Changing Selves: a Grounded Theory Account of Belonging to a Self-advocacy Group for People with Intellectual Disabilities[1]

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Purpose To explore the experience of belonging to a self-advocacy group for people with intellectual disabilities, and how membership of such a group impacts on individual members.
Methods Eight people with intellectual disabilities, who belonged to a self-advocacy group for at least 6 months, were interviewed about their experiences of membership. A grounded theory approach was used to generate and analyse the interview data.
Results A model of the impact of belonging to a self-advocacy group for people with intellectual disabilities on individual members' self-concept is developed. The model proposes that participants' self-concept changes as a result of group membership and that this process of change involves six key categories: joining the group; learning about and doing self-advocacy; becoming aware of group aims and identity; experiencing a positive social environment; identifying positive change in self-concept and seeing the future of self and group as interlinked.
Conclusion Membership of a self-advocacy group for people with intellectual disabilities changes the self-concept of participants. The processes surrounding these changes have important implications for self-advocacy groups both, in recruitment and in supporting group members.

Keywords: grounded theory, intellectual disability, self-advocacy, self-concept

Introduction

The last 30 years have seen the emergence of a new social movement, the rise of self-advocacy groups for people with intellectual disabilities (Goodley 2000). While there is natural diversity amongst groups and members regarding the meaning of self-advocacy, Mitchell (1997) believes that consistent themes emerge. These include those stated by People First (1996), a self-advocacy organization run by people with intellectual disabilities, who define self-advocacy as speaking and standing up for yourself, standing up for your rights, making choices, being independent and taking responsibility for yourself.

Despite the rapid growth of self-advocacy groups for people with intellectual disabilities and the debates over

the potential influence such a movement has on challenging the assumptions of normalization (Brechin & Swain 1989; Szivos 1992), there has been surprisingly little research in this area. The research that has been carried out has primarily focused on the concrete, using survey methods to look at the diversity in the structure and organization of groups, including who they are affiliated to, their aims and the role of their facilitator/advisor (e.g. Crawley 1982, 1988, 1990; Browning *et al*. 1985; Cone 2000). A few research studies have interviewed group members with the aim of understanding what self-advocacy means to group members, and their views on the aims and achievements of self-advocacy (Simons 1992; Sutcliffe & Simons 1993; Bristol Self-advocacy Research Group 1997). What is missing from the research is an understanding of what 'self-advocacy means to a member of a self-advocacy group in terms of identity, self-hood, personal biography and personal ambition' (Goodley 2000, p. 4).

There have been only two studies that have offered in-depth understandings of the experience of self-advocacy

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[1] The term 'intellectual disabilities' is used here, in view of the journal's international readership. However, where self-advocates own words are given, we have not changed 'learning disabilities', as it is the usual UK term.

for people with intellectual disabilities. Working alongside coresearchers from the Hackney People First group, Mitchell (1997) undertook both group discussions and in-depth interviews with self-advocates and their family members to understand how self-advocacy impacts on family life. Qualitative analysis produced themes which included the experience of restriction, being treated differently to siblings and wanting more independence. Mitchell (1997) also found that her participants reported that self-advocacy time was not used to discuss and address these matters.

As part of a wider study, Goodley (1998) has produced an insightful and interesting piece of research that aimed to examine the impact of self-advocacy on the life experiences of people with intellectual disabilities. Goodley (1998, 2000) worked collaboratively with five 'top self-advocates' to produce a life story of each person, and to present both the life stories and his own analysis of the main themes coming from these. He identified various themes, including that of the self-advocacy group, providing a place where people with intellectual disabilities can express their opinions and also importantly feel listened to. A second main theme was that the self-advocacy group provides a context for re-evaluating old terms, describing intellectual disabilities and coming up with new ones. Goodley concludes that self-advocacy groups give space for advocates to make sense of their social identity and to build on the skills and resilience that they had before joining the group.

Both studies highlight the impact that self-advocacy group membership has on members' lives. Goodley especially shows how such membership influences the individual's self-concept. The aim of the current study was to build on the work by Goodley (2000) and Mitchell (1997), and explore advocates' experience of group membership and their own assessment of the impact it has on their lives and sense of identity.

