Operationalising quality and delivering positive outcomes in disability services – putting values into practice through person-centred active support

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Outline

Part 1 (1010 – 1055)

- Defining and measuring quality – recent findings
- Quality of life as a "sensitising notion" and as a framework for quality monitoring and improvement.
- The importance of "active engagement"
- Everyone can participate

Part 2 (1115 – 1140)

- Person-centred active support – the four essentials
  - Every moment has potential
  - Little and often
  - Graded assistance to ensure success
  - Maximising choice and control
- What is needed for success?

Innovative Frameworks for measuring quality

- Research commissioned by EASPD to inform a new European Framework for ensuring Quality of disability services
- Desk research
- Aim was to identify innovative frameworks of service quality that were:
  - Outcomes-focused
  - Related to quality of life

From https://www.easpd.eu/publications-detail/report-on-innovative-frameworks-for-measuring-the-quality-of-services-for-persons-with-disabilities/

Quality of life domains and some example indicators (Schalock et al. 2002)

Domain	Examples of indicators
Rights	Human Rights – e.g., respect, dignity, equality, privacy, family life, freedom from harm
	Legal or civil rights – e.g., citizenship, access, due process, voting
Self-determination	Choices/decisions, autonomy, personal control, and personal goals
Interpersonal relationships	Access to family; positive interactions with others; Intimate and personal relationships; friendship; participating in social activities and events.
Social inclusion	Community presence/integration (living in ordinary housing dispersed in the community, accessing the same facilities and range of activities as people without disabilities) and participation in activities in the community
	Community roles and contributions
Personal development	Access to education; Skill development; Meaningful occupation and demonstrating competence
Material well-being	Financial status; Employment status, Housing Status; Possessions
Physical well-being	Health status, nutrition; recreation and activity; physical safety from abuse and basic physical needs met.
Emotional well-being	Safety and security; happiness and contentment; positive experiences and self-esteem; Lack of stress.

N.B.
1. Quality of life = having your basic needs met plus access to higher level outcomes such as choice, personal development, social inclusion etc.
2. The eight domains are stable across individuals, culture, country etc. However the precise *indicators* of each domain can vary by culture, personal preference, experience etc.
3. "Sensitizing notion" not just a "metric"

Quality of Life

What we found….

- The Schalock et al. (2002) Quality of life Framework was the most comprehensive and inclusive of all the outcomes frameworks.

- All of the outcomes included in the 20 frameworks/tools could be mapped to one of the eight QoL domains, either at domain level or at indicator level.

- Many of the other frameworks only included one or two of the indicators under each domain.

- Many of the frameworks and tools that existed conceptualised/measured outcomes primarily in a subjective way

- Issues with relying solely on subjective measurement of quality of life and service quality.

- If we want to ensure that services are good for everyone, including those who cannot complete surveys or be interviewed, then we have to ask the question "what does good *look* like" – what would we *see* if people were having a good quality of life?

Resulting quality framework

Structures →

- Resources
  - Staffing
  - Environment
  - Equipment
  - External advice
- Ethics, attitudes and expectations
- Policies and procedures
- Leadership

Processes →

- Support practices
  - Ethos/culture
  - Working methods and skills
  - Environment and planning
- Helping staff work in that way
  - Training
  - Practice leadership & support
  - Teamwork

Outcomes

- Users
- Families
- Staff

From https://www.easpd.eu/publications-detail/report-on-innovative-frameworks-for-measuring-the-quality-of-services-for-persons-with-disabilities/

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".

