

A systematic review of community participation measures for people with intellectual disabilities

Abstract

Background: Community participation is considered a fundamental aspect of quality of life and one of the essential goals of services for people with intellectual disabilities (ID), yet there is no agreed way of measuring community participation.

Method: Two systematic searches were performed across eight electronic databases to identify measures of community participation and identify validation studies for each measure. Measures were included if they were developed for adults with ID, measured extent of participation and had published information regarding content and psychometric properties. Each measure was evaluated on the basis of psychometric properties and in relation to coverage of nine domains of community participation from the *International Classification of Functioning, Disability and Health (ICF)*.

Results: Eleven measures were selected with the quality rating scores varying substantially ranging from 2-11 of a possible 16.

Conclusions: The majority of measures were not sufficiently psychometrically tested. Findings suggest a need for the development of a psychometrically robust instrument.

Introduction

Community participation and quality of life

Public policymaking and service delivery relating to people with ID is heavily influenced by concerns in regard to quality of life. Schallock, Verdugo and

Braddock (2002) identified eight domains of quality of life, validated in a series of cross-cultural studies. These domains are personal development and self-determination (reflecting the level of independence); interpersonal relations, social inclusion, rights (reflecting social participation); emotional, physical, and material well-being. Jenaro et al. (2005) highlighted that 'community integration and participation' was one of the three most commonly referenced published indicators for the domain of Social Inclusion. In addition, theoretical models of human functioning such as the Disability Creation Process Model (Fougeyrollas et al. 1998), the International Classification of Functioning, Disability and Health (ICF) (WHO 2001), and the Theoretical Model of ID by the AAIDD (Luckasson et al. 2002), all include community participation as a fundamental aspect of human functioning.

In spite of the apparent importance of community participation, there remains confusion in regard to terminology and definition. In an extensive review Amado, Stancliffe, McCarron, and McCallion (2013) concluded that there is no clear consensus on the differences amongst the terms integration, inclusion, community participation, and community belonging. Chang, Coster & Helfrich (2013) provided some helpful clarity here by suggesting an extension of the definition of participation provided by the World Health Organisation International Classification of Functioning, Disability and Health (ICF) of *involvement in life situations, to autonomous (to an extent) social interaction with the environment in terms of involvement with various life situations*. They then used this clarification of participation to define community participation and its need to focus on activity outside of household life, with activities outside the household requiring different or even advanced capabilities, such

as mobility in the community and socializing with more people. Chang et al.'s (2013) definition of community participation will be used for the purposes of this study– '*active involvement in activities that are intrinsically social and either occur outside the home or are part of a nondomestic role*'. This was chosen as it sought to address the limitations of the ICF definition of participation and included involvement of the individual with their environment, such that community participation is distinguished from the domestic life domain. Thus the individual can be considered to be participating in their community without a physical presence, for example engagement via social media.

Measurement of community participation

There are clear arguments that services, in their efforts to enable improved quality lifestyles for their users, should include the facilitation of community participation in the daily lives of people with ID. If services are to be held accountable for the community participation of the people they serve, it is difficult to imagine how this be could be achieved or monitored without an accurate measure of community participation.

Verdonschot, De Witte, Reichrath, Buntix and Crufts (2009) report broadly that instruments measuring community participation among adults with ID were often ad hoc and unvalidated. Chang at al. (2013) conducted a meta-analysis of community participation measures for people with disabilities, looking specifically at their content and ICF domain coverage. Amongst the 17 measures reviewed, only four were specifically designed for people with ID. However, this review was not exhaustive of the measures available and

neither were psychometric properties examined. This highlights the need for a comprehensive review of community participation measures for people with ID.

Aims

This review will be narrative in nature and based on a systematic search. It will identify and critically evaluate the available measures of community participation designed for adults with ID, examine the content and psychometric properties, highlight limitations and provide guidance on the selection of community participation measures. To the authors' knowledge, this is the first review that critically examines the psychometric qualities and content of such measures developed for this population.

Methodology

The review conforms with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al., 2009).

