

Identifying conceptualizations and theories of change embedded in interventions to facilitate community participation for people with intellectual disability: A scoping review

Christine Bigby  | Sian Anderson | Nadine Cameron

Living with Disability Research Centre, LaTrobe University, Bundoora, Vic., Australia

Correspondence

Christine Bigby, Living with Disability Research Centre, LaTrobe University, Bundoora, Vic, Australia.
Email: c.bigby@latrobe.edu.au

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Background: Little progress has been made towards community participation of people with intellectual disability despite it being a policy aim since the 1980s. We aimed to identify the features of programmes designed to support community participation.

Method: A scoping review was conducted of peer-reviewed literature between 2000 and 2015, about interventions to support community participation for adults with intellectual disability.

Results: A small body of evidence relates to the design and effectiveness of interventions to enhance community participation. Seventeen studies reported programmes reflecting three conceptualizations of community participation (as social relationships, as convivial encounter and as belonging) that used strategies such as active mentoring, facilitative support worker practice and arts-based programmes.

Conclusions: Studies showed the diverse and person-centred nature of community participation and demonstrated the need for larger-scale studies of promising interventions that include details of costs, and strategies to guide implementation of policies to support community participation.

KEYWORDS

adults with intellectual disability, community participation, effective interventions, national disability insurance scheme, programme design

1 | INTRODUCTION

Community participation is a central theme in policies seeking to create a better life for people with intellectual disabilities. In Australia, the landmark 1986 Australian Disability Services Act aimed to support people with disability to live “as valued and participating members of the community.” Similar aims are replicated in more recent national policies and international treaties (Commonwealth of Australia 2011; National Disability Insurance Scheme Act 2013; United Nations 2006). Nevertheless, community participation is a contested and ambiguous concept. It exists within a terminological forest (Sinason, 1992) where

prefixes such as “social” and “community” to words such as “inclusion,” “integration,” “participation” are interchangeable (Simplican, Leader, Kosciulek, & Leahy, 2015). Definitions of community participation range from expansive to narrow, encompassing multiple or single life domains (e.g., domestic, leisure, work), or arenas (e.g., social, political, economic), and the term is used both as an overarching concept or as a subcomponent of social inclusion. The absence from empirical research of consistent conceptual frameworks (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012; Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014; Simplican et al., 2015; Verdonschot, De Witte, Reichrath, Buntinx, & Curfs, 2009) combined with interchangeability of terms has created a

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conceptual maze. This means that policymakers and those who design and deliver interventions to support community participation are offered little clarity about intended purpose or outcomes of programmes.

In this article, the present authors focus on adults with intellectual disability, briefly describing different ways that community participation has been conceptualized, and review the small body of literature about interventions designed to support community participation, exploring the theories of change and conceptualizations that unpin these. Empirical evidence overwhelmingly suggests that significant progress has been made towards supporting the presence of adults with intellectual disabilities in mainstream communities as consumers in public and commercial spaces, or as residents in neighbourhoods (Verdonschot et al., 2009). The literature is, however, replete with conclusions that despite increased community presence, several decades of policies have not achieved community participation for adults with intellectual disabilities, irrespective of the particular definition that is adopted (Amado, Stancliffe, McCarron, & McCallion, 2013; Bigby & Fyffe, 2010; Gray et al., 2014; Overmars-Marx et al., 2014; Walker, 1999).

These conclusions reflect one of the most common understandings of community participation which is based on the principle of normalization (Wolfensberger, 1972) and distinguishes between community presence, as the use of facilities or services available to everyone, and community participation, as being part of a growing network of relationships that include people with and without intellectual disability (O'Brien & Lyle, 1987). This conceptualization of community participation places importance on particular kinds of places and personal relationships. Presence in mainstream places is regarded as a precursor to the formation of personal relationships (Ager, Myers, Kerr, Myles, & Green, 2001; Amado et al., 2013). In turn, personal relationships provide opportunities to participate in formally organized or informal activities in public and private places. Often particular types of relationships that people with intellectual disabilities have, or might have, are seen as more important than others, such as those with people who do not have disabilities (Cummins & Lau, 2003), those that are freely given rather than paid (Amado, 2014) or those that involve reciprocity (van Alphen, Dijker, van den Borne, & Curfs, 2010).

Other conceptualizations of community participation are based on the World Health Organization's (2001) International Classification of Functioning (ICF) framework. For example, in Verdonschot et al.'s (2009) review of empirical findings about community participation, it 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" (p. 304). Similarly, Dusseljee, Rijken, Cardol, Curfs, and Groenewegen (2011) define community participation as "performing daytime activities while interacting with others" (p. 4). These conceptualizations are broader and less prescriptive than the presence/participation binary based on the principle of normalization. They also give significance to activities in addition to place and social interactions. However, approaches based on the ICF definition (World Health Organization, 2001) do not consider the qualitative aspects of activities, where they occur or with whom, or subjective experiential elements of community participation.

As it has become clearer that experiences of being in mainstream places, often simply referred to as "the community," are not

"unambiguously virtuous" (Bates & Davis, 2004; p. 201), more attention has been given to choice and the subjective aspects of community participation (Milner & Kelly, 2009; Simpican & Leader, 2015). Hall (2013, p. 259) for example, considers community participation to entail subjective feelings, a sense of belonging and social relationships, which he views as a transformative process where a person "moves towards a sense of attachment and belonging to proximate and distant others." Hall (2013) and others (Anderson & Bigby, 2017; Darragh, Ellison, Rillotta, Bellon, & Crocker, 2016; Frawley & Bigby, 2015) illustrate how segregated groups, based around activities such as drama, sports or self-advocacy may be places of community for people with intellectual disability, where through participation they gain a sense of belonging. While participation in a community of peers is important in its own right, the sense of belonging or identity derived, as an artist or sports person, for example, may also facilitate participation in other, perhaps more mainstream communities, through activities such as exhibitions or sports carnivals. In some ways, this conceptualization of community participation links conceptually back to the principle of normalization and the privileging of socially valued roles such as artist or sportsman.

