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# Community participation of people with an intellectual disability: a review of empirical findings

**M. M. L. Verdonschot,[1] L. P. de Witte,[2] E. Reichrath,[3] W. H. E. Buntinx[4] & L. M. G. Curfs[4]**

1 *Vilans, Hoensbroek/Governor Kremers Centre, Maastricht*
2 *Vilans, Hoensbroek/Maastricht University, Maastricht*
3 *Vilans, Hoensbroek*
4 *Maastricht University, Maastricht/Governor Kremers Centre, Maastricht*

## Abstract

*Study design* A systematic review of the literature.
*Objectives* To investigate community participation of persons with an intellectual disability (ID) as reported in empirical research studies.
*Method* A systematic literature search was conducted for the period of 1996–2006 on PubMed, CINAHL and PSYCINFO. Search terms were derived from the International Classification of Functioning, Disability and Health. Three investigators assessed the relevance of the initially identified studies using predefined content and methodological selection criteria. Included domains of community participation were: (1) domestic life; (2) interpersonal interactions and relationships; (3) major life areas; and (4) community, civic and social life.
*Results* Of 2936 initial hits, 23 quantitative studies eventually met the selection criteria and were included in the study. Only two studies are based on a theoretical framework. Research instruments were various and were most often *ad hoc* and not validated. The average number of persons in the social network of people with ID appears to be 3.1, one of them usually being a professional service staff member. People with ID are 3–4 times less employed than non-disabled peers; they are less likely to be employed competitively and are more likely to work in sheltered workshops or in segregated settings than those with other disabilities. People with ID are less likely to be involved in community groups, and leisure activities are mostly solitary and passive in nature. Most of the people with ID had been accompanied in an activity by training/therapeutic staff.
*Conclusion* It can be concluded that on the basis of empirical evidence, within the time frame of this literature search, little is known about community participation of people with ID. Many researchers did not clearly define community participation and were concerned with limited areas of community participation; research is seldom based on a theoretical framework. Most studies focus on people with mild ID, and there are few reports of the subjects' sample. However, one conclusion can consistently be drawn from the review: people with ID living in community settings participate more than people living in a segregated setting, but their participation level is still much lower than non-disabled and other disability groups.

**Keywords** community participation, intellectual disability

Correspondence: Manon Verdonschot, Vilans, PO Box 8228, 3503 RE Utrecht (e-mail: m.verdonschot@vilans.nl).

## Introduction

Over the last 30 years, people with intellectual disability (ID) have increasingly been living in community settings rather than in segregated facilities. People living in the community are assumed more likely to use community resources and to have more opportunities to experience relationships and roles, such as neighbour, friend, club participant, which are essential to being part of a community. Therefore, community participation is a major goal for all disabled people, but one which can be particularly difficult to achieve for adults with an ID. Community participation is not only a goal but also a 'process by which other goals are achieved' (cited in Myers *et al.* 1998). Evidence from previous studies has suggested that 'community presence' and enhanced opportunities are more readily attained than actual participation (Myers *et al.* 1998). Past studies have found that many residents in all types of community-living facilities rarely participated in basic leisure activities of the greater society, such as engaging in hobbies and visiting friends.

Recent theoretical models of human functioning, such as the International Classification of Functioning, Disability and Health (ICF) (WHO 2001), the Disability Creation Process Model (Fougeyrollas *et al.* 1998) and the theoretical model of ID by the American Association on Intellectual and Developmental Disabilities (Luckasson *et al.* 2002), shifts focus from an intraperson approach to a social ecological approach. Each of these models includes 'community participation' as an essential dimension of human functioning. Consequently, support policies and actions should also include the facilitation of community participation in the daily lives of people with ID. An important support question is how contextual conditions could be improved to achieve a productive, fulfilling and participative life in the community. Prior to designing any instruments to assess community participation as well as before developing any policies to improve participation, it is relevant to look into the empirical research literature to identify useful evidence-based knowledge. It is the aim of the present study to conduct such an inquiry.

The definition of participation in the present study is based on the ICF (WHO 2001; Dalemans *et al.* 2008; Van der Mei *et al.* 2006). Participation is defined as the performance of people in actual activities in social life domains through interaction with others in the context in which they live. Four social life domains are included: (1) domestic life; (2) interpersonal life (including formal relationships as well as informal social relationships, family relationships and intimate relationships); (3) major life activities consisting of education (informal, vocational training and higher education) and employment (remunerative and non-remunerative, excluding domestic work); and (4) community, civic and social life (including religion, politics, recreation and leisure, hobbies, socialising, sports, arts and culture).

In spite of the great attention to community participation of people with ID, little is yet known about the actual community participation of people with ID in the different life domains and about problems and successes they experience in their community lives. The aim of this study is to present a review of the empirical research literature of the last 10 years about community participation by people with ID. This time frame was chosen to focus on the construct of participation as conceptualised in more recent theoretical models of human functioning.

## Methods

### Search strategy

Publications were selected from PubMed (1996–2006), CINAHL (1996–2006) and PSYCINFO (1996–2006) databases. In all search strategies, we combined several terms for 'population' with a broad range of keywords related to 'outcome'. The keywords used for 'population' were: Intellectual disability OR Intellectual disabilities OR Intellectually-disabled OR Intellectually disabled OR Intellectually impaired OR Intellectually handicapped OR Mentally disabled persons OR Mentally handicapped OR Mentally disabled OR Mentally retarded OR Mentally impaired OR Mental retardation OR Learning disabilities OR Learning disability OR Learning disorder OR Developmental disabilities OR Developmental disability OR Developmentally impaired OR Developmentally disabled. The keywords used for 'outcome' were: Activities of daily living OR Activities OR Community functioning OR Community integration OR Community involvement OR Community participation OR Community inclusion OR Involvement in a life situation OR Participation OR Social integration OR Real life environment OR Quality of life OR Domestic life OR Homemaking OR Shopping OR Interpersonal interactions OR Formal relationships OR Informal social relationships OR Family relationships OR Intimate relationships OR Friendships OR Social networks OR Major life roles OR Education OR Vocational training OR Employment Community life OR Civic life OR Social life OR Recreation OR Leisure activities OR Hobbies OR Socialising OR Sports OR Arts OR Culture.