Inclusion/Exclusion criteria

Community participation scales could conceivably either measure the amount/frequency/ variety of community participation, or the experience/ satisfaction with/ impact on wellbeing of community participation. Whilst both dimensions are important, they serve different functions. The latter can provide insight into meaning and internal experience, whilst the former can provide quantifiable, standardized information to detect change or compare with other settings/populations (Chang et al., 2013). This review focused on measures of the quantifiable level of community participation as these are the type of measures are widely used in empirical research involving investigation

investigating of community participation as both a dependent and independent variable. This review considered measures that have published findings on psychometric properties and have been reported in at least one peer-reviewed journal in English. Measures that were not developed for adults with ID were also excluded. Broader measures such as quality of life scales were only included if they incorporated a quantifiable subscale devoted to community participation.

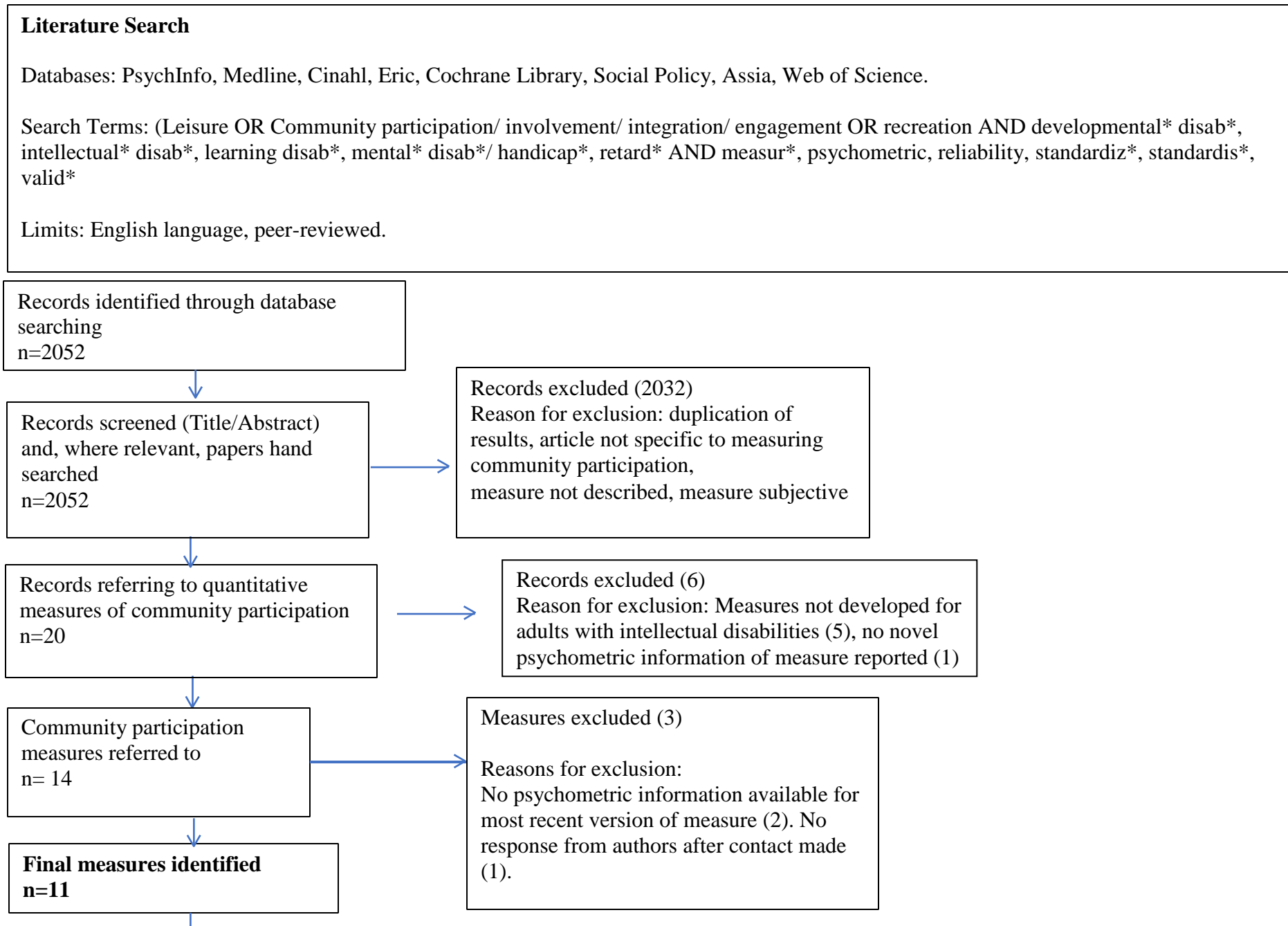
Information sources

The following databases were used to search for relevant papers: PsychInfo, Medline, Cinahl, Eric, Cochrane Library, Social Policy, Assia and Web of Science. Searches were performed from the date of 1950 until 19th June 2017. An initial search was performed to identify measures of community participation. A hand-search was carried out based on the references of relevant papers found from the initial search. With the eleven measures selected, a second round involved searching the above databases for any further studies examining psychometric properties for each of the measures. Where papers were not available via databases, authors were contacted for full texts. Where measures were reported in publications but not freely available, authors/publishers were contacted for a copy of the measure. A full description of the search strategy and search terms can be found in Figure 1. The search included the terms community participation/ involvement/ integration/ engagement or recreation as there is evidence that these terms are used indiscriminately with no clear consensus on the differences in usage (Amado et al. 2013). Where relevant, the most recent version of a measure

was reviewed. If the community participation items within a measure were confined to one subscale, then the subscale would be examined.

Wide search terms were used to minimise the chances of missing relevant literature to ensure that only measures relevant to the Chang et al. (2013) definition of community participation were selected through the inclusion/exclusion criteria and screening process.

Figure 1: Process of selection of reviewed papers



Quality Criteria

Measures were rated for quality using an adapted version of Strauss et al.'s (2016) quality criteria. These criteria are a modification of Terwee et al.'s (2007) quality criteria for health status measures and include Barker, Pistrang, and Elliott's (2002) 'rules of thumb' for evaluating psychological measures. The first author rated the quality of the scales using these criteria and discussed areas of uncertainty in with the second author. Six randomly chosen measures were independently rated by the third author with 100% inter-rater agreement. In line with Strauss et al.'s (2016) guidance, measures were given a score of two if there was evidence for a criterion being fully met, one if the criterion was only partially met, and zero if the criterion was not met or if no relevant data were reported. Scores were summed to provide an overall rating. The total possible score for any measure was 16. If multiple authors had published conflicting information then the majority of published data needed to meet the quality criteria.

