This article was downloaded by: [Professor Christine Bigby]
On: 13 December 2014, At: 15:09
Publisher: Routledge
Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK

Journal of Intellectual and Developmental Disability
Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/cjid20

"She's been involved in everything as far as I can see": Supporting the active participation of people with intellectual disability in community groups

Diane Craig[a] & Christine Bigby[a]
[a] Living with Disability Research Group, Department of Social Work and Social Policy, La Trobe University, Melbourne, Victoria, Australia

Published online: 11 Nov 2014.

To cite this article: Diane Craig & Christine Bigby (2014): "She's been involved in everything as far as I can see": Supporting the active participation of people with intellectual disability in community groups, Journal of Intellectual and Developmental Disability, DOI: 10.3109/13668250.2014.977235

To link to this article: http://dx.doi.org/10.3109/13668250.2014.977235

PLEASE SCROLL DOWN FOR ARTICLE

Taylor & Francis makes every effort to ensure the accuracy of all the information (the "Content") contained in the publications on our platform. However, Taylor & Francis, our agents, and our licensors make no representations or warranties whatsoever as to the accuracy, completeness, or suitability for any purpose of the Content. Any opinions and views expressed in this publication are the opinions and views of the authors, and are not the views of or endorsed by Taylor & Francis. The accuracy of the Content should not be relied upon and should be independently verified with primary sources of information. Taylor and Francis shall not be liable for any losses, actions, claims, proceedings, demands, costs, expenses, damages, and other liabilities whatsoever or howsoever caused arising directly or indirectly in connection with, in relation to or arising out of the use of the Content.

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden. Terms & Conditions of access and use can be found at http://www.tandfonline.com/page/terms-and-conditions

Journal of Intellectual & Developmental Disability, 2014
http://dx.doi.org/10.3109/13668250.2014.977235

Routledge
Taylor & Francis Group

ORIGINAL ARTICLE

"She's been involved in everything as far as I can see": Supporting the active participation of people with intellectual disability in community groups

DIANE CRAIG & CHRISTINE BIGBY

Living with Disability Research Group, Department of Social Work and Social Policy, La Trobe University, Melbourne, Victoria, Australia

Downloaded by [Professor Christine Bigby] at 15:09 13 December 2014

Abstract

Background The social processes that operate in community groups need to be better understood if people with intellectual disability are to be included in such groups. This study aimed to identify the nature and impact of the group processes on the active participation of people with intellectual disability.

Method Extensive field notes were taken during 2 years of participant observation whereby 5 people with a moderate level of impairment were supported to participate as individuals in community groups for periods of 5 to 10 months. Analysis used a critical realist approach.

Results Active participation was influenced by the interaction of 5 key social processes: leadership response, characteristics of the participants with intellectual disability, access to expertise, the presence of an integrating activity, and dealing with the difference dilemma.

Conclusions By revealing these processes, the study identified a number of interventions and ways of approaching community groups that have the potential to increase the extent to which people with moderate levels of impairment become active participants.

Keywords: *social inclusion, participation, community groups, contact theory, moderate intellectual disability*

Introduction

Several decades of policy change centred around deinstitutionalisation, recognition of human rights, and achieving greater social participation have undoubtedly led to an increased quality of life for people with intellectual disability in western countries such as Australia, the United States, and the United Kingdom (Kozma, Mansell, & Beadle-Brown, 2009). However, increased physical presence of people with intellectual disability in the community has not been matched by a corresponding increase in their social relationships with other community members and participation in the social and recreational organisations that make up civic society (Clement & Bigby, 2009; Forrester-Jones et al., 2006; Robertson et al., 2001). It has been suggested that they occupy a distinct social space, with social networks that comprise peers, staff, and families (Clement & Bigby, 2009). Some evidence suggests that people with more severe levels of intellectual disability fare even less well both in terms of engagement in their own homes and in community life (Ager, Myers, Kerr, Myles, & Green, 2001; Mansell, Beadle-Brown, & Bigby, 2013). Attitudes have been found to persist among staff that community inclusion is more suited to those with mild intellectual disability (Bigby, Clement, Mansell, & Beadle-Brown, 2009; Bigby, Cooper, & Reid, 2012). This may be compounded by the use of images of people with less severe forms of disability in public representations of disability policy (Burton & Kagan, 2006).

Reinders (2002) suggested that progress toward greater social participation of people with intellectual disability requires change to the social processes that continue to disadvantage them. Relatively little

Correspondence: Christine Bigby, Department of Social Work and Social Policy, La Trobe University, Melbourne, Australia. E-mail: C.Bigby@latrobe.edu.au

© 2014 Australasian Society for Intellectual Disability, Inc.

Downloaded by [Professor Christine Bigby] at 15:09 13 December 2014

research, however, has looked beyond the attitudes and skills of direct support staff. Contact theory may offer a way into understanding the situation of people with intellectual disability (Fishbein, 2002; Makas, 1993). It posits that continuing social exclusion of minority groups may be due to the lack of opportunity for interaction or prejudicial attitudes, and that casual contact alone between members of an "in-group" and an "out-group" is insufficient. Contact theory developed in the mid-1950s in response to the political need to find ways of changing attitudes toward minority and racial religious groups. A significant body of research over the next 50 years consistently found that contact between a dominant in-group and marginalised out-group leads to favourable outcomes only when it occurs under certain conditions (for reviews, see Brewer & Brown 1998; Pettigrew & Tropp, 2006). Conditions necessary for favourable outcomes are that contact (a) allows opportunities for a meaningful level of communication that is personal in nature, frequent, and of reasonable duration; (b) promotes equal status; (c) fosters cooperation in working toward shared goals; and (d) takes place within an environment where there is authority support (Allport, 1954; Novak & Rogan, 2010; Pettigrew & Tropp, 2006).

Contact theory has since been applied to a range of minority group populations. Most of the research in intellectual disability has been done in educational environments in response to policy changes requiring the inclusion of students with disability in mainstream rather than segregated environments (Fishbein, 2002; Makas, 1993). Other than the work of Novak and Rogan (2010) and Novak, Feyes, and Christensen (2011), who used it to research employment, contact theory has not been used to consider the social participation of adults with intellectual disability. However, some aspects such as the opportunity for regular interaction in the context of shared interests are evident in the work of researchers such as Clement and Bigby (2009), Amado (2012), and Walker (1999).

