

# **Promoting a good life in the community for people with intellectual and developmental disabilities - successes and challenges**

**Julie Beadle-Brown**

Reader in Intellectual and Developmental  
Disabilities

Tizard Centre  
University of Kent

# Promoting a good life in the community

- Deinstitutionalisation – an ordinary home in the community is a necessary condition for a better quality of life
- But it is not sufficient – staff care practices are essential – an enabling approach to support
- Active Support
  - Understanding the concept
  - Evidence base
- What is needed for success?

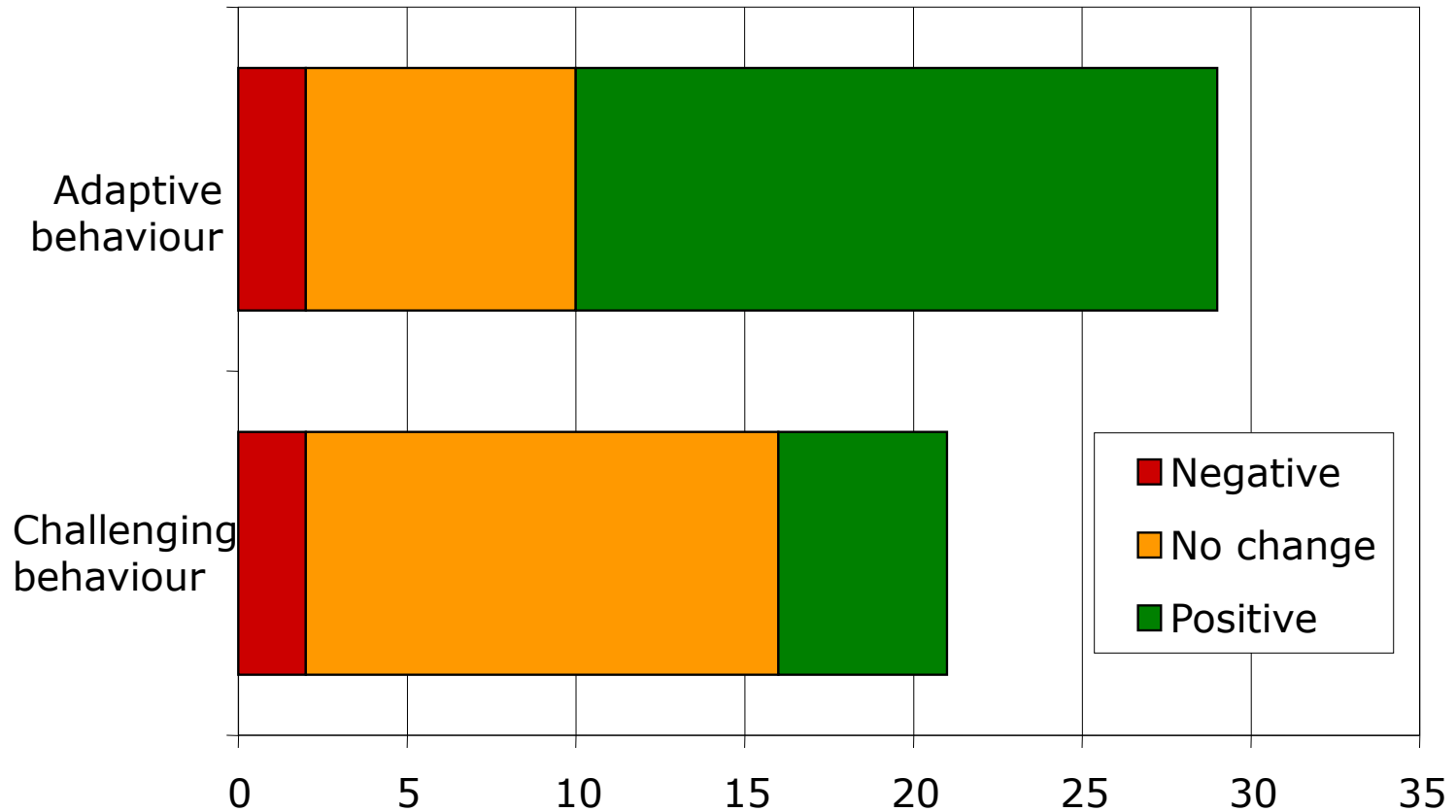
A home in the community

# **DEINSTITUTIONALISATION**

# Deinstitutionalization

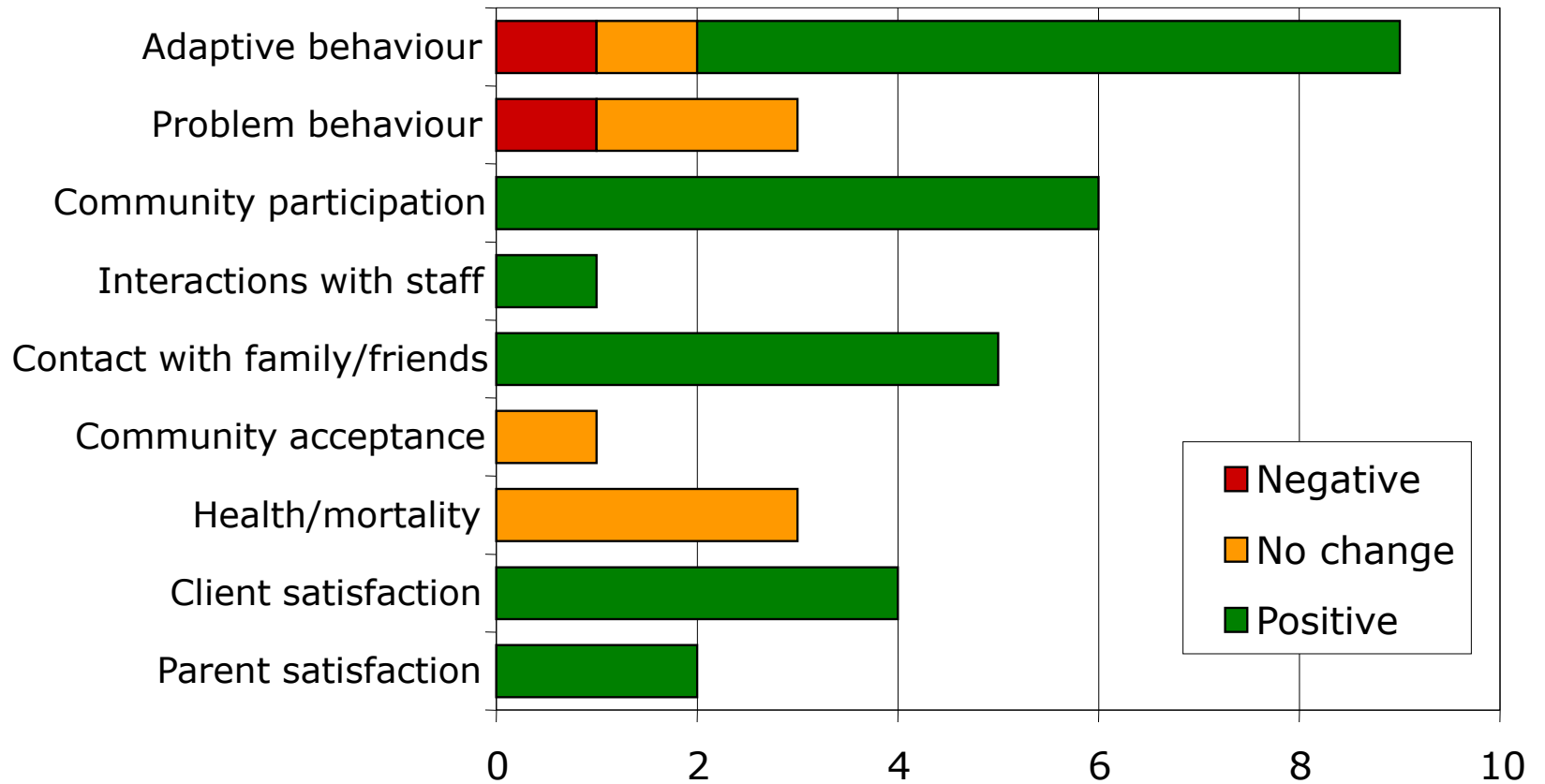
- In Scandinavia, UK, USA, Australia – deinstitutionalization has been a major trend for 30-40 years.
- However apart from in Scandinavia and UK process of closing old ID hospitals is not complete.
- Only starting in many countries
- Even in those countries where complete there are worrying trends towards re-institutionalization.
- Important not to be complacent or allow economic crisis to force decisions that are hard to undo