More recently, researchers have begun to disrupt the binary between community presence and participation using ideas about *encounter* and the diverse and fluid social networks that characterize modern cities (Bigby & Wiesel, 2011, 2015; Bredewold, Tonkens, & Trappenburg, 2016; Laurier & Philo, 2006; Wiesel, Bigby, & Carling Jenkins, 2013). Convivial encounters are a particular type of encounter-social interactions that are neither free mingling in public places (presence) nor based on long-term relationships (participation as understood by O'Brien & Lyle, 1987) but where there is a shared identity or activity and a sense of pleasantness or warmth (Fincher & Iveson, 2008). They can be fleeting and singular, such as an exchange in the supermarket queue, intermittent, such as recognition and greeting by the proprietor or other patrons at a local shop, or longer and episodic, such as regular exchanges with other participants in a yoga class. There is potential for such convivial encounters to develop into lasting or deeper relationships (Bigby & Wiesel, 2011); however, encounters are important in themselves. Gestures such as a nod or a wave "contribute to a sense of recognition and of 'feeling at home' in a neighbourhood" (Bredewold et al., 2016; p. 3381). Convivial encounter as a fluid conceptualization of community participation brings together core components identified in other perspectives without embedded normative assumptions. Seen by Simpican et al. (2015, p. 25) as a way to "modernize" community participation, the concept of convivial encounter avoids reference to the kind of continua frequently relied on by other understandings of community participation. It accords equal value to diverse combinations of place, interaction and activities but incorporates an experiential element of conviviality or pleasantness.

The failure to make significant headway with community participation has occurred despite significant investment in programmes to support community living, employment, daytime activities, leisure and recreation. For example, in Australia in 2014–2015, the Federal Government spent eight billion dollars on specialist disability services (Parliament of Australia, 2016), and in the State of Victoria, as institutions closed, relocated residents were guaranteed a place in a

small group home and day programme, both with mandates to support community participation. In the UK, for example, the person-centred planning processes designed to support community participation, that were implemented as part of the Valuing People policy, have not significantly changed the composition of the social networks of people with intellectual disability (Ratti et al., 2016).

This limited progress is typically understood through the binary of presence and participation and explained as due to weak programme implementation or service design (Beadle-Brown, Bigby, & Bould, 2015; Clement & Bigby, 2009; Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008). Commonly identified factors include poor staff practices, such as group-based outings and use of anonymous public spaces (Bigby, Clement, Mansell, & Beadle-Brown, 2009; Walker, 1995); inadequate staff training or supervision; misinterpretations of policy intent by staff (Beadle-Brown et al., 2015; Bigby & Wiesel, 2015; Clement & Bigby, 2009); or design problems such as omission of support for building social relationships (Bigby, Bould, & Beadle-Brown, 2016).

Simplican et al. (2015) suggest that lack of conceptual clarity may be an explanatory factor that impedes effective service design and delivery by hindering communication, understanding of goals and agreement among stakeholders. In programme logic terms, making clear the underlying theory of change—the central proposition about the way change comes about for target/s of the intervention that informs its strategies or actions is important to success (Clement & Bigby, 2011; Funnell & Rogers, 2011; Rossi, Lipsey, & Freeman, 2004). Rogers' diffusion of innovation theory posits that observability of outcomes and absence of complexity about meaning are important to policy and programme implementation (Reidy, Swerisson, & Bigby, 2010; Rogers, 2003). For example, the multiple and often unclear purposes, without measurable outcomes, of day centre programmes may account to some extent for their limited success in facilitating community participation (Simons & Watson, 1999; Simpson, 2007). Moving beyond programme design, a socio-ecological approach can also be used to analyse the plethora of obstacles and facilitators of the interactions between people and their environments at the core of community participation (Amado et al., 2013; Simplican et al., 2015).

The implementation of the National Disability Insurance Scheme and accompanying growth of individualized funding in Australia is likely to have a similar impact to the personalization policies in the UK, which reduced reliance on day centres to support community participation and opened possibilities for more dispersed and individualized interventions (see, e.g., Whitaker & McIntosh, 2000). Evidence about the effectiveness of interventions; clarity about purpose; underlying assumptions; and intended outcomes will assist in the design of innovative programmes or interventions to support community participation.

This article reports the findings from a literature review that was the first stage of a study to investigate promising interventions to support community participation of people with intellectual disability. In undertaking the review, the present authors aimed to identify how interventions (or individualized interventions delivered in the context of a programme) conceptualized community participation and the features of promising interventions. The present authors also aimed to develop a framework that could be applied in the second stage of

this programme of research for identifying and evaluating potentially effective innovative programmes. This article reports on three key questions: (i) "How do interventions designed to facilitate community participation for people with intellectual disability conceptualize their aims and community participation?" (ii) "What theory of change and facilitation strategies do interventions have?" and (iii) "How effective are interventions in achieving anticipated outcomes?"

2 | METHODOLOGY

2.1 | Design

The review followed the approach for scoping reviews suggested by Arksey and O'Malley (2005), which facilitates an iterative process of review to ensure the literature is comprehensively covered, producing both in-depth and broad results. The starting point was the ICF (World Health Organization, 2001) conceptualization of community participation, used by Verdonschot et al. (2009, p. 304), "the performance of people in actual activities in social life domains through interaction with others in the context in which they live," and our focus was on the social rather than political, educational or economic domains.

2.2 | Search strategy

A systematic search was undertaken of the following databases which include all the major journals in the fields of disability and social work: CINAHL, PsycINFO, MEDLINE and PubMed. Keywords for searching included the following: cognitive impairment, intellectual disability, developmental disability, learning disability, intellectual disability, PIMD, participation, community participation, social participation, community engagement, social engagement, active engagement, inclusion and day service. This search yielded 4,534 results after duplicates were removed. Due to the volume, items published prior to 2,000 were removed, leaving 1,424 items. Inspection of abstracts revealed large numbers of articles pertaining to acquired brain injury and other cognitive impairments such as dementia which, when removed, left 175 items. Book chapters were removed as these are not peer reviewed and consolidate existing knowledge rather than report empirical data about interventions, which left 103 articles. An additional search, undertaken using the term "friendship," yielded five additional items and hand searching identified another 12, bringing the total to 120 articles.

The abstracts of these remaining articles were read so that our final inclusion criteria could be refined to reflect the research questions about the nature of specific interventions designed to facilitate community participation. The inclusion criteria were as follows: report of empirical research about the nature and effectiveness of a specific intervention (programme or practice) to facilitate community participation; regardless of the specific terminology used, the intervention aimed to facilitate Verdonschot et al.'s (2009) broad definition of community participation; the intervention was in respect of adults with intellectual disabilities; written in English language published in a peer-reviewed journal between 2000 and 2015. To determine inclusion of articles, the second author read all 120 abstracts and proposed the inclusion

or exclusion of each. Proposals to remove articles were reviewed by the first author, and where there was disagreement, both authors read the full article again and discussed any differences in order to reach a consensus. The articles removed fell into the following groups: reporting of broad empirical data about or an aspect of community participation for particular subgroups or from broad multifaceted initiatives (e.g., Andrews et al., 2014; Power, 2013; Sullivan, Bowden, McKenzie, & Quayle, 2016); conceptual articles theorizing the nature of community participation (e.g., Bates & Davis, 2004; Bigby, 2012; Hall, 2010; Simpican et al., 2015); analysis, commentary or reviews of policies or strategies to support community participation without empirical data about outcomes (Amado, 2014); general articles describing perspectives of people with intellectual disability about community participation (e.g., McClimens, Partridge, & Sexton, 2014; Welsby & Horsfall, 2011); and, describing broadly, factors associated with or barriers and facilitators to community participation (Abraham, Gregory, Wolf, & Pemberton, 2002; Beart, Hawkins, Kroese, Smithson, & Tolosa, 2001). Decisions about some articles involved considerable discussion about whether data about a specific intervention was reported. For example, the decision was made to exclude "Social inclusion through football fandom: opportunities for learning disabled people" (Southby, 2013) as this reported on participants experiences of being football fans and the phenomena of fandom rather than a specific intervention to support people with intellectual disability to be fans. One hundred and three articles were removed following this process leaving 17 articles that reported empirical research on specific community participation programmes or interventions. These articles are summarized in Table 1.