The quality criteria were as follows:

- Face validity. Each item within each measure was assessed as to whether or not it measured community participation as defined by Chang et al. (2013). Items that referred to activities often carried out alone or at home were not classified as community participation. If an item included both community participation and non-community participation elements it was coded as "unclear". The number and percentage of community participation items were calculated for each measure. To obtain a score of two, measures needed to contain 100%

community participation items. A score of one was given to measures comprising 50% community participation items.

- Content validity. The extent to which community participation was comprehensively sampled by the measure. Following the procedure adopted by Chang et al (2013), community participation items were classified into one of nine ICF domains of community participation: (1) assisting others (who do not live in the same household) (ICF domain code d660), (2) particular interpersonal relationships (d730-d779), (3) education (d810-d839), (4) work and employment (d840-d859), (5) economic life (d860-d879), (6) community life (d910), (7) recreation and leisure (d920), (8) religion and spirituality (d930), and (9) political life and citizenship (d950). Items that fit the definition of community participation but were not codable into any of the 9 domains (for example using public transport) were classified as “other”. For a score of two all nine domains had to be covered, and items had to have been generated in consultation with both experts and people with ID. A score of one was given if at least four domains of the ICF were covered, irrespective of type of consultation.
- Factor structure. A score of two was given where exploratory factor analysis (EFA) followed by confirmatory factor analysis (CFA) were conducted or where CFA was shown to support a previously proposed theoretical factor structure. A score of one was given if only EFA was conducted (without CFA) and if the EFA supported the factor structure. A score of zero was given where either factor analysis was not

conducted or where EFA and/or CFA were conducted and did not support a proposed factor structure.

- Internal consistency. To ensure that items in a (sub) scale were inter-correlated and thus measuring the same construct, factor analyses (or principal components analysis) had to have been performed on an adequate sample size (7 x the number of items and $N > 100$) and Cronbach's alpha had to be between 0.7 and 0.95. A score of one was given if acceptable Cronbach's alphas had been calculated.
- Reliability. Test-retest reliabilities and (where relevant) inter-rater reliabilities had to reach $r = 0.70$ for this criterion to be fully met. For a score of one, one of these would be missing or the majority of coefficients do not reach 0.7.
- Convergent and discriminant validity. To test the extent to which scores related to other measures in a manner consistent with theoretically derived hypotheses, it was required that all of the results were in line with expectations. At least two correlations of at least $r = 0.50$ were required with theoretically related constructs in order to demonstrate convergent validity for a score of two. A score of one was given when only one correlation reaching 0.5 was reported or there were two or more correlations of at least $r = 0.50$, but also one or more correlations were not in consistent with theoretically derived hypotheses.
- Floor and ceiling effects (i.e. the number of respondents achieving the highest or lowest possible scores). In line with commonly accepted criteria (McHorney & Tarlov, 1995), for a score of two no more than

15% of the sample should have received the top or bottom score on a scale. For a score of one an arbitrary criteria of 25% was set.

