

Active Support: an evidence-based approach to responding effectively to complex needs

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Outline

What does “responding effectively” look like?

- Defining quality
- What outcomes are we aiming to achieve?
- What do these look like in practice?
- What does research tell us is needed to ensure these outcomes?

What is person-centered active support

Active Support as the foundation for a holistic approach to support for people with “complex needs”

What does “responding effectively” look like? – service quality

The framework most commonly used to conceptualise the quality of health and social care services is Donabedian’s model:



Defined as the factors that affect the context in which care is delivered e.g. physical environment, equipment, and human resources, as well as organizational characteristics such as staff training and payment methods; can also include external factors

Defined as the practices/ways of working between staff and those receiving support. E.g. active support
Also management practices – how managers support staff to work in ways that improve user outcomes – e.g. practice leadership

Most commonly defined in terms of the quality of life of the people supported. But Donabedian also included outcomes for staff and for families.

Conceptualising positive outcomes

- ❖ Many different ways of conceptualising outcomes but the concept of “quality of life” is particularly useful even when thinking about an educational context.
- ❖ Helps us to think holistically about individuals.
- ❖ Has been developed and tested in many different cultures and although the “indicators” might vary from culture to culture and person to person, the domains remain applicable.
- ❖ Applies to everyone.
- ❖ Concept initially used in the field of intellectual and developmental disabilities as a “sensitising notion” - a framework for what services should focus on in terms of supporting better outcomes for people.
- ❖ Sometimes used to mean “life satisfaction” but we will use it much more broadly.
- ❖ Quality of life requires two things:
 - ❖ Having your basic needs met
 - ❖ Life enrichers/enhancers



The Quality of Life domains

Domain	Examples of indicators	
	Basic level	Enhanced level
Emotional well-being	Feeling safe, free from harm and stress, happy	Having a sense of self-esteem and self-worth; feeling fulfilled
Physical well-being	Physical needs met – food, personal care, access to health care; mobility; activity	Exercise, feeling fit and well
Material well-being	Shelter	Some possessions, income
Personal development	Purposeful activities, opportunities to learn and develop, e.g access to education	Learning new skills and knowledge; variety of experiences in different life areas
Social relationships	Access to family, positive interactions with others	Friendships, intimate and personal relationships
Social Inclusion	Presence in the community – using the same facilities and accessing same activities as everyone else	Participating in the community, being a valued member
Self-determination	Control over what happens	Choices; Working towards and attaining personal goals and aspirations
Rights	Privacy, dignity, barrier free environments	Being an active citizen (e.g. voting, political participation etc).

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, interactions, choices and decisions.

We call this participation ‘ACTIVE ENGAGEMENT’.

Disengagement

Doing nothing or just doing passive or sensory activities that are not adding to QOL but may be important for the person

