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What does good look like?

A guide for observing in services for people with learning disabilities and/or autism

Written by Julie Beadle-Brown and Bev Murphy, with input from Serena Brady, Nick Gore and the PBS Academy

1. INTRODUCTION

What is this resource?

This resource provides an overview of what good support looks like in services for people with learning disabilities and/or autism. The definition of "good" is based on both research and good practice and emphasises the nature and quality of the support needed to ensure good quality of life outcomes for people with learning disabilities and/or autism.

In addition to having basic needs met (e.g. physical needs, shelter, food and drink, dignity, safety), quality of life encompasses access to what Schalock and colleagues¹ call "life enrichers" – these are the things that UK policy often associate with quality of life:

- Social inclusion (including relationships)
- The opportunity to have new experiences, develop skills and gain in independence
- The opportunity to experience real choice and control and the opportunity to access our civil rights.

For those with learning disabilities and many of those with autism, support to access and make the most of the opportunities available is critical to achieving these aspects of quality of life.

This guide starts from the point that services are providing for individuals with a wide range of needs.

- Up to 90% of people with learning disabilities have communication difficulties, with around half having significant difficulties with both expressing themselves and understanding what others say²
- Approximately one third of people with a learning/intellectual disability living in a community setting will also have a diagnosis of autism³.
- As many as 15% of people with learning disabilities known to services show behaviour that may be considered challenging⁴.
- For those who also have a learning disability, challenging behaviour is often linked to their autism⁵.
- Between 40 and 70% of services, support at least one person who was rated by staff as showing severe challenging behaviour^{6,7}
- Between 42 and 53% of services, support at least one person with autism^{6,8}

- Recent research in community settings for people with learning disability by Tizard Centre and United Response⁶ has indicated that those with learning disability AND autism are significantly more likely to show challenging behaviour than those with just a learning disability:
 - 100% of those with a learning disability and autism were reported by staff to show some challenging behaviour (physical aggression, self-injury, destruction, hyperactive and inattentive behaviour or repetitive behaviour), compared to 78% of those without autism.
 - 50% of people with autism showed challenging behaviour rated as severe in terms of its impact on their quality of life, compared to 20% of those without autism.

This means that services have to be able to meet a variety of different needs in the people they support. In addition, there is substantial overlap between the approaches to support across different types of disabilities. This guide has at its foundation a holistic approach that starts with each individual and provides the right type of support to meet each person's needs. It focuses on four different elements, each of which provide increasingly specialised responses to individual needs:

- Support for engagement in meaningful activities and relationships
- Support for communication
- Autism friendly support
- Support for individuals who display challenging behaviour

Support for engagement in meaningful activities and relationships will be needed for everyone, although the nature of the support will vary by severity of people's disability. As noted above, for many people support for communication will also be required. Although ensuring the support and environment is predictable, reduces stress and supports independence is important for all people, such approaches are particularly important for people with autism. If services are providing these elements, the need for more intense or specialised support related to challenging behaviour is substantially reduced. However, for a relatively small number of people, more specialist approaches to supporting those who display challenging behaviour may be needed.

Each 'one' builds on the last – if outcomes are good for people being supported then what staff, managers and the paperwork show is less important. If outcomes are not good, then each level is important to work out where the problem might lie and how it can be rectified.

The guide is not intended to be a comprehensive overview of any one approach but rather a set of observable practice that can indicate that a service is implementing person-centred approaches such as person-centred active support, The National Autistic Society's SPELL framework, Total or alternative and augmentative Communication, and Positive Behaviour Support. However, useful sources of further information on these approaches have been provided in the Resource section. Specific Positive Behaviour resources are available on the PBS academy website, including the 'What does Positive Behaviour Support Look Like' observations checklist:

http://pbsacademy.org.uk/serviceinspection

For each of these four elements this guide will outline what good practice looks like and why each element is important. Evidence will be drawn from a number of sources:

- Observations of what the individuals being support are doing
- Observations of what staff are doing
- Observations of what managers are doing
- Systems and processes that are in place through records and talking to those present during the visit.

Who is it for?

The resource can be used by anyone who might observe a service. This includes formal inspectors (e.g. from the CQC), experts by experience, professionals, and researchers. There is a separate group of resources on the PBS Academy website for family carers and people with learning disabilities (see Additional Resources).

Where can it be used?

The resource applies to any setting that supports people with learning disability or autism. This can include residential services, assessment and treatment services, schools and colleges as well as providing a useful framework to assess the support provided by domiciliary, outreach or supported living services to people living in their own (or the family) home.

It is less likely to apply to secure forensic services, as some of the elements may be hard to effectively implement within the necessary constraints of the service. However, the resource could still be used in these settings with this borne in mind.

How does it fit?