- Interpretability. Consideration was given the degree to which qualitative meaning could be attached and to whether there is an indication of how scale scores might be interpreted. For example, whether normative data are available and whether possible subgroups of people with ID (e.g., people in different settings) were tested for differences. A score of two was given if data were presented for subgroups of people with ID and a comparison group of people without ID. A score of one was given if data were presented only for people with ID

Results

Review of identified measures

2052 papers were identified, with eleven measures included after screening titles, abstracts, and full texts. Table 1 provides the psychometric properties of each measure. Following Table 1, each measure is described in further detail.

Table 1: An overview of psychometric properties

Measure	Face validity	Content validity: Domains of ICF captured (including 'Other')	Content validity: item generation (recipient and expert groups consulted?)	Internal consistency: Cronbach's alpha (for total scale and subscales)	Test retest reliability: <i>r</i> (time between testing)	Convergent Discriminant validity: correlation (Pearson's <i>r</i>) with measures of related constructs	Floor/Ceiling effects	Interpretability: means and SD of scores of a reference population (norm values?) Subgroups tested for differences?
Life Experiences Checklist (LEC; Ager 1990, 1998)	30% community participation items	7	No	Total = 0.721	Total: $r = 0.93$, Subscales: $r = 0.91$ to 0.96 (one week) Reported elsewhere: Total: $r = 0.721$	Correlation with ICI of 0.78 pre-move and 0.72 post-move Correlation between LEC category of 'Leisure' and GCPLA category of 'Leisure, sport and recreation' of 0.74 , and between LEC category of 'Opportunities' and GCPLA category 'Facilities/Amenities' of 0.55 .	No floor or ceiling effects observable from the reference data. However not an intellectually disabled sample	Undergraduate students and general population Adults with ID: Institution and community living (scores were significantly higher after a move to the community)
Index of Community Involvement (ICI; Raynes, Pratt and Roses, 1979)	100% community participation items	6	No	Total = 0.85 (group) and 0.77 (individual) Reported elsewhere: Total = 0.59 , 0.689 and 0.62	Reported elsewhere = 0.8	Correlation with LEC of 0.78 pre-move and 0.72 post-move Correlation with systematic observation of activity of 0.16 and 0.20 , $p < 0.05$	Not reported	Adults with ID. Residential setting: Institution and community living (scores were significantly higher after a move to the community) Adults with ID: Older people's homes and ID homes (scores were significantly higher in ID)

homes regardless of whether people had an ID). Mean scores but not standard deviations are reported

Guernsey Community Participation and Leisure Assessment (GCPLA; Baker, 2000)	83% community participation items	7	Yes: Expert	Frequency scores = .93, Level of support scores = .82	Self report format: Range: r = .87, Activities alone: r = .97, Activities with peers: r = .93, Activities accompanied: r = .96, Very frequent activities: r = .56 (two weeks) By proxy format: Range: r = .83, Very frequent activities: r = .84, Activities with peers: r = .8, Activities alone: r = 0.46, Activities supervised: 0.47 (two weeks) Reported elsewhere: Range: r = .72, Very frequent activities: r = .86, Activities alone: r = 0.97, Activities accompanied: r = 0.69, Activities with peers: r = .81, Activities supervised: r = 0.80 (10-13 weeks)	Correlation with Adaptive Behaviour Scale: = 0.33 Correlation with three-week diary: 'Indoor leisure' = 0.652, 'Facilities/Amenities' = 0.737, 'Total score' = 0.682, Correlation between GCPLA 'Leisure, sport and recreation' and LEC 'Leisure' = 0.742, LEC 'Opportunities' and GCPLA 'Facilities/Amenities' = 0.552, Significant correlations between GCPLA range scores and Community Goal Rating Scale, ABS	No floor or ceiling effects observable from the reference data.	Adults with ID and staff comparison (staff Range, Alone and Peer accompanied scores were significantly higher) Residential setting: Resettlement from hospital to community setting (Range scores were significantly higher after resettlement)
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						Part 1 and place of residence are reported without values. The three variables account for 38% of the variance in range scores ($F(3,56) = 11.37; p < 0.01$).		
Life Circumstances Questionnaire (LCQ; Ashman, Hulme & Suttie, 1990)	90.91% community participation items	7	Yes: Expert	Not reported	Not reported	Not reported	Not reported	Yes, adults with ID before, during and two years after resettlement from an institution, and separated according to whether participants moved to cluster centres or the community. Mean scores increased significantly over time and increased by a significant amount more for the participants resettled to the community.
Community Integration Scale (CIS; Heller & Factor, 1991)	83.3% community participation items	5	Unable to access original publication	Total = 0.80 at baseline and 0.79 at three-year follow up. Reported elsewhere: Total = 0.57 at baseline and 0.85 at	Not reported	Correlation with Adaptive Functioning Scale within ICAP: $r = 0.51$ (time one) and $r = 0.54$ (time two) Correlation with Decision Making Scale = 0.74 Correlation with residential setting (nursing homes and community settings): $r = -0.64$	Not reported	Adults with ID and comparison sample of caregivers

