

From Social Exclusion to Supported Inclusion: Adults with Intellectual Disability Discuss Their Lived Experiences of a Structured Social Group

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Background People with intellectual disability often have few friends and experience social exclusion. Recognising this gap, supported social groups with the aim of inclusion and interdependence were created by a supported employment provider.

Methods Interviews were undertaken with 10 adults with intellectual disability exploring their lived experiences of a supported social group. Data were analysed using descriptive phenomenology.

Results Two themes emerged (i) *supported engagement fosters wellbeing*, and (ii) *developing social belonging and connectedness*. Participants not only acknowledged the

support that they needed to participate, but also that the social group had changed their lives in many ways.

Conclusions Adults with intellectual disability want to socialise, have friends and be part of their community. For this to be achieved, they recognise the need to seek some form of support. With appropriate and targeted support, adults with intellectual disability can move from social exclusion towards supported inclusion and experience richer lives.

Keywords: friends, intellectual disability, meaningful activities, relationships, social inclusion, targeted support

Introduction

Better understanding the effects of social exclusion on adults with intellectual disability is a high priority for the community in terms of the social, health and economic costs that result as a consequence of social exclusion. Social exclusion, loneliness and a lack of friends present many people with intellectual disability with a health and well-being triple jeopardy (McVilly *et al.* 2006a). Social inclusion can be described as not only being present in a community, but also having meaningful social connections and participating in fulfilling social activities (Cummins & Lau 2003; Hall 2005; Overmars-Marx *et al.* 2013). Participation in meaningful social activities has

been demonstrated to have a significant positive impact on loneliness for people with intellectual disability (e.g. Stancliffe *et al.* 2014; Wilson *et al.* 2015). Yet, many people with intellectual disability remain socially isolated, and hence lonely, as they require support to access social opportunities and face added physical barriers. One major barrier for people with intellectual disability to regularly access and socialize with friends has been noted to be a lack of travel skills (Department of Health, 2011). Although the association is not clear, Gilmore & Cuskelly (2014) suggested that the ramifications of loneliness and social exclusion could potentially contribute to the known mental and physical health inequalities that further exacerbate social exclusion.

Inclusion and health

Australian research using national population data has shown that compared to their non-disabled peers,

Note: A semicolon between quotations from participants indicates a different participant; phrases or words in [brackets] have been added by the research team.

young adults with a long-term disability experience entrenched and multiple disadvantage (Emerson *et al.* 2013). This includes being more likely to be unemployed long term, have mental health problems, lack a voice in their community and have fewer support Networks from friends. The seeds of lifelong disadvantage are sown early and are socially determined; adults with intellectual disability experience poorer physical and mental health, exercise less, have poorer diets and have more sedentary lifestyle behaviours compared to people without intellectual disability (Emerson & Hatton 2014; Lante *et al.* 2014). Further, rates of overweight and obesity, linked to diabetes, hypertension and cardiovascular disease, are high in people with intellectual disability (McGuire *et al.* 2007). The relationship between sedentary lifestyles, chronic illness and disability is unequivocal. Many of the determinants of chronic illness for people with intellectual disability are fully modifiable (Davis *et al.* 2014). The beneficial outcomes from a more physically active life include increased community participation, improved quality of life, increased social skills, better mental health and improved self-confidence. Although the importance of participation and inclusion to health and well-being is well known, people with intellectual disability are likely to need support in this area of life just as they need support in many other areas of life.

Research involving people with a physical disability demonstrates that by simply removing environmental barriers, participation in meaningful activities can be increased (e.g. Law *et al.* 2015). Yet, for people with intellectual disability, the barriers extend well beyond the environment and include support with planning, organizing, travel training, money, communication and support to participate in a given activity (Lante *et al.* 2014). Finding novel interventions to increase the activity, social inclusion, social contacts and friendships for people with intellectual disability is urgently needed. A recent audit of disability research in Australia found that much of the research simply describes problems and less is focussed on solutions to these problems (Centre for Disability Research and Policy, 2014).