With policy and good practice guidance

Both the outcomes identified above and the approaches described below are consistent with International conventions and UK policy. There are many relevant pieces of policy and guidance, for example:

- UN Convention on the Rights of Persons with a Disability
- The 2001 Valuing People white paper
- The 2007 Mansell Report on Challenging behaviour
- Valuing People Now (2009)
- Raising our Sights (2010)
- Positive and Proactive Care (2014)
- Think Autism (2014)
- Driving up quality code
- the Positive Behavioural Support Competence Framework (2015)

At the core of all of these, are the same outcomes and values identified above:

• Gaining in independence (through engagement in meaningful occupation and the opportunity to learn new skills, at home, in school, in education or in paid or voluntary work)

- Becoming more included in the community (as an individual and as a citizen)
- Experiencing real choice and control delivered through well-led services that provide personalised, positive and proactive approaches that respond to the needs of the individual and compensate for severity of disability or the presence of additional difficulties (such as physical or sensory disabilities, autism, health conditions such as epilepsy, or the presence of challenging behaviour).

With registration and inspection processes:

All four elements outlined in more detail below, are relevant to the following CQC Key Lines of enquiry used when inspecting services 9:

- Are they safe?
- Are they effective?
- Are they caring?
- Are they responsive to people's needs?

In addition, the final element focused on systems and processes supports the rating whether services are well-led.

How to use the resource

The resource can be used during observations to help the observer know what to look for and how to evaluate the service. It includes a number of key areas to look for, a rationale for why the area is important, and what you should see if a service is providing good support, and a checklist which helps you to rate a service based on what you observed.

2. SUPPORT FOR ENGAGEMENT IN MEANINGFUL ACTIVITIES AND RELATIONSHIPS Engagement in meaningful activities and relationships means taking part, rather than passively observing, activities or interactions. This is important as it ensures that individuals are able to take part in activities around them and to develop and maintain strong relationships and social networks.

Engagement in meaningful activities and relationships is likely to lead to opportunities to experience new things, to make choices and have control over your life. It fosters personal development, supports social interaction and inclusion, ultimately leading to improvements in physical and emotional well-being.

People with learning disabilities, particularly those with profound and multiple learning disabilities, are often passive by-standers in the activities and interactions going on around them, leading staff to have low expectations and provide few opportunities for people to demonstrate and or develop the skills they have. Having the opportunity to demonstrate and develop skills, often leads to changes in staff's beliefs about individuals competency and worth and gives those supported a sense of personal worth and identity. Such positive approaches and expectations are also important in developing the quality of life of people with Autism.

The shared activities and experiences associated with engagement in a range of activities and interactions promote the development of effective communication by giving both staff and those supported real things to communicate about. We also know that when people are more engaged they show less challenging behaviour, in particular repetitive, stereotyped behaviour.

Research tells us that there are only two factors that dictate how much time people spend engaged in meaningful activities and relationships: the level of ability of the person and whether or not staff are supporting them using an enabling style of interaction (active support).

Quick information:

Active Support booklet:

www.unitedresponse.org.uk/active-support-guide

Engagement in meaningful activities video: www.youtube.com/watch?v=cChw2D6wsm4

What does good engagement in meaningful activities and relationships look like?

The people being supported are:

Actively taking part in a wide range of activities around the home and in the community (not just watching others). This should include both social interaction and non-social activities.

Involved in ways that match their individual needs and preferences - not necessarily whole of the activity or on their own (e.g. doing small parts, stopping and starting, receiving graded assistance)

Involved in everyday choices (e.g. what to eat or drink, what colour sheets to put on their bed etc.), and the bigger decisions (such as where to live in the future, what staff they would like to support them, what job they might like to do etc.).

Controlling when/how things happen

Able to access food and drink of their choice, when they need and want it (except in exceptional circumstances e.g. if people have Prader-Willi syndrome, diabetes etc.)

In contact and interacting with friends and family members in a range of ways on a regular basis.

Going to places to meet other people with similar interests regularly as the basis to developing new relationships.

The staff are

Identifying opportunities for, and supporting people in a range of meaningful activities and relationships at home and in the community. This should include household, paid and voluntary employment, leisure, community and social.

Supporting interactions and relationships

Supporting people with just enough help and support to ensure success (including those with the most complex needs) – not too much otherwise people do not develop independence, not too little otherwise people will fail.

Supporting people to gain new experiences,

in small manageable chunks to supplement or gradually replace preferred, sensory orientated activities (e.g. twiddling, carrying things, childrens toys, passive activities such as watching cars go by) rather than taking them away.

Taking every opportunity to maximise people's choice and control (i.e. giving people lots of opportunities to make choices, support to understand the options and the opportunity to try new things).

Using a warm, respectful and positive style of interaction that enables and encourages people rather than being controlling, bossy, negative or disrespectful.