				four-year follow up.				
TRIAL Leisure Assessment Battery (TLAB; Dattilo & Hoge, 1997)	60.6 % community participation items	7	No	Not reported	Invalid methodology	Not reported	Not reported	Adults with and without ID (scores were significantly higher for adults without ID)
Leisure Assessment Inventory (Hawkins, Ardivino, Rogers, Foose & Olsen, 2002)	69.8% community participation items	6	Yes: Expert For the Spanish version two focus groups of adults with ID were consulted	Not reported	Leisure Participation Index: r = .55 (one year) Reported elsewhere: Leisure Participation Index: r = .84 (one year)	Correlation with Life Satisfaction Scale – Modified: r = 0.27 Correlation with GENCAT subscales: Personal Development: r = -0.18 Self Determination: r = 0.22 Social Inclusion: r = 0.20 Contrary to expectation: Negative correlation with social communication skills: r = -0.24 and community living skills: r = -0.26 (Inventory for Client and Agency Planning)	Not reported	Adults with ID

						No correlation found with Integral Subjective Scale		
Use of Community Facilities Scale (UCFS; Chou, Lin, Pu, Lee & Chang, 2008)	100% community participation items	4	No	Total = 0.81	Not reported	Adaptive Behaviour Scale (Taiwanese version) scores were a significant predictor of UCFS scores (Beta = 0.20, p<0.001). QOLQ scores were not significantly correlated with UCFS scores.	Not reported	Yes, adults with ID, according to residential status (mean scores significantly higher in small residential homes than in group homes or institutions).
Community Participation Inventory (CPI; Stancliffe & Keane, 2000)	100% community participation items	5	No	Number of places used = 0.54 Frequency of use = .21 Number of places used without support = 0.73	Not reported	Not reported	Not reported	Group mean scores are reported. Standard deviations are not reported. Scores for Frequency and Number of places used without staff support were significantly higher for participants living in semi-independent settings than those living in group homes
Six Monthly Interview Schedule (6MIS; Lowe & de-Paiva, 1988)	94.4% community participation items	2	No	Not reported	Test-retest reliability is reported as percentage agreement: 97.4%; range 89.5-100%. (3 months)	Not reported	Not reported	Not reported
		8	Yes: Expert	Total = 0.85	Not reported	Correlations with Family Need Scale,	Not reported	Not reported

Inclusion Measure (Neeley-Barnes & Elswick, 2016)

81.8% community participation items

specialised care, $r = .06$; financial $r = .197$; future concerns $r = .09$

The Life Experiences Checklist (LEC; Ager 1990, 1998)

A self or proxy checklist with five domains: Home, Leisure, Relationships, Freedom and Opportunities. Only the domain of 'Leisure' consists entirely of community participation activities.

Index of Community Involvement (ICI; Raynes, Pratt & Roses, 1979)

A Yes/No informant based checklist of 15 activities done in the past month, designed for use in the USA and later modified for use in the UK (Raynes, & Sumpton, 1986). The ICI is scored by totaling each item checked with a maximum score of 15.