Social networks and friendship

Friendship and interpersonal relationships are a normal and expected necessity of life; friendship provides companionship, assistance, emotional support and fosters self-esteem and well-being (Hartup & Stevens 1999). Unfortunately, adults with intellectual disability

have fewer social networks and less genuine friendships than those without intellectual disability, and often the networks and friendships that do exist are closely linked to family relationships, peers with similar disabilities and service providers (Gilmore & Cuskelly 2014). For people with more severe intellectual disability, they reportedly have even fewer social networks and friendships beyond families (Kamstra *et al.* 2015). Although families and support staff are not typically classified as genuine friendships, it remains important not to discount these relationships as vital pathways to social inclusion. In fact, research that asked adults with a mild-to-borderline intellectual disability about their social networks identified that they were not only satisfied with their social networks, which included family and professionals, but also found a significant association between the network characteristic of *affection* assigned to family and professionals, and self-rated quality of life (Van Asselt-Goverts *et al.* 2015).

Adults with intellectual disability working in supported open employment often live alone or with family and do not tend to access disability services other than a disability employment service (DES) whose sole funded focus is on work skills and employment outcomes. As a result, many people with intellectual disability remain segregated, isolated and lonely. Although an unquestioned right-based commitment to social inclusion has progressed disability policy and practice, many people with intellectual disability still face barriers to social inclusion (Van Asselt *et al.* 2015). Reinders (2002) argued that inclusion for people with disabilities relies more on their social networks rather than any declaration of their rights. Without well-developed and supported social networks, goals of inclusion for people with intellectual disability may remain elusive.

A number of studies have reported that people with intellectual disability feel that the development of intimate friendships was only ever likely to be with another person with intellectual disability (e.g. McVilly *et al.* 2006b; Gilmore & Cuskelly 2014). Suggested barriers to socially inclusive friendships for people with intellectual disability are perceptions of relationship equality and their experiences with being socially rebuffed and dominated by people without intellectual disability. Barriers to social inclusion also include social exposure to prejudice and feelings of stigmatisation, physical access barriers and personal factors such as a lack of confidence and mental health difficulties (Jahoda *et al.* 2010; Van Asselt *et al.* 2015). More specific physical

barriers include living too far away from friends, travel problems, lack of time, insufficient money, fear of going out, health problems and inadequate support (Emerson & Hatton 2014). Van Asselt *et al.* also stated that enablers of social inclusion were the *creation and development of friendships* through supported community participation, occupying valued social roles, community presence, social skill development, meaningful activities and choice. This involves finding ways to support activities and participation with other people so that friendships can form and flourish. As Reinders (2002) articulately states: '...the real challenge that people with intellectual disabilities pose for us (is) not so much what we can do for them but whether or not we want to be with them. Ultimately, it is not citizenship, but friendship that matters' (p. 5).

Defining social inclusion

Several authors have noted the lack of a clear definition for social inclusion and a range of widely used terms – such as inclusion, integration, community participation and community belonging – add to this lack of clarity (e.g. Amado *et al.* 2013). The problem is that without a clear definitional framework, the widely stated goal of social inclusion for people with intellectual disability cannot actually be measured and therefore influence research, policy and practice. Simpican *et al.* (2015) reviewed the seminal literature and presented a model of social inclusion based on two core domains: (i) interpersonal relationships and (ii) community participation. Using an ecological framework, each domain covers categories of relationships (e.g. family and friends) and participation (e.g. employment and religious), functions of relationships (e.g. emotional and instrumental), degree of community participation (e.g. presence and encounters), structures of relationships (e.g. length and reciprocity) and structures of participation (e.g. segregated and mainstream). It is noteworthy that this model does not *exclude* certain types of relationships, such as with paid staff or family, from being inclusive and nor does it *exclude* certain activities that may be perceived as being segregated and, therefore, not inclusive. As they rightly argue: social inclusion is for everyone – individuals with intellectual disability, people with intellectual disability as a group and members of society who benefit from the participation and inclusion of others *regardless* of ability. This ecological framework is based on the premise that an increase in one domain will lead to the strengthening of the other: more community participation = strengthened social networks; stronger

interpersonal relationships = increased access to and involvement in the community.

What the literature does lack, however, is the voice of people with intellectual disability who, with support, have started to counter social exclusion, have friends and participate in society. Current research tends to focus on describing the myriad of problems related to social inclusion, rather than on the narratives of people who have benefited from a social intervention. This study seeks to fill that gap in our knowledge. Anecdotal narratives from members of a supported social group suggested that for many of them, the social group had positively changed their lives in different ways. Capturing these socially inclusive narratives from people with intellectual disability is vital to form the basis of future social interventions to support the social connections and relationships of people with intellectual disability. Our aim was to explore and better understand the lived experiences of adults with intellectual disability who were members of the structured social group.

