



Høgskolen i Molde

Does research facilitate participation?

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Background

- Yes and no
- Participation is often defined very narrowly
- Poor understanding of participation
- Low expectations about involvement of people with disability

Preparation for participation

- Participation is improved but not great
- We will continue to make mistakes but must learn from them

Normalization principle (Nirje 1985)

- Just like everyone else
- Normal rhythm of the day, week, year and life cycle
- Normal economic conditions
- Normal environmental conditions
- Normal respect
- Normal sexual patterns of culture

Misconceptions of the normalization principle (Perrin & Nirje, 1985)

- making people normal
- specialist services are inconsistent with the principle
- it supports dumping people in the community with no support
- it is an all or nothing concept
- it is appropriate only for those with mild intellectual disability

Participation or presence

- A right to participate in the community
- To be supported to take up this right
 - thorough advocacy
 - self determination
 - personal centered planning. (O'Brien)
- In but not of the community (Todd, 1990)
- Has this changed?

ICF

- Participation a core concept
- Time consuming
- Not used routinely
- Cannot make a clinician client centred (Threats 2009)
- Interpreted according to clinician's expectations and experiences
- What is participation and does research have a role?

Participation Model (Beukelman & Mirenda, 2005)

- Systematic, common sense
- Barriers and facilitators
 - Policy
 - Practice
 - Knowledge
 - Attitudes
 - Environment
- Focus on strengths
- Does using this model improve participation?

A problem

- Adults with who use AAC rarely see a communication specialist
- Service is likely to be specific
- Service is likely to be time limited
- We focus on 'how to' rather than 'then what'

The reality

- Presence is important
- It does not guarantee participation
- Many people who use AAC are at home and lonely
- Why has participation not worked ?
- What was wrong with Nirje's call for equality

Maybe

- Understanding of participation has been superficial and is poorly defined
- Communication specialists have not been able to fully explore their role in supporting participation
 - Resources
 - Services
 - Limited focus on people with AAC politically and as activists

My focus

- Adults with complex communication needs
- Who may or may not have AAC
- Who do not have a severe level of intellectual disability
- Who are likely to have cerebral palsy
- An elite group?

Integration (van de Ven et AL. , 2005)

- Functioning in an ordinary way without receiving special attention
- Mixing with others without being ignored
- Taking part in and contributing to society
- Utilizing opportunities
- Being the director of one's own life

Functioning in an ordinary way without receiving special attention

- What is special?
- People ARE treated differently
- Without special attention how can people who use AAC participate?
- A social model approach-rights, anti discrimination legislation
- ICF – interactional approach
- How far have we come?

Mixing with others without being ignored

- People are ignored
- Friendships and loneliness
- Communication problems
- Lack of paid work or volunteering opportunities

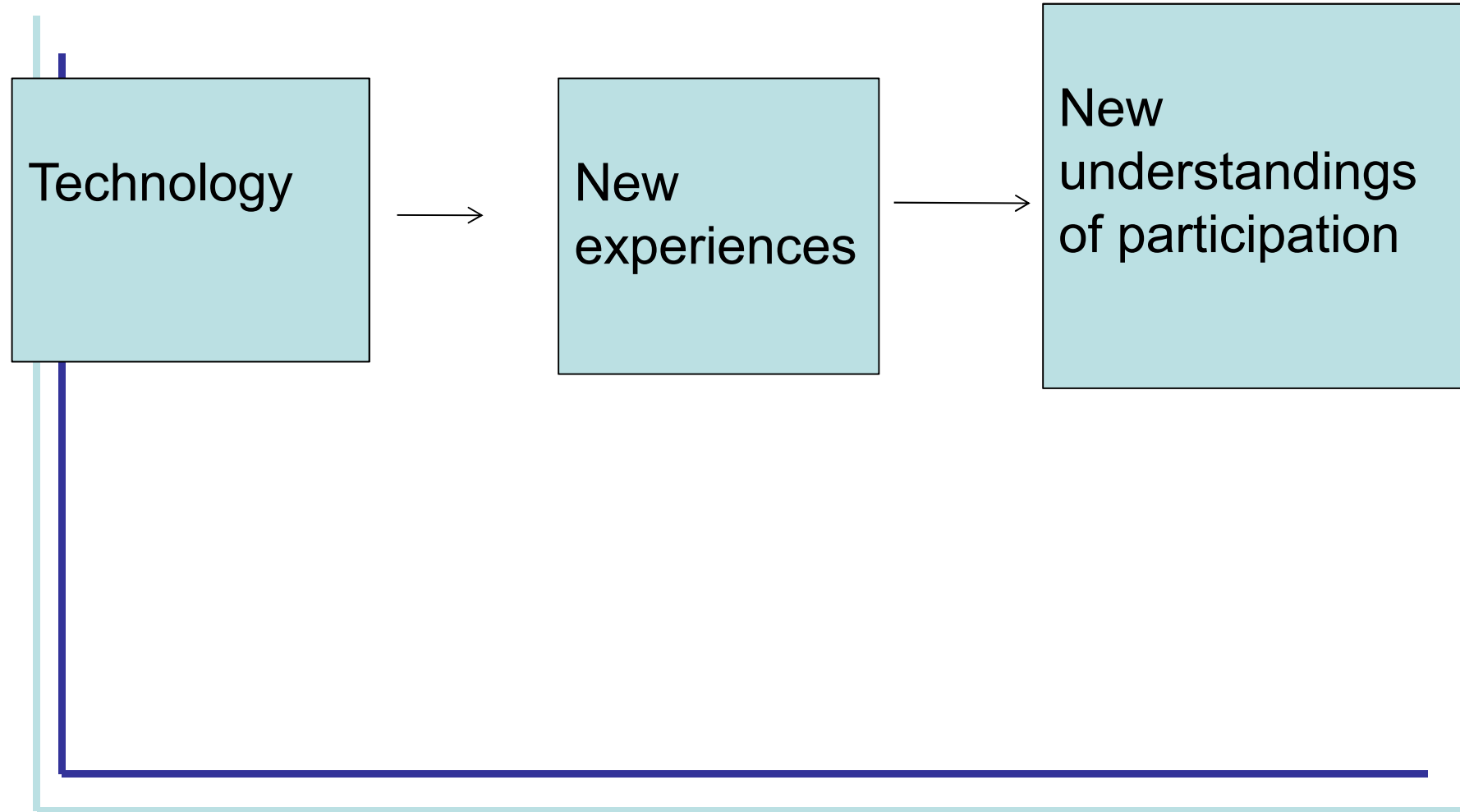
Taking part in and contributing to society

- Many ways
- Work
- Volunteering
- Communication is a major barrier
- Does our role extend
 - How?
 - Where?

Being the director of one's own life

- Communication is the crux
- Exclusion (e.g., dysphagia management)
- Learning to advocate
- Choices
- Self determination
- Better collaboration and sharing of knowledge

New tools



Conclusions

- Participation is more than a trip to the bowling alley
- It is being connected and accepted
- Making decisions about what to do and who with
- Managing our affairs to the best of our ability
- Taking advantage of opportunities
- Feeling satisfied with our lives

Conclusions

- Research can facilitate participation but we need:
 - Better links between research and practice
 - Stronger focus on adults
 - Stronger focus on 'typical lives'
 - To define and examine what do we mean when we talk about education, policy development or even participation