

Section 4

Self-advocacy in Action: Ethnographic Study with Four Groups

Chapter 9

Inside self-advocacy groups - typologies and dynamics

Introduction

Attention is now turned away from stories to actions in self-advocacy groups. This chapter describes and appraises self-advocacy in action in four groups. After describing how each group is organised, my ethnographic involvement will be used to appraise a number of points that emerge from previous literature about the organisation, workings and processes within groups. In all, 12 points are assessed:

The Centre-based group

1. The staff advisor's role is an impossible one (Hanna 1978 Worrel 1987, 1988, Dowson and Whittaker 1993, Curtis 1995).
2. Service systems constrain the development of 'real' self-advocacy (Worrel 1987, Crawley 1988, Clare 1990, Sutcliffe and Simons 1993).
3. Service-based groups are tokenistic with no real outcomes for members (Crawley 1988, Khan 1985, and Oliver 1990).

The Social group

4. Voluntary staff supporters bring their work with them to the group (see claim 1 and Crawley 1990).
5. Groups that function as social groups are not 'real' self-advocacy groups (Worrel 1987, 1988).

6. Independence is necessary for 'true' self-advocacy (Crawley 1990, Worrel 1988)

The Advocacy-supported group

7. Advocacy supporters are prone to advocate rather than support self-advocacy (Worrel 1988, Dowson and Whittaker 1993).
8. Divisional groups are too sophisticated (Daniels 1992, Braddock 1994, Flynn and Ward 1991).
9. The ambitions of self-advocacy groups get lost in the wider ambitions of advocacy organisations (Oliver 1990)

The Independent group

10. Paid independent advisors threaten the development of independence in a group (Oliver 1990, Dowson and Whittaker).
11. Member-orientated groups are the best (Worrel 1988).
12. Professional self-advocacy is the way forward (Sutcliffe and Simons 1993)

It is concluded that previous literature has simplified the multi-faceted dynamics within groups and ignored the inter-dependence amongst self-advocates that emerges in the various 'types' of self-advocacy group.

Some general analytical points

This chapter examines how self-advocacy is enacted inside different groups. Reference will be made to my observational field notes (ONs, and the meeting / event from which they were taken, following Schatzman and Strauss, 1973), the views of members collected in the group discussions

(GD), feedback from other organisations (FB) and group's own documents. *Appendix section 4, 6 to 12* include group discussion reports, group constitution feedback and evaluation reports that I drafted and presented to groups. Other documents that were used but not placed in the appendices, so as to maintain the anonymity of groups, included original group constitutions, information leaflets, training details and notes of telephone conversations and letters with advisors outlining group histories. Before describing and appraising each group a number of general analytical points will be made:

- First, the effort of supporters or advisors should be kept in mind. Many gave up their free time, picking people up before meetings and advocating for them at formal case conferences. They often bought the drinks at the bar and would put in the odd 20 quid when it was missing from subs.
- Second, the resilience of self-advocates emerged as a constant theme throughout my ONs, in spite of their daily experiences of discrimination.
- Third, to describe (never mind appraise) what was observed over a period of 14 months is a daunting prospect. Description and appraisal require simplicity and economy. This contrasts with the taking of field notes that is concerned with accumulating material (Walker 1981). The richness of group dynamics will only be picked at throughout this chapter.

Barnes (1994, p2) asserts that there is 'a moral onus on researchers at least not to add to any feelings of disempowerment or distress'. This chapter does

not attempt to undermine the actions of self-advocates or advisors but to shed light on some group dynamics of self-advocacy in action. Previous literature can be added to and appraised in some small way through an examination of self-advocacy from the inside, including the role of advisors, the impact of group type and the activities of self-advocates. Moreover, a contemporary picture is presented of what is happening in some self-advocacy groups in England.

Models of Self-advocacy

Sociograms of group structure

Worrel (1987, 1988) provides a starting point for the description and appraisal of the workings of self-advocacy groups. Worrel illustrates through the use of sociograms intra-group relationships between advisors and self-advocates. He presents two forms around which groups may be organised:

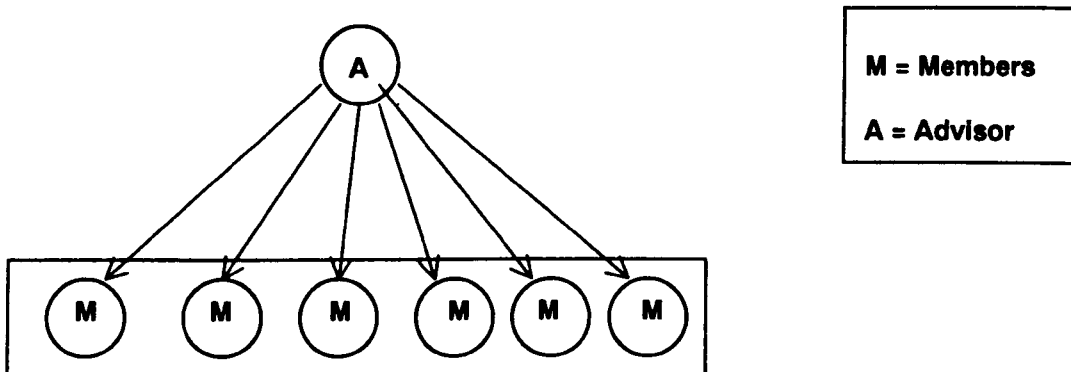


Figure 1. Advisor orientated group structure (based on Worrel 1988, p48)

Following Barb Goode, a Canadian self-advocate, groups that approximate figure 1 are not *People First* groups but 'Advisors' First' groups (quoted in

Worrel 1988, p31). Worrel argues that potentially this structure imposes a number of limitations upon group meetings and other subsequent activities. First, lines of communication are directed through the advisor and not between members. This may promote a paternalistic culture where 'advisors know best' (Khan 1985, Worrel 1987). Second, members are encouraged to depend on the advisor and not on one another - advocacy rather than self-advocacy (Tyne 1994). There is a risk that an autocratic, advisor-led environment is bred. Third, there is no model of membership control (Worrel 1988, p49). For Crawley (1982, 1988, 1990), McKenna (1986), Simons (1992) and Dowson and Whittaker (1993), advisor-orientated groups are most likely to be found in service-based types and in some coalition and divisional organisations. While these intra-group relationships may be useful in the initial stages of setting up a group, groups that keep this structure are inevitably limited thereafter (see Crawley 1988, Barnes and Wistow 1992c). Worrel (1988, p49) proposes an alternative way of organising groups that holds greater potential for self-advocate leadership and the self-empowerment of members. Worrel argues that advisors should promote a group dynamic that follows this model:

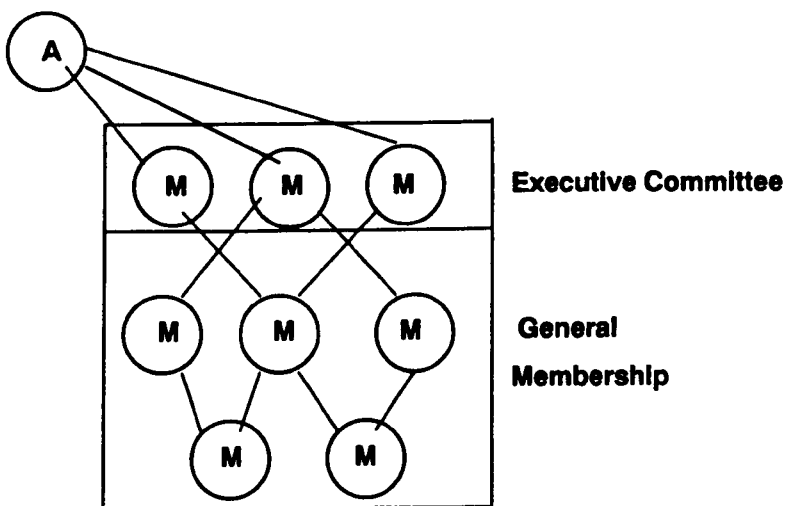


Figure 2 - Member-orientated group structure (based on Worrel 1988, p49)

The hierarchy presented in figure 2 reflects the intra-group relationships of a number of high-profile North American and UK *People First* groups (Worrel 1988, Simons 1992, Dowson and Whittaker 1993). Worrel proposes that this structure is preferable to that presented in figure 1 for a number of reasons. First, advisors' main port of call is the executive committee, which is comprised of a small number of self-advocates who have been voted on to the committee to represent the views of all members (*Speak for Ourselves of Newcastle* 1993). Second, a consequence of this committee is that members depend on the executive and one another rather than just the advisors for support. Communication occurs throughout the self-advocate group as devalued persons are placed in valued roles (Worrel 1988, p50). Third, an inter-dependent, interactive, co-operative culture is bred that helps to promote solidarity between members (Ibid.) - a key component of the self-organisation of disabled people (Oliver and Zarb 1989, Oliver 1990, 1996). A number of observers have suggested that this group structure is readily found in the 'autonomous group' and 'coalition' types (Worrel 1988, Simons 1992, Dowson and Whittaker 1993). Independence and non-accountability to service or divisional organisations provides the group with the potential for self-determination and self-organisation.

Processes within group structures

Worrel (1988, p50) recognises that the structure of groups does not unequivocally lead to different types of self-advocacy in action. The processes within groups are more complex than the sociograms present.

Consequently a number of questions remain. First, is there a link between group 'type' and ways of organising? Second, do the group structures proposed by Worrel exist in practice? Third, what group processes occur within these structures? Fourth, are these processes the consequence of group structure or of other deeper group dynamics? The remainder of this chapter examines the processes and dynamics of groups that occur in different groups. To make sense of these processes and dynamics, a number of points that emerge from the literature associated with self-advocacy in action will be considered in light of my observations of specific examples of self-advocacy in action.

Describing and appraising self-advocacy

(1) The Centre group – service based self-advocacy

The Context

The Centre Group meets in an Adult Training Centre that is situated on the woody outskirts of a city in the north of England. The nearest place is Quarry Village¹ about a mile away. Surrounded by trees and close to a small industrial park, the Centre is marked out by a sign reading 'Centre for Mentally Handicapped Adults'. The Centre is separated from built up areas and a high wooden fence surrounds the perimeter of its grounds. Some 40 years old, the Centre resembles a primary school at first sight. There is only one level, ensuring wheelchair accessibility and brightly coloured posters and artwork adorn many notice boards. Through the doors of the main

¹ All names of places and people have changed throughout Section 4.

entrance, visitors are faced with the reception desk where they have to sign in. Loud requests to staff and 'users' come over the tannoy system. Users stand in the corridors. The atmosphere is claustrophobic, what with the grating sound of the tannoy and the compact layout of the corridors and rooms. During my visits the canteen was always full of people but there was never any evidence of early morning coffee or tea.

'I met an elderly man, in his sixties, with walking stick in hand. He spoke of the dangers of crossing the roads round his way. "They drive like 'bliddy maniacs". Other greetings were offered when I entered the common room. An elderly woman with smiling eyes walked up to me. Gestures, Makaton, handshakes ... A teenage lad wrapped up in a winter coat took my hand but said nothing. The man with the walking stick re-appeared, "Oh this bliddy catheter's killing me - do you have that problem?" The staff members often sit together. My 'hellos' were always ignored' (ON, 1st meeting).

Some exchange eventually occurred between the staff and me:

'Over lunch, three female staff chatted about the weekend. Pubs and clubs were mentioned and jokes were exchanged. "I like the gardens", I interjected, looking out of the window. "Yes", replied the taller one, "We have to patrol that area in the summer - that's where all the snoggers go". In contrast, members of the Centre Group's and their advisor Louise are like a breath of fresh air. The meeting is like a sanctuary or refuge. Little wonder that many uninvited users who join the group beforehand and during meetings are shooed away by the members' (ON, 2nd meeting).

I wasn't to venture out into the Centre much after the first couple of meetings. Taylor and Bogdan's (1984, p85) description of 'total institutions' fit my own perceptions of the Centre, where 'for residents daily life is routinized and regimented'. Moreover, Potts and Fido's (1991, p11) reference to official documents written in the 1920s about long-stay hospitals has some resonances with my own mental picture of this Centre, 'colonies, homely and simple in character and free from unnecessary repressive and restraining methods'. The Centre Group's meetings continued in this wider institutional culture.

The group 'type' and format of meetings

The Centre Group fits descriptions of the service-system type identified in the literature, particularly the 'user committee' or 'working group' that attempts to represent the concerns of Centre users (see McKenna 1986, Crawley 1982, 1988, Brooks 1991). Between eight and ten members meet every week for two hours in a room in the Centre. This fills a morning of their week that would otherwise be taken by activities orchestrated as part of the Centre's curriculum. The group had been meeting for about three years when I started attending. The Centre set it up as part of an initiative. Users vote members onto the committee in an annual ballot box vote. Photos and pictures are used on the voting forms to help non-readers. I was unable to find out from members or staff if this had always been the case.

Meetings start with the writing of an agenda by Lesley, the chairperson, and other members (I'm a 'non-reader' she told me). Topics of discussion tend to converge around Centre issues like fund-raising, food in the canteen and

staff-user relationships. Often Centre matters have been written down on the agenda before hand by the advisor. However, personal issues come to the fore just as frequently. Lesley covers each point on the agenda:

“Don’t forget the group rules”, Lesley commands. She is quite a figure and members do conform, but she also has a sensitive side. Jane was upset by Lesley’s bossiness and ran off to the loo. Lesley followed behind, the pair returning arm in arm some moments later” (ON, 4th meeting).

Members of the group voted Lesley as chairperson and Denise as secretary. The group has no treasurer or funds. The group is supported by Louise a member of staff. She took over from a previous advisor - an independent volunteer (GD, *Appendix 4, 6*). Louise supports the group as part of her job:

‘As members sorted the chairs and tables and set about organising the agenda, Louise was in and out of the room, getting the kettle, cups, teabags, coffee and biscuits for ‘elevenses’” (ON, 1st meeting).

In addition to the weekly meeting, members take turns to attend meetings of a local advocacy development project. Also a number of guests have been invited along to the Centre Group including a speech therapist and the Centre manager.

Group structure

A general overview of intra-group relationships will now be provided, though these relationships will be considered in detail below. Following

Worrel's (1988) attempts, the Centre Group can be represented as a sociogram²:

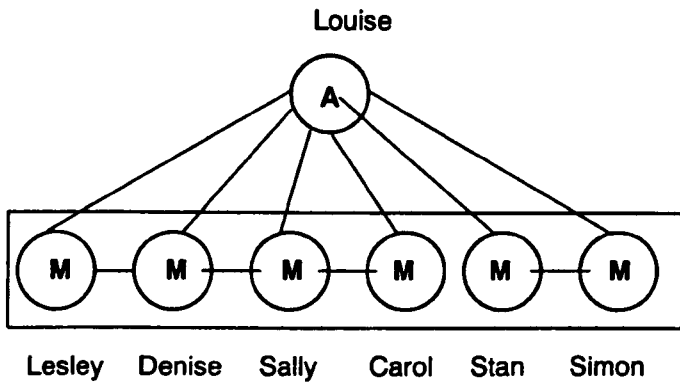


Figure 3 - Centre group's structure

This sociogram is similar to Worrel's 'advisor-orientated' group (see figure 1 above). Louise was a central figure in the group. Members often addressed her when they spoke in meetings and approached her when they had personal concerns. I found the group to have a friendly atmosphere:

'I like going to this group. That is - when I'm in the meeting and not in the Centre' (ON, 3rd meeting).

While Louise was obviously important to members, additional lines of communication existed amongst the membership. Perhaps characteristic of any meeting, self-advocates tended to chat together in small friendship groups. These membership ties and Louise's member-orientated role problematise Worrel's 'advisor-orientated' model. This appraisal is taken further in the subsequent section.

² For *all group sociograms* only some of the members are represented.

The Centre group and previous literature

Claim 1 - The staff advisors role is an impossible one

Previous literature has highlighted the dilemmas faced by staff advisors like Louise (Worrel 1987, Dowson and Whittaker 1993, Curtis 1995). Hanna (1978) sees the staff advisor as a contradiction, an impossible role, stifled by conflict of interests. Louise was central to the group working well, as members' themselves pointed out in the GD (*Appendix 4, 6*). However, figure 3 might create the impression that Louise's position promoted an advisor-orientated group (Worrel 1988, p48). Members were critical of Centre staff in the group discussion and during the meetings I observed. These views contrasted sharply with what they had to say about Louise:

'I'm buying his bike off him ... She listens to us a lot more than other staff do ... she makes the coffee ... she's alright - she's coping!' (GD).

Members saw Louise's staff role as beneficial. They spoke favourably about the support offered by Louise, differentiating this from the inadequate support offered by a previous independent supporter and other staff. Moreover, Louise encouraged group acceptance. She appeared able to manoeuvre herself out of a professional identity, to use spaces within her working week, to build relationships with self-advocates and to gain access to their 'structures of feeling' (Vincent and Warren 1997, p158):

'Lesley helps to support the 'special needs clients'. She had fallen out with one of the staff in the unit over her comments to another 'client'. She was very angry and upset about this and brought it to the group. Louise told Lesley that she should complain, "You can either see the Centre manager, I can see her for you, or we can go together". Lesley appreciated the advisor's support but said she would go on her own' (ON, 3rd meeting).

Louise had asked the group to be given a six weeks trial. She admitted that the group was already well organised and running smoothly prior to her coming in:

'In one of our few exchanges³ she told me that she was uncertain of the balance of the group, and wondered if it would be better if a more 'open meeting' was adopted, "So users could have the chance to bring up things they want to talk about"' (ON, 4th meeting).

Louise expressed an aim to get the group running without her being there - to let go and fade into the background - something identified as a prerogative of independent, non-staff advisors (Dowson and Whittaker 1993). Throughout my involvement with the Centre Group, Louise's actions challenged my preoccupations and previous appraisals that have assumed the worst about staff advisors. Indeed, Shoultz (1997a) found that some staff advisors welcomed the opportunity to support a self-advocacy group because they could break free from the shackles of professionalism. As one put it, 'I can be myself, as opposed to acting like a professional':

³ Louise tended to only speak to me only when members of the group were present.

‘Denise spoke for a long time to the group about two of the users who are having problems with their relationship, “What should we do” she asked. At no time did Louise shout her down. Instead she suggested that perhaps they should be left to sort it out for themselves, “Sometimes it’s better not to advise just listen”’ (ON, 1st meeting).

On the other hand, volunteer supporters may feel that they should at least do something, constructing and playing out (pseudo)professionalised ideas of support (Oliver 1990, Dowson and Whittaker 1993).

Claim 2 - Service-systems constrain the development of ‘real’ self-advocacy

Worrel (1987), Clare (1990) and Simons (1992) have expressed concerns with what could be called ‘reformist’ self-advocacy groups that concentrate on Centre rather than ‘real’ self-advocacy issues. As Lukes (1974, 1986) observes, power is often exercised by limiting the scope of decision-making and issues for consideration. The framing of institutionalised identities has historically threatened to deny people with learning difficulties a sense of self and autonomy (Goffman 1961, Potts and Fido 1991). Likewise, for Crawley (1988), attention is taken away from wider self-advocacy issues associated with choice and independence when service-based self-advocacy groups focus on Centre affairs. Centre issues were a central focus of meetings of the Centre Group:

‘Denise was unhappy about going on holiday and leaving her

boyfriend Simon. She was worried that a woman in the Centre would, “start to bother him”. Louise, although allowing Denise to talk, reminded her that the working group was, “A place to talk about things in the Centre, we can talk about that later together” (ON, 3rd meeting).

‘The Centre has received a £2000 donation, which means that they have £3500 towards the £5000 they need for the coffee bar. After announcing these details, Louise mentioned, “We will have to start fund-raising for the new lounge area” (ON, 3rd meeting).

These incidents appear to highlight how service-based groups emphasise members’ identities as Centre-users. There is something paradoxical about caring for the Centre in a context that, according to Worrel (1987), should be concerned with challenging the general inadequacy of services. Yet, as highlighted by the survey in Section 2 of this thesis, Centre issues are important to people with learning difficulties:

‘Members proudly told me of their involvement with a number of projects. These included canvassing the views of peers (leaflets were sent out to all the key-worker groups so they could decide what they wanted to eat at the Christmas meal) and fund-raising events that they had organised (like sponsored walking, car wash)’ (ON, 3rd meeting).

Beresford (1992), Beresford and Harding (1993) and Downer and Ferns (1993) identify the workings of Centres as significant concerns of self-advocates. Perhaps problems occur when Centre-based groups promote a

culture in which the identities of members are framed only in institutionalised ways. Members of the Centre Group were asked in the group discussion what they got out of the group. All said the group gave them the chance to be with friends, practice skills that had been denied to them before and opportunities to open up and speak out together. Rather than talking about their group membership in ways demarcated by the Centre, their explanations reflect hitherto general understandings of self-advocacy⁴, particularly collective identity (Dybwad and Bersani 1996, Oliver 1996). Wider self-advocacy issues were also put forward for consideration by the advisor:

‘Louise played the ‘Plain Facts’ tape, which talked about relationships. Many of the members nodded their agreement to the point being made about people with learning difficulties having the right to have relationships. Denise said that she would like to get married and live with Simon’ (ON, 5th meeting).

The Centre Group may appear limited on the outside and reformist in character because it works within the system (Vincent and Warren 1997). However, members framed what they got out of the group in ways that suggest that an ‘alternative framework of sense’ was being promoted (Vincent 1998). Nevertheless, there appears to be some authenticity in the negative appraisals of Service-based groups in previous literature. There were times when being service-based appeared to negatively impact upon group members. From my observations, these impacts appeared to be less to

⁴ See Crawley 1982, Williams and Shoultz 1982, Cooper and Hersov 1986, Amans and Derbyshire 1989, Simons 1992, Sutcliffe and Simons 1993, *People First Liverpool* 1996, *Huddersfield People First* undated, Kennedy 1997.

do with processes in the group and more to do with the larger Centre context and the standing of the group in the Centre's weekly curriculum. First, the fact that the group ran in the day sometimes caused problems:

'Sally has rehearsals for a new Play and will miss the next meeting. Dorothy has just got a college place after years of trying. Unfortunately the classes are on Wednesdays and she will miss the group' (ON, 2nd meeting).

Second, members were at times possessive of the group as a safe haven apart from the Centre in which it was located:

'At meetings, Stan pushes non-members out of the group. Other users that wander in are told to 'get out' by other members' (ON, 4th meeting).

The group could be seen as promoting an us (members of the Centre Group) and them (other Centre users) atmosphere:

'I used to walk past the room and see the group' (Stan on his thoughts on the group prior to joining, GD)

This possessiveness was understandable. When meetings ended, self-advocates stepped out of the room back into the Centre. With that they were back to being 'users':

'After the meeting I followed Louise into the dinner-hall. A long queue had formed leading to the serving hatch. I was led to the front

of the queue, the advisor had to get off early to take some 'clients' to a local college. No one asked if it was okay to push in. The advisor and I joined three other staff members in the queue. Two dinner-ladies were telling off three users. Earlier in the meeting of the working group Lesley had been unhappy with the attitude of the dinner ladies. I could see why. One of the staff, Maggie, reassured the dinner-ladies, "I'll sort them three out later". Maggie was some time before she joined the staff and me at the table. "I sorted them out", she announced, "thank god we finish at four o'clock today" (ON, 2nd meeting).

While each member of the working group returned to this climate of exclusion, the collective identity of the group elevated members and the advisor and together they challenged the conflicts of 'us and them' present in the oppositions of working group members -versus- other users, and staff -versus- users:

'Lesley is worried about one client who is being left on his own in a room with staff. "He shouldn't be in with the staff he should be with us"' (ON, 2nd meeting).

'Louise told the group, "You know how we have a staff meeting every month, well we decided that from now on if staff are away this will be registered in a book by reception"' (ON, 2nd Meeting).

Claim 3 - Service-based groups are tokenistic with little practical outcomes for members

There has been suspicion expressed in previous literature about service-system sponsorship of self-advocacy (Crawley 1982, 1988, 1990, *People First* of Washington 1984, Simons 1992, Dowson and Whittaker 1993, Tyne 1994). Centre Groups may be nothing more than token gestures in the name of user empowerment - contexts in which to extend existing training activities - stifling potentially radical outcomes of self-advocacy as service initiatives take precedence (Sutcliffe and Simons 1993, p80). My ethnography highlights a point picked up on in Chapter 7 - that people with learning difficulties use group contexts for their own and others' ends. As users of the centre, members of the Centre Group were interested not only in finding out about centre matters but also in how they could get involved:

'Denise told the group that when staff are in a meeting, early in the day at the Centre, she has noticed that other Centre-users who are not 'road-ready' or those who have fits are being left on their own without support. This was worrying because she had ended up supporting them herself and felt uneasy about it. Louise said that she would send a message over the tannoy to tell people where she would be if anyone needed her' (ON, 5th meeting).

'The Council are now going to charge 75pence a day for transport to and from college, the Centre and other places. Members were furious. They suggested that other users should be consulted about the charges. That afternoon, two members represented the group at a meeting of the county advocacy project. Denise brought up the

group's concerns about the transport charges' (ON, 2nd meeting).

These incidents highlight the centrality of Centre matters in users' lives and their desire for change. To suggest that service-based groups have no or little practical impact upon members assumes that such groups and various services have no worth at all in the lives of people with learning difficulties (McKenna 1986, Barnes, Prior and Thomas 1990). Members made links between themselves and other users and centre bureaucracy:

'Other trainees get something out of the group ... We can help others
- find out what is wrong and how we can help them ... We can help other users with special needs, security and special diets' (GD).

'I am struck by the strength of self-advocates to consider issues important to them and to support one another in speaking out. Often these issues are linked to the centre but why shouldn't these be important?' (ON, 6th and last meeting).