Method

Research design and overview of the study

As we wanted to explore and understand the lived experience of adults with intellectual disability, we used a descriptive phenomenological approach (Patton 2002). We conducted individual semi-structured interviews with adults with intellectual disability who were members of the social group. Interview questions were based on the following broad topics: (i) demographic data, (ii) social life before joining the social group, (iii) experiences when first joining the social group, (iv) experiences at the social group, (v) whether the social group had impacted their lives in any significant way and (vi) the views of significant others about their involvement in the social group.

Ethics and consent

Ethical approval was sought and gained from the Human Research Ethics Committees of The University of Western Sydney (Approval ID: H10901). All participants gave informed written consent to participate in an interview. Prior to each interview, participants gave verbal consent for the interview to be recorded using a digital voice recorder. One participant did not wish for the interview to be recorded, thus written notes and key quotes were taken as the interview progressed.

The social group

The social group in this study was specifically formed to provide an opportunity for DES clients from different areas of Sydney to connect socially with each other. Initially prompted by concerns from DES staff regarding the limited social networks of some of their clients, an unpublished study was undertaken, interviewing clients regarding the barriers they were experiencing in participating in mainstream and disability-specific social groups. Many said they did not want to go to a disability group, but were interested in meeting other DES clients or 'people like me'. Limitations in independent travel, especially at night, were a barrier to socializing with friends or work colleagues. Other barriers identified were as follows: did not want to be committed to regular activities such as sporting activities, not knowing anyone at an activity and having 'no one to go with'. Some people participating in mainstream sports or other activities as well as work activities identified that it was difficult to meet potential partners and that this was one of their aspirations.

As the DES programme not being funded to provide social/recreational activities, the group was established through DES staff members volunteering to coordinate monthly activities on weekends. The aim of the group was for members to develop friendships as well as the skills and confidence to move about the community that would enable them to undertake independent activities outside of the social group. There were no age restrictions on group membership, rather the group was based on people having shared interests and the need for an expanded social network. Therefore, some members of the group were significantly older than others, but this did not detract from the core focus of the group and the exclusion of older members would be discriminatory. As noted by Simplican *et al.* (2015), social inclusion is for everyone. After approximately 5 years, increased membership in the group and interest from people with higher support needs prompted the group to become a part of an existing recreational service.

Role of the coordinator

The coordinator arranged the schedule of activities in conjunction with group members, planning activities that once practiced, could be replicated by more independent participants in small groups of 2–4 group members without the coordinator present. The activities included a mixture of popular and recurring activities such as going to the movies or ten-pin bowling and

activities that may be a new experience for many such as seeing a local live band at a pub. Activities were always held in daylight hours, as the perception that public transport is unsafe at night means night activities would unlikely be replicated independently. Group members typically lived with family and traveled by car when going out, so had limited experience in using public transport beyond the specific routes they were trained to use (e.g. to commute to work or go to their local shopping centre). The social group met at the same meeting point at a transport hub each outing and public transport was used to travel to the activity, thereby providing group travel training to new destinations. The coordinator provided a written schedule of activities and additional support such as text message or phone call reminders where needed.

During activities, the coordinator kept in the background as much as possible, stepping in to provide practical assistance to individuals or the group only when necessary. Strategies used to facilitate independence and decrease reliance on the coordinator include selecting restaurants or cafés where customers order and pay at the counter rather than those where it is necessary to split the bill, and having each person individually pay for their own entry tickets for activities rather than the coordinator collecting money and paying as a group. The coordinator acted to build connections and potential friendships between people, especially new members by prompting conversations about shared interests. While the coordinator would step in to provide guidance if an individual's behaviour was seen as inappropriate to the setting, the social expectations were typically modelled and where necessary explained by other group members. The coordinator described an example of this where one group member who regularly told fanciful stories about his social life was quietly approached by two other group members who explained to him that they liked him, but found it annoying that he told stories about himself that were not true. Following this conversation, the stories stopped not only at the social group outings but also stopped at work, improving his relationship with his colleagues.