Keeping the people they support at the centre of what they do. Supporting people to be engaged and to achieve their potential / a good quality of life, should feel like and be reported as the most important thing that staff do.

3. COMMUNICATION

Many people with learning disabilities find it difficult to use or understand conventional methods of communication, such as speech, which often leads to individuals being misunderstood, experiencing failure and exclusion from events, activities and relationships. It is therefore important that each individual is supported to communicate and understand the communication of others using methods that are appropriate to their skills and preferences.

A lack of effective communication reduces an individual's ability to control their environment and influence other people, which can lead to frustration and result in challenging behaviour. It is sometimes possible to see a direct link between challenging behaviour and communication breakdown (e.g. when a person isn't able to communicate what it is they want). However, challenging behaviour may also result from repeated experiences of unsuccessful communication acts. Processing information presented verbally is difficult for everyone, but especially difficult for people with autism, who have difficulty with abstract concepts, literal understanding, sequences etc. Verbal communication is high arousal and therefore can exacerbate sensory overload. Using visual forms of communication to replace or accompany verbal communication plays to the visual and concrete strengths of people with autism.



Quick information:

Communication booklet: www.unitedresponse.org.uk/communication-resource

Communication video: https://youtu.be/yfq3EBjlibE

What does good communication look like?

The people being supported are:

Communicating use a range of methods which are individual to them and which staff notice and respond to.

Understanding other people's communication through the use of nonverbal, alternative and augmentative communication tools



The staff are:

Noticing when people are trying to communicate with them.

Supported people to develop and use communication methods which enable them to communicate with and understand other people. This may be through a range of methods (e.g. speech, manual signs, augmentative / alternative communication supports), but should be individualised – different people should have different forms of communication as people will vary in what works for them.

Using visual cues and a well organised environment to aid understanding and processing. This may include the use of gestures, objects, photographs, symbols, line drawings or other pictures, written words, or setting up the environment to ensure understanding by using labels and visual cues around the service.

Modifying their use of communication based on the individual's current needs (e.g. using less speech if the individual is agitated) as identified in communication passports or individualised communication plans.

4. UNDERSTANDING AND SUPPORTING PEOPLE WITH AUTISM People with autism often have particular needs which can relate to increased sensory sensitivity (e.g. to noise, light etc.), heightened anxiety (particularly in unstructured situations), difficulties understanding social interaction, and difficulties with planning and sequencing. There are a range of evidence based strategies for supporting individuals with autism and services should be aware of and trained to use such strategies as necessary. Each individual should be supported according to their own particular needs and preferences, in order to improve their quality of life. This section is based the SPELL framework, which was developed by the National Autistic Society in conjunction with people with autism, their families and professionals. It is a socially valid framework that supports the understanding of autism and the development of autism friendly environments and approaches. It is an individualised and person-centred approach that centres around 5 key elements:

- Structure
- **P**ositive Approaches and Expectations
- Empathy
- Low Arousal
- Links

The SPELL framework recognises the individual and unique needs of each person and emphasises that support, planning and intervention need to be organised on this basis. It promotes a number of interlinking themes known to be of benefit to people on the autism spectrum which build on individual strengths, reduce the disabling effects of the condition, increase the likelihood of engagement in meaningful activities and interactions and help form an ethical basis for challenging behaviour interventions.

Quick information:

More information about the SPELL framework: www.autism.org.uk/spell

SPELL framework video: https://youtu.be/jHrTjAOvY2k

What does good support for people with autism look like?

The people being supported are:

Comfortable and safe in their environment

Know what is expected of them and what is going to happen

Actively engaged in a range of activities and opportunities, not just special interest and/or self-stimulatory behaviours

Experiencing new activities as well as those that are familiar and routine

Included in and contributing to the local and wider community

Confident in expressing their views, wishes and personality

The staff are:

Using visual structure to help promote predictability, to share expectations, to help people be more autonomous in what they do, to help speed up processing etc.

Demonstrating positive approaches and expectations, working on the basis that people can do things if they are provided with the right amount and type of support – you should see people engaged, evidence that they get to try new things, the use of positive language. You might see staff using people's special interests to motivate them and support their development and participation.

Showing empathy - understanding and adapting their support to respond to how each person they support is affected by their autism, how they think and feel about the world, their sensory sensitivities, their specific strengths and weaknesses, their communication needs. Spoken language should be kept to a minimum or accompanied by written or picture forms of communication to promote understanding.

Providing a low arousal environment that responds to the sensory sensitivities of each individual (including in their own approaches to people – i.e. quiet, calm approach is normally seen as good practice); Attention to lighting and decor, sound, cluttered or disorganised environment, temperature. Environments need to be adjustable to suit the different needs of different individuals. People have a safe space to go to if they need a break.

