

**Appraising self-advocacy in the
lives of people with learning
difficulties**

Daniel Goodley

Volume 2

Appendices

Appendix

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Section 1 – Publications

Journal Articles and Book Chapters

Goodley, D. (1996a). Tales of Hidden Lives: A Critical Examination of Life History Research with People who have Learning Difficulties. *Disability & Society*, 11(3), 333-348.

Goodley, D. (1997a). Locating Self-advocacy in Models of Disability: Understanding Disability in the Support of Self-advocates with Learning Difficulties. *Disability & Society*, 12(3), 367-380.

Goodley, D. (in press, a). Supporting People with Learning Difficulties in Self-advocacy Groups & Models of Disability. *Health & Social Care in the Community*.

Goodley, D. (in press, b). Stories about Writing Stories. In L. Barton & P. Clough (Ed.), *Articulating with Difficulty: Research Voices in Special Education*. London: Paul Chapman Ltd.

Goodley, D. (in press, c). Culture, Self-advocacy and People with learning difficulties, In N. Watson, S. Riddell & H. Wilkinson (Ed.), *Disability, Culture and Identity*. London: Longman.

Conference and Seminar papers

Goodley, D. (1996b). *Creative Methodologies: The Use of Life Story Research with People with Learning Difficulties*. Paper presented at an Open Seminar, The Manchester Metropolitan University, Department of Psychology, March 1996.

Goodley, D. (1996c). 'How do you understand learning difficulties?' *Placing Inclusion in a Social Model of Learning Difficulties*. Paper presented at the Culture, Difference and Inclusion, 16th - 19th February 1996, Rutland Hotel, Sheffield.

Goodley, D. (1996d). *Life Stories and the Social Construction of Disability*. Paper presented at the Open Seminar, the Manchester Metropolitan University, January 1996.

Goodley, D. (1997b). *Discourses of Disability and Support*. Paper presented at the Critical Psychology Seminar series, Bolton Institute, Bolton, UK, November 1997.

Goodley, D. (1997c). *'Stories about writing stories': Re-appraising the Notion of the 'Special' Informant with Learning Difficulties in Life Story Research*. Paper presented at the British Educational Research Association Annual Conference, Symposium 'Still Making Difficulties', York University, York, UK, September.

Goodley, D. (1997d). *Life Stories and Self-advocacy*. Paper presented at the Social History of Learning Disability Conference 'Inclusion and Exclusion', Open University, Walton Hall, 10th December.

Goodley, D. (1998). *'Staff are Bad' : The Social Model of Disability and Professionals Working with People with Learning Difficulties*. Paper presented at the Policy, Failure and Difference Seminar, Ranmoor Hall, Sheffield, 13th - 15th February.

Appendix 1, 2

Tales of Hidden Lives: a critical examination of life history research with people who have learning difficulties

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ABSTRACT *This paper explores the use of life history research with people who have learning difficulties. [1] A number of strengths and weaknesses associated with the life history as a method of imparting life experiences are examined. Particular emphasis is given to the dilemmas that researchers may face in explicating the life histories of informants labelled as having learning difficulties. With reference to literature on narrative-based research and by drawing upon my own research experiences, I will argue that life histories reaffirm the personal in social theorising, whilst providing a methodology in which individual and social worlds may be drawn together. In addition, eliciting life histories may promote a vivid sense of the research process, thus demystifying the often over technical and jargonised nature of social scientific study. On the down-side, I will suggest that images of the 'imaginative researcher' and 'articulate informant' portrayed in much life history literature, threaten to stifle researchers' concerns with the inclusion of people with learning difficulties. Furthermore, I will draw attention to dilemmas that arise in making links between an individual's life history and social theory. Finally, problems relating to issues of bias and power are explored. In research involving people with learning difficulties, it is concluded that life histories cogently expose the experiences of people so-labelled and therefore deserve further usage albeit with critical assessment.*

Introduction

Although a current resurgence of interest in biographical methods has been identified (Bowker 1993), the utilisation of life stories and other human documents as research tools in the social sciences has a long history. In the field of learning difficulties, however, life history research has received relatively sparse interest. An intensive literature review by Whittemore *et al.* (1986) reveals a tradition rich in the beliefs, perceptions, and attitudes of parents, carers and professionals with the perspectives of people with learning difficulties seemingly left unrepresented. According to Turner (1980) absent insider stories of people with learning difficulties reflects a general pervasive assumption that such people are unable to articulate their

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own life experiences. Whilst accepting such prejudices exist and noting the bias towards the accounts of significant others (particularly parents), it is important that we do not ignore a body of research that has embraced the viewpoints of people with learning difficulties. Early examples of such accounts include *The World of Nigel Hunt* (Hunt, 1967), Robert Edgerton's (1967) *The Cloak of Competence*, Braginsky & Braginsky's (1971) *Hansels and Gretels* and the well known *Tongue Tied* account by Joey Deacon (1974). More recently, Fido & Potts (1989) cite the personal accounts of people who have been institutionalised, while Lea (1988) refutes pathologising clinical definitions via the poetry of people defined by such criteria. Booth & Booth's (1994) *Parenting under Pressure* explores the personal stories of parents with learning difficulties, whilst Atkinson & Williams' (1990) *Know Me As I Am* is perhaps the most explicit presentation of the writings and artwork of this labelled group. All in all, these writings remind us of the lives that exist behind a label. One paper particularly illuminates issues in the use of the life history method, namely, Bogdan & Taylor's (1976) 'The Judged not the Judges—An Insider's Perspective of Mental Retardation' in which the story of Ed is presented. This may be cited as a seminal paper from which followed much research (some mentioned above) focusing on the lived realities of people so-labelled. I will be coming back to this particular paper, along with my own research experiences, throughout my examination of the life history.

As narrative methods become increasingly in vogue, then it is inevitable that they will be used by researchers interested in the experiences of people with learning difficulties. Whilst I acknowledge that this may and should be seen as a positive step forward in the contemporary atmosphere of empowering research, blind acceptance of any methodology may bring with it dangerous implications. Critical examination is imperative. In this paper I identify a number of strengths and weaknesses of the life history when used with informants with learning difficulties.

Considering Strengths of Life History Research

The Personal Nature of Life Histories

Proponents assert that the major strength of the life history approach lies in its attention to insider perspectives. In the 1920's, Thomas and Znaniecki (1918–20) claimed that biographical materials constituted the 'perfect type of sociological material' (cited in Plummer, 1983, p. 64). Whilst I would not take such a radical position, I intend to argue that life histories do exist as an agency through which historically marginalised individuals may account for their own lives. Following Thompson (1988, p. 2), life histories may be viewed as a resource for transforming historical understanding and analysis. Here, a central place is given back to the people who made and experienced history, thus re-addressing their previous absence in dominant (and elitist) historical documentation. Providing a context for life histories:

gives history back to people in their own words. And in giving them a past, it also helps them towards a future. (Thompson, 1988, p. 265.)

The life history approach may also be seen as constituting a more favourable epistemological standpoint with respect to social understanding. Following Plummer (1983, p. 6) and Nisbet (1976, p. 21), a radical stance views the 'objective' methods of positivist social science as merely allowing the description of social phenomena, whilst failing to provide for their understanding. The life history on the other hand is presented as an approach which allows for the explanation of social phenomena. Thompson (1988, p. 7–8) proposes a major resource of life history research lies in its ability to clearly access the lived realities and social worlds of informants. Shaw's (1931) analysis elaborates further;

more than through any other social science approach, the life history enables us to know people intimately, to see the world through their eyes, and to enter into their experiences vicariously. (cited in Taylor & Bogdan, 1984, p. 81.)

Thus, the invitation to re-examine our preconceptions of another is prompted by the personal nature of a story, and the intimacy of the life history invites readers into another's world. Whereas tellers of 'official' documents strive for objectivity, the life history, as with any human document, is thoroughly personal (Stott, 1973, p. 7). We understand an official document intellectually, yet the human document is comprehended emotionally. Empathy accompanies insight—we know another's life because we feel it. As the informal, anecdotal and personalised elements of a story are internalised, then I would argue that these very qualities provide a direct route to social understanding. The phenomenological bases of this approach (re)cast light on the understandings we hold of individuals and their groups. Whilst narrative methods have received such contemporary popularity in view of growing post-modernist theory, the use of the life history (amongst others) does combat another more general growing frustration with the 'disappearing individual' in social theory (Whittemore *et al.*, 1986). Reinforcing the insider's subjective understandings of their own position prompts readers to challenge their own (often generalised) understandings of the tellers. In short our own 'truths' are quickly challenged by the personal narrative. Take the words of an informant with learning difficulties that I have spoken to: 'Why do people have to tell me what I have to do and what I haven't to do?'