Participants

Seven men and three women with intellectual disability aged between 19 and 48 who were members of the social group were recruited using a purposive sampling method to ensure variation in participants' ages, gender and length of time as a member (Patton 2002). All

participants had moderate intellectual disability (the supported employment agency's inclusion criteria), sound-expressive and sound-receptive communication skills, were fully mobile and had the capacity to learn how to travel on public transport around Sydney. Three of the authors attended one of the social group outings and gave a brief overview of the research project, what participation involved, and handed out the modified information sheets, consent forms and contact details to each social group member present. Information sheets and consent forms were all adapted into plain English with the use of symbols (e.g. voice recorder symbol) and photographs of the researchers to help explain difficult concepts such as how we would maintain privacy and confidentiality. Members of the social group who were interested in participating made contact with either the first or fourth author. The mean age of participants was 28.6 with a median age of 24 years. Nine worked part-time in open employment working an average of 20.5 h per week; the tenth and youngest participant was enrolled in a transition-to-work programme. Nine of the 10 participants lived at home with family, and only two participants were in an intimate relationship. The oldest participant (48 years) was 14 years older than the second oldest participant (34 years); although this may appear to be a significant and atypical age gap, the purpose of the social group was concerned about common interests and social contacts for adults without any age restriction.

Procedure

Interviews lasted between 30 and 45 min and were conducted at a time and location convenient to participants. Most interviews were held in the participant's home provided there was another person present in the home ($n = 6$). Where this was not possible, the remainder of the interviews were conducted in a private setting within a public location (e.g. library or café). At a number of the interviews conducted in the family home, a parent either sat with the participant ($n = 3$) at the participants request or was in a nearby room in the house ($n = 3$). All interviews were conducted by the first or second author; where the second author – an undergraduate student – conducted interviews, the first author was always present to provide interviewing technique support to that author. As neither interviewer had any prior involvement with the social group or the DES provider and thus were relatively unknown to participants, participants were more likely to be candid about their experiences.

Data analysis

All interviews were transcribed verbatim by the second author. Interview data were analysed using the approach to descriptive phenomenology described by Colaizzi (1978). Using this staged approach to analysis, *significant statements* are first drawn from transcripts and recorded separately to the transcript with a clear audit trail back to the transcript by stating transcript, page and line numbers. Following this, each statement is given a *formulated meaning* which is then sorted into *categories*, *clusters of themes* and finally themes. The first stages of data analysis were conducted by the first three authors with emergent themes discussed between all authors; the whole research team contributed to the final development of core themes. To ensure validation of themes and to compare the researchers' descriptions with participants' experiences, the second and fourth authors presented the findings back to the participants at a social group outing at a local park during September, 2015. Trustworthiness was enhanced by the clear audit trail during analysis, theoretical triangulation of the authors (nursing, social science, occupational therapy, public health and paramedic) and member checking (Krefting 1990). Final data analysis yielded 290 significant statements and 290 formulated meanings which were sorted into 16 categories, four theme clusters and finally two core themes; Table 1 illustrates the final thematic map with pertinent examples from the 290 formulated meanings. To ensure participant confidentiality, all participants' names were replaced with a pseudonym.

Findings

Our two core themes from this research were as follows: (i) *supported engagement fosters wellbeing* and (ii) *developing social belonging and connectedness*. These themes conceptualize the story of a group of adults with intellectual disability whom, before the social group '... would just sit at home and do nothing' (Grace) yet now participate in an array of community activities where '...I met new friends, met a girl, and just socialising with people ... my age ... and I can talk about things that I want to talk about' (David). The two theme clusters that relate to the first core theme are as follows: (i) socialization improves health and wellbeing and (ii) social engagement expands circle of friends; the two theme clusters that relate to the second core theme are as follows: (i) a diverse support system helps connect socially and (ii) psychosocial

Table 1 Final Thematic Map – core themes, clusters, categories and examples of formulated meanings