For the search in the selected databases keywords were adapted based on the possibilities of each database. The definitions of a keyword given in the thesaurus list of the specific database were used to determine whether a keyword was appropriate for use in the search strategy. The search was on title and/or abstract using the limits 'adolescents and adults', 'English' and 'Clinical Trial, Meta-Analysis, Review, Bibliography or Journal Article'.

## Procedure

Three investigators independently assessed the content relevance of the initially identified studies by using a 3-point scale (0 = irrelevant; 1 = possibly relevant; 2 = relevant). Content was evaluated against 'population' and 'outcome' terms. The references were scored in three phases:

- Phase 1: scoring the title by using the following predefined selection criteria: (1) period 1996–2006; (2) English language; (3) in title ID and aspects of community participation (domestic life, interpersonal relations, major life areas, education, employment, leisure activities, community life) and/or quality of life; (4) quantitative studies; and (5) western cultures. References with a total score below 2 were discarded as irrelevant. To ensure no relevant titles were discarded, references with a total score of two were assessed again by the three investigators, after discussion of the interpretation of criteria. Reassessed references with a total score below 3 were discarded as irrelevant;
- Phase 2: scoring abstracts using the 3-point scale by employing the following predefined selection criteria: (1) in abstract empirical data about how and on which level adolescents/adults with an ID participate in community; (2) quantitative studies; and (3) western cultures.
- Phase 3: scoring full text by one investigator using the 3-point scale and employing the following predefined selection criteria: (1) the group of persons with an ID is outlined in the population characteristics; (2) population characteristics are described; (3) methodology is described, and used measurement instruments are mentioned; (4) aspects of participation, as defined, are described; (5) aspects of participation are separately described as outcome; and (6) ID group is mentioned separately in the population characteristics, and the results are mentioned separately for the ID group, quantitative studies. References with a total score below 3 were discarded as irrelevant in phases 2 and 3.

Furthermore, the following journals were searched by hand: *American Journal on Mental Retardation* (1997–2006), *Mental Retardation* (1997–2006), *Journal of Intellectual Disability Research* (1996–2006); *Journal of Applied Research in Intellectual Disabilities* (2000–2006) and *Research in Developmental Disabilities* (1987–2006). The hand search was also conducted in three phases. Phase 1, scoring titles, is carried out by one researcher. Titles were scored on a 2-point scale (0 = irrelevant; 1 = relevant). Phases 2 and 3 were conducted to conform the procedure as described above.

In order to determine whether more articles from one author of selected articles were relevant, other articles by each author were searched and screened on title. Furthermore, other articles were gathered by screening the reference list of each selected article. The references were scored in the three phases as described above.

## Methodological quality assessment of the selected studies

A criteria list was used in order to assess the methodological quality of the selected studies. The list is based upon different criteria lists for non-randomised studies (Downs & Black 1998; Prins *et al.* 2002; Dalemans *et al.* 2008). This list consists of 15 items, describing aspects of informativity (six items), external validity (four items) and internal validity (five items) (see Table 1). All the selected studies were scored, using the list, by two authors.

**Table 1** Quality assessment of selected studies

| | Informativity | | | | | | | External validity | | | | | Internal validity | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Studies** | **a** | **b** | **c** | **d** | **e** | **f** | **Subtotal** | **g** | **H** | **i** | **j** | **Subtotal** | **k** | **l** | **m** | **n** | **o** | **Subtotal** | **Total** |
| Abraham *et al.* (2002) | + | + | + | + | – | + | 5 | – | – | + | – | 1 | – | – | + | + | + | 3 | 9 |
| Ager *et al.* (2001) | + | + | + | + | – | + | 5 | – | – | + | – | 1 | – | – | + | + | – | 2 | 8 |
| Ashman & Suttie (1996) | + | + | + | + | + | + | 6 | + | – | + | – | 2 | – | + | + | – | + | 2 | 10 |
| Botuck *et al.* (1998) | + | + | + | + | – | + | 5 | – | – | + | + | 2 | – | + | + | – | – | 2 | 9 |
| Buttimer & Tierney (2005) | + | + | + | + | + | + | 6 | – | – | + | – | 1 | + | – | + | – | – | 2 | 9 |
| Dagnan & Ruddick (1997) | + | + | + | + | – | + | 5 | – | – | + | + | 5 | – | – | + | – | – | 1 | 11 |
| Eliason (1998) | – | + | + | – | – | + | 3 | + | + | + | – | 4 | – | – | + | – | – | 1 | 8 |
| Emerson & McVilly (2004) | + | + | + | + | – | + | 5 | – | – | + | + | 2 | – | – | + | + | – | 2 | 9 |
| Forrester-Jones *et al.* (2006) | + | + | + | + | + | + | 6 | + | – | – | + | 2 | + | + | + | + | – | 4 | 12 |
| Hall & Hewson (2006) | + | + | + | + | – | + | 5 | – | – | + | + | 2 | + | – | + | – | – | 2 | 9 |
| Hall *et al.* (2005) | + | + | + | + | + | + | 6 | + | – | + | + | 3 | + | + | + | – | + | 4 | 13 |
| Hayden *et al.* (1996) | + | + | + | + | + | + | 6 | – | – | + | – | 1 | – | + | + | + | – | 3 | 10 |
| Luftig & Muthert (2005) | + | + | + | + | + | + | 6 | – | – | + | – | 1 | – | + | + | – | – | 2 | 9 |
| Mank *et al.* (1998) | + | + | + | – | – | + | 4 | – | – | – | – | 0 | + | + | + | + | – | 4 | 8 |
| Maughan *et al.* (1999) | + | + | + | + | + | + | 6 | + | + | + | + | 4 | + | + | + | + | + | 5 | 15 |
| Olney & Kennedy (2001) | + | + | + | + | – | + | 5 | + | – | + | + | 3 | + | + | + | + | – | 4 | 12 |
| Robertson *et al.* (2001) | + | + | + | + | + | + | 5 | – | + | + | – | 2 | + | + | + | + | – | 4 | 11 |
| Spreat & Conroy (2002) | + | + | + | + | – | + | 5 | – | – | – | + | 1 | + | + | + | + | – | 4 | 10 |
| Taanila *et al.* (2005) | + | + | + | + | + | + | 6 | + | – | + | + | 3 | + | + | + | – | – | 3 | 12 |
| Umb-Carlsson & Sonnander (2006) | + | + | + | + | + | + | 6 | + | – | + | + | 3 | + | + | + | – | + | 4 | 13 |
| Wilhite & Keller (1996) | + | + | + | + | + | + | 6 | + | – | + | – | 2 | – | – | + | – | – | 1 | 9 |
| Yamaki & Fujiura (2002) | + | + | + | + | – | + | 5 | + | + | + | + | 4 | + | + | + | – | – | 3 | 12 |
| Zijlstra & Vlaskamp (2005) | + | + | + | + | + | + | 6 | + | + | + | + | 5 | – | + | + | – | + | 3 | 14 |