Drawing on the International Classification of Functioning, Disability and Health (World Health Organization, 2001), Verdonschot, de Witte, Reichrath, Buntinx, and Curfs (2009) defined participation as the "the performance of people in actual activities in social life domains through interaction with others in the context in which they live" (p. 304). Craig's (2013) doctoral thesis refined this commonly used definition to distinguish more clearly between being present in a place such as a community group by simply attending, and being actively involved in the activities that occur in that place. She defined active participation for people with intellectual disability as occurring in groups when participants had equal membership status with other members, participation was mutually rewarding for members, participants worked cooperatively toward a common goal, and effective use was made of expertise to develop group capacity to support inclusion. The study reported in this paper uses this definition of active participation, as it opens the possibility to explore the depth of participation that occurs in different groups and enables comparison across groups.

The aim of this study was to identify the pathways to participation in community groups for people with a moderate level of intellectual disability, explore the factors that enable or constrain their active participation, and consider the implications of these for the practice of supporting active participation in community groups.

Method

Approach and participants

Contact theory and the proposition that the conditions under which contact occurs between a person with intellectual disability and members of a community group will affect the degree of active participation provided the theoretical basis for the study. It was a qualitative participant observation study, conducted in the metropolitan area of Melbourne, Australia. Five people were recruited with the assistance of senior staff from two day centres for people with disability. The first day centre, No Limits, was an industry partner in the companion research (Bigby et al., 2014) but went through several restructures and was unable to support the research process any further. A second day centre, Horizons, which had a reputation for quality services and known interest in research, was approached and agreed to help enlist further participants.[1] Participants were required to be over the age of 45 years, with a moderate level of intellectual disability, and be interested in joining a community-based activity. Level of impairment was determined in consultation with day centre and group home staff who knew participants well and had access to their case records.

Based on staff knowledge about how potential participants normally made decisions, each gave their own consent to participate in the study. Although it was clear that participants understood the immediate face-to-face aspects of the research, it was less certain that they had insight into its "hidden" aspects such as processes of data collection, analysis, and reporting. To support their understanding, consent and information forms were written in plain English and

Downloaded by [Professor Christine Bigby] at 15:09 13 December 2014

were signed in the presence of a staff member, who agreed to help each person understand the research as it unfolded. Consent was understood as an ongoing process of continual rechecking rather than a one-off event (Griffin & Balandin, 2004). The Human Ethics Committee of La Trobe University approved all research procedures reported in the manuscript.

The first author undertook the fieldwork over 22 months. She met regularly with the second author for supervision. A planning process with each participant informed the tasks of locating a relevant community group and negotiating their attendance. Each participant was then supported to attend a group, which initially meant they were accompanied to their group each week by the first author. Consent to involvement in the research was also sought from the members of each of the groups participants attended.

Table 1 summarises the characteristics of each community group and participant. All the groups were small, with fewer than 20 participants, but varied in their purpose, auspice, and the presence of paid staff.

Locating groups was a lengthy process, involving local networking, online research, and some cold-calling at likely organisations. The first author as a participant observer provided support to facilitate participants' inclusion in group activities, as well as observing their interactions and processes of engagement. A variety of strategies were used to promote participation, including identifying and supporting other group members to act as mentors,[2] making suggestions about contextual cues that might prompt involvement, identifying potential activities for a participant, and modelling respectful interactions. For example, the tendency of group members to render the participant invisible by talking to the first author or using patronising and childlike language required redirection of comments and modelling of language, as this field note from the men's shed illustrates:

> "Where's he live?" Allan asked me. I directed the question to Phil. "Phil, how many people do you live with these days?" and Phil turned to Allan and said, "I live in Farleigh with five others." "Is there someone there to help you?" Allan asked him. … "Good boy," Allan said as Phil finished the last [bicycle] spoke. "Well done, mate. Champion job," I echoed, and Allan said, "Yeah, champion job, mate."

The time spent by the first author driving participants to and from their group created an opportunity to get to know them, develop rapport, and appreciate their personal qualities. This was important in supporting participants to understand the demands of a new environment, as the first author acted as a trusted and familiar face helping to negotiate any difficulties until they gained confidence. Participants particularly needed assistance to read social cues about appropriate behaviour in groups. This was illustrated by Matthew's experience. Several volunteers had commented to the first author about how childlike they thought he was when he said things like "OOOOH, what a naughty boy I am." The first author thought this may explain the reluctance to have him on the premises without her, and talked to him about how his behaviour might be construed as immature and irresponsible.

Data collection

Ethnographic-style field notes were used to record what occurred in each group, and particularly the social interactions between participants and other group members, involvement in activities, and the

Table 1. Characteristics of participants and community groups

Participant	Age	Intellectual impairment	Housing	Day program	Type of community group
Helen	62	Moderate	Group home	No Limits	Cooking group, neighbourhood house, paid coordinator
Phil	48	Moderate and additional diagnosis of cerebral palsy	Group home	No Limits	Men's shed, community health centre, paid staff and coordinator
Matthew	58	Moderate	Group home	Horizons	Op shop, national charity, paid manager, volunteer staff
Sol	59	Moderate	Group home	Horizons	Walking group, sponsored by national healthy ageing charity, led by volunteer
Ruth	54	Moderate	Unit in cluster	Horizons	Community kitchen, Christian parish, leader paid church minister

Note. An op shop is a shop that sells second-hand goods, particularly clothing, and is usually run by a charity. Men's sheds are a grassroots community-based movement in Australia that aim to provide social support for men. (For more information, see Golding, Brown, Foley, Harvey, & Gleeson, 2007; Misan & Sergeant, 2011.)

Downloaded by [Professor Christine Bigby] at 15:09 13 December 2014

Table 2. Summary of field note collection

	Hours of observation in group	Number of months' observations in group	First group observation	Word count field notes from groups	Word count field notes from other sources
Helen	54	10 months	August, 2010	44,346	13,011
Phil	38	6.5 months	December, 2010	34,935	19,455
Matthew	30	4.5 months	April, 2011	32,037	11,713
Sol	28	7 months	March, 2011	43,786	4,769
Ruth	31	7 months	September, 2011	23,144	41,704
Other					8,173
Total	181			178,248	75,681

comments or reflections about participants made by group members. Across the five participants there were 181 hours of observation. In addition, semi-structured interviews were conducted with 11 mentors and group leaders about their perceptions of including the participant in the group (Table 2).

Data analysis

A narrative was written about each participant's experience in the group, which enabled a broad comparison across the groups and initial identification of the domains that would be the focus of analysis. NVivo Version 9 software (QSR International, 2010) was used as a tool for data management and data were coded using a "mid-range accounting scheme" (Miles & Huberman, 1994, p. 61). This approach lies part way between a priori and inductive coding, determining initial general domains within which inductive codes are developed. Such a scheme helps graduate data from micro to macro levels and to challenge the researcher to approach the data from different angles.