Grounded theory was chosen as the method for this study for several reasons. Firstly, it offered an in-depth way for the subjective experiences of advocates to be explored and for these to be retained in the analysis and write-up. This methodology also fitted in with the advocacy group's aims of having a voice and speaking up for oneself. Secondly, the aim of grounded theory is to build a theoretical model which is 'grounded in' the accounts of participants (Glaser & Strauss 1967). While there have been some interesting studies identifying themes emerging from individuals' experiences of self-advocacy groups for people with intellectual disabilities (Simons 1992; Goodley 1997), no theoretical understanding of the impact of the group on an individual member's self-concept has

been offered. It was hoped that by using grounded theory, such a model could be developed.

Method

Participants

The participants in this study were five men and two women, who belonged to an advocacy group for people with intellectual disabilities that had been established in 1997, and a female participant, who had experience of two advocacy groups. All the participants were of white English origin, and their ages ranged from 24 to 44 years. The only criterion for participation was that the participant should be a group member for a minimum of 6 months in order to have a substantial amount of experience to draw on in interviews. Six participants had regularly attended their group for 3 years, one for 8 years and another for 1 year.

The interview

The interviews were conducted at the participant's self-advocacy group offices, and lasted between 30 and 60 min. They were audio-taped with consent from the participant. Each participant was interviewed once. Interviews took the form of 'a directed conversation' (Lofland & Lofland 1983), which generally began by asking how people had joined the advocacy group. An interview outline was then used as a flexible guide to explore participants' experiences from this point in time.

This outline comprised four areas: the participant's experience of joining the advocacy group; the meanings that self-advocacy had for them; the perceived impact that being in the group had on participants' day-to-day lives and the reactions of friends, family and staff to the interviewee belonging to a self-advocacy group. (These areas and related questions were developed by the first author in consultation with the second and third authors).

Sometimes, participants struggled to answer open-ended or abstract questions, and were asked a more closed or simply a more factual question to facilitate information giving. At points, some participants used written information to describe their feelings or activities. This included showing their personal folders of activities that they were involved in, showing articles they had written in newsletters or finding information about the group. When this occurred, the interviewer asked permission to read out loud the information the participant had provided, and then analysed this as part of the transcript. The texts were also read in conjunction with the interview transcript to

gain an understanding of the meaning that participants gave to this written information. Lastly, one participant provided a video that had been made to tell their story. With their permission, the words on the video were transcribed and analysed alongside their interview.

Interviews were spaced out so that the transcription and coding from one interview influenced the interviewer's thoughts, and thus, questions for the next interview. Charmaz (1990) believes that 'If they (the researcher) find recurrent themes or issues in the data, then they need to follow up on them, which can, and often does, lead grounded theorists in unanticipated directions'(p. 1162). Therefore, although the original areas on the interview schedule continued to be explored, new questions were added to elicit further understanding of participants' experiences.

Researchers' background and beliefs

Elliott *et al.* (1999) have recommended that qualitative researchers clarify their values, interests and assumptions in order to help the reader to 'interpret the researcher's data and understanding of them, and to consider possible alternatives' (p. 221).

The interviewer and primary analyst (first author) had experience of working with people with intellectual disabilities through volunteer work, as an assistant psychologist and as a clinical psychologist. Although S.B. knew comparatively little about self-advocacy groups, she naturally had some preconceptions about the research. She was (and remains) very much in favour of self-advocacy groups for people with intellectual disabilities, and she views them positively.

The second and third authors who audited the analyses are both clinical psychologists. G.H. is also experienced in qualitative methods and L.B. has worked for many years with people with intellectual disabilities.

Analysis

Analysis followed the grounded theory procedures described by Strauss & Corbin (1998). The first stage of analysis involved open coding, which is the process of examining the transcript line by line and generating codes that categorize these pieces of data. Sometimes, when the meaning behind the content of the transcripts was not clear, a greater degree of emphasis was put on nonverbal information, such as tone of voice and intonation, in order to generate the code.

As coding of the transcripts continued, this process was repeated with new codes being created and other codes continually reappearing. After the transcripts had been coded in this way, both the codes and transcripts were reread in order to group codes together to create categories. Categories incorporated the stories of many people and sought to encompass the meanings of several codes under a more conceptual heading. For example, the code *activities* covered conferences, meetings and many other events. What these all had in common on rereading the data was that they were all about *learning and doing self-advocacy*. Therefore, this became a category heading with *activities* as a subcategory, which was then divided on the basis of function into different types of activity.

