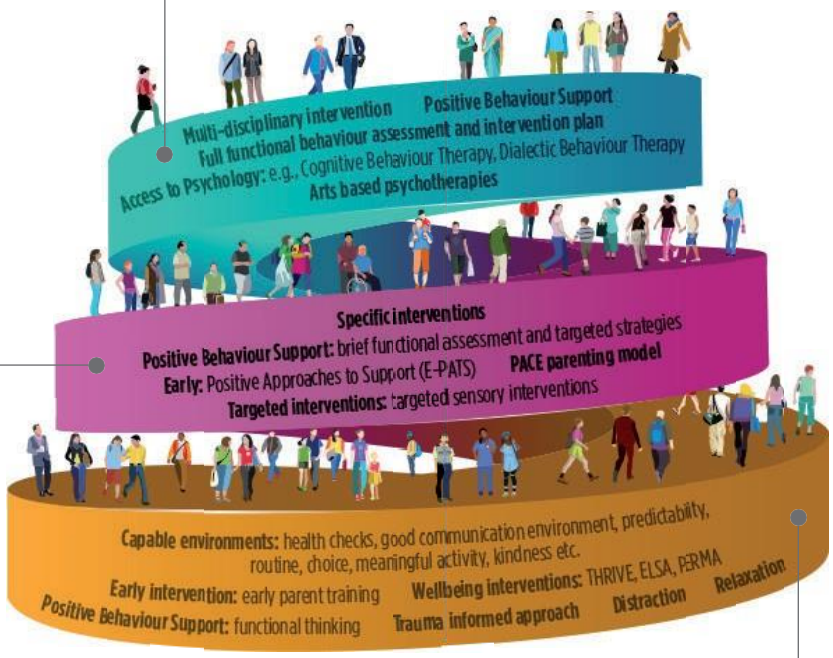
Jargon buster

MDT

Professionals from an MDT will have a high level of skill in assessing and intervening to support behaviour that may cause a high level of risk and harm to self and others. Such an MDT would include clinical psychology, psychiatry and depending on needs and where the care is being delivered, occupational therapy, speech and language therapy, learning disability nursing and physiotherapy provision.

Tier three: **Multidisciplinary support**

For 5% of people with learning disabilities, a multidisciplinary team (MDT) approach and multiple interventions will be needed – this is probably the only tier where medication or even detention might be used too, as a short term intervention to help people stabilise. As both of these options carry potential harms, the MDT should work with the family and the person to enable access to person centred community support, which may be a combination of approaches or interventions. It is not expected that the person will remain in tier three. The right support should mean they can move back down the pyramid as long as other tiers of support are in place.



Tier two: **Additional support**

In the second tier, which is about 15% of people with learning disabilities at any time, some additional support may be needed for a period of time.

Tier one: **Good support**

The first tier is basically good support where people's needs are met adequately. For people with learning disabilities and families, even access to what should be available to meet basic needs may be difficult, e.g., reasonable adjustments when accessing services. A communication passport that everyone can use is a good example of a tier one support.

More information on communication passports.
Downloads – My Communication Passport (mycommpass.com)

There is a need for consistency of approaches across all services that the person receives. A good example of this are communication passports, which are really helpful and can accompany the person to whichever environment they are in.

More information is available in the next section about the approaches and interventions mentioned in each of the tiers. The following two case studies provide examples of what the different tiers of support may look like.

Case study one

12 months ago, Arron (27 years old), a man who has a moderate learning disability and autism was in a residential service which was not meeting his physical, social or emotional needs. Arron was engaging in prolonged, frequent and significant self-injury, which was causing harm to himself and having a significant impact on the emotional wellbeing of his family and staff team. Arron was prescribed a large amount of medication to manage these behaviours, which had a sedative effect and prevented him from engaging in activities that supported his wellbeing. Arron struggled to tolerate the company of others and was unable to visit his family which had a negative impact on his, and his family's, wellbeing. Data recordings indicated that during March 2023 Arron engaged in significant self-injury (head banging) on 29 occasions and was given 'as required' (PRN) medication on 24 occasions to manage this behaviour.

Tier 3 support

It was agreed that a new placement was needed, along with a more appropriate support approach. The local community learning disabilities team and intensive behavioural support team worked together to undertake a comprehensive assessment to understand why these behaviours were happening, and a holistic Positive Behaviour Support (PBS) plan was developed to support Arron's move to his new home.

Embedding capable environments (Tier 1)

Since moving in early summer 2023, extensive work has taken place between health services and the staff team in Arron's new home. This work focussed on developing a person-centred communication system and upskilling staff to adopt an appropriate communication approach. An active support approach was implemented within the home to promote regular, meaningful activity and engagement that met Arron's sensory needs. The PBS Plan also focused on relational approaches, supporting the staff and Arron to develop a trusting relationship that would enable him to thrive and reach his full potential. Health professionals facilitated workshops and reflective practice sessions with the staff team to support a consistent, appropriate and effective approach.

Impact on medication use and quality of life

As a result of the interventions implemented between health services and staff in the home, and Arron's own skills and resilience, there was a significant reduction in behaviours of concern and the use of 'as required' medication. In November 2023, the number of incidents where Arron self-injured reduced to four, and no medication was used to manage behaviours. This represents an 86% reduction in self-injury and a 100% reduction in medication use to manage behaviours of concern within the first 5 months post-intervention.

Arron is now thriving in his new environment; he has increased engagement, choice, independence and autonomy. He has fulfilling, individual relationships with the staff that work within his home and his family have reported having enjoyable visits and feeling re-connected with their son.

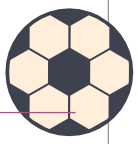
Case study two

Non-Pharmaceutical Intervention Framework

John is a 13 years old, year 9 student at a mainstream school. He loves sports and physical activities, particularly football. He has a great sense of humour. John has high levels of distractibility and impulsivity linked to a diagnosis of ADHD, and has a mild learning disability.

Tier 1 Good support

Both school and family have worked together to consider John's requirements around curriculum and the school environment. Timetabling is a fundamental factor to meeting John's needs as well as considering his movement between classrooms. The school have reduced the distractions on his routes (this has included consideration of furniture, location of doorways and windows where lighting may draw his attention when moving around the building). As can be seen, Tier 1 support has focused on creating a capable environment and making reasonable adjustments within the school.



Tier 2 Additional Support

Following a period of John finding it significantly harder to engage in lessons and his impulsive behaviours intensifying, additional support was needed. An analysis of John's presentation was necessary as the class teacher found the whole class learning was becoming disrupted. School staff and family considered what was happening before John's impulsive behaviours (the antecedent) and what was happening afterwards (the consequences) in order to identify patterns in behaviour. This additional support led to further adaptations to the curriculum being identified as well as changes to timings of routines and movement breaks (e.g. access to the outdoors and physical activities (circuit activities, ball games). Monitoring of these changes has shown that scheduled daily intervention has supported focus and engagement in lesson-based learning.

A child centred approach

Staff training has been around John's individual needs and presentation, rather than his overarching diagnoses and has been fundamental to meeting his needs. This child-centred focus has resulted in consistency of approaches and scripted responses when John starts to behave in ways that indicate he is struggling to self-regulate. Staff have a greater understanding of John's needs and acceptance of the key strategies of support, for example use of doodling, fidget things and the movement breaks (where John leaves the classroom at planned intervals with a member of support staff). Included in the de-escalation strategies is the use of an exit pass with access to a key place and person, for times when John's emotions are rising.

Staff have been able to plan learning accordingly, using turn and talk as a method of engagement and ensuring John is able to contribute to whole class input within the first three contributions, with use of a white board to record any further contributions (and avoid interrupting others verbally). Staff being aware of the potential need for movement, how this may present and having clear roles and responsibilities in the classroom has supported these approaches.

Tier 1 wellbeing interventions

Alongside the adjustments and support within the mainstream classroom, there are interventions in place focused on supporting emotional regulation and the development and embedding of independent strategies of support. This includes Emotional Literacy Support Assistants (ELSA) support, with the use of draw and talk, to engage in discussions around emotions. Scaling is used to identify the build-up of emotions, how it looks and feels and the strategies which could be used to support (including appropriate use of the exit pass). Use of comic strips to pre-teach these approaches is important, as well as reflecting on any incidents.

Fundamental to the success of these approaches and strategies, is the on-going communication with home. Daily updates from parents has ensured a proactive and responsive approach, for example when struggling with home based morning routines a 'meet and greet' and a physical activity before lessons was introduced. Together Tier 1 and Tier 2 support has been sufficient in providing a capable environment within which John can engage in his education and ensuring his emotional wellbeing is attended to. Responsive child-centred support has meant that Tier 3 support has not been necessary.

4. How we developed the framework

This section describes the range of consultation and review methods drawn upon to inform the tired approach to prevention. These include:

Online survey

An online survey was sent out across Wales by Improvement Cymru. The survey was sent out initially in April 2023 and with an extended deadline it was sent out again in August 2023. The survey sought to understand what interventions and approaches are currently being used in Wales to support people who at times may have behaviours of concern, and whether these are considered as suitable alternatives to medication. One hundred and twenty people responded to the survey, 45% were healthcare professionals, 27% social care professionals and 12% educational professionals. The remainder were family carers and one person with a learning disability (10%), or responded as 'other' (6%). You can read the survey results in full here.

Interviews

All Wales People First invited people with learning disabilities to join a forum in August 2023. Two people with learning disabilities (both female) were interviewed about their experiences of using medication and the alternatives that would better support them when they were in crises and thus showing behaviours of concern.

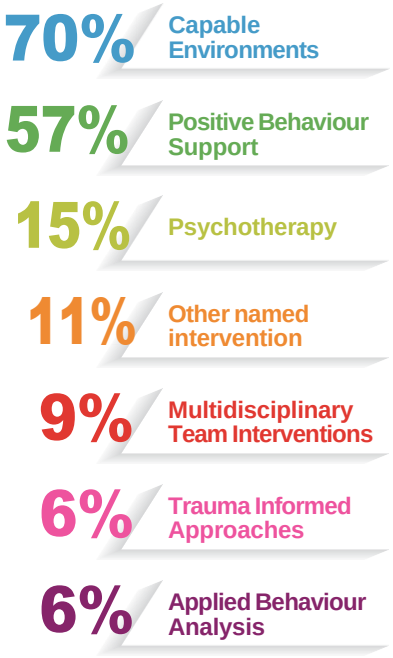
The All Wales Forum similarly invited family carers to join a discussion forum in August 2023. Two family carers (both mothers) volunteered and were interviewed separately via Zoom about their experiences of being prescribed medication for their family member (in both cases their sons) and what they thought about alternative approaches.

Literature review

A final component in addition to the above consultations was a review of the evidence (also known as a literature review). The review was undertaken by Manchester Metropolitan University to help understand the evidence base for several key interventions/ approaches for preventing behaviours of concern. The researchers looked at published evidence for the interventions/approaches, mainly through checking other published reviews for each of these. Please see the appendices for the detailed literature review.
A summary is given from p28.

Survey findings: interventions and approaches being used

Figure 4:
Interventions and approaches used by survey respondents in Wales, ordered by frequency of citation



From our survey we heard from family members and professionals supporting children and adults with learning disabilities about approaches (other than medication) that were being used to support people when behaviours of concern occurred. Participants completing the survey could list all approaches they had tried. These were then organised into groups and counted.

Some of the survey findings are summarised here and more details are available in appendix 2. The most frequently mentioned approach could be grouped under 'capable environments.' Capable environments are those in which people can thrive and are less likely to utilise behaviours of concern and might include things like having appropriate communication systems in place, having meaningful things to do, having consistent approaches to support, and having sensory needs attended to. Seventy per cent of survey respondents mentioned an approach that fits with the idea of providing capable environments. Another intervention frequently mentioned was Positive Behaviour Support or Behaviour Support Plans (57%). Psychotherapy was mentioned by 15% of people (this covers a range of therapies, including Dialectical Behaviour Therapy, Acceptance Commitment Therapy, Compassion Focused Therapy and other arts based psychotherapy). Other named interventions were mentioned by 11% of respondents (these included PACE approach − described below, Emotional Literacy Support Assistant's, training in de-escalation, Thrive (trauma informed, whole school approach to mental health and wellbeing), TIS (communication) approach, mechanical horse riding, rebound therapy, music therapy. Also mentioned were multidisciplinary team intervention (9%), trauma informed approaches (6%) and Applied Behaviour Analysis (6%).

Figure 5:
Interventions and approaches felt to be most effective, ordered by frequency of citation

People responding to the survey were also asked which approach or intervention they thought was most effective. Thirteen per cent of respondents felt that they could not choose one and that it was the range of approaches and interventions in combination that were important, or that different things worked for different people. Of those that were able to highlight just one or two key interventions or approaches that were most effective for addressing behaviours of concern (see figure 4), the majority emphasised Positive Behaviour Support (40%) or facilitating capable environments (via a range of approaches, 40%). Aside from this, 4% offered another named intervention as most effective, 4% cited psychotherapy, 3% multidisciplinary team interventions and 3% Applied Behaviour Analysis.

Based on these survey findings, a literature review was produced on the most frequently mentioned, and these have been incorporated within the tiered approach presented in section 3.

