

The barriers to social inclusion as perceived by people with intellectual disabilities

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Abstract Very little research has been done on social inclusion from the perspective of people with intellectual disabilities, including perceived barriers and remedies. Focus groups were held with 68 persons, mostly tenants in supported living or shared group homes. Qualitative data were obtained using a mix of workshop activities and small group discussions. Four main barriers were identified: lack of necessary knowledge and skills; role of support staff and service managers; location of house; and community factors such as lack of amenities and attitudes. Participants were able to identify a range of solutions for these barriers. Most of their proposals were in line with the aims of current government policy and good practice. These findings reinforce the contribution individuals could make to the planning of local services for themselves and others. This advocacy has been an essential element in reducing the social isolation of other marginalized groups.

Keywords intellectual disability; learning disability; residential accommodation; social inclusion; supported living

Introduction

'Inclusion' is one of the four key principles laid out in UK government policy for future service provision for people with an intellectual disability (Department of Health, 2001). Social inclusion has been largely defined in the field of disability as greater participation in community-based activities and a broader social network, although in wider society it also embraces other dimensions such as acting as consumers of goods and services or participation in economic and socially valued activities, such as employment and child-rearing (Burchardt et al., 2002).

There is extensive evidence for the social exclusion of people with disabilities in general (Oliver and Barnes, 1998) as well as those with intellectual disabilities in particular (Myers et al., 1998). Social models of disability tend to emphasize the contribution of specialist services to this exclusion, which was particularly evident during the era of the long-stay hospitals. Even so, it has become apparent that physical presence within a community does not guarantee greater social inclusion. Taking part in activities, and using local facilities, does not necessarily lead to meaningful social contact with others, particularly the non-disabled population (Ager et al., 2001).

Nonetheless, *Valuing People* acknowledged that housing can be the key to achieving social inclusion, but noted that the number of people supported to live independently in the community remains small (Department of Health, 2001). Indeed various research studies have identified marked variations in residents' social networks and community engagement across supported living arrangements, group homes and campus-style settings (e.g. Emerson et al., 2000; McConkey et al., 2006).

Equally a growing number of studies have documented the desire of people with intellectual disabilities to engage in more community activities (e.g. O'Rourke et al., 2004) and to have more friends (e.g. Froese et al., 1999). These goals are often mentioned in person-centred plans, although the attainment of these personal outcomes can be variable across services and individuals (Gardner and Carran, 2005).

However, the voice of the person with intellectual disability has often been missing from debates as to how greater social inclusion can become a reality for them. Other marginalized groups have used advocacy to achieve greater recognition of the discrimination they face and to create changes in society (Bersani, 1998). A basic requirement is for advocates to have an insight into the factors that contribute to their exclusion and strategies that can bring about change. However, people with intellectual disabilities are often dependent on others to make these strategic analyses, which may be one of the reasons why their social exclusion continues even though there have been major shifts in service delivery and policy to increase their community presence. For example, Bowes and Dar (2000) argue that the user voice is essential in getting a new perspective on services as well as developing more appropriate provision.

Valuing People sets the objective of enabling people with learning disabilities and their families 'to have greater choice and control over where and how they live' (Department of Health, 2001, p. 70, emphasis added). A number of recent studies have investigated people's choice of where they may live, which in the main tends to be in ordinary homes with family or friends, and close to local amenities (McConkey et al., 2004; McGlaughlin

et al., 2004). However, less attention has been paid as to how they live their lives, especially with respect to social inclusion.

The present study aimed to gain an insight into how people with intellectual disabilities who lived mainly in supported housing perceived the barriers to their social inclusion and the ways these barriers could be lessened or removed. This information would serve a number of uses. It would help to support greater advocacy by these service users at both an individual and a group level. It would also challenge service managers and support staff to review the strategies they use – or fail to use – in order to create greater social inclusion for their tenants and residents.

