

What does good support active support and positive behaviour support look like?

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Outline

- What does "good" look like?
 - Outcomes
 - Processes
- How do different processes work together?
- Indicators of good support
- "What does good look like" checklist

What should good services deliver?

Positive outcomes = better quality of life

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Quality of life domains

emotional well-being: *Feeling safe, happy, satisfied, having a sense of self-esteem. Helped by having safe, stable and predictable environments; positive feedback and opportunities to succeed.*

interpersonal relations: affiliations, affection, intimacy, friendships, interactions

material well-being: adequate and appropriate accommodation; ownership, possessions, employment; income.

personal development: Purposeful activities, learning new skills and knowledge, education .

physical well-being: health care, mobility, wellness, nutrition

self-determination: choices, personal control, decisions, personal goals

social inclusion: natural supports, integrated environments, participation

Rights: privacy, dignity, barrier free environments, contributing to society

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Quality of life domains....

- inter-related and intertwined
- outputs and outcomes/objective and subjective

Outputs	Outcomes
Physical well-being	
<ul style="list-style-type: none"> • Sees their doctor and other health professionals as needed • Has annual health check • Has a healthy diet • Gets exercise 	<ul style="list-style-type: none"> • Is physical well and fit. • Feels well • Can move around (may be assisted or using aids)
Emotional wellbeing	
<ul style="list-style-type: none"> • Gets treatment of mental health conditions as needed • Experiences success • Low stress environment 	<ul style="list-style-type: none"> • High self-esteem • Low levels of CB • Feels safe • General satisfaction with life/happiness
Personal development	
<ul style="list-style-type: none"> • Goes to school or college or has other opportunities to learn and develop new skills • Has new every day as well as more exciting experiences 	<ul style="list-style-type: none"> • Becoming more independent (even if the steps are small)

What does quality of life look like in practice?

- Being present AND Taking part 
- "Engagement in meaningful activities and relationships"
 - Doing something constructive with materials
 - Interacting with people – talking, watching and listening when someone is talking to you, showing, making eye contact and smiling
 - Taking part in a group activity – playing football etc.

Engagement is both an indicator of quality of life and a route to a better quality of life. Improving quality of life is key to reducing challenging behaviour.

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Engagement

- Needs to be active not just passive – not just observers or eavesdroppers
- Need a balance between things the person currently enjoys which may be passive (watching the sun going down, having a massage) or repetitive and new things in which the person is more actively involved.
- It is about adding not subtracting
- Ideally should be age appropriate and real – something that improves quality of life
- Doesn't have to be a whole task or interaction – can be brief or partial, stop-start, leading or just joining in.

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Why is engagement important – promoting Quality of Life?

- "Inactivity withers the body, and the mind" – engagement is good for us – physically and emotionally
- People show adjustment and happiness when they are engaged
- Experience underpins development
- It provides the basis for friendship and being together
- Engagement allows us to show who we are and what we can do
- It is the means by which we look after ourselves and those who we care about

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Quality of life

WHAT MAKES THE DIFFERENCE?

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What is needed for better quality of life (mostly learning disability)?

- Ordinary housing, dispersed in the community, is a necessary but not sufficient condition for better quality of life

Little research on these but we know they can be helpful (but not enough on their own):

- Supported living (i.e. where housing (owned or tenancy) and support are separate) gives people rights as a tenant, better material well-being and more choice over living situation
- Person-centred planning is important for co-ordination and development over time
- Person-centred thinking helps to promote the right attitudes – puts the person at the centre of their own lives and of staff activity
- Person-centred funding can improve control over who supports them, how and in what activities.

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What makes the difference

Research has found that only two things really make a difference:

- The level of ability/skills of people themselves
- How staff support people, minute by minute, day by day.

