Community Participation of People with an Intellectual Disability: A Review of Empirical Findings

MML Verdonschot, LP de Witte, E Reichrath, WHE Buntinx & LMG Crufs

Journal of Intellectual Disability Research, 2009, **53**, 303-318.

Reviewed by Bob McCormack

Introduction

- This paper is a review of 23 studies on community participation for the period 1996-2006, using the World Health Organisation's ICF Domains for Community Participation as it's framework. It assesses the strengths and limitations of these studies before drawing conclusions and making recommendations.
- In practice it was difficult to draw general conclusions from these very diverse studies, as they were not using similar definitions, or similar instruments, and were conducted in widely varying settings. In addition, most of the studies focused on people with a mild intellectual disability.

The WHO Framework

The WHO's International Classification of Functioning, Disability & Health (ICF) offers a model of human functioning which shifts the focus onto the social environment and the contextual conditions which inpact on functioning. The ICF's definition of participation has four social life domains:

1. ***Domestic Life*** (involvement in the running of your home)
2. ***Interpersonal Life*** (informal social relationships, family rehaltionships, intimate relationships, formal relationships)
3. ***Major Life Activities*** (education, training, employment, voluntary work)
4. ***Community, Civic & Social Life*** (recreation & leisure, sports, arts & culture, religious practice, socialising)

Selection of Studies

- Of 2,936 studies identified through database searches, etc, 23 were selected on the basis of relevance, metholodogy, language, and culture.
- They came from the UK, USA, Scandanavia, Ireland, Netherlands, Australia and Israel.
- Fifteen studies compared people with and without ID.
- Only one related to Domestic Life, while Interpersonal Life was covered in 12 articles, Major Life Activities in 10 articles, and Community, Civic & Social Life in 13 articles.

Domestic Life

The one selected paper in this area found that people with ID in the USA:

- Go to the supermarket frequently;
- Do housework in their own home 4.7 hours per week;
- Help family, friends or neighbours 2.6 hours per week.

Interpersonal Life (12 papers)

- The focus, the settings and the sample sizes varied and so the findings vary accordingly:
- Average number in the person's social network varied from 2 to 22 in different studies – the higher number included staff and other service users.
- UK studies found that a quarter meet friends, and their circles are smaller than non-disabled peers, and activities take place in public places. Those in private or supported accommodation had the widest range of social contacts and made more use of the telephone. Family contacts or visits were lowest in institutions.
- More women that men with ID were married, cohabiting or had a child.
- Intimate relationships were highest among those with mild ID while those with a severe ID were unlikely to marry or have children.
- Visiting friends is the commonest community activity for those with a mild ID.

Major Life Areas (10 papers)

The main research focus here was on employment:

- People with ID were 3 to 4 times less like to be employed, and had been working for shorter time that non-disabled peers; they were less likely to be employed competitively, and more likely not to move job.
- Among those with a mild ID, 785 attended mainstreem schools, but less that 5% had achieved a formal qualification by the age of 35.
- Among those with a severe ID, 21% had a job, but earned less money, had fewer interactions at work, and had less positive relationships with co-workers.

Community, Civic, and Social Life (13 papers)

Again studies from diverse settings produced varied findings:

- People went our from their home less than five times a week, many for short periods.
- The most frequent places were shopping, church and restaurants, mostly accompanied by staff, and with peers.
- Women were more likely to visit the cinema or library.
- Having someone come for a meal or stay over, was not common.
- People who were longer livng in the community, ate out and attended adult education classes more often.
- Even those with a mild ID were less likely to be involved in community groups than their non-disabled peers.
- The Irish study found the leisure activities of day service attendees were mostly solitary and passive.

Conclusions

- This 10-year trawl of the literature shows how patchy is our knowledge of community participation.
- The researchers argue for a common framework with a theoretical basis, for exploring community participation, such as the ICF used here.
- Almost all the research focused on people with mild ID.
- Most researchers developed their own *ad hoc* questionnaires, thus precluding comparisons with other studies and an overview of the current situation.
- While some studies compared institutions with community housing, here was little analysis of the influence of environmental factors such as supports, on community participation.

Reviewer Comments

- The variation in studies made the job of building up an overall picture very difficult. Put simply, different studies had different findings due to the enormous variation in the circumstances of the research.
- Most of the findings would not surprise the reader. What would be of interest is the interventions that bring about changes in people's community involvement – what facilitates greater community participation?
- The authors are justified in pointing to the lack of a coherent framework for analysing community participation. In this context, the community outcomes in the Personal Outcome Measures (POMs) may be useful:
    - Live in an integrated setting
    - Participate in the life of the community
    - Interact with other members of the community
    - Perform different social roles
    - Have friends
    - Are respected

  Irish data on these outcomes are published elsewhere (McCormack & Farrell, 2009)