Method

Participants

Participants from a range of supported living schemes and some residential homes across Northern Ireland were invited to one of six focus groups with between 10 and 20 people attending each one. All 68 attendees were self-selected as invitations were issued to the service who sought volunteers to attend the groups. There were 16 different service providers involved, including seven of the 11 health and social services trusts in Northern Ireland, five voluntary organizations, two housing associations and two private providers. In all 30 individual homes and schemes were represented in the sample; 37 (55 percent) participants were tenants in clustered or dispersed supported living schemes, 24 (36 percent) lived as tenants in group homes and 6 (9 percent) were residents of registered residential homes.

In total, 45 women (66 percent) and 23 men (34 percent) participated, aged between 21 and 82 years, with a mean age of 46 years. Prior to their current living arrangements, 22 (32 percent) had lived within their family, 19 (28 percent) had lived with a different service provider, 17 (25 percent) had been with the same service provider but in a different home/scheme, five (8 percent) had been in a long-stay learning disability hospital, one (1 percent) had been in foster care, and one (1 percent) had been in her own housing executive flat. Prior living arrangements were unknown for three (5 percent) participants. Seven (10 percent) of the participants had paid work up to four days a week, and 13 (19 percent) had a voluntary work placement up to four days a week. There were 24 (35 percent) participants who attend a day centre every day of the week and three (5 percent) who attended a further education college; a further nine (13 percent) did not attend any of the above, and had home-based activities or day care every day. Most were able to communicate verbally, with only two (3 percent) participants who communicated through staff – one with the use of a Lightwriter.

Information gathering

A focus group methodology was chosen as the dynamics of groups provides opportunities for peer support and validation of common experiences (Cambridge and McCarthy, 2001). Also it had proved successful in a previous study with a similar sample of participants (Barr et al., 2003).

All groups were held in community venues, except one which was held in a meeting hall attached to one of the housing schemes. The same agenda was followed each time. The same facilitator was present for all groups, with assistance provided by four staff from independent advocacy groups and by support workers who had accompanied the participants. The latter proved helpful in facilitating communication.

The first session started with an explanation of what would happen in the group; the confidential nature of what was said; and that participants could withdraw at any time without giving a reason. People had the option of leaving at this point but no one did so. Signed consent was obtained from each participant, and confidentiality and anonymity were emphasized for everyone present.

The group began with everyone introducing themselves and, as an 'ice-breaker', describing something 'nice' that had happened for them during the previous week. Responses were encouraged and prompted by the facilitator. The idea of 'social inclusion' was then introduced by showing photographs of people with and without learning disabilities in different community locations, such as at the swimming pool, shopping and having coffee with friends. The participants, as a group, were encouraged to describe the photographs and relate them to their own experiences.

They were then divided into small groups of four or five, and with the help of support staff they were asked to complete a worksheet called 'A day in my life'. They listed the different activities they did, who they were done with, and the transport they used. Examples of activities from the worksheets were transcribed onto a flipchart by the facilitator as each group reported back their contributions, and the individual sheets were also collected for further analysis.

Together as a group, an interactive discussion was facilitated based around the following questions and the answers were recorded on a flipchart by the facilitator:

- What activities do you enjoy doing or would like to do near where you live? Why is this?
- What helps you to get involved in these activities?
- How can the staff and the service manager help you more?

The second part of the focus groups involved four or five participants discussing a series of questions about what stopped them from doing

community activities and the solutions that might overcome these barriers. Again feedback was given to the whole group and comments were recorded on a flipchart. Throughout the facilitator repeated the contributions made and checked with the group if they had anything further to add.

The focus groups lasted between 4 and 5 hours, with breaks for refreshments and lunch. Participants were given contact details for the facilitator in case they had any queries or comments. A newsletter summarizing the main findings was circulated to all participants in the project.

Findings

The information from each of the focus groups was transcribed into an MS Word document, including the comments recorded both on the flipchart and on the individual worksheets. These were then analysed using 'latent content analysis'. This is 'the process of identifying, coding, and categorizing the primary patterns in the data' (Patton, 1990, p. 22). This was done in terms of what social inclusion meant to the participants, together with the barriers they experienced and how they might be overcome. The subthemes within each overarching theme were confirmed by an experienced colleague who had been uninvolved with the data gathering. Illustrative quotations drawn from different people are reported for each. After the fifth focus group, no new themes emerged, which suggests that data saturation had been achieved (Mays and Pope, 1999).