'A 'suggestion box' is positioned in the common room so that users can anonymously make suggestions and or complaints. Members of the Centre Group empty the box weekly and bring along the comments to meetings' (ON, 1st meeting).

These vignettes describe Centre Group members taking up the concerns of other centre users. Their actions may be indicative of what Lukes (1974) terms the constant, shifting nature of power-relationships that take place within institutions. A consequence of this shifting power was indicated in those times when actions by the group were taken out of the institution

(Centre) setting into other settings:

‘The group sends two representatives, usually Lesley and someone else, to meetings of a local advocacy development project. Consequently, the group has built up a number of useful contacts, one with a speech therapist who has worked with the group to produce a poster on ‘abuse’. The poster has been put up around Centres in the locality, highlighting yet again the group’s wider links’ (ON, 4th meeting).

‘Patricia is sick of the big words used in the minutes from the advocacy organisation meetings. Next time she will ask that they use short words and pictures’ (ON, 4th meeting).

The Centre Group appeared to have formed a number of relationships with potential practical outcomes:

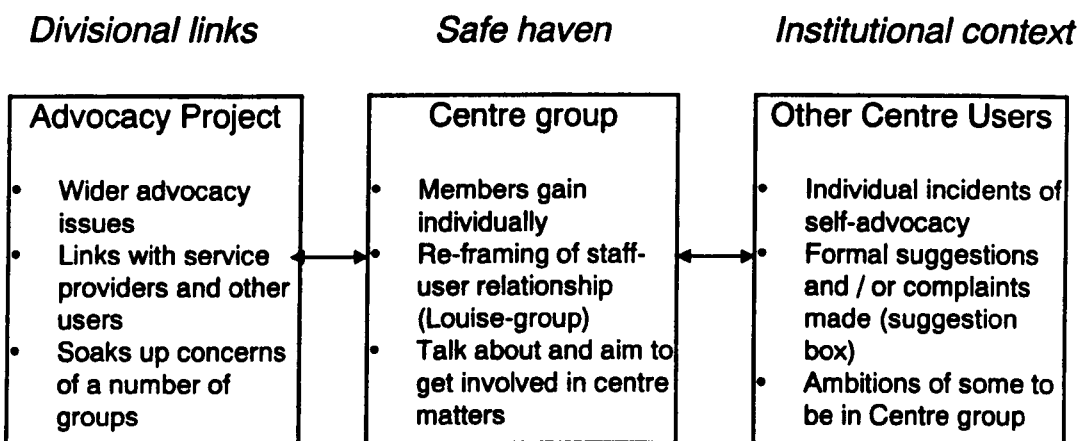


Figure 4 Potential for relationships between Centre group, users and advocacy project

There is, however, a danger of ignoring disabling barriers (Barnes 1990). As

referred to above, problems occurred when meetings ended and members went back to the larger Centre context. Institutionalised discrimination is hard to break through (Khan 1985, Oliver 1990). At least in the group members had a safe haven in which to speak out for themselves.

‘I said hello to everyone. I asked where Dorothy was. Dorothy is in her 70s. At the last meeting she had proudly told me about going to college and showed me a printout of her name that she had typed up in computer class. Louise, the advisor, stepped in. Dorothy had died. Lesley had represented the group at Dorothy’s funeral’ (ON, 6th and final meeting).

(2) The Social group – the merging of independence and professionalism

The context

At Lanley Day Centre in the late 1980s, users got together for annual ‘Shouting Out’ days. These have continued to this day but a number of users decided that they also wanted to meet away from the Centre and staff as a separate group. A lecturer from the local university, interested in self-advocacy, was taken on as the group’s supporter. The first meeting was held in late 1991 at Lanley Town Hall. People talked about work and pay, where they lived and what they did for themselves. They also voted on how often they would meet (every two weeks) and where (a local pub). By the next meeting the supporter had managed to get hold of a small sum of money from the local Health Authority. The group proceeded to vote in a Chairperson, Treasurer and Secretary. The Midland Bank was chosen for

the group's account. By the third meeting, it was decided that meetings would take place monthly, and the 'Social Group' [my pseudonym] was named. Over the next year, a social evening was held, links were made with *People First* groups and a service manager was invited to a meeting. Eventually the venue was changed to a quieter and more private social club. (This group history was obtained from Jurgen, who is one of the advisors).

The Social club is just off the main road and walking distance from the bus station in Lanley, a small market Town in the North East of England. Inside the social club, just off to the left of the bar area, is a small room where the group meets. It is partitioned off from an adjacent room where various Union and political pressure groups get together:

'I was one of the first to arrive. Two members were sat outside of the meeting room chatting together. A supporter stood at the bar with Christopher's Dad - a jovial chap who met and greeted members of the group as they made their way in before he left to drive home. Eventually we were all beckoned into the meeting room by Jurgen, one of the supporters' (ON, 1st meeting)

Members take a break half way through meetings:

'The bar staff are friendly as members of the group order orange, coke, bitter shandies and packets of crisps and nuts. Other punters can be distant ... The noise level was like any busy bar area as members congregated around the bar. Another meeting was being held in the snug area of the bar. Someone from this meeting asked the staff to pull down the shutters "because of the noise". Karen, the

comedian of the Social Group, shouted over, “We making too much noise for you then?!!” (ON, 1st and 4th meetings combined).

Members of the Social Group mixed with others who used the Social Club.

The 'group type' and structure of meetings

The Social Group transcends group types presented in the typology literature (Crawley 1982, 1988, 1990, McKenna 1986, Simons 1992, Dowson and Whittaker 1993). Up to 17 members attend evening meetings for two hours every three weeks. Members make their way to meetings by foot, taxi, bus or get lifts from supporters. The group has no formal ties with parental or professional organisations. It meets in an independent, non service-based context and members attend voluntarily. Membership was built up by word of mouth through members and supporters. However, some service and divisional ties exist in the support that is offered to the group. Two members of staff from local services voluntarily offer support in their own time – Virginia (a service manager) and Neil (a keyworker to two of the members). Advocacy assistance is represented by Sheila, who is setting up an advocacy project just outside Lanley, and was sitting in the group to ‘learn about advocacy’ (as she informed me, ON, 3rd meeting). ‘Independent’ advice is provided by Jurgen (who in addition works in an unpaid capacity with Virginia in supporting self-advocacy in Lanley Centres) and June (an employee of British Rail). Up to five supporters could be present at a meeting. The group pays for the rent of the room out of their modest funds, which they have received from Lanley Health Authority and a local business.

During my involvement, Christopher who had been voted in as chairperson by the group for the last two years chaired meetings. Ken was vice chairperson and took over when Chris could not attend. Jurgen wrote an agenda in his notebook at the start of the meeting, which he used to keep track of what members had to say:

‘Jurgen asked Chris to open the meeting. Then Jurgen asked members if they had anything that they wanted to say. Stories of outdoor pursuits, birthdays, nights out and accidents were offered. Jurgen asked the contributors not to go into detail until they were asked later by Chris’ (ON, 1st meeting).

‘Vice-chair Ken was in the hot seat tonight. When all possible topics for discussion were collected in, Jurgen asked him to chose someone to speak. He immediately plumped for Cliff his housemate who was upset’ (ON, 5th meeting).

In addition to weekly meetings, members know each other from centres, homes and other service-based ‘Speak Out’ groups. Jurgen and Virginia have ensured that the Social Group is represented at a number of User Consultation meetings in Lanley.

Group structure

General group dynamics are highlighted in the depiction of Social Group meetings as a sociogram:

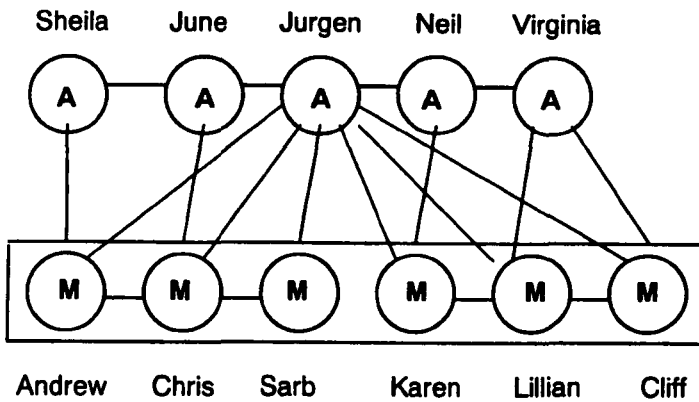


Figure 5 - Social group's structure

Jurgen was one supporter who played a central role in the running of the group: collecting the news and views of members at the start, supporting the chairperson Chris, applying for money, looking after incoming mail and the group's bank account. He was a focal point for members when they divulged information or made requests. The number of advisors to members appeared to fragment the lines of communication into working pairs or groups of supporter-member(s). A contributing factor may have been the professional-client relationships that were brought into the group, for example, in the case of Neil being Karen's keyworker at the Centre. In addition, there was a lot of communication amongst advisors.

Similar to the Centre Group, solidarity was evident amongst members in spite of the advisor-member relationships. At first sight the Social Group's sociogram approximates the 'advisor(s)-orientated' group structure (figure 1). However, delving deeper into group processes highlighted the complexities of support and inter-dependence of members.

The Social group and previous literature

Claim 4 - Voluntary staff supporters bring their work with them to the group

As noted above in Claim 1, self-advocacy literature has viewed staff support as a paradoxical and contradictory venture. These appraisals focus on staff advising in service-based groups (Crawley 1990). However, the Social Group combined an independent, non-service context for meetings (social club) with voluntary support from two professionals. When professionals offer their support voluntarily and outside of the service system this invites questions about the standing of previous literature on the 'staff advisor'.

A point of caution should be made at this stage. Schatzman and Strauss (1973, p127) warn against the inevitable pinning down of observations into discrete analytical categories. Maybe I was sensitised to view Virginia and Neil's interactions as directly reflecting their staff roles. Perhaps I saw more than was really there. Moreover, it is difficult to say what members really made of their supporters' professional credentials, or indeed whether members were consistently aware or bothered about their supporters' staff roles. However, there were a number of incidents that could be seen as examples of staff advisors bringing their work along with them to the group. One of the key criticisms of staff advising is the clash of accountabilities to the group and to colleagues and services (Hanna 1978). For Worrel (1987, 1988), groups can be stifled when members pick up on supporters' conflict of interests (see Vincent and Warren 1997):

'Karen: Staff say one thing and then they say another. You don't

know which way to go. Now if they want to see me they should come to my house, not me traipse back and forward to their offices.

Angie: Yeah, I hate one of the staff, she said .. [eyeing advisors]. Well, I'd best not say' (Paraphrased and written as ON, 5th meeting).

A general air of 'professionalism' seemed to have been brought into the group:

'I observed a number of occasions when staff supporters shared comments about members - how members were getting on at their new houses, what jobs they were doing, when members were next due to meet up with staff. This was especially evident between Virginia and Neil, colleagues at a local Centre' (ON, 6th meeting).

'Max explained to the group that he had hit a member of staff. Neil, a keyworker in the daytime, obviously worried that this might become a new sport amongst service users, took the moral high ground, "It's wrong to hit anyone"' (ON, 7th meeting).

In the latter vignette Virginia employed what may be termed an advisor-centred intervention (see next chapter). Rather than talking through the incident with Max to see if he had good reason for his outburst, a service-based programme was offered. Further evidence appears to support the idea of staff bringing their work along with them:

'The group meeting was made up five supporters and six members. The members sat quietly for about five minutes as the supporters talked amongst themselves. Then Karen, one of the members, piped

up, "It's like a staff meeting in here". Jurgen, one of the culprits acknowledged Karen's remarks, "Yes supporters - shut up". Ken, who had looked particularly disinterested, turned to me, winked and remarked, "You'll sleep well tonight, Danny" (ON, 6th meeting).

Conversely, when an esprit de corps amongst a staff body disappears this may have ramifications for self-advocates:

'Andrew asked Virginia to have a word with a member of staff at the Centre who was making his life a misery. Although Virginia obviously felt for Andrew her professional relationships were complicated, "I would do Andy but we don't speak to each other anymore, we had a row"' (ON, 8th meeting).

Rosenhan (1973, p258) concluded in his classic study 'Sane in Insane places':

'Our overwhelming impression of the staff was of people who really cared, were committed and were uncommonly intelligent. Where they failed, as they sometimes did painfully, it would be more accurate to attribute those failures to the environment in which they, too, found themselves than to personal callousness. In a more benign environment, one less attached to global diagnosis, their behaviours and judgements might have been more benign or effective'.

Perhaps, at times, Virginia and Neil couldn't get out of their 'work roles' by the time they had got to meetings of the Social Group. If this is the case then, paradoxically, this inability was at times advantageous to the group:

'It's difficult to understand what Sarb is saying. Jurgen suggested that if I couldn't understand Sarb then I should ask him to repeat what he had said. Vacant stares and "eh... yesss" irritate him ... I couldn't understand Sarb tonight. He was frustrated with me so turned to Virginia, a long-time staff-acquaintance in various service settings and she repeated what he had said' (ON, 1st and 4th meetings combined).

'Virginia and Jurgen brought in the draft of their user-accessible leaflet on service consultations. Over the next 45 minutes they went through the leaflet. Members responded to the points that were made, pictures were picked out, and anecdotes presented' (ON, 5th meeting).

Virginia's high-profile job and Jurgen and Neil's service links allowed information to quickly seep into the group. They told members about changes in services and bounced back and forth ideas between the Social Group and other self-advocacy groups (including working and tenants groups in Lanley Centres and homes). However, a question mark remains over the relative benefits of supporters' staff status to self-advocates.

Claim 5 - Groups that function as social groups are not 'real' self-advocacy groups

Worrel (1988) warns against self-advocacy groups that are organised around social or leisure activities. The Social Group can be seen as such a collective. My involvement made me re-appraise my understandings of self-

advocacy that I had gleaned from the literature. What is chaotic to an outsider may be organised for the insider (see for example Marsh, Rosser and Harré 1978). Corbett (1991) argues that it is easier to pin notions of disorder and abnormality on to minority groupings. Often the Social Group was not unlike a night out in the pub with my mates, but because members of the Social Group have learning difficulties there was an urge to see something shambolic. For devalued people, society rules that indelicate behaviour must be reprimanded and sanctioned (Booth 1990, p31). The Social Group appeared to provide a context away from the surveillance of others:

‘Tonight, as usual, people were shouting, teasing, laughing, discussing and arguing. Sarb decided to join me in a New Year drink. Instead of his usual pint of orange he had a lager. Some twenty minutes later he seemed quite pissed’ (ON, 4th meeting).

‘Lillian told me about the problems she’s having in her house. “It’s no good to bottle things up”, she concluded ... Ken got his pint of bitter shandy in at the bar. “They don’t like me drinking”, he told me about the staff in his house’ (ON, 3rd and 5th meetings).

Worrel (1988, p16) notes that people who have been labelled are often very alone in their personal lives. The Social Group provided members with extra opportunities to make friends:

‘Cliff is very demonstrative and affectionate. He often grabs your hand, holds your leg or puts his arm around you. Sometimes he smacks you playfully on the head. Some people don’t like such

displays of affection. Like the chap at the bar, fag in mouth, pint in hand, obviously distressed by Cliff rubbing away on his bald head! Another member, Carol, is very quiet and a great listener. Cliff came up and grabbed her face. She laughed and put her hands on his face as well, "What are you doing?", Cliff smiled. They sat together' (ON, 2nd meeting).

'Ken and Cliff fell out. Cliff told Ken to 'piss off'. Afterwards Ken informed me, "I do feel sorry for Cliff. I go and see my mother every weekend, but he only sees his family now and again"' (ON, 6th meeting).

Begum (cited in Campbell and Oliver 1996, p96) notes that a failing of the wider disability movement has been the lack of opportunities for people to meet up socially and develop support systems for one another. Having a culture develops identity and the confidence to open up (Whittemore et al 1986, Goode 1992, and Todis 1992):

'At the last three meetings Jarrod has told me exactly the same things, "I'm Jarrod, I work at Kwiksave in the warehouse, I like trams, do you? I went to France, to Paris and Bordeaux with my mother 33 years ago, have you been abroad?" This meeting Jarrod told me about his trip to the countryside' (ON, 8th meeting).

Moreover, the Social Group was not just about having a pint with friends. The meetings appeared to provide an accepting environment where personal concerns could be shared (Simons 1994):

'Ken told the group that on Thursdays the staff in his house collect 'his wages' from work at the local college and give him a bit every day. At first, the supporter, Jurgen, put this down to Ken's misunderstanding - "You don't get wages, Ken" - then twigged, "Ken, did you know that the money you get is from your benefits?". "No", replied Ken. He has never seen his post office book and didn't know he had one - "The staff must have it" he realised ... Sarb's brother 'minds his wages' for him ... Jarrod gets paid for working at Kwiksave but it goes straight into his bank account opened by his Mum. Jarrod doesn't know how much he gets a week' (ON, 6th meeting).

'Lillian wants her own flat. She hates the group home, the staff treat her like a child and tenants pick on her. "Wouldn't you be lonely?", asked Neil. "No I'd have me cat" ... Cliff and Ken don't have keys to their house. Sarb and Max do, but the latch is left off for them by their brother and Mum ... Karen said that the staff watch her having a bath' (ON, 4th and 5th meetings).

The chance to socialise was appreciated (GD, *Appendix 4, 7*) which in time raised important elements of self-advocacy. To denounce the Social Group as not a real self-advocacy group ignores the importance of friendship (Taylor and Bogdan 1989) and the positive implications of group identity (Campbell and Oliver 1996). That said, like all friendship groups and meetings, tensions emerged in the Social Group:

'Sarb is easily bored. When members chat away he is prone to put his head in his hands, sigh loudly, shout, "Boring", or walk out into

the bar. However, he contributes a lot, draws up leaflets introducing the group and wants “to talk about work and money but not rubbish” (ON, 4th meeting).

Similar tensions emerged in all groups.

Claim 6 - Independence is necessary for 'true' self-advocacy

The Social Group exemplified the pros and cons identified in the literature about self-advocacy groups that meet in independent contexts without financial or organisational accountabilities to carer, professional or advocacy groups (Crawley 1982, 1988, 1990, McKenna 1986, Simons 1992, Dowson and Whittaker 1993). Members appreciated meeting outside of service settings, including group homes - as Karen put it, ‘You can talk to people away from home’ (GD) – and appeared at ease with themselves and the supporters:

‘Chris was talking about his views on services. Jurgen, apparently assuming that Chris was addressing only him, said, “Tell your views to the whole group Chris”. “I am speaking to the group thank you very much”, he replied’ (ON, 9th meeting).

‘Jurgen asked the group to name places where people had treated them well. Andrew told the group about a brilliant Pizza he had had at Pizzaland. Jurgen, the supporter, responded, “That’s nice, but we’re talking about places which have treated you well, not which places are good to eat in”. “I know”, replied Andrew, “Let me finish. The staff are lovely in Pizzaland. They always make me feel

welcome” (ON, 9th meeting).

Side by side with these shows of confidence, were the pragmatic limitations imposed by the group’s independence. Previous literature has recognised the financial struggles and lacking resources of ‘independent groups’ (e.g. Simons 1992). The Social Group highlighted other factors. First, in contrast to the Centre Group, the Social Group’s monthly meetings meant that roles were vaguely defined and unpractised:

‘Chris, the chair, is continuously prompted by advisors to keep the group in order ... Chris was back tonight - he’s missed the last few meetings – so Jurgen reminded him of the format of the meetings’ (ON, 1st and 7th meetings).

Second, transport was a problem – with some members not attending the group because staff or carers had forgotten to book taxis. Third, the group’s limited funds prevented them certain ambitions:

‘Chris suggested that the group should have a Christmas meal in a restaurant, which could be paid out of the group’s kitty. Jurgen reported that the group only had £65’ (ON, 5th meeting).

Fourth, picking up on Sutcliffe and Simons (1993, pp80-81) observations, members only had a short amount of time in which to speak up in:

‘During’ news’ an advisor told Cliff, “You’ve had your turn - now give others a go”. Are staff pushy? Well, perhaps they too feel the limits imposed by only meeting every three weeks’ (ON, 3rd

meeting).

Fifth, progress was slow and practical outcomes were little. Whereas the Centre Group pushed for issues to be put in the Centre curriculum, supporters were often frustrated:

'Graham is being picked on at work ... Lillian is sick of being treated like a child by staff ... Cliff and Ken still have their benefits given out in small sums by the staff. At the Xmas meal, which cost a fiver and clearly pointed out in the letter sent to their house, they arrived with only 3 quid each ... Jurgen asked, "What can we do to help?"' (ON, 1st, 3rd, 4th, 6th meetings).

Paradoxically, when formal, practical and measurable outcomes of the group were observed, this appeared to be linked to the non-independent elements of the group's structure:

'Virginia is carrying out some in-house evaluation of the Centre she manages. She asked if members got anything out of the group ... Virginia and Jurgen have produced a user-friendly booklet on consultation procedures for new services. They went through this with the group. Members agreed with many of the points especially the bit which read, "Everyone should say what they want to do during the day no matter where they live", which was met with a resounding "YES!"... Jurgen sent a letter to the Centre outlining a member's complaints with staff' (ON, 3rd, 4th, 5th, 6th meetings).

In a number of specific ways, those supporters with professional status

brought with them the potential to act upon self-advocates' concerns about service-related issues:

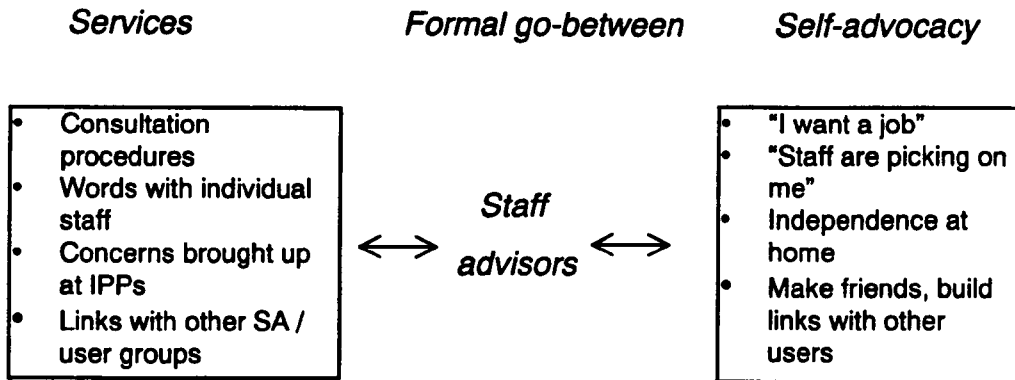


Figure 6 - Potential relationship between Social group, professionals and services

However these relationships can falter if self-advocacy becomes lost in the system:

'A user consultation meeting was called to launch Lanley's Social Services, Health Commission and Health Care Trust consultation plans for voluntary groups, carers, staff and users. Social Group members were represented twice - as a voluntary group and as individual users. Although service provision plans have already been drafted, and are to be put into practice in 3 months time, Lanley authorities aim to 'consult' (after the event). At no time were users with learning difficulties adequately addressed. Language used in the meeting by authority representatives included 'fait accompli', 'participative communication', 'consultation membership', 'passive recipients' and 'logistics of communication' (ON, User Consultation meeting).

‘At the next meeting Jurgen asked those that had attended what they remembered. “Max looked around the room and pointed, “I remember speaking to you Cliff, how are yer?”’ (ON, 6th meeting).

Involvement with the Social Group highlighted the positive and negative effects of being both independent and linked to service systems. On comparing the Social and Centre Groups, both sets of self-advocates appeared to gain something out of their involvement. Therefore, to say that independence is always best (or that it actually exists) may cloud over deeper dynamics within groups.

(3) The Advocacy-supported group – divisional links

The Context

In 1993, Bill Shackling moved 20 miles from his hometown to a group home in Cotshom. He quickly made friends with the other residents. Bill stood out, not only because of his extravert nature but also because of his long-standing involvement with a self-advocacy group in his old town. He was instrumental in setting up a resident’s committee in this new home. By chance, two workers from a local advocacy project - John and Paul - had been in contact with Bill’s old self-advocacy group. They were told that Bill had recently moved to Cotshom. The two workers were interested in developing self-advocacy links and met up with Bill soon afterwards. They offered to support a self-advocacy group that would meet separately to the residents committee. It was not long into 1993 before the Advocacy-supported Group got off the ground, also meeting in Bill’s house.

Bill's experience would prove to be invaluable. He and his housemates Rudi and Guy put up posters in local Centres inviting people to join the group. Consequently a number of new members joined, including residents from a local 'Autistic community'. Before long, some members from the original residents committee who had joined at the start had now left, so a new venue was sought. Bill, Rudi and Guy looked over a number of places before plumping for the Youth Club, handily located just down the road from their home. (This group history was obtained from John, one of the advisors).

The Advocacy-supported Group meets in the premises of a youth club in a quiet village in the Midlands. Cotshom village is Old England - winding, tree-lined roads, Victorian styled homes, listed buildings and church spires.

'I park up, I'm early by 20 minutes. One of the members pops his head out of a window, "Hello, are you Danny?" he asks. After checking with the group, Bill shows me in. As I walk in 'news' is just finishing. Each member talks about what they have been up to. Everyone has loads to say. I apologise for being early. Members put me at ease with greetings from every side of the room. I find a seat, just back from the circle of chairs, not too intrusive, while Bill asks for introductions. It is Erica's turn to be chairperson tonight and she skilfully goes around the room eliciting a piece of information from us all' (ON, 1st meeting).

Only the Advocacy-supported Group meets in the Youth Club on Thursday nights, which is situated behind a pub and close to Cotshom Village Church.