# Outcome of deinstitutionalisation - USA



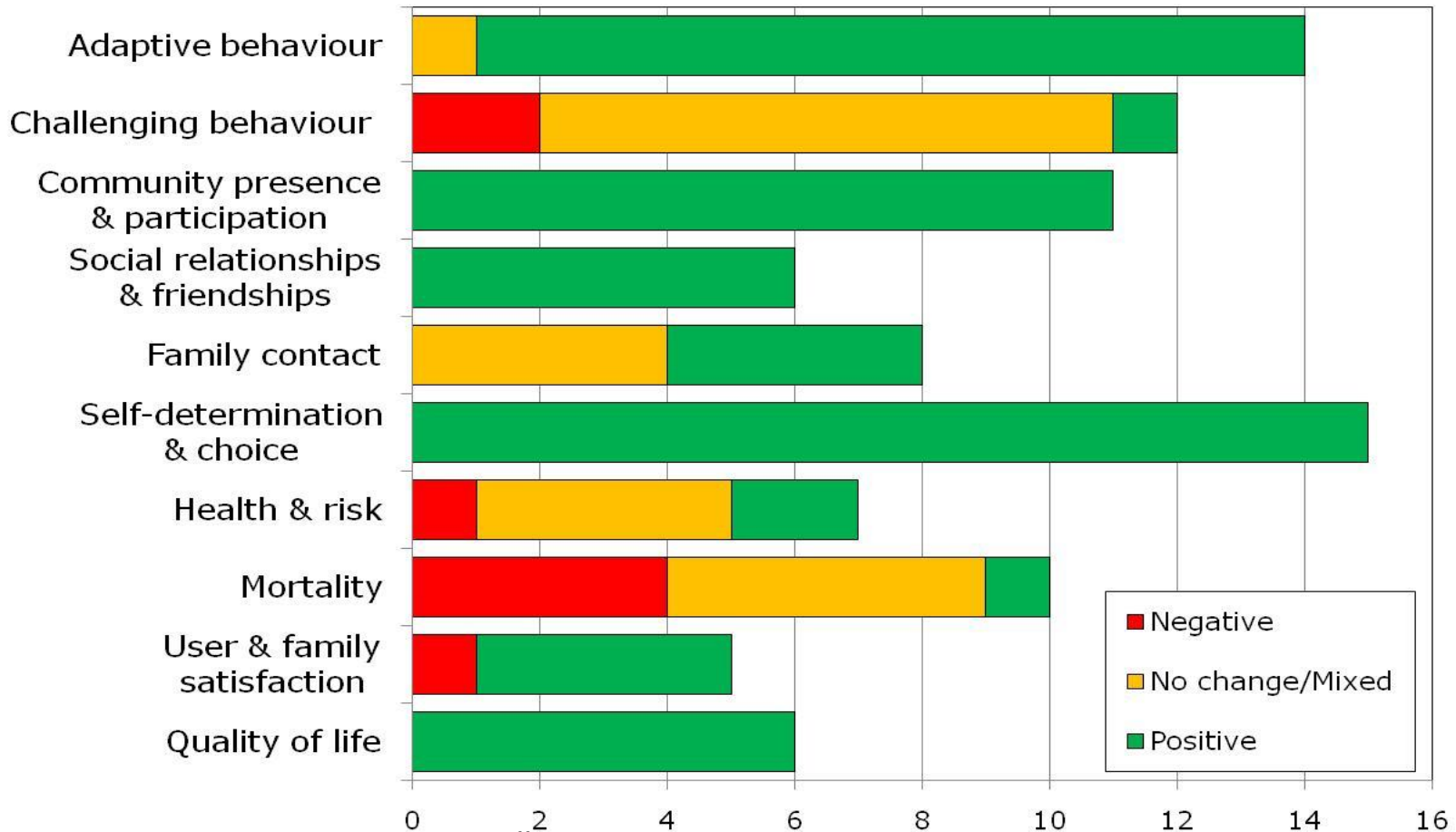
*From Kim, Larson and Lakin (2001)*

# Australian deinstitutionalisation studies



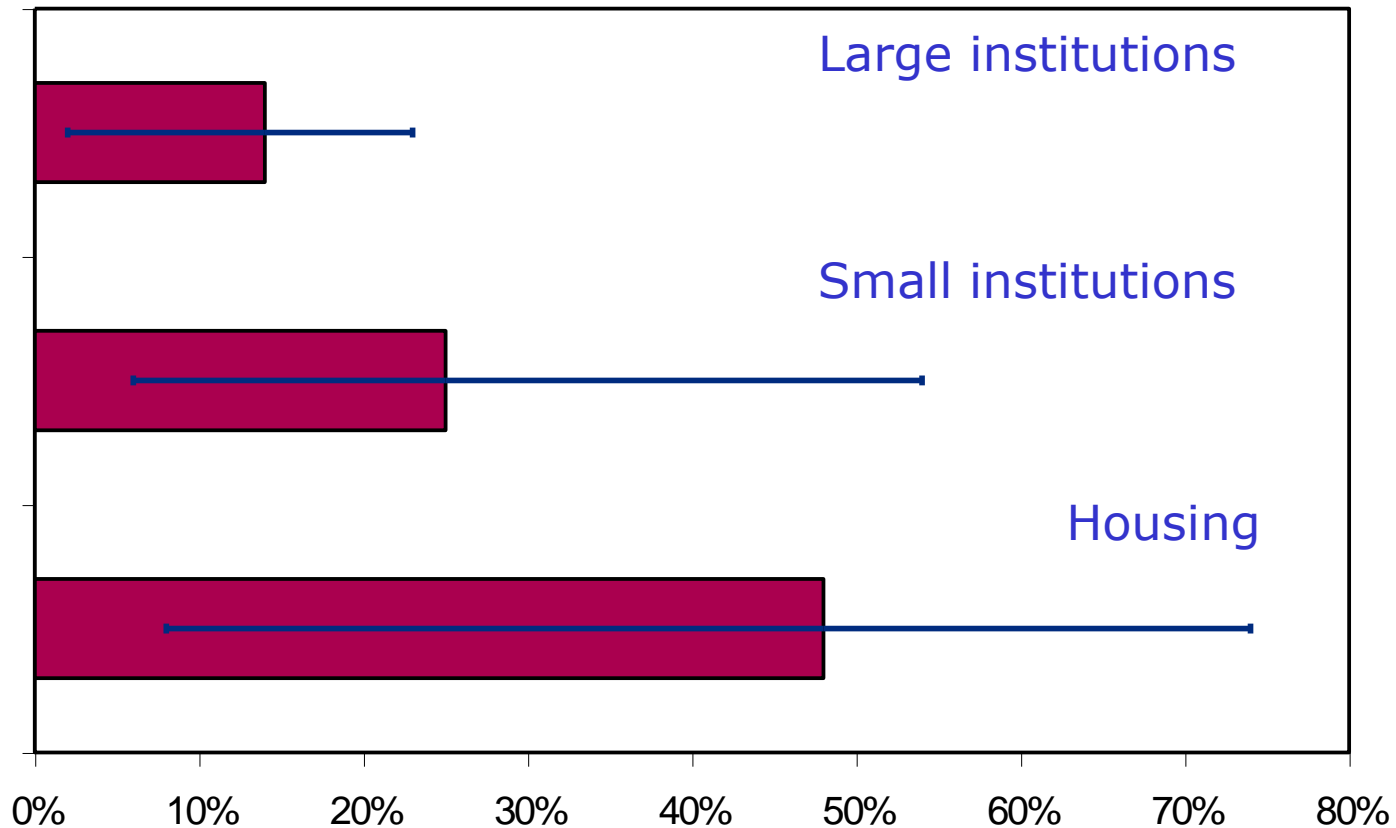
*From Young et al, 1998*

# Latest deinstitutionalisation studies



*From Kozma, Mansell  
and Beadle-Brown  
2009*

# Outcome in UK – variability in lived experience



*From Emerson and Hatton 1994*



# Engagement as a measure of quality of life

- And a route to quality of life...!

# Engagement

- Doing something constructive with materials
- Interacting with people – talking, watching and listening, showing
- Taking part in a group activity – playing football etc.

# 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) and new things in which the person is more actively involved.
- 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.

# Engagement in meaningful activity and relationships

*Some examples of engagement*

- cutting the grass
- asking newsagent for magazine
- putting items onto the supermarket checkout
- swimming
- polishing furniture
- delivering newspapers
- waving to/talking with the neighbours
- cheering on the team



# What disengagement means

## *Examples of disengagement*

- just sitting or standing
- pacing about aimlessly
- sitting in the car
- not acknowledging or responding to contact
- rocking, finger-flicking
- getting agitated or angry waiting for staff



# What do we know about levels of engagement in community based services?

- Compared to institutions – generally higher
- Smaller environments located in communities are generally richer in opportunities
- On average people spend between 40 and 50% of their time engaged in meaningful activities and relationships BUT enormous variability
- Those that can, do (unless staff stop them)
- Those that need help to make the most of opportunities, spend much of their time disengaged and isolated.