2.3 | Analysis

Articles were aggregated according to the aims of the programmes they discussed, under three key conceptualizations of community participation—drawn from the broader theoretical literature—as social relationships, convivial encounters and belonging. Strategies used to achieve aims were identified, and the ICF framework (World Health Organization, 2001) that defines participation as about *activities*, *place* and *interactions* was used to describe further the components of each programme (see Table 1). The aims and methods of the reported research about each of the interventions/programmes and evidence about outcomes were summarized in Table 2.

3 | FINDINGS

Data about 13 separate interventions were reported in the 17 articles, as four articles reported research about the same Transition to Retirement (TTR) programme (Bigby et al., 2014; Stancliffe, Bigby, Balandin, Wilson, & Craig, 2015; Wilson et al., 2013, 2015), and two reported on the same Friendship and Dating programme (Ward, Atkinson, Smith, & Windsor, 2013; Ward, Windsor, & Atkinson, 2012). Three articles reported on the international Special Olympics programmes, but the focus of these was sufficiently different for them to be treated separately. Of the 13 programmes, three were

time limited and established for research projects (Craig & Bigby, 2015; Lante, Walkley, Gamble, & Vassos, 2011; McClimens & Gordon, 2009) rather than as ongoing programmes. Table 1 summaries the way each programme was categorized, its facilitative strategies and the key components of its approach to community participation. Table 2 summaries and comments on the findings about outcomes for each programme.

3.1 | Conceptualizations of community participation

3.1.1 | Community participation as social relationships

Four programmes conceptualized community participation as the development of social relationships between adults with or without intellectual disability. The theory of change underpinning these programmes was that if support is offered to people with intellectual disabilities to make and develop relationships with others then, as well as enlarging their social network, it will lead to opportunities for them to participate in a wide range of activities, community groups and social interactions. The strategies used by these programmes varied, and in ICF terms (World Health Organization, 2001), the primary component was social interaction rather than activities or place.

Heslop (2005) reported research on five UK befriending services that focussed on building relationships between people with and without intellectual disability. The primary strategies used in these programmes were to recruit volunteers, match them individually, by personal interests, to a person with intellectual disability and support the developing friendship. The community membership project described by Harlan-Simmons, Holtz, Todd, and Mooney (2001) had similar aims to the befriending services but employed different strategies and used staff trained as "community builders" to work with individuals to support the creation of "community connections and meaningful relationships" (Harlan-Simmons et al., 2001, p. 171). In one respect, this programme may appear similar to the TTR programme as in some instances it involved connecting people to a community group but, unlike the TTR programme, the primary aim of community builders was to find community places that would act as a catalyst for longer-term relationships to develop.

Programmes with a similar purpose of building relationships, but with a slightly different focus, were described in the two articles by Ward et al. (2012, 2013). These programmes were confined to supporting development of relationships between people with intellectual disabilities, including extending intimate partnerships as well as friendships. Aimed to expand social networks as well as promote healthy relationships, they were developed in Alaska to "teach the social skills needed to develop healthy, meaningful relationships and to prevent violence in dating and partnered relationships" (Ward et al., 2012, p. 22). This programme's conceptualization of community participation was based on the notion that within a disability support programme, or other less segregated settings, establishing, supporting and developing relationships between peers with intellectual disability is the key to expanding the social networks of individuals, and increasing their

TABLE 1 Summary of articles included in review

| Conceptualization of community participation | | Description of ICF components | | | |
|--|---------------------|---|--|---|--|
| | Primary strategy | Activities | Place | Social interactions | |
| Ward et al. (2013, 2012), UK | Relationships | Support to meet and establish friendships or more intimate relationships with peers with disability | Incidental reliant on decisions made in context of matched relationships | Segregated, mainstream or private places | Friendship/partners people with disability |
| Heslop (2005), UK | Relationships | Recruitment of befrienders and matching for friendship of person with intellectual disability to person without disability | Incidental reliant on decisions made in context of on matched friendships | Mainstream or private places | Friendships with people without disability |
| Harlan-Simmons et al. (2001), USA | Relationships | Community builder matching person to community group and supporting interaction with others and participation in activities— with view to longer-term friendships | Interest related activities | Mainstream community groups | Convivial encounters and friendships with people without disability |
| Bigby and Wiesel (2015), Australia | Convivial encounter | Individual support for positive social interactions with people in mainstream places | Range from every day commercial transactions to activities in community group | Mainstream places, commercial, public, community groups | Convivial encounters with people without disability—regular, intermittent or singular |
| Lante et al. (2011), Australia | Convivial encounter | Individual support to undertake physical activity in mainstream gym | Physical activity | Mainstream gym | Convivial encounters with people without disability—regular, intermittent or singular |
| Craig and Bigby (2015), Australia | Convivial encounter | Facilitative support to community group members and individual to participate in social group and interact socially with other participants | Activity in a community group reflecting individual's interest | Mainstream community group | Convivial encounters with people without disability—regular in group context |
| Stancilffe et al. (2015), Bigby et al. (2014), Wilson et al. (2013), Australia | Convivial encounter | Facilitative support to community group or volunteer organization and voluntary mentor to support individual's participation in activities and social interaction with other participants | Activity in a community group or volunteer organization reflecting individual's interest | Mainstream group as member or volunteer organization with age peers | Convivial encounters with people without disability—regular in group or volunteer context |
| Wilson et al. (2015), Australia | Convivial encounter | Facilitative support to community group and volunteer mentor to support participation in activities and social interaction with other participants | Activity in a community group reflecting individual's interest | Mainstream community group which is gender specific | Convivial encounters with people without disability—regular in group context |
| Tedrick (2009), USA | Belonging | Establishment of segregated sports programmes with connection to mainstream sports | Sport | Segregated with some boundary crossing initiatives | Convivial encounters with other people with disability—regular in group context and intermittent with associated others without disability |
| Harada et al. (2011), USA | Belonging | Establishment of segregated and integrated sports activities, and support to take part | Sport | Segregated and integrated | Convivial encounters with other people with disability—regular in group context and intermittent with associated others without disability |