a, the purpose of the study is clearly described; b, the method of data collection is properly described; c, the main outcomes to be measured are clearly described in the introduction or methods section; d, the description of the characteristics of the population is sufficient; e, the response rate is ≥70%, or the information on the non-respondents is sufficient; f, the main findings of the study are clearly described: simple outcome data should be reported for all major findings; g, the subjects asked to participate are representative of the entire population from which they were recruited; h, the inclusion and exclusion criteria are described; i, the age range is specified; j, the study period is described; k, the data are prospectively collected; l, a comparison group is used and properly described; m, the measurement instrument(s) is/are described; n, the main outcome measures used are accurate (valid and reliable); o, age- and gender-specific outcomes are reported; +, positive; –, negative.

In the case of disagreement, the scores were discussed with the other authors.

### Data analysis

Studies were categorised as a quantitative study or a review. The reviews were used to find original papers but were not included themselves. The data in the articles were transferred into prepared forms and a database, containing the quality assessment results of the selected studies, the characteristics of the studies and the outcomes of the different studies per participation domain as defined above.

## Results

The search for publications resulted in 2936 initial hits, including 161 double references. Information on the number of papers generated is available on request.

Twenty-three quantitative studies met the predefined selection criteria and were included in our study. The total score (maximum score = 15) on the quality assessment ranged 8–15 (see Table 1). The lowest scores were on the aspects of internal validity. One review was found concerning community integration of people with learning disabilities, based on material from 1970s to 1998 (Myers *et al.*

1998). References used in this study that met our predefined selection criterion were already included in our study.

The finally selected studies were conducted primarily in the UK (nine studies) and USA (eight studies), followed by Scandinavia (two studies), the Netherlands (one study), Australia (one study), Ireland (one study) and Israel (one study). One study was conducted in both the UK and Australia (Emerson & McVilly 2004), and one study was conducted in both Israel and the USA (Botuck *et al.* 1998). Used measurement instruments were quite diverse. They varied from *ad hoc* questionnaires, some validated questionnaires and interviews; the number of participants in these studies ranged from 36 to 1 748 900. Fifteen studies compared outcomes of persons with ID with other groups.

Two studies based their study on a theoretical framework. Hall *et al.* (2005) based their study on the ICF and Eliason (1998) based his study on Blau's (1977) macro structural theoretical strategy. Most studies made use of a cohort design.

Table 2 summarises the following aspects of the selected studies: (1) author and year of publication; (2) participation domain studied; (3) country in which the study is conducted; (4) theoretical framework; (5) study design; (6) data collection method; (7) sample size; (8) sample age; and (9) used measurement instruments in the study. Only five studies provide a clear definition of their target group.

'Major life areas', mainly employment, was studied in 10 articles. Community, civic and social life was studied in 13 articles, and interpersonal life in 12 articles. Only one article described domestic life (Wilhite & Keller 1996). The articles concerning the major life domain all described employment, and one of them also described education (Hall *et al.* 2005).

## Major findings

### *Domestic life*

Domestic life is about carrying out domestic and everyday actions and tasks. Areas of domestic life include acquiring a place to live, food, clothing and other necessities, household cleaning and repairing, caring for personal and other household objects and assisting others. Only one of the selected studies, carried out in the USA, reported aspects of domestic life (Wilhite & Keller 1996), which was described by the authors as part of the topics integration and productivity. Integration was defined in the study as the use by persons with developmental disabilities (DD) of the same community resources and activities that are used by and available to other citizens, as well as contact with citizens without disabilities. Productivity was defined as engagement in income-producing work by persons with DD or in work which contributes to a household or community.

According to Wilhite & Keller (1996) people with DD go to the supermarket frequently, perform house work in their own home 4.7 h per week and help family, friends or neighbours 2.6 h per week.