The group 'type' and format of meetings

The Advocacy-supported Group has divisional links (with an Advocacy Project) and shares a number of characteristics with 'autonomous type' groups identified in the literature (Crawley 1982, 1988, 1990, McKenna 1986, Simons 1992, Dowson and Whittaker 1993). 11 hard-core members voluntarily attend evening meetings once a month for two hours in the independent setting of the Youth Club. The group has three advisors. John and Paul support the group as part of their jobs as Advocacy Project workers and take it in turns to attend alternate meetings. George, a nurse in the daytime, offers voluntary and independent support every meeting. His primary job is minute taker. Membership has been built up by word of mouth in homes, Centres and Advocacy Project activities. Members pay subs each meeting to pay for the rent of the Youth Club.

Meetings start with the writing of an agenda on a flipchart:

'Becca wrote down the agenda on the flip chart paper, including 'News', 'Annual report' (of the Advocacy Project) and 'A.O.B'. "What's A.O.B. stand for?" asked Paul, "Any other business", replied some of the members in chorus' (ON, 3rd meeting).

The chairperson job is shared. Each member is assigned a meeting to chair once a year:

'John put up a flipchart with dates of meetings for the next year. Members shouted up when they would like to chair a meeting and

John wrote up names by the dates' (ON, 5th meeting).

During my involvement Guy held the treasurer position and was assisted by his housemate Rudi:

'Towards the end of the meeting, Guy tacked up a piece of flipchart paper on the wall. On the paper he had written details of the group's Post Office account which he went through for the benefit of members: how much they had before the meeting, deductions for milk and biscuits, additions for subs, account at close of meeting' (ON, 5th meeting).

A number of residents of Cotshom Village attend the group like Bill, who shares a house with Rudi and Guy and lives next door to his brother Richard. In addition, up to five residents from a local 'Autistic Community' arrived at the doors of the Youth Club in the Community mini-van. Close friendship groups were observed. Members share homes, services and activities offered by the Advocacy Project such as the drama group, sports club and Project Committee meetings. The group had invited a musician along to a meeting where a group song was written which "expressed the group's theme" (Taken from minutes obtained from treasurer at the 4th meeting).

Group structure

Before delving into the group processes of the Advocacy-supported Group, a number of group dynamics can be highlighted by a sociogram:

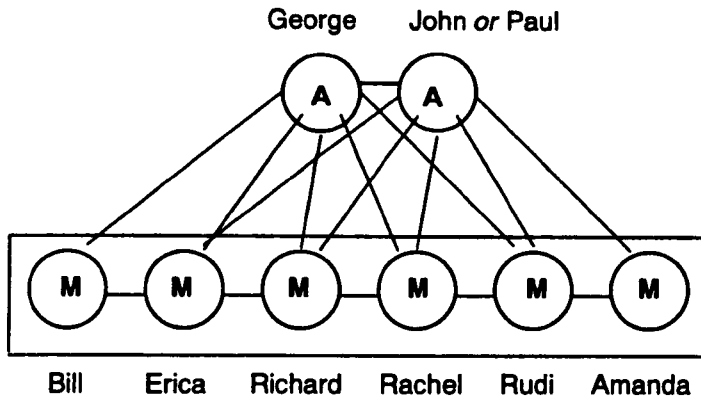


Figure 7. Advocacy-supported group's structure

An initial facet of group dynamics that I picked up on was the interdependence and solidarity amongst members:

'When coffee break came, members made their way over to the kitchen hatch where Richard was asking for requests for tea or coffee. Over the next 15 minutes people sat and chatted. No one spoke to me. It was great' (ON, 4th meeting).

These close ties appeared to exist regardless of advisors' interventions. In contrast to the Social Group, I did not pick up on any obvious advisor-member working relationships. Instead, lines of communication between advisors and members were prominent when members requested information or support. Involvement with the Advocacy-supported Group highlighted some gaps between the assertions in the literature and the realities of group dynamics.

The Advocacy-supported group and previous literature

Claim 7 - Advocacy supporters are prone to advocate rather than support self-advocacy

Worrel (1988) and Dowson and Whittaker (1993) warn against advisors lapsing into advocacy. Sutcliffe and Simons (1993) call this the problem of the 'balancing act'. There is a fine line between encouraging people to be assertive and being assertive for people:

'A good organizer pushes to get things done but does not do for other people' (Worrel 1988, p52).

Daniels (1982) identified problems in the transition from Parent Advocacy to Self-advocacy, with advocates finding it hard to relinquish power to those they were committed to speak up for. Such problems have relevance in view of the survey's findings about the rise of Advocacy-supported self-advocacy groups (see Chapter 5). Following this line of enquiry does a professional advocate status create problems for advisors dealing with the aforementioned balancing act? I noted a few occasions when supporters jumped the gun:

'Rudi said that he has helped to make a video on residents' rights⁵. John directed Guy to put down on the minutes that "Rudi will bring the video to the next meeting". Rudi was not asked, he stopped talking and the advisors discussed the possibility of getting a video

⁵ This illustrates another criteria that could be used in identifying group 'types' - members' links with other self-advocacy groups.

player' (ON, 5th meeting).

'George is a sentence finisher. When Erica speaks she does so in a long ... right ...brok ...right ... en ... okay ... mann .. hmmm ... er. George tends to get in there before she has finished' (ON, 3rd meeting).

These vignettes highlight the superficiality of the 'Advocate advisor = advocating advising' relationship. First, George's voluntary independent status indicates that advocacy interventions can come from any advisor regardless of their status. I observed advisors enacting what could be termed 'advocacy interventions' across all four groups (see next chapter). Second, the above vignettes show advisors pushing the group along. While this may seem problematic, the group only met monthly. With time as valuable as it was, it seems premature to write off supporters' actions when they were trying to ensure that everyone had a say and that things got done. Third, when literature highlights the impact of forceful advisors, the actions of self-advocates may be forgotten:

'Tonight, deciding who would chair each meeting and when, Amanda was asked when she wanted to be in the hot seat. "Well I'd rather not, thank you very much, my concentration wanders". Even when pushed Amanda remained resolute' (ON, 3rd meeting).

I observed a number of interventions by advisors that discredit claim 7:

'Graham likes Disney films. At Christmas he got a book on Walt Disney which he brought along to a group meeting. Graham told the

group, “The book alleges that he was prejudiced, anti-Semitic and an aid to the FBI in putting his workers forward to the board of un-American Activities”.⁶ After this articulate summary, Graham asked, “What do people think about that?” Silence. John looked bemused, as did others, but carefully brought the situation around by asking who had seen any Disney films. Jane had seen 101 Dalmatians. Others joined in. Then the advisor asked the group what prejudice meant, a discussion ensued’ (ON, 3rd meeting).

‘Towards the end of our phone conversation about me coming down to the group, Paul demanded that I feedback some of my findings to the group [see *Appendix 4, 8*]. I mentioned the possibility of talking with individual members to which Paul replied, “Hold it! You’re saying something different now”’ (Telephone conversation, ON taken afterwards).

If advocacy status is to be accepted as an impacting factor then why should it be negative? Booth (1991, p27) asserts that advocacy partnerships can act as an effective antidote to the power of professionals and the authority of service staff. John and Paul’s formal divisional links may have equipped them with the confidence and backup to challenge institutions, whether they be service-based or not:

‘John the advisor announced that following the group’s letters to Cotshom council yellow lines are going to be put down to prevent

⁶ Graham was rather a character. Well spoken and intense he would often draw me into a long discussion on current affairs. The last time I spoke to him, he was concerned about Tony Blair’s ‘New Labour’.

the many parked cars which the group believe are hazards for people crossing the road' (ON, 5th meeting).

The financing and training of workers may promote an ethos that embraces self-advocacy (Wolfensberger 1972). Moreover, an advocacy base may provide advisors with a network to overcome isolation and share anxieties, ideas and strategies (Sutcliffe and Simons 1993, p88). However, from my observations, the 'advocate advisor = advocacy relationship' appears only to scratch the surface of group dynamics. Interventions of advisors and members existed underneath labels that appeared to be associated with advocacy support.

Claim 8 - Divisional groups are too sophisticated

Advocates' voices are strong (Braddock 1994, Tyne 1994). Dangers exist in sophisticated others speaking over and for vulnerable people (Daniels 1982, Flynn and Ward 1991). The Advocacy Project's 'sophistication' appeared to have an impact when the group dissolved into the larger organisation:

'At the advocacy organisation AGM. John, the advisor, addressed the audience. He then gave a convoluted spiel about advocacy falling into 'three key issues' - (1) short-term advocacy, (2) develop consultation between users and services and (3) self-advocacy projects. I hope others understood because I didn't. Later, the treasurer's report - the chap made a science out of accounting and spoke of 'these people' advocacy is helping. He asked for a vote on the finances, about what I can't say, members with learning difficulties looked bemused, voting cards in hand' (ON, Advocacy

Project AGM).

In this sense 'sophistication' may actually mean inaccessibility or exclusion (Sutcliffe 1990, p28, Sutcliffe and Simons 1993, p104). Back inside the group, divisional status appeared to have less significance. Members considered many issues in accessible ways:

Jane shouted to the group "Manchester ... bombing, bombing". Within seconds Paul had picked up on this asking the group, "You know what Jane is talking about? The Manchester bombing?" Rudi said that he had seen in on TV, "It makes me wild". It was decided that the group would talk about the bombing later on in the meeting, this was recorded in the minutes - "Bill asked the group their feelings. Guy had relatives in Manchester and his first thoughts were for their safety. Edward's anger showed through and he asked why people cannot live in peace.... The group feel the introduction of CCTV is helping to reduce the acts of violence ... lots of ideas but no easy answers" ... Soon the talk moved to the general point of 'nasty people'. Rudi said that it's not always difficult to walk away from nasty people, others agreed citing incidents of bullying and abuse. Paul wound up the discussion for the group, "You are all saying how it is not always easy to stick up for yourself" (Minutes obtained from supporter and ON from 5th meeting).

In the group, members included one another, at the AGM their interdependence took second place. Claim 8 appears to have authenticity with respect to wider group links. However, read superficially it may downplay self-advocates actions within self-advocacy groups.

Claim 9 -The ambitions of the self-advocacy group get lost in the wider ambitions of advocacy organisations

Organisations for disabled people can be criticised on the grounds of the interests they actually serve, whether they be of the establishment, the careers of the professional staff or the personal aggrandisement of key individuals through the honours system (Oliver 1990, p115). Advocacy organisations may be prone to similar failings:

‘At the end of the meeting one of the group’s advisors stood up and thanked the local MP for coming along. After that, the manager of the advocacy organisation, the staff at the local ATCs and SECs and the volunteer advocates, were called upon and applauded for “all their hard work”. No one thanked people with learning difficulties’ (ON from AGM).

By contrast a number of incidents in the Advocacy-supported Group highlight the congruence of some advocacy and self-advocacy issues. For example:

‘The advisor brought in a report on the new DDA. The treasurer, Guy, said it was a good idea and sent off for 20 more so that every member could have a copy ... Paul is completing the Annual report for the advocacy project and wanted to know what people get out of the group’ (ON, 4th and 5th meetings).

Members got to know each other in a wide variety of contexts like drama,

football and music clubs set-up by the Advocacy Project. This interdependence appeared to be channelled back into the group:

‘Rachel smells her hands, rubs her face, says nothing. Paul asked her if she wanted to be chairperson, we waited ... “Yes - she does”, says Erica her housemate, “She just winked”’ (ON, 6th meeting).

‘News is greeted with empathy. Unhappy tales are met with empathic sighs and encouragement - “You’ll be fine”. Happy anecdotes are given a round of applause’ (ON, 1st meeting).

According to Oliver (1990, p113), incidents of self-help are characteristic of the new disability movement, which is culturally innovative in the part it plays in struggles for genuine democracy, equality and justice. Consequently, claim 9 can be turned on its head:

Advocacy ambitions

Self-advocacy ambitions

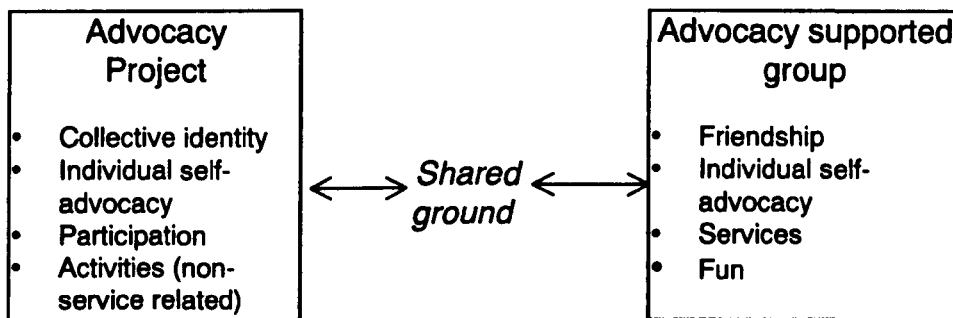


Figure 8 – Potential relationship between advocacy-supported group and advocacy project.

A key analytical point that emerges is the extent to which the Advocacy-supported Group is affected by the wider Advocacy Project. Outside of the

group, the project had both negative (like exclusion at the AGM) and positive effects (providing opportunities for people to make friends). However, like the Centre Group, intra-group dynamics appeared to be more the result of particular advisor and member interventions. These dynamics exist behind the superficial organisational ties which typology literature attaches so much importance to. Perhaps ethnography highlights group processes that are not easily placed into discrete organisational categories.

(4) The Independent group - professional self-advocacy

The Context

The Independent Group is based in an office in Blaketon Town Centre in the North of England. The group's office is a two-up, two-down terraced house, which contains a computer, photocopier, telephones, fax, kitchen and four meeting rooms. Previously the group had met in a building owned by Social Services, which was situated some three miles outside of Blaketon. The new office is not owned by services and is conveniently placed close to the bus station. A leaflet obtained from the group provides a brief history and introduction:

'The Independent Group is an innovative, independent self-advocacy project based in Blaketon. The project is run and managed by people with a learning difficulty, supported by three part-time workers. There are only a handful like it in the country. The main aim of the group is to support adults with learning difficulties in speaking out, making choices and decisions, becoming aware of their rights and to manage the Independent Group themselves. In early 1992 a group of

people got together to form a steering group to set up the Independent Group - five people with a learning difficulty, a member of Blaketon Coalition for Disabled People, a person who worked for MENCAP and two people from Blaketonshire Centre for Integrated Living (BCIL) who were holding the money obtained from voluntary services. The steering group drew up a person specification for the job of project support worker, interviews were held and presentations given. Members with learning difficulties on the interview panel could not separate two people. They suggested a job share. They [Dennis and Julia] agreed and started in late 1992.

By mid 1993 there were 10 new members meeting in Blaketon every Thursday. The group provided a training day on making information accessible to non-readers and soon after acquired their own office space in a community building. Computer, phone, copier, fax, TV, video, camcorder and kettle were all acquired. They became active in the Blaketon Coalition of Disabled People to show what things are important to people with learning difficulties and continued to carry out training days on 'self-advocacy' and related issues for service users, students and staff. Presently, ... 20 people are involved in the project' (sic, Official introductory leaflet obtained at 1st meeting).

My first meeting with the group took place in their 'old office':

'I had spoken to Andy, the vice-chairperson, on the phone about visiting the group. When I arrived I was led into a room by one of the members, where a circle of people including self-advocates, three advisors and a suited chap met me [who turned out to be a

representative from BCIL]. Everyone introduced themselves before one of the members gave a 20 minute introduction to the group' (ON, 1st meeting).

Other notes taken after this first meeting, picked up on themes that ran throughout my involvement (in italics):

'The group seems to function in a *professional, business like manner*. Having its own offices and independent status along with the funding of supporters hints at *bureaucracy*' (ON, 1st meeting).

As with all the groups, members and advisors were welcoming:

'Supporters remained relatively silent throughout the session. One chap, in his forties, [Dennis], was particularly non-intrusive and he introduced himself in an understated and humble way' (ON, 1st meeting).

The group 'type' and format of meetings

The Independent Group has some characteristics of all the different 'types' identified in the literature (Crawley 1982, 1988, 1990, McKenna 1986, Simons 1992, Dowson and Whittaker 1993). The group has autonomous type qualities through its independence in terms of meeting place, status of advisors and voluntary membership of members. Also, service-system links exist in two ways. First, two of the supporters, Dennis and Julia, have both worked for services at some point during their involvement with the Independent Group. This has been problematic for both of them. Julia left

her half time job as care assistant after her line manager accused her of spending too much time with the group (ON, 5th meeting). Dennis has also had confrontations with service management over his attempts to promote self-advocacy:

‘Dennis told me that in addition to the Independent Group, he was supporting a Centre-based group. The members of the latter group had decided that they wanted to have their meetings outside of the Centre. They arranged to meet in a social club and Dennis told them that they were to phone if they needed him. Some days afterwards the Centre manager called Dennis into her office and demanded to know why the group had met outside, “They could have been run over”. Dennis had replied, “I could also have been run over - is that a problem? Should I have stayed indoors?”’ (ON, 4th meeting).

Second, the group is offered as an alternative to day services by Blaketon County Council. The group receives a sum of money from the Council that pays for the lease of the office premises and Dennis and Julie’s salaries (‘paid (by group) independents’, see table 4, Chapter 5). Accountability to the County Council became particularly evident when the Council requested an independent evaluation of the group during my involvement. I was asked to carry out this evaluation (for a copy of the Council’s report see *Appendix 4, 11*, for a copy of the group’s report see *Appendix 4, 10*).

There are also divisional origins. The group received an initial sum of money from Blaketon Voluntary Services, MENCAP were represented on the initial steering group and charity money pays the salary of a third supporter (Matthew). During my time with the group, grants from County

Council and Charities were either coming to an end or being reassessed. The group was therefore in the process of applying for National Lottery money (they were successful in their bid). Finally, the group has a number of coalition relationships, as the above excerpt from the official leaflet points out, with Blaketon Coalition of Disabled People and BCIL. The latter group is represented on the Independent Group's management committee that meets three or four times a year. However, as Robert pointed out to me, the group has become progressively independent and separated from BCIL, especially since taking on and employing three independent supporters (ON, 4th meeting).

The majority of my contact time with the Independent Group was during 'drop in' days (my term). These sessions were attended by up to 12 members and all three advisors on various days of the week from mid-morning to mid-afternoon. 'Drop in' days were not organised around a meeting, though members would chat over coffee and packed lunches, help out with photocopying and answer the phone. During the days I attended, members also prepared for Executive Committee meetings that took place every Tuesday from 10am until 3pm at Blaketon Town Hall and for training sessions that the group gets paid for:

'Andy was preparing the agenda for the meeting on Tuesday. The TV was on in the other room, Imran and Matthew [the supporter] chatted together over lunch, Colin told me about his organ lessons ... Robert showed me the flipchart that he had used along with Andy and Dennis [supporter] at a recent training day' (ON, 3rd and 4th meetings).

'Agenda items of executive committee meeting, June 13th 1996: (1) New Office, (2) Workers [supporters] Wages, (3) Funding, (4) A.O.B. [including writing of Annual Report, upcoming Training Days]' (ON, taken from agenda obtained from executive).

The elected members of the executive committee were Robert (Chairperson), Andy (Vice-chairperson), Jane (Secretary) and Jonny (Treasurer). I was to attend one executive meeting and spoke with two organisations that had received training from IG (see *Appendix 4, 10 and 11*).

Group Structure

The Independent Group structure can be represented as a sociogram:

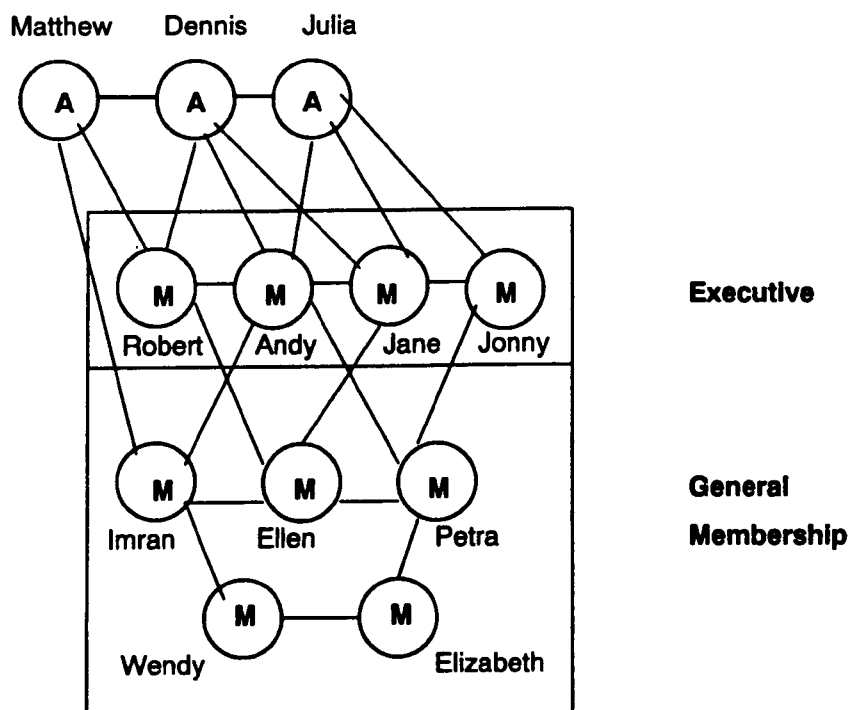


Figure 9 - Independent group's structure

This sociogram closely approximates Worrel's (1988) favoured 'member-orientated' form of organisation (see figure 2 above). My involvement with the Independent Group gave me access to dynamics that occurred inside this type of group organisation. A number of general points emerged. First, advisors had to deal with a clash of accountabilities to the group as a business (for example in the long-winded application for funds), to the executive committee (with whom much time was spent preparing agendas and training programmes) and to the general membership (who dropped into the group instead of Day Centres). Second, the membership was split into executive and general membership groups. While both groups made up the self-advocate base and supported one another, tensions emerged in this hierarchy. Third, the tendency for general membership to 'drop in' and not be involved in regular meetings raised questions over what and whom the group was for. The Independent Group exemplifies what could be termed the bureaucratisation or professionalisation of self-advocacy.

The Independent group and previous literature

Claim 10 - Paid Independent advisors threaten the development of independence in a group

Dowson and Whittaker (1993) are sceptical about paid support, seeing it as contravening a key aim of the advisor's role - to work oneself out of a job. Oliver (1990, p115) is equally suspicious of those who are paid to support disabled people. How can supporters overcome the conflicting interests of non-intrusive support (at best doing little) with the fact that they are paid to support (which at worst is tied to career advancement)? When members of the Independent Group were asked for their views on paid supporters there

were no objections:

'I think its jolly good we pay them, they earn their money, its intense work' (GD, see *Appendix 4, 9*).

Without wanting to downplay members' views, I observed a number of incidents that highlighted the dilemmas of paid support. First, commendable though it was, I wrote in my field notes about the possibilities of advisors following a work ethic congruent with their paid performative roles and professional ethos (Vincent and Warren 1997, p147):

'Dennis and Julia share the supporters job, him coming in half the week, her the other. They both fill their time with as much as possible. Is there a danger that their 'doing' becomes 'doing it for people' which is not the point?' (ON, 5th meeting)

Being paid for support may lead advisors to focus on their own personal (career) development:

'Matthew enthused to me about his job, "I've learnt to use the computer, its great" ... Julia told me that she will concentrate on supporting the group since she resigned from the her job as a careworker' (ON, 3rd and 4th meetings).

Second, members were concerned that if no funding was received then the group would fold (see GD). One of the main reasons for seeking funding was to pay for supporters, as made explicit in the group constitution:

‘The group would be in a position to help Blaketon County Council fulfil objectives two and three of its Community Care Plan for Services for people with a learning difficulty for 1995-6 ... The group is different from a Day Centre in that all members are equal ... workers [supporters] are told what to do by members and are there to support people to be in control of the group. They are needed to be an advocacy voice and if required do administration and continuity work’ (sic, Extract from Constitution obtained at 1st meeting).

The ‘official-speak’ in this document also illustrates what different parties expect off paid advisors. The latter sentence (apparently written for the County Council) describes support which sounds very much like professionalised notions of advocacy and work for people with learning difficulties or what Vincent and Warren (1997, p158) term ‘performative management’ by professionals. Third, because of the pressures of trying to get supporters’ posts funded, the executive committee and supporters spent a lot of time considering possible funding bodies:

‘Julia and Dennis spent much of last week sat in a room of the [new] office filling out the National Lotteries Charity board application form. Matthew spent his time downstairs with the members ... Half of the meeting was spent talking about funding, bank details and payment methods for supporters’ wages’ (ON, 8th meeting and executive committee).

It seems somewhat paradoxical for a self-advocacy group to rely on supporters getting paid. On the positive side, paying advisors for day-to-day support provided advisors with long-term and frequent opportunities to

conceptualise their support:

‘At the next training day offered by the group, Dennis is to sit next to Andy and prompt him with key-words so he can talk about his experiences of staff attitudes towards sex and people with learning difficulties’ (ON, 3rd meeting).

Meanwhile, executive power over supporters was also displayed:

‘The executive took a vote on the windows of the office being cleaned every week. Robert asked why Dennis was not voting, “He can’t vote he’s a supporter” reminded Ellen ... The group are changing the payment arrangements for the supporters. Now wages come directly from the group’s bank account ... ‘The committee needs to think about whether to give a cost of living pay rise to supporters’... the group offer a training day on “what is a good supporter?” Their supporters are involved in drafting up the agenda for the day’ (ON, 7th, executive committee meeting and extract from agenda).

Opportunities exist for groups to develop the job specifications of paid supporters. The executive committee members, along with the help of other members and supporters, had prepared written documentation outlining what constituted ‘a good advisor’:

‘A good support worker is: patient, helps people to choose, put yourself in someone else’s shoes, action - to make things happen, power, where to go can let someone take risks ... A bad support

worker: doing it for other people, people who think they know best, playing god, not listening, no time to give, heart not in it, telling people what to do' (sic, taken from training notes, obtained at 6th meeting)

Finally, in keeping with observations of advisors' interventions across all four groups, advisors supported members in empowering ways:

'Imran's father doesn't want him to come to the group. He would prefer to see him at the Centre. Petra acknowledged that she would have to ask her keyworker if she could come along to training day. Dennis spoke with them both about how they could resolve these constraints' (ON, 8th meeting).