(Continues)

TABLE 1 (Continued)

| Conceptualization of community participation | | Description of ICF components | | |
|--|---|-------------------------------|--|---|
| | Primary strategy | Activities | Place | Social interactions |
| McConkey et al. (2013), Europe | Belonging Establishment of segregated sports programmes with deliberate pairing to peers without disability in other programmes | Sport | Segregated but boundary crossing initiatives | Convivial encounters with people with disability—regular in group context and intermittent with associated others without disability |
| Darragh et al. (2016), Australia | Belonging Establishment of segregated arts activity. Support to develop talents, as catalyst for interaction with other artists and public | Arts and music | Segregated but boundary crossing initiatives through exhibitions, performances and sales | Convivial encounters with people with disability—regular in group context and intermittent with associated others without disability |
| Stickley et al. (2012), UK | Belonging Establishment of segregated arts activity. Support to develop talents, as catalyst for interaction with other artists and public | Arts | Segregated, boundary crossing initiatives through performances and visits from mainstream students | Convivial encounters with people without disability—regular in group context and intermittent with associated others without disability |
| McClimens and Gordon (2009), UK | Belonging Individuals matched to students as trainers in a university setting to support blogging | Internet blogging | Mainstream places, virtual and real used by value peers without disability | Convivial encounters with other people without disability—regular in group context and on line |

social interactions and participation in activities in various mainstream or segregated places.

3.1.2 | Community participation as convivial encounter

Our analysis suggested that, although not explicitly, four programmes conceptualized community participation as convivial encounter, that is as social interactions, that are neither free mingling in public places nor based on long-term relationships, where there is a shared identity or activity with others and a sense of pleasantness or warmth. The distinguishing feature of these programmes was that the encounter occurred in public non-segregated places, or community groups or volunteer organizations with others who do not have disability. The theory of change evident in these programmes was that supporting people with intellectual disability to join mainstream community groups, undertake volunteer work or engage in social interactions in commercial or public places would lead to episodic, intermittent or singular convivial encounters. In these programmes, the ICF (World Health Organization, 2001) elements of activities and place were the means for facilitating positive social interactions.

Craig and Bigby (2015) described the case study of Helen who participated in many shared activities as part of a cooking group, primarily comprised of older men, who accepted her and interacted with her in a friendly way. Not all of the case studies described in this article involved this type of shared activities, or acceptance or warm interactions by group members. Craig and Bigby (2015) identified *active participation* (which broadly equates with convivial encounter) as occurring only when the person with intellectual disability had equal membership status in the group, participated in mutually rewarding activities and worked cooperatively with other members towards a common goal, and where the group utilized advice about supporting access for people with disability. The four articles about various aspects of the TTR programme described very similar types of participation by individuals with intellectual disability in community groups or as volunteers in organizations. A common feature of these programmes was that the person with intellectual disability did not join the group with a peer or small group of other people with intellectual disability.

The strategies employed to facilitate participation were described in the action research project reported by Craig and Bigby (2015). Individual support was given to individuals with moderate intellectual disability to join and participate in a community group that reflected an understanding of their interests. Support extended beyond face-to-face work with the individual including scanning the community for groups for their potential participation, negotiation with group leaders about initiation and ongoing attendance, as well as training and advice to group members. A similar approach was used, though with a participant group with milder levels of intellectual disability, in the TTR programme (Bigby et al., 2014; Stancliffe et al., 2015). This programme was targeted at older workers in a supported employment setting and had a clearly articulated set of processes which are described as, “promoting the concept of retirement, laying the groundwork for inclusion

TABLE 2 Summary of evidence about outcomes from reviewed community participation programmes

| | Type and aims of study | Methodology | Findings | Comments |
|------------------------------|--|--|--|--|
| Ward et al. (2012) | Document the "treatment fidelity" of the Friendship and Dating Program conducted for 20 sessions, twice per week for 10 weeks, aimed to prevent violence in dating and partnered relationships and teach social skills for healthy relationships for adults with intellectual disability | Mixed methods process evaluation. 31 participants with intellectual disability and 11 facilitators. Self-report completion of measures of Social Networks and Interpersonal Violence and interview | Increase in participants' social network size. Measure of comprehensiveness showed that agency staff delivered content of the programme successfully with minimal training | Small-scale rigorous study, larger sample size needed for efficacy evaluation |
| Ward et al. (2013) | Evaluate impact of the Friendship and Dating Program on size of participants' social networks and incidents of interpersonal violence experienced | Mixed methods process evaluation. 31 participants with intellectual disability and 11 facilitators. Self-report completion of measures of Social Networks and Interpersonal Violence and interview | Increase in size of participants' social network and reported incidents of interpersonal violence had reduced. Ten-week follow-up post-programme showed increase in network size maintained | Small scale some drop out in completion of post-programme questionnaires. No outcome measure of participants' knowledge about sexuality, sexual health and healthy relationships |
| Heslop (2005) | Identify key issues faced by befriending services, factors which may contribute to good practice and make recommendations for future good practice | Qualitative. Interviews and questionnaire with 15 workers from 7 services, and interviews with 34 people with intellectual disability, 42 befrienders and 46 parents/carers from the same 7 services | Many activities engaged in by the participants and their befrienders were home based such as watching a video. Difficulties with the recruitment, training and retention of befrienders. People with intellectual disability had limited choice about nature and frequency of contact with their befrienders | No mention in methodology of how data were analysed, little supporting evidence for conclusions such as qualitatively the services in the study were a good thing |
| Harlan-Simmons et al. (2001) | Provide stories illustrating the intentional strategies and concerted effort necessary to support creation of community connections and meaningful relationships for people with intellectual disability | Qualitative, longitudinal case study (3 years) using observation and informal interviews with 3 older participants with intellectual disability, family and community members | The community building process made a positive impact on social networks, bringing "a variety of community relationships into their (participants') lives." (p. 179) | In-depth case studies findings potential for testing with larger sample |
| Bigby and Wiesel (2015) | Identify microlevel practices of support that facilitate individuals with intellectual disability to have convivial encounters | In-depth qualitative methodology. Unstructured observations of people with intellectual disability and their support workers in a variety of community setting. 26 participants with intellectual disability (mild to moderate), mostly male, most of whom lived in group homes and 5 of whom had challenging behaviours | Convivial encounters between people with intellectual disability with strangers in community places can be facilitated by support workers. Staff practices included the following: passive monitoring of the encounter where the support worker avoided a direct role in the interaction; acting as an interpreter, assisting both parties in the encounter to communicate by reassuring uncertain members of the public and providing appropriate education to strangers about the capabilities of a particular individual; intervening in the encounter in an attempt to modify the behaviour of the person supported or the stranger encountered; use of gestures to initiate Encounters, creation, by workers, of an atmosphere that invited exchange. Knowing how to apply which approach requires a high degree of judiciousness | Inductive in-depth qualitative study, conceptual findings potential for testing with larger sample |