Guernsey Community Participation and Leisure Assessment (GCPLA; Baker, 2000)

A structured interview or by-proxy questionnaire containing 49 items in six categories: Services, Public transport, Indoor leisure, Leisure, Sport and recreation, Social and Facilities/Amenities. Items are rated for frequency and level of support required. Scoring includes a Range score (sum of regular activities), a Busy score (sum of very frequent activities), four Independence scores (sums of activities requiring levels of support), a Total score and Total Community and Total Leisure scores.

Life Circumstances Questionnaire (LCQ) Community Access' subscale (Ashman, Hulme & Suttie, 1990; Ashman & Suttie, 1996)

A proxy, semi-structured interview with nine sections, including a 'Community Access' section comprised frequency scores in relation to 20 activities. All data found regarding the LCQ came from the closure of one Australian institution.

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Community Integration Scale (CIS; Heller & Factor, 1991)

A direct (Yes/No response) and a by-proxy (No/ 1-3 times a month/ Weekly/ 2+ times a month) structured interview with 12 possible activities with an option to specify one further activity. Scores on the informant report version are the mean frequency rating, whilst scores on the direct interview version are the sum total of 'yes' responses.

Leisure Assessment Inventory (Leisure Activity Participation Index) (Hawkins, 1991; Hawkins, Ardovino, Rogers, Foose & Olsen, 2002)

This is a Self-report structured interview regarding current participation in 53 activities divided into three domains: Social Activities, Activities at Home and Physical Activities. Scores are sums of 'yes' responses yielding indices of Interest, Preference and Constraint. Unfortunately, this instrument is not freely available. Contact was made with the authors and publishers; however, it was not possible to obtain a copy of the 2002 publication. Earlier publications by the authors and subsequent publication by Badia et al.(2012) provided enough information to include the LAI in this review, although it is possible that some information is missing.

Use of Community Facilities Scale (UCFS; Chou, Lin, Pu, Lee & Chang, 2008)

A self-report measure where participants indicate the frequency with which they participate in 18 community activities. Scores can vary from 0 to 54, with higher scores indicating greater levels of participation. No further studies were found reporting psychometric evaluation of the UCFS.

Community Participation Inventory (CPI; Stancliffe & Keane, 2000)

A by-proxy measure containing 18 community activities. Three scores are generated: number of places used in past three months, frequency of use (sum of frequencies)

and number of places used without support. No further papers were found reporting psychometric properties.

Six-Monthly Interview Schedule (6MIS; Lowe & de-Paiva, 1988)

A by-proxy structured interview including 18 types of community activities (including an 'other' category). The number of facilities used in previous six months, and frequency of contact are scored. Also frequency of contact with relatives and friends was recorded. No further papers were found reporting psychometric evaluation

Inclusion Measure (Neeley-Barnes & Elswick, 2016)

A by-proxy measure containing 11 community activities rated on Likert-type scales ranging from 1 (almost never) to 5 (almost always) on a typical week. No instructions for scoring the measure were given and no further papers were found reporting psychometric evaluation.

Results suggest that current measures of community participation for adults with ID have issues with thorough psychometric evaluation. In terms of face validity, only one of the eleven measures reviewed contained 100% community participation items (see Table 2). However, no measure received the full two points for content validity as they contained between three and seven of the nine identified ICF domains of community participation (see Table 3). Additionally, relevant experts were rarely consulted in the process of measure development and people with ID were only consulted in one case.

Table 2: Number and percentage of community participation items

Instrument	Total (N)	CP items	Non-CP items	Unclear items
LEC	50	15 (30.0 %)	30 (60.0%)	5 (10.0%)
ICI	15	15 (100%)	0	0
GCPLA	53	44 (83.0%)	9 (17.0%)	0
LCQ (Community Access subscale)	22	20 (90.91%)	1 (4.55%)	1 (4.55%)
CPI	18	18 (100)	0	0
TLAB (Activity Checklist)	132	80 (60.6%)	52 (39.4%)	0
LAI (Leisure Activity Participation Index)	53	37 (69.8)	16 (30.2)	0
CIS	12	10 (83.3)	1 (8.3%)	1 (8.3%)
UCFS	18	18 (100%)	0	0
6MIS	18	17 (94.4%)	0	1 (5.6%)
IM	11	9 (81.8%)	0	2 (18.2%)