Lived experience perspectives

People with learning disabilities interviewed reported the following things were important to ensure they had a good life:

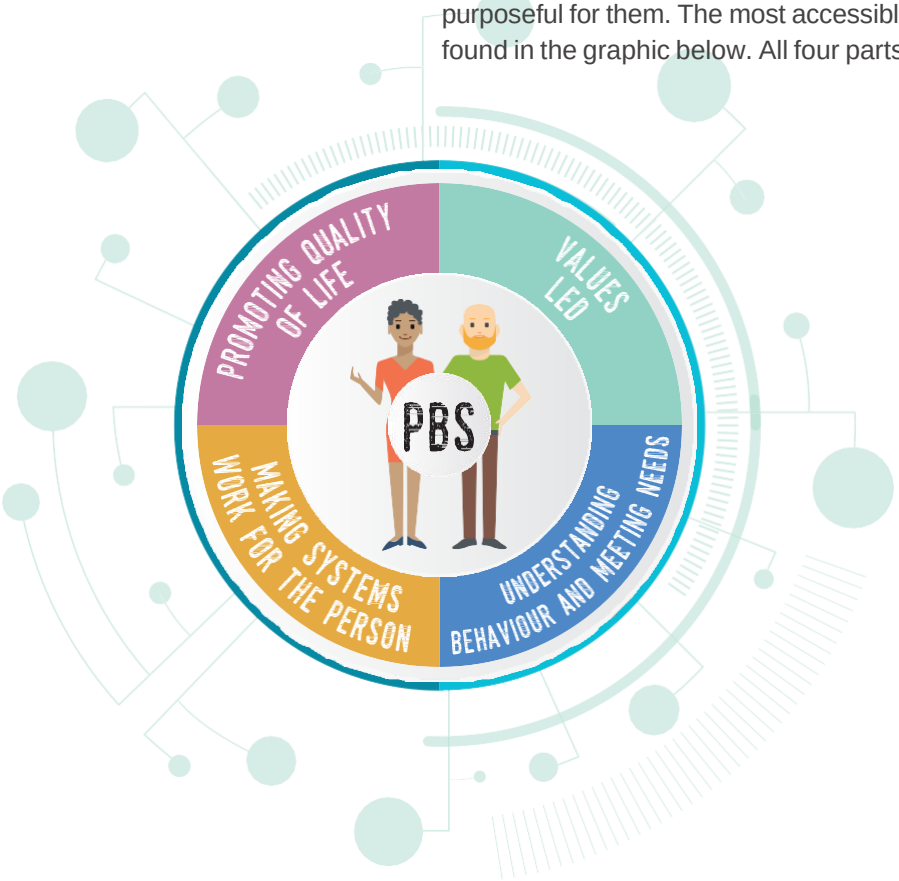
Family carers said:

What is the evidence?

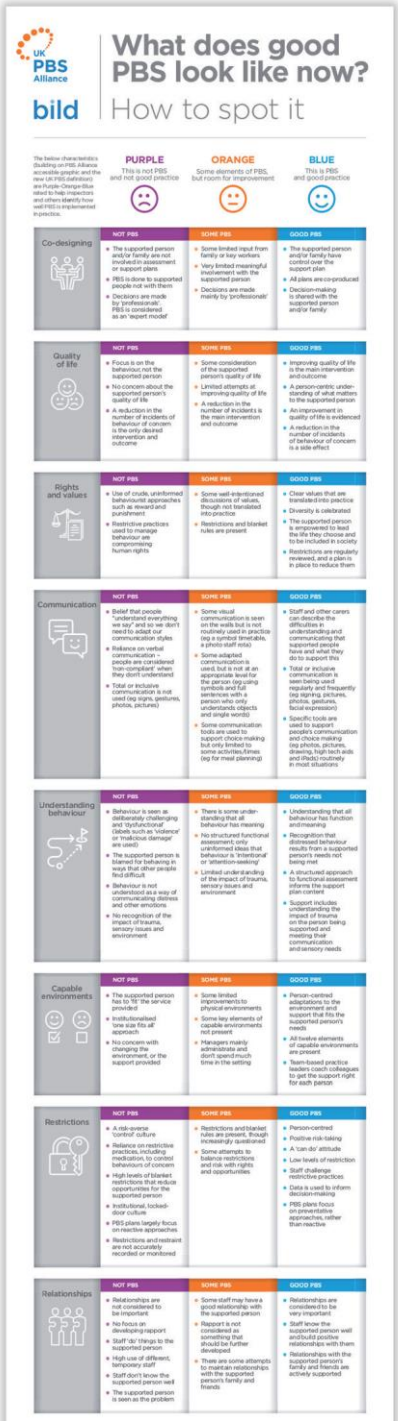
Here we share some key findings from the evidence review, along with links to where you can get further information or support related to the approach. This does not mean that these are recommended approaches as this document does not replace clinical and person centred decision making around the needs of the individual and their family. Further details are available in appendix 1.

Positive Behaviour Support (PBS)

PBS is not a single intervention or programme. It is rather a person centred framework that incorporates a strong values base, looks at changes to the systems and environments around a person based on developing a good understanding of what they need to thrive. The main aim is to improve the quality of life for people and others that support them. It is often described as a blend of science and values but is led by values and does not use punishment. It was developed in the 1980s by practitioners who found behaviour modification practices distasteful. PBS seeks instead to promote individual rights by changing support to fit the person rather than the other way round. At its heart is the assumption based on learning theory that the actions people do are meaningful and purposeful for them. The most accessible description of PBS is found in the graphic below. All four parts need to be present.



PBS is ever evolving and good PBS practitioners will have a good understanding of trauma and be committed to coproduction. This resource has been coproduced to help people understand what good PBS is.



PBS is best delivered by people that know the person well and who are curious and want to find out what the problem might be for the person if they are doing things that are concerning or having an impact on their quality of life. There are different levels of training from awareness to masters degrees. Like person centred practice, PBS has, in some instances, been adopted by services and organisations that have not had the knowledge, skills and resources to do it well. It is often confused with Applied Behaviour Analysis and physical intervention training.

Developing a capable environment (see page 31) for a person in which they have most of their needs met and can thrive in is a key part of the Positive Behaviour Support Framework. All the elements that make up a capable environment for a person for example Active Support and access to a good communication environment are some-times referred to as tier one prevention strategies in PBS. The idea of a capable environment isn't exclusive to PBS and it is found in other frameworks or models that include prevention and early intervention.

Evidence

- Studies that reported positive outcomes of PBS considered mainly a reduction in behaviours of concern.
- Some research findings suggest that training community intellectual disability services staff in PBS, is no more effective than 'treatment as usual' in reducing behaviours of concern.
- Research designs and outcome measures used mean it is hard to develop a good understanding of the effectiveness of PBS across lots of different research studies.
- The conditions required for the successful adoption of PBS vary depending on the context.
- In organisations and services, senior leadership and practice leadership are essential for good implementation, alongside the right level of expertise and empathic skills.
- Data are typically gathered from staff and sometimes parents, but data from children/ adults with learning disabilities must be included in future research.

It is important to note that PBS is not a treatment intervention - rather it is a way of providing care and support to improve a person's quality of life. It should take into account the person's needs, wishes as well as an understanding of the likely causes of any behaviours of concern. As such, a PBS approach will draw on a variety of approaches and interventions in combination. This makes it difficult to evaluate and means different types of evaluation may be needed. Some supports that form part of a PBS approach, like providing capable environments may require less of an evidence base as they align with providing a reasonable adjustment or are simply foundations for 'good support.'

Links to further information

Information on Positive Behaviour Support

- **Information on PBS from the Challenging Behaviour Foundation**
  https://www.challengingbehaviour.org.uk/information-and-guidance/positive-behaviour-support/getting-behaviour-support/

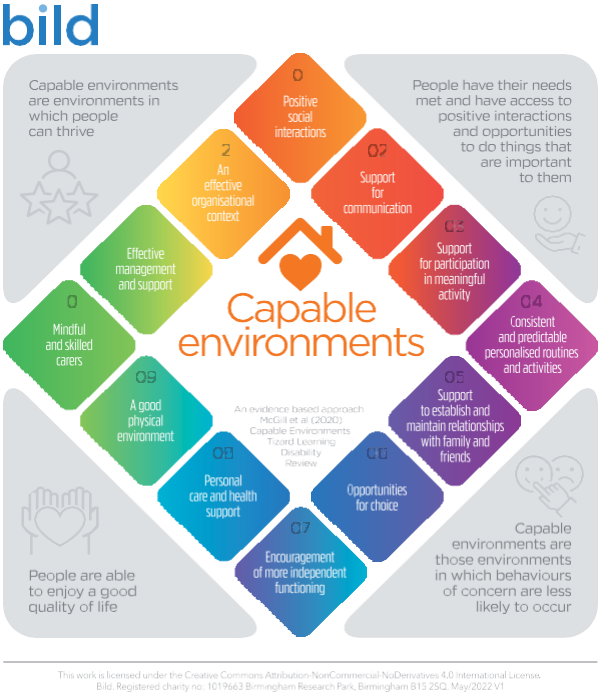
- **The PBS Academy**
  http://pbsacademy.org.uk/

- **Bild**
  https://www.bild.org.uk/

Capable environments

Capable environments are those environments in which people can thrive. The majority of their needs are met most of the time. For people with learning disabilities and autistic people, sadly this is not always the case. People do not always have access to good health care, support with communication, and skilled carers who can ensure that people have meaningful activities, choice and predictability.

Lots of people in the survey named different elements of capable environments as alternatives to pharmaceutical interventions.



Evidence

- Research by McGill et al., 2020, shows that there are 12 elements that need to be in place to provide a person centred, capable environment for a person. link to infographic
- If these 12 elements are in place for a person, it is less likely or rare that behaviours of concern will arise, because they are not needed.
- In this document we think this is 'Tier one support' – support that everyone with a learning disability and behaviours of concern are entitled to.
- The aspiration should be that if we work on making all environments capable environments, fewer people will need interventions at higher tiers of support.

Links to further information

Information on Capable Environments

- **United Response Information on Foundations of Good Support**
  https://www.unitedresponse.org.uk/resource/aspirations/
- **Achieve together – capable environments**
  https://www.achievetogether.co.uk/a-good-life/

Active Support

Active Support is a person centred way of supporting individuals to have a better quality of life and is one approach to providing a capable environment (e.g., support for meaningful activities) and is sometimes used alongside PBS. Active Support focuses on individuals having the right level and type of support at the right moment so they can participate in everyday activities and take full part in their own lives. It supports individuals to maintain those skills they already have and try new things out in a safe, supported and enjoyable way. It enhances the relationship between the person and their supporter and ensures that people have meaningful and predictable ways to spend their time.

The 'hotel' model of support (doing for) does not feature Active Support

Active Support (doing with) in action

Links to further information

Information on Active Support

- **Challenging Behaviour Foundation Information on Person-Centred Practices**
  https://www.challengingbehaviour.org.uk/information-and-guidance/person-centred-support/

- **North Wales Together Information on Active Support**
  https://northwalestogether.org/active-support/

Trauma Informed Care/Practices (TIC)

> Trauma informed practices or care, focus on support and care practices with the principles of safety, choice, collaboration, empowerment, and trustworthiness at its heart. It promotes the understanding of the widespread impact of childhood adversity and trauma across the life course with the aim to promote potential pathways for recovery while seeking to avoid retraumatisation.
>
> (SAMHSA, 2014)

Evidence

- Adults with a learning disability may be more vulnerable to traumatic experiences and physical, sexual, and emotional abuse, and experience more negative life events than adults without learning disabilities.
- The literature suggests that they also encounter specific trauma related to the experience of disability itself. This would suggest this population is particularly suited to TIC.
- Increased training on recognising and responding to trauma is needed among staff supporting those with a trauma history, if organisations are to move towards TIC.
- To date there are few studies exploring TIC in services that support adults with a learning disability who are likely to have been impacted by a trauma history.
- Evidence is mainly from interviews and focus groups. Most studies are from staff perspectives.
- Mixed reviews from staff about this approach.
- Limited studies involving children.

Links to further information

Information on Trauma Informed Care/Practices (TIC)

- **Trauma Informed Care Implementation Resource Centre**

  https://www.traumainformedcare.chcs.org/what-is-trauma-informed-care/

- **Information on Trauma Informed Care/Practices (TIC)**

The Adverse Childhood Experiences (ACE) Hub Wales have produced the TrACE toolkit to support the development of trauma-informed approaches.

https://acehubwales.com/trace-toolkit/

Safewards

> Safewards is an internationally adopted framework that provides interventions to reduce conflict and containment in healthcare settings. Safewards consists of ten core interventions that were identified through a rigorous testing and refining process.
>
> (Bowers et al., 2015)

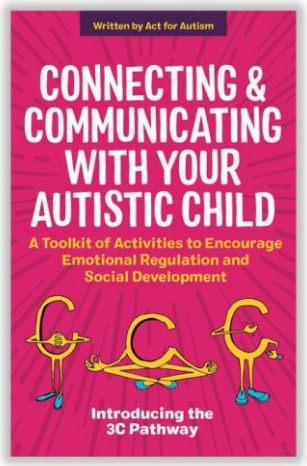
Evidence

- There is no research evidence related to learning disability and the use of Safewards.
- While there is evidence to suggest that Safewards is effective for reducing conflict and containment in general adult acute mental health services, there is not enough high quality research to support its effectiveness in settings beyond this.
- Further, larger research studies, are required in order for the effectiveness of Safewards to be established across the range of settings where it is currently used.
- Most staff and patients reported Safewards improved therapeutic relationships, cohesion, and ward atmosphere.
- Safewards improved the experience of safety from the perspective of staff and consumers when combined with ongoing training and leadership.