The next stage of axial coding involved exploring the generated categories further in order to begin to move towards a theoretical understanding of the data. In axial coding '... categories are related to their subcategories to form more precise and complete explanations about phenomena' (Strauss & Corbin 1998, p. 124). This involved producing a written description of each category, as well as a diagram representing the relationships between a category and its subcategories

The next stage of selective coding aimed to present findings as a set of inter-related concepts, rather than a list of codes. To facilitate this process, the primary analyst followed Strauss & Corbin's (1998) suggestions of writing the story line of the data, noting again what kept coming up in the interviews and what felt important. This was also performed for just one participant before developing written and diagrammatic representations of the relationships between categories.

Lastly, theoretical sampling was used as a way of further developing categories by exploring variation in the data with the aim of incorporating new properties and dimensions (Dey 1999). This sampling is not predetermined but evolves from the research process (Strauss & Corbin 1998). After interviewing seven participants belonging to the same group, it was felt that these codes and categories could be further developed by comparing the experience of the existing participants with the experience of an advocate in a different group. The eighth participant had belonged to two self-advocacy groups and had been an advocate for 8 years.

Credibility checks

The following two methods were used:
1 The analyses and results of the study were presented to seven of the eight participants as a group. Results were sent to the eighth participant who couldn't attend. The participants felt that the results represented their experiences well, and were pleased their own words were used.

2 The original transcripts were read by the second two authors to review the coding 'for discrepancies, overstatements or errors' (Elliott *et al.* 1999, p. 228). Discussion around this generated two additions to the codes/categories. Abuse was added as a subcategory of the category *negative treatment by others*, and the concept of *status* replaced the original category name of 'new roles and responsibilities' as it captured the content of the category better.

Results

The core theme that emerged from all eight interviews was that of 'changing selves'. This theme captures a process of change in individual self-concept that resulted from belonging to a self-advocacy group for people with intellectual disabilities. Participants reported a gradual change in self-concept as they made the transition from being outside the group to identifying themselves as group members. Participants described themselves in new ways in comparison to their past selves. They described change within themselves and in the ways they interacted with others, and attributed these changes to group membership.

A model was developed through analysis of the participants' words to offer an explanation for how this change in self occurred. Six key categories emerged from the transcripts as being involved in the process of change in participants' self-concept through self-advocacy group membership (Figure 1). These categories, their codes (in italics) and their relationship to other categories are described below.

Joining the group

The process of joining the group involved several steps. None of the participants actively sought out the group, but were *invited to join* on an individual basis by a member of staff, or an advocate member. Participants described an *initial uncertainty* about what the group involved, who it was for and how it may help them.

> I thought I'd try it out {. . .} just to see what it was like and so I went.

Motivation to join was varied and influenced by participants' *past experiences*. Participants expressed a need to have a *concrete experience* of the group before they made up their minds. They all attended an initial meeting and found that they enjoyed the experience.

> I was like excited and you know like emotional and you know and thinking I've got something to do at last, and I'm thinking you know, yes, and I'm excited, yeah, yippee.

At this stage, participants described uncertainty around who and what the group was for, their role in the group and how it might help them.

Learning about and doing self-advocacy

This category encompassed the concrete activities of self-advocacy that formed the basis of what the group did. Through these activities, participants began to understand
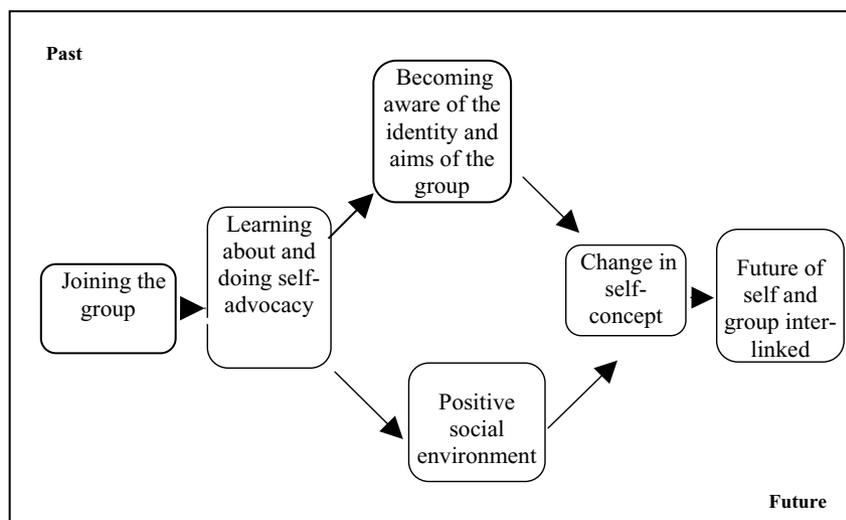