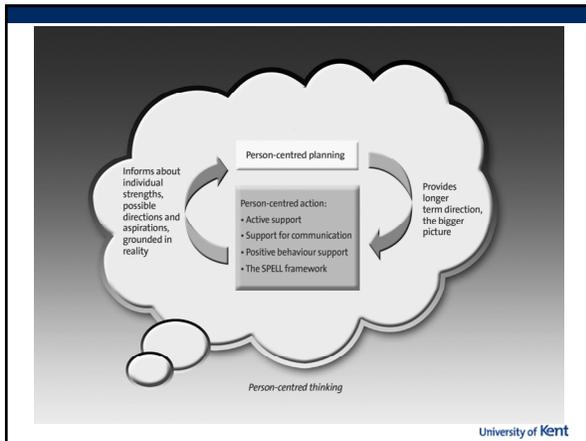


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Key to getting people engaged and improving quality of life

- An enabling and empowering style of interaction - person-centred active support
- A positive and supportive environment (the SPELL framework)
 - Accessible, predictable and easy to navigate - promotes independence and a sense of control
 - Based on respect, understanding/empathy, awareness of needs
 - Consistent support and clear expectations
- Additional strategies tailored to the needs of people supported

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1. Person-centred active support

- Providing enough help to enable people to participate successfully in meaningful activities and relationships
- So that people gain more control over their lives, gain more independence and skills and become more included as a valued member of their community
- Irrespective of degree of intellectual disability or presence of extra problems
 - With enough of the right help, EVERYONE can take part in all the activities going on around them and can have more control over their lives.

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Communication and active support

- Much easier to communicate with people when there is something meaningful to communicate about. Gives something concrete not just abstract to interaction over.
- Supporting communication (and as a result positive interactions and relationships) is an integral part of active support (and positive behaviour support).
- You might need some additional tools and perhaps even additional input but you can do a lot to develop communication skills through active support
- Communication/interaction is an "activity" and the 4 essentials apply
- Thinking about how we communicate (e.g. reducing verbal communication and using visual supports) is also important even for autistic people who don't have an associated learning disability e.g. providing information or instructions in written format is often very helpful.

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3. Providing a Positive supportive environment: The National Autistic Society SPELL framework

- **S**tructure – helps to make the environment predictable, reduces anxiety and promotes independence
- **P**ositive approaches and expectations – with the right support people can and will engage, develop and take control of their lives; people have skills and interests, not just deficits (not Hannibal Lecter)
- **E**mpathy – understanding how people see and experience the world around them (and inside them) is important for understanding their behaviour
- **L**ow arousal – creating environments that promote development and calmness and reduce unhealthy stress (NOT NO AROUSAL)
- **L**inks – working together in partnership focused on positive outcomes for the individual.

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Introduction to helpful approaches

- The SPELL framework was originally developed to understand and respond to autistic people
- **BUT**.....
 - we all need structure in our lives
 - we all need to be seen positively, valued and allowed to pursue our interests
 - we all need other people to have empathy for our point of view and us theirs
 - we all need to reduce unhealthy stress and confrontation in our lives
 - we all need to be treated fairly and consistently

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Active support and providing autism friendly environments

- Recent research has shown that those with learning disability who also have autism are more likely to show challenging behaviour than those with just learning disability.
- Autism is often overshadowed by learning disability or mental health conditions and go unrecognised
- Important to understand and respond to autism in order to prevent and reduce challenging behaviour.
- Particularly important for the Transforming Care cohort
- Active support is essentially how we achieve Positive approaches and expectations

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Responding to challenging behaviour

- Prevention is better than cure....
- But sometimes need a more detailed assessment and intervention when people have already developed challenging behaviour.

The most effective intervention framework is:

Positive Behaviour(al) Support

First developed in mainstream schools in the USA; later introduced to schools and adult services supporting children with intellectual disabilities and other conditions.

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Positive behaviour support

- A way of working with people who present challenging behaviour, which doesn't focus narrowly on the challenging behaviour and trying to reduce it
- Focuses on positive, preventative and educational approaches, that give people skills and improve their quality of life.
- Involves careful assessment of the function of the challenging behaviour, changing the situation so that triggering events are removed, teaching new skills that replace challenging behaviour, minimizing natural rewards for challenging behaviour and an emphasis on improving overall lifestyle quality.

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● Based on this assessment and understanding, a PBS plan is developed – should include both proactive and reactive strategies:

- Avoidance of support arrangements that punish the person in any way or create unnecessary restrictions on their freedom of movement and choice
- Support for the individual that enables the greatest possible reduction in the occurrence of challenging behaviour in the context of the best possible **quality of life**

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Skills teaching...