Social inclusion

Four main themes were apparent in participants' discussions and reflections on the experiences of being present in community settings:

- talking to people
- being accepted
- using community facilities
- opportunities.

Talking to people Participants frequently commented on meeting and talking to people.

Yes ... I am a part of the community ... they talk to me, and I talk back to them.

Knowing people to say hello to when you go downtown.

Participants gave mixed reactions, with some feeling that people in the community were positive towards them, and others reporting that the community did not respond and talk to them, or make them feel included.

I don't think I am included ... I want people to help me be a part of the community.

Others felt that their own personal friendships and relationships were the best way of them getting to meet others in the community.

I can be a part of the community because I go out with my boyfriend ... so I meet and talk to people.

Being accepted A second theme revolved around how they were treated by other people and their wish to be accepted by others.

I'd like not to be made to feel different ... and to feel safe.

Participants commented on how they had been singled out due to their disability, or had been ignored.

Sometimes people make fun of me.

People talk to staff instead of talking to me ... I don't like feeling left out.

Using community facilities Involvement in the community also meant using community resources, including access to facilities and venues, as well as mainstream services such as doctors or dentists.

It's good living near the town centre, for the shops, schools, church and my GP.

I can go downtown to walk my dog, and meet my friends and play pool.

The availability and cost of transport were also very important in accessing community amenities.

[We need] more accessible transport which is affordable ... and more volunteers to take me out to social events.

Sometimes there's not enough money to get taxis to places I want to go.

Other participants felt there was a dearth of activities open to them.

There aren't enough activities for us to get involved in.

I wish there were more voluntary work opportunities ... and more social venues close to home.

Opportunities Participants appreciated that the opportunity for social inclusion was limited sometimes by the location of their home and its proximity to facilities as well as by the availability of staff to support them.

I feel I could go out by myself, but staff don't allow us.

If staff are sick, then there's not enough staff [to take you out].

[There is] no private room in our house where you can talk to friends.

Participants who were now living in supported living schemes felt they had more opportunities for social inclusion.

I get doing what I want, and there's plenty of company.

I am living with my best friends . . . like we are one big family.

I am given a lot of freedom, a lot of support . . . the local people are very good to me. Everything I need on a daily basis, work, centres, social life, is there for me.

Conclusions For the participants in this study, social inclusion meant meeting other people in ordinary settings and being treated similarly. However, in all four subthemes relating to social inclusion, participants recounted both positive and negative experiences. This suggests that social inclusion is a reality for some but not for all persons, or that it occurred in some settings but not others. Possible reasons for the variations could not be ascertained given the nature of this study but they are explored elsewhere (McConkey et al., 2006).

Barriers to social inclusion

In all the focus groups, most of the discussion centred around the barriers that the participants felt they encountered in meeting with others and joining in community activities. The four main themes to emerge from the analyses are presented diagrammatically in Figure 1 along with examples of the subthemes grouped within each.

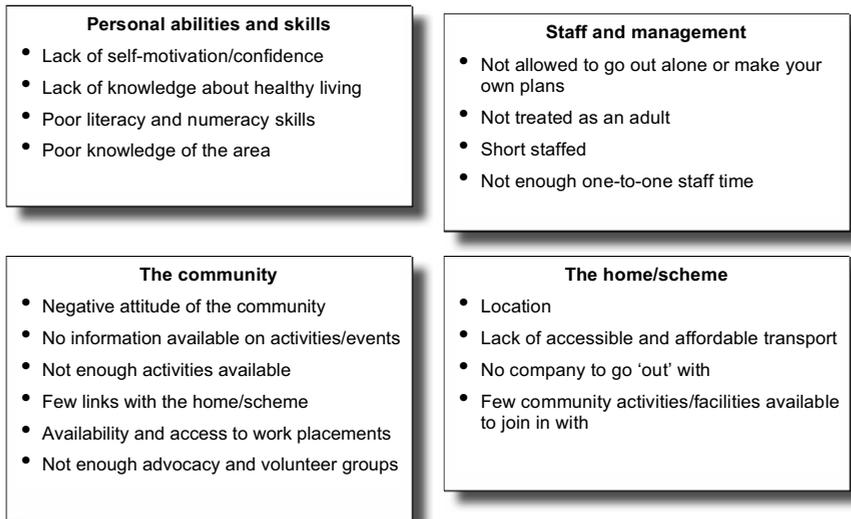


Figure 1 Perceived barriers to social inclusion

Participants appreciated that their own lack of skills created difficulties for them which further reduced their confidence and motivation.