Links to further information

Safewards

- **Safewards**
  https://www.safewards.net/



Sensory Integration Therapy/sensory interventions (SIT)

Our sensory systems help us all to make sense of the world around us. Children and adults with a learning disability may experience differences in processing sensory information. This may make them more likely to seek out some forms of sensory stimulation or more likely to avoid other forms of sensory input (including finding these aversive). Moreover, sensory input can be overwhelming and be a case of anxiety. Behaviours of concern can similarly have a sensory based cause. A range of adaptations to the environment may be enough to support lowering of anxiety or other sensory based interventions may be needed to help the person to self-regulate, or to provide them with additional sensory input in a safe and enjoyable way.

Sensor Integration therapy is a specific form of intervention. SIT is used to help children learn to use all their senses together – that is, touch, smell, taste, sight, and hearing.

It is claimed that this therapy can improve behaviours of concern or repetitive behaviour. It includes balance treatments, movement therapy, and exposure to sensory input. These are carefully designed, physical activities and accommodations, which are designed to help the brain to adapt and allow the person to process and react to sensations more efficiently.

Evidence

- Reviews of research focused mainly on children.
- Very limited empirical evidence to support its application, e.g., studies comparing SIT to no treatment found only a small effect. However, when SIT was compared to alternative interventions, differences were not significant.
- Studies are flawed with the nature of the treatment not clearly defined. Studies are hard to compare due to use of different outcome measures.

Links to further information

Information on Sensory Integration Therapy/ sensory interventions

The Royal College of Occupational Therapists provide more information about sensory processing and occupation

https://www.rcot.co.uk/sensory-processing-and-enabling-occupation

- **Sensory Integration Education**

  https://www.sensoryintegrationeducation.com/pages/what-is-si

More information about supporting the sensory processing needs of children:

https://bcuhb.nhs.wales/services/hospital-services/neurodevelopmental/advice-and-support/sensory-sensitives/

Playfulness, Acceptance, Curiosity and Empathy (PACE)

PACE was developed by Dan Hughes more than 20 years ago as a central part of attachment focused family therapy, with the aim of supporting adults to build safe, trusting, and meaningful relationships with children and young people who have experienced trauma. It is based on the way that caregivers interact with very young infants. It describes a way of relating to others or 'a way of being.' It pays attention to how we deliver messages to children and young people through our communication. The principles offer a useful framework from which we can develop 'attunement' and strengthen our relationships with children and young people.

Evidence

- The authors present evidence that supports each component of PACE.
- The need for individualised and responsive treatment as part of PACE is cited as a reason for the lack of evidence.

Links to further information

Information on PACE

- **Dyadic Developmental Psychotherapy**
  https://ddpnetwork.org/about-ddp/meant-pace/

Dialectical Behaviour Therapy (DBT)

DBT is a type of talking therapy based on cognitive behavioural therapy. It is adapted and focuses on people who feel emotions very intensely. The therapy aims to help the person:

- understand and accept difficult feelings;
- learn skills to manage feelings;
- make positive changes in your life.

Evidence

- DBT has strong evidence of its efficacy based upon several randomised control trials in populations with a range of specific mental health problems.
- There is some evidence that it has helped people with learning disabilities to develop coping skills and increase their use of mindfulness.
- A review of evidence concluded that the therapy can be adapted for people with learning disabilities, but that more evidence of its effectiveness was needed.
- Different outcome measures have been used across studies making them hard to compare.

Cognitive Behaviour Therapy (CBT)

CBT is a type of talking therapy. It is a common treatment for a range of mental health problems. CBT teaches coping skills for dealing with different problems. It focuses on how thoughts, beliefs and attitudes affect feelings and actions.

Evidence

- Overall, the evidence base for the use of CBT for people with mental health problems who do not have learning disabilities is well established.
- There has been little research into the effectiveness of CBT components of therapy with people with intellectual disabilities, including many of the adaptations that have been used or developed.
- A review of evidence suggests CBT to be moderately effective in the treatment of anger and depression and that individual treatment may be better than group treatment.
- The quality of research evidence for CBT in children and young people with learning disabilities is poorer than that for adults.

Mindfulness

Mindfulness is a technique that originated from Buddhism. Mindfulness involves focussing attention purposefully in a non judgmental, non reactive way on the present moment and what is happening in an individual's mind, body, and the world around them. Mindfulness approaches differ from existing therapy programmes as they aim to help people to focus on the present moment, to accept difficult to change symptoms or situations, and to enable different ways of viewing and responding to situations. Mindfulness is cultivated through formal practices such as the body scan, mindful movement and sitting meditation, which are integrated into everyday life as a coping resource to improve physical and psychological wellbeing.

Evidence

- There is some emerging evidence to suggest that mindfulness may be helpful for people with intellectual disabilities who have anger problems. A review of 12 studies which involved teaching mindfulness to people with learning disabilities, some of whom were adolescents, concluded that there was emerging evidence to suggest that the intervention is effective.
- The majority of the studies used were of single case studies, and mindfulness had been used most frequently with aggressive behaviour.
- Mindfulness had also been used as a technique for supporting carers and staff working with people who have learning disabilities and parents caring for a child with learning disabilities. Research evidence in this area is only just developing.
- Research in this area is only developing and some studies have indicated less positive experiences. It may not be any more effective than traditional progressive muscular relaxation techniques for example.

Links to further information

Psychological therapies

- **Cognitive Behaviour Therapy**

  https://www.mind.org.uk/information-support/drugs-and-treatments/talking-therapy-and-counselling/cognitive-behavioural-therapy-cbt/

- **Dialectical Behaviour Therapy**

  https://www.mind.org.uk/information-support/drugs-and-treatments/talking-therapy-and-counselling/dialectical-behaviour-therapy-dbt/

- **Mindfulness**

  https://www.mind.org.uk/information-support/drugs-and-treatments/mindfulness/about-mindfulness/

When considering psychological interventions, it is important to recognise that many ‘branded’ therapies contain similar interventions and approaches to each other. All psychological therapies are based on a small number of core theoretical approaches - namely behavioural, cogntive behavioural, psychodynamic/psychoanalytic, systemic, and humanistic models. Modern research increasingly explores the ‘core components of change’ in psychological treatment rather than focusing on the evaluation of branded and manualised treatments.

This way of thinking about psychological treatment is more compatible with the principles of person centred care. There is always the need to tailor psychological treatments for PWID around their individual cognitive needs. Given the limited evidence base - as most research has been done on the use of specific psychological treatments in the general population – delivering treatment from the perspective of a detailed assessment is important.

5. When medication may still be needed

There may be times when medication is still needed, possibly for a short period of time, alongside other interventions and approaches. Provision of good information about medication when this is being suggested, has been started, or needs reviewing, is needed. The Challenging Behaviour Foundation have produced an interactive online 'pathway' (https://medication.challengingbehaviour.org.uk/pathway/) which helps to make sure people are only taking the medication they need and that they can do this safely. Whilst the pathway contains some information about national guidance in England, the broader advice is still likely to be helpful.

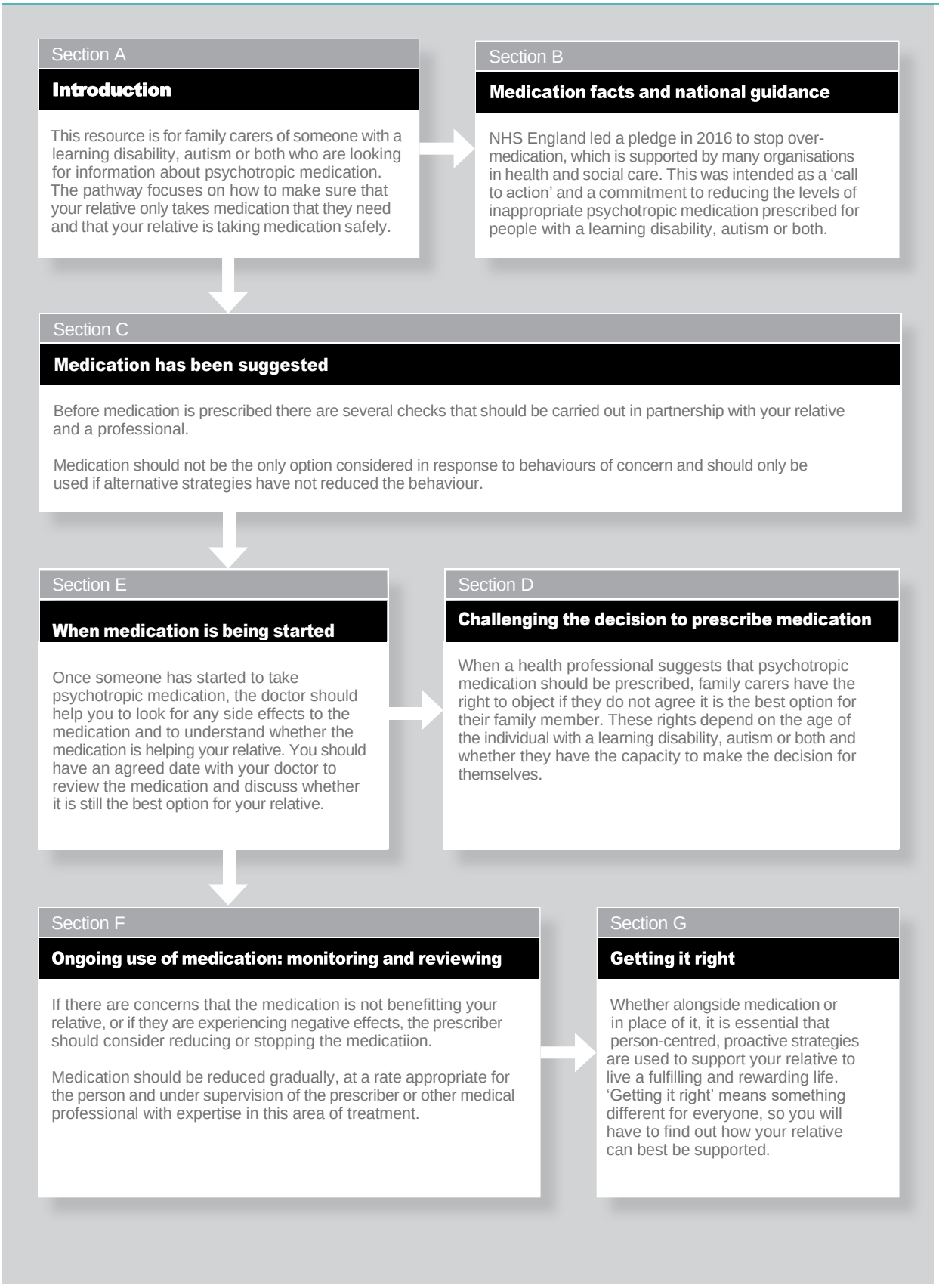
Links to further information

Medication pathway

Interactive online 'pathway

https://medication.challengingbehaviour.org.uk/pathway/

Medication pathway



6. Recommendations

> “The term ‘coproduction’ describes working in partnership by sharing power between people who draw on care and support, carers, families and citizens.”
>
> (SCIE)
> https://www.scie.org.uk/co-production/what-how/

Promoting the use of non pharmaceutical interventions in Wales for people with learning disabilities, in the ways outlined in this framework, will involve a range of different stakeholders working together to support the person and their family. Coproduction will need to be a key process to facilitate this. Coproduction as a vehicle for individual care and support planning with the person and their circle of support, as well as coproduction of appropriate wider services.

The Social Care and Wellbeing Act 2014 Statutory guidance sets out that: ‘coproduction should be used to develop preventative, strength-based services, support assessment, shape the local care market, and plan information and advice services.’

Is coproduction just personalisation?

SCIE outline the links as follows

> “Coproduction has developed over a similar time period as ideas around services that are person-centred or tailored to the needs of the individual. And some have said that coproduction is essential to making services more personalised.”

It is not the aim of this framework to recommend a specific approach or intervention, that is a matter of clinical judgement. However, to facilitate putting this framework into practice, information from policy, the literature review and consultations have informed a number of recommendations which would support putting into practice the approaches and interventions outlined in the tiered approach. This includes activities that need to happen with or by the systems around the person as well as by commissioners.

1. The person

Throughout care and support planning the person with a learning disability should be at the centre, given a voice and included in decisions affecting them as far as possible. This will include making reasonable adjustments to make services accessible, such as providing accessible information. Where the person lacks capacity to make decisions about their care and support, including responses to behaviours of concern, such as the use of medications then a best interests decision would need to be made and in some instances a Deprivation of Liberty Safeguards assessment made.