ICF Domains of Community Participation	LEC	ICI	GCPLA	LCQ	CIS	TLAB	LAI	UCFS	CPI	6MIS	IM
Assisting others (d660)	-	-	-	-	*	*	*	-	-	-	-
Particular interpersonal relationships (d730-779)	*	*	*	*	*	*	*	-	-	-	*
Education (d810-d839)	-	-	*	*	-	*	*	-	*	*	*
Work and employment (d840-d859)	*	-	-	*	-	-	-	-	-	-	*
Economic life (d860-d879)	*	*	*	*	*	-	*	*	*	*	*
Community life (d910)	*	*	*	-	-	*	-	-	-	*	*
Recreation and Leisure (d920)	*	*	*	*	*	*	*	*	*	*	*
Religion and spirituality (d930)	*	*	*	*	*	*	*	*	*	*	*
Political life and citizenship (d950)	*	-	-	-	-	-	-	-	-	-	-
Other	-	*	*	*	-	*	-	*	*	*	*

Table 3 ICF domain coverage of community participation measures

Only one measure had been subject to factor analysis, this same measure was also the only one to have scored the full two points for internal consistency. Only five of the measures reported acceptable Cronbach's alphas. In terms of test-retest and inter-rater reliability criterion, only three measures scored the full two points, with the majority of measures either not reporting or reporting unacceptable correlations. For the criterion of convergent and discriminant validity, only one measure reported discriminant validity with a further five measures producing acceptable correlations with theoretically related constructs (with at least two correlations reported) with one of these reporting a correlation contrary to expectation. Four of the measures had not reported any correlations with related constructs.

Only one measure ruled out the issue of ceiling and floor effects in an ID sample. For the final criterion of interpretability, seven of the measures reported reference data, however subgroup comparisons were largely limited. Table 4 represents the overall quality ratings of all measures.

The GCPLA achieved the highest score on the quality criteria (11/16), followed by the LEC scoring 8/16. The GCPLA scored higher than the LEC due to a) stronger face validity as a measure of community participation and b) floor and ceiling effects being ruled out in an ID sample. Both measures were lacking factor analysis, the LEC was missing two domains of the ICF and the GCPLA was missing three, with the LEC lacking specificity and taking longer to administer.

Table 4: An overview of each measure's quality ratings

Measure	Face validity	Content validity	Factor Structure	Internal consistency	Test-retest/ Inter-rater Reliability	Convergent Discriminant Validity	Floor/ ceiling effects	Interpretability	Total
LEC	0	1	0	1	2	1	1	2	8
ICI	2	1	0	0	2	1	0	2	6
GCPLA	1	1	0	1	2	2	2	2	11
LCQ	1	1	0	0	1	0	0	2	5
CIS	1	1	0	1	0	1	0	2	6
TLAB	1	1	0	0	1	0	0	2	4
LAI	1	1	0	0	1	1	0	1	4
UCFS	1	0	0	1	0	0	0	2	5
CPI	1	1	0	0	0	0	0	1	3
6 MIS	1	1	0	0	1	0	0	0	1
IM	1	1	2	2	0	1	0	0	7

Rating:
 0=criterion not met/insufficient data to rate criterion;
 1=criterion partially met;
 2=criterion fully met

Discussion

This review identified the measures that have previously been used in research to evaluate community participation for people with ID. Eleven measures were identified being published between 1979 and 2016 and all identified measures were found to have significant psychometric weaknesses. Specific shortcomings concerned content validity in particular, along with lack of attention to factor analysis, reliability and discriminative and convergent validity. A clear definition of the sample, in terms of demographics and level of ID was often not provided. Few of the studies used a representative sample and, in comparison studies, participants were often not matched. Perhaps more fundamentally, significant issues were found in regard to content validity and few of the measures involved people with ID or experts in their development.

It has been argued that social participation instruments are biased in favour of white, western, middle class, intellectual values (Dijkers, Whiteneck and El-Jaroudi, 2000). As socially and culturally constructed concepts, leisure experiences are impacted upon by the inequalities of society (Sasidharan, 2002). Dijkeers (2010) question the wisdom of developing a single measures that is appropriate across age groups, sexes, socioeconomic classes and cultures. The authors of the measures reviewed here do not address the issue that values may have been implicitly assumed, with the cultural and ethnic diversity of participants often either not reported or not representative of a multicultural society.