Coding techniques described by Strauss and Corbin (1990) and further developed by Charmaz (2006) were used. Initially the codes were descriptive and many related to questions about what participation looked like, what drove it, and what changed over time. This led to a more focused level of coding and the development of categories. This process continued until there was saturation of categories and a sense of a pattern and stages within the groups had developed. For example, language in four of the five groups relating to the participant "fitting in" or "being manageable for the group" was coded initially as an *in vivo* code (phrases used repeatedly) under the domain of "meaning." Groups had set various conditions of entry for the inclusion of participants and when these were identified they were coded and grouped together. The codes related to fitting in were then interpreted as a desire to maintain the status quo of the group and collapsed into a category of this name.

Initially, in-case coding was done for each group and then a cross-group comparison was made to develop a "cognitive map" (Miles & Huberman, 1994, p. 134) of how groups changed over time. Although there were different factors at play within each group, it was possible to draw out directional processes and common themes across groups. A cycle of examining identified stages of initial anxiety, discernment within groups, degrees of acceptance and extent of active participation for each case, and testing hypotheses about the directional processes was followed. The outcome of this analysis was identification of a pathway for entry and factors related to a discernment process.

Trustworthiness. Methods of data collection and analysis were carefully documented to ensure confirmability and objectivity of findings. During the analysis, conclusions were linked back to the data using quotes from the field notes. In movement back and forth from data to coding, competing explanations for the findings were sought using tables and supervision discussion.

To ensure reliability and dependability, the collection of data were driven by the research questions and working hypotheses that had been theory driven. The study design was congruent with the research questions in that data were collected over a substantial period of time to observe the changing processes within the groups.

Detailed descriptions of events in each case were written to ensure internal validity, credibility, and authenticity. Interviews and the verbatim words of participants in the field notes were compared across the various scenarios and produced converging conclusions about the nature of participation. There was a theoretical coherence between these findings and the wealth of research in contact theory. Each concrete situation was different but findings about group types, the stages of discernment about how they would accommodate the person with intellectual disability, and features of active participation were

Downloaded by [Professor Christine Bigby] at 15:09 13 December 2014

described in such a way as to be externally valid and transferable; that is, used as a point of comparison in similar studies.

Findings

Two pathways to participation in community groups

Two different participant pathways to entry were identified, and the subsequent factors that contributed to each group's adjustment and support for their participation. As Figure 1 shows, the initial approach to four of the five groups was met with a response that differentiated the potential participant from other community members. In these groups participants commenced with an unequal membership status. For Ruth, the participant in the fifth group, the community kitchen, entry was similar to others seeking to join the group. As Figure 1 shows, some of the subsequent factors that affected participation differed depending on whether a differentiated or undifferentiated entry pathway had occurred. These factors are explained and illustrated in the following sections with thick descriptions drawn from the data.

Initial anxiety: Fitting in and being manageable

The leaders who had a differential response showed a level of anxiety about the participant joining the group. For example, the manager of the op shop said, "Look I am worried about the effect Matthew's presence will have on my volunteers. They find change hard." Access to the men's shed took 5 months to negotiate. It was made particularly difficult by an assessment process that tried to direct Phil to the "most appropriate" group, one that was especially for people with disability. The assessor expressed doubts about Phil's skill level and his need for additional support: "He has a wheel chair and we were told he is difficult to understand." As this field note records, the senior manager had reservations about Phil's application to join the "mainstream" shed:

> Details given by the carer in response to the various questionnaires form the basis of decision-making. I know he wants to go to the men's shed but it all comes down to his skill level and whether we decide this will best meet his needs. We think the acquired brain injury group would be good for him. Frankly, [as the service manager and person responsible for assessment] I am feeling pressured to take Phil and

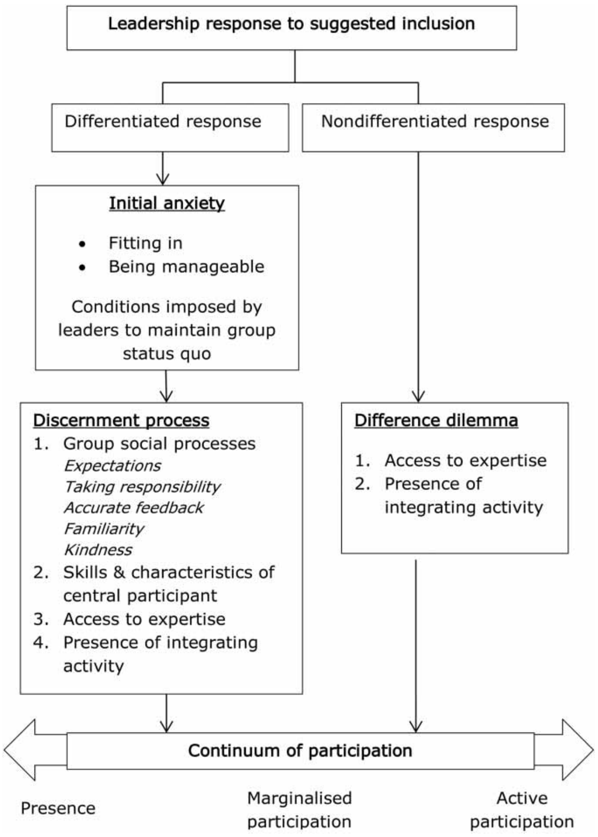

Figure 1. Overview of the factors affecting the extent of active participation in community groups.

Downloaded by [Professor Christine Bigby] at 15:09 13 December 2014

> he might turn out to be not suitable [for the men's shed].

Group leader concerns about participants "fitting in" centred around not upsetting other members, their personal characteristics, and ability to conform to group norms. For example, the manager of the op shop, when approached about Matthew becoming a volunteer, said:

> I don't care about problems he may have but a sunny disposition is what matters so he can fit in with everyone else here. Fitting in is important.

Participants were expected to have or be able to quickly develop skills leaders felt were necessary to participate in the group. As one staff member in the men's shed commented about Phil:

> In the first couple of weeks we tried to do some things to help him. Talk to him, that sort of thing, but I couldn't connect with him and the conversation didn't go anywhere. Like you couldn't joke with him, and let's face it, there wasn't much Phil could do. We tried a couple of things … but the novelty wore off. So we tended to just let him hang out.