'At the meeting with Norma and John from the County Council, Dennis appeared to avoid eye contact with them. When they posed questions, Dennis would look over to Robert and Andy – alerting everyone present to the two people who represented the Independent Group' (ON, first meeting for evaluation report).

However, a question mark remains over the relative benefits of groups paying for support.

Claim 11 - Member-orientated groups are the best

In light of the similarities between the Independent Group (figure 9) and Worrel's (1988) 'member-oriented' group (figure 2), a number of arguments presented by Worrel in favour of this group can be appraised

(Worrel 1988, see particularly pp49-51). First, the advisors' main point of call in the Independent Group was indeed the executive committee. This was particularly the case between Dennis, Julia and executive committee members Robert and Andy:

'Dennis had spent the week with Robert and Andy preparing for the meeting today ... at various times throughout the meeting, the three would consult one another. Dennis still took very much of a back seat' (ON, meeting with County Council representatives and IG).

In addition, the third supporter Matthew appeared to spend most of his time with the general membership who dropped in:

'Matthew was having 'the craic' with Imran and Carol. He's really natural with everyone' (ON, 4th and 6th meetings).

Second, while there were strong links between the members and the executive, these were not perfect. For example, it appeared that only a select few benefited from the executive / general membership hierarchy:

'Ellen thought that a room in the new offices would be ideal for the photocopier. Robert reminded her that such decisions have to go to the management committee ... Imran asked to join the Tuesday meetings. He was informed by Dennis [supporter] that he would have to be voted on to the committee' (ON, 7th and 8th meetings).

'Friday appears to be mainly about preparing for Monday - although some only drop in on this day. Andy [vice-chair] appreciates the

executive meetings, “I get to talk to my friends rather than keyworkers”. For Andy, Friday is when he winds down from the week’ (ON, 3rd meetings).

The general membership was separated from the executive that met away from the offices in the Town Hall. Third, the group had an air of formality that appears at odds with Worrel’s point about solidarity being bred through the ‘member-orientated’ structure (see figure 2 above). The Independent Group’s hierarchy and formal structure were evident in the strict adoption of certain rules during ‘drop-in days’:

‘Matthew told Jonny not to interrupt when he was speaking, then he apologising to Jonny explaining that the rule is to let people speak. There would seem to be structure even over small talk ...Petra, a member of the executive, reminded Imran about the not shouting rule’ (3rd and 8th meetings).

As Fairclough (1989, pp64-66) points out, formality in any group setting constrains content of discussion, status of members and group relations. Politeness and preoccupation with rules can undermine the productivity of group decision making. However, there were many incidents when actions of the executive trickled down amongst the membership. For example:

‘Three office premises were visited and videotaped. On the Friday all members came in to view the video and choose which would make the best office’ (ON, 3rd meetings).

Moreover, the general membership said that they got a lot out of the group

(see GD), regardless of the group's hierarchy and formality. There were various levels of personal gain:

'Imran loves coming in on Friday. It's a lot better than the Centre, which he maintains is 'boring' ... so as not to fall out with his parents he has told the taxi-driver that on Fridays he goes to IG, but to 'keep it quiet'. He also got one of the members to help him write a note to the Centre telling them why he wasn't there' (5th and 8th meetings).

Formally, the executive got on with running the group, which dealt with the problems of time identified in the Social and Advocacy-supported Groups, and the general membership benefited accordingly. Informally, I observed inter-dependence between executive and non-executive members. Below the bureaucratic surface, self-advocates supported one another and gained in various ways.

Claim 12 - Professional self-advocacy is the way forward

The Independent Group represents a particular type of self-advocacy that is described in the literature - professional self-advocacy (see for example Sutcliffe and Simons 1993, pp103-110). Links with BCIL (which produces self-advocacy literature and offers training) and funding aspirations (including accountabilities to current funding bodies) has meant that the group's activities are wide-ranging:

'Members of IG attend disabled peoples forum meetings, work with social services, health, community education, other voluntary organisations, take part in sexual and emotional needs training and

training with BCIL. As well as learning new skills and getting better at old skills, members are getting more confident in speaking up, more confident in getting information, making choices, making changes, meeting new people, challenging people using jargon instead of simple words, and enjoying themselves! The members are also developing skills as managers of a project, speaking out skills - such as in meetings, doing training, giving information, chairing meetings, taking minutes, doing the petty cash, accounts, office skills, using equipment, challenging how meetings are run and how people are treated, how minutes are written, with big words and jargon' (sic, Official introductory leaflet).

The Independent Group was particularly concerned with the activity of training. The other three groups in this study had little money and tended to be organised around meetings and social, Centre or Advocacy activities. By contrast, the Independent Group was well funded and spent a lot of time organising training programmes. The group benefited in a number of ways by offering training. First, by referring to training, the group could show in a practical, formal and measurable way what funding bodies were getting for their money. Hence, the County Council asked for feedback from organisations who had received training to be included in the evaluation report (*Appendix 4, 11*). Second, the group's preoccupation with maintaining a high level of funding was served through the income generated from training:

'Andy told me that the group receives £300 for a day's training ...
'South Blaketon Advocacy have asked us if we will do some work at Blaketon hall for two days on a ward (ON, 3rd meeting and Extract

from Agenda to Executive Committee meeting).

Organisations who had received training from IG were very positive in their feedback. For one, a representative of 'Do it Now' an advocacy organisation, the Independent group had challenged her own role as an advocate:

'She remarked that there was perhaps a tendency for advocacy workers to think they are doing the right thing and to feel smug with themselves. The Independent Group made her think more deeply about many aspects of her job ... the group's dislike of 'jargon' illuminated the inaccessibility of much advocate work' (Extract from feedback *Appendix 4, 11*).

Similarly, Blaketon College's Special Needs Department has used the group to inform their self-advocacy courses. The group constitution had made Julie Bently, a lecturer on the course, more aware of non-readers and people with visual and hearing impairments (Extract from feedback *Appendix 4, 11*). The quality of the training programme may have been enhanced by the group's divisional links:

'I got a chance to leaf through a folder on self-advocacy written by BCIL that was on top of the filing cabinet... some members have done training with BCIL training department, one Independent Group member is now a trained counsellor as part of BCIL's counselling service (ON, 4th meeting and extract from introductory leaflet)

Potentially, then, the Independent Group (IG) has a number of organisational relationships:

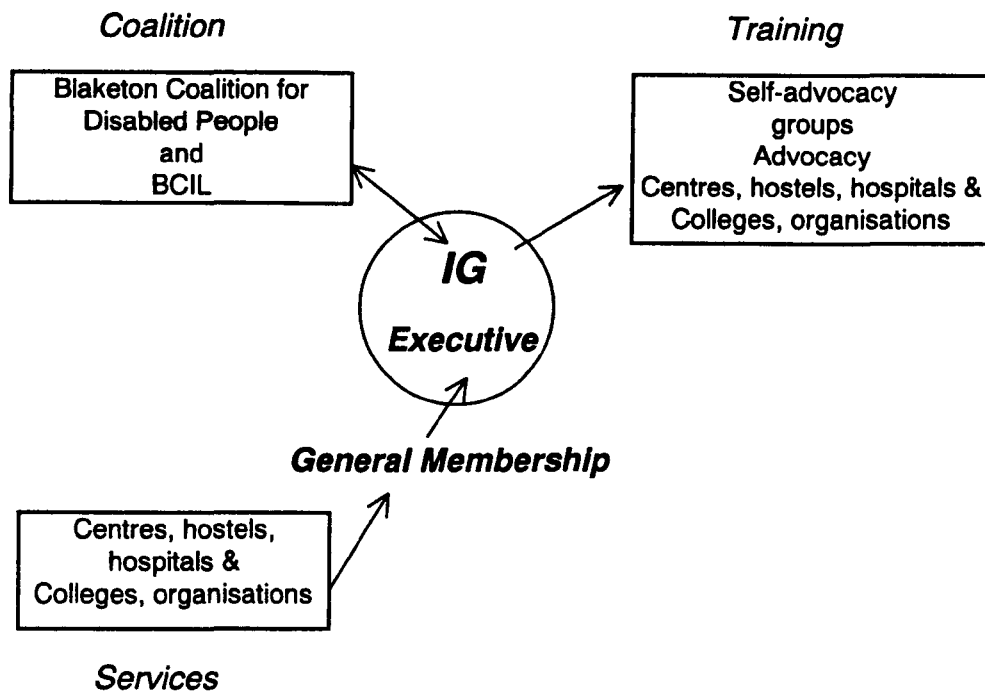


Figure 10 - Potential relationship between IG and various organisations and services

Yet while the group strives for these business like relationships, what about the people who come to the group instead of Day Centres? Members are proud of the group.

‘The first we had was owned by social services, we chose this and we love it ... it’s beautiful, lovely - it’s our office’ (GD, *Appendix 4*, 9).

Membership for some, particularly those on the executive, was about having a job to do:

‘I asked Andy why he had joined the group and he told me, “I’m

doing it for a change. I'll probably try and work with old people at sometime". Jonny told me that he works at the local ATC's Garden Centre, making furniture. He gets £5 a week but has to pay £6.50 day Centre charges' (ON, 4th meeting).

Other members talked about what they got out of being in the group as an alternative or addition to other activities.

'At the Centre I'm working with this man who cannot speak or talk but he's a joy to work with ... You do what you do instead of what they want you to do ... there's more friends here than at the Centre' (GD).

Page and Aspis (1997) suggest that self-advocacy has become an industry open to the exploitation of services and professionals. The Independent Group may also be open to exploitation by services that offer token gestures to self-advocacy by getting the group in to do a day's training. Below these formal business-like relationships, executive and general members gain in different but personally important ways. The Independent Group presents different levels of organised self-advocacy.

Conclusions - dynamics over typologies

This Chapter has described and appraised some of the group dynamics and processes in four self-advocacy groups. A number of general conclusions can be drawn from the above analysis:

- First, all groups to varying extents transcend group ‘types’ identified in the literature. The organisation of self-advocacy draws upon a number of service, divisional, coalition and autonomous characteristics.
- Second, it has been shown that there is often a gap between previous literature and the realities of group processes. While this does not mean previous literature is redundant, group dynamics are complex, messy and not easily categorised.
- Third, the four groups present four different albeit overlapping ways of organised collective self-advocacy, each with advantages and disadvantages. Some of the members I spoke to were involved in more than one self-advocacy group⁷. Sutcliffe and Simons (1993, p17) suggest that ‘there is value in diversity and in having a wide range of opportunities open to people’. In the self-advocacy movement, groups have the potential to serve different areas of life:

‘Even though their capacity to overthrow power structure is minimal, they have begun to introduce a new language of critical discourse that departs profoundly from the theory and practice of conventional politics’ (Boggs 1996, p22).

- Fourth, previous appraisals that have pointed out ‘good’ and ‘bad’ ways of organising self-advocacy ignore what self-advocates get out of being in groups. For example, it seems analytically simplistic to say that the Independent Group was better than the Centre Group when members of

⁷ Users of the Quarry Village Centre who were not involved with the Centre group may have been involved with other self-advocacy groups.

both groups got something out of being involved with collective self-advocacy. There were many incidents of members getting as much out of the groups as they could. 'Type' did not necessarily prevent members gaining from involvement, nor did it prevent advisors putting in as much as they did to the groups.

- Fifth, groups may provide a catalyst for members to develop self-help, friendships and confidence. For two of the groups, members only met once a month, for the other two group members met weekly. Consequently, groups can provide contexts in which relationships are formed but are taken further outside of the group.
- Sixth, self-advocacy was not organised by groups in therapeutic, educational or libertarian ways. Like the narrators in section 3 of this thesis, self-advocacy appeared to be about people choosing to embrace a context in which to make friends, gain confidence and try out new things. Groups had built up relationships with other groups, services, divisional and coalition organisations. However, the salient dynamics within groups appeared to lie in the inter-dependence amongst self-advocates.
- Seventh, groups can be seen as reformist, some more than others, as they work within the system often in collaboration with seemingly exclusive groups. However, what may be reformist to the outsider is radical to the insider. Members provided one another with support and promoted frameworks of meaning and self-reference that contrasted with outsider assumptions of inability (Vincent 1998).

- Eighth, opportunities for shared membership have been illustrated alongside the threat posed by wider disabling environments. Though the Centre Group existed as a pocket of resistance in the wider Centre context, this wider exclusive zone existed nonetheless.

Sutcliffe and Simons (1993, p17) conclude, 'There is no 'right' or prescribed form of self-advocacy'. The four groups were bound together by various intra-group processes and embraced different concerns of members from social events to formal training programmes. However, is there something that over-rides structure, organisation and process inside groups, and is implicated in promoting 'good self-advocacy'? The next chapter delves deeper into self-advocacy in action, across groups, by considering the support offered by advisors and self-advocates.

Chapter 10

Across self-advocacy groups – support and models of disability

Introduction

This chapter takes further the challenge of appraising self-advocacy in action. The support offered by advisors will be addressed. Drawing upon field notes it is suggested that previous literature has failed to account for the multi-faceted nature of support. This failure has resulted in simplistic attacks on professional (staff) advisors, a lack of conceptualisations of support that are grounded in models of disability, and has ignored the self-determination of self-advocates with learning difficulties themselves. Presented in this chapter are vignettes of support ('interventions') offered by advisors that can be seen as either empowering or disempowering. Interventions are understood in terms of where they lie on a continuum of support, where at one end is the Social Model of Disability and the other end the Individual Model of Disability. Five pairs of intervention are presented reflecting polar ends of the social-individual model continuum. With reference to disability theory it is argued that those interventions that are drawn towards the social model end of the continuum offer a more authentic means of promoting self-advocacy skills inside groups. Finally, in addition to the support of advisors the inter-support networks of self-advocates are presented. By looking across groups it is concluded that collective self-advocacy reflects dynamics that are made up of various interactions, which in turn, can be understood as reflecting different discourses of disability.

The advisor role – interventions and discourses of disability

The various positions that advisors hold complicate the doing of self-advocacy. Previous literature has proposed that an advisor's status – independent / staff and paid / voluntary – has implications for the support of self-advocates (Worrel 1987, 1988, Dowson and Whittaker 1993). The previous chapter problematised understandings of advisors espoused in previous literature on a number of levels. These problems were particularly evident in the case of 'staff advisors':

1. To assert that staff advisors support is inevitably limited by their professional status does a disservice to the individuals who exist behind that label. For example, while the staff advisors in the Social Group, Neil and Virginia, appeared to bring their work with them to the group at times, they did not always act 'like staff'. Moreover, Louise's actions in the Centre Group failed to fit the characteristics drawn up in the literature of staff supporting.
2. Previous analysis about staff advising is static and conservative. It not only holds that structure basically positions people to behave in a certain way (staff role - bad advising), but that resistance to exclusive or oppressive structures is impossible (staff advisors are only part of the paternalistic control of people with learning difficulties). It appears that the logical conclusion of this analysis is to do away with staff supporters all together. However, as this thesis has shown so far, staff advising is a reality and requires understanding.

3. Resilience of self-advocates in the face of adversity is ignored. It is assumed that a particular type of support will causally result in a particular type of self-advocacy - people with learning difficulties benefiting or suffering accordingly – but what of the input by self-advocates?

In this chapter these three problems will be broached in the following ways. First, rather than considering the advisor's role as a direct reflection of a particular 'type' (e.g. staff advisor), I will present how advisors are open to different types of actions or interventions (Dowson and Whittaker 1993). Second, one way of trying to draw together what these interventions mean for self-advocacy is to analyse how they reflect different understandings or discourses of disability. Therefore I will consider interventions as a reflection of discourses or practices (see Fairclough 1989) associated with two models of disability - the individual and social models (Barnes 1990, Oliver 1990, 1996, Morris 1996).

Finally, advisors' actions will not be considered alone. I will also refer to the actions of self-advocates themselves that occurred, in addition to advisor interventions, and which augmented the development and organisation of self-advocacy. I will specifically focus on those actions that encouraged the progression of self-advocacy within the group – actions that reflect discourses of self-help, collective identity and social action (aspects of the social model). Their impact on the 'doing of self-advocacy' was as important as the actions of advisors. This chapter builds upon four previous papers (Goodley 1997a, 1997b, 1998, in press, a).

Understanding support as 'interventions'

The idea of 'intervention' has been picked up on by Dowson and Whittaker (1993, pp31-32) who identify six categories of action which may be employed by the advisor:

- Prescriptive interventions - aim to give advice, recommend a behaviour or course of action,
- Informative interventions - aim to give knowledge or information,
- Confronting interventions - challenge attitudes, beliefs or behaviours,
- Cathartic interventions - provoke a release of tension,
- Catalytic interventions - elicit information or opinion from the group,
- Supportive interventions - affirm the value or worth of the group.

Building on the notion of intervention my analysis tries to link together the actions of advisors (and later self-advocates) with models of disability.

Interventions as a reflection of discourses / models of disability

Chapter 3 examined how dominant discourses of disability inform understandings of what causes 'learning difficulties', how it is experienced, through to the ways in which it is treated. To understand disability in terms of 'discourse' ties together subjectivity and practice (Skrtic 1995a). According to Fairclough (1989, p23) discourses are social phenomena in the sense that whenever people speak, listen, write, read or act, they do so in ways that are determined socially and have social impacts:

‘How a discourse exerts power is through individuals who become its carriers by adopting the forms of subjectivity and the meanings and values which it propounds. This theory provides an understanding of where our experience comes from and can explain why so many of our experiences and opinions are sometimes incoherent and contradictory’ (Sidell 1989, p268).

Moreover, a relationship exists between social events and more durable social structures that shape and are shaped by these events. Discourses and practices are inseparable (Fairclough 1989, p28): both refer to either what people are doing on a particular occasion, or what people habitually do given a certain sort of occasion. That is, both can refer to either (linguistic) action, or convention:

‘The social nature of discourse and practice always implies social conventions - any discourse or practice implies social conventional types of discourse or practice ... people are enabled through being constrained: they are able to act on condition that they act within the constraints of types of practice - or of discourse. However, this makes social practice sound more rigid than it is, ... being socially constrained does not preclude being creative’ (Ibid.)

This last sentence links into an important point about discourse and practice, that where there is power there is also resistance (Foucault 1975). This notion of resistance to oppressive discourses recognises a key issue associated with power. People are not simply empty vessels receiving powerfulness or powerlessness, people reproduce power in various ways,

with good or bad effects upon themselves and others. Oliver (1996, p144) points out that:

‘Understanding societal responses to long-term disability is no simple task and requires us to analyse ourselves and the discourses we use in order to talk about our world’.

For Cicourel (1980) when researchers are accounting for discursive or social interactions then they need to make explicit reference to broader cultural beliefs. Taking advisors’ interventions within groups, this chapter examines how these interventions reflect and reproduce discourses and practices of disability. It appeared that advisors were open to reversing, changing, moving, building upon and rejected all together their interventions with self-advocates. Throughout my ethnography it was as if ‘good’ and ‘bad’ interventions were available to advisors, just as different discourses float above and between people with meanings slipping and sliding (Howe 1994, p522). There appeared to be some advisors who were prone to draw upon discourses of disability that assumed individual pathology, whilst others seemed more able to clearly link practice with assumptions of competence. However, all advisors’ interventions were fluid and ever changing. Following Skrtic (1995b, p42), the disciplinary power of disabling discourses can lead supporters unconsciously or unintentionally to operate under the taken-for-granted contentions and customs of their ‘knowledge tradition’. Conversely, other discourses can be embraced which inform more empowering practice. So what are these discourses?

Discourses and practices of disability - the individual and social models

As outlined in chapter 3, learning difficulties, and disability in general, has largely been understood in terms of individual impairment. Consequently, impairment whether it be physical, or 'of mind', is perceived as creating disability (WHO 1992). This understanding of learning difficulties (and disability in general) embraces what has been called the individual model of disability or Personal Tragedy Perspective (Oliver 1990). Discourses originating from the individual model locate disability within the individual, and his / her impairment. Further discourses and practices emerge of personal pathology, of individual difficulties and of dependency in the face of care. Moreover, people so-labelled are required to adjust to their environments, be the recipient of professional expertise and medical dominance, and are the focus of policy that at best intervenes and at worse controls (see Oliver 1996). By placing disability resolutely in the realms of personal tragedy, the individual model perpetuates a culture of dependency and non-acceptance. As with most dominant regulatory discourses, it is hard for people to break through and away from the concept of learning difficulties as individual pathology. Consequently, those that step out of this socially prescribed role flout the rules, challenge dominant hegemony, and threaten the very foundations of society's understanding of disability. When people with learning difficulties step out of the passive role assigned by society, and take up the active role of *self-advocate*, the resulting drama is unfamiliar. Consequently, if the actions of advisors are embedded in an individual model of disability then their support appears to be at odds with facilitating the self-determination of self-advocates (Goodley 1997a, 1997b).

In opposition to the dominant individual perspective that locates disability in the realms of individual impairment, the alternative social model of disability attends to the ways in which society disables (see for example Barnes 1990, Oliver 1990, Morris 1991, 1996, Swain, Finkelstein, French and Oliver 1993). To find the dominant origins of disability we are encouraged to turn attention away from the individual onto a society that excludes. Disabled people are disabled by a social, economic, cultural and political contemporary climate. The application of the social model of disability permits a different way of conceptualisation and practising self-advocacy. The discourses and practices of the social model address notions of social problems, of societal / environmental barriers and of independence in the face of self-advocacy. Moreover, there are demands for societal adjustment and calls for individual and collective responsibility of all societal members to re-dress disabling environments (see Oliver 1996). Now when people with learning difficulties step out of the passive role assigned by society, and take up the active role of self-advocate, this feeds into the political aims of the social model. Where once stood a model of learning difficulties as individual inadequacy now stands a model that embraces individual and collective empowerment (Schlaff 1993). The focus is shifted away from a focus on what people cannot do, to what people can do. Consequently, if advisors adopt a social model of disability in their support then this appears to be congruent with facilitating the self-determination of self-advocates (Goodley 1997a, 1997b).

Inclusive and exclusive support - Individual and social models of intervention

The links made above between discourse, models of disability and the actions of advisors and self-advocates are at this stage speculative. The subsequent analysis therefore delves deeper into the relationship between discourses of disability and the support of advisors. Throughout the chapter particular reference will be made to components of the individual and social models. A useful summary of the continuum between the two models is provided by Mike Oliver (1996, pp33-34), which is re-produced in *Appendix 4, 14*. Following Lukes (1974), people are often not consciously aware of the ways in which they (dis)empower others. The same could be said about the advisors in the four research groups in this study. However, by grounding an analysis of their actions in models of disability, I aim to provide a framework for uncovering the meaning and affects of interventions. Five pairs of interventions will be considered, each pair reflecting polar ends of the individual-social model continuum. While many of the vignettes from the previous chapter could be included in this analysis of support, additional vignettes are the main focus of this chapter.

(1) 'Advisor centred' - v - 'Self-advocate centred' interventions

Those interventions that are drawn towards the **Advisor centred** end of this first continuum can be seen as practices of an individual model of disability. Typically advisors respond to the requests of self-advocates with, 'I'll have a chat with someone on your behalf' or, 'Don't worry yourself, I'll sort out your problem'.

'Jim lives in a group home and is very unhappy with his bed, "It is too narrow". One of the supporters, a manager of one of the nearby ATCs, told Jim, "That's being sorted out for you"' (Social Group, ON, 3rd meeting).

'Karen mentioned that she was worried about her 'sick note' that she needs to collect her benefits. One of the supporters, who happens to be Karen's keyworker, told her, "Someone's sorting you out with that"' (Social Group, ON, 7th meeting).

'Matthew the advisor has a tendency to tell off members. He told people to be quiet because he wanted to talk to Robert. There is a fine line between group rules on 'not talking when others are' and disciplining people' (Independent Group, ON, 3rd meeting).

Here support was individualised in terms of 'staff-client' like relationships. Issues and concerns that others may share, or may later have to deal with, were not made public within the group. Instead there was fragmentation into 'working pairs' and the group did not collectively dealing with a member's concerns. As Worrel (1988, p39) observes:

'Professionals are trained to see members as clients ... to deal with people one-to-one with measurable and predictable results. This approach doesn't work with a group that is growing and evolving as it goes along'.

Advisor centred interventions may uphold professional ethics and a preoccupation with 'client needs' (Gilbert and Specht 1976). Moreover, an

expert advisor culture of paternalism may be bred (see Khan 1985) and self-advocates may find it difficult to challenge inadequate interventions alone. Now in this culture, the self-advocate asking for support may feel intimidated. Those benefiting are primarily the advisors:

‘It flatters our ego to feel we are needed, it is often so much easier and quicker to do things ourselves’ (Dowson and Whittaker 1993, p14).

‘It is tempting to let this attention go to our heads’, Worrel 1987, p34).

Advisor-centred interventions may also build up or give an appearance of an esprit de corps with other ‘professionals’. This can dissuade self-advocates from criticising ‘fellow professionals’ and other advisors. Examples of this are typified by the advisor reacting to criticisms of professionals with, ‘Well they’re doing their best’ responses. Bachrach and Baratz (1970, p6) cited in Lukes (1974, p18) observe that power may be, and often is, exercised by confirming the scope of decision making to relatively ‘safe’ issues:

‘Members were talking about their key-workers. Karen said that she was unhappy with her’s, “He’s never there, I don’t know why he bothers”. Ken agreed, “They come and go”. A supporter reminded Karen that keyworkers work shifts. Karen later went on to say her keyworker was like “a guardian angel”’ (Social Group, ON, 5th meeting).