Three levels of engagement

Disengagement	Passive involvement	Active engagement
Doing nothing or just doing passive or sensory activities that are not adding to QOL but may be important for the person	Passive or sensory involvement that adds to their quality of life	Active engagement adding to people's quality of life beyond having basic needs met (doesn't matter how much help is needed)
Being disengaged - sitting, standing, sleeping, waiting for something to happen, resting, holding or just manipulating an object (not using it for something functional), repetitive behaviour, getting agitated or angry while waiting on staff, not responding when someone makes contact with you	1. Having things done to you or for you to meet your physical or emotional needs - when you can't actively do them yourself either due to level or type of disability or it is a specialist task that needs specialist skills or the result of a real choice e.g. having your teeth examined by the dentist; having your hair cut by the hair dresser; receiving an injection; having physiotherapy or a massage; 2. Doing things that are passive or sensory because they are nice and/or make you feel well, calm, less anxious etc. e.g. watching the sun go down; walking around the park on your own; listening to music or playing with a sensory toy or fidget to reduce anxiety at the dentist.	1. Actively participating in an activity or task that is functional in nature and involves the use of materials or equipment (e.g. vacuuming the floor, painting a picture, putting an appointment in your diary, cutting the grass, playing tennis, writing in a book, using a camera. 2. Actively interacting with another person - talking to them, listening to them, showing them something, watching as they show you something. 3. Taking part in a group activity - playing football or a computer game with others; discussing a question, planning a holiday or trip, problem solving a situation.

Engagement can look different for different people
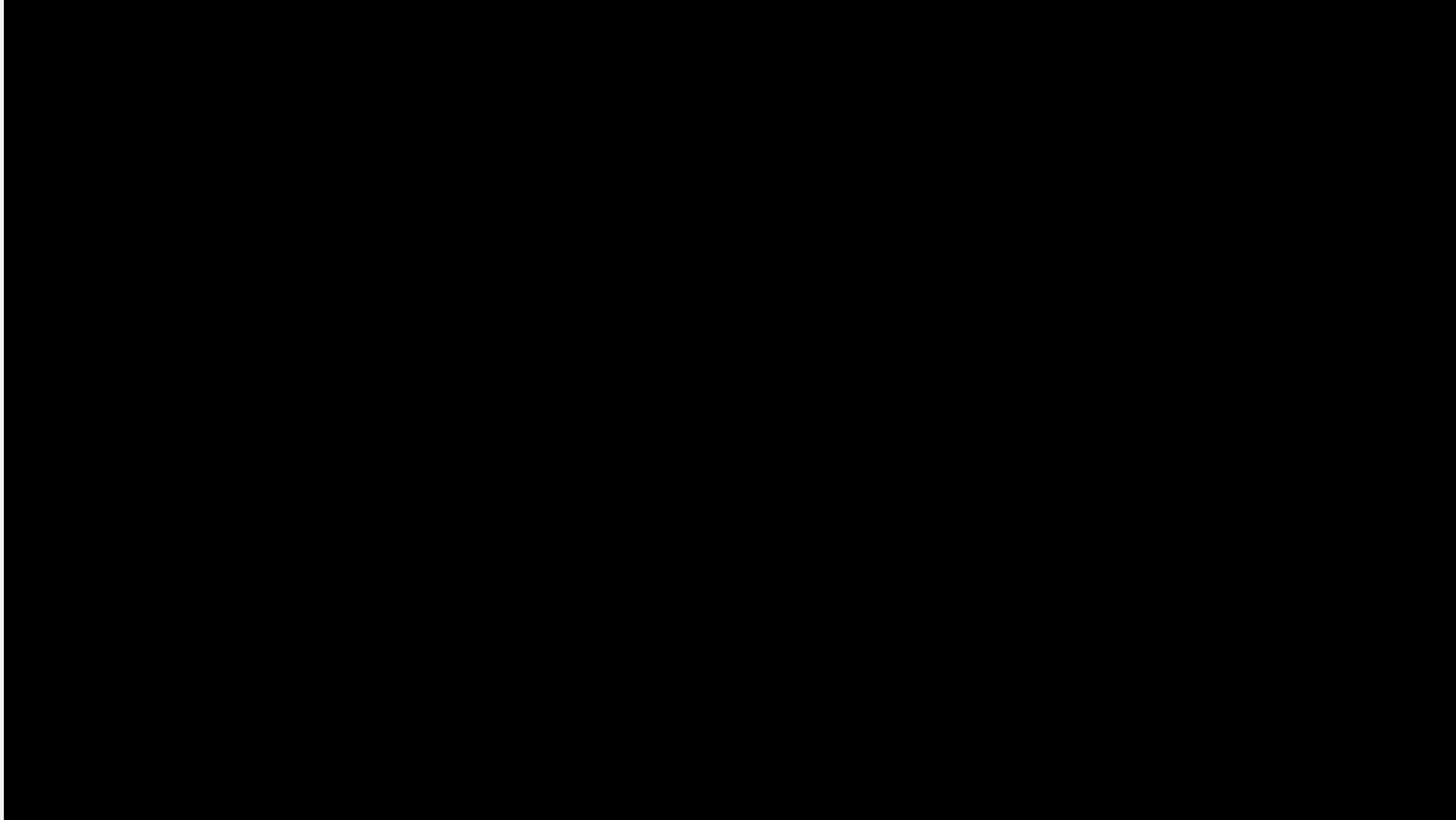
It can be:

- Doing the whole activity, interaction or task.

- Just doing part of it.

- Continuous, throughout the activity.

- Stop-start, dipping in and out of the activity.

- Taking the lead role.

- Joining in as an active participant.

Example of disengagement

Examples of engagement – remember to focus on *what* they are doing not *who* they are

Engagement can be captured in an instant

Remember...most things we do are made up of lots of different parts.

One activity, interaction or task can have many different components and the level of participation might vary throughout depending on preference, current skills and difficulties.

Someone might be actively engaged in one component, passively involved in another and need someone else to do one part for which they don't (at least for now or today) have all the skills or energy needed or which they don't like doing.

Example

Preparing the potatoes for dinner is made up of lots of different steps, which will differ depending on what type of potato you are having and who is doing the cooking and in what context (at home, just for yourself or for guests, at work etc)

- If I am doing mashed potato, usually the potatoes need to be taken out of the fridge, peeled , cut, picked up from the board and put in the saucepan, rinsed, water added, salt added, placed on stove top, timer set or testing with a fork to see if cooked, drained, dried, butter and milk added, mashed, transferred into a serving dish and carried to the dining room table.

- You might have some different steps or not do some of these things at all.

- An individual might be able to ask Google Home or Alexa to set the timer but not be able to reach over the steaming pan to test whether the potatoes are cooked (because they can't stretch that far).

- They may be willing to hold on to the knife to cut the potatoes but not want to lift them up and put them into the pan because they don't like the feel of them and don't want to wear gloves.

Is disengagement a problem?

- It depends…
    - On the balance across someone's day
    - OK to rest but we can only benefit from relaxation if we have been active and busy
    - We all need some disengagement (usually around 6-8 hours a day …. It is called SLEEP!)
    - Sometimes we need time to rest or do things that are important *for* us in order to help us get involved, especially in something new, more complex or challenging
- Need a ***balance***
    - Between disengagement, passive involvement and active engagement
    - between new AND familiar experiences,

Is the first person *actively engaged*?

- **Pete** is writing an email to his employer

- **Charlotte** is putting an appointment into her calendar on the phone

- **Ingrid** is staring out her window waiting for the noise from the workmen digging up the road outside so she can make a phone call

- **Troy** is listening to two members of staff discussing what they did at the weekend

- **Anna and Brigit** are discussing where they might go for their next outing

- **Maria** is standing by the photocopier waiting for the handouts for her training tomorrow to finish printing

- **Christine** is sitting on her balcony watching the sun go down

- **Julie** is having her back massaged

- **Mark** swings the tennis racket and hits the ball back over the net

- **Hazel** is sitting quietly with her eyes closed while the hairdresser shampoos her hair

- **Jasmine** takes her position on the starting blocks, bending over ready to dive into the pool when the starting gun is fired