A second source of anxiety was the group's capacity to accommodate the participant without being diverted from its purpose. Leaders felt the participant had to be "be manageable" for the group. For example, one of the cooking group mentors commented:

> It's manageable with one there. I am all for the idea of integration, I really am, but there should be a good ratio. Like if you had five that could help [provide support] but had 30 disabled [*sic*] people, well it won't work will it? We're outnumbered sort of thing.

Only on condition the status quo is maintained. Various conditions on the entry and continued participation of participants were imposed by leaders as a way of dealing with their anxiety and maintaining the groups' status quo. Conditions included that all members agreed to have the participant in the group, the participant's behaviour was nondisruptive, the presence of the group leader or the first author to provide supervision, participation only at certain times, other group members continuing to be comfortable, and having a trial period. For example, at Phil's first session at the men's shed he was told:

> You can come for a couple of hours at a go for, say, 3 months, then, if that works, well, we might be able to extend it and then review it all in 6 months.

The walking group agreed to Sol's participation after all members had been consulted, but this continued to be conditional upon group leaders being present. The leader said:

> We spoke with everyone in the group and asked them if this would be OK. Everyone is fine with it, but we [the group leaders] are away in May and it would be better if Sol didn't come then. We'd also like a couple of months after Christmas before we welcome him back so that we can settle everyone else in first.

Discernment processes

As study participants' attendance began, a process of discernment occurred as group members and/or staff adjusted to the presence of the participant. Groups grappled with dilemmas as they attempted to balance their own needs and norms with the changes required to include the participant. A complex interaction of factors shaped the eventual nature of each participant's participation. As illustrated in Figure 1, common factors at play across all groups were access to expertise and the presence of an integrating activity. Some factors varied across groups. In the groups where a differentiated entry response had been made, additional factors emerged within the group social processes, and the skills and characteristics of participants. In the group that had a nondifferentiated response the difference dilemma became apparent.

Group social processes. Five social processes were identified that helped to build or detract from a positive and supportive environment for active participation.

Expectations: "The group's open to anyone in the local community." In each group, members had expectations that this was the right or wrong place for the participant to be. The quote above is from the leader of the walking group. In several other groups, however, members inferred that the needs of the participant would be better met elsewhere, as illustrated by the following comments made by the op shop manager:

> This organisation has a proud history of supporting people with disabilities. We have sheltered workshops for people like Matthew. Things are set up that way there. This is not the right place for him to be.

In these cases the onus was on the participant to demonstrate their suitability for the group.

Taking responsibility for participation: "It's better if we all chip in to help." In all groups, participants

Downloaded by [Professor Christine Bigby] at 15:09 13 December 2014

experienced friendliness from members. When this was linked to a collective sense of responsibility to support participation, greater involvement in group activities seemed to be fostered than when responsibility rested solely with the group leader.

Provision of accurate feedback: "Just tell him only a handshake, thanks, and no hugs." Participants had little experience of nonsegregated social environments, and at times their social skills were at odds with accepted norms. Only in one group, however, did members give direct, accurate, and consistent feedback about behaviours they found troubling, which helped participants to adapt to expectations. For example, at first it was upsetting for Helen to be told by group members, "don't stare," or "pay attention," in what she felt to be a "growly voice." But over time, and with some support from the first author, she was able to use this feedback to change her behaviours and began in turn to be described by group members as "easy to be around" and a "joy." The field notes recorded:

> Rafe started to show Helen how to get the mixture into the cooking tin without making a mess. Helen was distracted. "Helen watch please!" he said sharply. "Sorry, Rafey, I am watching now," she replied contritely. After he left she said to me, "He shouted just like that too last week" and shrugged. [Unlike in earlier weeks when she cried after being spoken to in a similar manner] there were no tears this time and she wasn't at all worried about it either from the look on her face.

In contrast, members of the op shop complained to each other and the first author about Matthew's childish behaviour but did not give him any feedback that it was unacceptable. Yet when the first author talked with him about the effects of describing himself in childish terms he was immediately able to make adjustments.

> Deidre had brought a birthday cake in for Matthew. Matthew said, "Is that because I am such a good boy? I got a cake. I am a good boy today." … [After the group had moved away] I said to Matthew, "Why do say you are a boy? You know people with disabilities often get treated as children, don't they?" He looked at me seriously: "Yes they do and that's not right." "Well, I think when you say 'I am a good boy' it makes it harder for others to treat you as a man." … A little later I heard Matthew saying to the manager, "Look at this! I am such a good man today!"

Familiarity with intellectual disability: "I've had experience with people like that so I know what I am dealing with.". Group members with prior contact with intellectual disability were more comfortable in the presence of the participant, and were often the first to reach out and include them in conversation or activities. They modelled interactions for others in the group, and if uncomfortable moments occurred, tended to put the behaviour of participants into perspective. Their influence seemed to help to avoid other group members interpreting the participants' presence in a negative light.

Presence of kindness: "It makes me feel I am doing something nice for someone." Every group differed in the contact that members had with participants. For example, in the cooking group everyone interacted frequently with Helen, whereas fewer than half of the walking group members did so with Sol. Nevertheless, when interactions did occur they had a quality of genuine warmth and positive regard. Group members' interactions often established a human connection between those with and without intellectual disability, as captured in this field note:

> I must say walking behind them watching Sol excitedly gesturing and talking and Jim next to him, nodding, asking questions, taking what he said seriously, smiling at him. I was very touched. It was a lovely sight. "We will share your umbrella, Jim, if it rains." Jim told him he was welcome under it.

Personal skills and characteristics of participants

In the groups where there had been a differentiated entry response, participants' use of initiative, willingness to try, and people skills affected how members responded to them. Despite the good intentions in some groups, unless participants could be assertive and initiate interaction or place themselves into group activities, they risked slipping into invisibility and an observer role. Exhibiting initiative or a willingness to try had a positive impact and was more likely to lead to offers of assistance, as other members perceived them to be trying to help, or fit in themselves. Several participants who were unable to do this were labelled as "demanding" and "hard work." Having people skills, such as a friendly, engaging manner and the ability to get on with others, also increased the likelihood that others in the group were more supportive of their participation.

Access to expertise

The nature of the participants' impairments meant that members in all five community groups needed assistance to read cues and to respond appropriately

Downloaded by [Professor Christine Bigby] at 15:09 13 December 2014

to participants. As the field note from the walking group illustrates, input from the first author helped members understand the nature of the impairment, to set boundaries, know what sort of support to provide, and to be more confident in interacting with the participant:

> Sol said to everyone at the table, "I want a diet Coke. You bring me one next week." When there was no reply he turned to me and said, "You get me a diet coke next week." I was aware that the others around the table were listening and interested in how I would respond. "Well, no way, Sol! Why should I bring you a drink when you have your own money and can walk to the supermarket from your house. You could go and get yourself one this afternoon. I don't want you to ask me to bring you a Coke when I know you are perfectly capable of getting your own!" Sol looked at me with a grin. "Well, OK, then I will." There were chuckles around the table.