No attempt was made by the supporter to discover whether or not Karen had good reason for being unhappy with the absence of her key-worker. It was assumed that the key-worker's presence was only dependent on her shift-work (her competency stifled by structure), and the implication was that Karen failed to understand shift-work (Karen's incompetence). Supporters conveyed the notion that the job of a professional is an important but difficult one. Consequently, typical of the individual model of disability, professional work was accepted unquestionably and people with learning difficulties' experiences were ignored (Barnes 1990, Oliver 1996):

· 'I had been asked by the group to write up and illustrate a leaflet introducing their group. Cliff had asked me to write, "Some of our supervisors are treating us badly". Presenting the leaflet at the next meeting Cliff gave me a 'thumbs up' for putting his comments down. Two advisors seemed to take a different perspective, "That bit about the supervisors sounds awful" said June. The other, Virginia, put her head in her hands' (Social Group, ON, 4th meeting)

Whether or not Cliff's comments 'sound awful' did not appear to be the point - they were after all his opinions. In defence of the advisors, they did not suggest that the comments be taken out of the leaflet, but, if such concerns are shared by advisors, how can self-advocates feel comfortable in criticising staff and in turn build a collective identity inter-twined with dissent (see Shakespeare 1993b, Campbell and Oliver 1996)? At worst, an atmosphere of untouchable 'expert authority' is bred, and others' ineptitude is justified by being ignored. There seems to be a tacit notion that supporters of all kinds should be praised not criticised. Such ideas heighten the

vulnerability of people with learning difficulties (Breachin and Walmsley 1989).

As Lindow (1993, p185) argues, there are still too many people who accept paternalistic services and are therefore grateful to be noticed at all - 'We can let them know that they deserve better'. In accordance with this I observed many interventions that appeared to be drawn towards the **self-advocate centred** end of the continuum. These were characterised by, 'Why don't you have a chat with someone', or 'I'll support you tackling your problem' responses to requests. Three vignettes from the Centre Group highlight this:

'Dorothy is sick of people pushing in front of her in the dinner queue. The advisor suggested that they could, "Have a chat with the staff on dinner duty"' (ON, 3rd meeting).

'Denise was interested in the story of a couple with learning difficulties who had bought their own house. "I'd love to do that" she told the group. The advisor suggested to Denise that she should talk about it at her IPP' (ON, 3rd meeting).

'Lesley told the group she wasn't interested in going to the local advocacy project meeting because as a 'non-reader' she finds it difficult to read the minutes - "They should use pictures". Louise suggested to Lesley, "You should have a quiet word with the people there to see if they will change the format of the minutes"' (ON, 5th meeting).

In these interventions the advisor appeared to intervene in ways that did not enforce her authority over the group. Over time, through encouraging members to speak out, the support that one self-advocate receives may be passed between peers. This links into the inter-dependent aspect of the social model (Oliver 1996). Issues and concerns that others may share, or may later have to deal with, were made public within the group. In doing so, advisors made it known that they were there for members to offer support and back up their ambitions. The dynamics of this intervention can go further with advisors sustaining self-advocates' criticism of (fellow) professionals. These interventions were evident in the Centre Group as presented in the last chapter:

'Lesley is sick of a certain member of staff picking on her. Louise, the advisor, suggested she go see the manager and put in a complaint. She would go with her if Lesley wanted her to' (ON, 3rd meeting).

There were occasions when interventions fell into the mid-ground, between advisor-centred and member-centred. For example, some members sought out advisors for one-to-one chats:

'Lillian told me that she was having problems at home. "People won't pull their fingers out". She mentioned to me, and later to the group, that she, "Can't get a word in edgeways"¹ with the group and prefers to talk with one of the advisors, Jurgen, at breaktimes' (Social Group, ON, 4th meeting).

¹ Lillian felt so strongly about this that she also mentioned it in the group discussion.

‘Imran spends most of his time with Matthew the supporter. They are inseparable’ (Independent Group, ON, 2nd meeting).

These interventions share characteristics of a client-staff relationship. While not ideal, there was often only so much time for dealing with individual concerns in the group meetings. Action could be taken far more quickly on a one-to-one basis. Also, people may not want to talk in front of a larger group, preferring a one-to-one, though later may gain the confidence to do so. One-to-one relationships provide a strong counter-balance to the general tendency of services to treat people with learning difficulties in a blanket way (Flynn and Ward 1991). However, according to Dowson and Whittaker (1993, p10), they should exist for self-advocates and not for advisors. When interventions fell into this mid-ground questions remained over who benefited the most from the intervention. Advisors themselves may learn how to support self-advocates through these ‘working pairs’ and eventually translate this to the larger group. There may be times when it is only right to advocate for someone who feels powerless, lacks speech or who asks for advocacy (Booth 1991). However, those interventions which pull towards the ‘self-advocate centred’ end of the continuum appeared to be more readily compatible with the promotion of collective self-advocacy and less aligned with professional definitions of need and individual problem-solving (Vincent and Warren 1997, p158).

(2) ‘Deficit’ - v - ‘Capacity’ Interventions

At one end of this continuum of support, **deficit**, advisors lean too far towards presuming incompetence on the part of self-advocates (Booth and Booth 1992, p65). This is an intrinsic part of oppressive discourses that

position disability in the realms of individual pathology, personal problem and individual incapability (see Booth and Booth 1994). Koegel (1986) pessimistically observes that there is a tendency to assume incompetent behaviour on the part of people with learning difficulties and to attribute this exclusively to physiological causes. For Safilios-Rothschild (1981), supporters who view incompetence in others, help to enhance their own rewards of 'helping' and 'caring'. When someone is unable to do something, we will do it for him or her, we feel needed, but our control increases as a result. This was evident in the Social Group:

'Cliff has reported to the group many times of being bullied by supervisors at work and staff in his group home. Tonight he mentioned it again. One day after work, the taxi did not turn up as had been ordered, and he told the group how he angrily reacted to this lack of punctuality by hitting a staff member. One of the staff advisors said to another, though loud enough so the group and Cliff could hear, that, "Cliff is always taking out his anger on others". She told him that she would put him down for a place on the new 'anger management course' run at one of the Centres where she works (ON, 7th meeting)'.

'Ken told the group that he had asked one of the staff members in his house if he could make a cup of tea. He had said yes but on boiling the kettle another member of staff came in and told Ken to stop. Ken said this was because they thought he might scald himself. The advisors suggested that he ask the staff in his home to show him how to make a cup of tea' (ON, 5th meeting).

No one asked Cliff why he reacted like he did, or took into account the frustrations he had been feeling. The supporters might have considered what had made him feel so angry and perhaps supported him in bringing up his grievances at his workplace and home. No one asked Ken if he had made a cup of tea before. There was a focus immediately on what he couldn't do, and ways and means of remedying these deficits. Ken's capabilities were not considered. When I asked him if he had made tea before he replied, 'Oh yes, I make it for the mother when I saw her at weekends'. Probing wider social reasons for someone's actions opens up numerous causes (Guskin 1963, Koegel 1986, Booth and Booth 1992). Ken later told me that he had been in institutions for 22 years and was on the same ward with Cliff, who is some ten years older, suggesting an even longer spell of incarceration. These life experiences may explain Cliff's anger and perhaps he just wanted someone to be on his side. Friedman-Lambert's (1987) profile of Martin Levine, a Canadian self-advocate, is relevant here. Levine recalls punching a fellow (non-disabled) employee at a work placement after being the butt of some hostile ridicule. As Friedman-Lambert tried to suggest some alternative ways by which Levine could have handled the situation, Levine replied:

'Come on Phil, what would you do?' (Ibid. p16).

Cliff continued to get a hard time from some of the supporters. There appeared to be a generally pervasive assumption of his 'deficits':

'Cliff told the group that he had fainted at work because of the heat and nearly fallen into one of the machines. June, a supporter, asked,

“Is that because you were in the wrong room?” (Social Group, ON, 8th meeting).

This understanding of people as incompetent can potentially suppress the formation of a valued collective identity within the group (see Campbell and Oliver 1996). When self-advocates are trying to help one another, assuming inabilities can disturb supportive interactions between peers, discourage risk-taking, self-belief and reinforce self-appraisals which augment deficits (Wilson 1992, p31):

- ‘Lillian said she needed to phone a taxi to get home. One of the members, Karen, offered to sort it out. “What’s the address Lil’?”, she asked, “24 Coathall Lane” replied Lillian. Off Karen went but one of the supporters, Jurgen, was not happy, “She’ll confuse that with her own address”, he warned another supporter. Karen returned and was asked which address she had given on the phone, replying “24 Coathall Lane”. Even this was not enough for another supporter, June, who now questioned Lillian’s knowledge “I’d best ring Lillian’s house to see that address is right”. “No it is”, shouted up Jurgen’ (Social Group, ON, 9th meeting).

I also fell into the trap of treating people as stupid:

‘Imran found an old lighter in my car. He asked me if he could have it. I gave it to him with a patronising warning, “Now don’t go burning down your mother’s house will you?!” He looked at me with despair and retorted, “I’m not fucking stupid you know”’ (Independent Group, ON, 6th meeting).

In contrast there were many occasions when advisors opposed pathological assumptions of inability, sometimes espoused by self-advocates, taking a **capacity perspective** (Booth and Booth 1994):

‘As the meeting went on a young Asian man stood outside peering through and knocking on the window. The members shouted at him to “go away”. The advisor suggested that he was trying to get their attention because he wanted to join the group. One of the members exclaimed, “He wouldn’t understand”. The advisor replied, “You don’t know what he understands”’ (Centre Group, ON, 4th meeting).

This alerted members in the group to the notion that a person’s abilities are not a mere reflection of some assumed ‘impairment’. Moreover, the social bases of a person’s ‘problems’, an important construction of the social model of disability, are reiterated:

‘One of the members, Denise, said that a particular user in the Centre was “being a right pain”. The advisor reminded Denise, “He has a lot of problems at home you know. You should bear that in mind”’ (Centre Group, ON, 5th meeting).

‘Virginia explained ‘problem behaviour’ as when people have a bad day or get upset and then might feel angry. Jarrord asked, “What like hitting you?” “That’s right”, replied Virginia’ (Social Group, ON, 4th meeting).

‘Rudi admitted, “It’s not always easy to stick up for yourself against nasty people”. Paul [supporter] agreed, “Yes some people don’t listen do they?”’ (Advocacy-supported Group, ON, 5th meeting).

To reiterate the views of the Canadian self-advocate, Pat Worth, it is important that advisors reject a focus on supposed deficits and emphasise competence:

‘The major barrier is *attitude*. People see out disability only, they don’t see our ability. We may have a handicap but we’re not the handicap’ (Quoted in Yarmol 1987, p28, italics in the original).

(3) ‘Talking over’ - v - ‘Talking with’

Supporters can take on the role of advocate and speak for others. This becomes problematic when it takes on expertise and care components of the individual model (Oliver 1996, p34) and becomes **talking over**:

‘I asked Robert how the group had got on with the training day they gave some weeks back. He was helpful enough to get out the flip chart that they used as the agenda for the day and started to talk me through it. Unfortunately Matthew, the supporter, jumped in, “I’ll explain that shall I Robert?” and took over’ (Independent Group, ON, 3rd meeting).

‘Jurgen the advisor insisted that the group move on to another topic of discussion, even though they had failed to resolve a previous

issue. June, the other advisor, laughed, “Well they weren’t interested in that anyway!” (Social Group, ON, 8th meeting).

These actions were unhelpful because they downplayed the motivation of people to speak up for themselves. This relates to a personal tragedy discourse, where the voices of those with socially ascribed power override the voices of the powerless (Barnes 1990). Simone Aspis of *London People First* warns that accountability is paramount:

‘People with learning difficulties must be asked what changes they would like, then the professionals should be supporting us, involving us, and making sure what’s being said is accessible’ (Quoted in George 1995, p17).

When this does not occur, for Wise (1973), advocating can take on an inappropriately confrontational slant:

‘Ken was talking to Andrew about his work. At the same time, the group was discussing a questionnaire that had recently arrived. Jurgen, the advisor, asked Chris the chairperson to “tell Ken to be quiet”’.

Chris : Be quiet Ken.

Ken : Okay.

Chris : Sorry Ken.

Ken : That’s okay’ (ON, 5th meeting).

Having to tell off Ken was obviously uncomfortable for Chris. The only way Chris could do it was by later appealing to his friend. Here advocacy

went too far, the voice of the supporter dominating, but in this case self-advocates were still able to maintain cohesion. Instead, **talking with**, assumes the collective and individual responsibility elements of a social model of disability (Oliver 1996). Advocacy constitutes a new helping relationship (Biklen 1973). From this, relationships may emerge between advocating advisors and self-advocates:

‘I heard Lillian tell the supporter Neil, “The group aren’t listening to me”. She wanted to talk about the way staff treat her in her house. Neil started to tell the group that Lillian was unhappy, from this Lillian butted in, “They don’t treat me proper, they treat me like a child”’ (Social Group, ON, 5th meeting).

Neil’s intervention was positive as it brought in a shy member of the group into the process of their own advocacy - dispersing the issues under attention throughout the group. At the same time, naiveté promoted by an exclusive society can be challenged by providing information (Worrel 1987, 1988):

‘Louise asked if the members had received the letter on green paper from the County Council. Some members said they had received it but had not had a chance to read it. Others knew nothing about it. The Council is now going to charge 75pence a day for transport to and from college, the Centre and other places. The members were furious. Carol said that all members of the Centre and staff should have a big meeting to talk about these new charges’ (Centre Group, ON 2nd meeting).

‘Dennis and Julia showed the group the completed application form for Lottery funding that they had just finished’ (Independent Group, ON 3rd meeting).

‘Two supporters have written a leaflet on the new consultation document for services for people with learning disabilities (sic). Part of the meeting was spent discussing these issues, members felt the leaflet was a good idea and well presented - the pictures were particularly helpful’ (Social Group, 5th meeting).

‘Talking with’ links into a conceptual understanding of independence. As Elsa (in Campling 1981, p85) puts it:

‘It annoys me when able bodied people hold forth about how we should be as independent as possible. Of course we should be but I’d like to hear some talk about the able-bodied being a bit more independent too - how many of them cut their own hair, for goodness sake?’

Similarly for French (1993) ideas of ‘independence’ applied to disabled people have gone too far, individualising disability, pushing people to be as independent as possible, even when impairment or lack of experience prevent people from doing things they may never be able to be do. Some people will never be able to read, others may never have enough confidence to speak out in a large group, while certain individuals will lack experience of finding out about their own rights (Simons 1992). Numerous environmental deficiencies give rise to a multitude of inabilities (Booth and Booth 1994). Here, then, independence should be substituted for inter-

dependence (Oliver 1996) – something that historically able-bodied have had an innate right to while disabled people have denied it in line with misplaced notions that, ‘They need their independence’. These miscomprehensions were sensitively challenged through advocacy by many of the supporters I observed and respectful climates were encouraged.

(4) ‘Expertise’ -v- ‘Experience’

The two ends of this continuum could also be described as: ‘Forgetting why you are there in the first place’ - v - ‘Knowing why you are there’. The former can lead people to ignore the original reasons for their support, like at the AGM of a larger advocacy organisation, which the Advocacy-supported group attended (see previous chapter). Supporting the advocacy skills of another can be thwart with problems (see Wise 1973). Not being self-critical can promote an ‘us and them’ mentality, emphasising expert opinion of which self-advocates are aware of, as shown at a ‘service users consultation meeting’ attended by members of the Social group:

‘Virginia, one of the group’s advisors, stood up to introduce herself. “I’m at Bingley lane hostel”, “IN CHARGE”, shouted one of the self-advocates!’ (ON, User consultation meeting)

To be fair, many of the supporters showed reflexive qualities when examining their actions. A bad intervention could be reversed:

‘At the start of the meeting it was Becca’s turn as chairperson. Becca was writing out the agenda and asked, “How do you spell ‘news’?” Erica, a fellow member, shouted up, “I know Becca, n...e...” George

the supporter ignored Erica, interrupting, "It's n...e...w...s". Later Becca asked how to spell 'annual'. Erica started to answer, George interrupted, but seeing the error of his ways encouraged her, "Sorry Erica go on" (Advocacy supported group, ON, 3rd meeting).

Addressing difficulties from a social model of disability re-affirms the human nature of people over their purported 'difference'. This leads us to the 'knowing why you are there in the first place' stance - the **experience** position (Oliver 1996) - typified by supporters giving primacy to the experiences of self-advocates. Take for example this vignette presented in the previous chapter:

'The British Telecom engineer walked into the office. Looking around the room his gaze finally fell upon Julia [the supporter]. "I've come to sort the phones out, is that right?" he asked. Julia shrugged her shoulders and looked over to one of the members Robert. "What d'yer reckon?" she asked Robert. "Yes that's right, we need the phones fitted upstairs and downstairs", Robert replied. The engineer and Robert went upstairs and were still chatting away half an hour later' (Independent Group, ON, 6th meeting).

Julia's skilful prodding of Robert ensured that he took on the role of negotiator. The engineer changed in his interaction from a chap unsure of how to act, to someone who felt comfortable to chat away. A similar incident occurred with the same group but a different supporter:

'Robert, Jonny and Andy went to the bank to pay in some money. We were stood at the counter, along with Dennis the supporter. The

clerk looked up to catch the eye of Dennis. However, Dennis must have anticipated this and was looking over at Robert. The clerk noticed this and asked Robert what she could do for him' (ON, 6th meeting).

When advisors remembered why they were there this appeared to be associated with maintaining acceptance, tolerance and understanding. However, this meant that potential conflicts with self-advocates could occur:

- 'The advisor asked the group what prejudice meant. Amanda said it was like a black woman and a white man getting married, "You see many of 'em around". John, the advisor, replied, "Yes and people don't think its right do they?" Amanda's reaction was unexpected - "No I don't think it's right". When asked why, Amanda replied, "It's difficult to explain". John asked Amanda if she would accept that people should have the choice. "Yes I do, its up to people innit?" replied Amanda generously' (Advocacy supported group, ON, 3rd meeting).

Dowson and Whittaker's (1993, p31) put forward the 'confronting intervention' as a way of tackling members intolerance. An example of this would be:

'After we've talked so much about respecting people, I feel really angry about the way you just spoke Sally' (Ibid.).

By contrast, the above vignette in the Advocacy-supported Group shows the advisor embracing Amanda's perspective without prescribing how she should think. Giving space and time for people to speak out is a necessary part of self-advocacy's beginnings (Downer and Ferns 1993, pp142-143). To knock down others because their opinions are incongruent with your own can prevent people from even starting to self-advocate. Another difficult issue was that of the 'dominant member'. A number of advisors appeared to be more than able to handle this difficulty:

'Lesley was being rather self-righteous with Carol, "You shouldn't push in the queue Carol it's wrong". Louise stepped in marvellously, "Well, you can't blame Carol for trying!" The group laughed. Lesley responded, "I didn't shout at her". Louise asked Carol, "Is that right, she didn't shout at you?"' (Centre Group, ON, 6th meeting)

This links into the collective responsibility and identity component of the social model (Finkelstein 1993, Oliver 1996, Morris 1996) - forging bonds and commonalties with one another, challenging actions that are destructive. Diffusion tactics encouraged others to have a say in ways that did not disempower others.

(5) 'Missing the point' - v - 'Addressing the point(s)'

There were many complex ways in which supporters threatened to stifle the self-determination of members. At times, this was linked to focusing on the trivial - or **missing the point** (see Worrel 1987, p34):

'Sarb had spent a lot of time making posters for the group. He had stencilled in the group's name and cut out some pictures from a Trade Union brochure. This finished draft had been photocopied onto A3 paper and presented a striking poster for the group. One of the supporters made only one comment, "You'll have to take out the trade union name for copyright reasons". No other comments, good or bad, were given' (Social Group, ON, 2nd meeting).

'Chris got out a pen from his bag, and asked me, "Do you like it? It's new". June, the supporter, was seated nearby listening and asked Chris in a patronising drawl, "Is that a new pen?" Chris looked bemused. Later Sarb went to the bar for a drink. He returned, as always, with a pint of lager and sat down beside Chris. June looked up and asked, "Are you thirsty Sarb?"' (Social Group, ON, 9th meeting).

This was very similar to my own ridiculous comments to Jim:

'Jim was reading a magazine on car tyres. I asked him what he was reading and he replied, "a magazine on tyres". He then turned away, probably concerned that he might catch my 'Asking-stupid-questions-deficit-disorder'' (Social Group, ON, 2nd meeting).

While these interactions now seem laughable they are actually potentially harmful. Treating people as 'retarded' has the knock on effect that 'acting like the retard becomes second nature' (Guskin 1963). For Worrel (1988, p55) an ignorant advisor misses the first and most important step of support. Without listening carefully and assisting people to express themselves,

advisors may miss out on important questions that people are asking themselves:

‘Sarb is sick of having no money. June asked, “What is it about not having any money that you don’t like?” “Not having any”, Sarb replied’ (Social Group, ON, 7th meeting).

Similarly, salient issues associated with choice are ignored.

‘Carol has been told that she and her colleagues are moving workplaces. Advisors asked what work she’d be doing there, one of them reassured Carol, “You’ll like it there”’ (Social Group, ON, 4th meeting).

Advisors did not find out if Carol was asked if she would like to move. Instead it was tacitly accepted that others had made decisions for her and these were there right decisions. Self-advocates may need to be reminded of their own rights and resources, thus, advisors **address the point(s)** (Worrel 1988). Too often the failure of others to recognise the self-determination of people with learning difficulties suppresses their sense of worth (Atkinson and Williams 1990). On occasions too numerous to mention, many of the members of all four groups I observed would ask a supporter, or me if they could go to the toilet. My response was, ‘You don’t have to ask me’. In addition, many of the advisors (and self-advocates) had wonderfully delicate ways of prodding people into opening up. Supporters would often reply to members’ cathartic expressions, ‘You obviously feel really strongly about that’, ‘You seem to be angry’, thus reinforcing people’s concerns as

important (as with Dowson and Whittaker's 'cathartic intervention'). Both advisors and self-advocates appeared to be skilled at this:

'Imran suggested that the group keep a record of the phone calls they have made. Matthew [the supporter] went around the office telling people about Imran's 'brilliant idea'' (Independent Group, ON, 4th meeting)

'Jane often repeats things verbatim from the TV. "Now go over to Gillian Shepherd ... what do you think Mrs Shepherd ... education". Paul [a supporter] noted, "That's a good point about education Jane, did you see it on the news?" Jane replied, "Yes". "Good", continued Paul, "What do others think about education?"' (Advocacy-supported Group, ON, 5th meeting).

There was movement away from the specific to the general - periphery to the centre of self-advocacy. In the latter vignette, Jane's views were validated and the debate was extended to others. One of Jane's peers, Bill, recognised the use of Jane's commentaries:

'It's good because Jane tells us news we have missed' (Advocacy-supported Group, ON, 5th meeting).

Two other vignettes from the Social Group highlight how simple questions from advisors can address basic human rights, from risk-taking to independence:

‘Virginia asked the group if they had their own keys to their homes. Adam said he had. Virginia asked him, “Do you let yourself in when you get home?” “No”, said Adam, “ My mother leaves the door open for me”’(Social Group, ON, 5th meeting).

‘Lillian said that she’s not allowed to use the stove at home. Virginia asked, “Why? Have you used it before? Will the staff let you?” Lillian replied, “No they won’t because I burnt myself”’ (Social Group, ON, 5th meeting).

Addressing concerns of self-advocates can help to build up collective identity of the group - an important aspect of the social model (Finkelstein 1993, Oliver 1996, and Morris 1996). More about this below.

Conclusion – conceptualising advisors’ support

It would appear that the support of advisors is changeable. As with the previous chapter that rejected previous literature’s preoccupation with group ‘type’, this chapter so far has brought into question the relationship between advisor status and ‘good’ and ‘bad’ support. In contrast to previous literature, my ethnography suggests that types of support do not neatly fit with types of advisor. Instead, the fluidity of support means that advisors can support on good and bad ways, and these interventions can be understood as reflecting positions on individual-social model continuums.

Not just advising - self-advocates supporting one another

In addition to advisor interventions, self-advocates themselves created a group setting that facilitated the development of self-advocacy. Their actions magnify the self-help element of a social model of disability, where disabled people move towards personal and social action through the resource of collective identity (Shakespeare 1993b, Hales 1996). As Crawley (1988) points out, self-advocates are a lot more able to promote the empowerment of their 'less-able' peers than even the most well meaning advisor. Goode (1992, p205) suggests that inter-dependence amongst people with learning difficulties' over-rides notions of incompetence held by others. In his case study of Bobby, a 50 year old man with learning difficulties, videotaped recordings of Bobby with his friends showed Bobby behaving 'more competently' than when he was in the company of staff and researchers. This, Goode concluded, was the direct consequence of friends not seeing any problems with the way Bobby acted. Similarly, Schapiro's (1976) account of the advocacy support lent by senior citizens to a collection of deinstitutionalised people supports the viability of informal (self)advocacy relationships. My observations picked up on many supportive skills of members though I am not trying to paint a perfect picture. Some members openly disliked one another, some were bossy, others dismissive. Yet considerations of support would be lacking without attention to the ways in which self-advocates themselves bolstered group cohesion and encouraged one another to speak out for themselves. It is worthwhile to include these vignettes as they suggest that there is more to promoting self-advocacy than advising (Siegel and Kantor 1982). Support can therefore be understood, revamped and changed, in accordance with what self-advocates can do for themselves.