2. Family support

Families are very often relied upon for providing care to a family member who has a learning disability and is presenting with behaviours of concern. Early support should be offered for families following initial identification of a learning disability.

Professionals often work closely with family members in order to indirectly support the person. This should be done in such a way that recognises their knowledge and expertise, as well as considers their resources to be able to draw on approaches or follow intervention plans.

As such families will need good quality and accessible information, such as:

- Simple guides that outline core principles of approaches and therapeutic interventions that have an evidence base. Such guides should help to identify what to do and where they can get support.
- Information on what professionals to expect support from throughout the tiers in this framework, and how much support might be provided. The qualifications and activities the different professional groups may offer, and how they review whether things are working (e.g. evaluation or assessments).
- Information about pathways to accessing supported living.
- Information about the rights and associated laws and processes that support them to have their rights enacted, e.g. access to independent advocacy.

People with learning disabilities and their families may need additional support at times, this might be respite services or intensive support services and accommodation available close to home where additional support can be provided.

3. Workforce

The workforce across health, social care and education need clear training expectations and standards for delivering support aligned with the three tiers presented in this framework. Resourced multidisciplinary teams who can reach into all communities (including rural areas) of Wales are needed. MDT teams will have transparent and objective processes for assessing and triaging people to services or support.

4. Outcome evaluation

Understanding whether an approach or intervention is effective is important to reviewing and ensuring the right support in place. Evaluation of outcomes for individuals should focus on positive outcomes for the individual (e.g. improved quality of life) as well as assessing changes to mental and emotional states or the reduction of behaviours of concern.

Standardised outcome measures may be utilised such that these can inform commissioning decisions. Taking this further, innovative approaches to curating a Wales wide data repository as a core minimum data set could demonstrate population need and outcomes of services and interventions across time.

5. Commissioning

None of the above recommendations will be possible without good commissioning based in an understanding of local needs to facilitate support and service planning. This may also involve cost models that align with the tiered approach presented in this framework. It will also mean ensuring availability of further education options, respite, supported living, and residential services that can provide capable environnements as a minimum expectation. Personalised residential solutions such as supported living (and pathways to obtaining these), should be available for everyone, including those with more complex presentations (as per the Welsh Commissioning guidance, congregate residential care should not be relied on as the only option for this group). This mean commissioning will also need to be suitably flexible to adapt when individuals needs change (either increase or reduce).

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Safewards

Finch, K, Lawrence, D, Williams, M O, Thompson, A R and Hartwright, C (2022) 'A systematic review of the effectiveness of Safewards: has enthusiasm exceeded evidence?' *Issues in Mental Health Nursing*, 43(2), 119–136.

Ward-Stockham, K, Kapp, S, Jarden, R, Gerdtz, M and Daniel, C (2022) Effect of Safewards on reducing conflict and containment and the experiences of staff and consumers: a mixed-methods systematic review,' *Int. J. Ment. Health Nurs*, 31, 199–221.

Sensory Integration Therapy/ sensory interventions

Barton, E E, Reichow, B, Schnitz, A, Smith, I C and Sherlock, D (2015) 'A systematic review of sensory-based treatments for children with disabilities,' *Research in Developmental Disabilities*, 37, 64–80.

Leong, H M, Carter, M and Stephenson, J R (2015) 'Meta-analysis of research on sensory integration therapy for individuals with developmental and learning disabilities,' *J Dev Phys Disabil*, 27, 183–206.

Leong, H M, Carter, M and Stephenson, J R (2015) 'Systematic review of sensory integration therapy for individuals with disabilities: single case design studies,' *Research in Developmental Disabilities*, 47, 334–351.

McGill, C and Breen, C J (2020) 'Can sensory integration have a role in multi-element behavioural intervention? An evaluation of factors associated with the management of challenging behaviour in community adult learning disability services,' *British Journal of Learning Disabilities*, 48, 142–153.

PACE

Becker-Weidman, A and Hughes, D (2008) 'Dyadic developmental psychotherapy: an evidence-based treatment for children with complex trauma and disorders of attachment,' *Child and Family Social Work*, 13(3), 329–337.

Golding, K S and Hughes, D A (2012) *Creating loving attachments: parenting with PACE to nurture confidence and security in the troubled child*. London: Jessica Kingsley Publishers.

Dialectical Behaviour Therapy

McNair, L, Woodrow, C and Hare, D (2017) 'Dialectical behaviour therapy (DBT) with people with intellectual disabilities: a systematic review and narrative analysis,' *Journal of Applied Research in Intellectual Disabilities*, 30(5), 787–804.

Panos P T, Jackson J W, Hasan O and Panos A (2014) 'Meta-analysis and systematic review assessing he efficacy of dialectical behaviour therapy (DBT),' *Research Social Work Practice March*, 24(2), 213–223. doi:10.1177/1049731513503047.

Cognitive Behaviour Therapy

Hofmann S G, Asnaani A, Vonk I J J, Sawyer A T and Fang A (2012) 'Efficacy of cognitive behavioural therapy: a review of meta analyses,' *Cognitive Therapy Research*, 36(5), 427–440. doi:10.1007/s10608-012-9476-1.

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Mindfulness

Chapman M J, Hare D, Caton S, Donalds D, McInnis E and Mitchell D (2013) 'The use of mindfulness with people with intellectual disabilities: a systematic review and narrative analysis,' *Mindfulness*, 4, 179–189. doi:10.1007/s12671-013-0197-7.

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Appendix 1
Literature review of approaches and interventions

Approach or intervention	Key principles	Who is it for and when should it be used (which tier)?	Summary of evidence base	Skills needed to use the approach (who can deliver it)	Lived experience of the intervention	Signpost to further information
Positive Behaviour Support (PBS)	It consists of four defining features: (a) Application of behavioural science. (b) Multiple interventions to provide ecologically valid, practical support. (c) Commitment to durable lifestyle outcomes. (d) Implementation within organisational systems for sustained effects. (Dunlap et al., 2009). Major components for the successful introduction of PBS in disability services: 1) Characteristics of PBS. 2) Characteristics of those using PBS. 3) Environmental context. PBS is not a single intervention or programme. It is rather a framework that incorporates a strong values base, systems change, and supports utilising scientific knowledge and technologies based on primarily, but not limited to, behaviour analytic principles. Definitions of PBS reflect the different contexts in which the framework has been applied, including mainstream schools in the USA and residential or community settings in the United Kingdom.	The conceptual framework and principles are sufficiently broad so that they can be applied in a variety of disability settings where PBS may be introduced. There are few published sources detailing steps towards the adoption of PBS, indicating a tendency to ignore the myriad of considerations necessary for reaching the decision stage where practice can commence and be maintained with a degree of confidence within a disability service. Unable to find reviews that were conducted in special education settings addressing the implementation of PBS for children and young people with developmental disabilities. Data on experiences with PBS implementation can be beneficial in improving support for practitioners, and hence aid successful PBS implementation. Scottish Government framework provides guidance on the knowledge and capabilities practitioners at different levels should have in relation to PBS for people with learning disabilities who show behaviours of concern and mental health problems "as the separation of behaviours of concern and mental health is often a false dichotomy". Welsh Government Reducing Restrictive Practices Framework: PBS is highlighted as an example of an approach that includes the key components required to support effective person centred practice.	PBS is primarily viewed as a method for addressing behaviours of concern. Studies that reported positive outcomes considered mainly a reduction in behaviours of concern. Measurable improvements with regards to quality of life is rarely demonstrated. Considering the emphasis that the PBS framework places on quality of life outcomes, the lack of evidence of reporting of these outcomes is disappointing. The findings on the outcomes of PBS interventions suggest that they are generally effective in increasing adaptive behaviours and decreasing behaviours of concern of children and young people with developmental disabilities in special education settings. However, some findings suggest that training community intellectual disability services staff in PBS, is no more effective than treatment as usual in reducing behaviours of concern. The lack of more robust high quality methodological designs employing a control group, such as randomised controlled trials, and the heterogeneity of outcome data. across studies, make it difficult to assess precisely the effectiveness of PBS in special education settings.	The conditions required for the successful adoption of PBS vary depending on the context, and this is where the difference between PBS in schools and PBS in disability services becomes most obvious. Generally, the pyramidal 'train the trainer' systems seemed to work well, but it is not clear if those responsible for training second generation staff are given specific instruction to do so, or if the second generation staff are expecting to learn from those who receive initial training. Studies do not describe replicable procedures for this cascading process. It can be implemented in a number of ways, including via a single practitioner, via professional teams offering interdisciplinary contributions to the PBS framework, and via a system wide implementation comprising a tiered model of prevention that covers an entire organisation or geographical area. Scottish Government framework: Adults with learning disabilities who display behaviours of concern are supported by staff who meet the 'direct contact competencies' highlighted in the Positive Behavioural Support Academy's Positive Behaviour Support Competence Framework, adults with learning disabilities who have (non complex or high risk) behaviours of concern have Behaviour Support Plans that are developed, implemented and evaluated on an individual basis, adults with learning disabilities who display behaviours of concern are supported by staff who meet the 'behaviour specialist/ supervisory/managerial competencies' highlighted in the Positive Behavioural Support Academy's Positive Behaviour Support Competence Framework. NICE guidelines: Ensure that staff providing direct support to children, young people and adults with a learning disability and behaviours of concern have the 'direct contact' level competencies of the Positive Behavioural Support Academy's Positive Behaviour Support Competence Framework.	General positive attitude towards PBS by stakeholders seen through-out the literature. Social validity data was typically gathered from staff and sometimes parents, but data from recipients must be included in future research.	Beqiraj, L, Denne, L D, Hastings, R P and Paris, A (2022) 'Positive behavioural support for children and young people with developmental disabilities in special education settings: a systematic review,' *Journal of Applied Research In Intellectual Disabilities*, 35(3), 719–735. (Dunlap, G, Sailor, W, Horner, R H and Sugai, G (2009) 'Overview and history of positive behaviour support,' In W Sailor, G Dunlap, G Sugai, and R Horner (Eds.), *Handbook of positive behaviour support* (pp.3–16). Springer Publishing Company.). Hayward, B A, Poed, S, McKay-Brown, L and McVilly, K R (2021) 'Introducing positive behaviour support (PBS) into disability services for successful adoption: a synthesised systematic review,' *British Journal of Learning Disabilities*, 49(2), 145–161. Konstantinidou, I, Dillenburger, K and Ramey, D (2023) 'Positive behaviour support: a systematic literature review of the effect of staff training and organisational behaviour management,' *International Journal of Developmental Disabilities*, 69(1), 29–44. NHS Education for Scotland (2017) *Supporting psychological wellbeing in adults with learning disabilities: an educational framework on psychological interventions for practitioners working with adults with learning disabilities in Scotland*. NICE (2018) *Learning disabilities and behaviour that challenges: service design and delivery* [NG93]. Royal Commission (2023) *Restrictive practices: a pathway to elimination*. The University of Melbourne, University of Technology Sydney, The University of Sydney. Welsh Government. (2022) *Reducing restrictive practices framework. Guidance on reducing restrictive practices in childcare, education, health and social care settings*.

Approach or intervention	Key principles	Who is it for and when should it be used (which tier)?	Summary of evidence base	Skills needed to use the approach (who can deliver it)	Lived experience of the intervention	Signpost to further information
Trauma Informed Care/ practices (TIC)	Emphasizes organisational practices based upon principles of safety, choice, collaboration, empowerment, and trust-worthiness. It is an organisational change framework that promotes the understanding of the widespread impact of childhood adversity and trauma across the life course with the aim to promote potential pathways for recovery while seeking to avoid retraumatisation (SAMHSA, 2014).	Evidence suggests that adults with an intellectual disability may be more vulnerable to traumatic experiences and physical, sexual, emotional abuse, and experience more negative life events than adults without intellectual disabilities. Additionally, the literature suggests that they also encounter specific trauma, related to the experience of disability itself. This would suggest this population is particularly suited to TIC. However, some can find the choice element overwhelming when they haven't had such control before. Scottish Government framework: Adults with learning disabilities are supported by staff who provide a service that is 'trauma informed.'	Challenges integrating TIC with intellectual/ developmental disabilities services were noted in four areas: the individuals, the staff, establishing a flattened hierarchy, and in interagency collaboration (i.e., with the state institution). Not many reviews, data is mainly from interviews and focus groups. Increased training on recognising and responding to trauma is needed among community staff supporting those with a trauma history if organisations are to move towards TIC. To date there are few studies exploring TIC in services that support adults with an intellectual disability who are likely to have been impacted by a trauma history. Limited studies involving children. Most studies from staff perspectives.	An understanding of trauma is central to TIC. Staff members who had been with the programme a shorter time expressed lower levels of perceived collaboration and empowerment than those who had been employed longer. It is possible that newer staff members were responding to the approach of a different site manager or perhaps that collaboration and sense of empowerment are associated with level of confidence in one's position that increases with experience. Furthermore, it is plausible that trust between newer staff members, and those who are more seasoned, develops over time, and as trust increases, greater collaboration follows. Welsh Government Reducing Restrictive Practices Framework: All practitioners and carers should have value based training and ongoing support in developing skills to work within a preventative framework. This training should include understanding of trauma and trauma informed care. Scottish Government framework: Staff providing TIC to adults with learning disabilities have ability to apply evidence based approaches and techniques for assessing neglect, abuse, and other trauma with appropriate sensitivity, ability to deliver interventions to promote safety and stabilisation, and ability to contain emotions in appropriate ways and support people in distress.	Mixed reviews from staff, research focuses on staff perceptions rather than service users.	Hassiotis, A, Poppe, M, Strydom, A, Vickerstaff, V, Hall, I, S, Crabtree, J, Omar, R, Z, King, M, Hunter, R, Biswas, A, Cooper, V, Howie, W and Crawford, M J (2018) 'Clinical outcomes of staff training in positive behaviour support to reduce challenging behaviour in adults with intellectual disability: cluster randomised controlled trial,' *British Journal of Psychiatry*, 212(3), 161–168. McNally, P, Irvine, M, Taggart, L, Shevlin, M and Keesler, J M (2022) 'Exploring the knowledge base of trauma and trauma informed care of staff working in community residential accommodation for adults with an intellectual disability,' *Journal of Applied Research in Intellectual Disabilities*, 35(5), 1162–1173. (SAMHSA (2014) SAMHSA's concept of trauma and guidance for a trauma-informed approach. Available at: https://store.samhsa.gov/sites/default/files/d7/priv/sma14-4884.pdf (accessed 27.11.23)). Welsh Government. (2022) *Reducing restrictive practices framework. Guidance on reducing restrictive practices in childcare, education, health and social care settings.*