(Continues)

TABLE 2 (Continued)

| Type and aims of study | Methodology | Findings | Comments |
|---|---|--|---|
| Lante et al. (2011) Examine the physical and psychosocial benefits of engagement in a programme of physical activity | Mixed methods evaluative case study. 2 participants with intellectual disability. Accelerometer to measure physical activity. Interviews conducted with participants and support staff | Neither participant recorded recommended levels of moderate intensity physical activity. Qualitative data indicated programme gave opportunities for social contact with other gym users and had social/emotional benefits for participants who enjoyed social praise as a result of their engagement | Small-scale case study—little depth to qualitative analysis |
| Craig and Bigby (2015) Identify the nature and impact of group processes on the active participation of people with an intellectual disability in community groups | Action research and participant observation over 10 months in 5 community groups. 5 participants all aged over 45 years with moderate intellectual disability each in a different community group selected to represent their interests. In-depth field notes of interactions and social processes in groups. Critical realism guided analytical approach used inductive and abductive techniques | 3 of the 5 cases met the criteria of active participation; being afforded equal membership status, members working together to achieve common goals around a shared activity. Factors affecting active participation were positive leadership response to inclusion, participants with intellectual disability who had friendly dispositions and relatively good social skills, access and acceptance by the group to expertise about disability, the groups' use of an integrating activity and flexibility and capacity to deal with difference among members | In-depth case studies, theoretically driven, conceptual findings potential for testing with larger sample |
| Standcliffe et al. (2015) Evaluate the success of the Transition to Retirement programme and its model of active mentoring support for participation in community groups by assessing participants' loneliness, social satisfaction, depression, life events, quality of life, community participation, social contacts and work hours before and 6 months after joining a community group | Mixed methods. Two matched groups of 29 participants, most with mild intellectual disability. Self-report and proxy reliable and validated measures; health-related quality of life, UCLA Loneliness Scale, Worker Loneliness Scale (modified), Glasgow Depression Scale, Mini Psychiatric Assessment Schedules for adults with Developmental Disabilities Checklist. Weekly logs of participation and social contact. [linked to Bigby et al., 2014; Wilson et al., 2015, 2013] | Positive outcomes - relative to pre-test. Six months post-test intervention participants had made significant gains in terms of making new inclusive social contacts, spending time with new acquaintances, participating for more time in mainstream community activities and reducing their weekly work hours as planned | Small-scale but rigorous design |
| Bigby et al. (2014) Describe the programme logic and implementation challenges of the Transition to Retirement programme | Descriptive. Data on implementation process collected for 24 participants in 24 groups or volunteer situations. Data included field notes, filed notes, time logs and minutes of discussions among team members. [linked to Standcliffe et al., 2015; Wilson et al., 2015, 2013] | Logic model described as: promotion of retirement, laying the groundwork, involving identifying appropriate community groups for retirees to join, constructing the reality, involving a person-centred approach to getting individuals involved in the group (being sure of their interests, helping map a new routine for them and supporters, training and supporting mentors in the group and offering ongoing monitoring and additional support was necessary) | Logic model description of Standcliffe et al. (2015) |
| Wilson et al. (2015) Examine the participation of older men with lifelong disability in community-based Men's Sheds | Mixed methods collective case study. Subset of data from Transition to Retirement Program. [linked to Standcliffe et al., 2015; Bigby et al., 2014; Wilson et al., 2013] | No significant changes from pre- to post-tests in self-reported health-related quality of life measures but significant post-test increase in social satisfaction for those engaged with Men's Sheds. Mentors expressed a willingness to include people with disability in the Shed and also reported that they felt that they had themselves benefitted from being a mentor | Subset of data from Standcliffe et al. (2015) |

(Continues)

TABLE 2 (Continued)

| Type and aims of study | Methodology | Findings | Comments |
|---|---|--|--|
| Wilson et al. (2013) Explore the experience of being a mentor supporting a previously unknown person with an intellectual disability | Qualitative. Subset of data from Transition to Retirement Study. Interviews with 14 mentors who supported 11 different individuals with intellectual disability in 11 Men's sheds. Analyse using constant comparative approach. [linked to Stancliffe et al., 2015; Bigby et al., 2014; Wilson et al. 2015] | Positive finding re use of mentors to support participation of an individual with intellectual disability in community group or volunteer situation (see main study findings). Mentors trained using the "no different from us" model see past the disability to the person, they are community leaders and offer natural support in the group context. Mentors self-selected so may have already held positive attitudes about the inclusion of people with intellectual disability | Subset of data from Stancliffe et al. (2015) |
| Tedrick (2009) Explore the meaning and benefits of participation in Special Olympics for people with intellectual disability, and analyse the impact of age-related change on the athletes and their parents | Qualitative case study. three participants with intellectual disability aged over 65 years and their parents | Participants developed sports skills and fitness, described having enhanced self-esteem, having met a lot of others through Special Olympics. Some had formed friendships with other participants, acted as mentors. Age-related changes in the athletes may impact on their future participation. Reliance on parents to facilitate involvement meant future participation be limited due to parental ageing or ill health | Small-scale case study - little depth to qualitative analysis |
| Harada et al. (2011) Describe and compare examples of Special Olympics and Unified Sports programmes in different countries | Descriptive programme data | Three million individuals with intellectual disability in 180 countries participate in Special Olympics programmes and 150,000 people participate in Unified Sports in seven regions. no outcome data, provides a "chance to play sport... be a part of society.. a platform for the development of social relationships..." | Descriptive |
| McConkey et al. (2013) Evaluate outcomes of the Unified Sports programme across five countries (Serbia, Poland, Ukraine, Germany and Hungary) in terms of participant's personal experiences, impact on social inclusion and processes perceived to enhance social inclusion | Qualitative, phenomenological. Short (average 15 min) individual and group interviews with athletes, partners, coaches, community representatives from 4 teams in each country designed to gather personal experiences and insights into the programme (no information re overall number of participants). Collected on one day to coincide with event | Outcomes included, personal development of athletes and partners, formation of inclusive and equal bonds, alliances with families, schools and community and sports organizations, and broader positive perception of athletes with disability in community. Suggested as impacting on bonding and bridging aspects of social capital | Weak design, re sampling, data collection and no information re participant numbers or characteristics |
| Darragh et al. (2016) Examine the impact of participating in the Tutti Arts day programme on the social and emotional well-being of young adult participants with intellectual disability | Qualitative. Five participants with intellectual disability aged between 21 and 27, purposively sampled. Semi-guided interviews with participants, family members, support workers Thematic analysis | Participants felt happier and more confident. Enjoyed activities, public approbation for their work, had developed friendships with others at the group which meant participation had expanded individual social networks | Small-scale descriptive study |