From a single sentence, extracted from the larger story, this remark challenges the general assumption that the views of people with learning difficulties do not exist (Atkinson & Williams, 1990, p. 8). In turn, we feel a person's thoughts on 'societal oppression' (broken free of grand theoretical narrative) and their active questioning of their environment. Moreover, this voice of dissent starts to lead us away from beliefs that 'people who know no better life wish for no better life' (*ibid.*).

Another demonstration of the power of the personal can be found in Bogdan & Taylor's (1976) life story of a person labelled as mentally retarded. This story reminds us of the individual(s) behind the labels. Attention is drawn to our own assumptions and prejudices as we see Ed and his social world emerging through his

story, consequently encouraging a move away from generalised and pathological concepts of mental retardation to insights which are immersed within (and emerge from) a personalised account:

differences take on less importance. The person's own words force us to think of subjects as people, and categories of all kinds become less relevant. (Bogdan & Taylor, 1976, p. 52.)

Story-telling is an ancient and by all accounts universal phenomenon (Bruner, 1987, p. 16). Adopting the life history approach taps into a huge source of available data—we are all tellers of stories, though we will vary in the way that we tell them. Stories appeal to our own positions in life resonating as another's story collides with our own. As readers our own lives will provide the most immediate and natural framework for understanding the life of the informant (Frank, 1979). Through promoting empathy, emotion and feeling in the reader, the life history approach directly affirms the subjective meanings held by the informant and opens up the social worlds that they inhabit.

The Life History as a Context for Combining Social and Individual Worlds

Attempts to combine social and individual perspectives can be found throughout the history of the social sciences. In psychology, we may cite theorists within the Frankfurt School (blossoming in the 1920–30s) as pioneers in attempting to combine social theory (Marx) and individual theory (Freud). Similar tensions have existed within sociology as writers are encouraged to move from deterministic sociological understanding to considerations of the individual. Plummer (1983, pp. 52–54) notes that social theory has continually gravitated between reified concepts of social structure (epitomised within positivist ideas of social order) and solipsistic notions of mind (as in the case of post-modernist social theory). Closing the gap between the individual and the social order remains a constant source of debate. Attempts by social theorists to combine the social and individual have been attacked on the grounds that they are over-theoretical, are often riddled with jargon and, in some cases, may be simply wrong. On the latter point a criticism is directed at social theory that fails to 'ring true'. Schutz (1964) takes a radical position here and suggests that certain theories flounder when they fail to adequately immerse themselves within the worlds of those that they attempt to understand. An inadequate theory, then, may only be a 'a fictional non-existing world constructed by the scientific observer' (*ibid.*).

The life history, on the other hand, has been appreciated as a more direct, less-jargonised and insightful method of representing the individual (our story-tellers) and society (Whittemore *et al.*, 1986, p. 8). Corradi (1991, p. 106) asserts that explanations of the interaction between the individual and the social world are instantly provided by the life history. Stories not only present the subjective definition of a situation, as accounted for by their tellers, but they also highlight the

social constraints upon each individual. I feel that this clarity is shown in the following extract from an informant that I spoke to;

these lads put me in the toilets and made me take me shoes and socks off, and made me show me six toes.... I didn't want to and they made me do it...they even put cigarette marks on me. Those supervisors just left me to be bullied and that's why I couldn't tell no one...no one would believe me.

Even in raw form, a simple transcription, this informant's words instantly reflect society's treatment of people with learning difficulties. For Bertaux (1981, p. 36), when these stories take the form of a life history, the underlying sociocultural relationships of a person's life are clearly disclosed. We hear the personal reminiscences of the storyteller and at the same time are drawn to the broader structural horizons which function as backgrounds to the narrative—permeating private lives (Bertaux-Wiame, 1981, p. 261). In short the life history provides a link between public and private worlds, giving substance to the social worlds of the tellers—social worlds which are often concealed and mystified by social scientific jargon. Moreover, a person's story reminds us of the fluidity of individual experiences, something often lost in grand social theory, enticing the reader into an examination of the constantly changing nature of individual and social reality;

experience is a stream, a flow; social structures are seamless webs of criss-crossing negotiations; biographies are in a constant state of becoming and as they evolve so their subjective accounts evolve. (Plummer, 1983, p. 55.)

Hence, the story clearly elicits, and I believe that to be an important quality, the fluctuating social background of the teller. Narrative invites understandings which are moving, ever-changing and flexible—just like the stories we hear every day. In addition, the life history challenges a dominant belief held about people with learning difficulties—namely, that 'these people' form a homogeneous population—'they are all the same':

It is individual life courses which...highlight the heterogeneity of individual appearance, residential history, past employment or prospects for work, emotional response to personal limitation or adversity,...thus for the similarity of past events that may be found in the lives of the retarded, the life history can inform us of the highly variable manner in which the retarded have responded to these crucial life events. (Whittemore *et al.*, 1986, p. 14.)

Through acknowledging the variability of experience as shown by life histories, as researchers we are making a simple, but necessary step towards empowering our tellers. In recognising the individual aspects of a life, we reaffirm the individuality of the informant. Understandings which (over)emphasise the structural bases of oppression may seriously undermine the dignity of individuals making up that oppressed group. The life history approach, due to its early emphasis on subjectivity, suggests that we should suspend (or at least pull back from) interpretations that

instantly move to a macroperspective. Thus, at one and the same time, Ed's story (Bogdan & Taylor, 1976), reminds of the strength of human resilience in the face of discrimination whilst exposing the 'powerful ideological monopolies' (*ibid.*, p. 51) that constrain and subordinate him. Therefore, from Ed's story we see that institutionalisation is:

a function of a variety of social and economic contingencies—family difficulties, lack of alternatives—more than the nature of the person's disability or treatment needs. (*ibid.*)

However, at the very same time we are also shown that these structural relations have not completely hindered Ed's strength and resilience:

I wish they could see me now. I wonder what they'd say if they could see me holding down a regular job and doing all kinds of things. I bet they wouldn't believe it. (*ibid.*)

As a method for eliciting both individual and social worlds, the life history provides a bridge between the informant's own life and the general culture of his or her social group. To do so in such a direct and personal manner allows the reader to feel and think of the person's story and the society against which it stands.

Collecting Life Histories—the vivid sense of research(er) experience

The personal qualities of the life history, its commitment to subjectivity and its challenge to abstract (positivist) notions of self and society, has primed many researchers within the field to consider their own roles. This often goes under the title of 'researcher reflexivity'. Contemporary celebrations of researcher reflexivity are not as new and ground-breaking as some theorists would have us believe. Stott (1973, pp. 152–153) observes that reflections on the research process are closely connected to the Chicago School tradition in sociology. Warner & Lunt (1941, pp. 5–6), for example, took pains to ensure the reader gained what John Dollard called 'a vivid sense of the research experience'. Furthermore, feminist uses of biographical methods have strengthened calls for honest appraisals of the researcher's role (e.g. Stanley, 1990; Harrison & Stina Lyon, 1993).

The particularly intimate experience of obtaining someone's life history elicits numerous issues associated with the researcher's role. To examine these issues many life history researchers have therefore tried to demystify their research. Tony Parker perhaps provides the most radical stance in introducing his 1963 book *The Unknown Citizen*: 'This is an unscientific study by an untrained observer of an insufficiently understood problem'.

Although the majority of proponents of life history research would hesitate in taking such a humble position, reflection is upheld as a necessary part of the research exercise. Broadly speaking, two aspects of this challenge may be identified: first, reflections on the role of the researcher when life stories are collected; secondly, reflections on the researcher's role in writing up and presenting the life stories. I

would suggest that these considerations become even more important when our informants have learning difficulties.

First, the way researchers are perceived by (potential) informants will have an impact on the collection of life histories. I do not feel that it is a controversial to suggest that all researchers should enquire exactly how their informants see them. For those involving people with learning difficulties, however, a common perception may emerge. Jan Walmsley (1993, p. 42) observes that is highly likely for informants to place researchers in the ranks of professionals. From my own experience I have been spoken of as that 'nosy student'—a highly undesirable perception however correct it may be! These do not leave us with insurmountable difficulties. After all the exploration of such possible perceptions may actually strengthen the research and the life histories that emerge. Tremblay (1959), amongst others, observes that attention to informants' understandings validates both the research process and the researcher's role. This need for reflection on the research process is further highlighted in my own field notes following one interview:

I fired lots of quick, impatient questions at Matt [pseudonym]—he said that he felt 'grilled like a tomato'! On listening to the tape I became increasingly aware of how impatient I had been. Silence is golden—unsurprisingly shutting up let Matt speak! Time to think over questions is something that most interviewers would allow for—so why didn't I? Nerves? Uncertainty? Literature on interviewing people with learning difficulties suggests direct, snappy and quick questions are better but this assumes that all interviewees with learning difficulties are the same—they're not!