Approach or intervention	Key principles	Who is it for and when should it be used (which tier)?	Summary of evidence base	Skills needed to use the approach (who can deliver it)	Lived experience of the intervention	Signpost to further information
Safewards	Safewards is an internationally adopted framework that provides interventions to reduce conflict and containment in healthcare settings. Safewards consists of ten core interventions that were identified through a rigorous testing and refining process (Bowers et al., 2015).	Whilst there is evidence to suggest that Safewards is effective for reducing conflict and containment in general mental health services, there is insufficient high quality empirical evidence to support its effectiveness in settings beyond this. Further research using robust methodological designs with larger, more representative samples is required in order for the effectiveness of Safewards to be established across the range of contexts in which it is currently being applied. Complete lack of learning disability research in this area.	Most staff and consumers reported Safewards improved therapeutic relationships, cohesion, and ward atmosphere. Staff and consumers reported improved ward atmosphere, leading to consumer centred, recovery oriented care. Safewards improved the experience of safety from the perspective of staff and consumers when combined with ongoing training, leadership, and time for consolidation.	The ward manager(s) and their staff need to decide how they will implement each of the interventions on their wards, and to do that they need to look at the intervention instructions and view the video training packages. If you decide to have a ward champion for each intervention, agree with the ward teams about who will champion which intervention. Welsh Government Reducing Restrictive Practices Framework: All practitioners and carers should have value based training and ongoing support in developing skills to work within a preventative framework such as Safewards.	Lack of research of people with learning disabilities that have experienced Safewards, research focuses on psychiatric inpatients.	Bowers, L, James, K, Quirk, A, Simpson, A, Stewart, D and Hodsoll, J (2015) 'Reducing conflict and containment rates on acute psychiatric wards: the Safewards cluster randomised controlled trial,' *International Journal of Nursing Studies*, 52, 1412–1422 Finch,K, Lawrence, D, Williams, M O, Thompson, A R and Hartwright, C (2022) 'A systematic review of the effectiveness of Safewards: has enthusiasm exceeded evidence?' *Issues in Mental Health Nursing*, 43(2), 119–136. NHS Education for Scotland (2017) *Supporting psychological wellbeing in adults with learning disabilities: an educational framework on psychological interventions for practitioners working with adults with learning disabilities in Scotland.* Royal Commission (2023) *Restrictive practices: a pathway to elimination.* The University of Melbourne, University of Technology Sydney, The University of Sydney. Ward-Stockham, K, Kapp, S, Jarden, R, Gerdtz, M and Daniel, C (2022) Effect of Safewards on reducing conflict and containment and the experiences of staff and consumers: a mixed-methods systematic review,' *Int. J. Ment. Health Nurs*, 31, 199–221. Welsh Government. (2022) *Reducing restrictive practices framework. Guidance on reducing restrictive practices in childcare, education, health and social care settings.*

Approach or intervention	Key principles	Who is it for and when should it be used (which tier)?	Summary of evidence base	Skills needed to use the approach (who can deliver it)	Lived experience of the intervention	Signpost to further information
Sensory Integration Therapy/ interventions (SIT)	Ayres (1972, 1979) suggested that SIT facilitates speech and language acquisition by enhancing the efficiency of sensory processing at the brain stem level, which then provides the foundation for more complex, higher level cortical processing, particularly central auditory processing, which is necessary for language development. The main component of SIT involves controlled provision of sensory stimulation in order to elicit a response from the student, called an adaptive response. The adaptive response is thought to be an important indicator of successful modification of the neurological systems that process sensory information. SIT was suggested to be particularly effective for younger children in the belief that the higher plasticity of their younger brains would ease the change in the neurological system.	This form of treatment was warranted for children who had been diagnosed as having learning disabilities and those who had language, learning and reading problems, particularly problems related to auditory and language processing dysfunction. The American Occupational Therapy Association has supported the application of SIT procedures and techniques with children who have been diagnosed with learning disabilities, pervasive developmental disorder/autism, and chronic psychosocial dysfunction.	Reviews are predominantly concerning children. Much controversy surrounds this approach because of the small amount of empirical evidence to support its application. Studies comparing SIT to no treatment yielded a statistically significant but small effect. However, when SIT was compared to alternative interventions, differences were non significant. Numerous methodological flaws were identified, such as issues in clearly defining treatment and evaluating integrity, poor quality of research, and diversity of outcome measures. There was little evidence that SIT was an effective intervention for any diagnostic group. An assessment of the quality of methodology of the studies found most used weak designs and poor methodology, with a tendency for higher quality studies to produce negative results. Based on limited comparative evidence, functional analysis based interventions for behaviours of concern were more effective than SIT. Overall, the studies do not provide convincing evidence for the efficacy of sensory integration therapy. The research on sensory based treatments is limited due to insubstantial treatment outcomes, weak experimental designs, or high risk of bias. Although many people use and advocate for the use of sensory based treatments, insufficient evidence exists to support their use. Extreme lack of recent, up to date, studies in this area. Sensory integration strategies do appear to be used within multi element behavioural intervention but are cited as behavioural rather than sensory integration strategies.	Traditionally administered by occupational therapists, has become an increasingly popular approach used by speech and language pathologists to remediate language and learning deficits.	Lack of service user perspective of SIT in research, as studies are outdated and mainly involve children.	Ayres, A J (1972b) *Sensory integration and learning disorders*. Los Angeles, CA: Western Psychological Services. Ayres, A J (1979) *Sensory integration and the child*. Los Angeles, CA: Western Psychological Services. Barton, E E, Reichow, B, Schnitz, A, Smith, I C and Sherlock, D (2015) 'A systematic review of sensory-based treatments for children with disabilities,' *Research in Developmental Disabilities*, 37, 64–80. Leong, H M, Carter, M and Stephenson, J R (2015) 'Meta-analysis of research on sensory integration therapy for individuals with developmental and learning disabilities,' *J Dev Phys Disabil*, 27, 183–206. Leong, H M, Carter, M and Stephenson, J R (2015) 'Systematic review of sensory integration therapy for individuals with disabilities: single case design studies,' *Research in Developmental Disabilities*, 47, 334–351. McGill, C and Breen, C J (2020) 'Can sensory integration have a role in multi-element behavioural intervention? An evaluation of factors associated with the management of challenging behaviour in community adult learning disability services,' *British Journal of Learning Disabilities*, 48, 142–153.

Approach or intervention	Key principles	Who is it for and when should it be used (which tier)?	Summary of evidence base	Skills needed to use the approach (who can deliver it)	Lived experience of the intervention	Signpost to further information
Playfulness, Acceptance, Curiosity and Empathy (PACE)	PACE was developed by Dan Hughes more than 20 years ago as a central part of attachment focused family therapy, with the aim of supporting adults to build safe, trusting and meaningful relationships with children and young people who have experienced trauma. It is based on the way that caregivers interact with very young infants. It describes a way of relating to others or 'a way of being.' It pays attention to how we deliver messages to children and young people through our communication. The principles offer a useful framework from which we can develop attunement and strengthen our relationships with the children and young people we work with.	Using PACE helps adults to slow down their reactions, stay calm and tune into what the child is experiencing in the moment. It supports us to gain a better understanding of what the child is feeling. In tricky moments it allows us to stay emotionally regulated and guide the child through their heightened emotions, thoughts and behaviours. In turn, PACE helps children and young people to feel more connected to, and understood by, important adults in their life and ultimately, to slow down their own responses	There is no formal research evidence base that we can find for this approach. There are a number of blogs and videos that can be found under 'signpost to further information' but no dedicated published research. The Welsh Government (2022) however recommend its use in training in their guidance stating that "all practitioners and carers should have value based training and ongoing support in developing skills to work within a preventative framework. Examples of preventative frameworks include Positive Behavioural Support, recovery based approaches, restorative justice, Safewards, and PACE."	This approach sems to be targeted at teachers, educational psychologists and parents.	No evidence found.	PACE.pdf Information on PACE can be found on the DDP website at: https://ddpnetwork.org/resources/library/subjects/pace/ Golding, K S and Hughes, D A (2012) *Creating loving attachments: parenting with PACE to nurture confidence and security in the troubled child.* London: Jessica Kingsley Publishers. NHS Education for Scotland (2017) *Supporting psychological wellbeing in adults with learning disabilities: an educational framework on psychological interventions for practitioners working with adults with learning disabilities in Scotland.* Welsh Government. (2022) *Reducing restrictive practices framework. Guidance on reducing restrictive practices in childcare, education, health and social care settings.*

Psychological therapies						
Approach or intervention	**Key principles**	**Who is it for and when should it be used (which tier)?**	**Summary of evidence base**	**Skills needed to use the approach (who can deliver it)**	**Lived experience of the intervention**	**Signpost to further information**
Dialectical Behaviour Therapy (DBT)	DBT was originally developed by psychologist, Dr.. Marsha Linehan, to treat chronically suicidal individuals (Linehan, et al., 1991) for mindfulness and self management.	DBT evolved into a comprehensive cognitive behaviourally based treatment for borderline personality disorder (BPD). Consequently, DBT is specifically focused on the following hierarchically ordered behavioural targets to: (1) Decrease life threatening suicidal and parasuicidal acts. (2) Decrease therapy interfering behaviours (e.g., extensive phoning of therapist, premature leaving of therapy). (3) Decrease quality of life interfering behaviours (e.g., depression, substance abuse). (4) Increase behavioural skills (e.g., emotional regulation).	DBT is often identified as having strong evidence of its efficacy based upon several randomised control trials. Several previous meta analyses have sought to establish efficacy. Two of those systematic reviews were qualitative (Koerner and Dimeff, 2000; Scheel, 2000); one looked at aggregate improvement across a variety of diagnoses (e.g., BPD, bulimia nervosa, binge eating, and depression) and did not examine specific symptom change (Ost, 2009); and one was published in German population that would be encountered across treatment settings. There is no evidence that we could specifically find in relation to its efficacy in learning disability populations, albeit some mental health problems for which its targeted may be found in those with learning disabilities. In summary, the evidence for DBT and psychodynamic therapy, although promising, remains sparse. This should not be used as a reason to not offer psychological therapies to people with intellectual disabilities (see Langdon, Kehinde and Parkes 2020)	Both DBT and CBT interventions are commonly delivered by mental health professionals, Specialist training is available at various levels.	Limited information found in relation to LD on the reviews.	Koerner, K and Dimeff, L A (2000) 'Further data on dialectical behavior therapy,' *Clinical Psych-ology: Science and Practice*, 7:104–112. Langdon, P E, Kehinde, T and Parkes, G (2020) 'Psychological therapies with people who have intellectual disabilities.' In: Oxford textbook of the psychiatry of intellectual disability. Oxford: Oxford University Press. Linehan M M, Armstrong H E, Suarez A, Allmon D and Heard H L (1991) 'Cognitive-behavioral treatment of chronically parasuicidal borderline patients,' *Archive of General Psychiatry*, 48, 1060–1064. Ost, L G (2008) 'Efficacy of the third wave of behavioral therapies: a systematic review and meta-analysis,' *Behaviour Research and Therapy*, 46:296–321. Panos P T, Jackson J W, Hasan O and Panos A (2014) 'Meta-analysis and systematic review assessing he efficacy of dialectical behaviour therapy (DBT),' *Research Social Work Practice March*, 24(2), 213–223. doi: 0.1177/1049731513503047.