Passive involvement

Passive or sensory involvement that adds to their quality of life

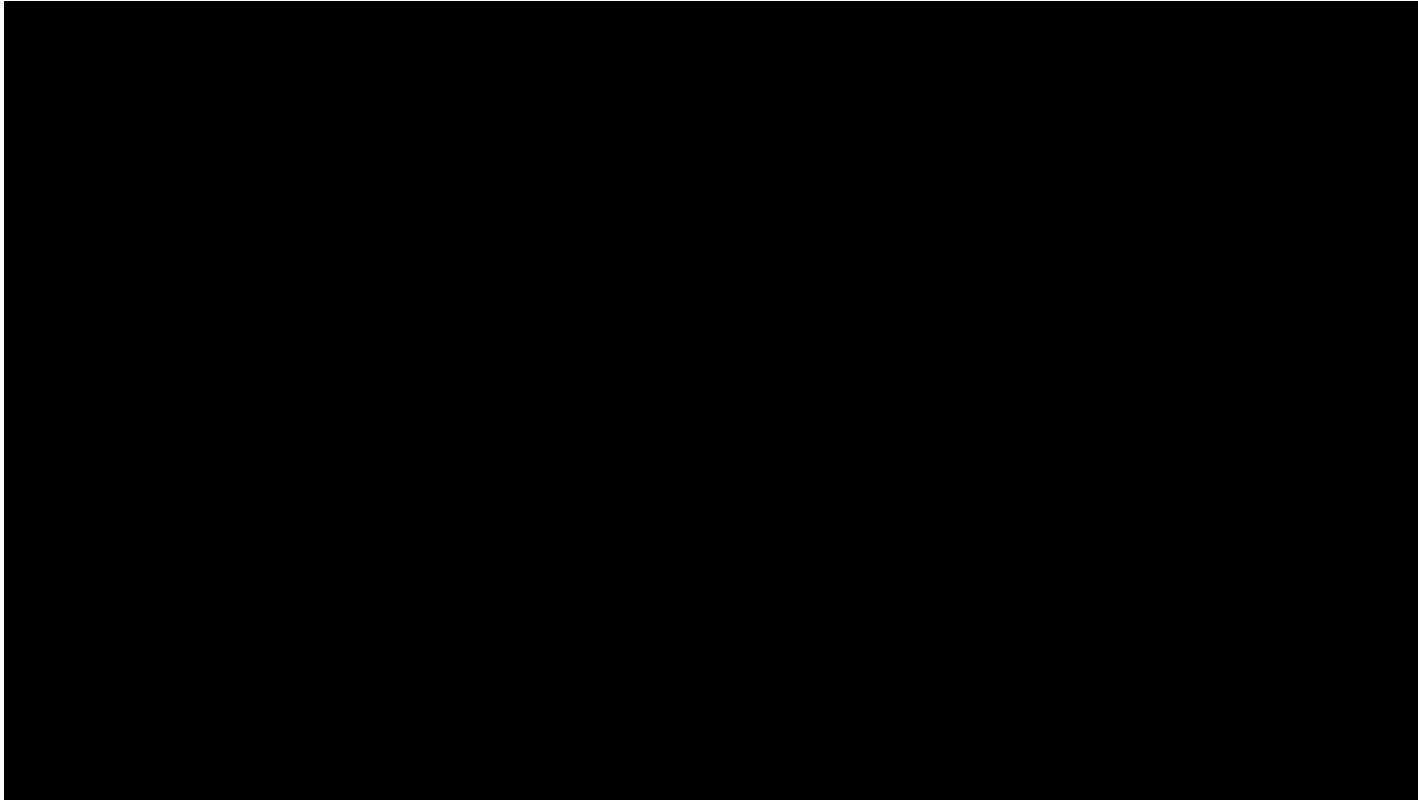
Active engagement

Active engagement adding to people's quality of life beyond having basic needs met (doesn't matter how much help is needed)

An example of disengagement....



What does good look like...



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

It is

- The route to quality of life
- An indicator of quality of life
- An indication that we are doing a good job

Policy into practice; Values into action

- ❖ Lots of helpful policy exists, giving people with disabilities rights
- ❖ Most organisations we work with have good values
- ❖ Many refer to improving quality of life

BUT

- ❖ Often there is an implementation gap.
- ❖ Research tells us that general population spends over 90% of waking day actively engaged
- ❖ People with intellectual and developmental disabilities spend less than 50% of time engaged and spend large amounts of their day with no contact from anyone.
- ❖ Those with the most severe and complex needs are least likely to be engaged and participating.
- ❖ We know it is possible to achieve much higher levels than are often found.

What is needed to increase engagement and Quality of life – review of research

Necessary but not sufficient:

- Ordinary housing, adequate and appropriate to needs, dispersed in the community
- “Enough” staff or hours of support (i.e. usually conceptualised as to keep someone safe and meet their basic needs)

Helpful but not enough on their own

- Person-centred planning – 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.

What makes the difference in engagement and QoL?

Research across almost 5 decades tells us that two factors consistently determine quality of life:

- the level of functional ability of the individual themselves – those with higher support needs generally experience poorer quality of life outcomes
- the nature of the support people receive, minute by minute, day by day – when people receive support that is enabling and empowering, doing *with* not doing *to* or *for*, outcomes are better.
- Over the years this way of working has become known as “person-centred active support”.

Person-centred active support

The way of providing support that has been consistently found to bring about change in quality of life of people with intellectual and developmental disabilities.

- ❖ 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 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.