- Is an important part of PBS for helping develop people's skills and independence and improve Quality of Life.
- Two approaches:
 - specific skills teaching sessions
 - Exposure to tasks and activities that use the skills in a natural way, with enough support to ensure success (person-centred active support)

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Active Support and SPELL – creating capable environments and supporting proactive approaches

- Active support gives those providing support the skills they need to improve people's quality of life
- Active Support and SPELL help those providing support to have positive approaches and expectations
- SPELL in particular helps us to reduce stress and anxiety; both emphasize the importance of predictability and consistency.
- Active support promotes the development of new skills in the natural environment (which we know is more successful in many ways) and meaningful social inclusion
- Active support and SPELL help those providing support to understand how to give people choice and control – supports supported decision making

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Active support and SPELL – informs our functional assessment

- Active support and SPELL allows us to really get to know people,
 - Through sharing experiences, trying new things and observing their responses – e.g. to establish their preferences, desires, communication level etc.
 - through helping us understand how people experience the world; their sensory issues; how they process information etc.
- Critical for doing a good functional assessment and developing a PBS plan.

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Active Support and SPELL – supportive processes

- Active Support and SPELL support good links with all stakeholders involved in the person's life, care and support.
- Active support requires front-line leaders to be practice leaders – important for PBS too.
- Active support embeds processes that support the monitoring of the outcomes of PBS – in particular a focus on the positive, quality of life outcomes for people (i.e. not just on the reduction of challenging behaviour) –e.g. observations are a key part of this.
- Active support requires staff to be working as team and needs good staff support systems – all of which are also important for PBS.

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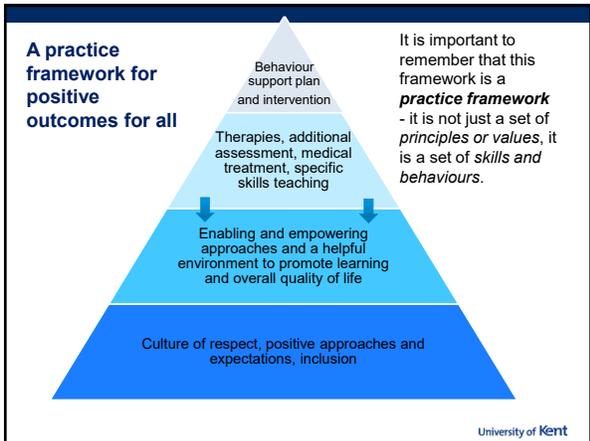
A PBS plan on its own is not usually enough

....especially when people have a disability, mental health condition or traumatic history

- Those providing support (in any environment) need some additional knowledge and skills so they can:
 - Enable and empower people to be actively involved in all aspects of their lives (including their learning and skill development) which will in turn help to improve their quality of life
 - Understanding people's needs and experiences so that their environment can be adapted to take account of these
 - Reflecting on their own values and past experiences and understanding how these may be influencing how they respond to young people.

A PBS plan is not needed for everyone...

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It is important to remember that this framework is a **practice framework** - it is not just a set of *principles or values*, it is a set of *skills and behaviours*.

Good person-centred active support

What would you see? What would you not see?

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Good person-centred active support – what would you see

- People engaging in a range of meaningful activities and relationships that vary in nature and grow over time (Every Moment has Potential).
- People receiving support for activities, tasks and interactions that is tailored in intensity, duration, presentation and pace to their skills, interests, preferences and needs (Little and often)
- People receiving just enough of the right help and support so that they experience success (Graded Assistance)
- People having choice where possible and those choices being respected but more importantly having control over the things they need to do (Maximising choice and control)

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Good positive behaviour support

What would you see?

What would you not see?

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Good positive behaviour support – what would it look like?