Challenging advisors' interventions

People with learning difficulties are not passive in the doing of self-advocacy and are able to offer 'instrumental' (practical) and 'expressive' (emotional) support to their peers (following Wolfensberger 1972). In my ethnography, members knew when advisors were starting to take over and challenged support:

“Louise mentioned that the tape recordings they have made of the meetings are very difficult on the ear. These tapes are used firstly, for writing up the minutes and secondly, are available for ‘clients’ in the Centre. She suggested that in future, one of the members, like Simon, could go into a quiet room and read out the main points from the minutes, which would be taped. The recording would be a lot clearer and so allowing other clients the chance to hear what had been talked about in the working group. Lesley the chair, stepped in, “Hold on - what about other people reading the minutes out as well as Simon?”. The advisor agreed and said she had only used Simon as a ‘for instance’” (Centre Group, ON, 4th meeting).

‘Matthew [a supporter] swore and the members in the room at that time shouted him down - “You know the rules Matt, no swearing”’ (Independent Group, ON, 3rd meeting).

Here members themselves were resilient enough to challenge dominant supporters. As Ken said soon after Karen’s outburst, ‘Even Danny’s falling asleep, you’ll sleep well tonight Danny!’ (ON, 6th meeting).

Resisting assumptions of deficit

Sometimes members resisted assumptions of inability, incompetence or inappropriateness that were held by others:

‘Karen had recently had a meeting with an educational psychologist because, she joked, “I’m dumb in the head”. A supporter who works at the college suggested that this meeting be arranged because Karen “was not joining in in class”. Karen disagreed - “No, I were bored”’ (Social Group, ON, 7th meeting).

‘Virginia [an advisor] suggested that members in the group should be taught how to cook. At the back Karen piped up, “I can cook already”’ (Social Group, ON, 4th meeting).

‘Imran’s Dad doesn’t like him coming to the group and would prefer him to be in the Centre. “Centre’s fucking boring - I prefer the group”, Imran explained. To avoid conflict with his Dad and the Centre staff, Imran told me that he took away the dates of the next meeting - one for the Centre and one for the taxi driver - to take him to the group not the Centre’ (Independent Group, ON, 5th meeting).

Even at formal meetings self-advocates were skilled at challenging others prejudices:

‘Karen spoke for the group to an audience of staff, parents and ‘users’: “In our group we talk about our hobbies, interests and worries we have. People with learning difficulties are just like

anyone else you know” (Social Group, ON, Users consultation meeting).

‘Representatives from the local council suggested that in order for me to canvass the opinions of members smaller groups should be used so that, “People with speaking problems have a chance to talk”. Robert agreed “Yes, some us never shut up and others can’t get a word in” (Independent Group, ON, meeting with Council).

‘Some of the members of the group are actors and dancers in a drama group. Towards the end of the meeting they came to the front and performed a new play they have been working on. Afterwards, with the musical accompaniment of supporters, they wrote a song. Clive, shouted out, “Hold onto your dreams don’t let them go” (Advocacy-supported Group, ON, Advocacy project AGM).

Sharing experiences and self-help strategies

Self-advocates themselves encouraged one another to open up, accept, listen and share skills and experiences. Being in Centres or houses together ensured that people know one another’s foibles:

‘Sarab is having problems at home. His brother picks on him and tells him what to do. Karen agreed, she hates it when staff watch her having a bath’ (Social Group, ON, 6th meeting).

‘It was Bill’s turn to chair the meeting. Around the group members offered their news and views. Erica took her time to think about what

she had done, "I'm just thinking", the group waited patiently. Bill gave her time to speak and skilfully moved on to the next person, "Thank you for that Erica, now Rachel what have you been up to?" (Advocacy supported group, ON, 2nd meeting).

'Jane jumped up out of her seat and lashed out at Erica. Erica was shook up, "You did make me jump". Then Jane got up and went over to apologise, kissing Erica on the cheek. Erica responded, "That's good of you Jane - well done"' (Advocacy supported group, ON, 6th meeting).

This acceptance spread to potential members. Membership of certain groups was open, unconditional and encouraged:

'Guy told the group that a woman at his Centre wanted to come down to the group. He asked the members what they thought. Richard was honest but fair "Well she's a bit of a pain sometimes, but why not?" Bill was not happy, "She's naughty", Guy was defensive, "Yes he was, but she's changed"' (Advocacy supported group, ON, 4th meeting).

'At the executive committee meeting, members were discussing the work that one of the supporters, Matthew, does for another self-advocacy group. Andy argued, "That group needs more training, they didn't even know what 'self-advocacy' meant". Ellen defended the group, "Yes, but Matt doesn't use that long word with them they use short words like 'speaking out'". "Oh, I'm sorry" replied Andy"' (Independent Group, ON, executive meeting).

Advocacy amongst self-advocates

Often the sharing of skills takes on characteristics of advocacy. Friends know friends:

‘Rachel does not speak often. She spends her time quietly and apparently contentedly smelling her fingers and looking around the room. At break-time Bill asked her if she would like a cup of coffee or tea. Erica, who lives with Rachel, replied, “She likes coffee don’t you Rachel?” Bill looked at Rachel, “Coffee then?”’ (Advocacy supported group, ON, 5th meeting).

Whatever the group, some members are more articulate than others and skills can be distributed so others benefit. Ferguson (1897, p56) argues that more should be spoken about interdependent living and co-operative work as opposed to independent living and competitiveness. Paradoxically, the path to greater independence is one that reinforces the idea of interdependence and co-operation (Williams 1989, p257):

‘Robert suggested that any documents on the new office premises should be photocopied and circulated to all members’ (Independent Group, ON, 4th meeting).

‘Guy, the treasurer, shares the group’s accounts with the members by referring to the flipchart on which the balance of the account before and after the meeting is presented’ (Advocacy-supported Group, ON, 5th meeting).

‘Every Friday Robert, Andy, Jonny and Petra sort out the agenda for the meeting on Monday (which uses words and pictures), write and post letters and sort out the finances’ (Independent, ON, 2nd meeting).

‘Andy decided that details about the annual costs for the new offices should be photocopied and given out to all members’ (Independent Group, ON, 3rd meeting).

Providing encouragement

Encouraging peers linked into the process of deciding – a process that is as important as the outcome of a decision (Worrel 1987, p32):

‘Each time a member gives their news bring the reaction of a loud and enthusiastic round of applause. By the end, the room is full of smiles. At one meeting Becca was ecstatic, “Danny - Rudi thinks I’m doing a really good job as chairperson”’ (Advocacy supported group, ON, 1st meeting).

‘Lesley goes to the advocacy development project. She suggested that someone else could come with her and she’d support them’ (Centre Group, ON, 3rd meeting).

‘At the executive committee meeting Robert went round the group to ask how many times a week the office windows should be cleaned. Some weeks before, the group was moving to their new offices. Imran has difficulty walking so the others put belongings in the van.

Andy told everyone, "Imran makes an excellent supervisor"
(Independent Group, ON, executive meeting).

'One of the residents in Lillian's house is violent towards her. Jarrord suggested, "You should stick up to them. I do - I shout out loud until someone comes"' (Social Group, ON, 5th meeting).

Humour

Finally, in all four groups, there were particular members who fulfilled the role of group-comedian, able to make people laugh and put others at ease:

'Karen looked depressed. As it came to her turn to give her 'news' she told everyone that she had to go the dentist the following day. "Are you okay?" asked one of the supporters, "Yes", said Karen, "My appointment's at tooth' hurty!" (Social Group, ON, 9th meeting)

'One of Imran's favourite sayings is 'Get real'. A number of the members and I were walking around the town to get some shopping and as we passed the market, a chap on the fruit and veg' stall shouted, '50p for a pound of toms'. 'Get real!' shouted back Imran" (Independent Group, ON, 6th meeting).

"Graham was chatting away as usual. Becca turned to Bill, looked up and joked, 'Eeee, that Graham's like a tin of marbles!'" (Advocacy supported group, ON, 3rd meeting)

“As I entered the room Lesley greeted me with an enthusiastic rendition of ‘Oh, Danny boy’. Members thought this was a scream, falling about laughing hysterically” (Centre Group, ON, 2nd meeting).

“Rudi has broken his arm, ‘No weight lifting for a while - eh Rudi!’ somebody shouted from the back’ (Advocacy supported group, ON, 6th meeting).

Conclusion - conceptualising support in practice

This chapter has conceptualised some of the interventions of advisors in terms of their position on five social-individual model continuums of support. In addition, some aspects of the solidarity amongst self-advocates have been presented. This exploration of advisor and self-advocate interventions has highlighted the complexities of support and delved further into the group dynamics presented in the previous chapter. Lukes (1986, p14) asks that we turn attention to the person:

‘Who takes the big decision, those that are irreversible, whose consequences risk being prolonged indefinitely, and being experienced by all the collectivity’s members’.

In the four groups, advisors had the power to take big decisions but self-advocates were not powerless. By understanding the link between actions and discourses of disability it is possible to become aware of the larger implications. Those advisors and members that supported well, listened and

acted in ways that challenged the discourses that silenced and disabled. There is more to advising than status or position. Self-advocates can be powerful but this needs to be recognised and reinforced. In terms of applications for policy-makers, service-providers and supporters, two general points emerge. First, following Means and Smith (1994), in the contemporary culture of 'user empowerment' and widespread adoption of self-advocacy, there may be a tendency to become obsessed with the changing elements of service provision and support. However, as this chapter has indicated, there may still be a need to consider the basic assumptions that underlie the way we address, talk and act with oppressed groups such as people with learning difficulties. Second, people of any (oppressed) social group are capable of individual and collective determination. Consequently, there may be a need to move away from paternalistic notions of 'empowering' people to practices that incorporate those self-empowering actions that already exist. By doing so self-advocates can be supported, by listening and acting in ways that challenge those discourses that silence and disable.

Chapter 11

Observing self-advocacy groups - grounded subjectivity and doing ethnography

Introduction

‘If we are to understand the way that power operates within a particular context, we have to examine the detail of that context, and to interrogate our assumptions regarding the various power configurations’ (Paechter 1996, p76).

This chapter examines some issues associated with method and analysis in the doing of ethnographic research. Running in parallel to the research for this thesis was my involvement as a volunteer to a self-advocacy group. This section will explore how these two experiences were connected. I will consider how learning to be a volunteer helped me build up what I will call a ‘researcher template’. This template provided me with a working framework through which to control, temper, assess and check some of my observations and analyses. First, researcher subjectivity with respect to ‘knowing’ research participants will be considered. Second, the ways in which my involvement as a volunteer impacted upon the doing of ethnography will be examined. Third, a number of dilemmas that I faced in participating in people’s lives will be explored. Finally, a number of questions are posed and links are made between this study and participatory research.

Introducing subjectivity

This first section examines the centrality of researcher subjectivity to ethnography. Three themes are introduced: subjectivity as a resource, subjectivity and the 'knowing researcher' and subjectivity and 'getting to know'.

Subjectivity as a resource

The positivist concern with objectivity in research has been consistently challenged. Non-positivistic research has replaced objectivity with subjectivity (see for example Allport 1947, Berger and Luckmann 1987, Walker 1981, Steele 1986, Grant 1992, Stanley 1990, 1994, Walmsley 1993, Shakespeare, Atkinson and French 1993, Burman and Parker 1993, Bannister, Burman, Parker, Taylor and Tindall 1994, Sparkes 1994). Consequently, the subjectivity of the researcher is considered to be a strength of research not a weakness:

'Subjectivity is a resource, not a problem, for a theoretically and pragmatically sufficient explanation... It is always worth considering, then, the 'position of the researcher', both with reference to the definition of the problem to be studied and with regard to the way the researcher interacts with the material to produce a particular type of sense' (Bannister et al 1994, p13)

The subjectivity and position of the researcher are addressed through a process of reflexivity. Attempts are made to explicitly account for the role

of the researcher within the research project. The reflexive account is displayed to provide the reader with insight into the position of the researcher within method (e.g. Walker 1981, Booth and Booth 1994), analysis (e.g. Shakespeare et al 1993, Atkinson et al 1997) and the production of ideas (e.g. Stanley and Wise 1993, Walmsley 1995). If the idea of specificity is accepted - that knowledge gained from research is a product of a particular time and specific place - then the impact of the researcher's own subjectivity is necessarily referred to (Bannister et al 1994, p15). Issues associated with the effects of the researcher's experiences, values, opinions, politics and actions upon analysis are also asked. However, there are problems in providing reflexive accounts:

'Self-evaluative [reflexive] accounts seem in the main to be written (and expected of) three main groups: established researchers looking back on mistakes they are assumed to have learned from, PhD candidates writing methodological appendices, and action-researchers, who are often teachers. The latter two groups are made up of some of the least powerful individuals in the research community, and it is pertinent to ask who their accounts are for, and how they affect the power-knowledge relations within that community' (Paechter 1996, p92).

Nevertheless, reflexive accounts expose some relationships between the position of the researcher and the research culture that is under investigation.

Subjectivity and the 'knowing' researcher

Feminist literature has long recognised the importance of subjectivity within the research exercise (see for example Bhavnani 1990, Stanley and Wise 1993, Morris 1996). A major concern has been the position of the researcher in relation to research participants. Certain strands of feminism argue that only women researchers can truly grasp their female participants' worlds because they, like their participants, experience and 'know' what it is like to be a woman in patriarchal society. In a widely cited piece, Oakley (1981) suggests that the women involved in her research were able to open up to her because of their recognition of commonality. The richness of material she uncovered was directly related to:

'The formulation of a relationship between interviewer and interviewee' (p31).

Moreover, Oakley argues that the women opened up because they saw in her another woman who shared their way of seeing the world. Stanley and Wise (1993, pp227-228) describe this experience of 'knowing' as an 'epistemological privilege', with women researchers having access to an 'a priori' knowledge of their female informants' subjective realities by virtue of their shared experiences of patriarchy. Another way of viewing Oakley's claims, according to Stanley and Wise, is that Oakley may have felt that she was a 'knower' of her interviewees' realities because their experiences fitted with her own life experiences. This type of a 'knowing subjectivity' is formed on an ad hoc basis with one 'ontological preference' of researchers being an identification with her informants lives (Stanley and Wise 1993, p228).

Stanley and Wise (1993) recognise this 'knowing subjectivity' is problematic. For a start, Oakley fails to point out that commonality may be extended beyond gender to race, class, sexuality and disability. Morris (1996) has challenged the ontological preference of many feminists to ignore the experiences of disabled women:

'We are outraged that our voices are silenced so that our oppression is not recognised ... The exclusion of disabled women means that the accounts of women's experiences are incomplete ... Moreover, this exclusion also renders feminist theory and analysis incomplete for there is no attempt to understand the interactions between the two social constructs of gender and disability' (Morris 1996, pp4-5).

Working from the presumption that one can have an 'a priori' or 'ad hoc' knowledge of another's culture is disputable. This is especially evident for black, working class, gay and disabled groups, whom for a variety of socio-political and cultural reasons fail to be represented in academia at large. In terms of my study this idea of the 'knowing position' is complicated even further when, in contrast to informants, the researcher is not disabled (Parker and Baldwin 1992, Barnes and Oliver 1997). The extent to which I (as a non-disabled, white, male, middle-class researcher) share experiences of exclusion with people with learning difficulties is highly questionable. The only 'ontological preference' available to me appears to be 'not knowing', particularly because of my lacking experiences of being disabled by society.

Subjectivity and getting to know something about informants' lives

Another way of considering the position of the researcher refers to a gradual process of learning to know some things about informants - 'getting to know'- if you like. 'Getting to know' is located in the ethnographic project of immersion within a culture and may be seen as anthropological by design. It is a process that with hindsight was a necessary part of my research. A major tool of anthropologists when they are attempting to understand another's culture is participant observation. As Malinowski put it, the ethnographer attempts to grasp:

'The native's point of view, his relation to life, to realize *his* vision of *his* world' (Italics in original, 1992 p25 in Edgerton 1984, p498)

Immersion within the culture under investigation sensitises the observer to the subtle rules, roles, social etiquette and tacit understandings that exist in that culture. Over time as one becomes more familiar with a given culture then one becomes more culturally aware. Yet the process of getting to know another is complicated and constantly ongoing. For Peberdy (1993, p50):

'Participant observation is the foundation of anthropological research, and yet is the least well-defined methodological component of our discipline. It involves establishing rapport in a community, learning to act so that people go about their business as usual when you show up ... and to a certain extent participant observation may be learned in the field'.

'Knowing' refers to an ongoing project of building a researcher subjectivity that learns from the experiences of people in the field under investigation.

This project is one that resonates with my own research experiences. The 'field', for me, was constituted not only by the research contact with four research groups but also by my independent involvement as a volunteer to a self-advocacy group prior to, during and after the ethnography.

Grounding my subjectivity in self-advocacy in practice

My experiences of self-advocacy played a part in how I interacted with research groups. These experiences also seeped into the stages of analysis and writing up. In the first year of my research I became involved as a volunteer to a self-advocacy group and this has continued to the time of writing (three years). The following account describes the group. Names have been changed to preserve the anonymity of members but the description is authentic:

'The group meets in an independent meeting room based in the town centre for two hours every three weeks. They have now been going for ten years, have around 20 members and are supported by one unpaid, independent advisor who has been involved on and off with citizen and self-advocacy. She has never been a paid worker for services for people with learning difficulties and this independence is undoubtedly a major strength. From the first meeting it became obvious to me that members felt comfortable and relaxed enough to say whatever they want. At the first meeting I introduced myself saying that I was prepared to come along and help in anyway I could. "How can I help you?" I asked, "You can't" shouted Paul to the general amusement of the group! After a vote I was accepted in and have been going since early 1995.

A general agenda is followed each meeting. Members start off with 'news and views' mentioning what they have been up to. Next, the minutes of the last meeting are checked with reports from the advisor, secretary and 'member advisor' being given. There are various 'officers', ranging from chairperson, transport and recruitment officers through to tea and coffee makers. The emphasis is on everybody having a job. Members stand for the various positions at an annual vote. The advisor and volunteer positions are also reviewed and voted on. One self-advocate, Betty, holds the member advisor position. She was instrumental in initially setting up the group. Her position is also annually reviewed. Following the reports, various other issues are covered from fund-raising, to invited speakers, through to role-playing exercises and discussions on themes such as sticking up for yourself, relationships and independent living. My primary role is one of minute-taker. The group asked me to write down what was mentioned in the meetings, type them up and provide pictures representing issues raised. They also asked me to produce a leaflet for the street collection, an invitation to the 10 years anniversary party and to send letters to various funding bodies and charities asking for money'.

The group has helped me to carve out some understanding of self-advocacy groups in practice and to appreciate the heterogeneous experiences of people with learning difficulties. My role as observer in the ethnographic study for this thesis was partly formulated through my experiences as a volunteer. Usher (1995, p50) notes that the very elusive nature of subjectivity makes it difficult for researchers to enter into a process of

reflexivity. Identifying those aspects of subjectivity that shape research is a daunting exercise. Usher suggests that:

‘Because reflexivity is an integral and constitutive part of any research practice it need not be imposed in a direct and obvious way’ (Ibid.).

While accepting that participant observation is often a messy, serendipitous and arbitrary process, a number of experiences as a volunteer affected how I saw, acted with and understood the four research groups. These experiences contributed to the building up of what I will term my ‘researcher template’. It is to this template that I will now turn.

Building a researcher template – reflecting on theoretical observational notes (ONs)

My involvement as a volunteer was informative in the development of my role as observer. After meetings I would make observational field notes (ONs, Schatzman and Strauss 1973, pp99-103) but backtrack and try and compare my ONs with my experiences as a volunteer. My volunteer status may have meant that I was too close to the processes that I observed in the research groups - I lacked an ‘objective’ stance. Perhaps I was primed to see what I considered good and bad practice in ways that may have said more about my ideas of being a volunteer than my views of the research participants. My volunteer and observer roles overlapped in ways that were advantageous to the ethnographic project. A number of overlapping experiences come to mind, five of which are outlined below.

Recognising individuals and stifling social structures

There are many different people in the self-advocacy group I am involved in:

‘James is in his sixties now and walks with two walking sticks. He wanted to go to Tech and asked that the Centre lay on transport for him so he could go down and see his friends. Eventually his requests were granted and a taxi picks him up from the Centre to take him down to tech. Paul, like James, has spent a lot of his life inside group homes. He loves football and writes down the scores of each match every weekend. Witty and outspoken he encourages others to speak up for themselves. He is waiting for a social worker to find him a house back in his hometown. Jean first came to a meeting last year but did not return for some months. The staff in her home would not let her walk to meetings on her own because they said she was not ‘road-safe’. With the help of the group, following long-winded bureaucratic complaint procedures, she became a regular at meetings, getting in by taxi. Recently, however, she has not attended, apparently the staff are not waking her up in time. Over the last four months she has lost three stones in weight and has asked people not to tempt her with chocolate biscuits. Irene looks after her mother who is old and frail. She works part-time in the library and has done some reception work at the centre. She no longer comes to meetings because her mother gets upset when she leaves. Asif is the group’s secretary and lives with his parents. He works at least six days a week, two of them on the market selling shoes. He is saving up for his holidays. Sophie is a lively and loud member of the group. She is

currently touring the county with her drama group presenting a show in which she is one of the dancers. This freedom of movement contrasts with her earlier experiences of life in an institution where she was made to wear weighted boots’.

Like any social group the members described above have very different lives but also have some shared experiences. As I got to know more about them they allowed me to start ‘getting to know’ about disability on three levels:

- **Individuals** - I was reminded of the people that exist behind a label of ‘learning difficulties’. James, Jean, Irene, Asif and Sophie, people with learning difficulties, are far from constituting a homogeneous group (Whittemore, Langness and Koegel 1986). They are people first. Behind the social construction of disability individual lives exist.
- **Social structures** - I was sensitised to socio-political structures that stifle life opportunities by listening to the experiences of members shared at meetings. Their accounts allowed me to contextualise the theoretical and political explanations of disabling society offered in the literature of the social model (e.g. Oliver 1990). Their stories gave me a view of disablement in individual lives.
- **Resilience** - I soon came to recognise resilience in the face of adversity. People have rich experiences to reflect upon. Even when institutions, professional attitudes and societal discrimination threaten to prevent the emergence of lives - lives still go on. With this in mind I was reminded that labelled people are not passive recipients of oppression. They are

active and resilient social members (Skrtic 1995a, 1995b, 1995c, Ferguson 1987).

The label of 'learning difficulties' would creep in and out of my way of seeing and continues to do so. Some stories were very similar to my own: watching the cup final, going out for a drink with friends, health worries, earning money to spend on holidays. Stories were told of getting jobs, becoming responsible, being creative, wanting to be heard and shouting up for rights. At the same time some stories were novel and alien to my own: people being put in a house with strangers, not being asked where they would like to live, prevented from going out because others think they are incapable and of archaic treatments in institutions. I was forced to see people having to shout up for their basic human rights, yet doing it nonetheless.

Before I was angry about labels, treatment regimes, professional attitudes and the like. Now I was livid. I hated to hear about challenging behaviour, of ADD or other medicalised terms. I continued to pull up my friends and family when they said, 'Isn't it sad'. As I got to know Jean, Asif, Sophie and the rest of the group, labels seemed inappropriate, sympathy misplaced, notions of individual problems not representative. I didn't know them as the product of conditions or syndromes. I only got to know bits about them as people over time. They prompted me to try and develop a way of 'knowing' that recognised individual lives whilst being sensitive to disablement. A process of 'getting to know' was initiated, which I have tried to follow in and outside of my research, though I often fall back into prejudiced ideas. I continue to pull myself up on thoughts and comments that I have made, which are simplistic and attend to disability as an individual problem. As

with Goode and his colleagues (Goode 1992, p207), I now try not to use a high-pitched, slow and patronising drawl when talking to people with learning difficulties.

Looking for things in ethnography - The pre-set and the unknown

As Glaser and Strauss (1967) point out, qualitative methods are impressionistic. Many of the observations I made in the field were prompted by a desire to see particular things:

‘The group moved into their new offices today and I was looking for evidence of self-advocates calling the shots with the move. I wasn’t disappointed’ (Independent Group, ON, 5th meeting).

‘The group was meeting with representatives of the County Council. I was watching to see how advisors Julia and Dennis supported the members’ (ON, County Council meeting).

My volunteer role meant that I had contextualised some research ideas before meeting the research groups. However, I also aimed to learn from the groups and to avoid framing my ONs in terms of pre-set categories (see Charmaz 1995, Harré 1981, Bannister et al 1994, p74). This aim of learning from the group was supported by my experiences as a volunteer. The general feel that one could get of a group could change from meeting to meeting. For example in ‘my group’:

‘It seems to be more chaotic, chatty and frivolous when Betty isn’t there. She seems to stifle people - perhaps intimidate. It’s as if two distinct groups exist: the Betty-absent and Betty-present’

Awareness of these varying dynamics was an important part of me ‘getting to know’. Attempts were made to sit back and learn from the research groups, not to assume too much from one meeting and to keep an open mind. Through my subjectivity being bound up in my own role as volunteer, I was permitted a way of seeing that was transferred to the ethnographic context - in this case to look for particular aspects of the culture but to learn from it as well.

Disciplining cynicism

Schatzman and Strauss (1973, p110) assert that the ‘model researcher starts analysing very early on in the research process’ (p110). Accordingly, I made a number of ‘theoretical ONs’ from the early stages of involvement with research groups. Sometimes a re-think of my field notes revealed cynicism on my part. Take the following extract from my observations of a ‘bad supporter’:

‘A supporter brought up the issue of service charges. Why they had to bring it up I am not sure because it didn’t receive much attention. What about what members have to say?’ (Social Group, ON, 2nd meeting)

A further look at my field-notes shows a re-think on my part:

‘Initially I was suspicious of the advisor introducing a discussion topic - what would the outside observer make of it? Dominant and intrusive, ‘disempowering’, but is this not a role of the supporter to bring along information?’

A questioning narrative (me as volunteer) existed alongside the theoretical narrative (me as observer). I remembered bringing along some notes on the Disability Discrimination Act to ‘my group’. I would hope that doing this for the group was not ‘disempowering’. The interventions of the advisor in the Social Group were seen differently when I re-examined the ONs with my volunteer hat on.

