It's Not About Helping More, But Helping Better: Active Support in Action

Julie Beadle-Brown



Focus for today



- Setting the context putting policy and ideology into practice
- Understand the importance of Active Engagement
- Provide an introduction to the four essentials of Active Support
- Draw on the research around Active Support



Policy into practice; values into action

People with disabilities...

...have the same human rights as everyone else.

UN Convention on the Rights of Persons with Disabilities

What should the UNCRPD mean for people

- Choice and control
- Participation and inclusion
 - Education
 - Work
 - Community life
 - Leisure, sport, culture
 - Family life
- Independent living

Quality of Life



Basic needs met

e.g. Shelter, food and drink, clothes, dignity, safety, human rights, control



"Life enrichers"

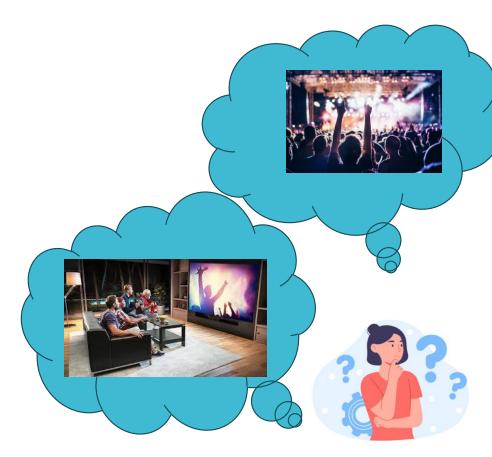
e.g. learning, relationships, choices, social inclusion, civil rights

8 domains



Quality of life – some important points

- Quality of Life is made up of the same factors and relationships for all people (i.e., for those with and those without disabilities). The eight domains go across cultures, countries, age groups and individuals.
- 2. What each domain looks like for any one individual will depend on a range of factors current skills, preferences, experiences and even the state of the nation they live in. Will change over time.
- 3. Goals and learning **new** skills are important but not the only things in life.



Social inclusion

What does quality of life look like in practice?

To experience an enhanced level of quality of life on any domain, requires the person to be actively taking part in everything that is going on around them – in activities, tasks, interactions, choices and decisions.

- Being able to meet our basic needs as independently as possible is important for our emotional well-being (e.g. self-esteem)
- We cannot learn or develop if we never do anything new
- We cannot make real choice and have control if no experience and nothing to control
- We cannot become more included, accepted, valued in our community if we never go and participate in the same places and activities as other people.
- We cannot build relationships if we have no shared interests and activities

We call this participation 'ACTIVE ENGAGEMENT".

1. Disengagement



DISENGAGEMENT





- Doing nothing or just doing passive or sensory activities.
- not adding to QOL but may be important **for** the person



EXAMPLES

- Just sitting or standing
- pacing
- waiting for something to happen
- getting agitated
- manipulating objects
- self-stimulatory or repetitive

2. Passive involvement



PASSIVE INVOLVEMENT



 Passive or sensory involvement that adds to their quality of life





EXAMPLES

- Having things done to you or for you to meet your physical or emotional needs

 you are letting them happen
- Doing things that are passive or sensory because they are nice and/or make you feel well, calm, less anxious

3. Active Engagement

Something that is adding to quality of life beyond having basic needs met (doesn't matter how much help is needed)



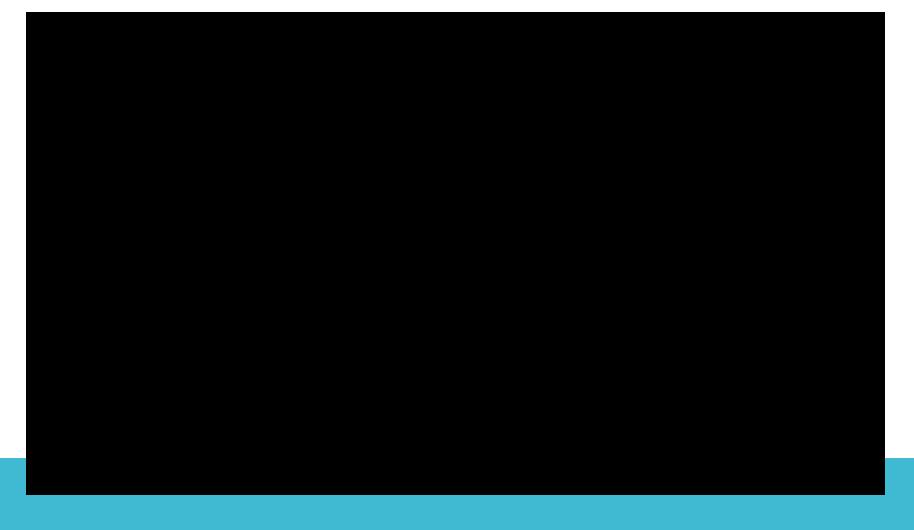
EXAMPLES

- Actively participating in and activity or task that is functional in nature and involves use of materials or equipment
- Actively interacting with another person
- Taking part in a group activity

Person-centered Active Support



Disengagement versus Active Engagement



Disengagement versus Active Engagement

Is disengagement a problem?...... It depends

- On the balance across someone's day
- OK to rest if you have been busy; It is ok to be tired, to have a headache, to just not like something....
- We all need some disengagement (usually around 6-8 hours a day
 It is called SLEEP!)

