Promoting the inclusion of people with intellectual and developmental disabilities – lessons from the UK and Australia

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Outline

- What would we see if people were experiencing real social inclusion?
- What does research say about what is necessary for people to be socially included?
- Person-centred active support
- How widespread are such approaches in the UK, Australia and more widely?
What would we see?

...if people were really socially included

- People taking part
- In ordinary activities
- Everywhere
- With other people
What do we know about promoting outcomes more generally?

- Most research relates to people with intellectual disability
- Main outcome explored was engagement in meaningful activities and relationships (minute by minute participation)
- Lots of factors explored
- Living in the community is necessary but not sufficient
Once living in the community...

...only two things emerge as strongly influencing outcomes

- Severity of disability
- Whether those providing support enable and empower – do things *with* people rather than *for* or *to* them.

ACTIVE SUPPORT
What is needed for social inclusion?

- To live in ordinary housing dispersed in the community – same types of housing as other people.
- Support to access the community according to our needs
- Opportunities and support to develop our skills so that we can take part in the community.
- Support to interact with others in the community, with support that is discrete and enabling
Person-centred active support

- Providing enough help to enable people to participate successfully in meaningful activities and relationships (Engagement)
- So that people gain more control over their lives, gain more independence and become more included as a valued member of their community (Quality of life)
- Irrespective of degree of intellectual disability or presence of extra problems (such as autism, challenging behaviour, epilepsy..)
What is 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

- 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.
- 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.
What engagement means
some practical examples

- 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
- Writing a story
- Using the computer
- Teaching someone else
- Solving a maths problem
- Choosing nail polish
What disengagement means
some practical examples

- 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
- Not responding to contact from others (e.g. when communication not matched to person’s needs)

“Inactivity withers the body, and the mind”
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, at home, at work and in the community is an opportunity for people to participate, to learn new skills, to have experiences that enables them to make future choices

- We find the parts people can do and provide support to fill in the gaps
Little and Often

- New experiences are easiest in small doses
- Working at people’s pace (giving people time to respond)
- 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 at that time and in that activity
- 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 have control of when, how and for how long we do it.
Some examples of active support

Katy baking

Michael and Jo cooking
Examples of active support

Maximising Jacob’s choice and control

Tom and Robert doing newspaper delivery
How widespread is active support?

- In a random sample of care homes in the UK – approximately 20% of people are found to receive consistently good active support.
- In a sample of small good homes and supported living services nominated by organisations as “good”, 35% of people received good support.
- On average, people spent less than 50% of their time engaged and spent 75% with NO contact from staff or others.
- More able = more engaged
How widespread is active support?

- Similar findings in Australia
- No data available on quality of support available in most other countries

BUT

- Awareness being raised and active support now being implemented in some areas in US, Canada, Croatia, Ireland, and Norway.
Person-centred active support resources

- [https://www.youtube.com/channel/UCeeTvLnOkjRj5M6715orqdg](https://www.youtube.com/channel/UCeeTvLnOkjRj5M6715orqdg)
- [http://www.unitedresponse.org.uk/Shop/person-centred-support-dvd](http://www.unitedresponse.org.uk/Shop/person-centred-support-dvd)
- [https://www.pavpub.com/an-introduction-to-active-support/](https://www.pavpub.com/an-introduction-to-active-support/)
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