Thus, researchers need to also confront their own perceptions of informants, if unfair, they may hinder the research process. Being sensitive to both our informants and our own feelings, perceptions and speech will make us more able to hear their stories.

Secondly, researcher awareness is linked to issues of 'contamination' (Plummer, 1983, p. 113). Thompson (1988, p. 230) notes that the translation of speech into prose instantly mutilates the story being recanted. Take the following extract of an interview from my own research:

Q[me]: So...in ten years time how do you think you'll be feeling?

A[informant]: The same.

Q: The same as what?

A: The same as what I am now.

Q: And how do you feel today?

A: I just take it as it is.

Q: Is it good or bad?

A: I don't feel bad.

Q: Do you feel it's good?

A: No in the middle.

I feel that the written form of this extract fails to convey the reality of the interview.

My approach around this point in the interview was directive. The informant had taken a very thoughtful approach throughout our meetings, but in this extract it would seem that his responsiveness is limited. This is simply unfair as his responses became stifled by my efforts to move on. Converted to prose the reader does not get a picture of the speed of the interaction (it was actually very protracted) and there is no indication of the time taken by the informant or myself in considering questions/responses (the informant was thoughtful, I was over-eager). For interviews in general, the act of transcription instantly fails to afford the reader a clear feel for the interaction.

Moreover, the issue of contamination increases in complexity when the researcher writes the informant's story. With respect to the above interview extract would it be fair for me to write the following?

I just see the future as it is today—neither good nor bad. I don't see things changing for the better or worse.

Plummer (1983, p. 113) argues that researchers using life histories can legitimately move from little or no contamination (in cases where informants' pure and raw accounts are presented) through to accounts where the researcher's hand is dominant in (re)presenting stories of inarticulate subjects (in the case of my attempt above)—as long as this contamination is acknowledged. For the researcher involved with people with learning difficulties, who due to a number of social (and individual) reasons will lack articulation, increased concerns over contamination will be felt. The diachronic collection of any life history, although losing pure informant introspection, nonetheless, does invite greater researcher awareness and accountability—something sadly lacking in other methodologies.

Researcher awareness is a necessary part of any methodological approach that purports to be empowering. Indeed, I would assert that life history research can lay claims to giving a voice to people with learning difficulties in a particularly cogent way when the voice of the researcher is also heard. To acknowledge the pen of the researcher in the writing of life histories does not detract from the potency of the narrative, rather it excavates many issues of power that are often submerged amongst the rhetoric of 'empowerment'.

Considering Weaknesses of Life History Research

Major methodological and theoretical discrepancies have been identified within the life history method. Often challenges, originating from alternative social science perspectives, are in many ways objections to aspects of the life history which its proponents identify as strengths. For example, whereas the positivist may pinpoint the lack of a representative sample as a major limitation, the life historian perceives their attention to individual stories as transcending such de-personalised criticisms. As Bruner (1987, p. 14) observes, the necessary quality of stories is their notable instability, reflecting an epistemological commitment to the fluidity of subjective meaning. Even on accepting the strengths of the life history approach a number of dilemmas do emerge. Three will be addressed.

Life Histories and the (Un)imaginative Researcher

The proposition of moving from abstract theory to insider perspectives has set the life history researcher an unenviable task. Sacrifices may have to be made. Hollway (1989) highlights the trepidation that may afflict the inexperienced researcher on entering a context conspicuous by the absence of standard research practice. This anxiety is increased, and I am referring here to my own feelings, when the prospective life history researcher surveys the related literature. Generally, the literature presents the researcher as someone needing both imagination and resoluteness. For example 'It is perhaps to the tools of the novelist, the poet and the artist that the social scientists should turn' (Plummer, 1983, p. 106). Grand designs indeed! Yet if the role of the researcher implies 'listening beyond' the words of our informants and tapping into 'the speech of a social culture' (Bertaux-Wiame, 1981, p. 260) then the role is definitely a challenging one. The most powerful of life stories would seem to tap into grander ideas of creativity;

It is not only through the facts and opinions given, but perhaps through the imaginative and narrative skills with which they are put together, that we perceive the speaker's deeper historical consciousness. (Thompson, 1988, p. 242.)

Is it no surprise, therefore, that life history research was submerged under a tide of quantitative methods which asked less of the researcher? Even if these skills were acquired a further problem presents itself. Plummer (1983, p. 90) is clear on which responsibilities lie with the informant in the production of life histories: 'the subject should be fairly articulate, [and] able to verbalise'.

The picture that emerges sees the researcher being placed in the role of creative writer with the informant assuming a role of coherent narrator. Such assumptions, however, fail to account for life history research involving inarticulate subjects—a banner under which we may place (some) people with learning difficulties. For example how would Plummer deal with the following (taken from my own research):

Q[me]: Well, what I would like you to do is to tell me some experiences and things that have happened in your life?

A[Informant]: Experiences?

Q: Yeah, experiences—things that have happened in your life.

A: I don't know if I've got any.

Q: Well let me explain—you tell me about some things that have happened to you in your life, good or bad.

A: Good or bad?

Q: Can you tell me something that happened in your life that is good.

A: Good?

Q: Yeah, something you have nice memories of.

A: [Silence].

Q: Birthdays?

A: [Silence]

The failure to consider the importance of inarticulate people renders much life history research fragile (Stott, 1973, p. 195) the researcher's role seems increasingly unenviable, faced with (previously unrecognised) dilemmas.

For Williams (in Brechin & Walmsley 1989, p. 257) these dilemmas can be resolved though the use of 'imaginative strategies of communication' (see, for example, March, 1992; Minkes *et al.*, 1994). For the informant I cite above, our construction and referral to his 'lifepan' (a visual plan surveying 'good' or 'bad' experiences from birth to the present day) soon promoted more elaborated reminiscences.

However, demands that are made on the creativity and imagination of the researcher may lead some to shy away from the task. If, as Nisbet (1976) argues the 'creative heart of the artist' has been lost in the social sciences, then the researcher role presented in life history literature is hardly desirable. In comparison with more orthodox methodologies, guidance on the use of the life history method is unrepresented in methodology texts. This reflects the dismissive attitudes of many academics to life history research (Plummer, 1983, p. 74). On reading a life history some may feel that they have left the world of social theory for the world of idiosyncratic description. Frank (1979, pp. 71–72) observes similar scepticism:

Life history documents stand so close to the prescientist world view that the professional attitude of social scientists seems to reject them outright.

Thus presented with Ed's story (Bogdan & Taylor, 1976), the reader may feel like they have moved away from the theoretical representation of disability in society, left with unsubstantiated anecdotes. Devoid of the 'expert researcher's' hand of authority, the reader may feel let down—left with fables, concrete conclusions absent. However, even if we do oppose the majority view and take up the challenge of doing life history research, failure to acquire the proffered skills necessary for presenting life stories of people with learning difficulties may have damaging repercussions. If the researcher fails to adequately acquire the grand characteristics outlined in the life history literature then what becomes of the representation of informants lives? What if I fail to truly grasp the understandings of informants who, although lacking articulation, do have important stories to tell.

In truth, these creative resources may have been mystified by some writers and perhaps all the researcher can offer in their defence is a commitment to the people they attempt to represent (Parker & Baldwin, 1992, p. 200). Imagination may blossom through empathy.

Dilemmas in Balancing the Social and Individual in Life Histories

Though the personal nature of the life history necessarily reaffirms individual subjectivity, dangers exist in overlooking the social aspects behind the story. Oral historians such as Thompson (1988, p. 258) point out that too much emphasis on the individual aspect of accounts may fail to present 'the cut and thrust of contemporary political narrative and the unseen pressures of economic and structural change'.

Inasmuch as the life history permits the reader to understand how the tellers social context is constituted, turning a blind eye to the social order in pursuit of individual subjectivity may fail to adequately represent the individual's world. The researcher may be criticised for identifying too closely with his or her informants. Whyte's classic 1943 study *Street Corner Society* highlights the difficulties that may occur through the development of a close research relationship. For Stott (1973, p. 170) the strengths of Whyte's work were also its weaknesses. Though Whyte's closeness to the cornerboys enabled him to picture their attitudes towards society, he strongly endorsed their contempt for the 'college boys' of Cornerville, for non-Italian teachers and social workers.