Figure 1 The six key category participants described as central to the process of change in self-concept.

the group's aims and identity, and to experience the support it offered. Participants described a range of activities through which they became aware of what self-advocacy was and what it did. These activities can be divided into three broad subcategories of *training for self-advocacy*, in which specific training events took place to help participants learn about self-advocacy, *informing others* about upcoming activities and the role of the group.

> We used to go to different day centres and talk about self-advocacy.

Also, a more two-way process of *information giving and gaining* with people both with and without intellectual disabilities.

> I think the planning committee is very good. I can speak up for meself as well. Tell em what I think and that.

The identity and aims of the group

The *identity* of the group included its *organization*, e.g. the role of facilitator and volunteers, and its *history*, and importantly for the participants, *who the group was for*.

> It's for people with learning disabilities.

Participants described three interlinking aims of the group, which encapsulated the role of the members. These were:

1 *To speak out for self and others*: This was very important to participants and came up in the transcripts again and again. It involved speaking out about the rights of oneself and of people with intellectual disabilities in general.

> I speak up about people's rights, erm about bullying and that, and respect {. . .} I think it's very good cos I can {. . .} speak up for meself and others as well.

2 *Changing services* for people with intellectual disabilities: Services were often seen as unsatisfactory and the group was seen as having a role, through meetings and conferences, of effecting change.

> No jargon, better transport, buildings not accessible. Not up to scratch really. It's discrimination against people with learning disabilities.

3 *To support and help people*, both one-to-one and, more generally, by providing practical and emotional help.

> I'd say it's about {. . .} helping each other and sticking up for each other.

Through realizing the role and aims of the group, participants came to see the group as something important and worthwhile, and their role as group members as significant and meaningful. This gave them a feeling of *status*. This status came from belonging to a group that the participants felt was important, deserving of respect and that people listened to. It also came from participants taking on new roles, such as committee member or chair person.

> I was a director. I was a director of a role play, about bullying. Standing for your rights. I were very good.

> We had about 70 people come (to a conference). To get our message across to social services and the police. To make things better for people with learning disabilities.

This sense of *status* was an important factor in contributing towards the changes they identified in themselves.

A positive social environment

Participants described the positive social experience that resulted from being part of the group and joining in its activities. All participants felt that they had made *new friendships* through the group, both with other members and/or with the facilitator and other group workers. Participants felt that the group and its members provided *support and help* of both an *emotional* and *practical* kind. Practical support included having a person without intellectual disabilities going along to meetings to help the participant follow the proceedings.

> Well . . . comes with me (to meetings) and she explains what's going off and what it meant, and they like explain to me because I don't understand the half of it.

Emotional support is described as other group members and the facilitator being there to talk through difficulties or worries with the participants.

The model proposes that alongside the process of becoming aware of the group's identity and aims, this positive supportive environment, where participants felt listened to and valued, contributed to changes in individual member's self-concept.