- **Felicity** sits and watches as Jimmy empties the dishwasher

- **Laurie** pours some milk into her coffee

Why is engagement so important

- A route to quality of life and an indicator of quality of life

"Inactivity withers the body, and the mind" – engagement is good for us – physically and emotionally
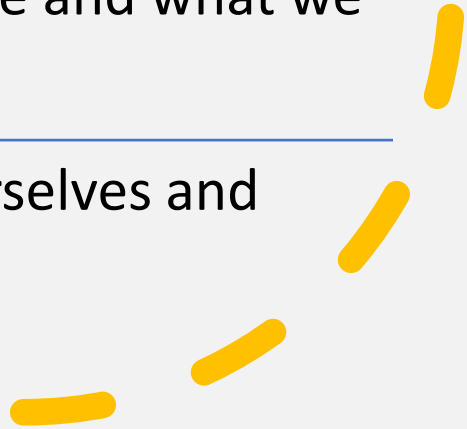
People show adjustment and happiness when they are engaged

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

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.

CCLN
California Community Living Network

PAVE
The Way Forward

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 general 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.
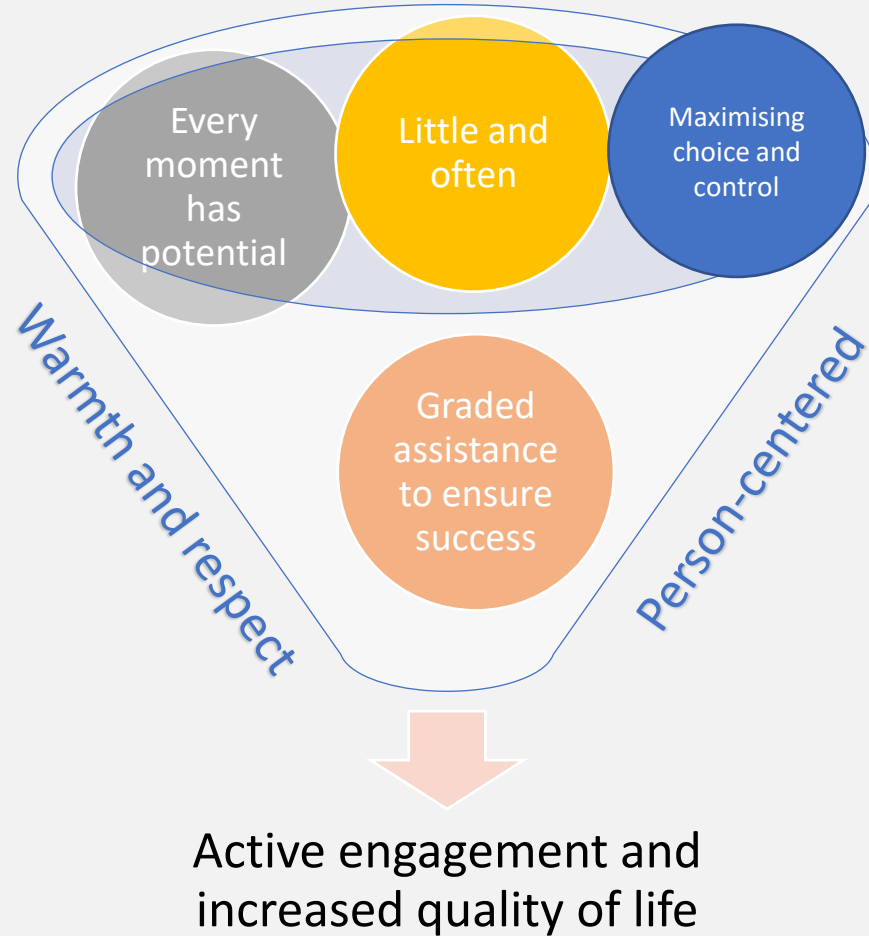
Remember every "behaviour" requires a skill to execute

BREAK

Person-centred active support

Every moment has potential

Little and often

Maximising choice and control

Graded assistance to ensure success

Warmth and respect

Person-centered

Active engagement and increased quality of life

Every moment has potential…..