Presence of an integrating activity

The presence of an integrating activity provided a means for the participant to be brought into the action of the group and placed into a situation where they were involved in some way. In the walking group, for example, the process of gathering together prior to the walk was used by leaders to make sure everyone, including Sol, had someone to walk with.

The difference dilemma

The way Ruth became a member of the community kitchen was no different from that of others without intellectual disability. However, despite the very positive and inclusive attitude of the leader and other members, her intellectual disability brought to the surface the "difference dilemma" (Stainton, 2005). This is the need sometimes for people to be treated differently to achieve the same basic capacity for participation. For example, initial observations showed that Ruth was slipping into a passive observer role and needed a higher level of direction than other participants to exercise a choice about active involvement in the group.

> I asked [the volunteer] what happens if someone is sitting there by themselves. "It depends … Sometimes people want to be left alone, don't they? You want to be friendly but you can't push it. It's OK to sit there if that's what they want to do.

It was clear from Ruth's eager response to a direct and personal invitation to participate in specific cooking tasks that she required more than the general invitation issued to everyone present. Some of the kitchen work carried a higher risk for Ruth, given her poor dexterity, and though she could travel independently by taxi to the kitchen, she had difficulty remembering addresses. These things required some adjustment in the approach of group leaders, and at times, to ensure her safety, meant that information had to be divulged about her and shared with group members that was contrary to the ethos of the organisation. For Ruth to be an active participant in the kitchen, her differences from other members had to be acknowledged and some adjustments made to standard practices in the group.

A continuum of participation

The factors affecting the nature of each participant's experience in their group are summarised in Table 3. At the cooking group and community kitchen Helen and Ruth were fully involved as active participants. They helped to plan menus, took an equal share of cooking tasks and were invited to social events with other group members. Comments by others in the groups indicated they had benefitted in some way personally from the experience and had enjoyed their company: "I like Ruth. We have fun together mucking around."

In contrast, Phil and Matthew experienced a more marginalised form of participation. Phil died unexpectedly 5 months into the data collection, so the possibility of his ongoing participation did not have to be confronted. The lack of an integrating activity meant he often did tasks on his own, and as his mentors were not particularly active, most of his time was spent in the role of marginal observer. One of his mentors commented on this in an interview after his death:

> That's something with hindsight I'd have done differently. Asking the other men to assist Phil with jobs. It creates a bit of a connection … we could have set up interactions between him and the others. Tasks together and not on his own all the time.

Matthew, like Phil, remained on the margins of the group. Although the other op shop volunteers were very friendly and engaged in considerable banter with him, they refused to work with him. No one took responsibility for his participation; the manager didn't think this was the right place for him and refused to have him on the premises unless the first author was there, as illustrated by this comment from the manager:

Table 3. Summary of the factors affecting participation in each group and nature of participation

Factors affecting participation	Helen, Cooking group	Sol, Walking group	Matthew, Op shop	Phil, Men's shed	Ruth, Community kitchen
Initial response of leadership	Differentiated		Nondifferentiated		
Discernment processes/Group social processes					
(1) Expectations (right place)	Yes	Yes	No	No	N/A
(2) Group responsibility	Yes	No	No	No	
(3) Accurate feedback	Yes	Partial	No	No	
(4) Familiarity	Yes	Yes	No	No	
(5) Kindness	Yes	Yes	Yes	No	
Participant skills and characteristics					
(1) Use of initiative	Yes	Yes	No	No	N/A
(2) Willing to try	Yes	Yes	No	No	
(3) People skills	Yes	Yes	Yes	No	
Integrating activity	Yes	Yes	No	No	Yes
Access to expertise	Yes	Yes	Yes	Yes	Yes
Difference dilemma	No	No	No	No	Yes
Nature of participation	Active	Partial	Marginalised	Marginalised	Active

> He is so distracted they end up playing with him basically and can't get their own work done. It is not their job to supervise Matthew.

Matters came to a head one day, when Matthew was made to stand at the entrance of the shop waiting anxiously until the first author arrived. He found this to be "humiliating and embarrassing" and said he "felt dreadful." He later made the decision to withdraw from the op shop.

Sol's experience at the walking group was located midway between active and marginalised participation. Lack of willingness for the group as a whole to share responsibility for his inclusion meant his participation was restricted to times leaders were present. Discomfort with some of his habits, coupled with the reluctance to give him accurate feedback, meant too that group members did not invite Sol to attend social events with them.

Participants' response to participation

The initial anxiety of participants about attending a community group was unsurprising given the extent of their segregation and social isolation. Although three of the five participants with intellectual disability had some contact with family members, all of their activities were disability specific, undertaken in the company of other people with intellectual disability. They all lived with a group of others with intellectual disability. Making a choice about which or what type of group to join lay outside their experiences, which meant they were reliant on the judgement of the first author exercised in collaboration with staff who knew them well. As Phil said, "I am scared. What if I don't like it? I don't know what a men's shed is." Matthew was visibly shaking when he said, "I have big butterflies." Despite their misgivings, within the first 2 weeks of attendance each person had made a comment similar to Ruth's, who said, "I love it here. I want to stay here." It was not all smooth sailing as participants negotiated this new environment away from the protected world of disability services. Helen burst into tears quite often in the early weeks when group members snapped impatiently at her: "They are being mean to me." Sol was hurt and angry when he realised he was being excluded from a group social event and shouted, "When are you going? It's because I am not a member isn't it? You won't take me!"

Despite these challenges, none of the participants wanted to give up attending the activity. Even when Matthew decided to leave because he experienced the group's exclusion of him without supervision as "wrong and hurtful," he first negotiated with the first author and day centre manager an agreement that he would be supported to find "another job like this one." Without exception, all five participants, at some point, described this as the "best" thing they did. At the conclusion of the research project Matthew was volunteering in another op shop and Sol, Helen, and Ruth continued in their groups. Sadly, Phil died some 8 months after joining the men's shed. Conversations with participants over many months gave some clues as to why this activity was so important. It provided stimulation and gave them something to talk about and to take pride in with both staff and peers. Staff in Matthew's

Downloaded by [Professor Christine Bigby] at 15:09 13 December 2014

Downloaded by [Professor Christine Bigby] at 15:09 13 December 2014

group home and day centre, for example, said on a number of occasions, "It's all he talks about now. He comes in and tells us all about it." Helen and Sol were "up at dawn" on the group days to get ready. Sol, Helen, and Ruth all had experiences of being out in the community with staff when their names were called out in public by someone from their group. Helen on one occasion in a shopping centre said to her worker, "This is my friend Rollo from cooking!" and they talked for a while about what they had cooked the previous week. Helen then talked about this encounter for many weeks afterwards; it was important to her to be recognised in this way. Individualised activity appeared to matter. Matthew said, "This is my job. This is my place now. Doing men's work." Phil sat on the margins of the group and when asked how he felt about this replied, "I love being here. Just hanging out with the men. That's what I do. Hang out with them." He continued to attend even when he became ill.