Providing a highly consistent level of support with all staff working with any one individual in a similar way – the way that is documented in the support profile/plan as the person's preferred way – as well as working collaboratively with the individual where possible to develop treatment and discharge plans, working with others involved in the individual's life – their family, friends, other professionals, etc., and connecting the person to mainstream society with support for success.

5. SUPPORT FOR PEOPLE WHOSE BEHAVIOUR IS DESCRIBED AS CHALLENGING Where displayed, behaviours that challenge are known to have a significant negative impact on an individual's quality of life. Best practice and evidence says that such behaviour is functional; this means it allows the individual to access something they need, or to escape something that is unpleasant.

Positive Behaviour Support requires services to assess the function of behaviours that challenge in order to develop positive, evidence based supports to prevent and reduce behaviour. This should involve modifying the environment and support to make behaviour less likely, supporting people to be engaged in a range of meaningful activities and relationships, teaching the individual new skills to ensure that they have an alternative way of meeting their needs, and managing behaviour safely if it does occur. A key feature of Positive Behaviour Support is its rejection of punishment as an effective or acceptable response to challenging behaviour.

Positive Behaviour Support focuses primarily on prevention strategies and must include:

1. Details of the **Proactive Strategies** staff use to reduce, over time, the need for the person to behave in ways which are challenging

2. Details of the **Reactive Strategies** to be used to respond to a person's challenging behaviour when it occurs, with the least restrictive strategies first. This plan must outline if and when restrictive interventions (including chemical, mechanical and physical restraint) should be used, the nature of the intervention and what to do afterwards.

Many of the preventative strategies related to environmental modifications and teaching skills identified as part of Positive Behaviour Support are addressed by the approaches described in other parts of this booklet (i.e. Active Support, Effective Communication, The SPELL Framework).

Quick information:

Positive Behaviour Support Booklet: www.unitedresponse.org.uk/positive-behaviour-support-guide

Positive Behaviour Support video: www.youtube.com/watch?v=epjud2Of610

Positive Behaviour Support in practice video: www.youtube.com/watch?v=uz9Am-7kVYg

What does good support for people whose behaviour is described as challenging look like?

The people being supported are:

Including in a range of activities which are matched to their ability (not too simple, not too difficult) and experiencing success

Being supported positively despite the presence of challenging behaviour



NB: If Positive Behaviour Support is well implemented, you should see little evidence of challenging behaviour.

The staff are:

Actively supervising each individual (move, scan, interact) to avoid incidents of challenging behaviour

Ensuring the physical environment and support area are modified to meet the needs of the individual

Ensuring activities are matched to the ability of individual (not too simple, not too difficult), and that the individual experiences success in activities

Ensuring transitions between activities are efficient and orderly for the individual

Using skills teaching to enable the individual to learn skills that replace challenging behaviour (e.g. communication) in meeting their needs.

Rewarded and encouraged positive behaviour (e.g. attention, praise, access to activities)

Noticing if people are getting anxious or agitated, checking if they are ok, intervening early to distract or give people a break (not seclusion). You might not realise that is what you are seeing but you can ask staff about what had been happening afterwards.

Responding to verbal and non-verbal communication

Managing behaviour in compassionate and respectful ways that maintain the safety of everyone involved.

Offering a rest, a change of activity or a different approach to support, as listed in the individual's behaviour support plan if challenging behaviour occurs, rather than complete withdrawal of activity or punishment (including verbal reprimands)

Only using restrictive interventions as a last resort and in line with the individual's behaviour support plan.

What does good look like?

6. SYSTEMS, PROCESSES AND LEADERSHIP

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Effective services are underpinning by effective systems, processes and practice leadership.

Systems and processes are needed to ensure effective use of the resources available, consistent ways of working and effective reviewing. Effective planning for the individual's supported (through person centred planning and reviews) and the development of staff's skills and knowledge (through coaching and training) need to be focused on continuing to improve the quality of life and quality of support provided. But good systems and processes are not enough.

Quick information:

Practice Leadership Booklet:

www.united response.org.uk/practice-leadership

What is Practice Leadership video: https://youtu.be/Hx4j7f3WYHE

Practice Leadership and Role Modelling video: https://youtu.be/LrZMvcuOmeo **Practice leadership** has been identified as a critical component in ensuring the delivery of high quality person centred services.

Practice leadership is defined as the development and maintenance of good staff support for the people served through:

- **Focusing** in all aspects of our work on the quality of life of the people we support and how well staff support this.
- Allocating and organising staff to deliver better support, when and how the people we support need and want it.
- **Coaching** staff to deliver better support by spending time with them providing feedback and modelling good practice
- **Reviewing** the quality of support provided by individual staff in regular one-to-one supervision and finding ways to help staff improve it.
- Utilising regular team meetings to review how well the staff team are enabling the people we support to engage in meaningful activities and relationships and to find ways to improve.