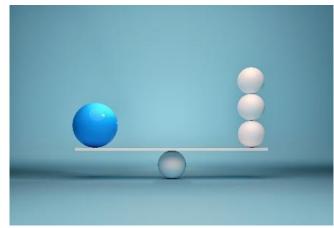


Need a balance between

Active engagement

Passive involvement

Disengagement



Why is engagement so important?



- "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

What do we know about increasing engagement and quality of life?

- Research tells us that HOW support is provided is critical
- The way that staff (or others) support people can compensate for the other key factor that impacts on the quality of people's lives level of support needs.
- ➤ HOW = enabling and empowering individuals in all elements of their lives More time doing things WITH people rather than just doing TO or FOR them.
- We call this PERSON-CENTERED ACTIVE SUPPORT

Person-centred active support

Focuses on enabling and empowering people to *actively* participate in all aspects of their lives and in all the opportunities offered at home, at work, at school, in the community – in activities, tasks and interactions/relationships (*active engagement*).

So that people become *more* independent, have *more* control over their lives and become *more* included as a valued member of their community (*quality of life*).

Irrespective of the degree of disability or the presence of additional needs and challenges (zero rejection – no one is too disabled, "complex", "difficult", sick....).

Everyone can participate...

- With enough of the right help, EVERYONE can take part *more* in all the activities going on around them and can have *more* control over their lives, even if they don't have all the skills needed.
- You are never too young or too old to be more engaged.
- Support (human and equipment) bridges the gap between what people can do and what is needed for success.









What does active support look like?

What would we see staff doing?

Every moment has potential



Everything that happens at home, at school or college, at work and in the community is an **opportunity**

- to participate,
- to learn new skills,
- to practice existing ones
- to discover new interests or enjoy existing ones
- to interact with others
- to use your body (physiotherapy)
- to have experiences that enable you to make future choices

Little and Often



- New experiences are easiest in small doses
- Not rushing but working at people's pace
- Lots of opportunities spread across the day better

Making it simple to understand and to be able to respond – sensitive invitations





Providing the right support to ensure success (graded assistance)











- Providing the *right* support for *that* person in *that* activity at *that* time
- Just enough support to ensure success (you are not teaching but enabling (often repeatedly) successful participation)
 - Provide less support to increase independence and control.
 - Provide more support to ensure success.

Maximizing Choice and Control



- *Can't have control if nothing happening to have control over need to support action and respect decisions while engaged.
- Broaden experience by encouraging participation 'little and often' (try before you buy...)
- *Especially important for those who show behaviour that results in restrictive responses and limits their quality of life.
- Sometimes we don't have choice over what we do but can have **control** over when, how and for how long we do it.

Remember... rarely is there just one way to do anything....

Person-centred is finding how the person likes or needs to peel potatoes....



















Community, Relationships & Work

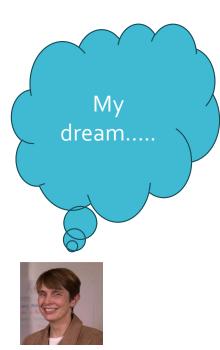
Supporting more than one person at a time.
Active support does not require 1:1

Person-centred active support is about getting the best of both worlds – skilled support and warm interactions.

Laughter, shared interests and shared activities build trust and rapport, for children and adults.











What happens when we do active support well

What do we know from research?

- People get more engaged
- People experience a greater range of opportunities and activities
- People participate more in the community
- People have more choice and control
- ❖ People experience better emotional well-being less depression, less challenging behaviour (at least for many and for others a better quality of life in spite of challenging behaviour).
- People learn new skills

What do we know from research?

- Staff are more satisfied in their job and less likely to leave
- Active Support is cost-effective funders get value for money.

What do we know is needed to make Active Support happen?

An introduction to the research on implementation

Summary of findings from Bigby et al. (2019)

Figure 1.Combined data sets predictors of good Active Support

Staff culture - supporting wellbeing Similarity levels of adaptive behaviour

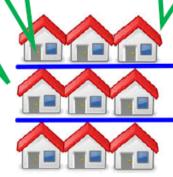
Size of the service – 6 or less residents Presence of organisational management features:

- Senior leaders shared prioritisation of practice and Active Support
- Senior leaders strongly supporting practice leadership
- Practice leadership close to front-line service delivery
- Concentration of practice leadership tasks with front line management



Individual level

Higher levels of adaptive behaviour



Service level

Stronger practice leadership More staff trained in Active Support More positive staff perception of quality of management



Organisational level

Smaller number of services Greater time implementing Active Support

Thank you!

For more information: J.Beadle-Brown@beadlebrownconsulting.com