Witnessing such enthusiasm led to changed perceptions in group home staff about the value of this activity and a willingness to support ongoing group attendance. For example, when first told about the research, Sol's group home manager had said, "You've chosen the wrong person in Sol. He is aggressive with women. It just won't work." Her experience of how much it meant to Sol to be part of the group, the positive contact she had with group leaders, and their affirmative comments about Sol, led to support of individualised activity. The group home manager was the one who advocated on his behalf later with leaders.

Discussion

The participation of the five people with intellectual disability in their respective groups fell along a continuum from marginal to active. The findings demonstrate that the nature of their participation was influenced by the complex interaction of factors: (1) leadership attitude toward inclusion of a person with intellectual disability; (2) social processes within the group, about expectations of whether the group was the right place for a person with intellectual disability, where responsibility should lie for supporting their participation, provision of feedback about behaviour, familiarity with people with intellectual disability, and kindness toward a participant with intellectual disability; (3) the skills and characteristics of the person with intellectual disability, particularly their use of initiative, willingness to try, and people skills; (4) the presence of an integrating activity; (5) access to expertise about supporting people with intellectual disability to participate; and (6) dealing with the difference dilemma.

These findings have implications for practice in supporting community groups to be better prepared for the participation of a person with intellectual disability, identifying the types of groups where participation is more likely to be successful, as well as how people with intellectual disability might be better prepared to participate in groups. The findings demonstrate too the utility of contact theory in this area of practice, and reflect some of the conditions it identifies as necessary for positive interactions between marginalised groups and others, particularly the importance of authority support, and opportunities that facilitate meaningful interaction, equal status, or foster cooperation. The extent and type of authority support enacted through the initial response from leaders set the scene for participants' entry into the group and guided group member attitudes toward them. Leaders' responses were fundamental in determining if participants entered the group as equal members or accompanied by anxiety and with conditions attached. These findings suggest that entry into community groups for people with intellectual disability is unlikely to be straightforward and may require skilled and lengthy negotiations and resources to comply with the conditions laid down.

To some extent, the response of group leaders may be predictable, as all the leaders in this study responded in a way that was consistent with the organisational context in which they operated. The men's shed, for example, was part of a community health structure that was funded to provide services for people with "chronic and complex care needs" and did so through a process of assessment and allocation to groups based on the type of disability and support needs. The structure and processes of this service worked in a way that supported the congregation of people with disability, and was contrary to the type of active community participation being pursued in this study. The idea that the best way to meet the needs of a person with a disability was offering a disability-specific program was also embedded in the organisational structure of the op shop. Its very purpose was to raise funds to provide for disability-specific services. In contrast, the parish church environment of the community kitchen with its clear agenda of the social inclusion of all people shaped the response of its leader to accept the participant with intellectual disability as an equal without specific conditions.

Being aware of the support or otherwise for social inclusion in the authority structures of organisations may be important for practitioners on the ground in

Downloaded by [Professor Christine Bigby] at 15:09 13 December 2014

deciding whether or not to seek the entry of a person with intellectual disability into a particular group. This type of knowledge suggests, however, that the inclusion agenda requires attention at the level of organisational policy and priorities in order to foster the type of authority support that will promote community participation. For example, armed with the knowledge from this study, prior to placing future volunteers in op shops run by this particular charity "selling" the concept of active participation to both the statewide volunteer coordinator and director of mission may well increase the likelihood of a more positive response by the local manager and the view that directly "supporting people like Matthew" to volunteer is part of their organisational mandate.

The proposition from contact theory that for positive outcomes contact should be over a sufficient period of time and be structured in a way that gives people the opportunity to get to know one another (Novak & Rogan, 2010; Pettigrew, Christ, Wagner, & Stellmacher, 2007) was reflected in these findings. These conditions existed in the two groups, the community kitchen and cooking group, where participants actively participated. They had regular members who worked alongside the person with intellectual disability and an integrating activity (meal preparation) that fostered an opportunity for contact that was frequent and structured for personal rapport. As previous research has shown (Antaki, 2012; Novak et al., 2011), structured tasks facilitate cooperation and increase the possibility of status equality. People with moderate impairment cannot depend on their conversational ability to participate in a group, whereas working alongside another person toward a shared goal creates the conditions in which frequent and personal interaction can occur. Such contact enables group members to move beyond stereotyping to the warmth and genuineness of responses that can happen when people get to know each other as unique individuals.

In the walking group, contact between Sol and other members only partially met the conditions suggested as necessary by contact theory for a positive outcome, due in part to the way the group was structured. Although it was a "walk and talk" group and had an integrating activity to ensure everyone had a walking companion, it was a casual "drop in" group. This meant Sol did not have the level of regular or consistent contact that was necessary for members to have the chance to get to know him as an individual. Despite Phil's attendance at the men's shed for over 6 months, there were no indications of a growth in positive attitudes toward him. This is possibly because the actual contact between him and the others mostly fitted the definition of casual contact or proximity (Makas, 1993; Pettigrew et al., 2007) rather than being of a personal nature.

Within disability research there have been inconsistent results about the relationship between contact and outcomes for people with intellectual disability, which can in part be explained by the inconsistency in the way contact has been conceptualised. In this study, contact was conceptualised in a way that was consistent with the original work of Allport (1954) and later researchers citing his work, and this study's results supported this body of work. The extent to which the favourable conditions were met was reflected in the level of participation achieved.

Tensions for community groups

In attempting to accommodate the needs of a person with intellectual disability in their group, leaders faced a tension between their own personal desire to help, beliefs about the rightness of inclusion, and the need to protect the purpose of the group. The op shop manager, for example, expressed a genuine desire to accommodate Matthew and was distressed at his decision to withdraw. But it was a money-making concern run on business principles, and there was pressure on the manager by virtue of her role in the organisation to ensure profit levels were maintained and her volunteer workforce kept happy.