- Everything that happens at home and in the community is an opportunity; an opportunity for people to:
  - Be actively engaged (even if they don't have all the skills needed to do the task completely or independently)
  - To interact with others
  - To learn something new or practice an existing skill
  - To make a choice or have control

- Supporters move from thinking "what can this person be involved in?" to "how can I involve him in what is going on now"?

- To find opportunities we have to:
  - break things down,
  - work out what people can do and what help we need to provide to bridge the gap,
  - be flexible (and creative) about where, when, how etc.

Little and Often

- Making it easy for people to participate by
  - Breaking activities, tasks and interactions into smaller, more manageable chunks as needed
  - Working at the pace of the individual – allowing people time to process and respond
  - Reducing distractions
  - Providing communication that works for the individual
  - Making the situation speak for itself

It is the person who says how little is little enough....
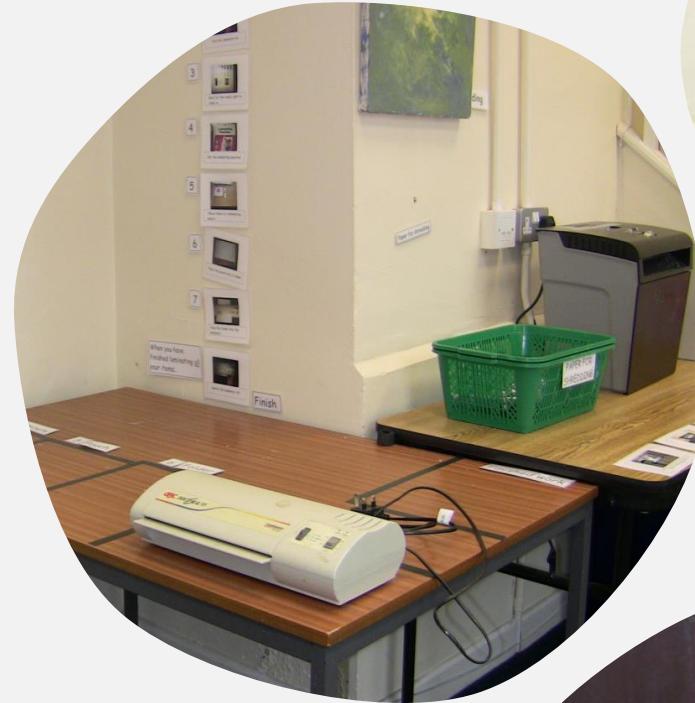
Graded assistance to ensure success

- Providing the right type and amount of help for *that* person, in *that* activity, at *that* time...
  - Help will vary by individual to take account of skills, needs and preferences
  - Help will vary by activity/interaction or time – people likely to need more help when activity is new or when they are tired or over aroused/stimulated

- Just enough help to ensure success
  - not too much or you are taking away the person's independence and control.
  - Not too little or they will fail

- Sometimes the "right" support is to stand back and let the person get on with whatever it is they want or need to do

Graded Assistance
Providing just enough
Of the right support
To assist this person

Video on graded assistance

Graded assistance….

… Also involves

- Ensuring the environment is supportive, promotes independence, reduces stress, helps people to manage risks.

- Make the most of equipment available to ensure people can be as independent as possible in tasks and interactions.

- Ensure a positive and helpful style of interaction – it is not just about *what* we do but **how** we do it.

