“She’s been involved in everything as far as I can see”: Supporting the active participation of people with intellectual disabilities in community groups

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Research problem

- On-going social exclusion of people with intellectual disabilities from the life of the wider community
- Continue to occupy a distinct social space
- Lack of opportunity to engage in freely chosen relationships with people in the wider community
Research questions

• What influences how community group participants respond to and support a person with an intellectual disability to participate in a community group?

• What changes to social processes are necessary to promote the active participation of people with intellectual disabilities who have a moderate level of impairment?
Research design

- Participant-observation study
- Supported five people with moderate level of impairment to participate on an individual basis in mainstream community groups (community kitchen, walking group, men’s shed, cooking group and opportunity shop)
- Data in the form of field notes collected 5-10 months over two years. Supplemented by interviews and secondary documents (181 hours observation of central participants in groups; 254 000 words in field notes)
- Researcher role included planning, providing education and support to group members, facilitating meaningful contact and encouragement to central participants
## Central participants and their groups

<table>
<thead>
<tr>
<th>Community group</th>
<th>Organisational context</th>
<th>Leadership</th>
<th>Central participant</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cooking group</strong></td>
<td>Neighbourhood house</td>
<td>Paid co-ordinator</td>
<td>Helen</td>
</tr>
<tr>
<td><strong>Men’s shed</strong></td>
<td>Community Health Centre</td>
<td>Paid co-ordinator and staff</td>
<td>Phil</td>
</tr>
<tr>
<td><strong>Opportunity shop</strong></td>
<td>National charity and not-for-profit service provider</td>
<td>Paid manager, voluntary staff</td>
<td>Matthew</td>
</tr>
<tr>
<td><strong>Walking group</strong></td>
<td>National ‘healthy ageing’ interest group</td>
<td>Voluntary leadership</td>
<td>Sol</td>
</tr>
<tr>
<td><strong>Community kitchen</strong></td>
<td>Christian church: local parish initiative</td>
<td>Paid leader (church minister)</td>
<td>Ruth</td>
</tr>
</tbody>
</table>
Data analysis

Philosophical framework of critical realism

Insights drawn from contact theory (Allport, 1954)

Stages

• Detailed case narratives
• Use of NVivo for data management
  Mid-range accounting scheme (Miles and Huberman 1994)
• Retroduction- ‘thinking backwards’
  – Application of data to domains of social life (Houston, 2010)
  – Identification of generative mechanisms underpinning social processes in groups
• Cross case analysis of mechanisms
  • Identification of features of active participation
Overview of social processes and generative mechanisms

**Leadership response to suggested inclusion**

- Differentiated response
- Non-differentiated response

**Initial anxiety**
- Fitting in
- Being manageable

**Difference dilemma**

**Discernment process**
- Group social processes
  1. Expectations
  2. Taking responsibility
  3. Accurate feedback
  4. Familiarity
  5. Kindness

**Skills and characteristics of central participant**

**Features of active participation**
- Equal membership status
- Mutually rewarding for participants with and without intellectual disability
- Working cooperatively toward a common goal
- Effective use of expertise to develop capacity

**Community presence** → **Marginalised participation** → **Active participation**

**Generative mechanisms**
- Authority support
- Faith based idealism

**Generative mechanisms**
- Classification
- Role differentiation
- Protectionism
- Meaningful contact
- Empathy & perspective taking

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Findings: differentiated response

Initial anxiety
- Fitting in, being manageable
- Conditions imposed

Discernment process
- Group social processes
  - Expectations (beliefs about right place, wrong place)
  - Taking responsibility (shared across group or designated)
  - Accurate feedback (to adjust to group norms)
  - Familiarity (prior contact-level of comfort and modelling for others)
  - Kindness (presence of genuine warmth and positive regard)
- Skills and characteristics of central participant
  - Use of initiative, be willing to try, people skills
- Access to expertise
- Presence of integrating activity
Findings: non-differentiated response

Community kitchen as exception

- Difference dilemma
- Access to expertise
- Presence of integrating activity
Findings: features of active participation

- Equal membership status
- Mutually rewarding for participants with and without intellectual disability
- Working cooperatively toward a common goal
- Effective use of expertise to develop capacity

Concept of continuum of participation
Dilemmas

Tensions for disability support staff

- Beliefs and practices do not promote active participation
  - Ambivalence about community response to intellectual disability and benefits of individualised, community-based activity
  - Desire to protect from discrimination
  - Resource allocation prioritises group based activity
  - Risk management culture

Tensions for community groups

- Participation of person with intellectual disability may threaten group status quo
- Genuine desire to help set against protection of group purpose or level of comfort
Implications of findings for support of groups

Approaching groups and early negotiation
- Conditions for meaningful contact (frequency, duration, structured activity that fosters cooperation)
- Authority support
- Mentoring role that facilitates shared responsibility
- Effective use of expertise
- Presence of integrating activity

Group interventions
- Shaping expectations, accurate feedback, taking responsibility, building on familiarity, conditions for kindness
Implications for policy and practice

Adequate preparation of people with intellectual disabilities
- Role of person-centred active support

Commitment of disability support staff
- Addressing ambivalence

Attending to structure
- Cooperation between group homes and day centres
- Flexible funding options

Resource allocation for promotion of participation
- Skilled facilitator and support person
References


Thank you

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