### *Interpersonal life*

Interpersonal life includes formal relationships as well as informal relationships (friends), family relationships and intimate relationships (sexual relationships and relations with a spouse). With regard to interpersonal life, 12 studies were found. The study of Luftig & Muthert (2005) was omitted in the result description, because of the lack of facts on interpersonal life in this study.

Table 3 outlines the main results of the 11 remaining studies. According to Dagnan & Ruddick (1997), the mean number of persons in the social network of people with ID was 3.1, and over 90% had at least one person in their social network. Robertson *et al.* (2001) found a mean number of two in the social network of people with ID living in community-based residences. Forrester-Jones *et al.* (2006) had different conclusions. They found that the average network size of people with ID living in the community was 22 members. One-quarter of this network was other service users, and 43% were staff. Only one-third of members were unrelated to learning disability services.

According to Ager *et al.* (2001), 25% of people with ID meet friends, but people with ID were less likely than their peers to have six or more friends or relatives with whom they were in regular contact (Hall *et al.* 2005). According to Emerson & McVilly (2004) people with ID living in supported accommodation are more likely to be involved in activities

**Table 2** Characteristics of the selected studies

| Author (year) | Participation domain* | Country | Theoretical framework | Design | Data collection | Sample size | Sample age (years) | Measurement instruments |
|---|---|---|---|---|---|---|---|---|
| Abraham *et al.* (2002) | IV | UK | No framework | Cross-sectional study | Questionnaire and interviews | Fifty adults with learning difficulties (no definition) | 23–65 | Guernsey Community Participation and Leisure Assessment |
| Ager *et al.* (2001) | II and IV | UK | No framework | Cohort study | Questionnaires and diary | Seventy-six adults with ID (no definition) | 21–92 (mean 53) | Life Experience Checklist and Index of Community Involvement |
| Ashman & Suttie (1996) | II and IV | Australia | No framework | Cohort: national representative survey | Questionnaire and interviews | Four hundred and forty-six adults with ID (no clear definition) | ≥55 | Self-made 36-item questionnaire |
| Botuck *et al.* (1998) | III (employment) | Israel and USA | No framework | Cohort: longitudinal study | Forms filled in by employment training specialist | One hundred and nine adults with ID (no clear definition), severe learning disability (definition based on federal definition) or psychiatric disabilities | 70–60 | Self-made forms |
| Buttimer & Tierney (2005) | IV | Ireland | No framework | Cohort study | Questionnaire | Thirty-four students with mild and moderate ID (no definition) | >16 | Trail Leisure Assessment Battery |
| Dagnan & Ruddick (1997) | II and IV | UK | No framework | Cohort study | Questionnaire | Fifty-two adults with learning disabilities (no definition) | ≥60 | Social network questionnaire |
| Eliason (1998) | IV | USA | Framework based on macro structural theoretical strategy (Blau 1977) | Cohort study | Questionnaire and interviews | Some 2560 adults with developmental disabilities (no definition) | | Instrument developed for this study based on quality of life |
| Emerson & McVilly (2004) | II | UK and Australia | No framework | Cohort study | Questionnaire | Some 1542 adults with ID (no definition) | ≥18 (mean 49.3) | Index of Community Involvement |
| Forrester-Jones *et al.* (2006) | II | UK | No framework | Cohort study | Questionnaire | | | The social Network Guide |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Hall *et al.* (2005) | II, III (employment and education) and IV | UK | In accordance with the participation concept of International Classification of Functioning, Disability and Health (WHO 2001) | Prospective follow-up of a British-birth cohort | Several questionnaires and database study | Some 4038 people: 134 people with mild ID or severe ID (ID as defined by the ICD-10) and 3904 people functioning on normal intellectual level | Birth cohort of 1946 | Self-made questionnaire |
| Hall & Hewson (2006) | IV | UK | No framework | Cohort study | Diaries | Fifty-one people with ID | 22.5–61.8 (mean 35.7) | Diaries |
| Hayden *et al.* (1996) | IV | USA | No framework | Descriptive and analytical study | Questionnaire and interviews | One hundred and ninety adults with ID (no definition): 6.3% mild ID, 4.2% moderate ID, 31.6% severe ID and 57.9% profound ID | ≥20 | Self-made questionnaire |
| Luftig & Muthert (2005) | II, III (employment) and IV | UK | No framework | Cohort: longitudinal study | Questionnaire | Seventeen people with learning disability and 19 people with ID (no clear definition) | (mean 23.6) | Self-made 16-item questionnaire |
| Mank *et al.* (1998) | III (employment) | USA | No framework | Cohort | Questionnaire | Three hundred and twenty-nine adults with ID (no definition) | | Self-made questionnaire |
| Maughan *et al.* (1999) | II, III (employment) | UK | No framework | Prospective follow-up of a British-birth cohort | Several questionnaires and database study | Two hundred and seventy-five adults with mild ID (IQ ≤ 70 at age 11) | 33 (Birth cohort) | Several self-made questionnaires and the Malaise Inventory |
| Olney & Kennedy (2001) | III (employment) | USA | No framework | Cohort study | Database of the Adult Disability Follow-Back Survey | Some 16 728 adults with ID (no clear definition) | 18–65 | Nation Health Interview survey |
| Robertson *et al.* (2001) | II | UK | No framework | Cross-sectional design | Questionnaire | Five hundred and forty adults with ID (no definition) | (mean 45.1) | Social Network Map |
| Spreat & Conroy (2002) | II | USA | No framework | Longitudinal study | Questionnaire | One hundred and seventy-seven persons with ID (no definition) | | Developmental disability quality assurance questionnaire |