Psychological therapies

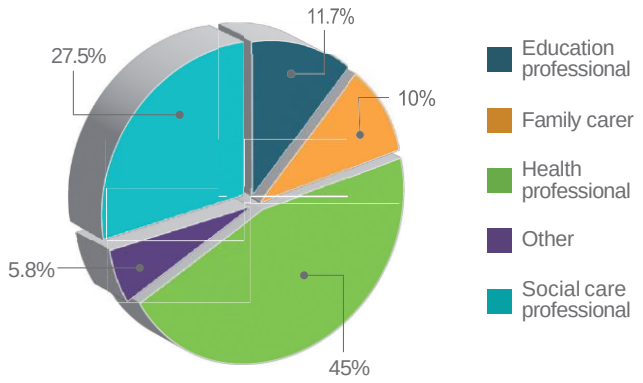
Approach or intervention	Key principles	Who is it for and when should it be used (which tier)?	Summary of evidence base	Skills needed to use the approach (who can deliver it)	Lived experience of the intervention	Signpost to further information
Cognitive Behaviour Therapy (CBT)	CBT refers to a popular therapeutic approach that has been applied to a variety of problems. CBT refers to a class of interventions that share the basic premise that mental disorders and psychological distress are maintained by cognitive factors.	The core premise of this treatment approach, as pioneered by Beck (1970) and Ellis (1962), holds that maladaptive cognitions contribute to the maintenance of emotional distress and behavioural problems. According to Beck's model, these maladaptive cognitions include general beliefs, or schemas, about the world, the self, and the future, giving rise to specific and automatic thoughts in particular situations. The basic model posits that therapeutic strategies to change these maladaptive cognitions lead to changes in emotional distress and problematic behaviours. Since these early formulations, a number of disorder specific CBT protocols have been developed that specifically address various cognitive and behavioural maintenance factors of the various disorders. Although these disorder specific treatment protocols show considerable differences in some of the specific treatment techniques, they all share the same core model and the general approach to treatment.	In a review of CBT in 2012 (Hofmann et al.) the authors identified 269 meta analytic studies and reviewed a sample examining CBT for the following problems: substance use disorder, schizophrenia and other psychotic disorders, depression and dysthymia, bipolar disorder, anxiety disorders, somatoform disorders, eating disorders, insomnia, personality disorders, anger and aggression, criminal behaviours, general stress, distress due to general medical conditions, chronic pain and fatigue, distress related to pregnancy complications and female hormonal conditions. Additional meta analytic reviews examined the efficacy of CBT for various problems in children and elderly adults. The strongest support exists for CBT of anxiety disorders, somatoform disorders, bulimia, anger control problems, and general stress. Eleven studies compared response rates between CBT and other treatments or control conditions. CBT showed higher response rates than the comparison conditions in seven of these reviews and only one review reported that CBT had lower response rates than comparison treatments. In general, the evidence base of CBT is very strong. However, additional research is needed to examine the efficacy of CBT for randomised controlled studies. Moreover, except for children and elderly populations, no meta analytic studies of CBT have been reported on specific subgroups, such as ethnic minorities and low income samples or indeed learning disability populations. Overall, the evidence base for the use of psychological interventions for people with mental health problems who do not have intellectual disabilities is well established, while a comparable evidence base for people with intellectual disabilities remains lacking. The most thorough evidence exists for the use of interventions drawn on CBT, and while there has been a focus on modifications and adaptations to help with accessibility, the evidence is not markedly robust. There is substantial evidence that children, adolescents, and adults with learning disabilities are at increased risk of developing mental health problems, with some estimating the prevalence of mental health problems amongst this population to be as high as 50%. Regardless of the relationship between learning disability and comorbid mental health problems, historically, many people were simply excluded from 'talking' psychological therapies. This disdain, while reflecting wider societal attitudes, was often portrayed as driven by an assumption that people with learning disabilities were unable to benefit from 'talking' psychological therapies because of difficulties associated with their general intellectual functioning, which would likely have a negative impact upon their ability to take part and benefit from the process of 'talking' therapy. Many researchers have tried to tackle this assumption, and while there is no doubt that there is a remarkably high need for psychological therapies amongst this population, many have demonstrated that there is a relationship between verbal reasoning skills and ability to complete tasks thought to be integral to successfully completing some aspects of certain psychological therapies; for example, cognitive mediation skills are considered an important skillset for CBT, which may be difficult for some people with a learning disability. Others have reported that people with a learning disability may have difficulties discriminating between differing emotional states, and again, this is important, as some ability to understand, report, and discuss emotions are part of some psychological interventions. However, there is also evidence that while there may be a relationship between improved psychotherapy outcomes and increasing verbal reasoning skills, there is also evidence that those with poorer verbal reasoning skills may actually make greater improvements following therapy (Langdon et al., 2020).	Consistent with the medical model of psychiatry, the overall goal of treatment is symptom reduction, improvement in functioning, and remission of the disorder. In order to achieve this goal, the patient becomes an active participant in a collaborative problem solving process to test and challenge the validity of maladaptive cognitions and to modify maladaptive behavioural patterns. Thus, modern CBT refers to a family of interventions that combine a variety of cognitive, behavioural, and emotion focused techniques. Although these strategies greatly emphasize cognitive factors, physiological, emotional, and behavioural components are also recognised for the role that they play in the maintenance of the disorder..	Many researchers have tended to focus on whether people with intellectual disabilities have the necessary skillset to allow them to successfully take part in CBT. Some authors have suggested that many of the interventions for people with intellectual disabilities making use of cognitive therapy actually tend to focus more heavily on the use of behavioural therapy, at the expense of cognitive interventions, bearing in mind that CBT for many disorders does focus heavily on behavioural interventions (e.g., exposure and response prevention). Nevertheless, the underlying issue is whether people with intellectual disabilities are able to take part in the 'cognitive' interventions which are thought to require increasing verbal reasoning skills, an understanding of emotional states, and cognitive mediation skills. Simplification of techniques and language, using an array of creative and simplified methods is needed. There has been little research into the effectiveness of CBT components of therapy with people with intellectual disabilities, including many of the adaptations that have been used or developed. The overall goal of CBT treatment is symptom reduction, improvement in functioning, and remission of the disorder. In order to achieve this goal, the patient becomes an active participant in a collaborative problem solving process to test and challenge the validity of maladaptive cognitions and to modify maladaptive behavioural patterns.	Beck, A T (1970) 'Cognitive therapy: nature and relation to behavior therapy,' *Behavior Therapy*, 1:184–200. Ellis, A (1962) *Reason and emotion in psychotherapy*. New York: Lyle Stuart. Hofmann S G, Asnaani A, Vonk I J J, Sawyer A T and Fang A (2012) 'Efficacy of cognitive behavioural therapy: a review of meta analyses,' *Cognitive Therapy Research*, 36(5), 427–440. doi:10.1007/s10608-012-9476-1. Langdon, P E, Kehinde, T and Parkes, G (2020) 'Psychological therapies with people who have intellectual disabilities.' In: *Oxford textbook of the psychiatry of intellectual disability*. Oxford: Oxford University Press.

Psychological therapies						
Approach or intervention	**Key principles**	**Who is it for and when should it be used (which tier)?**	**Summary of evidence base**	**Skills needed to use the approach (who can deliver it)**	**Lived experience of the intervention**	**Signpost to further information**
Mindfulness	Mindfulness is a technique that probably originated from Buddhism and yoga. It is a mental state of focusing on the present moment in a non judgemental way and has been reported to have a moderate effect in the general population. Mindfulness involves focussing attention purposefully in a non judgmental, non reactive way, on the present moment and what is happening in an individual's mind, body and the world around them. Mindfulness approaches differ from existing therapy programmes as they aim to help people to focus on the present moment, to accept difficult to change symptoms or situations and to enable different ways of viewing and responding to situations.	Mindfulness is a core strategy within treatment packages such as mindfulness based stress reduction (Kabat-Zinn 1990) and mindfulness based cognitive therapy. The former is a structured group programme consisting of eight weekly 2–2.5 hour sessions with daily home assignments and a day retreat between weeks six and seven. Mindfulness is cultivated through formal practices such as the body scan, mindful movement and sitting meditation, which are integrated into everyday life as a coping resource to improve physical and psychological wellbeing.	There is some emerging evidence to suggest that mindfulness may be helpful for people with intellectual disabilities who have anger problems. Hwang and Kearney reviewed twelve studies which involved teaching mindfulness to people with intellectual and developmental disabilities, some of whom were adolescents, concluding that there was emerging evidence to suggest that the intervention is efficacious. The majority of the studies made use of single case designs, and mindfulness had been used most frequently with aggressive behaviour, but there were studies using the technique as an intervention for deviant sexual arousal, anxiety and obsessive compulsive disorder, smoking, and for weight loss. A variety of modifications to the techniques were described when used with people with intellectual disabilities, including longer self practice periods of up to one year, often for those with increasing complexity, and a greater degree of intellectual disability. Role play, verbal instructions, pictorial aids, and the use of audio recordings to help with instruction was also employed. Mindfulness had also been used as a technique for supporting carers and staff working with people who have intellectual disabilities, parents caring for a child with intellectual disabilities, while a recent randomised controlled trial using 'mindfulness based PBS' with staff members within an institution for people with severe and profound intellectual disabilities had been completed. There is evidence of the effectiveness of mindfulness for managing various physical and psychological health problems including stress, anxiety, depression, pain and disordered eating (Baer 2003; Chiesa and Serretti 2010; Fjorback et al. 2011).	Anyone can employ mindfulness techniques, although parents and staff are mostly the recipients of training, with good effect. A range of people with different levels of mindfulness skills and experience have provided mindfulness training. In the majority of studies, mindfulness training was provided by a single therapist experienced in the practice and teaching of mindfulness. Training has also been provided by ward or community based therapists trained in mindfulness techniques or in rarer instances by a person with intellectual disabilities. In most studies, mindfulness training was provided to participants with intellectual disabilities individually. Mindfulness training programmes have been provided in various settings, including institutional settings, such as psychiatric hospitals and forensic mental health facilities, and community settings with people living in group or family homes.	Mindfulness training has been shown to be successfully provided in a range of community and institutional settings and by experienced mindfulness practitioners, staff trained in mindfulness techniques, family members, and people with intellectual disabilities themselves. Studies suggest that whilst benefits can be achieved by providing mindfulness training and practice directly to people with mild and moderate intellectual disabilities, people with intellectual disabilities also benefit if their staff and family receive mindfulness training.	Baer, R A (2003) 'Mindfulness training as a clinical intervention: a conceptual and empirical review,' *Clinical Psychology: Science and Practice*, 10(2), 125–141. Chapman M J, Hare D, Caton S, Donalds D, McInnis E and Mitchell D (2013) 'The use of mindfulness with people with intellectual disabilities: a systematic review and narrative analysis,' *Mindfulness*, 4, 179–189. doi:10.1007/s12671-013-0197-7. Chiesa, A and Serretti, A (2010) 'A systematic review of neurobiological and clinical features of mindfulness meditations,' *Psychological Medicine*, 40(8), 1239–1252. Fjorback, L O, Arendt, M, Ørnbøl, E, Fink, P and Walach, H (2011) 'Mindfulness-based stress reduction and mindfulness-based cognitive therapy – a systematic review of randomized controlled trials,' Acta *Psychiatrica Scandinavica*, 124(2), 102–119. Hwang, Y S and Kearney, P (2015) *A mindfulness intervention for children with autism spectrum disorder: new directions in research and practice*. Springer Publishing Company. Kabat-Zinn, J (1990) *Full catastrophe living: using the wisdom of your body and mind to face stress, pain, and illness*. Dell Publishing; New York. Langdon, P E, Kehinde, T and Parkes, G (2020) 'Psychological therapies with people who have intellectual disabilities.' In: *Oxford textbook of the psychiatry of intellectual disability*. Oxford: Oxford University Press.

Appendix 2
Bild medication survey

Survey respondents

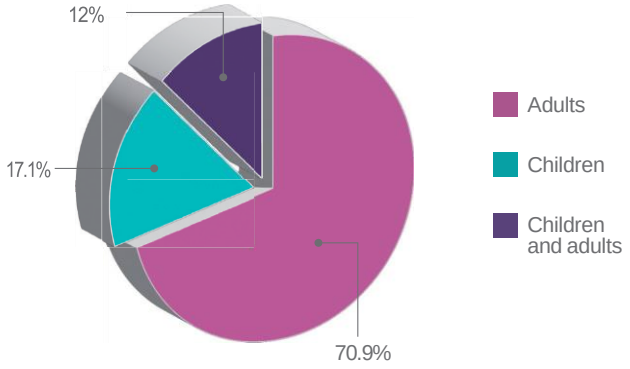
Figure 1: **Survey respondents**



There was a total of 120 respondents to the survey. Figure 1 shows the perspectives of those who completed the survey. 45% were healthcare professionals, 27% social care professionals and 12% educational professionals. The remainder were family carers and one person with a learning disability (10%) or responded as 'other' (6%).