Who is the Practice Leader?

Job titles can be confusing - the practice leader is the person who has day-to-day oversite of the support being provided. Often called the Service Manager or Team Leader this person has authority/ capacity to organise team meetings, lead supervision and coaching within the team, organise day to day resources and routinely work where support is being provided.

What do good systems, processes and leadership look like?

Managers/Team Leaders are:

Developing a shared vision and commitment within the team – with a clear focus on the people being supported.

Maximising the use of resources both internal (budget, staffing hours and equipment) and external (community projects, social networks and volunteers)

Ensuring individual tools and resources are available and in use consistently (e.g. Communication aids, assistive technology)

Ensuring daily planning systems are used consistently and reviewed on a regular basis

Routinely modelling the behaviour and skills expected of staff and frequently observing and giving feedback on staff's practice.

Utilising information from formal and informal reviewing processes to discuss and establish individual and collective action to improve individual's quality of life and/or the quality of support being provided.

Utilising team meetings to review, develop consistent approaches, problem solve, celebrate success, action plan and motivate the staff team.

Ensuring supervisions are focused on

the support provided and the continued development of staff's knowledge, skills and confidence.

Systems and processes are in place to:

Provide a responsive and flexible plan for what's going to happen throughout the day, which are communicated and accessible to people being supported, staff and others.

Produce relevant, up to date, individualised support plans, which are based on appropriate assessments (i.e. identify strengths and support needs rather than focusing deficits/weaknesses) in the following areas (as appropriate)

- Skills and interests
- support preferences
- health and physical needs
- Communication
- sensory issues
- behaviour

Provide evidence-based monitoring and

reviewing of quality of life outcomes for those supported including

- health and wellbeing
- behaviour/use of restrictive intervention
- levels of engagement/activities and check that activities actually happened.
- relationships and developing social networks
- skill development
- empowerment, community involvement and citizenship

Ensure the provision of training for all staff

including core and statutory training (e.g. health and safety, care certificate), person centred approaches (e.g. Active Support, Communication and PBS), and service specific training (e.g. Autism, Epilepsy)

Involve the individuals being supported and those who care about them in planning and reviewing support and quality of life, including the achievement of specific goals.

7. THE OBSERVATION PROCESS

Observation might involve:

- Observing people
- talking to people about their experiences of support
- talking staff (and others) about the support they provide
- looking at records and plans

When & how long to observe

The ideal time to observe is leading up to a meal time – perhaps an hour leading up to lunch and an hour leading up to the evening meal. The reason for this is that research has shown that this period of time is the richest in opportunities for engagement and for choice – if people are not engaged and empowered during this period of the day, then it is highly unlikely that they will be engaged and empowered at other times. This period is also a time where you will have the opportunity to observe staff attitudes and their management of risk. It will become clear whether it is a risk averse culture or an enabling culture based on risk management. It also allows you opportunities to observe communication, and whether staff are using visual structure etc. appropriately.

Quick information:

Why is observation important video: https://youtu.be/FZyySEnicHw Observers should spend ideally 2 hours formally observing during a visit – especially in larger services. In smaller settings (2 people or less) they should aim for two half hour sessions. But even if you don't have this long you can still use this tool to structure your observations and feedback whether you have 15 minutes or 2 hours.

- you might select one or two sections of the checklist (e.g. engagement & communication) because you feel more confident in observing/ commenting on this or want to find out more about them
- you might select certain sections because your information so far indicates a need to focus on this
- you might use all the sections and complete as much as you can in the time available

Top tips for observing:

- Ensure staff and the people being supported (as much as possible) know who you are and why you are there
- Walk into the room to a position where you can observe the person being supported, avoid eye contact with anyone and stand as still as possible.
- Wear flat, soft-soled shoes that will not make a loud sound on stairs or hard floors. Close doors carefully. Do not handle materials, move objects or otherwise intervene in the environment unless someone's safety is directly threatened.
- Do not go into rooms where a person might be reasonably expected to be asleep in bed, undressed, or working with a member of staff on an activity which might be disrupted by another person coming in.
- Once you have finished observing, put away your checklist (and/or notepad) and tell everyone that the observation has finished and spend some time talking about what you have seen during the observation and/or giving people an opportunity to check out some of the things they may have like to discuss/explain during the observation.