THEME: Supported engagement fosters wellbeing	THEME: Developing social belonging and connectedness
<i>Theme clusters</i> Categories Examples of formulated meanings A. Socialization improves health and wellbeing Sedentary lifestyle is common without social network Without social activities, sedentary activities are typical Without social group, I'd stay at home Positive lifestyle change Social group has changed life positively Recognizes that friendship changes lives Enjoyment and excitement brings happiness Enjoys meeting with the group and anticipates future outings Remembers excitement at hearing of a social group Supported social activities increases physical activity and participation Social group is about meeting people and beats sitting at home Social outings also mean getting out and being physically active B. Social engagement expands circle of friends Social group has increased social circle The social group has led to new friends and social opportunities Social group has increased social circle Social interactions and friendships most important Spending time with friends at the social group is the best thing Friends are the most important feature of group, regardless of activity Increased social maturity has led to new and independent social networks Social group spawned a separate, smaller group Has been able to develop own social network	<i>Theme clusters</i> Categories Examples of formulated meanings A. A diverse support system helps connect socially Socialization is difficult when a support network is lost or absent Without the social group, social isolation remains Maintaining friendships without support is hard Regular social activities are either with family or done alone Without Mum's hobbies, I'd stay at home Social activity was mainly with family otherwise alone Logistical support Outings are good; organizing is done for us Relies on communication from group leader Parents support and value the social group Parents are happy that new friends are being made Parents notice the enjoyment the group brings Functional skills facilitate participation Has some pre-existing train and bus travel skills Communication skills makes participation easier B. Psychosocial connection develops a sense of belonging Increased confidence and competence Talking to others is easier now Social group has changed social confidence Doing something for the first time can be difficult Needed encouragement to go to first group outing Shyness at first, but got easier over time Group dynamics can create conflict Conflict within the group strained other social connections Sometimes different personalities make it difficult Awareness of personal barriers Health problems impact on social activities and participation It's a shame to miss a group, but work sometimes comes first

connection develops a sense of belonging. Together, these are the factors that, from the perspective of the participants, conceptualize their lived experiences of the social group. The participants were fully aware of and acknowledged the types and amount of support

that they required and that without the supported structure of the social group, they would likely revert to sedentary lifestyles on their days off from work. Moreover, the participants are clear that their inclusion and participation in the social group has positively

changed their life in many ways, but most of all that they now have a significantly greater number of people that they can call their *friends*.

Supported engagement fosters wellbeing

Socialization improves health and wellbeing

The social group offered participants' socialization opportunities that promoted escape from a largely sedentary lifestyle towards a healthier, active and fulfilling life. For example, before the social group, Jack stated that he would 'sleep a lot, cos I was bored and all I can do is sleep and sleep and sleep... just wasting my life'. Sitting at home watching TV was a common response when asked about the type of activities performed before the social group: (Frank) 'I just did nothing, sit at home doing nothing ... just watch TV... watching DVDs'; (Brad) 'I would just stay at home ... I'd be at home playing my Play Station 4'. When participants did report getting involved in activities from home, it was usually always with family and was associated with the hobbies and interests of parents. For example, David goes to the football with his family: 'well mainly going to the football ... my dad goes and ... my brother Kieran, sometimes mum goes, a family day out ... but I don't really do anything by myself', and Andrew attends his mother's hockey club: 'I go to hockey with mum ... mum plays hockey ... so I go there with mum and I enjoy that'. Other activities included socializing with extended family for birthdays and other celebrations, for example: 'we [family] sometimes go on picnics or if it's someone's birthday we would either go to their place ... but if we didn't have anything planned I would just sit at home and do nothing' (Grace).

The type and range of supported activities were reportedly vast, and participants noted not only the enjoyment of activities and the increase in their physical activity, but also some of the effect that it had on their well-being: 'And now, now that I'm out, I've gained a few pounds... I feel more better as a person... I'm just more healthier' (Jack). Activities included visiting fun fairs, annual festivals, the beach, the cinema, the aquarium, museums and points of interest within and around Sydney. For example, Andrew stated that they 'get to go to Luna Park [fun fair]... so they're things I just don't have the confidence to do by myself, I wouldn't be able to'. Brad gave an overview of many places they had been with the social group: 'we go to Bondi... Central Coast... all over the place ... the Art

Gallery'. Chris also talked about other trips where they meet at a park and play some sport: 'we travel on the train ... and go to a picnic in the park, and we take part in events like softball'. Participants were also able to compare the social group activities with their previous sedentary lifestyles:

I really like it cos it's more going out and you're more, you're not at home bored out of your skull in a way, you're sort of more out talking to people, get to know 'em, get to know 'em a bit better and then you're sort of more doing things... one week it could be the movies, next week it could be a lunch, the following week it could be something different, sort of mix it up a bit ... better to do something out there and then what is to be inside (Frank)

Social engagement expands circle of friends

Participation in the social group led to an increase in the size of all participants' social networks: '...you're constantly meeting new people from each group ... it's just a nice day out spending time with people, getting to know other people ... meeting new people... I just wanted to start getting to know other people' (Grace). That is, while the activities were fun, it was more about the friends: 'the activity [is good], but the friends you meet along the way [were more important]' (Helen). Many participants also mentioned reconnecting with old school friends whom they had not seen for some time: 'One person I haven't seen for over a whole year, I meet them there' (Brad); 'I've made some new connections that I had from the past' (Grace); 'and I actually know one ... ones in the social group that I used to go to primary school with' (David).

All participants spoke about the most important feature of the social group: that you 'get to meet a lot of people' (Chris), that 'the friends you make ... you can lean on them' (Brad), having friends meant that you are 'learning from other people' (Helen) and 'just hang out and ah, get to have friends' (Ian). Some participants also spoke about having things in common with friends such as age: 'Hang with people my age ... I don't get the social life with people my age ... that's the good thing about the social group' (David). A small number of participants also spoke about having a disability in common, for example: 'See other people with different ... like similar disabilities' (Grace).

From this expanding circle of friends and with increased social and travel skills, some participants have now interacted socially outside a supported social network, something that most had never previously thought possible. For example, Brad now has a small group of friends who meet up independently to go bowling: 'I go bowling, I catch up with my friends I made through this outing [social group] thing ... I catch up with them once a month ... at [the] bowling alley'. Another group of participants met independently at a local club for dinner one evening after Helen initiated the first phone call: '[a] few of us went down the workers and went down for dinner ... [a] few people from social group, we all decided to do that at night... it was [my] first time' (Eddie). 'Ah, I've got, I've got some people from [the social] group, their [phone] numbers ... we just hand each other our numbers. They hand me their phone number and I hand them my number' (Ian). When reflecting on this dinner, Ian stated: 'Yea it was good, [I] haven't done anything like that before, that was the first time'.

Developing social belonging and connectedness

A diverse support system helps connect socially

It became evident that many of the participants wished to connect and belong socially, but often lacked the functional skills to bring this about independently therefore needing targeted support and assistance: for many, they needed significant support for their first encounter with the group: '[the paid group leader] takes me out first...' (Chris);

when I went to the first outing ... my mum came with me cos it was up in the city ... I don't really like cities that much ... mum came with me ... to learn new things because it's ... trains are very hard to go around (Frank)

Other logistical support that facilitated participation in the social group included detailed planning and budgeting: 'last year I wasn't gonna go in the camp cos of money ... then [the paid group leader] organized everything ... and ... I could pay it off' (David). For many participants while they had a printed calendar of forthcoming events, many did not use the calendar: 'No, it's on my calendar... I think it's in ... I'm not quite sure yet ... [the paid group leader] gives a ring and lets us know' (Chris). What did become apparent was that one central skill that all participants possessed was how

to use a phone with text messages and phone calls central to the organizing of an outing: 'Cos I gotta ring up [the paid group leader] ... find out when the next one's on ... she usually sends me a message to let me know ... the day before, she usually sends me a message to let me know' (Eddie);

Usually [the paid group leader] is the one that, that's usually looking after all of us... tell me where it is and I tell her when I'm going ... she'll either call me or text, text me... [but] if I don't get it then I wouldn't know (Ian)

Other key skills included sound travel training skills and a good knowledge of the often complex Sydney train network: 'I get the train from Glenfield...I get a train from Glenfield to Liverpool and back the same way ... by the train' (Eddie); 'we meet the Campbelltown people at Campbelltown, and then meet the rest of 'em at Liverpool or Bankstown' (David). Many participants had learnt their travel skills either in school, in a transition-to-employment programme with the DES provider or from parents: 'my mum's very good at travel training me. ... yea, so I travel all by myself' (Jack).