Not being able to use the bus or train or taxi on my own. Not being able to go to [town] on my own to go shopping.

I have to ask people if there is any activities going on. If the staff would let us know about more activities.

Knowing the area; wouldn't know where shops are.

Road safety – crossing the road; getting knocked down.

However, they felt that service policies and the availability of staff also inhibited community participation.

Would like to have more staff, to get out more. Have more activities. I like getting out.

Because of my care needs – I would always need an assistant and they are not always available so I am limited in where I go for social activities.

You still have to let staff know when you are going out and when you are back. I go out with my husband to the shops.

The location of the residence or the home was another barrier they identified.

Transport is a big problem and I cannot take part in as many things as I would like to because there are not enough accessible wheelchair buses and I am charged more for buses and taxis because I am in a wheelchair. I don't think this is very fair.

In a smaller town I feel I could go out on my own – I'd know the area.

I wish there were more social venues close to my home.

They also cited various features within the local community as contributing to their exclusion.

Be careful who you talk to, because they could take advantage of you; knowing who it is OK to talk to.

Some people don't understand me, if they tried a little harder.

To meet friends in the community and be able to go with them to different places. To be able to be more involved in more community groups.

Overcoming the barriers Figure 2 summarizes the various solutions proposed by the participants to overcome the barriers they had identified. These have been grouped into the same categories as Figure 1, although they were elicited generally in the group discussions. Some of these were

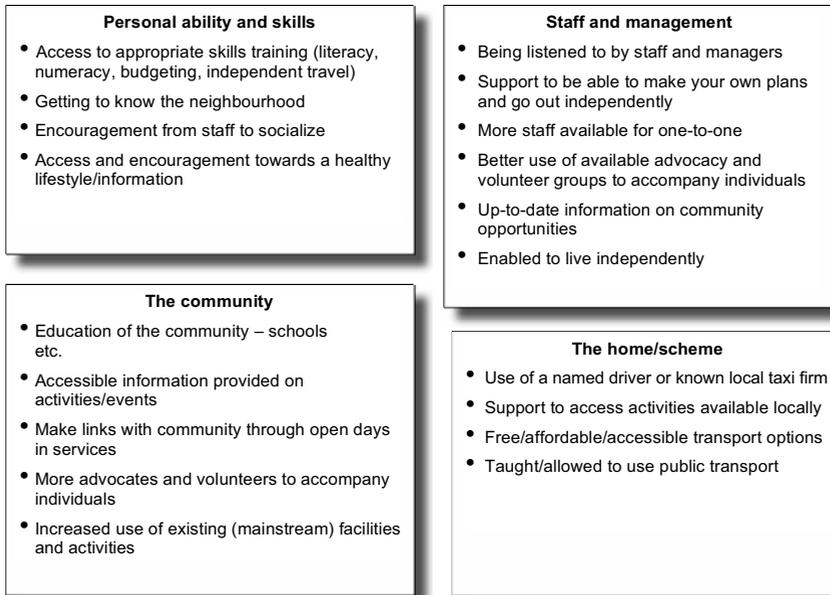


Figure 2 Suggested solutions to the barriers to social inclusion

prompted by the group facilitators but on the whole participants did appear to have a clear understanding of what was required to change the situations they had experienced or were presently experiencing. Indeed individuals were able to recount examples from their own lives, such as moving to supported living, to illustrate their proposals.

Discussion

This study demonstrated that individuals with intellectual disabilities were able to identify the barriers they had experienced to social inclusion and they could articulate ways of reducing or removing them. Many of their proposals were in line with the aims of current government policy and good practice. However, they bring a new dimension to our understanding, especially the contribution these individuals could make to the planning of local services both for themselves as individuals (O'Brien et al., 1997) and for larger numbers within a defined locality (Ward et al., 2004).