How to observe

During the observation, you should attempt to capture a picture for as many people as possible who are supported by the service. In larger settings you might need to include just a sample. Ideally you would want to include in the observation those who are recorded or identified by staff as showing severe challenging behaviour and for whom seclusion or restraint (physical, mechanical or chemical) is being used. However, you also want to include some of the "quieter" people – as they are often the people who are neglected, often inadvertently, as staff focus on the people who show or have potential of showing challenging behaviour. The best sample strategy is generally to rotate around those in the environment focusing on each individual for a set amount of time (e.g. 5-10 minutes) but of course sometimes this isn't possible dependent on the environment and the individual. As such the key thing is to try to get a sense of what is happening for, to and around as many individuals as possible during the course of your visit.

Be careful to also pay attention to what staff doing. You will find it useful to make some notes as you go – write down in particular examples of what you hear staff say and how they communicate with the people they support. Note whether staff are interacting with the individual or doing other things.

In addition to the formal observation, you will also be able to draw on your informal observations, your conversations with staff and with the people being supported and also on your perusal of plans and records in completing the checklist below. You ideally would complete as much as you could of the checklist after a formal observation period but then would firm up your ratings at the end of the day, having talked to people and consulted plans and records.

It is really important that you rate what you actually see, without making adjustments for the perceived level of ability, or the perceived level of challenging behaviour or difficulty faced by staff. The checklist contains things that we know can be achieved even for those with the most severe and complex needs. Many environments prevent these things happening – in particular bigger more restrictive services, make it really difficult for staff to be individualised, enabling and empowering in their approach. However, it is important to record reality so that we can get a true picture of what is happening in all services and help services to improve the outcomes experienced by the people they support.

For each of the	following statements, ra	te how true the item is c 2	on the follow	wing scale:		
Not Seen	Could do much bette			Lots of strong po hard to do bette		
ITEM			SCO	RE		
	eople engaged in ful activities and re	elationships?	0	1	2	3
Things to	o consider	Working		Not	Working)
supported for themse possible – e care things themselves face, servin table? Do you see part (with o support) in real and ag activities ar service – ho education, Is there evio regularly ge shopping, I work, socia the local co Are people active in th just sedent. Is there a ra things avail environmer independer Do people contact wit and friends visits of fan home and	a range of e appropriate ound the pusehold, leisure, gardening, social? dence that people et to access eisure, education, al activities out in ommunity? supported to be eir activities, not ary activities? ange of lable in the nt for people to do					

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Not Seen	Could do much bette	er Strong points bu improvement ne			of strong po I to do bette		
ITEM			SCC	ORE			
	aff consistently sup Ils to engage and o		0		1	2	3
Things to	o consider	Working			Not	Workin	g
empowerin participate their lives, or methods ar as preferred support pro- Are they us verbal com communica to supplem communica necessary re communica Are staff no responding to communica ls it clear the is based on and an agre	munication, ation aids etc. ent verbal ation or if eplace verbal ation? oticing and when people try nicate? nat communication an assessment eed plan for that that all staff use						

For each of the	e following statements, ra 1	te now true the item is c	on the toll	owing	y scale:			
Not Seen	Could do much bette	er Strong points bu improvement ne			s of strong po d to do bette			
ITEM			SCO	ORE				
supporte	e an accessible wa ed and staff to kno ng that day?		0		1	2		3
Things to	o consider	Working			Not	Work	ing	
helps peop going to ha the next fe will be sup Does this re is actually of the time? If reasonable not? E.g. il or they req something later etc. Is this indiv each perso and their p	ual structure that le predict what is appen at least over w hours and who porting whom? elate to what going on at f not is there a explanation why lness of individual, uested to do different, or to go idualised so that n has their routine lan reflected, not an for everyone?							

	10110001119 statements, ra	te how true the item is c	on the folic	wing sc	ale:			
Not Seen	Could do much bette	r Strong points bu improvement ne			strong po do bette			
ITEM			SCC	ORE				
	aff supporting pec ce real choice and		0		1	2	3	3
Things to	o consider	Working			Not	t Workir	ng	
Are people do they have than one of from as the day? Do they have control as p activities un order they long they do Do they have of food, drive room is dece in terms of their own p possessions Do they have when familivisit? When people activities or food that is day are state	being offered/ ve available more ption to choose by go through the ve as much possible over how fold – e.g. the do things, how lo them for etc. ve choice in terms ink, how their corated at least soft furnishings, personal s etc.? ve choice about y and friends can ble request even a particular s not available that ff dismissing their supporting them							

0	1	te how true the item is c		Jvving	3			
Not Seen	Could do much bette	r Strong points bu improvement ne			s of strong po d to do bette			
ITEM			SCC	DRE .				
and posit	aff warm, respectf tive towards the p and their families?	eople they	0		1	2		3
Things to	o consider	Working			Not	Worki	ng	
Are staff us respectful la Are staff wa appropriate interactions Do staff tre dignity? Do staff hav expectation they suppor on the basis can and wil all areas of enough sup Do staff use approaches interactions – calm, foct	ing positive, anguage? arm and in their ? at people with ve positive as for the people rt – do they work s that people Il participate in their lives with oport? e low arousal in their s with people used, paying o people's sensory							