**Table 2** *Continued*

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Taanila *et al.* (2005) | III (employment) | Finland | No framework | Prospective follow-up of a birth cohort in North Finland | Several questionnaires and database study | One hundred and forty adults with ID (IQ < 70 at age 14); 160 adults with borderline ID (IQ = 71–85 at age 14) | Birth cohort of 1946 | Questionnaire on the child's health, development and school performance. Questionnaire on life situation, lifestyles, employment and health |
| Umb-Carlsson & Sonnander (2006) | II, III (employment) and IV | Sweden | No framework | Cohort study | Questionnaire | One hundred and ten adults with ID (no clear definition) | 32–45 | Self-made 233-item questionnaire |
| Wilhite & Keller (1996) | I, II, III (employment) and IV | USA | No framework | Cohort study | Interviews (face-to-face) | One hundred and ninety-nine adults with developmental disabilities (mental or physical impairment, manifested before age of 22, which results in functional limitations in some areas of major life activity): 44% ID and 12% cerebral palsy | ≥22 | Self-made questionnaire used as interview scheme |
| Yamaki & Fujiura (2002) | III (employment) | USA | No framework | Cohort: national representative household survey of non-institutionalised adults | Interviews | Some 1 748 900 adults with developmental disabilities (same definition as Wilhite & Keller) | 22–65 | Survey of Income and Programme Participation questions |
| Zijlstra & Vlaskamp (2005) | IV | the Netherlands | No framework | Descriptive and analytical study | Questionnaire and diary | One hundred and ninety-six adults with profound ID and multiple disabilities (PMID: no definition) | ≥18 | Self-made questionnaire |

* (I) domestic life; (II) interpersonal interactions and relationships; (III) major life area; and (IV) community, social and civic life.
ICD, international classification of disease; ID, intellectual disability; PMID, profound and multiple intellectual disabilities.

**Table 3** Interpersonal life

| Author (year) | Results |
|---|---|
| Ager *et al.* (2001) | Fifty per cent of the respondents with intellectual disability (ID) had any contact with people in the community, such as shop assistants, local people or neighbours; 24% meet a friend; 31% meet relatives. |
| Ashman & Suttie (1996) | Almost 50% of the participants received at least yearly visits from family members. The highest incidence was reported for those living in private dwellings and nursing homes, and the lowest for those living in institutions. Those in private dwellings had most contacts via telephone and mail, and they were also those who had the widest range of social contacts. Only 36% made visits out of their residences to friends, although 36% also received visits from friends. |
| Dagnan & Ruddick (1997) | Ninety-two per cent of people with learning disabilities (LD) has at least one person in their social network; the mean number of people in a social network was 3.1; 52% have some form of contact with family or co-residents; 29% have contact with people without LD, of which 12% have contacts with advocates. |
| Emerson & McVilly (2004) | Over a 4-week period, the median number of occurrences of all friendships activities with friends with ID was two and with friends without ID none. |
| Forrester-Jones *et al.* (2006) | The average network size was 22 members. One-quarter of network members were other service users with ID, and a further 43% were staff. Only one-third of members were unrelated to LD services; these included family members (14%), social acquaintances and other friends (11%) and contacts working in shops, pubs and cafes. |
| Hall *et al.* (2005) | Participants with severe ID were unlikely to marry or have children. A majority with mild ID did marry (73%) and have children (62%). People with ID were less likely than their peers to have six or more friends or relatives with whom they were in regular contact. |
| Luftig & Muthert (2005) | Ninety-four per cent of people with LD and of people with ID were single; 6% of unmarried respondents were parents of children. |
| Maughan *et al.* (1999) | Some 94.7% of women with mild ID had established marital/cohabiting relationships by their early thirties; 46.9% had had at least one child; 79.5% of the men ever were in a stable cohabiting relationship; 43.5% of the men had at least one child. |
| Robertson *et al.* (2001) | The median size of participant's social networks (excluding staff) was two people; 83% has a staff member, 72% a member of their family, 54% another person with ID and 30% a person who did not fit into any of these categories in their social network. |
| Spreat & Conroy (2002) | There was an increase in family contact subsequent to placement in supported living arrangements. Persons living in the institution had about nine family contacts per year, while persons living in the community had about 18 family contacts per year. |
| Umb-Carlsson & Sonnander (2006) | Some 39.4% women vs. 28.2% men were married; no differences between women and men with ID on family and social relations. |
| Wilhite & Keller (1996) | Visiting friends most engaged community activity by respondents with developmental disabilities. |

with friends who also have ID, and most friendship activities take place in the public domain rather than in more private settings. Robertson *et al.* (2001) came to similar conclusions. They found that 54% had another person with ID in their social network. Ashman & Suttie (1996) found that those in private or supported accommodations had the widest range of social contacts and most contacts via telephone and mail. Furthermore, 83% had a staff member, 72% a member of their family and 30% a person who did not fit into any of these categories in their social network (Robertson *et al.* 2001).

Ager *et al.* (2001) concluded that 50% of the respondents with ID had any contact with people in the community, such as shop assistants, local people or neighbours. One-third met relatives. According to Dagnan & Ruddick (1997), 29% had contact with people without ID, and 12% had contacts with advocates. Umb-Carlsson & Sonnander (2006) found no differences between women and men with ID on family and social relations. Fifty per cent of older people with ID (55+) received at least yearly visits from family members. The highest incidence was reported for those living in private dwellings and nursing homes and the lowest for those living in institutions (Ashman & Suttie 1996). Spreat & Conroy (2002) found that people with ID living in supported living arrangements had twice as many family contacts per year as people living in an institution (18 vs. 9).