About the people supported

Figure 2: **Age range of people with learning disabilities being supported by respondents**

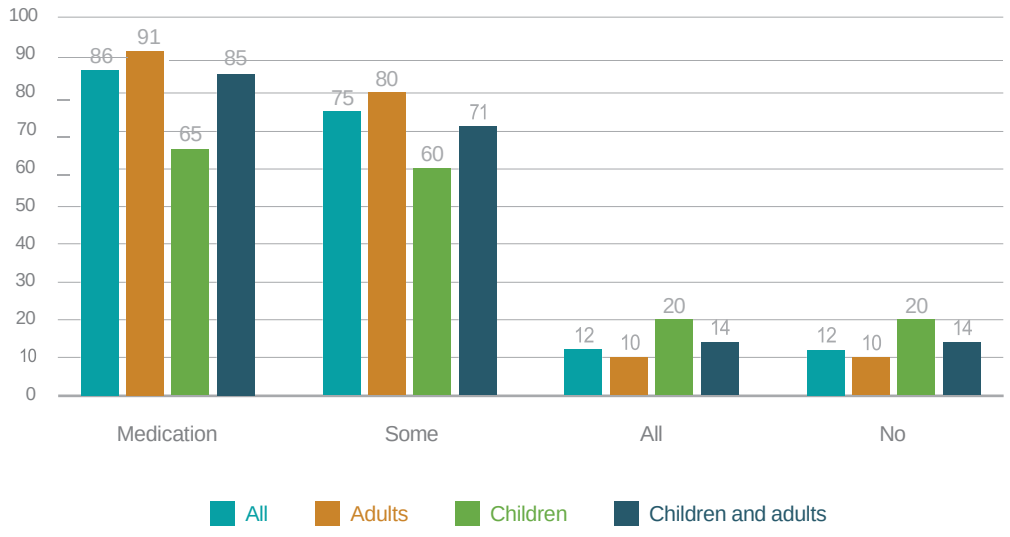


Survey respondents were supporting adults (over 18) with a learning disability (71%), see figure 2. The remaining respondents supported both adults and children (12%) or only children (17%) with a learning disability. 96% of survey respondents indicated that the people they supported exhibited behaviours of concern.

Use of medication for behaviours of concern and alternatives

Of the 120 survey respondents, 86% indicated that the person/ people they supported were taking medication to manage the behaviours of concern, 98% of whom said that the medications were prescribed (two respondents indicated this varied, either because they support a range of people or because the person they support has some medication prescribed and some not). When breaking this down by the ages of the people supported, it can be seen (figure 3 below), that respondents supporting adults with a learning disability reported the highest use of medication for behaviours of concern (91%), followed by 85% of respondents supporting both children and adults and, 65% for respondents supporting children with a learning disability. Some caution may be needed when interpreting the survey responses as it might be the case that more people supporting people taking medication responded to the survey as they had a greater interest than those supporting people who were not taking a medication.

Figure 3: **Percentage of respondents reporting that people they support are on medication and whether alternative interventions/approaches could be used**



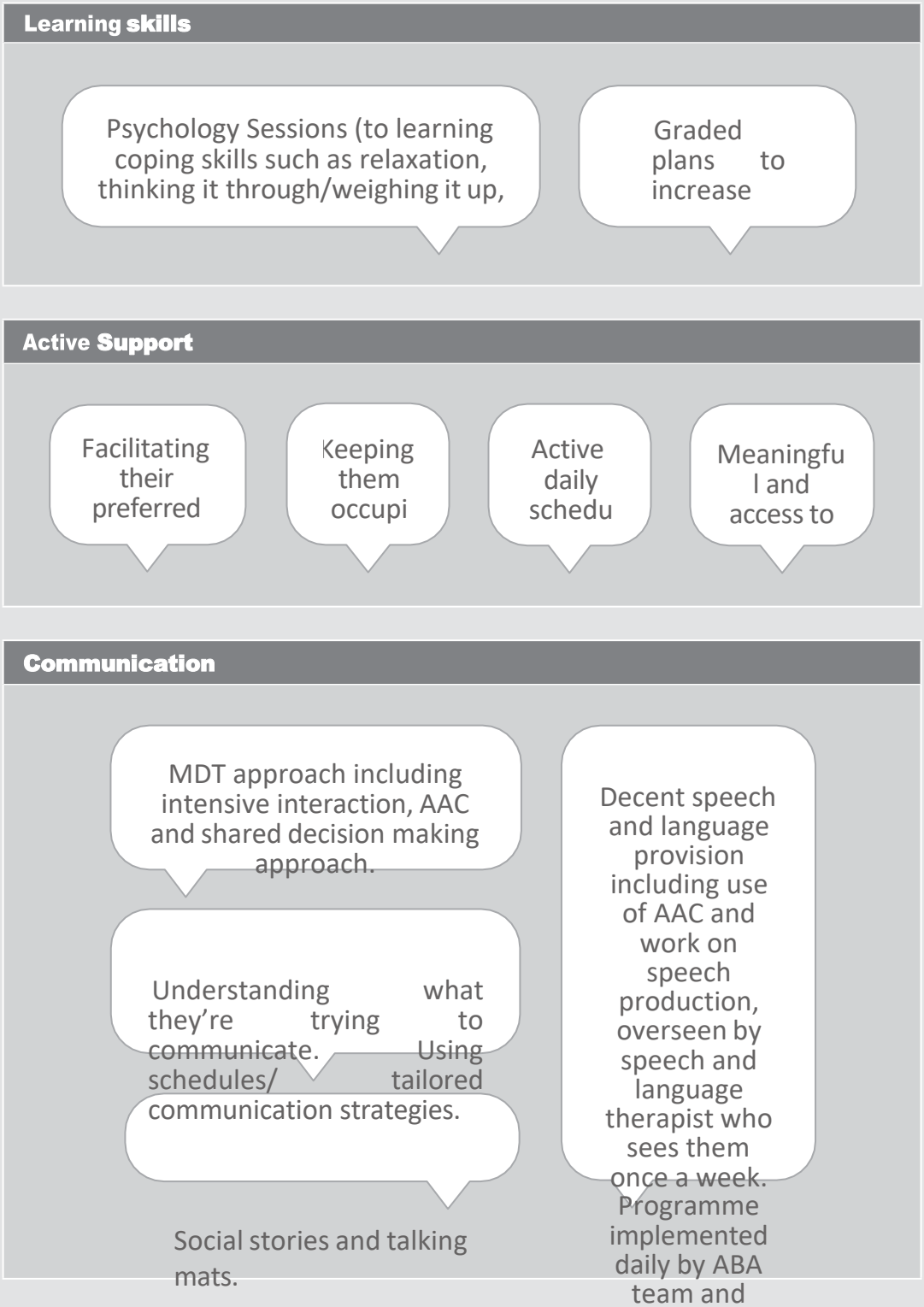
Survey respondents generally offered alternative strategies that might be utilised to help support the person/people whose behaviours challenge others (92%), the qualitative responses offered are summarised next. In suggesting alternative strategies 75% of respondents felt that these interventions/approaches could replace medication use on some instances, 12% felt they could replace medication for all cases and 12% felt that medication might still be needed alongside the alternative approaches/ interventions (represented by the 'no' responses in figure 3). A slightly higher percentage (80%) of respondents supporting adults felt that the suggested interventions/approaches could be used instead of medication some of the time, this figure was smaller for those supporting children and adults (71%) and smaller still for those supporting children only (60%). When considering if the interventions/approaches could be an alternative all the time the respondents supporting children more often reported this could be the case (20%), compared to respondents supporting children and adults (14%) and adults only (10%). The same proportion of respondents felt that medication may still be required alongside the alternative interventions/approaches, i.e., 20% for children, 14% for children and adults and 10% for adults only.

Suggested alternative interventions/approaches

Survey respondents suggested a range of alternative approaches and interventions (92% of respondents shared at least one alternative intervention they had tried), examples are provided in table 1 below. These could be organised into a number of broad thematic groupings. Firstly, suggestions focused on factors that could be grouped by the concept of capable environments, for example, teaching skills, good communication strategies, support for meaningful engagement, structure and routine, sensory approaches, ensuring choice, control and coproduction of a person's support. Also mentioned were the need for consistent support that avoids triggers, utilises data to inform practice, avoids use of restraint and restrictive practices, and ensures support and reflective space for staff. Linked to the idea of capable environments many respondents specifically mentioned Positive Behaviour Support or Applied Behaviour Analysis. In addition, other psychosocial and health related interventions were also shared. More broad responses were also given that related to positive approaches, kindness and improving quality of life. Finally, two family carers did not feel there were any effective alternative interventions. For one of the family carers this was linked to the scarcity of services to offer support and guidance.

Table 1. Quotes to illustrate the range of approaches and interventions as alternatives to medication.

Capable environments



Structure

Scheduled and non-scheduled talk time with staff, structured timetables (with clear visuals), visual activity planners.

A structured and clearly understood routine, knowing what is happening next and staff who are regular.

Sensory approaches

Movement breaks, considering sensory processing needs – not as effective as medication through low arousal techniques.

Decent occupational therapy provision, including sensory integration, overseen by occupational therapist who sees them once a week, programme implemented daily by ABA team and parents.

Coproduction, choice and control

Ensuring service users are fully involved in

Working with parents and other

Supporting the person to have as much control over

Person centred

Shared decision

DIRM principle (does it matter – strategic capitulation can be very

Avoiding triggers

Understanding the triggers and avoiding/ eliminating these.

Providing time and space for a person to 'reset' and move from fight/flight to social engagement.

Consistency of support

An agreed understanding with the person/involved others why a person is using a behaviour. An agreed understanding of a person's needs and outcomes and best approaches. Agreed consistent approaches in services and across the person's life. Consistent staffing wherever possible.

Data

Robust monitoring and reporting to analyse any patterns in behaviours that challenge.

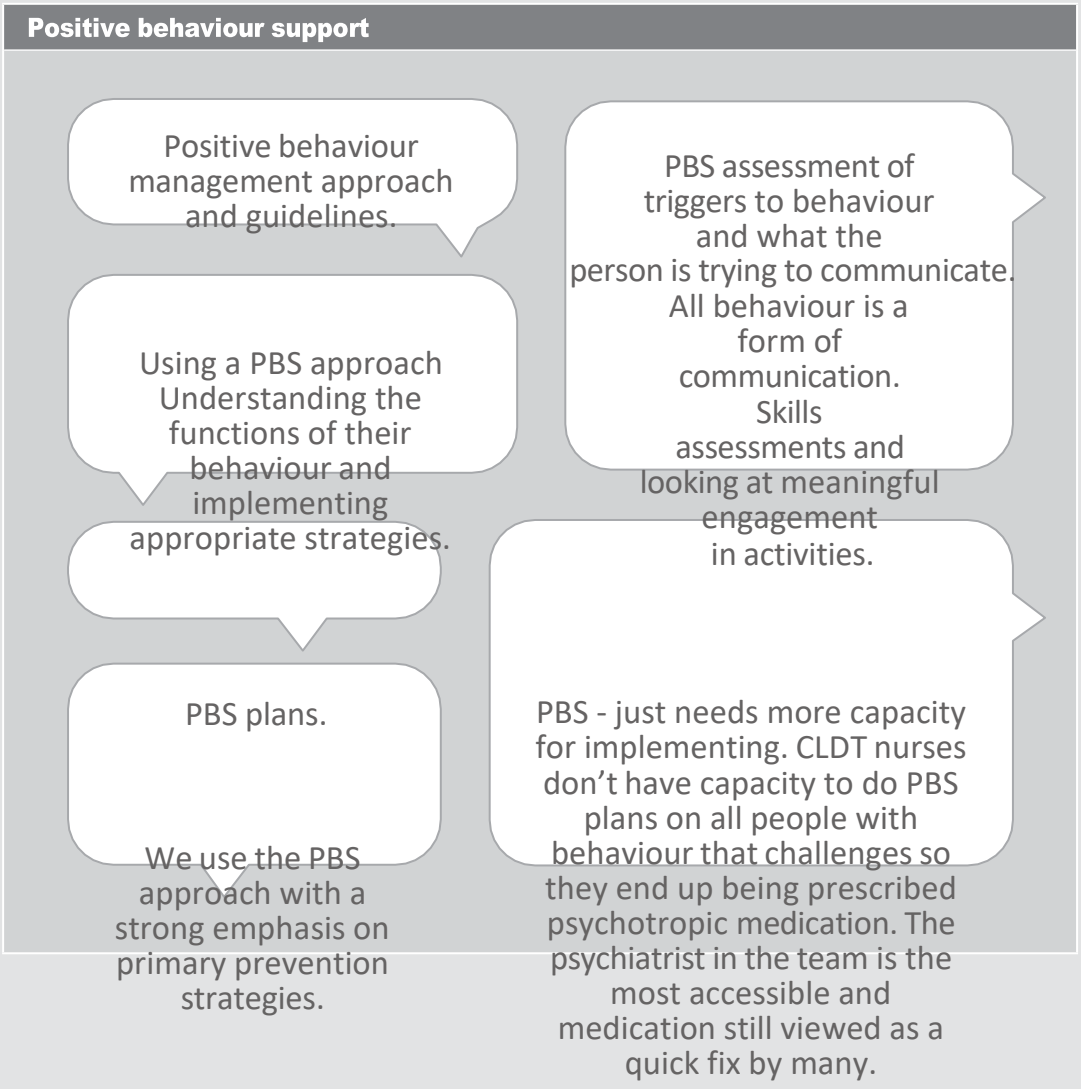
Reducing restraint and restrictive practices

Restraint reduction.