Maximizing choice and control
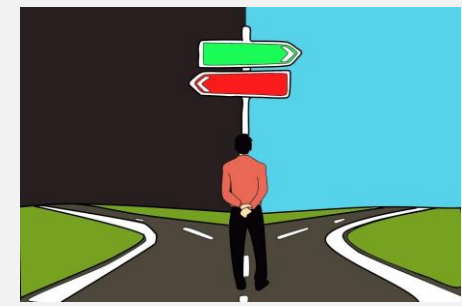
- Real (informed) choice requires:
  - Alternative/options
  - Experience of those alternatives
  - A way to understand what is being offered and to express your decision (and for your decision to be understood)
  - A history of having your decisions respected

- Trying new things (little and often) is key to making and supporting choices and decisions
  - Gives people experiences on which to draw for making decisions
  - Allows us to observe people's reactions to understand their preferences, communication etc.

- Supporting choice or decision-making is just like any other activity – use the means of communication that are accessible to the person – objects, photos, pictures etc.

- Remember open choices often provoke anxiety – we need to give people options from which to choose.

- It is ok for people to say NO especially if this is based on experience where the support is good – It is ok for people to disklike things or be tired, ill etc. BUT If people are saying 'no' all the time then they are saying the support isn't working for them.

Maximizing choice and control

- Sometimes we might not have choice over what we have to do but we can have control over how, when, where….

- Requires those providing support to set aside their personal preferences, standards, values and ways of doing things in order to let people have control over the HOW.

- Aim is to support people to be successful and provide enough support to make people's participation and contribution real. Rarely is there just one 'proper' way to do things.

- Control is a basic need for all of us, essential for our quality of life and a key to reducing challenging behaviour.

Rarely is there just one way to do anything....

Person-centred Active Support

- Is not just about tasks and activities; it is also about relationships

- It is not about teaching but people will learn by exposure to new opportunities and support to succeed and to practice in real life situations

- It is not a special session but HOW we work with people whenever we provide support in any context – whether it is for 5 minutes or for 12 hours.

- It is not a "recipe" book for all activities for all people – it is a set of principles that allow you to enable a wide range of people in a wide range of situations.

- Is not just for DSPs and social service agencies – can be used by parents, therapists, clinicians, teachers….

- It is not just for people with "disabilities", it is what works for everyone

- It's not about paperwork or plans, although some planning and recording helps consistency and predictability, reduces anxiety,