More women than men with ID were married (39% vs. 28%) (Umb-Carlsson & Sonnander 2006). Most informal and intimate relations outcomes were reported on people with mild ID in the identified studies. Visiting friends is the community activity most engaged by people with mild ID (Wilhite & Keller 1996). According to Hall *et al.* (2005), 73% of people with mild intellectual impairments married. Maughan *et al.* (1999) found more women than men (95% vs. 80%) with mild ID establishing marital/cohabiting relationships by their early 30s and more women (47% vs. 43%) than men had at least one child (Maughan *et al.* 1999). Only Hall *et al.* (2005) reported on outcomes of people with severe ID. They concluded that people with severe intellectual impairments were unlikely to marry or have children.

### *Major life areas*

The major life areas topic appeared in 10 articles. The domain consists of education, work and employment, and economic life. None of the selected publications described how and/or how many people with ID engage in economic life, and only one study described engagement in education by people with ID (Hall *et al.* 2005). Ten studies described employment. In five studies, the main research topic was employment (Botuck *et al.* 1998; Olney & Kennedy 2001; Yamaki & Fujiura 2002; Taanila *et al.* 2005; Mank *et al.* 1998). In one study, the research topics were both patterns of employment and independent living (Luftig & Muthert 2005). In the other four studies, the research topics were social outcome (Hall *et al.* 2005), living conditions (Umb-Carlsson & Sonnander 2006), psychosocial functioning (Maughan *et al.* 1999) and productivity (Wilhite & Keller 1996). All these concepts included employment.

Table 4 reports the main results of the 10 publications concerning employment outcomes. People with ID are 3–4 times less employed than the non-disabled (Maughan *et al.* 1999; Yamaki & Fujiura 2002; Taanila *et al.* 2005), and they are more likely to have more and longer unemployed periods than those without disabilities (Taanila *et al.* 2005). According to Maughan *et al.* (1999), more men than women with ID (57% vs. 15%) had any period of unemployment at age 23–33. Furthermore, working adults with ID are less likely to be employed competitively and much more likely to work in sheltered workshops and other segregated settings than those with other disabilities (59% vs. 5%) (Taanila *et al.* 2005).

Most results were reported on people with mild ID. About 65% of this group of people is employed (Hall *et al.* 2005; Luftig & Muthert 2005). Almost 50% of people with DD were working for pay full-time or part-time (Wilhite & Keller 1996). According to Maughan *et al.* (1999), more men than women (69% vs. 39%) with mild ID are employed at age 33. Of all people with mild ID who had been employed once, almost 53% said that they had held the same job since graduating the high school programme (Luftig & Muthert 2005), and Botuck *et al.* 1998 reported that 77% changed jobs at least once. The largest areas of employment for people with mild ID were welding trades (17%), service industry jobs (14%) and factory jobs (11%). Analyses revealed that people with mild ID are more likely to be engaged in less skilled jobs, such as services industries and factory positions (Luftig & Muthert 2005). Yamaki & Fujiura (2002) reported that the majority of the employed workers with DD engaged in either service occupations (23%) or labouring jobs (29%). In the study of Botuck *et al.* (1998), the first jobs of the developmentally disabled were primarily in maintenance (30%) and retail (24%) sectors. Umb-Carlsson & Sonnander (2006) also looked at differences in gender. Of those occupied with productive activities, women typically worked in service areas, whereas men work in farming, forestry, gardening and industrial production.

Mank *et al.* (1998) and Hall *et al.* (2005) reported on people with severe ID. Hall *et al.* (2005) found that 21% of this group had one or more jobs. Mank *et al.* (1998) reported supported employees with more severe ID earned significantly less money, had

**Table 4** Major life – employment

| Author (year) | Results |
|---|---|
| Botuck *et al.* (1998) | Twenty-eight per cent of individuals with developmental disabilities retained their jobs for 12–24 months; 72% changed jobs during 24 months; first jobs were primarily in maintenance (30%) and retail (24%) sectors. |
| Hall *et al.* (2005) | Sixty-seven per cent of people with mild intellectual disability (ID) had one or more jobs; 21% of severe ID had one or more jobs. |
| Luftig & Muthert (2005) | Ninety-four per cent of the students with specific learning disabilities were employed; 68% of people with developmental disabilities (mild ID) were employed. The largest areas of employment were welding trades (17%), service industry jobs (14%) and factory jobs (11%). |
| Mank *et al.* (1998) | Supported employees with more severe ID earned significantly less money, had worked fewer months in their current job and had fewer interactions at work. Furthermore, those with more severe ID were perceived as having lesser work rate, work quality and less positive relationships with co-workers. |
| Maughan *et al.* (1999) | People with mild ID were four times more unemployed than the non-retarded comparison group; 68.5% of men vs. 38.6% of women are employed at 33; 7.7% men vs. 25.4% women had no job at age 23–33; 14.3% men vs. 5.3% women had more than five jobs at age 23–33: 56.8% of men vs. 14.9% of women had any period of unemployment at age 23–33. |
| Olney & Kennedy (2001) | Working adults with ID are less likely to be competitively employed and much likely to work in sheltered workshops and other segregated settings than people with other disabilities (58.4 vs. 5.3%). |
| Taanila *et al.* (2005) | Some 24% of individuals with ID vs. 65% of individuals without ID were employed; over one-third of individuals with mild ID (IQ = 50–70) did not receive a disability pension, and their working periods were fewer and shorter. |
| Umb-Carlsson & Sonnander (2006) | More women than men were provided care and enriching experiences; women typically work in service areas; men work in farming, forestry, gardening and industrial production. |
| Wilhite & Keller (1996) | Almost half of the sample (48%) was working for pay full- or part-time. However, the average number of hours per week spent in working for pay was 9.39. Respondents reported 2.08 h per week volunteering with community groups. |
| Yamaki & Fujiura (2002) | Some 27.6% of adults with developmental disabilities vs. 75.1% of general population had a job; 12% is part-time employed; 16% is full-time employed; 23% of the employed workers with developmental disabilities engaged in either service occupation, 29% in labourer jobs. Janitor was the most frequently reported job title (10%). |

worked fewer months in their current job and had fewer interactions at work. Furthermore, those with more severe ID were perceived as having lesser work rate, work quality and less positive relationships with co-workers.