Another extract from ONs shows a time when I thought I had identified a ‘bad group’:

‘The group really functions just in terms of a social activity. People seem to just come along for a drink and a chat with friends. Bill Worrel’s of the world would have a problem with this’ (Social Group, ON, 1st meeting).

It makes me cringe to read these theoretical ONs now - ‘*Just* in terms of a social activity’- indeed! Similar analysis could be made about ‘my group’:

‘There is Carl who says nothing at meetings but still comes and Pam who likes to meet her friends and then go into town afterwards shopping’.

The ONs for the Social Group were re-assessed soon afterwards:

‘... But surely aren’t members making friends? Integrating them selves? They are a close, they go off and chat with each other, just like you would down the pub. Aren’t these important parts of self-determination?’ (Social Group ON, 1st meeting continued)

Acknowledging difficulties and skills

Advising someone to speak up for himself or herself is contradictory. There is a fine line between telling and helping, doing for and encouraging someone to do it for himself or herself. There were times when the interventions on the part of advisors in the research groups could have been misunderstood or their significance not picked up on had I not had experience of advising myself. Some examples of this come to mind where my own experience allowed me to see and perhaps ‘know’ the significance of a supporter or advisor’s act.

For example, dominant and passive members will be present in any group setting, yet difficulties arise when a large proportion of members are new to or inexperienced in meetings. Further dilemmas emerge when some members take over and at worse, threaten the standings of others. For example, an issue of personal significance was the ‘bolshy member’. This scenario occurred in ‘my group’:

‘Betty said that she felt the group wasn’t a ‘proper self-advocacy group’. She named two members that she felt were ‘letting the group down’. Pointing to Ronan she said, ‘He never said anything at that meeting we went to, he just sat at the back’. Then turning to Sophie,

Betty shouted, “She lets the group down shouting and acting up in the centre”.

I was unsure how to handle this incident. Betty continued to criticise and started to name members who she saw as a ‘let down’. I tried to resolve the issue by saying that there were ways of saying certain things. As Ronan said to me after the meeting:

‘It’s not what Betty says it’s just the way she says things that hurts’.

After the meeting I agonised over whether or not I had handled the incident in the most helpful way. I also shared some dilemmas that were experienced by advisors in the four research groups:

‘Sarab was speaking about what he got out of meetings. He told members that he liked to come to meetings to talk about work and money, amongst other things, but others, “Just talk rubbish”. The supporter Jurgen reflected back to the group what Sarab had said. Jurgen mentioned how Sarab wanted to speak about certain things but others didn’t, “Well that’s the polite way of putting it”, Jurgen joked’ (Social Group, ON, 9th meeting).

Jurgen ensured that Sarab’s opinions were recognised but at the same time de-fused the situation, making Sarab’s comments less threatening for others. I welcomed and recognised how well Jurgen dealt with this difficult issue because I had been in similar situations.

Acknowledging self-advocates' views

As evident in my ONs, importance was attached to the views and actions of self-advocates throughout the ethnography. 'My group' helped me to learn about the importance of such views and actions:

'Jean had not been to the last five or six meetings of the group. One of the members had heard from Jean that the staff were not letting her come down to meetings. It was decided that one of the members, Betty, and I should go down to Jean's group home and find out exactly what was going on. As we walked to Jean's home Betty was furious and said how typical it was of staff to do such things. On arriving at the home we made our way into the office of a senior member of staff - Eva. Betty asked Eva why Jean was not being allowed to come to meetings. Eva explained how Jean was not 'road safe' and that a member of staff was needed to accompany Jean when she was crossing the roads. The trouble was, Eva said, answering Betty's question but looking at me, there was only one member of staff on today, so Jean had to stay at home. A short while later another member of staff walked in. Betty said, "Well there's another member of staff - can't she walk with Jean?"'

It was enlightening to see how Betty's speaking up was being challenged by Eva answering Betty's questions to me. I remember avoiding eye contact with the member of staff by looking at Betty. I am not sure whether or not this really helped or supported Betty as she tackled the staff. Yet I did notice that the staff member interacted more and more with Betty as the meeting progressed. Moreover, Betty dealt with situation incredibly well

without my input. Situations like this also allowed me to develop strategies that were employed in the research groups:

‘At the meeting with Norma and John from the County Council, Dennis appeared to avoid eye contact with them. When they posed questions, Dennis would look over to Robert and Andy – alerting everyone present to the two people who represented the Independent Group’ (ON, first meeting for evaluation report).

I dealt with this interaction (also cited in chapter 9) by speaking over Matthew to ask Robert how he thought the day had gone. With eye contact firmly on Robert he eventually told me, and Matthew stopped talking. Like Matthew I often fall into the trap of talking over others. Indeed I am sure that I have been a lot ruder than Matthew was. Here subjectivity bound up in my own role as volunteer allowed me a way of seeing that was transferred to the ethnographic context and informed my interaction with others.

Doing ethnography – problems of participation

When social contexts become research contexts they are changed (Parker and Shotter 1990). Researchers become part of the cultures that they describe, and researcher and participants interact to produce the data (Charmaz 1995). While attempts were made to undertake the ethnographic method in ways that did not markedly change the group processes, some issues emerged as a consequence of immersion. The personalised aspect of ethnography created a number of dilemmas.

Observer or helper – a case of mistaken identity

The participant part of my observer role was problematised during my involvement with the Social Group. By the time of our second meeting, advisors were positioning me alongside them:

‘Jurgen [advisor] took a vote. One of the members, Ken, noting that I was not putting my hand up asked why. Jurgen explained, “Helpers can’t vote”’ (Social Group, ON, 3rd meeting).

Luckily members were on hand to remind their peers of my reasons for being there:

‘Ken asked me to talk about my project again, I asked the group if it was still okay to sit in’.

Each group was told of my aims to sit in on their meetings. I did not want to become a short-term advisor. This did not preclude certain types of participation:

‘The group had been talking about services and holidays came up. Sarb said something to the advisor Virginia and she told the group that he didn’t want to go on a ‘segregated holiday’. Sarb started to cry. One of the members, Karen, told Sarb that she’d go out of the meeting room with him for a chat. He declined and asked me instead. Outside we got a drink from the bar, found a seat and Sarb told me that he has no friends. I asked him if he could go on holiday with his brother, but he told me that his brother doesn’t want to go. I

suggested that he had a word with Christopher [the chairperson] who I know from what Sarb has told me is an old friend - "You could go away with Chris". He perked up a bit and after we'd finished our drinks we walked back into the room. "That's a good idea that", said Sarb, "I'll have a word with Chris" (Social Group, ON, 7th meeting).

On other occasions I was reminded that the rewards I felt in feeling that 'I'd helped someone' were arrogant and disregarded how self-advocates helped out one another (see Dowson and Whittaker 1993, p14):

'Andrew cried tonight. He asked to have a private word with me in the break. He told me that his mother hadn't seen him in five years. She only lives a couple of miles away. This really upsets him; "I can't deal with it". I said that it must be really hard and he had every right to feel sad and angry. After a while I suggested that he should think about the things that make him happy. I asked him if he had any friends. "Yes", Karen piped up, "I'm your friend Andrew". "So am I", said Angie. "I'll be your mother now" announced Karen as she put her arm around Andrew. Then I got up to get a drink from the bar and said I'd be straight back. I got chatting with Cliff at the bar and as I was talking to him Andrew jumped up and ran through into the next room crying. I felt terrible, I wasn't sure if I should be supporting him. Karen followed Andrew out the room" (Social Group, ON, 8th meeting)

I felt useless. Shortly afterwards Andrew returned with Karen:

“ ... They were hugging and kissing as they came back in. Andrew said he was okay. Later on at the end of the meeting as I left to catch my bus I shouted over to Andrew, “Keep your chin up”. He laughed and Karen shouted back, “Thanks for the therapy session!” (Social Group, ON, 8th meeting).

There is more to ethnography than simply observing. Feelings are reciprocated as relationships grow - though often self-advocates could support one another anyway. However, there were a number of encounters when I had to stop myself from getting too involved:

‘One of the advisors, Matthew, keeps suggesting that we go out for a drink. I said that we should ask if any of the members wanted to. He said that that was an idea but why didn’t him and me go out? This doesn’t seem right. I’m there principally to learn about what self-advocates get out of the group not to have a cosy get-together with the advisors’ (Independent Group, ON, 5th meeting)

‘The group meeting was made up five supporters and six members. The members were quiet, the supporters talking between themselves. Then Karen, one of the members, piped up, “It’s like a staff meeting”. “Yes”, I joined in, “ now could all the members leave - this is an advisors’ meeting!” A supporter heard this and agreed, “Yes helpers shut up” (Social Group, ON, 6th meeting).

There was no real need for me to intervene because Karen had already dealt with the advisors. There are dilemmas in participant observation and a constant re-negotiation of the role from observer to participant.

Observer as worker and ally

At times groups assigned me a worker's role. The Social Group requested that I re-do their group constitution and write a leaflet introducing them (*Appendix 4, 12*). The Advocacy-supported Group were talking about voting one meeting, so I sent them a copy of my attempt to make voting procedures accessible (*Appendix 4, 13* – all groups were eventually sent this). The Independent Group asked me to come down with my car to help move belongings into new office premises. Later, they asked to become involved in evaluating their group for the County Council (see *Appendix 4, 11* for County Council report):

‘At the meeting with the group and representatives of the County Council (Norma and John), Norma announced that he would like a meeting with me without members of the Independent Group being present. The group accepted this ... [At our meeting] Norma, presented me with a number of letters of complaint about the Independent Group from parent of an ex-member. The Mother had complained that the Independent Group was encouraging her son to speak out in ways that she felt he was incapable of. Norma queried whether or not I should follow it up as part of the evaluation’ (Independent Group, ONs from meeting with group and Council, meeting of Norma and me).

My evaluation was meant to be ‘independent’ but I felt accountable to the Independent Group:

'I suggested to Norma that this one complaint could unfairly sway the evaluation in a negative direction, after all I pointed out, "I bet the Council gets far more complaints and many of those don't get heard". Norma agreed and the complaint was not followed up in the report. Instead she requested that the group forward her a copy of their complaints procedure' (ON, meeting of Norma and me).

Groups gave me a participatory role that became something separate to a researcher role, whereby I had to ask where my loyalties lay.

Leaving the group and group discussions

I felt tensions in being part of members' lives and then leaving when the research ended:

'I reminded the group that the next meeting was my last. People said they would miss me. Sarb asked if we could go on holiday together. I said I couldn't afford it and suggested he talk to Chris about it. Karen asked when I'd be coming again. There was talk of the Xmas meal and I told her I'd love to come down. There's something really shitty about all of this. Just another temporary figure in people's lives. But let's not forget - do I mean that much? No!'" (Social Group, ON, penultimate meeting).

'I feel sad. I come in for a few months, get involved, people open up, then I go. It doesn't feel right' (Advocacy-supported Group, ON, last meeting).

Groups were told that their involvement was central to my attempts to try to understand self-advocacy and of my hopes that other self-advocacy groups would get something out of reading about them. In addition, group discussions were used to tackle the process of disengagement. In these sessions members were asked, 'So what do you get out of self-advocacy?' Afterwards, written and pictorially presented feedback reports of what members said were given back (*Appendix 4, 6 - 10*). Other reports, evaluations and group constitutions that I had been asked to complete were also finished and handed to groups (*Appendix 4, 10-13*).

These steps allowed me to leave groups in a clear way. My involvement has had an impact on groups although I am sure not to the detriment of those involved. I hope that participants' share the sentiments expressed in the comment by Rudi, the vice-treasurer of the Advocacy-supported Group:

'We've learnt a lot from you Danny and we hope you've learnt a lot from us' (GD, *Appendix 4, 8*).

Lessons for participatory research

My ethnography set out to uncover some of the processes within self-advocacy groups. No attempts were made to employ a participatory approach to research - whereby research participants engage in the process of analysis and writing up. A number of recent studies have employed a participatory approach (Whittaker, Gardner and Kershaw 1991, Whittaker, Gardner and Spargo 1993, Atkinson 1993, Aspis 1997, Atkinson, Jackson and Walmsley 1997, Mitchell 1997b, 1998, March, Steingold and Mitchell 1997, Stuart 1997). My ethnography highlights a number of issues and

questions that could be considered by researchers who aim to adopt this approach to research:

- As the research groups were self-advocacy groups, they could have been used as a supportive resource for working on participatory methods (see March, Steingold, Justice and Mitchell 1997). Accessible introductory booklets that were used in the ethnography (*Appendix 4, 1 and 2*) could be taken further and employed in negotiating analysis.
- The activities of self-advocacy groups share aims with the participatory action research (PAR) literature (Friere 1970, Reason 1988, 1994), such as: co-creation of realities through participation, discovering ways of living in collaboration with each other, promoting participation of people in their own life experiences. Future research could make links with self-advocacy groups and support present and future developments. However, are there dilemmas in merging everyday self-advocacy activities with academic research programs?
- The ethnography highlighted the self-empowering actions of self-advocates. This raises questions about empowering research. Does the notion of empowering research pre-suppose that people need empowering and thus reaffirm their subordinated status by ignoring that that they are involved in their own emancipation already?
- Following Clough and Barton (1995), Swain (1995), Barton and Clough (in press) and Goodley (in press, b), this chapter has highlighted the dilemmas of getting involved in people's lives. I felt less anxious about stepping in and out of participants' lives because of the support

networks that already existed within groups. However, what about researching lives of people who lack support networks? Is it ethical to research vulnerable and lonely people, even when a PAR approach is adopted? After all, what happens when the research ends?

- There are difficulties in researchers coming into a culture that they have no previous experiences of. Conversely, if researchers have invested time in that culture beforehand, are they then too close to what they are trying to understand? Researcher subjectivity may ‘get to know’ something about the culture under investigation but is this a necessary pre-requisite for ethnography?
- Though an analytical framework may well be developed with research participants, questions remain over who owns the analysis (see Atkinson, Jackson and Walmsley 1997)? Who has the final say over what is concluded?

While I anticipate developing participatory methods in future research, I can only hope that the analysis provided in this section of the thesis authentically captures the perspectives of some of the self-advocates in ‘my group’ and the research groups.

Conclusions – ethnography and participation

This chapter has considered some of the impacts that researcher subjectivity has on the research process. First, subjectivity, the position of the researcher and notions of ‘knowing’ were introduced. Second, my involvement as a

volunteer was addressed to examine how my experiences formed a background narrative to the ethnography narrative. Third, a number of dilemmas associated with ethnographic involvement were outlined. It would appear that being a volunteer enhanced the ethnographic method and analysis. Fourth, a number of issues that arose out of my ethnography were presented to make links with participatory research. On reflection, it would appear that the building up of a researcher template enhanced access and subsequent interactions with groups. My personal experiences allowed me to pick up on some of the subtleties and complexities of group dynamics.

Section 5

Revisiting Self-advocacy

Chapter 12

Conclusions - Revisiting self-advocacy in the lives of people with learning difficulties

Introduction

This chapter draws the thesis to a close. The first section reflects upon what the study set out to uncover by recapping on the initial literature review, reiterating the theoretical bases of the thesis and critically summarising how the study set out to appraise self-advocacy. The second section draws together a number of analytical connections from the empirical sections of the thesis. These include variation and complexity in the movement, the impacts of group 'type' and organisational dynamics, supporting self-advocacy, a priori resilience of people with learning difficulties, groups as a context for furthering self-advocacy, self-advocacy and self-definition, inter-dependence and culture and the need for self-advocates to call the shots. The third and final section presents a number of questions that remain unanswered and therefore point ways forward for future research. A number are outlined, including self-advocacy and impairment, commonality between self-advocates and other disabled activists, the self-advocacy movement and the disability movement, leaving self-advocacy, types of self-advocacy and participatory research - a framework for future research.

Reflecting on what the thesis set out to uncover

This thesis set out to appraise self-advocacy in the lives of people with learning difficulties. The following section will revisit the initial literature review, reiterate the theoretical bases of the thesis and critically summarise how the study set out to appraise self-advocacy.

Setting the scene

Chapter 2 presented a review of the self-advocacy literature. This review documented the rise of a movement of excluded and labelled people who have organised themselves on local, national and international levels. The chapter examined definitions of individual and group self-advocacy, origins (from services and *People First* groups, in Sweden, North America and Britain), various organisational ties (services, independent and citizen advocacy) and the growth of self-advocacy as a new social movement (Shakespeare 1993b, Bersani 1996, pp265-266). Next, the components of groups were outlined, including members (self-advocates), supporters (or advisors), meeting place, format of meetings, roles of self-advocates (including chairperson, treasurer, secretary) and financial support and implications (for example, whether or not to pay advisors). A number of tensions within the movement and inside groups were also pinpointed. The organisation of groups in terms of ‘type’ (autonomous, service-system based, divisional and coalition) and the status of advisors (voluntary versus paid, staff versus independent) emerged as prominent themes within the literature (e.g. Crawley 1982, 1988, 1990, McKenna 1986, Worrel 1987, 1988, Simons 1992, Clare 1990, Sutcliffe 1990, Sutcliffe and Simons 1991, Dowson and Whittaker 1993).

Chapter 3 theoretically contextualised the self-advocacy of people with learning difficulties. A short history of some of the facets of dominant contemporary understandings of disability was traced. It was argued that this model – the individual model of disability - is preoccupied with deficit, reinforces pathology and therefore provides an incompatible understanding of the self-advocacy of people with learning difficulties (e.g. Barnes 1990, Oliver 1990, Morris 1991, Swain et al 1993, Hales 1996, Shakespeare and Watson 1997). By contrast, understandings of disability that emerge out of disabled people's experiences and actions – the social model of disability – more readily embrace the self-determination of people with learning difficulties whilst recognising the effects of disabling society (see for examples Atkinson and Williams 1990, Booth and Booth 1994, Oliver 1996, Goodley 1997a). Finally, to make the social model of disability even more inclusive of people with learning difficulties, literature associated with a 'sociology of impairment' was used to deconstruct diagnostic criteria that are used in the assessment of 'learning difficulties' (e.g. Townsend 1969, Mercer 1973, Bogdan and Taylor 1976, 1982, Ryan and Thomas 1980, Kurtz 1981, Whittemore, Langness and Koegel 1986, Goodley 1996c). This chapter set the theoretical tone of the thesis.

Against the historical and theoretical background set out in chapters 2 and 3, three questions were posed. First, what is the nature of the contemporary self-advocacy movement? Second, how do self-advocacy groups impact upon the lives of people with learning difficulties? Third, how do self-advocacy groups work? The empirical sections of this appraisal aimed to answer these three questions thus building upon what was already known about the self-advocacy of people with learning difficulties and the social model of disability.

Going about the appraisal of self-advocacy

The empirical work aimed to describe some of the developments that had occurred in the self-advocacy movement, illuminate self-advocacy in some aspects of the lives of a few people with learning difficulties and to embed an appraisal in the workings of a small number of self-advocacy groups. Chapter 4 set out the empirical work. Three methods, each with their own strengths and weaknesses, were introduced.

The survey – assessing the movement

A postal survey was chosen to examine the nature of the contemporary self-advocacy movement. 134 self-advocacy groups in the UK responded. The survey provided a wide and shallow description of self-advocacy groups. The components of groups were highlighted, including the status of advisors, self-advocate membership, roles, rules, funding details, meeting place and affiliation. Moreover, these findings permitted a description of group typology and variation within the movement.

Life stories – the lived experience of self-advocacy

The survey did not extract the meanings of self-advocacy in the lives of self-advocates. Therefore, the experiences and views of five top self-advocates were collected and life stories were written in order to explore the impact of membership of self-advocacy groups. Five life stories were written collaboratively with narrators and one narrator wrote her own story. It was argued in chapter 4 that the life story method has a number of strengths including inviting personal narratives, addressing the abstract, accessing meaning through stories and inviting researcher reflexivity (e.g. Parker

1963, Turner 1980, Thomas 1982, Thompson 1986, Atkinson and Williams 1990, Kidder and Fine 1995). However, a number of limitations were also pinpointed. These included life stories as only reflecting part of a person's story, bias in storytelling and problems with relying on stories and storytellers (e.g. Moffet and McElheny 1966, Stott 1973, Nisbet 1976, Widdicombe 1993, Sparkes 1994, Chatman 1995). Life stories picked up on some of the influences of self-advocacy groups on narrators' life experiences and illustrated some additional themes about life as a self-advocate.

Ethnography – self-advocacy in action

It was decided that ethnography would be carried out with four groups in order to investigate self-advocacy in action. The Centre, Social, Advocacy-supported and Independent Groups were the focus of the study. Group meetings were attended, observational field notes were taken, group discussions were carried out and groups' provided their own documents. 92 hours contact-time was spent in total with the groups. A number of strengths associated with the ethnographic method were identified in chapter 4. These included a bottom-up and grounded appraisal, ethnography as an appropriate method for the study of new social movements, exploring the notion of empowerment and reflexivity (e.g. Glaser and Strauss 1967, Edgerton 1967, 1976, Walker 1981, Charmaz 1995). In addition, a number of limitations were noted included researchers only seeing what they want to see, research participants only showing what they want researchers to see and the problems associated with ethnography changing research cultures under investigation (e.g. Orne 1962, Schatzman and Strauss 1973, Gerber 1990, Parker and Shotter 1990, Swain 1995). The ethnography illuminated deep group dynamics that existed under group type and advisor status.

Evaluating methods – making information accessible

This thesis attempted to access the perspectives of a few insiders of the movement through the use of accessible methods. The postal survey employed a self-advocate friendly survey pack (*Appendix 2, 2-4*). However, advisors completed a third of the returned questionnaires and no attempts were made to gain members' responses in these cases (chapter 5). On a more positive note, self-advocates completed 26% of the returned questionnaires and the accessibility of the survey pack was appreciated (see 'Comments from respondents about the questionnaire and survey', chapter 5).

Section 3 presented the personal narratives of five self-advocates (chapter 6 and *Appendix 3, 5*). Narrators were provided with an introductory handout (*Appendix 3, 1*) and the first drafts of their life stories. They checked over the storied forms of the experiences that they had imparted in the interviews (see chapter 8). One informant asked for his story to be recorded as spoken words on an audiotape, another wrote her own story. Attempts were also made to explore the construction of narrative, acknowledge words of informants and writers and examine some of the processes involved in collaborative life story research (see chapter 8, and *Appendix 3, 3* for extracts of annotated narratives). It was concluded that collaborative life story constitutes a method in which people with learning difficulties become involved in the telling of their own stories – sometimes with others, sometimes alone (chapter 8).

Section 4 drew upon the speech and actions of self-advocates in four groups (chapters 9 and 10). Groups were presented with introductory handouts during access (*Appendix 4, 1*) and before group discussions (*Appendix 4, 2*).

Material from the group discussions was written up as feedback reports (see *Appendix 4, 4-10*) and other documents requested from the groups were drafted combining prose and pictures (*Appendix 4, 11-13*). Attempts were made to channel observational notes through a ‘researcher template’ that drew heavily on my experiences as a volunteer. On reflection, it appeared that the building up of a researcher template enhanced access and subsequent interactions with groups. My personal experiences allowed me to pick up on some of the subtleties and complexities of group dynamics (chapter 11).

Accessible methods were used in this study in an attempt to include self-advocates in the negotiation of my research involvement in their lives. This study did not set out to include participants in the stages of analysis and participation remained at a descriptive level (see Lather 1986, p265). Consequently, participants were not consulted about the analyses that evolved. This thesis is limited to *my* appraisal of self-advocacy drawing on the resource of insider perspectives of self-advocacy. The next section considers a number of general conclusions that can be drawn out from my appraisal.

Making analytical connections

A number of themes emerged from my attempts to answer the three questions posed above. These include: variation and complexity in the movement; the impacts of group ‘type’ and deeper organisational dynamics; supporting self-advocacy; a priori resilience of people with learning difficulties; groups as a context for furthering self-advocacy; self-advocacy and self-definition; inter-dependence and culture and the need for self-advocates to call the shots.

Variation and complexity in the movement

In Chapter 5, the responses to each survey item were summarised and used to highlight developments within the movement. Self-advocacy groups were organised under various names (the most common being *People First*), the size of groupings ranged from less than 10 members to as many as 500 and meetings took place in a variety of contexts, with Centres and Rooms away from Centres being well represented (34.8% and 31.1% respectively). A number of groups were just starting up at the time of being sent the survey (49% were 4 years old or less) while a few had been going for a decade or more (4%). In terms of financial support, nearly a third of groups received service-system support and another third had independent backing (in terms of advisors funding, see table 5, chapter 5).

A thematic analysis of group discussion topics highlighted the concerns of respondents. These included personal issues, relationships, fun, Centre charges and wages, protests, professional intervention, homes and employment. However, it was unclear whether these were the concerns of self-advocates or advisors. Finally, responses to the survey displayed the various statuses of advisors introduced in Chapter 2, with paid staff and paid independents both being represented (29.3% and 26.9% respectively). In addition, other advisor roles emerged such as paid by group independents, voluntary staff, advocacy development workers and various mixed support by staff and volunteers. Advising self-advocates appears to be a growing vocation (Page and Aspis 1997).

The variation within the movement was further touched upon by an analysis of the response set of 134 groups in terms of group typology. Various criteria were used to identify those group types identified in the literature:

autonomous, service-system based, divisional and coalition. The findings from this analysis implied overlap between types. 74 groups did not fit any type identified in the literature. Variation occurred between and within groups. While various factors of group organisation were described, the postal survey failed to explain the influence of type upon group dynamics. Section 4 took up this challenge of explaining the effects of group organisation.