- People are experiencing a good quality of life (if necessary, in spite of their challenging behaviour)
- People displaying reduced amounts of challenging behaviour

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Indicators of good support – Inputs/structures, processes and outcomes

- See handout

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Importance of observation

- Allows us to look at outcomes/lived experience/ quality of life of the people supported – can be objective if good definitions used
- Allows us to see the quality of staff support.
 - Preparation and every moment has potential
 - Presentation and communication
 - Graded assistance
 - Successful engagement
 - Helpful, positive style of interaction.
- Does not require people to be able to communicate verbally
- Can allow us to look at different things in a short period – e.g. resources available and leadership which can help explain why things are the way they are.

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Scenario – how would you monitor outcomes?

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“What does good look like” checklist

<https://www.unitedresponse.org.uk/what-does-good-look-like>

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“What does good look like” tool

- The guide is not a comprehensive overview of any one approach but rather a set of observable practices 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.
- Can be used in any environment in which people with learning disabilities, autism or both are supported.
- Harder to use in forensic/ high secure units but can still be useful.

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The checklist

Evidence is drawn from a number of sources:

- Observations of what the individuals being supported are doing
 - Observations of what staff are doing
 - Observations of the environment
 - Observations of what managers are doing
 - Systems and processes that are in place through records and talking to those present during the visit.
-
- Can use some or all the sections to check the quality of services.
 - Can rate what you see in each of the 12 domains or just use it to give feedback and develop an action plan.
 - Have to rate the reality of what you see not make allowances for how difficult the client group might be or the nature of the environment.

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Twelve sections

1. Are people engaged in meaningful activities and relationships?
2. Are staff/other supporters consistently supporting individuals to engage and communicate
3. Is there an accessible way for those being supported and staff to know what’s happening that day?
4. Are staff supporting people to experience real choice and control?
5. Are staff warm, respectful, empathetic and positive towards the people they support and their families
6. Are people showing any behaviour that might be described as challenging and if so do staff respond with strategies consistent with positive behaviour support

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7. Do you see evidence that each person's health and well-being needs are known?
8. Do staff identify skills teaching targets based on what is important to the individual, developing their independence, and skills relating to the function of any behaviours which challenge?
9. Is there evidence that a range of assessments are conducted for each person and the results used to develop support?
10. Is there evidence that individuals are supported to be involved in all aspects of their support (including assessments, planning and reviews) in whatever way they can (e.g. through taking part in meetings or having their preferences assessed and respected)?
11. Do you see senior staff and managers leading good practice?
12. Other observations, questions and notes

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What's working and what's not working?

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Questions?

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Some key resources and references

- Mansell, J., & Beadle-Brown, J. (2012). *Active support: enabling and empowering people with intellectual disabilities*. London: Jessica Kingsley.
- Beadle-Brown, Julie and Hutchinson, Aislinn (2016) Person-centred active support – the cake not the icing. In: Carr, Alan and Linehan, Christine and O'Reilly, Gary and Noonan Walsh, Patricia and McEvoy, John, eds. *Handbook on Intellectual Disability and Clinical Psychology Practice*. Routledge, Abingdon, Oxfordshire, pp. 211-239. Available at: <https://www.routledge.com/9781138806368>.
- Beadle-Brown, J., Murphy, B and Bradshaw, J (2017) Person-centred Active Support (Training Pack) <https://www.pavpub.com/person-centred-active-support-2nd/>

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Links to online information and resources

- <https://www.unitedresponse.org.uk/active-support-guide>
- <https://www.youtube.com/channel/UCeeTVLnOkIRi5M6715orqdg>
- <http://www.unitedresponse.org.uk/Shop/person-centred-support-dvd>
- <https://www.unitedresponse.org.uk/communication-resource>
- <https://www.unitedresponse.org.uk/Blog/practice-leadership-summit>
- <https://www.unitedresponse.org.uk/communication-resource>
- <https://www.unitedresponse.org.uk/working-with-communities-guide>
- <https://www.unitedresponse.org.uk/what-does-good-look-like>
- <https://www.unitedresponse.org.uk/positive-behaviour-support>
- <https://www.unitedresponse.org.uk/Handlers/Download.ashx?IDMF=8c7754d3-a96b-49f2-958e-76164ba07aba>
- <https://www.unitedresponse.org.uk/foundations-of-good-support>

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