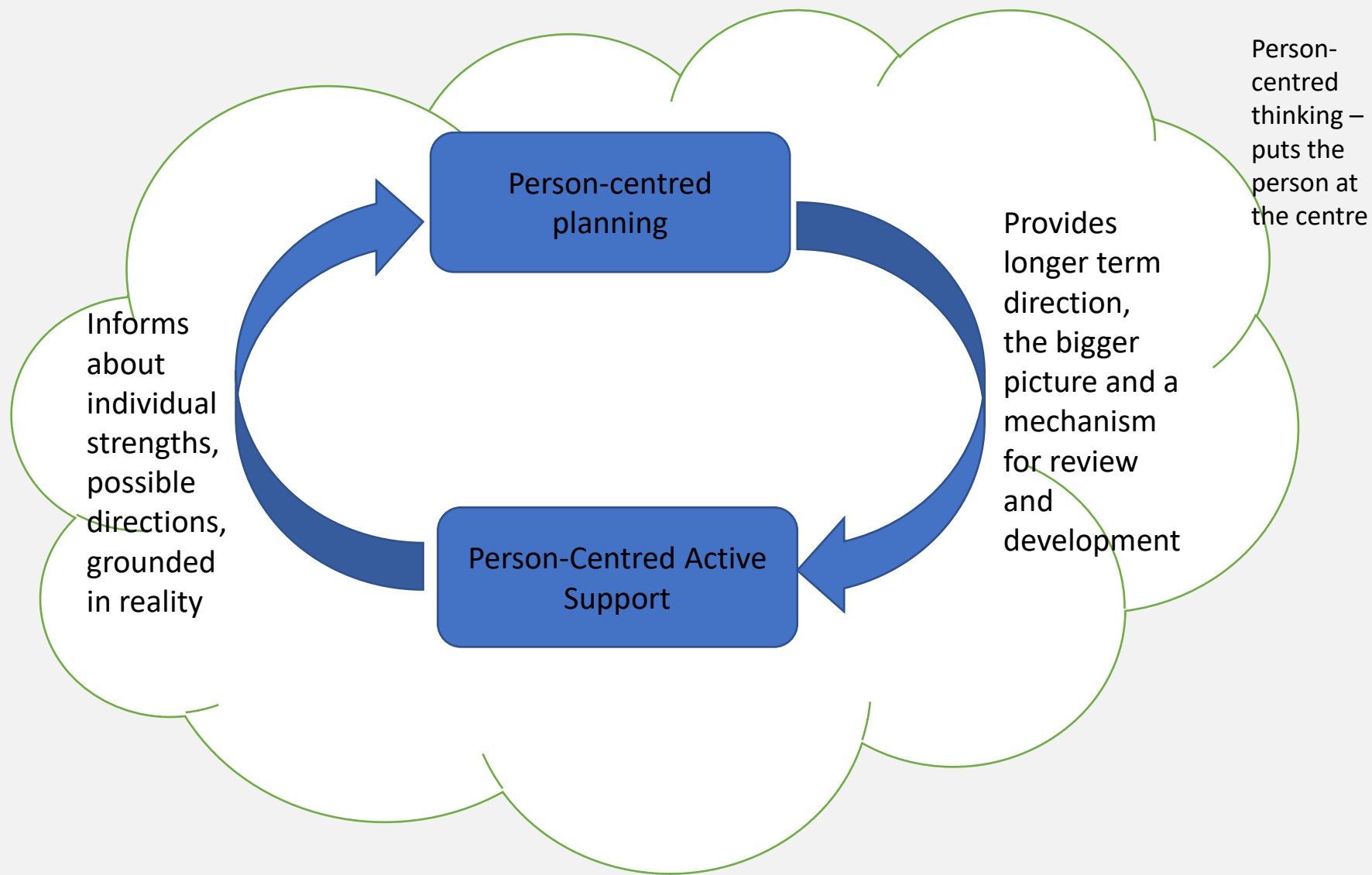# Person-centred active support – what is needed for success

- Does **not** require one-to-one staffing. Once skilled, staff can support more than one person at a time. But it does take practice, especially when supporting people with higher support needs.

- Requires those who provide support to have both the *knowledge* of active engagement and the four essentials and the *skills* to put them into practice.

- This requires training

- This training must include hands-on, in situ coaching as well as training

- This also requires those who provide support to be motivated to work in this way

# Person-centred active support – what is needed for success (cont'd)

- Practice leadership is a key part of the implementation picture
  - Leading by example – prioritizing the quality of life of the people supported
  - Guiding and interpreting – sharing the vision and translating policy into practice
  - Organising and allocating
  - Coaching
  - Reviewing through supervision and team meetings

- Senior managers have to ensure that the motivational context is supportive of approaches such as person-centred active support.

- An important element of this is what is measured and how it is measured – OBSERVATION IS CRITICAL

- Alignment of wider context (policy, quality assurance, funding structures) with the aims of person-centred active support makes implementation easier and more likely.

Person-centred thinking – puts the person at the centre

Person-centred planning

Provides longer term direction, the bigger picture and a mechanism for review and development