The development of the relationship and attention to individual understandings may elicit the most vivid of stories, but immersion may lead to misrepresentation. Furthermore, following Denzin (1970), the overly-immersed researcher may be disempowering to his or her informants. In attempting to articulate the stories of the inarticulate, the researcher must reflect upon their own interpretations of the events presented to them. Sympathy for informants' injustices is all very well until those feelings start to take over the researcher's representation of the story. For people with learning difficulties, as with other marginalised groups, it is highly likely that experiences of oppression will be imparted. Yet if life stories are to provide an insight into human resilience then researchers must ensure that their own sympathies do not lead them into representing their informants only as victims: to continuously reassert the experience of subordination may be just as disempowering as the original experience of discrimination. My choice of an informant's experience of harassment earlier in this paper could be criticised on the grounds that it merely reinforces victim stereotypes of people with learning difficulties. Moreover, selectively emphasising informants' experiences to confirm political and/or theoretical concerns held by the researcher, may fail to elicit the essential characteristics of each individual's account of their social groups (Stott, 1973, p. 200).

This balancing act between the personal and social does call into question the explicit aims and interests of the researcher. This may explain why some researchers do not attempt deeper sociocultural assessment of their informants' stories—though this introduces another problem. Resistance to analyses is exemplified by Bogdan & Taylor's (1976, p. 51) position: 'Ed's story stands by itself as a rich source of understanding. We will resist the temptation to analyze it and reflect upon what it tells us about Ed'.

Stood alone, life histories may tap into the reader's own sociopolitical frames of reference, but to decide against making references with social theory could reduce individual stories into nothing more than sound-bites. Failure to locate stories in social theories of disability may seriously jeopardise informants' words—leaving them open to interpretations elaborating individual pathology over disabling environments.

To draw links between an individual's story and the possible societal structures that function as a background to that person's life, not only raises questions of researcher interpretation, but also again opens up debates over concepts of 'truth' and objectivity. Questions about how and why certain conclusions are made do

highlight the problematic role of the researcher in taking the life history a stage further than simple presentation. Here, perhaps, the researcher can only call upon ideas of researcher reflexivity and account for the inferences they make. Yet another problem emerges. In tune with current concerns with participatory research, researchers need to ask how far they should involve informants in the analyses that are made. Erlandson, *et al.* (1993), following an approach of naturalistic inquiry, assert that any analyses should be created under the watchful eye of the informant (or 'stake holder'). This is all very well and good, but research that involves people with learning difficulties taps into a subordinated group of people who have long been prevented from having a say in their lives, never mind working as co-researchers on an academic project. Whilst research has started to involve people with learning difficulties in an authoritative way (e.g. Whittaker *et al.*, 1991, 1993; Downer & Ferns, 1993) it remains to be seen exactly how researchers can truly involve these informants with the conclusions that are made.

Issues of Bias and Power Within Life Histories

The credibility of life histories is sometimes viewed as a function of the extent to which they remain faithful to the reality of the story-teller (Harrison & Stina Lyon, 1993). Such propositions may be admired, as the researcher attempts to discard the role of expert in turning to the informed storyteller. However, to merely assume that 'authority' is passed over to the informant seriously blurs issues of power and bias enmeshed within the process of collecting stories. Further dilemmas occur in the case of research that involves inarticulate subjects.

Sources of error are well documented within life history research. Plummer (1983) and Oakley (1981) have noted various sources of bias that may seriously affect the telling of a story. These include the informant's tendency to rehearse a story and/or in some cases lie. In addition, Bruner (1987, p. 13) observes that informants often ascribe intentions to actions after the event. Methods designed to address such bias have taken many forms. Commonly proposed are checks for consistency, for example, between accounts of the same event or experience in different interview sessions (Klockars, 1977, cited in Taylor & Bogdan, 1984). A result of checking the informant's words is that real reasons are revealed for the presence of contradictions and confusion. As trust and rapport develop modification of a story might be expected. Inconsistency may be a normal feature of a developing research relationship rather than a sign of bias. To ask whether our informants are telling the truth may be irrelevant (Dean & Foot Whyte, 1978, cited in Walmsley, 1993). What is important is to understand why they present their stories like they do.

More significantly, a major source of bias stems from the researcher's own preoccupations. Such interests may lead the researcher to highlight some points at the expense of other experiences that hold greater significance for the informant. In Ed's story (Bogdan & Taylor 1976), considerations of institutionalisation are clearly explicated. Yet the reasons for elaborations around this theme are unclear. Do we conclude that the experience of institutionalisation is a salient aspect of Ed's life or

a reflection of Bogdan and Taylor's own (political) interests? Again a measure of critical self-awareness on the part of the researcher is called for as they monitor their input into an account.

Considerations of bias become even more complex on involving people with learning difficulties. When inarticulate informants are involved, sources of bias originating from the researcher take on a more primary concern. For people who are unable to present long and elaborate anecdotes, the researcher may be placed in the role of interpreter or biographer. Such roles run the risk of researchers imposing their own assumptions, understandings and ambitions upon the stories that emerge. In turn, if the life story is taken as the basis from which sociological understanding emerges, whose understandings are presented?

In my own research one informant exclaimed: 'I don't want to go to work'. Should I conclude that this informant has fallen into learned helplessness following a decade of discrimination in the work place? Or has she simply chosen to take time off work as she prefers watching the television all day? Also, if the only articulation available was 'no work', the various interpretations available are further extended. Following Moffet & McElheny (1966), what a story is about is a question of how it is told. We cannot separate the tale from the telling as beneath the content of every message is intent. If my interpretation is dominant then the intent that I give to the narrative may actually reflect my motivations and not those of the informants.

Hence, there is more to hearing a story than listening to the words. The life history as with any other method is open to exploitation. To give a voice to people with learning difficulties may well be empowering, but in masking the processes involved in eliciting stories, researcher may well be part of a process of disempowerment (Bhavnani, 1990, p. 146). It is up to the researcher involved in the collection of life histories to be aware of their impact on the stories told and to acknowledge their input.

Conclusion: the valid role of the life history

You must begin to tell your stories—tell people what has happened to you.
(The words of a self-advocate cited in Sutcliffe, 1990, p. 21.)

The life history reaffirms the place of individual creativity in research. It offers us a way of seeing that originates from the individual and encourages us to overcome our ignorance of the lived experience of labelled groups. People with learning difficulties are writing their own histories and setting out their agendas for the future. Perhaps nowhere is this more apparent than in the rapidly developing self-advocacy movement. From self-disclosure and reflection self-advocates may form a solid base of identity from which they may continue to grow. Consequently, the assumption that the views and opinions of people with learning difficulties, neither exist nor matter is thereby challenged, and we are alerted to the potential of lives that as a society we continue to stifle.

Life histories provide one method in which the experiences of people with learning difficulties can be presented. However, the stories of these informants are

not just for the attention of other researchers—they are also, and perhaps most importantly, the greatest resource for those who share similar experiences of disabling society. I would assert that the ultimate project for researchers is still to be accomplished, that is, to produce ways and means in which these experiences can be made accessible to people with learning difficulties. Calling upon the everyday artefact of stories allows a good starting point.

NOTES

- [1] The term learning difficulties is chosen in this paper, as opposed to other related synonyms, such as mental handicap, mental impairment and learning disabilities. This reflects the preferred terminology of those involved in the self-advocacy movement. As one self-advocate clearly puts it; 'If you put "people with learning difficulties" then they know that people want to learn and to be taught how to do things' (quoted in Sutcliffe & Simons 1993, p. 23).

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Appendix 1, 3

Locating Self-advocacy in Models of Disability: understanding disability in the support of self-advocates with learning difficulties

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ABSTRACT *Recent appraisals of self-advocacy groups of people with learning difficulties have tended to focus on the constitutional and structural facets of groups whilst failing to explicitly engage with disability theory. This paper explores different understandings of disability and examines how these are or can be implicated in the self-advocacy movement. First, the effects of the dominant individual or personal tragedy model of disability on self-advocacy will be examined with reference to the advisor's position. It is argued that if advisors hold such understandings of disability then they threaten to stifle the self-determination of self-advocates. Secondly, self-advocacy framed in terms of the alternative social model of disability will be presented. It is argued with reference to the advisor's role that self-advocacy is best understood and practised when it is grounded in this persuasion. Here, the views of self-advocates themselves are called upon. Finally, understanding self-advocacy in terms of the social model is taken further. It is suggested that self-advocates themselves directly challenge dominant understandings of disability in general and can contribute to the formulation of a social theory of disability.*

Introduction

The growth of the self-advocacy movement in England has potentially massive implications for people with learning difficulties (Williams & Shoultz, 1982). Contemporary demands for innovative methods of 'user participation' have intensified professional and policy maker interest in self-advocacy as a potential context for empowerment in action (Barnes & Wistow, 1992). This interest has resulted in the growth of a diverse assemblage of self-advocacy groups.