The impacts of group 'type' and deeper organisational dynamics

Chapter 9 addressed the complexities of group organisation outlined in the survey findings. Various in-group dynamics and processes of the Centre, Social, Advocacy-supported and Independent Groups were described. A number of findings emerged from this ethnography that went some way to explain how self-advocates and advisors were affected by the organisational form of the group. First, the four groups illustrated the overlap of group types. The Independent group, for example, while seemingly autonomous had characteristics of all four types. Second, organisational links appeared to have some effects upon the running of groups. Members of the Centre Group, for example, were stifled by the wider Centre context, the Social Group appeared to have a hidden organisational limitation in the form of staff advisors bringing their work with them into group meetings and the Advocacy-supported group was limited by time constraints of meeting times. However, delving into group processes uncovered deeper dynamics that appeared to have greater impacts upon the workings of the group.

The third conclusion was that members' actions appeared to transcend superficial aspects of group organisation. For example, while the Centre Group was stifled by the Centre context, members appeared to gain much

from membership, with the group providing a safe haven. Although the Social Group was limited in terms of time and money, members used meetings to see friends, publicly present grievances while integrating themselves in the culture of the social club. Therefore, fourth, rather than being dependent on ‘typology’, the organisation of groups was grounded in the relational ties between group members alongside the varying support of advisors. This last point was examined further in chapter 10.

Supporting self-advocacy

In Chapter 10, I continued to try and answer the question ‘how are groups organised’ by focusing on the support of advisors and self-advocates. A number of themes emerged. First, the application of models of disability in conceptualising support was displayed. Plotting advisor interventions on social-individual model continuums captured some of the styles and effects of support and provided an analytical technique for identifying good and bad practice. Second, following on from a rejection of ‘type’ as the determining factor in the organisation of self-advocacy (chapter 9), it was shown that the tendency of previous literature to dismiss professionalised support and uphold independent support was simplistic. Instead, third, support was specific, fluid and open to change by advisors in their interventions. This chapter turned away from conceptualisations of the bad or good advisor (presented in some of the advisor and typology literature, e.g. Worrel 1987, 1988) to incidents of bad (individual model) and good (social model) interventions (Dowson and Whittaker 1993). This analytical turn reflected Jackie Downer’s assertion:

‘Some professionals are ... *professionals*, other are ace - they know where the users are coming from ... it depends on the person’ (Jackie Downer, chapter 6, italics in original).

A number of individual-social model continuums were presented including ‘advisor-centred’ versus ‘self-advocacy-centred’, ‘deficit’ versus ‘capacity’, ‘talking over’ versus ‘talking with’, ‘expertise’ versus ‘experience’ and ‘missing the point’ versus ‘addressing the point’. This analysis contrasts with Mitchell’s (1998) findings, which emphasise the constraints of services and professional identity upon advising. An MPhil by Harrison (in press) focuses solely on advisors. It will be interesting to see how the findings from this study compare with those from this and Mitchell’s study. Fourth, the support of advisors was not the only contributing factor on the development of self-advocacy within the group. In addition, the ethnography highlighted the support offered by self-advocates, a theme that also emerged from an analysis of the life stories (see chapter 7). Self-advocates challenged advisors’ interventions, resisted assumptions of deficit, shared experiences and self-help strategies, advocated for and encouraged one another and provided humour (chapter 10). The self-empowering actions of people with learning difficulties constituted a major emerging theme of this thesis.

A priori resilience of people with learning difficulties

‘Although ‘enacted stigma’ or overt discrimination seems a pervasive aspect of the lives of people with learning disabilities, there exists a body of research which reveals that people with learning disabilities do not necessarily see themselves as disqualified from a variety of roles ... while it is typically assumed that this

denotes the strength of their convictions, there is a lack of data on how these convictions are informed or supported' (Todd & Shearn 1997, p344).

Chamberlin (1990, p323) notes that only when a group begins to emerge from subjugation can it begin to reclaim its own history. The self-advocacy literature presented in chapter 2 tended to focus on the self-determination of people with learning difficulties in terms of membership of self-advocacy groups. This thesis has shown that self-advocacy of people with learning difficulties may exist prior to joining groups (see chapter 7) and in addition to group structure (chapter 9) and the support of advisors (chapter 10). Resilience appeared to exist in spite of disablement – as pointed out by proponents of the social model of disability (chapter 3). The accounts presented in this thesis suggest that people so-labelled are resilient and determined throughout their lives. Consequently, the term 'self-advocate' may emphasise otherness and give the impression that people with learning difficulties only exhibit self-advocacy in self-advocacy groups. Likewise, the identification of a prior resilience raises questions about empowering research (chapter 11). Should research aim to 'empower' oppressed groups or does such an aim reinforce the victim status of people within these groups (Bhavnani 1990)? Moreover, when people empower themselves then how do researchers stand in relation to such self-empowerment – is research a help, a hindrance or meaningless?

Alongside shows of resistance, survey responses (chapter 5), stories (chapter 6) and observational vignettes (chapters 9 and 10) revealed disabling ideologies, environments, attitudes and actions that permeated the lives of self-advocates. There is a danger of romanticising the autonomy of self-advocates by ignoring their day-to-day experiences of oppression. Self-

advocacy groups appeared to provide a place in which self-advocacy could potentially be supported. For some people, like Phillip Collymore, joining a group may be instrumental in recognising and developing self-determination and resilience (chapters 6 and 7). Members of the research groups made similar points about the changes that occurred for them when they joined their group:

‘We were allowed to speak our minds’ (Colin, Independent Group, group discussion, *Appendix 4, 9*, see also *Appendix 4, 6 - 8*),

This thesis has recognised both resistance to and the continuing prevalence of disabling barriers.

Groups as a context for furthering self-advocacy

“You see her sometimes silent with her head pressed against the window, looking at the girls in the street. It’s as if she wanted to join in. But no-one’s going to come knocking on the door to ask her out” (A mother describing Bernice, her 21 year old daughter with learning difficulties, cited in Todd & Shearn 1997, p348).

A conclusion of chapter 7 was that self-advocacy groups provided the five narrators with a context for defining self-determination, a place to support one another, allowed friendships to blossom and offered opportunities for practical gains. Stepping into the workings of groups supported these conclusions (chapters 9 and 10). Members of the four research groups seemed to use groups as a context for self-expression (see *Appendix 4, 6 - 9*), even when the group was organised around service-based issues (Centre

Group) or took on the appearance of a disorganised social evening (Social Group). Valued members took on valued roles.

Nevertheless, tensions existed within groups, as with the breakdown of friendships (see Anya Souza's experiences, chapter 6) and in the hierarchies that appeared to exclude (see Centre group and Independent group, chapter 9). Further problems occurred when supporters assumed incompetence on the part of self-advocates (see chapter 9 'deficit'), ignored self-determination ('missing the point') and took too much of a 'hands on' approach (Social group - chapter 10). This thesis has recognised the influential role of the self-advocacy group on the development of members' self-advocacy.

Self-advocacy groups and self-definition

This thesis has touched upon issues of identity. In 1963, Howard Becker wrote that:

'The person who is thus labeled an outsider may have a different view of the matter. He may not accept the rule by which he is being judged and may not regard those who view him as either competent or legitimately entitled to do so... the rule-breaker may feel his judges are the *outsiders*' (Becker 1963, pp1-2, italics in original).

The stories and actions presented in this thesis highlight some issues associated with labelling, self and identity. First, similarities between disabled and non-disabled people were highlighted, like the anxieties of going to school, leaving and getting a job, the importance and difficulties of relationships, and hopes for the future (chapter 7). However, second,

difference was also reiterated but the values that were attached to difference were challenged:

‘You’ve got to keep reminding people - especially on the outside, you’ve got to remind them all the time that we are different to what they are, which, fair enough, we are. We’ve all got our own ways of living’ (Phillip Collymore, chapter 6).

This paradoxical point of emphasising difference and similarity was illustrated in Lloyd Page’s comments:

‘We’re just ordinary people with learning difficulties’ (Chapter 6).

Consequently, self-advocacy groups appeared to support members in recognising and perhaps celebrating their own understandings of difference whilst also challenging others who, in line with an individual model of disability, understand difference as an indicator of pathology:

‘Karen had recently had a meeting with an educational psychologist because, she joked, ‘I’m dumb in the head’. A supporter who works at the college suggested that this meeting be arranged because Karen ‘was not joining in in class’. Karen disagreed - ‘No, I were bored’ (Social group, ON, 7th meeting, from Chapter 10).

Following labelled groups’ understandings of labels taps into insider experiences rather than outsider expertise (Oliver 1996). As Jackie Downer put it:

‘Every experience is totally different and you need to go back and ask self-advocates’ (Chapter 6).

Inter-dependence and culture

‘Self-advocates who speak out raise important basic issues: freedom, fulfilment and self-determination. Nobody can speak more eloquently on these issues than the people directly concerned’ (Worrel 1988, p13).

A recent appraisal of the disabled people’s movement drew out inter-dependence and collective identity as key components of disabled people’s self-organisation (Campbell and Oliver 1996):

‘It is vital that all disabled people join together in their own organisation so that there is a creative interaction between disabled people who are involved with the politics of disability and disabled people involved in the arts. It is this interaction which can be particularly fruitful in helping us to take the initiative in developing a new disability culture’ (Finkelstein quoted in *Ibid.*, pp111-112).

This thesis found similar components of self-advocacy groups. Chapter 10 illustrated a number of interventions by self-advocates that promoted cohesion amongst the self-advocate body. Chapter 7 presented narrators’ opinions on whom the self-advocacy group was for and how the movement should develop. Whittemore, Langness and Koegel (1986) assert that people with learning difficulties are denied a culture. This denial of ‘culturisation’ (*Ibid.*) appeared to have been over-turned to some extent by the narrators in section 3 and the members of the research groups in section

4. Self-advocates represented in this study had membership of groups that appeared to constitute specific, perhaps not immediately apparent, and therefore hidden cultures.

First, the culture of each group was outed in a number of settings (see chapter 2): at high-profile conferences (1993 *People First* conference in Canada, see chapter 6); when groups lobbied the County Council over the state of the roads or the inaccessibility of consultation documents (see topics of group discussion, chapter 5, Advocacy-supported Group, chapter 9 and Phillip Collymore's story, chapter 6); and in meetings of advocacy or service user consultation meetings (Centre, Social and Advocacy Groups, chapter 9). Second, group actions and narrators' experiences link into a definition of culture as:

'The acquired knowledge that people use to interpret experience and generate social behaviour' (Spradley 1979, p7).

Chapter 9 exhibited smaller-scale cultural facets, like shared ways of running meetings (sharing the chairperson role, the Advocacy-supported Group), conventions over divulging information (getting members views written down at the start of the meeting, the Social Group) and in-group preoccupations (sorting out training programmes – the Independent Group). Third, groups appeared to give members access to an alternative framework of sense (Vincent 1998):

'When you've been locked up all your life, you can't make no friends. Now I'm starting to make friends ... *People First* ... [has] helped to bring me out of things that I wanted to be brought out of ...

I could tell you about the past, the future in 15 years time, how I'm going to cope, will I cope' (Phillip Collymore, chapter 6).

'By speaking out to other people in the group it gives you confidence to speak to other people' (Lloyd Page).

'It enables me to talk about my problems and to listen to other people's problems' (Graham, Advocacy-support Group, *Appendix 4*, 8).

Inasmuch as self-advocates were involved in the making of their culture, the larger exclusive, disabling culture continued to threaten their activity and ameliorate their disabilities. Self-advocacy could be viewed as a cultural artefact of disabling society. Worrel (1988) asserts that people with learning difficulties would no longer need self-advocacy groups in an inclusive culture where all members are each and everyone's advisors.

The need for self-advocates to call the shots

'There's a story about three baseball umpires standing behind home plate before the start of the game. It seems they were discussing their individual methods of calling balls and strikes. "I calls 'em as they are", said the first umpire, an idealist. The second umpire, a realist, said, "Well, I calls 'em as I see 'em". The third umpire, a pragmatist, shook his head in disagreement and said, "They ain't nuthin' 'til I calls 'em". The key for developmentally disabled [sic] and other handicapped people is to be in the position where they are "calling 'em". The key for anyone wanting to support or participate in the *People First* organisation is to help so-called "handicapped" people

get behind the plate and then let them “call ‘em”... The major role of the helper or advisor ... is simply to help handicapped people get “behind the plate” (Hanna 1978, p31).

This thesis has drawn attention to the self-organisation of people with learning difficulties. First, in section 3, narrators identified those people who they thought should be in control of self-advocacy. Joyce Kershaw insisted that people with learning difficulties should to be heading developments within the movement, for then:

‘They’d get more people helping them’ (my story).

Concerns were also expressed about advisors taking over (Jackie Downer). Second, group dynamics appeared to work well when they centred on the actions of self-advocates rather than reflecting the aims of the higher echelons of linked organisations. For example, in chapter 9, the Advocacy-supported Group members were ignored at the AGM of their affiliated Advocacy Project. This contrasted with the cohesion that was observed in their meetings. Likewise, the Centre group provided a safe haven away from the ideological constraints of Quarry Village Centre. Group dynamics appeared to be located in the social relations between self-advocates. Third, in chapter 10, examples of good support in which advisors’ interventions pulled towards the social model end of the five continuums, emphasised supporting self-advocates in their own self-empowerment (Oliver 1996, p34).

This point about self-advocates calling the shots has resonances with Page and Aspis’ (1997) position. They argue that the self-advocacy movement should remain in the hands of people with learning difficulties, instead of

becoming a context for promoting tokenistic service-interventions or therapeutic-cum-training programmes for people with learning difficulties. Self-advocates must call the shots, just as they have done during those times when they had to self-advocate in discriminating contexts of institutions and communities (chapter 7).

Questions that remain unanswered and possible ways forward

My appraisal has left many stones unturned. A number of questions remain unanswered and therefore point ways forward for future research. Some of these questions are outlined below, including self-advocacy and impairment, commonality between self-advocates and other disabled activists, the self-advocacy movement and the disability movement, leaving self-advocacy, types of self-advocacy and participatory research - a framework for future research.

Self-advocacy and impairment

‘The next few years are going to be about defining what that model [social model of disability] is and what implications it has for our own national movements and the international movement’ (Richard Wood, director of the BCODP cited in Campbell & Oliver 1996, p174).

The theoretical model that has underpinned this thesis, the social model of disability, appears to embrace the resilience of disabled people while recognising disabling barriers in society. The development of this model owes much to the growth of the disabled people’s movement in Britain. For

example, as documented in Chapter 3, definitions of impairment and disability proposed by the Union of the Physically Impaired Against Segregation (UPIAS, 1976) have been at the core of social model ever since (Swain et al 1993, Oliver 1990, 1996, Shakespeare and Watson 1997). In addition, the latter sections of chapter 3 suggested ways forward for making the social model even more inclusive of people with learning difficulties. The subsequent empirical work in this thesis brought up a number of issues associated with an inclusive social model of disability.

This thesis illuminated some understandings of the relationship between identity and impairment held by a few in the self-advocacy movement. In chapter 6, narrators made distinctions between themselves as people with ‘learning difficulties’ and people with physical impairments. While the former label was critically owned, the latter was viewed as undesirable:

‘Learning disabilities - I don’t like that, disability makes you believe that we are in wheelchairs and we can’t do anything for ourselves, when we can, We’ve got jobs now, we’ve got paid jobs’ (Joyce Kershaw, my story, Appendix 3, 5).

Self-advocates insist on being perceived as people first, fighting against the denial of humanity itself (Gillman, Swain and Heyman 1997, p690):

‘I’m lucky I’m not like people with severe learning difficulties’ (Jackie Downer, chapter 6).

Narrators’ reflections lend support to the development of an inclusive social model of disability that takes on board a sociology of learning difficulties and impairment (as argued in chapter 3, for example, Ryan and Thomas

1980, Ferguson 1987). Impairment is a personal experience (Morris 1996, Oliver 1996). The UPIAS definition may be acceptable to physically impaired people but it may reaffirm a denial of humanity for people with learning difficulties. Questions therefore remain over the appropriateness of the definition of impairment for self-advocates and, indeed, for physically impaired people (Hughes and Paterson 1997, Watson, Riddell & Wilkinson, in press).

Focusing on impairment could be viewed as watering down the social model (French 1993, Oliver 1996, Mitchell 1998). However, if one of the key points about this model is to embrace the experiences of disabled people (Oliver 1996, p34), then reconsidering the notion of impairment feeds into a wider project:

‘The continuing use and refinement of the social model can contribute to rather than be a substitute for the development of an adequate social theory of disability’ (Oliver 1996, p42).

Commonality between self-advocates and other disabled activists

While there may be distinctions in terms of impairment between self-advocates and physically impaired activists, this thesis has also touched upon commonality in terms of disablement and resilience. A number of disabling experiences previously documented by physically impaired activists also emerged in the accounts of self-advocates, including institutionalisation (Barnes 1990), exclusion from ordinary life experiences (Morris 1991), enforced dependency on benefits (Barnes 1991) and denial of work opportunities (Barnes 1996a). Simultaneously, the actions of self-advocates had parallels with the activities of organisations of disabled

people, including shared experience (Finkelstein 1993), activism (Campbell and Oliver 1996), radical actions in reformative collectives (Oliver 1990, see chapter 8) and challenging service interventions (Morris 1993a). Further research could draw together experiences from the self-advocacy and wider disability movement, making links and ascertaining shared ground.

The self-advocacy movement and the disability movement

‘It is no small challenge to the movement to ensure that barriers are eradicated so that no impaired group are disadvantaged’ (Campbell and Oliver 1996, p96).

This thesis has only scratched the surface of the relationship between the self-advocacy movement and the disability movement. In chapter 2, it was suggested that coalition links threatened to place self-advocacy issues in the background as articulate physically impaired activists came to the fore. Chapter 5 presented the difficulties in separating divisional and coalition types of group, as the overlap was so great. Moreover, Simons (1992, pp6-7) reports that few people with learning difficulties become involved in coalitions of disabled people. In chapter 9, the Independent Group saw their increasing independence from the Blaketon Council for Integrated Living and the Blaketon Council of Disabled People as positive developments. These findings lead only to vague understandings of the relationship between the self-advocacy and disability movements. Further research could assess the relationship between these two groups and see whether or not distinct identities exist, which may possibly lead to prejudice in the disability movement (as argued by Aspis 1996 in Campbell and Oliver 1996) and in the self-advocacy movement (as hinted at in chapter 7 of this thesis).

Furthermore, questions emerged about the role of the professional in organisations of disabled people. For Oliver (1990, 1996), when professionals become involved in organisations of disabled people, ambitions associated with career advancement and an uncritical acceptance of the individual model of disability threaten the inter-dependence of disabled activists. The appraisal offered in this thesis has been less damning of professionals that are involved in the self-advocacy movement. While accepting that professionals potentially bring along the baggage of a staff role (see chapter 9, the Social Group), the ethnography also highlighted a number of supportive interventions that were conducive to the workings of self-advocacy groups and appropriate to the development of members' self-advocacy (Chapters 9 and 10). Further research could follow up the role of the non-disabled supporter in organisations of disabled people, to see if a rejection of such support is hasty or acceptable.

Finally, the bureaucratisation of self-advocacy provides possible employment opportunities for people with learning difficulties. Such opportunities take on a salient character in light of the inadequacy of the DDA for promoting real work for disabled people (see Barnes 1996a). For example, while questions were raised over the Independent Group's preoccupation with training staff and others about self-advocacy (chapter 9), this group highlighted the involvement of disabled people in training policy-makers, professionals and carers in disability rights. Still, questions are also raised about whom or what the groups are for (self-help, training, politicisation and so on).

Leaving self-advocacy & types of self-advocacy

Questions remain unanswered about those who have left the self-advocacy movement. In chapter 6, Anya spoke about her fall out with a group that led to her leaving. In chapter 9 Andy, the vice-chair of the Independent Group, spoke about his reasons for working with the groups:

‘I’m doing it for a change. I’ll probably try and work with old people at sometime’.

Finding out why people move on from self-advocacy groups could help to establish the impact of group membership on life chances and how ex-members perceive group dynamics. Moreover, such a research focus may well broaden understandings of self-advocacy outside of groups.

In chapter 7, self-advocacy was tentatively defined as the public recognition of people with learning difficulties’ resilience. This appraisal has focused upon resilience in the publicly observable context of self-advocacy groups. In addition, questions are raised about the membership of various other contexts in which self-advocacy may well occur.

First, people with learning difficulties may boast membership of a number of self-advocacy groups. Bill Shankling from the Advocacy-supported Group was additionally involved with a residents committee and the Advocacy Project management committee (chapter 9). Self-advocates with multiple memberships would make ideal appraisers of the comparative groups. Second, self-advocacy in action can take different formats including Performance Arts, Drama groups and dance troupes. Bill Shankling and his peers met together in a drama group (this could be added

to Bill's list above) and showcased their performance at the AGM of the Advocacy Project. Incidentally, their performance was the only part of the meeting in which the presence of people with learning difficulties was acknowledged and made public. Self-expression can be found in many contexts. Third, self-advocates advocating for peers in a various contexts could be followed up and supported. Joyce Kershaw's stories showed her shouting up for her peers in the Centre (chapter 6), and Erica spoke up for her non-speaking friend Rachel in the Advocacy-supported group (chapter 9 and 10). Self-advocacy as it is couched in the experiences of people with learning difficulties can take on a number of forms.

Participatory research - a framework for future research

‘Simply increasing participation and involvement will never by itself constitute emancipatory research unless and until it is disabled people themselves who are controlling the research and deciding who should be involved and how’ (Zarb 1992, p128).

Following Swain (1995, p77), the appraisal presented in this thesis was initiated by me, at my discretion whereby I had ultimate control. Nevertheless, a number of emerging themes have relevance to participatory research that uses self-advocates as co-researchers. Such an approach could be used to address some of the questions that have been left unanswered by this thesis. Using self-advocacy groups may bring in insiders' perspectives on the workings of groups, leading to potential expert evaluation and advice. Two broad considerations about participatory research are now considered.

Commonality and resistance

Self-advocates in this thesis were aware of disabling barriers but also presented was their resistance. The good and bad sides of life (as a person with learning difficulties) were presented alongside one another (chapter 7). Disabled people are not ‘cultural dopes’ (Ferguson 1987, Ferguson and Ferguson 1995, Skrtic 1995a), Potentially, therefore, using self-advocates as co-researchers could help to temper research that makes difficulties by emphasising deficit, inability and passivity as an effect of disablement (Clough and Barton 1995, Barton and Clough in press). Instead, self-advocates in this thesis drew attention to capacity, ability and activity.

Co-research and support

The self-advocacy groups represented in this study by and large offered supportive contexts for their members. Moreover, using groups as co-researchers could address some of the problems that have been identified in research with vulnerable and lonely people (chapter 11). In the case of short-term research initiatives, groups could offer research participants (without membership of self-advocacy groups) access to ongoing support networks when research comes to a close. Such inclusive practices could tackle paternalism in empowering research where researchers go into people’s lives and then struggle to offer further support (Clough and Barton 1995). Self-advocacy groups as co-researchers could also address the dilemmas of non-disabled researchers being the primary collectors of disabled people’s accounts (see chapters 8 and 11). Physically impaired activists and researchers have argued that disability research must remain accountable to physically impaired people in their organisations of disabled

people¹. Similarly, self-advocacy groups could be consulted about research with people with learning difficulties. After all, participants in this study were already involved in consultation. Anya had talked about Down's Syndrome at conferences and had involvement with the Down's Syndrome Association (chapter 6). Joyce Kershaw addressed doctors and students (my story, Appendix 3, 5). The Independent Group trained up staff about self-advocacy and Social Group members spoke out at user consultation days (chapter 9).

A number of research projects have already made connections between self-advocacy and research. Services have been evaluated by researchers and self-advocates (Whittaker, Gardner and Kershaw 1991, Whittaker, Kershaw and Spargo 1993, Downer and Ferns 1993), a self-advocacy group for parents with learning difficulties developed out of an earlier researcher-led appraisal (Booth and Booth 1994, in press), while self-advocates have been involved as co-researchers in studies of the impacts of self-advocacy on family life (Mitchell 1997b, 1998, March, Steingold, Justice and Mitchell 1997) and the history of learning difficulties and institutionalisation (Atkinson, Jackson and Walmsley 1997).

Attempts have been made to meaningfully include people with learning difficulties in research, challenging notions of participatory research that has more to do with strengthening dominant ideologies than real shifts of power (Swain 1995, p89). Moreover, participants can use research contexts for their own means - as Joyce Kershaw and some of the research groups did in this study (see chapters 8 and 11). Self-advocacy groups appear to provide a useful starting point not only for the inclusion of people with

¹ See special issue on disability research, *Disability, Handicap and Society*, 7, 2, 1992.

learning difficulties in research, but also in the planning, carrying out and subsequent analyses of research.

Conclusion

‘The materialist doctrine that men (*sic*) are products of circumstances and upbringing, and that, therefore, changed men are products of other circumstances and changed upbringing, forgets that its men who change circumstances and the educator must himself be educated. Hence this doctrine is bound to divide society into two parts, one of which is superior to society. The coincidence of the changing of circumstances and of human activity can be conceived and rationally understood only as revolutionising practice’ (Marx 1845, ‘Theses on Feuerbach’ in Marx and Engels 1991, p28)

This chapter has reflected upon the appraisal of self-advocacy offered in this thesis. The first section recapped on what the study set out to do. The second section drew together a number of analytical connections from the empirical sections of the thesis. The third and final section presented a number of questions that remain unanswered and therefore point ways forward for future research.

An enduring image of my research was of people identified by an arbitrary label who, in spite of often adverse social conditions, were actively changing their circumstances. Their actions were, for me, revolutionising and so far removed from pervasive assumptions of deficit, incompetence and passivity. I can only hope that this thesis has authentically captured resilience exhibited in the lives of self-advocates. If captured, then in some

small way this study contributes to an understanding of self-advocacy and reminds us that people with learning difficulties are people first.

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