Person-Centred Active Support

Informs about individual strengths, possible directions, grounded in reality

- Person-centred planning and person-centred active support work together to help us deliver individualized, tailored services in the community.
- For many people we may need to add additional approaches/skills to DSP repertoires or within the circle of support
  - Alternative/ augmentative communication
  - Support for health and physical well-being
  - Intensive interaction
  - Mental health support
  - Behavioural support
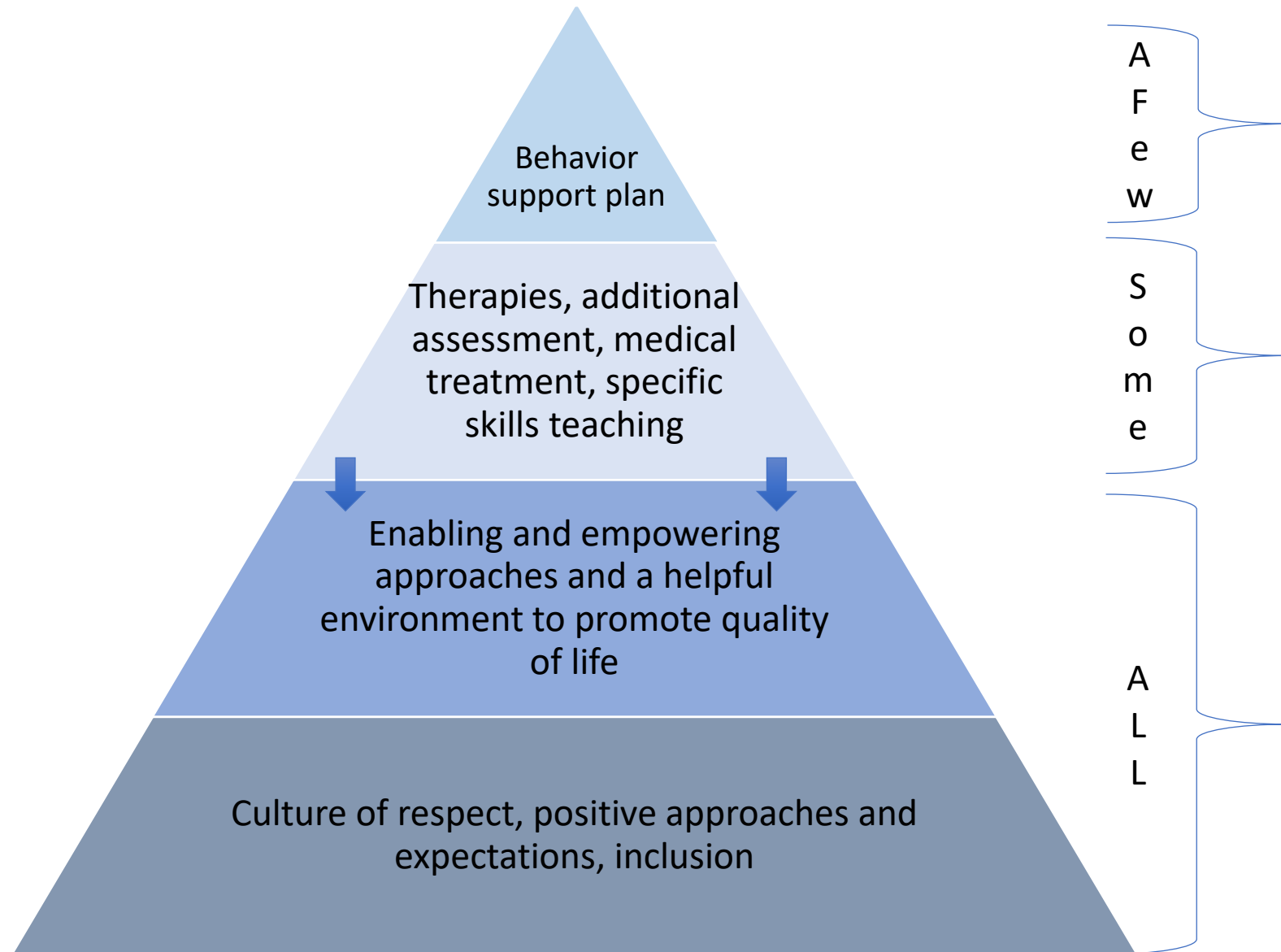
Video – bringing the principles together

Video – bringing the principles together

Questions?

For further information or questions, or for references for the research, please email:
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Thank you!