Previous appraisals of self-advocacy have tended to focus on the constitutional and structural facets of groups. Crawley's (1990) *typology* of groups, for example,

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has shone light on the multi-faceted nature of the movement. First, groups may be politically, financially and organisationally 'autonomous' (such as the People First organisation). Secondly, they may be 'divisional' in that they have developed out of existing parental or professionally led organisations (e.g. MENCAP). Thirdly, a 'coalition model' may be followed through affiliation with wider (disability) civil rights organisations (e.g. citizen advocacy). Finally, groups may be 'service-based' where self-advocacy workshops may constitute part of the ATC or SEC curriculum (see Crawley's 1988 study of trainee committees). Moreover, the various positions of *advisors*, involved with promoting the independence of group members, has further problematised the nature of self-advocacy (Worrel, 1987, 1988; Dowson & Whittaker, 1993). In contrast to the 'ideal' independent volunteer (Worrel, 1988), the advisor's position in the 1990s is multi-variant in its character, highlighted by professional, service-based and advocacy involvement. Meanwhile, many self-advocates and advisors have expressed concerns over recent developments within the movement (Tyne, 1994; George, 1995). Consequently, we *cannot* assume that the increase in the frequency of so-called self-advocacy groups directly relates to an increase in tangible and meaningful opportunities for self-advocacy and self-determination (Crawley, 1988, p. 47),

Although previous appraisals have provided a solid basis on which to examine the movement, they do, nonetheless, fail to explicitly engage with disability at the level of societal or theoretical discourse. This paper will therefore explore different understandings of disability and examine how these are, or can be, implemented in the self-advocacy movement.

First, I will examine how the dominant *individual or personal tragedy model* of learning difficulties threatens to stifle the self-determination of people with learning difficulties. Particular reference will be made to the advisor's position.

Secondly, I will consider how the alternative *social model of disability* can be applied to self-advocacy. Through the advice given by self-advocates themselves I will argue that self-advocacy is best understood, and practised, when it is grounded in this persuasion. Again, this will be considered in relation to the advisor's position.

Thirdly, conceptualising self-advocacy in terms of the social model will be taken further. I will argue that as self-advocates directly challenge dominant understandings of disability in general, and learning difficulties specifically, they can therefore contribute to the formulation of a *social theory* of disability.

Self-advocacy and the Individual Model of Disability

Over the last century through to the present day, 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. Following this then, 'impaired thought' *leads to* a myriad of disabilities; disabled learning, disabled interactions with others, disabled personal relationships, disabled sex lives and disabled parenting. Placing impairment and disability in such a causative equation individualises the concept of disability. For each individual with learning difficulties, their disabilities are the creation of their own

impairments. This understanding of learning difficulties (and disability in general) embraces what has been called the individual model of disability or Personal Tragedy Perspective (e.g. Oliver, 1990, 1995).

The Individual Model: an epistemological stance

The individual model of disability has at its epistemological origins, notions of disability and learning difficulties that are fundamentally located within the individual and his/her impairment. This gives rise to further discourses of *personal pathology*, of *individual difficulties* and of *dependency* in the face of *care*. Moreover, people so-labelled are required to (and need to) *adjust* to their environments, be the *recipient of medical/professional expertise* and *dominance*, and are the focus of policy that at best *intervenes* and at worse *controls* (see Oliver, 1995). By placing disability resolutely in the realms of personal tragedy the individual model perpetuates a culture of dependency and non-acceptance. We feel we can know another simply by their label and its corresponding 'objectively' prescribed characteristics. This 'knowing of another' has wide implications to the labelled individual (Goffman, 1963). As with most dominant discourses, learning difficulties as individual pathology, is hard to break through and away from. In most cases it is taken up, prescribed social acceptance, and limits our ways of seeing the individual behind the label. People with learning difficulties, these tragic figures in this sorry tale, are required to follow the socially prescribed script of disability. They are expected to play a generalised and all encompassing role which emphasises their 'significant functional inabilities'. It is little wonder, then, that:

Acting like the retarded person can become second nature. (Guskin, 1963, cited in Brechin *et al.*, 1981)

An individual that deviates from this well-worn script of disability, familiar to both disabled actor and non-disabled onlooker, will be prompted back to the original discourse. Those that step out of this socially prescribed role of learning difficulties 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 not one that we are familiar with. Moreover, unfamiliarity in this case breeds contempt, and at the root of this contempt is an unwillingness to listen to people with learning difficulties, either as individuals or through their representative bodies (Brisenden, 1989, p. 218).

The Individual Model: a threat to self-advocacy?

Self-determination of people with learning difficulties is a concept that lies uneasily within the dominant model of disability. If our views of people so-labelled are straight-jacketed by prejudices that reduce disability and impairment to synonyms, then it would seem that self-determination stands in direct contradiction to these

prevailing assumptions. Impairment, inadequacy and deficiency hardly parallel notions of growth, determination and capacity. Self-advocacy fails to fit the assumptions that underpin the individual model of disability.

However, it would be a mistake to believe that self-advocacy cannot be conceptualised within the individual model. I would argue that this is exactly what happens in many cases of self-advocacy and wherein only limited progress can be made by self-advocates. Let me just step into the role of the self-advocacy supporter that is immersed within the individual perspective:

As victims of their pathologies these people have been left in an unenviable position. As a civilised society it is only right that these unfortunate few should be given the right to speak out, to express their wishes, desires and ambitions. It is also only right that we listen. Sure, their impairments are largely unsurpassable, their self-determination will only be able to go so far as their inabilities will allow, but we must support them nonetheless.

The scenario that I have developed above, simply framed in terms of the individual model, is pessimistic to say the least. Yet, if those involved in supporting self-advocates were to share such an outlook then it is fair to conclude that self-advocates' ambitions can only be supported so far. For if we hold that impairment is all important and unsurpassable, then people with learning difficulties' self-determination can only go as far as these constructs of inability will allow: assumed inability hampering personal growth. When an advisor's understanding of disability is limited to constructions of impairment then self-advocacy will always be a continual struggle against perceived pathology.

Whilst the position described above is hardly representative, it would be a mistake to assume that beliefs held by supporters of self-advocacy are not framed in these ways. There are many people without learning difficulties who are genuinely engaged with and committed to the project of self-advocacy. Nevertheless, as in all areas of society, oppressive discourses of disability will undoubtedly abound within the self-advocacy movement. The individual model is *not* dead and buried. The challenge here, then, may be pitched at the level of discourse and political understandings: that is to uncover the understandings of disability held by supporters of self-advocacy groups.

The Individual Model as Implicated in the Advisor's Position

Advisors' facilitating self-advocacy groups are placed in a particularly powerful position. Bill Worrel, who has written extensively about the preferred characteristics of the advisor in *People First*, argues that this power should not be ignored. Moreover, he asserts that we should be asking exactly *how* advisors *use* their power in ways that will empower or disempower self-advocates (1988, p. 35). The role of the advisor is complicated further by an 'advisor-type' that has been found to be well-represented in the self-advocacy movement—the staff or professional advisor (Crawley, 1988). Observers such as Clare (1990) assert that there is an undeniable paradox in professionally led self-advocacy. Whatever the degree of sympathy or

commitment to people with learning difficulties felt by professionals they are still in a position that smacks of authority. Staff members of service systems are necessarily located in a position of power:

Their professional identity, and certainly their professional accreditation, will be based on their control of *knowledge about disability*. (Clare, 1990, p. 24—my italics)

In addition to the overt paradox of the staff advisor's position identified by writers within the self-advocacy field, I would also argue that a deeper more ideological contradiction exists: that the staff (advisor) role is often one steeped in a culture that *necessarily embraces* a personal tragedy model of disability. This 'control of knowledge about disability' by professionals is, as many have argued (e.g. Oliver, 1990; Morris, 1991; see also Swain *et al.*, 1993), firmly located within the individual model:

a whole range of pseudo-professions . . . physiotherapy, occupational therapy, speech therapy, clinical psychology, each one geared to the same aims—the restoration of normality . . . on the basis of *discreet and limited knowledge and skills*. (Oliver, 1995, p. 37)

Hanna (1978, p. 31) sees the professional advisor as being placed in a difficult if not impossible role. This problematic position has been largely understood in terms of a *conflict of interests*. Conflict occurs when the facilitation of self-advocates' independence clashes with maintenance of the professional role. So, for example, people with learning difficulties may be intimidated by their advisor's accountability to the centre they use, and may feel unable to complain about the services that are offered (see Sutcliffe, 1990, p. 27). Further problems occur when, as Dowson & Whittaker (1993, p. 44) assert, the advisor should be aiming to work themselves out of a job. Ideally, a reciprocal relationship forms. As the group increases in autonomy the advisor's input should decrease. But if the staff advisor reaches a stage where their assistance is no longer needed, how is that group now appraised by the centre management? If it fails to fit into the activities of the centre then why should it be supported at all? It would seem that the general principle of 'letting go' (Flynn & Ward, 1991, p. 132) directly opposes the very philosophy of professional intervention.