The tensions that arose about responding to participant behaviours that were outside the comfort zone of community group members raises a question of how much can be expected of ordinary people. The cooking group members while quite assertive about aspects of Helen's behaviour such as staring appeared to ignore her dribble as being too difficult to confront or comment on. Members of the walking group did not want to go out with Sol for lunch after seeing his off-putting table manners but were unwilling to say this directly to him. There was a level of discomfort about provision of feedback regarding childish or inappropriate behaviours. Reasons for the lack of feedback appeared to vary from a desire to protect—"I don't want to hurt his feelings"—to embarrassment. (For further discussion about the reasons for inaccurate feedback, see companion paper Craig & Bigby, in press.) Despite the warmth and friendliness of most group members, there were some people who were uncomfortable or unwilling to have close contact with the person with intellectual disability. This is indicative of a measure of ambivalence in the feelings of some people in the community toward intellectual disability and their own responsibility for "welcoming the stranger" (Clegg, 2006). The ongoing social isolation

Downloaded by [Professor Christine Bigby] at 15:09 13 December 2014

of people with intellectual disability means that many people, particularly older generations, have not had the opportunities to become familiar with people who have this type and level of impairment, which puts another perspective on their ambivalence. Notably, it was members already familiar with people with intellectual disability who were the first to reach out to participants. One would expect over time, as people with intellectual disability become a more familiar sight in the community and in groups, a process of adaption would take effect, and their presence will be seen as normal.

Several groups approached as part of the process of locating a community group for participants expressed reluctance and did not become part of the study. Despite the differences in the levels of participation across the five groups in this research, they all represent "success" in the sense that leaders agreed to have a person with intellectual disability in the group and did want to see a successful outcome for participants.

Fostering support for inclusion within community groups

In addition to the policy implications for authority support discussed earlier, this study suggests a number of ways that group processes can be influenced to increase the possibility of participation. Contrary to the findings in the contact theory research that children in school fared better when their disability was de-emphasised (Maras & Brown, 2000), in this study it was immediately apparent that such an approach was not helpful. Both leaders and members, even the most welcoming ones, required information to help them understand intellectual disability and provide enabling support. Community groups also needed information to make an informed decision about whether they were able to include the person with intellectual disability. Basic information about intellectual disability would be enhanced by resources that clearly articulate how to enable engagement, similar to those about active support (e.g., Mansell, Beadle-Brown, Ashman, & Ockenden, 2004) developed specifically for staff in the disability sector. Currently, there are few such resources that discuss support outside the sphere of disability-specific services or are addressed to those who work or participate in the wider sectors of community life.

Unlike schools, where a paid teacher takes responsibility within a supportive policy environment, in community groups it is often ordinary members of the public who are asked to agree to a certain amount of disruption or to provide direct support to a person with intellectual disability. The value of recruiting and training group members as mentors was demonstrated in this study, and shown to be an effective way of promoting participation, replicating the findings of the companion research with people with mild intellectual disability (Bigby et al., 2014). Mentors and those who have had prior contact with intellectual disability are ideally placed to facilitate meaningful contact between the person with intellectual disability and other group members. In addition to training and information provided about the effects of impairment on social functioning, these findings suggest that strategies are needed to expedite a sense of responsibility for inclusion by all group members and to encourage provision of accurate feedback about troubling behaviour. The finding in this study that groups had a need for "manageability" suggests it is optimal that there is only one person with intellectual disability in any group.

In addition to identifying the extent to which a group is likely to be able to provide the ideal conditions for meaningful contact, identifying an integrating activity could be part of early planning with groups. Groups may have the potential to provide activities for the person with intellectual disability but ensuring their involvement requires additional forethought. As part of this planning process, consideration needs to be given to the adequate preparation of the person with intellectual disability. For example, the social or other relevant skills for that particular group can be identified, and the participant supported to rehearse or transfer them from other environments, such as home or a day program, prior to attendance. In the op shop, for example, part of the frustration of the volunteers was his childish behaviour and their experience of Matthew's inability to undertake even a simple task unsupervised. There were several jobs he could have done with other volunteers with some preparation.

Limitations

As with similar qualitative designs, this study has uncovered new concepts as the basis for further investigation and hypothesis for testing. The findings provide a snapshot of the groups in this study at the particular time that data were collected, and the findings are not representative of community groups in general. They also relate to a particular group of people with a moderate level of intellectual disability, who were able to communicate verbally, attend to their own personal care, and did not have challenging behaviours.

Downloaded by [Professor Christine Bigby] at 15:09 13 December 2014

Conclusion

The closure of large institutions led to an increased community presence of people with intellectual disability but not an increase in their level of community participation. This study has shown that participation for those with moderate levels of impairment is a very real possibility as long as community groups are given specialised support, information about intellectual disability, and efforts are made to foster a particular set of contact conditions. However, groups will always have a primary purpose of meeting the needs of their members, and inclusion is a balancing act between opening inclusive spaces for people with intellectual disability and respect for the conditions under which this can happen. This study's contribution has been to build on previous research, especially regarding the processes in community groups, and complex responses of community members to the presence of a participant with intellectual disability and moderate level of impairment.

Acknowledgements

The authors are grateful for the financial contribution of the Australian Research Council to this research.

Conflicts of interest: None.

Funding

This research was supported under the Australian Research Council's Linkage Projects scheme (Project number: LP0989241) and with the assistance of two industry partners. The views expressed herein are those of the authors and are not necessarily those of the Australian Research Council or the industry partners. No restrictions have been placed on free access to or publication of the research data.

Notes

1. The names of all participants, organisations, and individuals have been changed. Some details of organisations have been disguised in the interests of reducing identifiability.
2. Mentors were trained in the principles of person-centred active support (Mansell et al., 2004) and were used more extensively in the companion study of people with mild intellectual disability and community groups (Bigby et al., 2014). Because of the presence in this study of the first author as participant observer, training of mentors was not a formal process but one of providing contextually based interpretation of behaviours and provision of information, as the need arose.

References

Ager, A., Myers, F., Kerr, P., Myles, S., & Green, A. (2001). Moving home: Social integration for adults with intellectual disabilities resettling into community provision. *Journal of Applied Research in Intellectual Disabilities*, *14*, 392–400. doi:10.1046/j.1468-3148.2001.00082.x

Allport, G. W. (1954). *The nature of prejudice*. New York, NY: Addison-Wesley.

Amado, A. (2012, July). *Social inclusion and community participation of individuals with intellectual/developmental disabilities.* Paper presented at the State of the Science Conference, Halifax, Canada.