Support for staff and reflection

Staff debrief after an incident to reflect and support.

Positive Behaviour Support/Applied Behaviour Analysis

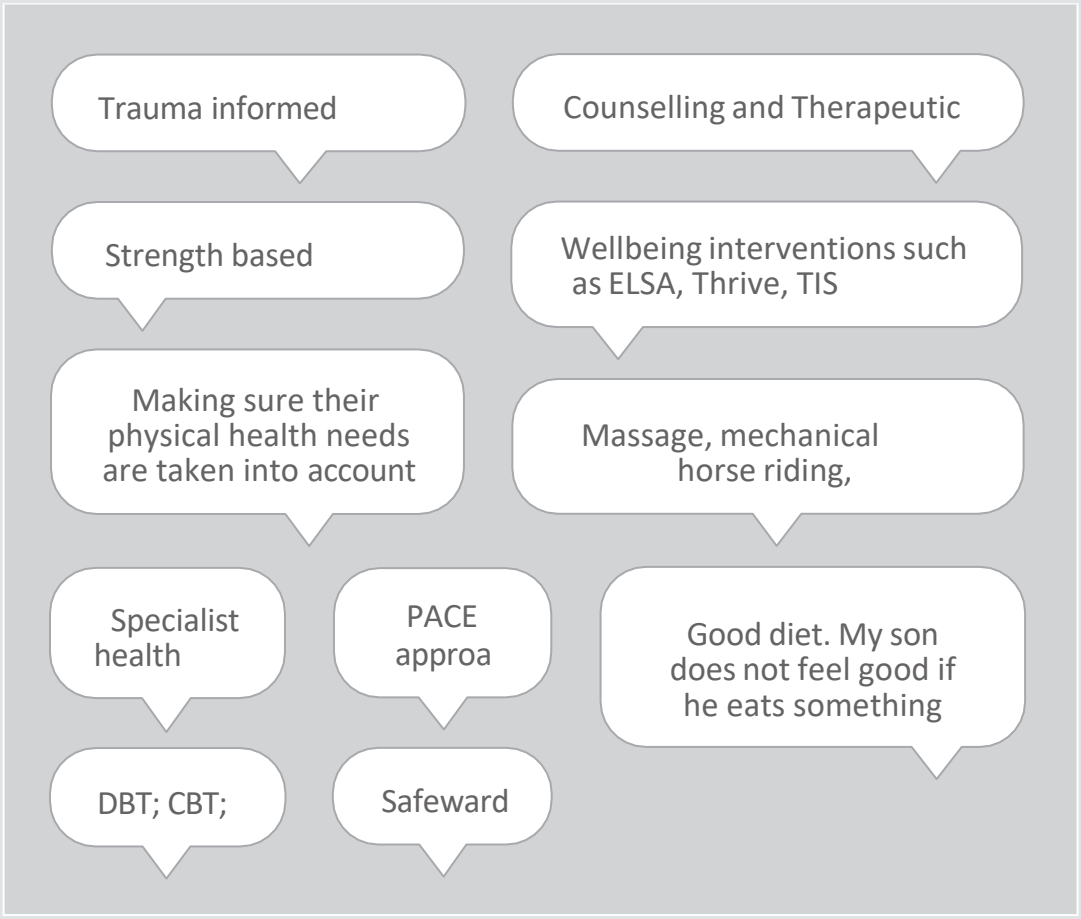


Applied Behaviour Analysis

Applied Behaviour Analysis - in school the ABA team collaborates with teachers, teaching assistants and other professionals to support teaching and learning for all pupils. The ABA team conducts assessments to understand why a learner may be engaging in behaviour that challenges. When we know what our learners are trying to communicate, we can teach them more appropriate ways to ask for what they want. The ABA team will support pupils as they learn how to cope

Bespoke programme of ABA interventions, with input from a speech and language therapist and occupational therapist, delivered by team trained to registered behaviour technician standard and overseen by a Board

Other interventions/approaches



Broad responses

Nothing is effective

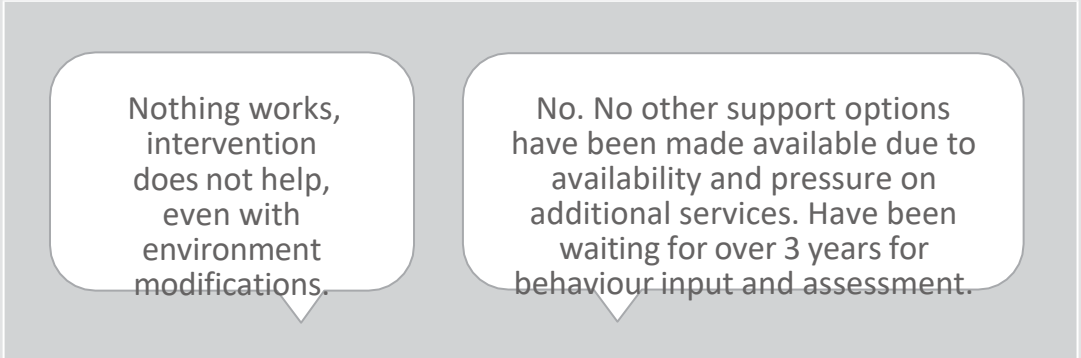
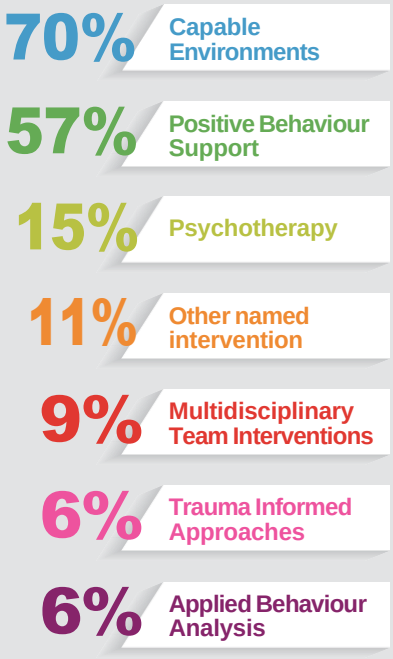


Figure 4:
Interventions and approaches used by survey respondents in Wales, ordered by frequency of citation



The qualitative data on alternatives were coded into broad thematic groupings which enabled a content analysis of the interventions people were using in Wales (see figure 4). Most frequently cited (70% of survey respondents) were approaches or interventions which can be grouped under the theme of capable environments (see table 1 for examples). Another highly cited intervention was Positive Behaviour Support or Behaviour Support Plans (57%). Psychotherapy was mentioned by 15% (this covers a range of therapies including DBT, ACT, CFT, Arts based psychotherapy). Other named interventions were mentioned by 11% of respondents (these included PACE approach, ELSA's, Thrive, TIS approach, mechanical horse riding, rebound therapy, CISS, CALDS, music therapy), also mentioned were multidisciplinary team intervention (9%) trauma informed approaches (6%) and ABA (6%).

For each of these approaches a content analysis is also provided by role type (see figure 5 below).

Figure 5: **Alternatives to medication by role type**

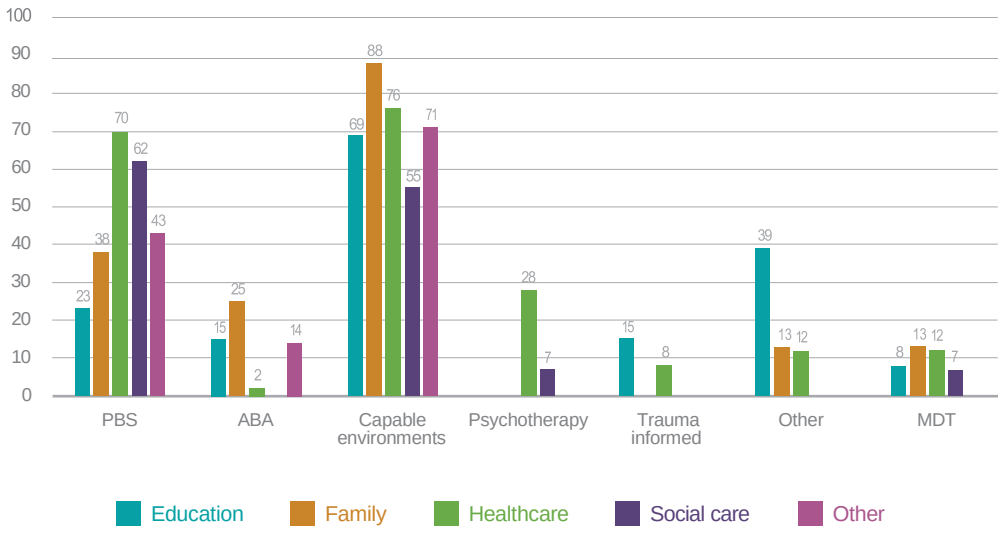
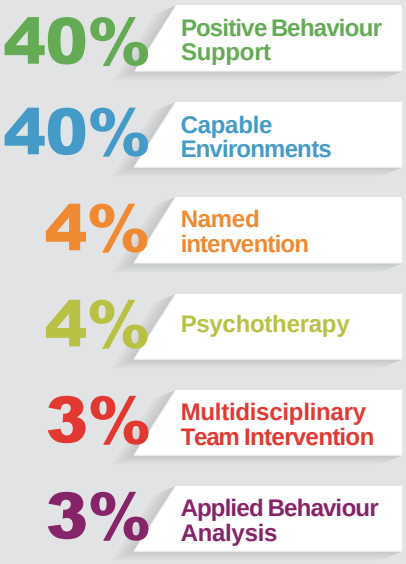


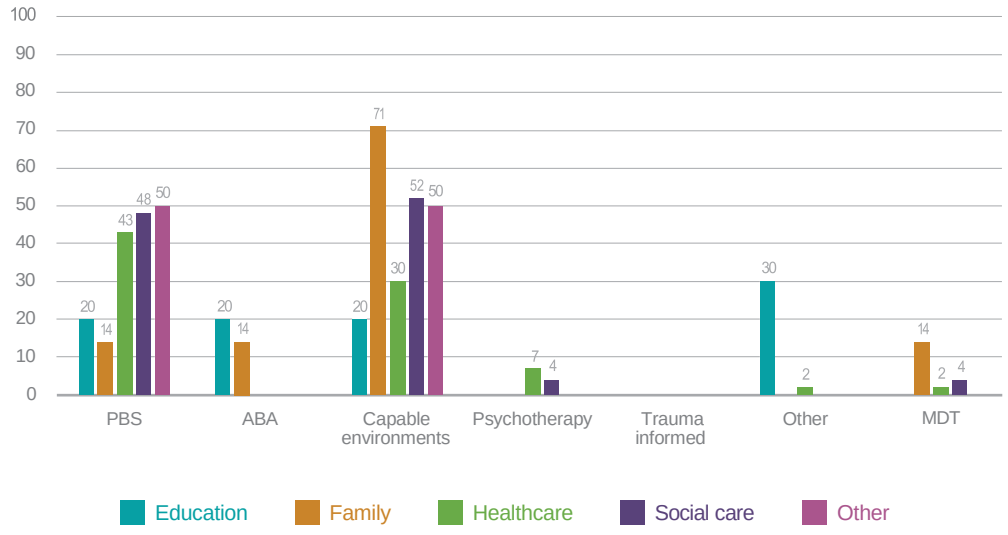
Figure 6:
Interventions and approaches felt to be most effective, ordered by requency of citation



Whilst participants offering a range of alternative options were asked to specify which intervention, they thought was most effective as an alternative to medication (see figure 6), 13% of respondents felt that they could not choose one and that it was the range of approaches and interventions in combination that were important or that different things worked for different people. Of those that were able to highlight just one or two key interventions or approaches that were most effective for addressing behaviours of concern (see figure 4), the majority emphasised Positive Behaviour Support (40%) or facilitating capable environments (a range of approaches, 40%). Aside from this, 4% offered another named intervention as most effective; 4% cited psychotherapy, 3% multidisciplinary team interventions and 3% Applied Behaviour Analysis. In figure 7 these have been delineated by role type.

Figure 7 below outlines the interventions and approaches thought to be most effective by role type.

Figure 7: **Most effective interventions/approaches by role type**



Some caution is needed in interpreting this data, for example:

- There are likely to be overlaps between PBS and providing capable environments and some approaches to PBS may include components of ABA.
- When people use PBS, this is a broad term for a range of approaches that may be used in combination and should look different for each individual.
- The fact that psychotherapy was mentioned by only 15% may reflect the sample that responded to the survey (i.e., it is likely both professionals and family members are supporting of caring for people who would not meet all of the pre-requisites to engage in some talking therapies).
- The sample for some role types are small (e.g., family and 'other') and as such the percentages only reflects the views of a small number of people.
- Finally, multidisciplinary teams are critical for the training, delivery and support for almost all of these interventions or approaches to greater and lesser extents and their role should not be undervalued even where not expressly mentioned by survey respondents. Of course scarcity of this resource may mean some people and their family have improvised and adapted what they can from online information about these interventions or learnt from trial and error (in particular approaches to providing a capable environment).