(Continues)

TABLE 2 (Continued)

| Type and aims of study | Methodology | Findings | Comments |
|---|---|--|--|
| Stickley et al. (2012) Describe the effects upon people who are engaged with arts programme | Qualitative, ethnographic Interviews, focus groups, observations. 50 participants over 2 years. Six participants, 3 artists/facilitators, 4 support workers, 3 organizers and 20 family & friends of participants interviewed | Personal and group benefits, greater confidence, development of relationships with other participants, increased in confidence and self-esteem. Increased interactions with community members, for example, with local college students who filmed the group | In-depth qualitative evaluative study |
| McClimens and Gordon (2009) Determine the utility of "blog-related technology" for people with intellectual disability, to increase social capital of participants and relationships | Qualitative. Used Social Capital Question Bank as basis for focus group with participants. Document analysis of on line blogs Adults with intellectual disability and varying levels of literacy and keyboard skills | Participants found social activity generated around the blogging exercise valuable rather than blogging per se which was concluded has "little do with social capital" (p. 28) | Exploratory, few details re participants or data collection and analysis |

of would-be retirees with intellectual disability in the community, and constructing the reality. The third component comprised five stages: planning, locating a group, mapping a new routine, recruiting and training mentors, and monitoring and ongoing support" (Bigby et al., 2014; p. 117). A key feature was active mentoring, developed from person-centred active support and co-worker support (Wilson et al., 2013), and utilized to ensure not only presence in the group but the occurrence of convivial encounters between the individual and group members. Active mentoring aimed to ensure provision of the right type and amount of individual support to enable the individual with intellectual disability to participate in the group. It involved identifying one or more volunteers from the group, and training them to use active support to help pinpoint group activities the person with intellectual disability might participate in, facilitate their engagement in activities and support social interaction with other group members. This approach was illustrated in Men's Sheds (Wilson et al., 2015) and a wide range of community groups and volunteering situations (Bigby et al., 2014; Stancliffe et al., 2015). Mentors are reported to have had positive experiences of this role, demonstrating the reciprocity that can occur when people with intellectual disability participate in community groups (Wilson et al., 2015). Significantly, however, as already described, in both these programmes, the support provided for participation extended well beyond individual face-to-face support provided in the group, either by the supporter (Craig & Bigby, 2015) or by the mentor (Stancliffe et al., 2015).

Places more anonymous than community groups, where people with intellectual disability may be known or recognized, were the site of the shorter convivial encounters described by Bigby and Wiesel (2015). This study investigated the support to people with intellectual disability in shops and other public facilities provided by direct support staff attached to accommodation services. It identified the nuanced judgements and skills involved in support that facilitated convivial encounters between people with intellectual disability and community members, and the way staff actions have the potential to facilitate and obstruct encounters.

The final article exemplifying this type of conceptualization was a case study of two people supported to participate in an exercise programme in a community gym (Lante et al., 2011). By locating the programme in a public facility, the programme aimed—in addition to providing physical and psychosocial benefits of engagement in physical activity to participants—to provide opportunities for social interaction with other gym users with and without intellectual disability.

3.1.3 | Community participation as a valued sense of belonging and identity

Five programmes represented Hall's (2013) conceptualization of community participation, as a sense of belonging to proximate or distant others. The theory of change informing these programmes was that participation in certain types of activities would create new identities such as artists, craftspeople, singers, actors or athletes for people with intellectual disability, and consequential opportunities for social interactions with peers as well as people without disability who may

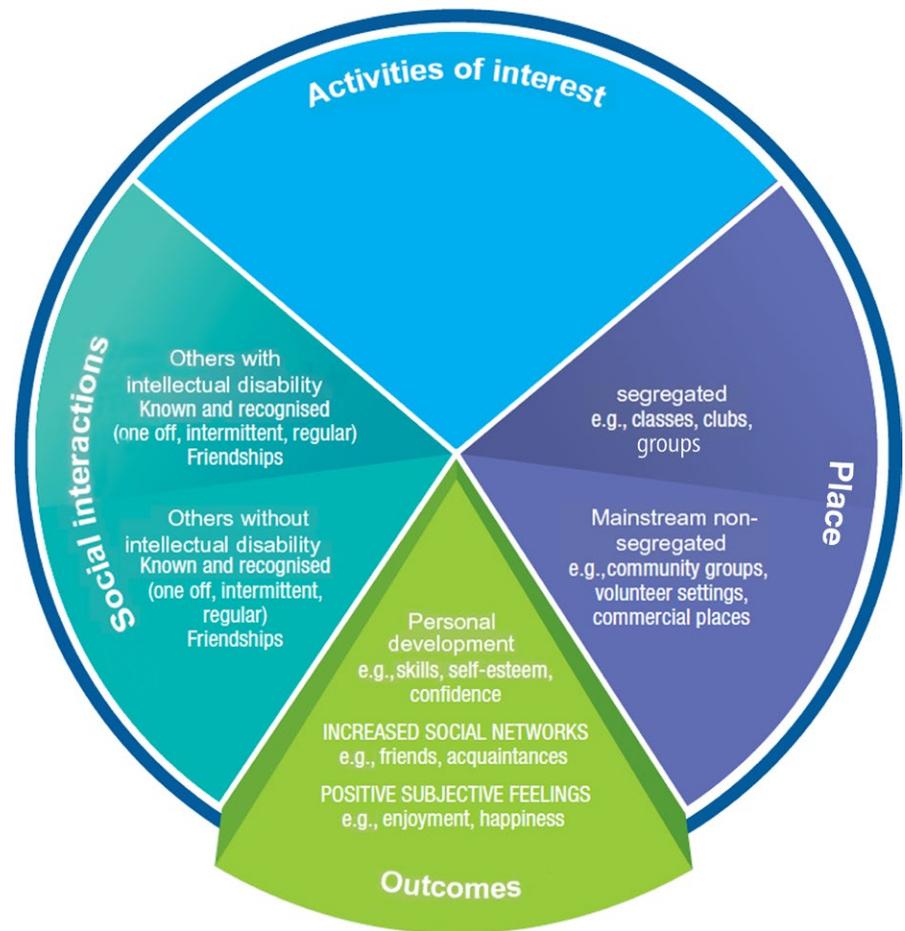


FIGURE 1 Heuristic of components and outcomes of community participation

have similar interests, be members of an audience or purchasers of artworks. The two most common types of activities were associated with the arts or sport, and one programme involved blogging. The ICF (World Health Organization, 2001) element of activities was prominent in these programmes, place was less important and often segregated, while social interaction was seen as the beneficial consequence of engagement in activities and the derived sense of belonging or new identity.