Psychosocial connection develops a sense of belonging

For many participants, they were shy at first when joining the group, but as time has worn on, they are now better at connecting socially through increased social confidence and competence and experience a sense of belonging: 'Yep ... the confidence is there... meeting new people, talking to them... travel by myself, more confident with that [too]' (Helen);

I mean the first time I didn't really know anyone ... that was hard ... but once I got to know 'em ... once I got to speak to 'em and that, we all seem to click ... shy, I was at first, it was just something new ... after a while, I've just gotten used to it (David)

Basically you don't know what to do [at first] ... you're in a new environment, you're in a sort of new area, you don't know if you're gonna get lost or anything else like that, so you just sort of get your head ... try to get your head around it... try to get used to it (Frank)

For one participant, he was able to reflect upon a key transition in his life and how this triggered his involvement in the social group and greater feelings of independence:

Bit shy, but I got talkative ... since the passing of mum... I'm always on my own... so I've got to come out of my shell... and associating with people again... [the social group has helped] make me feel more independent (Chris)

One participant also talked about how he derived a sense of satisfaction from helping other group members while on social group outings: '[the social group] brings out some of my personality ... I'm very caring ... so [the paid group leader] knows that I help, and I actually enjoy that cos I get to help my other team'. Participants were also self-aware of and acknowledged that group dynamics play a role in feeling connected and belonging to the group, but it did not hinder their involvement even when the group dynamic becomes difficult: 'one of my friends who actually have a boyfriend and ... it's a bit stressful... argument and all that type of stuff... and I hate being the third wheel' (Jack); 'one guy there and ... very immature ... I'm going to have to put up with him' (Andrew); 'If you get idiots in the group, you know it'd be different' (Frank).

Discussion

The qualitative findings generated from this study give us a better understanding of how both being and feeling socially included can have a vital and positive impact on the lives of people with intellectual disability. For the young adults, the supported social group countered loneliness, expanded the circle of people they could call friends, extended their social life beyond the family and gave them a sense of greater well-being. Most importantly, the social group reversed what appeared to be a largely sedentary and isolated life leading to greater social participation and physical activity. Although the supported social group might be referred to as 'segregated' given the core characteristic members had in common was intellectual disability, none of the participants discussed feelings of stigmatisation or a lack of social acceptance while engaging in activities within the community. By contrast, the participants derived a sense of connectedness through their shared experiences, identity and lives. These findings both confirm and affirm that the stated goals of the social group have, to a large extent, been achieved.

One of the key facilitators of participation in the social group was the presence of travel and other functional skills needed for independent community participation. These included, but were not limited to, train and bus travel skills, use of a mobile phone,

money skills, awareness of time, some problem-solving skills and communication skills. Critically, any limitation – slight or otherwise – in these skills was countered by the intervention of the paid social group coordinator. For example, participants talked about reminders of forthcoming social group outings via text and phone messages and of being taught travel routes by the paid coordinator. Although independent bus and train travel may not be possible for all people with intellectual disability, for many it is achievable with the right kind of training (e.g. Haveman *et al.* 2013) such as that offered by the paid social group coordinator. Participation in the social group provides regular opportunities to practice and further develop the skills relevant to independent participation in community leisure activities such as the use of public transport, purchasing entry tickets, ordering and paying for snacks/meals and negotiating decisions with others.

The value of using natural settings for providing training in functional skills for people with intellectual disability has been demonstrated in the acquisition of community living skills (e.g. Michie *et al.* 1998; Thorn *et al.* 2009) and in the successful transition from school to employment (e.g. Nazarov *et al.* 2012). In these interviews, participants spoke of increased confidence in using public transport and talking to others. For some, this has led to going out on their own with friends and without the support of family or paid support staff for the first time. A common feature of the participants' social lives was the extent and nature of lost friendships after high school had finished. Unlike the supported social group, once a young adult leaves school, there is no support mechanism beyond family – such as how to phone a friend and how to plan and travel to a meeting place at an agreed time – to underpin the functional skills required to maintain friendships over time. The specific strategies used by the paid coordinator have not been explored in this study, but the paid coordinator's background training in implementing applied behaviour analysis through the DES service may have contributed to the skills development described by participants.