Changes in self-concept

All participants talked about the changes they had noticed in themselves since joining the group.
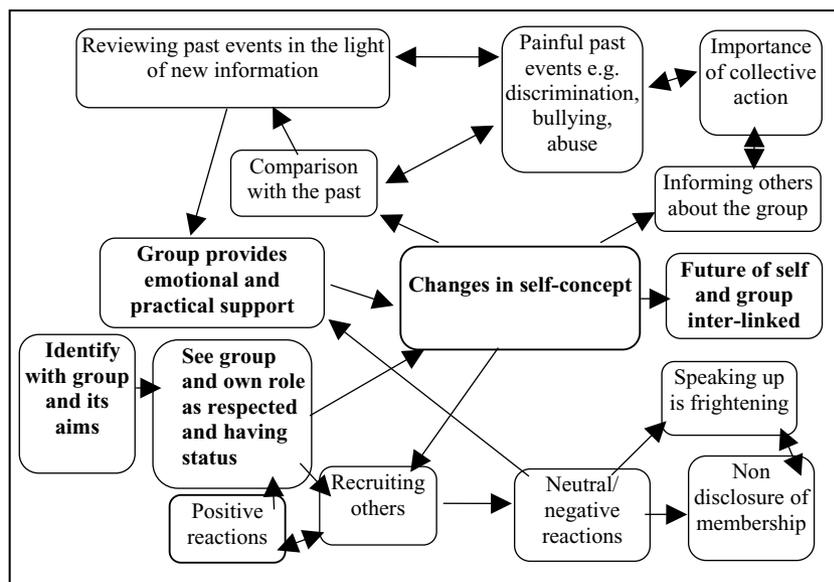
Figure 2 The category of 'change in self' explored in greater detail.

Its changed me a lot. It's brought me out to be confident for meself and that. Get control in my life an' that, an' that. Control.

(I've learnt) 'How to stand up for my rights, get my voice heard.

This category will be explored in greater detail below.

The future

The participants saw the *future of the group* as involving their *continuing membership*. When entering the group, participants began a process of change, and in the future, this changing self-concept is bound up with the group. Participants' *future self* included their *personal goals* for their future. However, membership of the group was, to a lesser or greater extent, seen as having a part in achieving these goals. For example, for one participant, the group was clearly seen as a way to help him achieve his goal.

I would like to carry on coming in, in here. I'd like . . . (group) to get me a house on my own as well so I can live by myself and some of my friends can help me and come round for tea.

For another participant, his future was very much bound up with the group. His desire to be famous was connected to being a positive role model for people with intellectual disabilities and spreading the word about self-advocacy.

Talk about self advocacy on things like 'Alive and Kicking', SMTV. {. . .} On 'Look North', the BBC news. I'd like to be famous.

Consequences and maintenance of changes in self-concept

The six key categories involved in the change in self-concept (see Figure 1) have been described above. Below, we focus on the category of self-change (Figure 2) in order to explore the important consequences to these changes in self-concept, and the ways participants had developed to maintain these changes when the changes came under threat.

Changes in self-concept were brought about by the support the group offered and the sense of status the participants developed. However, as Figure 2 shows, these changes in self-concept brought with them some often emotionally difficult processes. During interviewing, all participants talked about powerful and upsetting experiences of discrimination, bullying and physical abuse.

I'm always picked on by . . . Picked on, bullied at.

A young mother was rude to me (on the bus), because I'm disabled {. . .} She thinks I'm not capable. It makes me angry. I told her I was upset, gave her a good talking to.

For many, the more positive social experience and the changes in self, as well as new status, skills and

responsibilities, prompted a *comparison with the past*, which included reflections on these negative and emotionally *painful events*. One participant's recollection of her unhappiness at a previous job is contrasted to her experience of the self-advocacy group.

> It's picture frames they did. And we used to like 'oh come on work faster', which I couldn't. I'm a slow worker. So I think he (manager) got rid of me then 'cos I weren't as, I weren't fast enough. I could not hold a job down. That's why I've come here. {...} I love coming here though. I'm a lot happier than I were at ....

Some of these incidents came to be viewed more negatively because there was a confirmation through activities and talking about the group role that bullying, abuse and discrimination were always wrong, and that people with intellectual disabilities had rights that should be respected. This new emphasis in their lives meant that some participants felt that negative experiences in their past had a new meaning, an added unfairness and injustice. While this gave them a moral motivation to speak up, it also meant that they had to face up to *reviewing past events in the light of new information*, to understand how unfair these incidences were and to acknowledge that their past selves had tolerated this because they were unsupported and unaware of their rights.

In two statements, a participant highlighted his feelings of powerlessness before joining the group and gaining its support.