Similar arts programmes were described by Darragh et al. (2016) and Stickley, Crosbie, and Hui (2012). Both offered “day options” for young adults with an intellectual disability as an opportunity to engage in art and music-based activities. Tutti Arts, for example, aimed to “provide opportunities for artists with intellectual disabilities to create visual art and engage in theatre and drama and to make music.” (Darragh et al., 2016, p. 2). A central strategy of both programmes was the creation of a segregated group that enabled participants to develop artistic skills. Parallel strategies were to develop external connections to other artists or the public that enabled creative work to be exhibited or sold, and or brought participants into contact with others, often without intellectual disability with similar interests. For example, the location of the programme described by Stickley et al. (2012) in a disused cinema gave scope for interaction with students from the local area who filmed some of the activities.

The three sport-centric programmes had similar intent and strategies to the arts programmes. Harada, Siperstein, Parker, and Lenox

(2011) described two international programmes. The first, Special Olympics, ran groups and competitive events for athletes with intellectual disabilities often alongside mainstream events. The other, Unified Sports programmes, aimed to include people with intellectual disabilities in community sports teams where they trained and competed alongside peers without intellectual disability, known as “partners.” Both programmes have very large numbers of participants and offer opportunities to play sport as well as “to be a part of society” (p. 1142).

Tedrick's (2009) case study of three older participants in Special Olympics programmes demonstrates the potential benefits of this type of programme for all ages. McConkey, Dowling, Hassan and Menke's study (2013) offers insights into strategies used by Unified Sports programmes, such as “pairing” athletes with and without disabilities, and development of alliances with local sporting clubs and facilities, to create a sense of identity and provide opportunities for socializing with other sports people.

Based on a different type of activity, McClimens and Gordon (2009) described a programme aimed to create new identities for people with intellectual disability in the online world as bloggers. Participants were supported to develop blogging skills by students who acted as trainers. The programme was situated in a mainstream place (a university), but the group could be considered segregated as it comprised solely people with intellectual disability. Nevertheless, the activity of blogging and the identity of blogger subsequently formed was a potential social

role that, like sportsperson or artist, could be adopted by anyone in society.

3.1.4 | Summary of approaches to community participation

As Table 1 shows, each programme adopted one of three dominant conceptualizations of community participation and differing strategies for achieving its goals. Importantly, however, the common threads of community participation were also evident in each. As Table 1 and Figure 1 show, these programmes illustrated the differing ways that the ICF (World Health Organization, 2001) components of activities, place and social interaction were constructed, combined and given varying degrees of prominence. For example, the TTR programme prioritized place (mainstream community groups) and activities (based on individual interest) and sought pleasant social interactions in a community group where the person was known and recognized as an individual, rather than longer-term friendships. The same three components are present but emphasized differently in the Tutti Arts programme which prioritized participation in activities (with the potential to lead to a new social identity and valued role as an artist). Less important for this programme were place, which was segregated, and social interaction, which was usually with other people with intellectual disability and intermittently with others without intellectual disability who had a shared interest in art.

3.2 | Programme outcomes

Overall, as Table 2 shows, studies of community participation programmes have been predominantly small scale and qualitative and produced little robust evidence about outcomes, programme effectiveness or detailed descriptions of the programme logic or costs. Some of the general positive claims about outcomes made in these articles were not backed up by data (Harada et al., 2011; Heslop, 2005; McConkey et al., 2013). For example, the statement by Heslop (2005, p. 33) that “qualitatively the services in the study lived up to their reputation as being a good thing” was not supported by evidence about the success of achieving its aim of developing friendships between people with and without intellectual disability. Despite the differing conceptualizations of community participation and strategies adopted, outcomes were commonly framed in terms of personal development such as skills, self-esteem or confidence, increased social networks and subjective experiences such as enjoyment or happiness.

Several in-depth qualitative studies described both positive outcomes, and the concepts and processes underpinning these, providing a sound basis to scale up the programme or intervention and conduct larger more rigorous outcome studies (Bigby & Wiesel, 2015; Craig & Bigby, 2015). In two of the five case studies described by Craig and Bigby (2015), the participant was judged to be actively participating, regarded as an equal and a welcomed member of the group. These authors identified five influential social processes in these cases: positive leadership response to inclusion; participants with intellectual

disability who had friendly dispositions and relatively good social skills; acceptance by the group of advice about including a person with disability; the existence of an integrating activity, and flexibility and capacity to deal with difference among members (see Craig, 2013 for further details). These factors require further investigation and could be further tested in demonstration initiatives with other non-segregated community groups.

The practices that supported convivial encounters described by Bigby and Wiesel (2015) were very similar to those used in person-centred active support which is an enabling relationship between a person with intellectual disability and a supporter that facilitates engagement in meaningful activities and social relationships (Mansell & Beadle-Brown, 2012). There is significant evidence about the positive effects of active support on engagement of people with intellectual disability but the vast majority of research has been conducted in group home settings focussed on domestic rather than community arenas (Bigby & Beadle-Brown, 2016). Further research on the nature and effectiveness of this approach to practice in public or community places would help to identify the challenges and difficult judgements involved in providing this type of support in the community and ways in which practice might need to be adapted for various types of place.

The strongest design was the mixed methods, matched group approach used by Stancliffe et al. (2015) which, though small scale, provided positive evidence about outcomes for individual programme participants and perspectives from mentors involved in supporting participation. The collection of articles about the TTR programme provides insights into both the overall programme logic and the practices used within groups to support individual participation (Bigby et al., 2014; Stancliffe et al., 2015). This programme was focussed on the transition of older workers into retirement, but there is no reason why this approach to supporting participation in community groups could not be applicable to younger people, given that the initial phases of the intervention aim to understand individual preferences and seek out groups with activities that align with these.

The Special Olympics and Unified Sports programmes are large-scale international programmes offering opportunities for people with intellectual disabilities to train for, and compete in athletic events. The studies of these programmes, however, have weak methodologies and provide little evidence to substantiate claims that they provide; “access to the community” or “develop social relationships with their teammates which often carry over into their lives off the playing field” (Harada et al., 2011, p. 1135–1136).