They rightly identified their need to acquire the knowledge and competence required to become an active participant in community life, such as money skills, independent travel and the local geography. Various studies have shown that higher social competence is a predictor of greater social inclusion (e.g. McConkey et al., 2006). However, support staff may

fail to provide active assistance in helping tenants to acquire new skills especially if the individuals do not appear motivated to learn. Moreover support staff may lack expertise and experience in teaching others. At a minimum, service managers and staff need to be aware of the increasing number of multimedia training resources that are now available for use with this client group and they should be encouraged to make use of them, even though evidence for their efficacy is not always available. They should also be aware of the training opportunities for tenants that are available through adult and further education. Training may also need to be provided to staff in what has been termed 'active support' (Mansell et al., 2003). Throughout these endeavours the practical application of the skills needs to be uppermost so that the learners' motivation is maintained and social inclusion goals are achieved.

More generally the participants emphasized the need for staff to embrace a support rather than a caring role. The latter has tended to dominate in services for this client group. In particular, a re-evaluation of approaches to risk assessment is required so that the support provided and the safety mechanisms in place do not become a barrier to social inclusion which can be the case at present (Alaszewski et al., 1999). Greater opportunities for advocacy also feature in the participants' recommendations as a counterbalance to the power that service managers and staff are perceived to have over people's lives (Oliver and Barnes, 1998).

A predominant issue was availability of transport, especially for homes or schemes that were in more isolated locations. Although a range of solutions was offered, a basic starting point is for planners to consider the availability of community amenities or public transport when developing or choosing accommodation. However transport issues are likely to remain a problem in rural settings (Metz, 2003).

Participants also pointed out the change in attitudes that was needed from other people in the community. This is not only to counter the bullying that some persons experience but also to engender a positive welcome for community participation. Although all stakeholders have a contribution to make to this, often few sustained and systematic efforts are undertaken at a community level. However, research findings suggest that positive attitudes follow on from increased social contact; thus a priority is to provide opportunities for this to happen in social, religious, educational and work settings (McConkey, 2005). Participants noted that this could happen by people visiting their homes, which appears to be an underused strategy at present (Emerson and McVilly, 2004). Moreover tenants and support staff need either to be kept informed about the opportunities that are available locally or to actively seek such information. Ideally this needs to be available in an accessible format (Thurman et al., 2005).

Surprisingly there were some notable omissions from the barriers mentioned by the participants. Lack of money was mentioned only in the context of transport and the cost of taxis in particular. Informal reports from staff indicated that many tenants had accumulated savings which tended to be spent on holidays. Likewise, none of the participants viewed employment as a means for increasing their social opportunities, although this is often mentioned as a valued outcome by those with jobs (Simons, 1998). Also there were no mentions of personal characteristics such as challenging behaviours, epilepsy or communication difficulties that might be thought to increase a person's likelihood of social exclusion, although past research has not found this to be so (McConkey et al., 2006). Nor did participants refer to any policy documents or legal requirements as a means of promoting greater social participation. The probability is that they were unaware of their existence. In a national survey in England with nearly 3000 respondents who had learning difficulties, only 14 percent were aware of the *Valuing People* policy and 8 percent of the learning partnership boards set up to plan local services (Emerson et al., 2005).

Finally, the study had a number of limitations. People living with family carers were not included and those living in larger congregated settings were under-represented. Likewise there were few participants with limited verbal communication. All of these groups may be less aware of the issues around social inclusion and hence policy implementation must give particular consideration to their needs. Also the findings reported here reflect the local context in which individuals live and this may be different from other regions and countries. Local service audits alongside further research could address all of these shortcomings.

Ongoing research is exploring changes in tenants' social inclusion following the identification of person-centred goals; the availability of a training resource on this topic aimed at support staff and tenants; and their experience of sampling various social initiatives. A range of strategies is likely to be needed, but in all of them the involvement of people with intellectual disabilities is not only possible but essential.

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