0	1	te how true the item is c 2		wing	3		
Not Seen	Could do much bette	r Strong points bu improvement ne			of strong po to do bette		
ITEM			SCO	RE			
might be so do sta	eople showing any described as chall ff respond with st it with Positive Bel	lenging and if rategies	0		1	2	3
Things to	o consider	Working			Not	Workin	g
Is restraint of resort? Do staff app successfully strategies to frequency a challenging Are staff vio people's rea attention to communica identifying becoming of upset or fru	pear to be r using proactive o reduce the and severity of behaviour? gilant, watching actions, paying o their non-verbal ation, quickly if someone is over-aroused, ustrated and then ffuse the situation						

For each of the	e following statements, ra	te now true the item is c	on the follov	ving scale:		
Not Seen	Could do much bette	r Strong points bu improvement ne		Lots of strong po hard to do bette		
ITEM			SCOF	RE		
7. Do yo	u see evidence thand wellbeing need		0	1	2	3
Things to	o consider	Working		Not	Workin	g
health care	person have a plan? dence that people					
are support	ted to access and specialist					
kept relatin wellbeing?	ehensive records og to health & e.g. medication ctors' visits, health dures etc.					
	viduals supported their own health ing?					
lifestyle wh	courage a healthy ilst respecting an right to live the ey choose?					

ľ		1	te how true the item is c	on the foll	owing	y scale.			
	Not Seen	Could do much bette	r Strong points bu improvement ne			s of strong po d to do bette			
I	ITEM			SC	ORE				
	based on individua and skills	ff identify skills tea what is importan I, developing their relating to the fu rs which challeng	t to the independence, nction of any	0		1	2		3
	Things to	o consider	Working			Not	Work	ing	
	skills teachi	e systematic ng procedures, ting, modelling, .?							
		ught in a range of Its with a range of							
	(which may	individual teaching plan be part of their upport plan)?							

for each of the	1 1	te how true the item is c 2	on the follow	ang scale:		
Not Seen	Could do much bette	r Strong points bu improvement ne		ots of strong po hard to do better		
ITEM			SCOR	E		
assessme	e evidence that a r ents are conducted nd the results used support?	for each	0	1	2	3
Things to	o consider	Working		Not	Working	9
necessary? Is ongoing about a ran e.g. quality communica engagemen activity, cha behaviour e Are plans fo	s are repeated as data collected age of outcomes, of life, ation, skills, at in meaningful allenging etc.?					

	1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	te how true the item is o	on the foll	owing	scale:			
Not Seen	Could do much bette	r Strong points bu improvement ne			s of strong po d to do better			
ITEM			SC	ORE				
supporte their supp planning they can meetings	ere evidence that in d to be involved ir port (including ass and reviews) in w (e.g. through taking or having their pr and respected?	n all aspects of sessments, hatever way ng part in	1		2	3		4
Things to	o consider	Working			Not	Work	ing	
stakeholder family carer support wo if necessary all elements support, inc planning, al Are stakeho the individu to provide f service, and used to imp celebrate go Are stakeho	s, friends, rkers, specialists) are involved in s of an individual's cluding assessments, nd reviews? olders (including tal themselves) able feedback to the l is this feedback prove support and bod practice? olders provided g in aspects of the							
	dence that is are offered their emotional							
individuals can be invo the organisa recruitment	dence that is (including the who use the service) lved in shaping ation, e.g. on panels, steering viding feedback on							

Not Seen Could do much better Strong points but improvement needed Lots of strong points, hard to do better 11. Do you see senior staff and managers leading good practice? 1 2 3 4 Things to consider Working Not Working Are senior staff visible with staff rather than being in the office? Not Working Do they show skills in supporting people in person-centred approaches? Not working Do they take opportunities to give feedback to staff, to model appropriate behaviour if needed? Are they conducting regular, useful supervision with staff and supporting the team to keep the person they support at the centre of what they do through team meetings etc.?	0	following statements, ra	2		3		
11.Do you see senior staff and managers leading good practice?1234Things to considerWorkingNot WorkingAre senior staff visible with staff rather than being in the office?Not WorkingImage: Second	Not Seen	Could do much bette	51		• •		
Ieading good practice? Not Working Things to consider Working Are senior staff visible with staff rather than being in the office? Not Working Do they show skills in supporting people in person-centred approaches? Do they take opportunities to give feedback to staff, to model appropriate behaviour if needed? Are they conducting regular, useful supporting the team to keep the person they support at the centre of what they do Image: Content of the support at the centre of what they do	ITEM			SCOR	RE		
Are senior staff visible with staff rather than being in the office?Do they show skills in supporting people in person-centred approaches?Do they take opportunities to give feedback to staff, to model appropriate behaviour if needed?Are they conducting regular, useful supervision with staff and supporting the team to keep the person they support at the centre of what they do	-		and managers	1	2	3	4
staff rather than being in the office?Do they show skills in supporting people in person-centred approaches?Do they take opportunities 	Things to	o consider	Working		Not	Worki	ng
	staff rather office? Do they sho supporting person-cent Do they tak to give feec model appr needed? Are they co useful supe and suppor keep the pe at the centr	than being in the ow skills in people in tred approaches? the opportunities black to staff, to opriate behaviour if nducting regular, rvision with staff ting the team to erson they support re of what they do					