As Verdonschot et al. (2009) tentatively observed, a clear theoretical or conceptual framework behind the measures was often not apparent. This was especially the

case for measures that were designed for research studies. Most measures did not measure community participation as a distinct concept, but included items measuring a mixture of concepts such as functioning, domestic participation and level of support required. Some of the same ICF domains were missing in all instruments. Political life and citizenship, assisting others, and work and employment were only measured by one, three and three instruments respectively. The lack of items referring to activities that might be considered empowering is perhaps a sign that many of these measures are outdated and reflect times when people with ID were segregated and not considered to be full participating members of society. Many of the measures predated the publication of the ICF domains, although there was little evidence that the availability of the ICF domains had influenced the content of the measures with the mean number of domains covered by measures that predated and post-dated the ICF being identical at 5.75.

The extent to which the authors of the individual measures described above integrated the findings and research that used the other measures was notably lacking, as is evidenced by over half the measures failing to report convergent validity. The review leaves the impression that many measures were developed in isolation without reference to the existing measures. For example, for the newest measure in this review, the Inclusion Measure (Neeley-Barnes & Elswick, 2016), the authors claim that despite the large body of literature on inclusion, there is no validated and agreed measure. Whilst this may be accurate, the authors subsequently failed to cite any of the previously published measures that inform this systematic review. In part, this may reflect the confusion created by the use of different terminology, but in some cases may also reflect the mistaken assumption

that participation is simple to measure (Dijkers, 2010). The lack of a universally accepted measure, along with the failure to utilise methodologies and integrate findings from previous studies, significantly hinders the efforts of researchers to contribute to the task of delivering services that bring about optimal quality of life for people with ID. This state of affairs has been compounded by the absence of any review and guidance in relation to the available measures of community participation for people with ID. Hopefully this review will go some way to address this situation.

Future research

Community participation remains an important aspect of quality of life and the many endeavours reported in the ID research literature to measure the phenomena is perhaps evidence of a continued need for community participation to be measured in some way. For example, recent studies by Hassiotis et al (2017) and MacDonald, McGill & Murphy (2018) have used community participation of people with ID as a service outcome and specifically as a measure of quality of life. Of concern is that this was the sole measure of quality of life measured in both of these studies. Whilst community participation is an important foundation of quality of life, it cannot be considered synonymous with quality of life and there is a clear danger that researchers have focussed on this particular aspect of quality of life as, at least superficially, it would appear to be more accessible and easy to measure. This review has demonstrated that this clearly is not the case.

People with ID themselves should be the arbiters in relation to their own quality of life. However the challenges surrounding acquiescence and recency bias in self-reporting adults with ID, as well as communication difficulties to overcome in

individuals with severe and profound ID, make a persuasive pragmatic argument for the additional need for by-proxy measures in order to monitor lifestyles and help to facilitate any change desired.

This review has looked exclusively at measures of quantifiable level of community participation. Conroy, Fullerton and Brown (2002) highlight three factors to consider in determining or measuring community participation and relationships: frequency, choice, and intensity. All of the measurement instruments cited in this study address frequency, however none addressed choice or intensity. Service users able to exercise their free choice may choose not to actively participate. This links to Cummins and Lau's (2003) argument that overzealously facilitating community integration for people with intellectual disabilities has the potential to be stressful rather than beneficial. Cummins and Lau caution that people should be in control of their own level of exposure, and not be over-encouraged by family or support staff to take part in activities in order to be more 'normal'. Intensity or the depth of connection with other people is difficult to develop and to validate (Amado et al., 2013), and determining the complexities of personal preferences, satisfaction, and importance of particular relationships is an emerging research issue.

Thus there is also a need for measures examining experiential aspects of community participation. This will further aid the development of theory and understanding around community participation and have practical implications for how best to conceptualise and cultivate (at individual and societal levels) true community participation in ways that support individual values and choice.

Given the continued need for services to be held accountable for the community participation of the people who use those services, it is suggested that there is a need for a new measure that conforms to a currently held conceptualisation of community participation and adheres to the quality standards reported in this review. Specifically this should include being sufficiently psychometrically robust, engagement of people with ID and experts in the field with the development and delivery and adherence to currently agreed conceptualisation of community participation.

Conclusions

A systematic review of objective measures of community participation was undertaken and all identified measures were found to have significant weaknesses in relation to the quality indices used in this review. Currently no valid psychometrically robust measure of level of community participation exists for adults with ID. Given the apparent need, future research should focus on developing such a measure. Without an adequate measure, important information about this aspect of peoples quality of life may be missed, individual choice and change may not be meaningfully supported by services, and our understanding of what constitutes 'good' community participation (which may be different for different people) will likely be harder to further.

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