Remember every “behaviour” requires a skill to execute



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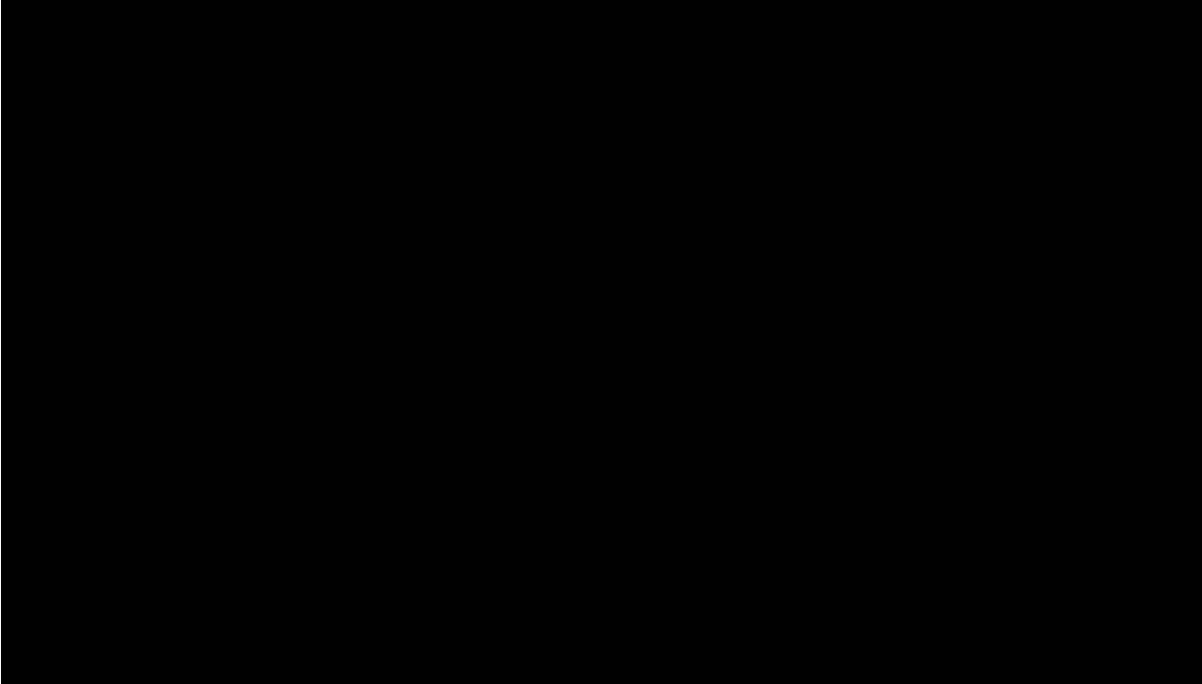
Four Essentials of Active Support

- Every moment has potential
- Little and often
- Graded assistance to ensure success
- Maximising choice and control

Every moment has potential

Every thing that happens at school or college, at home, at work and in the community is an opportunity for people to participate, to learn new skills, to interact with others to have experiences that enable them to make future choices

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Little and Often



New experiences are easiest in small doses

Working at people's pace

Lots of opportunities

Making it simple to understand and to be able to respond

Graded assistance to ensure success

- Providing the right support for that person in that activity at that time
- Just enough support to ensure success

Graded assistance to ensure success



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- Just enough support to ensure success

Maximising Choice and Control

Shaping up control while engaged by respecting decisions and supporting action

Broaden experience by encouraging participation 'little and often'

Especially important for those with challenging behaviour.

Sometimes we don't have choice over what we do but can have control over when, how and for how long we do it.



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Returning to people with complex needs

Historically, describing someone as complex might have been seen as a 'code' for too difficult, too disabled, too old, too challenging. However, we know that with skilled support and enabling approaches, everyone matters, and everyone can experience better outcomes:

- ❖ People with profound and multiple learning disabilities and older adults can be more actively involved. This active involvement is a protective factor in terms of both physical and emotional well-being.
- ❖ For those with behaviours that are described as challenging, having little to do and a lack of choice, is a major risk factor. Person-centred active support means that people have things to do and are given more choice and control.
- ❖ For those with the most communication challenges, person-centred active support provides a framework where, in the moment, support takes account of people's responses and where people are able to see the impact of what they are 'indicating'.
- ❖ For those with mental health difficulties, person-centred active support provides a framework for supporting people in helpful ways depending on what people are able to cope with. It supports people to build their sense of self-worth and their confidence and thus has positive impact on emotional well-being.

Thank you...

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