> It's helped me to stick up for myself. Now when people say something to me I just tell 'em. I give it back to 'em now. Like before I didn't have the chance to give it back.

> Before I could never speak up for my rights and you know, I got picked on and I couldn't do anything about it or anything.

For one participant reflecting on her unhappiness in a previous post (see above), there is an acknowledgement that the work place hadn't supported her and that she needed a work environment, such as the group, that did.

> I can't even work either. I can't work. That's why I've got a job here (at the group). I used to work at ... on 1998. I think 1998. I didn't like it there. We didn't have support.

In describing an incident where he lived when he had spat at a house mate, a participant acknowledged that he regretted his behaviour, but went on to identify his need for others to support and understand him.

> Shouldn't have done that. Got told off. Always accusing me. All I want is support.

These feelings were managed by participants turning to the group for emotional support through talking to other members and the facilitator about their experiences.

> Sometimes I'm really down and I just want to get it off my chest and tell ... (facilitator).

Later he continued that this was about things

> From the past and that. They come back to haunt me.

A second management strategy was found in participants re-emphasizing the *importance of collective action* and its effect, as opposed to individual action, which, in the statement below, was closely connected with powerlessness and vulnerability.

> It would be suicidal if we did things on our own. We need support from a self advocacy group in ... and there should be other self advocacy groups around to give support.

These difficult experiences were also managed by turning them into a means of *helping and informing others*. Participants use self-disclosure of painful events to emphasize the advantages of collective action and the need to speak out. This was achieved by telling their stories through a newsletter or video.

> I can't stand people that take the mickey out of me and people that take me for a fool. Some people have nothing better to do or they do it because they are jealous. People taking the mickey out of me makes me angry. I've got feelings and I don't like being hurt. (newsletter).

Alongside the difficulties of comparing a changed self to the past self, participants needed to have their changed selves positively validated by other people in order to maintain this new self-concept. Overall, the *reaction of others* was a positive one. These others included friends, family, staff, house mates, work colleagues and

professionals. The *positive reactions* of others recognized and acknowledged this change in self. Such reactions affirmed the worth of the group, participants' new status and reinforced the importance of being a group member.

> Yeah I show 'em (parents) what I do at work (the group). Show 'em my notebook. Do loads of words. {…} They're pleased with me.

However, self-concept was also influenced by the *negative* and even *neutral reactions,* in which some people did not ask about the group's or the advocate's membership of it.

> It's like the staff at … They don't want to know. They would take note about what we were saying to them but they're just not interested.

This made him feel?

'Annoyed'.

A participant described the reservations his parents had about his membership of the group.

> Well sometimes me mum and dad aren't very pleased with me so I have to sort it out on my own and explain what's happening down here (at the group) {…} Like joining the group in November and me mum and dad don't know what it's all about you see.

Speaking up, being more confident, declaring membership of a self-advocacy group for people with intellectual disabilities involved a risk of rejection and could be *frightening.* One participant gave this as a reason for some people leaving the group.

> Really because they're frightened of speaking up for themselves.

For some participants in some circumstances, the risk of talking about the group was too great and they made a conscious decision *not to disclose* their membership because the anticipated consequences were too negative. When asked if people at college knew about her membership, one participant was very definite.

> No, not, no I don't there, no only t'tutor. He thought it's good.

When asked why this was, she continued

> I don't know {…} Just don't want to talk about it {…} Just don't want to embarrass them (other students at college) {…} I get embarrassed you see.

Deep down, there is a sense of fear about revealing membership, and a distinction between safe and unsafe people to tell.

> I daren't tell 'em {…} I keep it a secret. I don't tell 'em at all. Keep it like, keep it a secret. I tell my friends at … and ….

Despite changes in self and the positive experience of the group, participants needed to weigh up the likely reactions of others and the impact this would have on them.

Discussion

In this study, the major impact of membership of a self-advocacy group for people with intellectual disabilities was found in the changes in participants' self-concept. Such changes, which include feeling more confident, speaking up for and sticking up for oneself, are a central aim of collective self-advocacy (Williams & Shoultz 1982). These changes are found in other studies of self-advocacy for people with intellectual disabilities (Whittaker 1991; Simons 1992; Bristol Self-advocacy Research Group 1997; Preston 1998; Goodley 2000). The main issues addressed by the model developed from this study are how these changes come to take place, what are the consequences of such changes for the individual and how are these changes maintained.