0	1	2	3
Not Seen	Could do much better	Strong points but improvement needed	Lots of strong points, hard to do better

uestions & Notes	
Marking	Not Marking
vvorking	Not Working
	Working

8. FURTHER RESOURCES

For more information on person centred approaches, see this DVD produced by United Response and Tizard, available at www.unitedresponse.org. uk at a subsidised cost of £15. You can also download the suite of Best Practice resources.



For more video clips, go to You Tube and look on the Person centred Support channel. www.youtube.com/channel/ UCeeTvLnOkjRj5M6715orqdg

For more information on the fit between Active Support and

PBS - see the Positive Behaviour Support and Active Support booklet developed by the Tizard Centre, Avenues Trust and United Response:

www.unitedresponse.org.uk/transforming-care

Positive Behavioural Support

animation, available at www.bild.org. uk/our-services/positive-behaviour-support/ capbs/pbsinformation/pbsvideos/introductionto-pbs/

For Positive Behaviour Support information and resources for a

range of people, including for family carers, people with learning disabilities, support workers, service provides, and commissioners available go to: http://pbsacademy.org.uk/

For the 'What does Positive Behaviour Support look like'

Checklist go to: http://pbsacademy.org.uk/ service-inspection/

9. FURTHER READING

Beadle-Brown, J., Leigh, J S, Whelton, R., Richardson, L., Beecham, J., Bäumker, T. and Bradshaw, Jill (2015) Quality of life and quality of support for people with severe intellectual disability and complex needs. *Journal* of Applied Research in Intellectual Disabilities, early online. https://kar. kent.ac.uk/48663/1/SS%20QoL%20 and%20QoS%20for%20JARID%20 submitted%2008012015%20for%20 self%20archiving.pdf

Department of Health (2014). Positive and Proactive Care: Reducing the Need for Restrictive Interventions. London: Department of Health. Retrieved from www.gov.uk/government/uploads/ system/uploads/attachment_data/ file/300293/JRA_DoH_Guidance_on_ RP_web_accessible.pdf

Mansell, J., & Beadle-Brown, J. (2012). Active Support: Enabling and Empowering People with Intellectual Disabilities. London, UK: Jessica Kingsley Publishers.

10. REFERENCES

¹ Schalock, R., Brown, R. T., Cummins, R., Mattkka, L., Felce, D., & Brown, I. (2000). Conceptualization, measurement and application of the concept of quality of life: a consensus document symposium. *Journal of Intellectual Disability Research*, 44, 452-452.

² Royal College of speech and language therapists (2013) *Five good communication standards: Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings* (www.rcslt.org/ news/docs/good_comm_standards)

³ Emerson, E and Baines, S (2010) *The Estimated Prevalence of Autism among Adults with Learning Disabilities in England Learning Disability Observatory* www.improvinghealthandlives.org. uk/uploads/doc/vid_8731_IHAL2010-05Autism.pdf

⁴ Sigafoos, J., Arthur, M., & O'Reilly, M. (2003). *Challenging behavior and developmental disability.* London: Whurr.

⁵ National Autistic Society. *Challenging behaviour* www.autism.org.uk/ challengingbehaviour retrieved 20/07/2016.

⁶ Beadle-Brown, J. & Murphy, B. (in preparation) Understanding the relationship between autism and challenging behaviour: the implications for support

⁷ Mansell, J., Ashman, B., McDonald, S and Beadle-Brown, J (2002) *Residential care in the community for adults with intellectual disabilities: needs, characteristics and services.* Journal of Intellectual Disability Research, 46 (8). pp. 625-633

⁸ Reanalysis of data reported in Netten, A., Beadle-Brown, J., Trukeschitz, B., Towers, A-M., Welch, E., Forder, J E., Smith, J E. and Alden, E (2010) *Measuring the outcomes of care homes.* Personal Social Services Research Unit http://kar. kent.ac.uk/27331/

⁹ Care Quality Commission (2015). *How we inspect and regulate: A guide for providers.* Retrieved from www.cqc.org. uk/content/how-we-inspect-and-regulateguide-providers