Hall *et al.* (2005) reported some education outcomes of people with mild ID: 78% were attending mainstream school, mostly secondary modern or comprehensive schools; 52% were attending special or approved schools. Less than 5% of those with ID had achieved some formal qualification by the age of 35.

### *Community, civic and social life*

Community, civic and social life includes recreation and leisure activities (hobbies, socialising, sport, arts and culture). The community, civic and social life domain was a topic in 13 identified articles. Three articles described leisure activities as an important part of the study (Abraham *et al.* 2002; Zijlstra & Vlaskamp 2005; Hall & Hewson 2006).

Table 5 summarises the main outcomes of the 13 publications concerning leisure activity outcomes. Individuals in institutional and community settings experienced almost five outside events per week (Eliason 1998). Eighty-eight per cent of individuals in community-based houses went out less than once a day, and 48% went out for less than an hour per day (Hall & Hewson 2006). Going out to a restaurant, attending church and shopping are frequently mentioned activities, especially by those who moved to a community setting (Hayden *et al.* 1996; Wilhite & Keller 1996). A majority of adults with ID under-

**Table 5** Community, civic and social life

| Author (year) | Results |
|---|---|
| Abraham *et al.* (2002) | Of 49 potential (community) activities, participants reported engaging between seven and 32 regularly and between three and 23 frequently; 28% identified no activities undertaken with peers, and 12% of activities involved peers, while 23% were engaged in alone; 62% reported no supervised activities, and only 7% of all activities were categorised as supervised. |
| Ager *et al.* (2001) | Those activities, which require a high degree of personal autonomy, such as having people to stay overnight, staying overnight with others or having people to visit for a meal, were less frequently reported. Over 80% of the sample undertook at least one activity in a public resource, such as a shop or leisure centre, suggesting a degree of physical presence within community; over 75% had been accompanied in an activity by training/therapeutic staff; over a 7-day period, less than half the sample were engaged in activities other than routine in-house tasks and pastimes for 4 h or more each day. |
| Ashman & Suttie (1996) | Results also indicate that the overwhelming majority of participants had little involvement in organised, community-based recreation or social programmes. A modest number of residents of hostels and supporting dwellings attend clubs or group activities organised by church groups, senior citizens clubs or day-care programmes. A smaller number (10–15%) are involved in sporting activities or other leisure activities, such as bowling or walking. |
| Buttimer & Tierney (2005) | Leisure activities of clients attached to day services were solitary, passive and family oriented. |
| Dagnan & Ruddick (1997) | Most people with learning disabilities take part in activities with co-residents; fewest take part in activities with people without learning disabilities. |
| Eliason (1998) | Individuals in institutional and community settings experience an average of 4.79 outside events per week. |
| Hall *et al.* (2005) | Those with mild intellectual disabilities were less likely to be involved in community groups (e.g. church, school, sports, local government) compared with their peers. There were no significant differences in informal social activities, such as going to the pub or social clubs. |
| Hall & Hewson (2006) | Eighty-eight per cent of residents went out less than once a day, and 48% went out for less than an hour per day; 55% of residents had no personal visitors at all during the 4-week period of the study. |
| Hayden *et al.* (1996) | Significantly more movers than stayers utilise churches, community education facilities and libraries. The primary activities engaged in by almost all of the movers and stayers were passive activities, including sitting around resting and watching TV or listening to radio and records. More movers (1) attend a community event; (2) went out to eat; and (3) attend an adult education class; more movers attended religious services than at baseline. Significantly more movers than stayers went grocery shopping, shopped personal items and did banking at follow-up. |
| Luftig & Muthert (2005) | Thirty per cent of respondents answered watching films was their chief recreational activity; 15% work on bikes and cars, watch TV and join job club groups. |
| Umb-Carlsson & Sonnander (2006) | More women than men with intellectual disabilities participated in certain activities, such as visiting the cinema and library, reading books and practicing hobbies alone. |
| Wilhite & Keller (1996) | Going out to a restaurant, attending church and shopping are frequently mentioned activities. |
| Zijlstra & Vlaskamp (2005) | Some 19.9% of total time available in a weekend was spent on leisure provision; most frequently recorded activities are 'audio-visual media', 'physically oriented activities' and 'play games'. |

took at least one activity in a public resource, such as a shop or leisure centre, suggesting a degree of physical presence within the community. Most of them had been accompanied in an activity by training/therapeutic staff (Ager *et al.* 2001), and most people took part in activities with co-residents (Dagnan & Ruddick. 1997). According to Abraham *et al.* (2002), 12% of activities involved peers. The activities which require a high degree of personal autonomy, such as having people to stay overnight, staying overnight with others or having people to visit for a meal, were less frequently reported (Ager *et al.* 2001). After a period of living in the community, people more frequently attended community events, went out to eat and attended adult education classes (Hayden *et al.* 1996).