Antaki, C. (2012). Seven interactional benefits of physical tasks for people with intellectual disability. *Intellectual and Developmental Disabilities*, *50*, 311–321. doi:10.1352/1934-9556-50.4.311

Bigby, C., Clement, T., Mansell, J., & Beadle-Brown, J. (2009). 'It's pretty hard with our ones, they can't talk, the more able bodied can participate': Staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research*, *53*, 363–376. doi:10.1111/j.1365-2788.2009.01154.x

Bigby, C., Cooper, B., & Reid, K. (2012). *Making life good in the community: Measures of resident outcomes and staff perceptions of the move from an institution.* Melbourne, Australia: Department of Human Services.

Bigby, C., Wilson, N. J., Stancliffe, R. J., Balandin, S., Craig, D., & Gambin, N. (2014). An effective program design to support older workers with intellectual disability to participate individually in community groups. *Journal of Policy and Practice in Intellectual Disabilities*, *11*, 117–127. doi:10.1111/jppi.12080

Brewer, M. B., & Brown, R. J. (1998). Intergroup relations. In D. T. Gilbert, S. T. Fiske, & G. Lindzey (Eds.), *The handbook of social psychology* (4th ed., Vol. 2, pp. 554–594). New York, NY: McGraw-Hill.

Burton, M., & Kagan, C. (2006). Decoding *Valuing People*. *Disability & Society*, *21*, 299–313. doi:10.1080/09687590600679899

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London, UK: Sage.

Clegg, J. (2006). Understanding intellectually disabled clients in clinical psychology. In D. Goodley & R. Lawthom (Eds.), *Disability & psychology: Critical introductions & reflections* (pp. 123–140). Basingstoke, UK: Palgrave Macmillan.

Clement, T., & Bigby, C. (2009). Breaking out of a distinct social space: Reflections on supporting community participation for people with severe and profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *22*, 264–275. doi:10.1111/j.1468-3148.2008.00458.x

Craig, D. (2013). *"She's been involved in everything as far as I can see": Supporting the active participation of people with intellectual disabilities in community groups* (Unpublished doctoral dissertation). Bundoora, Australia: La Trobe University.

Craig, D., & Bigby, C. (in press). Critical realism in social work research: Examining participation of people with intellectual disability. *Australian Social Work*.

Fishbein, H. D. (2002). *Peer prejudice and discrimination: The origin of prejudice* (2nd ed.). Mahwah, NJ: Erlbaum.

Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J., … Wooff, D. (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual*

Downloaded by [Professor Christine Bigby] at 15:09 13 December 2014

Disabilities, *19*, 285–295. doi:10.1111/j.1468-3148.2006.00263.x

Golding, B., Brown, M., Foley, A., Harvey, J., & Gleeson, L. (2007). *Men's sheds in Australia: Learning through community contexts*. Adelaide, South Australia: National Centre for Vocational Education Research.

Griffin, T., & Balandin, S. (2004). Ethical research involving people with intellectual disabilities. In E. Emerson, C. Hatton, T. Thompson, & T. R. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities* (pp. 61–82). Chichester, England: Wiley.

Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential settings for people with intellectual disability: A systematic review. *American Journal on Intellectual and Developmental Disabilities*, *114*, 193–222. doi:10.1352/1944-7558-114.3.193

Makas, E. (1993). Getting in touch: The relationship between contact with and attitudes toward people with disabilities. In M. Nagler (Ed.), *Perspectives on disability* (2nd ed., pp. 121–136). Hamilton, Canada: Health Markets Research.

Mansell, J., Beadle-Brown, J., Ashman, B., & Ockenden, J. (2004). *Person centred active support: A multi-media training resource for staff to enable participation, inclusion and choice for people with learning disabilities*. Brighton, England: Pavilion.

Mansell, J., Beadle-Brown, J., & Bigby, C. (2013). Implementation of active support in Victoria, Australia: An exploratory study. *Journal of Intellectual & Developmental Disability*, *38*, 48–58. doi:10.3109/13668250.2012.753996

Maras, P., & Brown, R. (2000). Effects of different forms of school contact on children's attitudes toward disabled and non-disabled peers. *British Journal of Educational Psychology*, *70*, 337–351. doi:10.1348/000709900158164

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage.

Misan, G., & Sergeant, P. (2011). *Men's sheds: A strategy to improve men's health*. Retrieved from http://www.ruralhealth.org.au/10thNRHC/10thnrhc.ruralhealth.org.au/papers/docs/Misan_Gary_D7.pdf

Novak, J., Feyes, K. J., & Christensen, K. (2011). Application of intergroup contact theory to the integrated workplace: Setting the stage for inclusion. *Journal of Vocational Rehabilitation*, *35*, 211–226.

Novak, J. A., & Rogan, P. M. (2010). Social integration in employment settings: Application of intergroup contact theory. *Intellectual and Developmental Disabilities*, *48*, 31–51. doi:10.1352/1934-9556-48.1.31

Pettigrew, T. F., Christ, O., Wagner, U., & Stellmacher, J. (2007). Direct and indirect intergroup contact effects on prejudice: A normative interpretation. *International Journal of Intercultural Relations*, *31*, 411–425. doi:10.1016/j.ijintrel.2006.11.003

Pettigrew, T. F., & Tropp, L. R. (2006). A meta-analytic test of intergroup contact theory. *Journal of Personality and Social Psychology*, *90*, 751–783. doi:10.1037/0022-3514.90.5.751

QSR International. (2010). NVivo (Version 9) [Computer software]. Melbourne, Australia: QSR International Pty. Ltd.

Reinders, J. S. (2002). The good life for citizens with intellectual disability. *Journal of Intellectual Disability Research*, *46*, 1–5. doi:10.1046/j.1365-2788.2002.00386.x

Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., & Linehan, C. (2001). Social networks of people with mental retardation in residential settings. *Mental Retardation*, *39*, 201–214. doi:10.1352/0047-6765(2001)039<0201:SNOPWM>2.0.CO;2

Stainton, T. (2005). Empowerment and the architecture of rights based social policy. *Journal of Intellectual Disabilities*, *9*, 289–298. doi:10.1177/1744629505059266

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Verdonschot, M. M. L., de Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research*, *53*, 303–318. doi:10.1111/j.1365-2788.2008.01144.x

Walker, P. (1999). From community presence to sense of place: Community experiences of adults with developmental disabilities. *Journal of the Association for Persons with Severe Handicaps*, *24*, 23–32. doi:10.2511/rpsd.24.1.23

World Health Organization. (2001). *The international classification of functioning, disability and health*. Geneva, Switzerland: Author.