Underneath all these contradictions is a *conflict of understandings*. That is, a clash between the project of self-advocacy which places independence at its core, and the requirements of a professionalised identity assigned to the staff-advisor, which is grounded in dependence. Here then is a conflict of discourse between *self-advocacy* that is potentially striven for by a group, and the *limitation of self* this is enforced by parentalistic authority in a professional climate (see Khan, 1985). More generally speaking the clash is between the ambitions of self-advocacy and the limitations imposed by dominant understandings that place impairment before ambition (the individual model).

It would seem, therefore, that the professional identity of the staff advisor will more readily embrace an individual model than say, an independent volunteer

advisor, who's position is not framed in professionalised ways. However, to make such a distinction superficially passes over dominant discourses of disability. Although there are serious dilemmas implicated in the professional advisor role, to point out 'good' and 'bad' supporters in such a way assumes that all professionals are unthinkingly rooted in oppressive practices, whilst others are not. This is a simplistic distinction. In short, *any advisor (or supporter) can hold prejudiced understandings of disability* which threaten the development of self-advocacy, whether they hold a professional status or not.

Here, then, we go back to epistemologies of disability. It is all too easy to apportion the blame on a supporter simply on the basis of their perceived status and its assumed implications. From my own research [1], whilst staff supporters are undeniably constrained by the professional climate around them this does not necessarily stop them challenging such constraints when encouraging self-advocacy. Understandings or discourses of disability are fluid, ever-changing and dynamic. Other discourses of disability to those inter-twined within an individual model do exist and inform intervention. Moreover, we can

champion the cause of a particular discourse [or way of understanding] . . . and . . . promote an existing (perhaps subordinate) discourse (as the 'empowerment' and 'giving a voice' model of research). (Parker & Burman, 1993, p. 170)

What alternative discourses of disability exist for advisors or supporters of self-advocacy groups? For an answer I would argue that we must turn to a social model of disability and the advice of people with learning difficulties themselves.

Self-advocacy and the Social Model of Disability

In contrast to the dominant individual perspective which locates disability in the realms of individual impairment, the alternative social model of disability attends to the way(s) *society disables*. Impairment and disability are not synonymous terms. Although a person may be impaired this does not causally relate to their disabled role in society. To find the dominant origins of disability we are encouraged to turn attention away from the individual onto a society that excludes, discriminates and stigmatises people with impairments. Disabled people are just that, people *disabled by* a social, economic, cultural and political contemporary climate:

If there is one firm conclusion to be made . . . it is that . . . mental retardation is as much or more a *social and cultural phenomenon* as it is a medical—genetic or cognitive—psychological one . . . The definition of retardation, then, and some of the consequences of being thus labelled are *concomitants of social life*. (Levine & Langness, 1986, p. 191, my italics)

The all-pervasive nature of the individual model threatens to stifle self-advocacy. An alternative approach, offered through the application of the social model of disability, permits a different way of conceptualisation and practising self-advocacy.

I will consider how self-advocacy may be grounded in a social model of learning difficulties.

The Social Model: an epistemological stance

The epistemological stance of the social model stands in opposition to the individual model. Following Parker & Burman (1993, p. 170) it can be seen as an alternative and subordinated discourse. In contrast to the individual model the social model accounts for the *sociocultural bases* of learning difficulties. Whereas the individual model gives rise to discourses of *personal pathology*, of *individual difficulties* and of *dependency* in the face of *care*, the social model navigates notions of *social problems*, of *societal/environmental difficulties* and of *independence* in the face of *self-advocacy*. Moreover, whereas the individual model requires that people with learning difficulties *adjust* to their environments and be the *recipient of medical/professional expertise* and *dominance*, alternative understandings demand *societal adjustment* and call for *individual and collective responsibility of all societal members* to redress disabling environments (see Oliver, 1995).

The social model is intertwined with notions of emancipatory theory, research and action. Disabled people are therefore urged to relinquish the socially prescribed script of disability and to take no further part in the tragic dramas that they have been assigned. Furthermore, in opposing societal roles of exclusion, many proponents of the social model assert that disabled people should go further and take up the challenge of political participation themselves:

It is society that has to change not individuals and this change will come about as part of a process of political empowerment of disabled people as a group and not through social policies and programmes delivered by establishment politicians and policy makers nor through individualised treatments and interventions provided by the medical and paramedical professions. (Oliver, 1995, p. 37)

Similarly, 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 an understanding of learning difficulties as individual inadequacy now exists a model that embraces individual and collective empowerment. The focus is shifted away from a focus on what people cannot do to what people can do. Consequently, the social model invites the promotion of self-empowerment and the inclusion of self-advocacy.

The Social Model: a better base to self-advocacy?

The self-determination of disabled people is a pivotal point of the social model. If our views are broadened by beliefs that emphasise competence over incompetence, understand disability in terms of societal prejudice, but also encourage individual and collective self-empowerment and agency, then self-determination stands in direct opposition to prevailing demeaning assumptions. By challenging notions of

impairment, inadequacy and limitation, the social model encourages a context to be formed in which people can strive for self-expression, growth and determination. For self-advocacy, encouraging this context calls again upon the role of the advisor. Let me just step into the role of the self-advocacy supporter that is immersed within this alternative perspective:

As a minority group subordinated by a disabling society, people with learning difficulties have been denied basic rights of self-expression and growth. As a civilised society it is only right that people with learning difficulties should be given the right to speak out, to express their wishes, desires and ambitions. It is also only right that we listen to what they want for they can inform us in the ways society should change for the better. Sure, some people will never be able to acquire certain skills valued by society, but we must understand why these are not valued and challenge our tendency to frame people with learning difficulties in terms of their 'inadequacies'. Their self-determination is so-often not constrained by their inability but by a society that fails to value people so-labelled. We must support their ambitions and not stifle them.

The scenario that I have developed above contrasts markedly with the one I presented in terms of the individual model. Conceptualised in this alternative way self-advocacy can be understood as a continually progressive and emancipatory activity. If we hold that impairment is *not* all important and unsurpassable, then people with learning difficulties' self-determination can go far further than these constructs of inability will allow. Disabling society provides the biggest opposition to personal growth, but a context for self-advocacy means that people with learning difficulties can *themselves* challenge the very societal structures that stifle such growth on a number of levels;

Self-advocates who speak out raise important basis issues: freedom, fulfilment, self-determination. Nobody can speak more eloquently on these issues than the people directly concerned. (Worrel, 1988, p. 13)

Thus, I would argue that when an advisor sees people with learning difficulties not as passive individuals constrained by impairment, but as people actively striving for their own self-determination in the face of a society that denies such rights, then self-advocacy can be supported in a far more empowering manner.

Again the challenge here may be pitched at the level of discourse and politics: uncovering the understandings of disability held by supporters of self-advocacy groups. I will therefore consider how advisors can understand their roles in ways that fit the social model of disability.

The Social Model as Implicated in the Advisor's Position

A key element of the social model is the grounding of *disabled people's experiences* within a political framework of empowerment. Therefore to understand how self-advocacy can be practised in ways that empower its members, it is necessary to listen

to what self-advocates say they want from their supporters. These words of advice fit neatly into three integral elements of the social model. First, that there should be organisations of disabled people; secondly, that we should consider support in terms of *inter-dependence*; and thirdly, that disability is a *heterogeneous experience*.