With regard to how change in self-concept takes place, the model proposes that it is not, as a training model of self-advocacy suggests, the act of teaching people how to do self-advocacy that on its own makes people more confident, etc. Instead, change is brought about by the processes stemming from these activities. Change occurs through the participants becoming aware of the 'aims and identity of the group', seeing these as meaningful, and gaining new roles and responsibilities which give them status. Experiencing a 'positive social environment' is important in providing participants with the friendship and support which facilitate change in their self-concept. Also, support helps participants to maintain these changes when they are threatened (e.g. by other peoples' negative reactions to group membership).

Reviewing the wider intellectual disability literature, it can be seen that these findings fit well with O'Brien &

Lyle's (1987) definition of what a good-quality service should provide for people with intellectual disabilities. They discuss five necessary accomplishments (community presence, relationships, competence, respect and choice), of which three are particularly relevant here. The category of 'a positive social environment' fits well with O'Brien & Lyle's belief that services should provide real opportunities for a variety of relationships, not just temporary and superficial ones with service providers. 'Group aims and identity' fit well with the two accomplishments of competence and respect. Competence is defined as a person with intellectual disabilities having the resources to get things done, including through their own skills, and the practical and emotional support of others. Respect involves being given respect by others and being seen as a valued member of the community.

Although changes in self-concept are widely reported in self-advocacy literature, this study's findings that these changes had emotionally difficult components do not seem to have been widely acknowledged. The present study found that making comparisons with the past and coping with negative reactions from others to group membership can be difficult, and can threaten newly acquired confidence and self-esteem. Simons (1992) reported some negative reactions from parents to self-advocacy. However, there are no studies which look at how such reactions affect members of self-advocacy groups for people with intellectual disabilities.

Turning to the wider literature, the negative aspects of change in self-concept have been discussed by Rose & Kiger (1995). In their overview of self-image and political action in the deaf community, they describe how, as deaf people come to feel more positively about themselves through collective action, they 'perceive injustice in a fundamentally different way than in the past . . . Out of perceived inequities come anger, resentment and mobilization for group action' (p. 524–5).

The findings of the study appear to have some important implications for self-advocacy groups. Firstly, they suggest that participants only came to see collective action as important after joining the group. Therefore, groups may find it fruitful to concentrate on recruitment and raising awareness of self-advocacy for people with intellectual disabilities. Groups also need to be aware that even positive change for their members may have difficult consequences, and that an important factor in maintaining changes in self-concept is the emotional support that the group can give. Time to talk and reflect on changes in oneself may be of great value to self-advocates.

Limitations of the study

Strauss & Corbin (1998) state that the aim of grounded theory is to build theory, and so, unlike in quantitative research, generalizability is not an aim of the methodology. Instead, grounded theory aims to offer 'explanatory power . . . that is, the ability to explain what might happen in given situations' (p. 267). This study offers a theoretical model built on the experiences of eight advocates, and therefore does not claim to offer explanatory power for the experiences of the large number of self-advocates in Britain. However, the model developed in this study can offer a starting point for developing further understandings of the experience of belonging to a self-advocacy group for people with intellectual disabilities.

In this study, participants were asked to retrospectively describe their experiences of joining a self-advocacy group and to consider the impact of joining such a group. From this, we have proposed a process model. However, whether the steps offered in the model take place as we hypothesized need to be tested prospectively. Finally, we must acknowledge, as with all qualitative work, our analyses will have been influenced by our own understandings. We have, although, sought to meet the standards set in the guidelines provided by Elliot *et al*. (1999). 'Owning one's perspective', 'situating the sample', and 'credibility checks' have been described in the 'Method' section. In the 'Results' section, we have attempted to achieve *coherence* by providing a summary of the model, and diagrammatic examples alongside the text. The model has been *grounded in examples* to help the reader judge our interpretation of the data. 'Accomplishing general vs. specific research tasks', that is, how far findings can extend to other contexts is discussed above. Lastly 'resonance with the reader' can only be judged by others, but it is hoped that while remaining grounded in the participants' words, the study has provided new understandings of self-advocacy group membership.

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