# Engagement – recent research

- People spend at least 75% of their time without any contact from staff or anyone else (usually more).
- On average people receive help to be engaged less than 5 minutes in every hour (usually less than one minute).
- In general people who live together do not interact with each other
- Most people spend most of their time sitting down – even when engaged – the “ipod generation”.

# Why is engagement important?

- “inactivity withers the body, and the mind”
- overt evidence of adjustment and happiness
- experience underpins development
- lifestyle/quality of life is the outcome –
  - Personal development
  - Emotional well being
  - Physical well being
  - Material well-being
  - Social relationships
  - Social inclusion
  - Self-determination, choice and control
  - Rights



# What factors explain variation in engagement

*Initial regression*

Active support

Resident adaptive behaviour

Behaviour problems

Potentially/severe problem behaviour

Staff number

Staff length of service

Seniority of staff

Age of project

Staff turnover

Management development

Active support training of senior staff

*Final regression*

Active support

Resident adaptive  
behaviour

*From Mansell et al 2003*

Active support

# **UNDERSTANDING THE CONCEPT**

# 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 become more included as a valued member of their community
- Irrespective of degree of intellectual disability or presence of extra problems

# Every moment has potential



# Little and often



# Graded assistance to ensure success

- Make the situation speak for itself
- Provide just enough help to ensure success – remember, you're not teaching, you're supporting successful participation
- Use the kind of help the person likes best
- Don't overwhelm the person with noise and interference; don't repeat failed support