What the supported social group offered participants was a functional structure to underpin the development of new friendships and counter loneliness. This structure gives the message to people with intellectual disability that their relationships are valued and important which is important for individual identity and to reverse feelings of powerlessness and limited agency (Sullivan *et al.* 2015). That is, the social group acts to both *create* and *develop* friendships and make the possibility of more intimate relationships more likely. A

supported social network is critical to the feeling and experience of social inclusion (Van Asselt-Goverts *et al.* 2015). In addition to the forming of interpersonal relationships, the social group also fostered physical activity and community participation. At an individual level, physical activity and community participation are critical to counter the social determinants of poor health (e.g. Emerson *et al.* 2013; Lante *et al.* 2014). Moving beyond the individual benefit to a more conceptual view, the supported social group mirrors Simpican *et al.*'s (2015) ecological model of social inclusion where the combination of interpersonal relationships and community participation coexist. That is, social inclusion is about all types of interpersonal relationships such as family, staff and friends that mutually support all types of community participation whether segregated or not. Most interesting was that despite the segregated membership of the supported social group, no participant mentioned anything about feeling stigmatized (e.g. Jahoda *et al.* 2010) as a result of their individual and shared identity as a person with intellectual disability.

Although the participants shared a common positive view of the social group and valued the friendships formed, most participants still talked about and relied upon family for other regular forms of social contact, community participation and for helping to organize participation in the social group. The importance of family relationships echo other research where regular contact with family members was important to individuals with intellectual disability (e.g. Van Asselt-Goverts *et al.* 2015) and greater involvement of family increased community participation (e.g. Amado *et al.* 2013). As might be expected, the more severe the degree of intellectual disability, the more critical family become as a social contact for people with intellectual disability (e.g. Kamstra *et al.* 2015). This is important as other research suggests that important aspects of close relationships for people with intellectual disability are about them 'feeling safe', having a 'secure base' and 'functional usefulness' in a relationship (e.g. Sullivan *et al.* 2016). Many supportive families provide this, and as our findings show, these characteristics underpin participation in the social group where friendships and other more intimate relationships have a chance of forming.

Limitations

It is possible that the adults with intellectual disability who agreed to participate in the study were those with

overly positive views about the social group as we did not hear any narratives that reported negative experiences. Further, as the social group evolved from the one DES provider based in Sydney, it is likely that the experiences may not reflect those of all people with intellectual disability who are part of a similarly structured group around Australia. In addition, the study participants all lived and were socialized to metropolitan Sydney, and so, it is not possible to generalize their experiences to people with intellectual disability who live in regional and remote parts of Australia. Although most of the participants identified their gender as male ($n = 7$) and the remainder as female ($n = 3$), we are unclear whether the interviewer's gender may have influenced participant recruitment and the recount of the narrative. More than likely, however, this simply reflects the larger number of men and boys living with intellectual disability and so is relatively reflective of the total population of people with intellectual disability.

The conduct of this study was limited by time constraints due to the study funding requirements. Increased time would enable triangulation of data through, for example, naturalistic observations at social group outings and the collection of more descriptive data using standardized measures to give a more detailed picture of participant demographics (e.g. social networks, loneliness and adaptive behaviour). In addition, the selection and use of appropriate outcome measures could be used in future; however, this would rely upon the collection of baseline data each time a new participant joined the group and would likely take some time to yield a suitable sample size for statistical power. Finally, narratives from family members about the impact of the social group on the lives of the adult with intellectual disability and the family unit would prove insightful.

Conclusion

This study illustrates that when individuals with intellectual disability are provided social support, they feel engaged and connected and can develop a sense of social belonging. These outcomes promote better health and well-being that minimizes the stigma, segregation and isolation often experienced by those with intellectual disability (e.g. Jahoda *et al.* 2010). Critical factors that underpinned participation in the social group was support and encouragement from family, a range of functional skills for community participation, the presence and regular contact from a paid

coordinator and a sense of belonging within the social group. The development of an individual's social network through a supported social group promotes social inclusion and community participation. With the creation of individualized supports in Australia in the form of a National Disability Insurance Scheme (NDIS), people with intellectual disability will need a range of support services that can promote social participation and inclusion. Understanding the lived experience of this group of adults has helped identify the types of interventions required to underpin future social programmes that can be purchased under the NDIS.

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Declaration of Interest

Michelle Brotherton voluntarily set up the inaugural social group about 5 years ago, but is no longer involved in the running of the social groups and thus had not met most of the current members of the social groups.

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