Starting from self-advocates: organisations of disabled people

The 'Speak for Ourselves' group of Newcastle have produced a highly informative video called *Start! How to set up and run a successful self-advocacy group* (1993). Behind the film lies a clear message; that self-advocates *themselves* can and should be involved as far as possible in the setting up and running of their own groups. Moreover, a clear point is made that interested people should be involved, inferring that a voluntary basis to group membership is desired. This may seem like a trivial point. Yet all too often in fitting with dominant models of care *for* and help *for* people with learning difficulties, there may be a tendency to forget the basic tenets on which self-advocacy is based. That is, that people *themselves* determine their own group membership. The necessity for active self-advocate involvement is picked up on by Hanna (1978, p. 31):

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's analogy reminds us that there are many ways of seeing and doing self-advocacy. Underpinning this diversity is a key element of the social model—that people with learning difficulties *themselves* decide how self-advocacy may progress. Similarly, the British Council of Organisations of Disabled People alerts us to the need for disabled people themselves to be active in their own empowerment. Bill Worrel (1988, p. 39) suggests that advisors should ask themselves' "Is that what I want, or what the group needs?". It is all too easy to lapse back into support that promotes parentalistic authority. Furthermore, because people with learning difficulties will so-often be grateful for being noticed at all, their experiences will be bound up in an acceptance of limited dependency-creating services (Lindow, 1993). It is up to the advisor therefore to promote a climate that emphasises the autonomy of self-advocates and to remind them that they deserve better.

The Advisor's Role as Supporter: support as an intrinsic part of life

Recognising that *everybody* has limitations, taps into another key phenomenon of a social model of learning difficulties, notably *inter-dependence*:

people are people, no matter what their abilities or limitations might be. . . . They may have limitations, *but everyone has limitations of one sort of another*. (Hanna, 1978, p. 31, my italics)

The social model does not suggest that disabled or non-disabled people develop self-determination devoid of support. As societal members, inter-dependence is a key aspect of independence and citizenship. Without the support of others our own roles in society would be seriously stifled—an experience common to people with learning difficulties. For people who have had their basic human rights denied by a society that excludes them support will be necessary in the initial stages of developing self-determination. This links into the *Speak for Ourselves* group of Newcastle's description of the advisor:

Someone who gives support especially in the early days . . . [and who] shouldn't run your group but help you to run it (*Start!*).

Just as with any form of inter-dependence there will be times when more guidance is required. Guidance and help are not static phenomena. People *without* learning difficulties have been afforded a perspective of inter-dependence as a fluid notion. There are times when we require more guidance, help and support than others. There are of course also occasions when we feel our own autonomy is sufficient. The same requirements exist for people with learning difficulties. Hence, following Dowson & Whittaker (1994, p. 44), for the advisor to work him or herself away from the group is to respect this basic desire for autonomy. As Capitol People First of Sacramento, California demand:

we need teachers not keepers. (Quoted in Booth & Booth, 1992, p. 67)

Just as we respect the fact that all people have the right to decide what they want from life, then we must remember that the most well-meaning, helpful, sensitive and committed advisor will never be able to do the job of self-determination as effectively as a well-prepared, well-trained self-advocate (Worrel, 1988, p. 13).

The Diverse Nature of Self-advocacy: the heterogeneous experience of disability

self-advocacy . . . can refer to a process of *individual* development through which a person comes to have the confidence and ability to express his or her *own* feelings and wishes. (Simons, 1992, p. 5, italics in original)

Under the dominant discourse of disability it is likely that people with learning difficulties will be considered a homogeneous group. In contrast, by attending to the personal experiences of disability the social model reminds us that disabled people's experiences, though shaped by many similar sociocultural structures, are multi-faceted. In turning away from incompetence to competence, and by emphasising choice and autonomy, the advisor's role implicated in the social model should

embrace this heterogeneity. Self-advocates have urged advisors to support the many aspects of their self-determination:

thinking for yourself, saying what you think, having relationships like anyone else, people listening to you, changing people's racist views about yourself, taking responsibility for yourself, making decisions, feeling good about yourself, feeling good about your own culture and way of life, standing up for your rights. (Downer & Fearn, 1993, p. 140)

Moreover, Downer & Fearn point out two basic rights that advisors should respect, and which may encompass the whole gambit of ambitions, experiences and wishes:

The right to make mistakes, the right to take risks. (Ibid.)

Self-determination and self-advocacy are vague notions that do not readily represent the diverse and fluid experiences of self-advocates. However, by recognising that these notions may take on many forms we remind ourselves that people with learning difficulties vary in their ambitions just like anyone else. Diversity should be celebrated and supported.

Listening to Self-advocates: refining the social model

Promoting the social model of disability is no easy task. Indeed, it is not uncommon to find disability absent in many texts which advocate the empowerment of oppressed groups. Even in the liberal (and radical) texts of feminism, critical race, gay perspectives and Marxist thought, disability usually only appears as an afterthought (if it is considered at all). Similarly, the social model of disability has received criticism over the exclusion of various perspectives. Recent debates over 'commonality' (see, for example, Finkelstein, 1993) have identified the absence of gender (Morris, 1991, 1993) and race issues (Stuart, 1993) within the social model. In addition, the place of people with learning difficulties within the alternative paradigm is arguably lacking (Goodley, 1996). This need not be the case.

Self-advocates, just like all disabled people, are the most able people when it comes to explaining the effects of disabling society. Their perspectives should be embraced if the social model is to encompass the personal and political aspects of disability. Self-advocacy is not a separate issue. It is intrinsically a part of a movement that threatens to break-down the dominant oppressive understandings of disability. As a source for political change self-advocates stand in *direct opposition* to prejudiced discourse and thus should be supported. Their perspectives should not be ignored when personal and political facets of the alternative paradigm link into a *social theory of disability*.

The social model as an epistemological stance encourages a way of seeing disability in terms of societal rather than individual inadequacies. By doing so, it alerts us to the ways in which society continually stifles the life chances of disabled people and justifies a climate of exclusion. In creating an alternative epistemological stance, then a social *theory* of disability can be proffered:

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, 1995, p. 42)

Many disabled writers have articulated the ways in which society oppresses but let us not forget others that have eloquently imparted the experiences of oppression and continue to offer alternative ways of seeing. Perspectives of self-advocates with learning difficulties can only strengthen the alternative discourse and work towards a social theory of disability. After all,

the biggest disability of all is people's attitudes—it's not us. (Self-advocate speaking at the People First International Conference in London, September 1988, quoted in Brechin & Walmsley, 1989, p. 127)

NOTE

[1] Ethnographic study of self-advocacy groups as part of a PhD research project.

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Section 2 – Postal Survey Appendices

Appendix 2, 1

Letter to self-advocacy group enquiring about mailing list for self-advocacy groups

Dear -----[*supporter of X self-advocacy group*],

I am writing with respect to the self-advocacy survey that I am carrying out as part of my research. I am not sure whether I spoke to you about this when we met at the England People First meeting in -----, however essentially my aim is to survey as many groups in Britain as possible. The survey is quite straight forward and looks at characteristics such as; names under which group's function, number of members and who they are (self-advocates, members of staff, parents, advisors), age of group, time and place of meetings, presence of advisor and their status, roles within group (i.e. chairperson, secretary, treasurer), structure of group meetings (e.g. evidence of agenda, minutes and election procedures), description of group discussions and the source(s) of each group's funding (e.g. local/health authority, charitable, self-funded).

Already I have sent out survey questionnaires to about 60 groups, as identified from your mailing list which you were kind enough to send me. However, as you pointed out, this list is rather dated and already I have received back a number of surveys with "address unknown" upon them. I have written to ----- [*England People First representative*] a number of times enquiring about a mailing list but as yet have not gained any response. At my recent visit with your colleagues at -----, it was mentioned that a large mailing list exists to whom you send your newsletter. In true begging style (I seem to be doing so much of it recently), I was wondering whether it would be possible for you to forward me a copy of this list. If this was the case, I would be able to post my surveys to these groups thus targeting a wider spectrum of groups.

I appreciate concerns that you and others in the group may have over who else may get hold of this list. Therefore I would ensure that the list is seen and used by myself and no one else.

If you have any further queries, please feel free to contact at the address / or telephone number above.

With Best wishes,
Danny Goodley



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Deputy Chair: David Phillips, M.Phil., Senior Lecturer in Social Policy

Appendix 2, 2

Correspondence Address:

30 Forres Road

Sheffield

S10 1WE

☎ 0114 2666206

LETTER 1 : TO PEOPLE FIRST
& OTHER SELF-ADVOCACY
GROUPS

To the Secretary / Chairperson

SURVEY OF SELF-ADVOCACY GROUPS

I am a research student at the University of Sheffield interested in what self-advocates think about self-advocacy. I would really like to hear your views and ask you to complete the enclosed questionnaire.