Although many of the programmes aimed to have both proximal and distal outcomes (immediate and longer-term consequential outcomes), there was little evidence of the latter. For example, interviewees observed that Tutti (a segregated arts programme in a mainstream place, Darragh et al. 2016) offered opportunities for engagement in meaningful and purposeful activities, created the chance for participants to assume valued roles as artists and, through performance opportunities, to receive public accolades. However, there was little evidence about more distal outcomes such as increased opportunities for social interactions or convivial encounters with community members without disability.

Outcomes of the programme described by McClimens and Gordon (2009) were a little different from those intended. While the programme sought to create identities for the participants as bloggers, a lack of "social capital" (described as the background characteristics of poor education, youth, and low wealth) made this difficult. The university environment, however, offered participants activity in a non-segregated place where they felt comfortable. There was also some evidence of the positive interactions with student trainers. Although it was not a central intention, this programme created opportunities for intermittent convivial encounters in a mainstream place, connected to attendance at the activity rather than a new identity as a blogger or friendships.

The studies by Ward et al. (2012, 2013) suggest the Friendship and Dating programme successfully led to more social relationships for participants with other people with intellectual disability, although there are no data about the durability or quality of these friendships. Similarly, there are few data about the relationships formed between people with and without intellectual disabilities supported by the befriending or community connections programmes (Heslop, 2005; Ward et al., 2012, 2013).

4 | DISCUSSION

The aim of this review was to identify promising interventions or programmes that support community participation of people with intellectual disability. In order to understand the nature of these programmes, the analysis sought to identify the assumptions made about the nature of community participation and the theory of change that informed programme design and strategies. The 13 programmes represented examples of the three dominant ways of conceptualizing community participation found in the broader literature reviewed in the first part of this paper, as social relationships (O'Brien & Lyle, 1987), as convivial encounter (Bigby & Wiesel, 2011) and as belonging (Hall, 2013). The differing designs and strategies employed by these programmes illustrate the diversity, both of approaches to community participation and its manifestation for individuals. The common threads of community participation were also evident, and the review has illustrated the differing ways that the ICF (World Health Organization, 2001) components of activities, place and social interaction were constructed, combined and given varying degrees of prominence in these programmes. Figure 1 is a useful heuristic for understanding the design of community participation programmes and generating discussion about the possible features and relative importance of each of the three components—activities, place and social interactions. It may help to avoid binaries such as presence and participation, and judgements that prioritize mainstream places and relationships between people with and without disabilities. The heuristic also captures the way programme outcomes were reported in the articles. In the main, these were subjectively, cast in terms of feelings of happiness or enjoyment, or changes to the individual in terms of skills development, self-esteem, confidence or increased social networks.

These findings reinforce the diversity of experiences that might be described as instances of community participation. They also highlight the importance of a person-centred approach in thinking about and supporting community participation for a person with intellectual disability, one that takes into account their individual preferences and choice. Individuals will combine the three components differently, perhaps emphasizing one more than others and preferring different types of place or social interactions. Importantly, one individual may seek out different types of community participation, piecing them together into a regular routine. For example, an individual could have membership of a segregated art group, participation in a bike riding club run at the local community centre, and a monthly pub meal with a group of friends with intellectual disability. Figure 1 might also be a useful tool for discussing with an individual their preferences about community participation or the different types of experiences that various programmes might offer them.

This review demonstrates the relatively small body of evidence pertaining to the design and effectiveness of programmes to support community participation. It has identified some promising approaches, particularly in the series of studies describing the use of active mentoring (Stancliffe et al., 2015), active participation in community groups (Craig & Bigby, 2015), facilitative support worker practices (Bigby & Wiesel, 2015), community builders (Harlan-Simmons et al., 2001) and the arts-based programme described by Stickley et al. (2012). The findings about the efficacy of these programmes, and the availability of well-described programme logics, though not so with respect to cost, suggest there is the potential for replication, larger-scale implementation and conduct larger more rigorous outcome studies.

These studies are also beginning to describe the type of microlevel practices, such as active support and active mentoring, as well as the need for skills such as locating and analysing social contexts such as community groups that are likely to be required of staff who work in community participation programmes. Importantly, some studies also illustrate the broader set of tasks involved in community participation programmes that do not involve face-to-face contact with the individual but are needed to build the foundations for their participation with a group or a person's support network. Language such as "individualized" or "person-centred" runs the risk of rendering invisible hidden tasks of interventions to support community participation such as identifying and evaluating groups with the potential to accept a person with intellectual disability as an equal member. Tasks such as these are connected to supporting a particular individual to participate rather than preparing the community in general, which is the province of broader community development/change type of work.

Nevertheless, these findings illustrate, an individual intervention can be delivered in the context of a programme such as the TTR programme that serves more than one person. This suggests that when investigating the efficacy of interventions to support community participation, attention must be given to microlevel practices and the work associated with the intervention that does not involve direct contact with the individual such as analysis of potential community groups. It also suggests that delivery of individual interventions can be brought together into programmes which, while still offering

individualized support, may enable better client outcomes by providing, on a more collective and economically sound basis, staff training, supervision, sharing of practice wisdom about community places and things such as human resource and accounting functions.

Notably, the findings suggest there is little rigorous evidence about programmes that give prominence to participation in sports-related activities as a means of building new identities and a sense of belonging. This may reflect the limited volume of research or absence of strong research methodologies about this type of programme. The cultural significance of sport as a means of breaking down social and racial barriers for other minority groups such as refugees, apparent in the grey literature and mainstream media sources (BBC, 2016; Human Rights Commission, 2006), suggests the potential of these programme in building a sense of identity and belonging that should be further explored. This is a potential area for further research and perhaps too, the implementation of demonstration programmes accompanied by rigorous evaluation.

The unintended outcomes of the blogging programme described by McClimens and Gordon (2009) suggested the potential of universities as places where convivial encounters between young people with and without intellectual disability could be fostered. Although usually cast in the arena of education rather than community participation, the inclusive higher education programmes found in the USA and Canada that support young people with intellectual disability to monitor classes and match them with student mentors may be worthy of further exploration (Jones & Goble, 2012).

The majority of the programmes identified in this review were not designed to fill people's days or provide respite care for parents or carers as had often been the case for more traditional day centres in the past (Bigby, Fyffe, Balandin, Gordon, & McCubbery, 2001). Rather, they offered support for singular, intermittent or regular but relatively short episodes of community participation, which may also have acted as a catalyst for further opportunities outside of the programme. Understanding more about programmes that effectively support community participation may help to tackle some complex questions, such as how to fill the daytime lives of people with intellectual disability who do not work; replace full-time attendance at day programmes/centres; or what constitutes a meaningful ordinary life of a person with intellectual disability. Such questions are particularly pressing for people with higher and more complex support needs for whom supported paid work may never be an option that society is willing to fund. These issues, however, are much broader and should not be confounded with understanding ways to support community participation.

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