Hall *et al.* (2005) studied community life outcomes for those with mild ID. They found that this group was less likely to be involved in community groups (e.g. church, school, sports, local government) compared with the non-disabled (Hall *et al.* 2005), but there were no significant differences between people with mild ID and the non-disabled in informal social activities, such as going to the pub or social clubs (Hall *et al.* 2005). Ashman & Suttie (1996) reported that a modest number of older residents (55+) in hostels and supporting accommodations attended clubs or group activities organised by church groups, senior citizens clubs or day-care programmes.

Buttimer & Tierney (2005) identified a range of leisure activities performed by students with an ID which were mostly solitary and passive in nature. Most mentioned recreational activities were watching films, working on bikes and cars, watching TV and participating in job club groups (Buttimer & Tierney 2005; Luftig & Muthert 2005). More women than men with ID participated in certain activities, such as visits to the cinema and library, reading books and practising hobbies alone (Umb-Carlsson & Sonnander 2006). People with severe ID spent 20% of total time available in a weekend on leisure provision. Most frequently recorded activities are 'audio-visual media', 'physically oriented activities' and 'play games' (Zijlstra & Vlaskamp 2005).

## Discussion

This study presents a review of the empirical research literature on community participation of people with ID in the period 1996–2006. A broad-spectrum search strategy was used in several databases. Although there were many hits, only 23 articles met the preset selection criteria. Hence, in spite of the great attention of the field towards community participation of people with ID, evidence-based knowledge about community participation appears to be very limited.

### Community participation of people with intellectual disability

One general conclusion can be drawn: people with ID living in community settings participate more than people living in segregated setting. However, the level of participation is still much lower than in the non-disabled and other disabled groups. Similar results are reported by Myers *et al.* (1998).

Participation in domestic life seems to be ignored as a study domain. Only one study briefly described this aspect of participation. Here it should be noted that the used inclusion criteria appear not to have captured the active support literature. With regard to interpersonal interactions and relationships, the social network of people with ID is relatively small and mostly consists of people with ID. Furthermore, intimate relations are only reported regarding people with mild ID. They are often married and/or have at least one child.

With respect to employment, it can be concluded that people with ID are 3–4 times less often employed than non-disabled. They are more likely to be employed in sheltered workshops and other segregated settings, and they are also more likely to be engaged in less skilled jobs.

Participation of people with ID in community, civic and social life increases when they have lived in the community for a longer period. A majority of adults with ID undertake at least one activity in the community. However, they are usually accompanied by a staff member, and most take part in activities with co-residents.

### Limitations of this study

The databases PubMed, CINAHL and PSYCINFO were searched for the period 1996–2006, making use of a combination of MeSH and text words that covered a wide range of the research population and participation-related terms. We retained publications evaluated independently by three investigators using preset selection criteria. In spite of these well-defined criteria, agreement of scores was not always achieved. However, in the case of doubt, other experts were consulted. Furthermore, we included articles found in the above-mentioned databases. We are aware of the fact that more relevant publications and reports, not included in the searched databases, could exist. Some of these were detected by searching and assessing relevant references of selected authors and from the hand search conducted. Furthermore, we chose to search for quantitative studies within the period 1996–2006.

Relevant data on community participation may also be covered in the field of qualitative research and in the period before 1996. Data on the period before 1996 were already described (Myers *et al.* 1998). We chose the last 10 years as the search window to be able to collect data about recent developments in community participation.

In spite of the broad search, the 'state of the art' of community participation by people with ID as based on empirical findings is still not clear. Most studies included people with mild ID, but a clear definition of the sample was seldom provided. Furthermore, data should be interpreted with caution. The methodological quality and the characteristics of the included studies varied greatly. Participation was often vaguely or just partly described, and a clear conceptual framework was mostly lacking. Very different instruments were used, most often self-made *ad hoc* questionnaires. Not all studies used a representative sample. By using a criteria list to assess the methodological quality of the selected studies, some categorisation of methodological quality could be attempted. All these aspects make it difficult to compare data and to draw an overall conclusion.

## Conclusions

It can be concluded that on the basis of empirical research, published within the time frame of this literature search, little is known about community participation of people with ID. Many researchers did not clearly define community participation or restrict their study to limited aspects of community participation. A valid conceptual framework is hardly referred to. The researchers in the present review used the ICF as a theoretical framework for conceptualising community participation. Because the ICF treats 'participation' as a dimension of general human functioning and because the construct of 'participation' is well defined and categorised, the ICF could be considered a valid theoretical framework for the study of participation in people with ID.

The selected studies mainly focused on people with mild ID. People with moderate and severe ID are seldom included in participation research. In addition, there seems to be a lack of validated instruments for the measurement of community participation in people with ID. The use of *ad hoc* questionnaires outside a theoretical framework is the rule in the selected studies.

Based on the results of the present study, some recommendations can be made for future research. First, future research into community participation of people with ID should use a valid theoretical framework to define and classify the construct of 'participation'. It is suggested to use the ICF as such a theoretical frame for future research. Second, future investigations need to focus on valid and suitable instruments to assess aspects of community participation in people with ID. The ICF can be recommended as a theoretical backdrop for the development of such instruments. The relevance of the ICF for the field of ID is even more obvious as it has been demonstrated that this framework is compatible with the American Association on Intellectual and Developmental Disabilities functional model of ID (Luckasson *et al.* 2002; Buntinx 2006). Third, studies should not be restricted to people with mild ID but should be extended to include people with moderate and severe ID. Fourth, an important future study might be an analysis of the influence of environmental factors on participation of people with ID. The role of support seems to be an important factor in the participation of people with ID. To fully understand and to be able to enhance the participation of people with ID, context-oriented research will be necessary. Again, ICF can be recommended as a theoretical framework as it includes the dimension of environmental context. Within the ICF framework, the chapter environmental factors are least developed and least researched.

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