# Graded assistance to ensure success – the right amount and type of help



# Maximising choice and control





Active Support

# **THE EVIDENCE BASE**

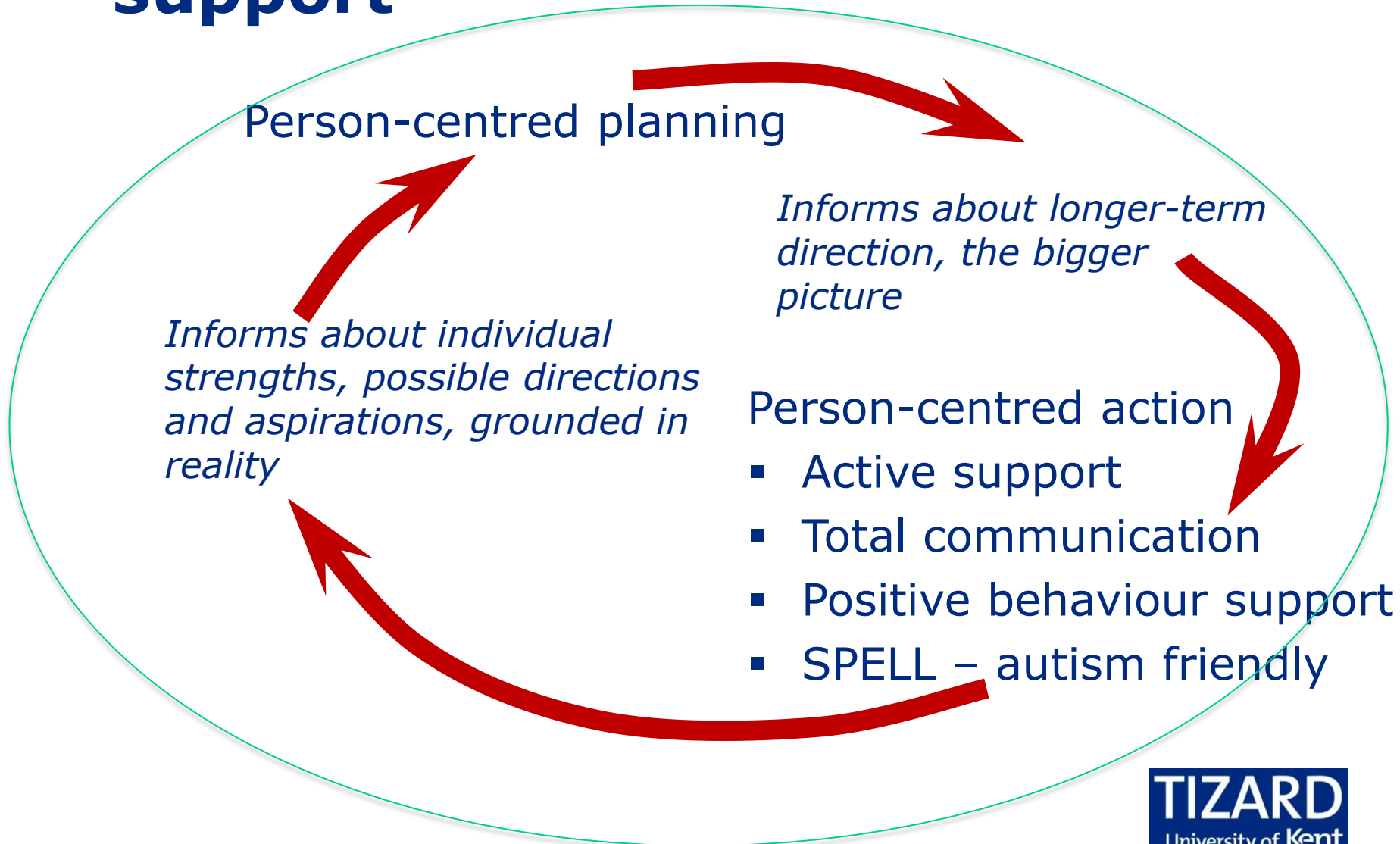
# Active support – the evidence base

- Increases engagement
- Increases independence
- Increases choice and control
- Increases social and community activities
- Reduces challenging behaviour
- Results in more reported contact with friends and with members of local community

Active Support

# **WHAT IS NEEDED FOR SUCCESS**

# Integrating Person-centred support



Person-centred thinking

# Contribution of other person-centred approaches

- Person-centred thinking is the context and puts the person at the centre of staff activity
- Person-centred planning provides direction
- For some people – those who are more able – that might be enough to make change in their lives
- But for those that need more support, the person-centred action is critical.
- “Active support IS the cake” (not the icing on the cake).

# Dispelling the myths

- Active support does not generally require more staff and thus not more money (once staff are trained and support systems in place).
- Recent study in UK found that where teams are providing active support staff are used more effectively and that costs of care packages are not more expensive
- Adding staff often results in less contact for the people they support, especially where active support not already being used.
- Good active support provided by creative staff in Croatia – lower staff ratio and very low pay.

# What is needed for success?

- Organisation

- Staff work as a team to support people using users' agendas and preferences as the starting point
- Consistent and balanced approach
- Supportive rotas/rosters and shift plans designed to meet the needs/wishes of people supported

- Skills

- training – key to giving skills and knowledge
- practice leadership – key to shaping up and then maintaining skills over time and keeping the message straight

# What is needed for success?

- Motivation
  - Values
    - Own values
    - Perceptions of management values
  - Consequences
    - Users
    - Peers
    - Managers



# Providing motivation

- Goal statements – clarity of focus
- Staff selection
- Performance management
  - Focus on engagement and active support
  - Maintain balance of incentives
- Staff promotion
- Managing the integration of person-centred approaches
- Alignment of policies, procedures and systems with the goals associated with PCAS

# Implementation of active support...

- Is not necessarily easy!
- Often requires a change of mindset and a change of processes, throughout the organisation
- Is the responsibility of everyone in the organisation not just the front line staff
- Requires a long term view.
- Needs an ongoing focus and high profile – needs to be at the centre of what the organisation does not just an add – on.

# But the benefits are substantial

- For the people supported
- For staff
- For the organisation
- For those funding services

# Summary: Achieving a good life in the community

## Lessons learnt

- Just moving people into smaller houses in community is necessary but not sufficient for high quality services.
- Institutional practices can exist in small homes, even in supported living
- Person-centred planning and thinking improves life on some domains but not others and is not enough on its own.
- What is most important is how staff support people in a person-centred way, to engage in meaningful activity (active support)
- Organisations need to have this as their core activity (the cake not just the icing).

# Resources and references

Mansell and Beadle-Brown (2012) Active Support Enabling and Empowering People with Intellectual Disabilities (Jessica Kingsley).

[j.d.beadle-brown@kent.ac.uk](mailto:j.d.beadle-brown@kent.ac.uk)