I would be most grateful if you would spend about 10-15 minutes completing the questionnaire.

When you have finished the questionnaire could you please place it in the stamped addressed envelope enclosed and send it back to me.

I also enclose a more detailed outline of my research for you and your members to read.

Thanks for your time, I hope to hear from you soon.

Danny Goodley.

Danny Goodley.

1 of 2



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☎ 0114 2666206

LETTER 2 : TO INDIVIDUALS
& ORGANISATIONS

SURVEY OF SELF-ADVOCACY GROUPS

I am a research student at the University of Sheffield interested in what self-advocates think about self-advocacy. I would really like to hear the views of self-advocates and their responses to the questionnaire that is enclosed with this letter.

If you are a self-advocate I would ask you and your group to please complete the questionnaire (perhaps you could do this at a meeting). If you are not a self-advocate, but you are involved with a self-advocacy group, could you please pass this letter on to the group. If you are not involved with a group but know of a self-advocacy group nearby, could I please ask you to pass on this letter.

The questionnaire will take about 10-15 minutes to complete and can be sent back to me in the stamped addressed envelope provided.

I also enclose more details about my research that will hopefully answer any questions you may have.

Thanks for your time, I hope to hear from you soon.

Danny Goodley

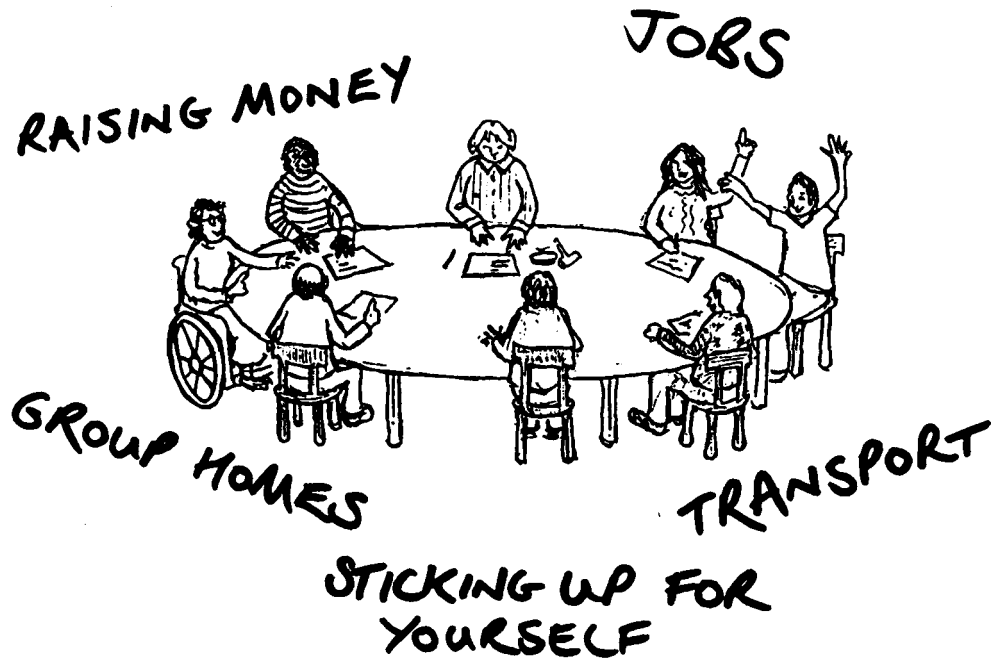
Danny Goodley.

2 of 2



Appendix 2, 3

**SURVEY OF SELF-ADVOCACY
GROUPS**



Danny Goodley
PhD Research Student
30 Forres Road
Sheffield
S10 1WE
☎ 0114 2666206



*This letter was sent
in addition to booklet
when Groups had
asked for more information (During pilot)*

Correspondence Address

30 Forres Road
Sheffield
S10 1WE

To the Secretary / Chairperson

SURVEY OF SELF-ADVOCACY GROUPS

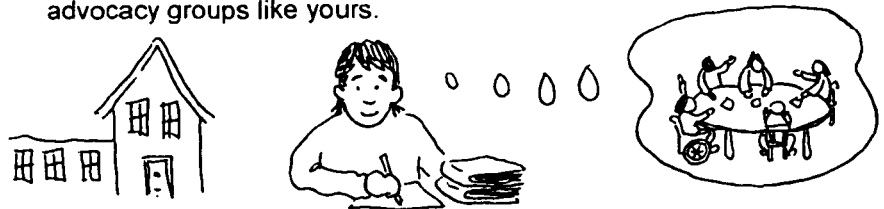
Thank you for completing and returning the questionnaire that I recently sent to you.



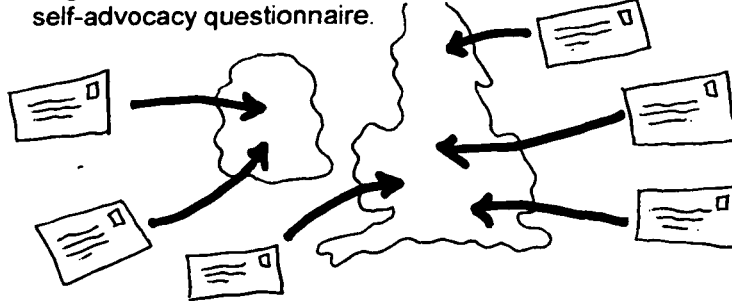
You asked for more details about me, the survey and my research.



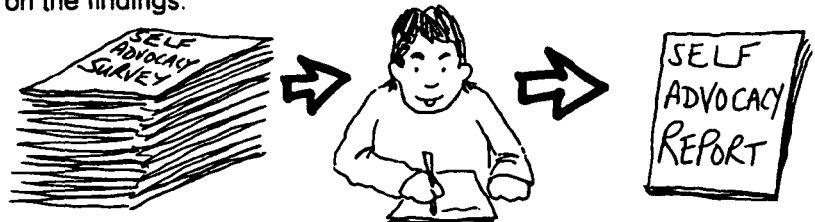
I am a PhD student at the University of Sheffield interested in self-advocacy groups like yours.



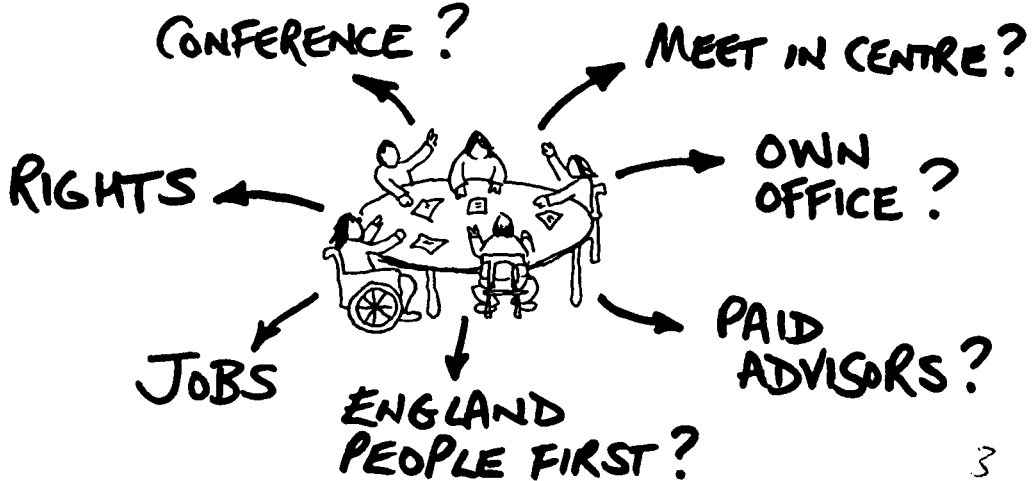
Over the next two years I will be asking all self-advocacy groups in England, Wales, Scotland (and hopefully Ireland) to complete my self-advocacy questionnaire.



When all the questionnaires have been returned I will write a report on the findings.



As self-advocacy is growing it is facing lots of big decisions.



3

I am hoping my report will help all groups to understand what self-advocacy is like now and where it is going in the future.

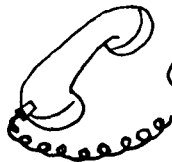


I hope to make sure that the report is finished in two years time.



1997

If you want to know anything else please do get in touch.

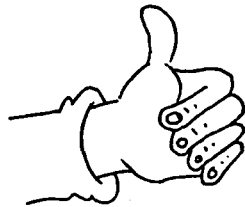


0114 2666206

OR



Once again thank you for completing my questionnaire.



THANKS!

Best Wishes,

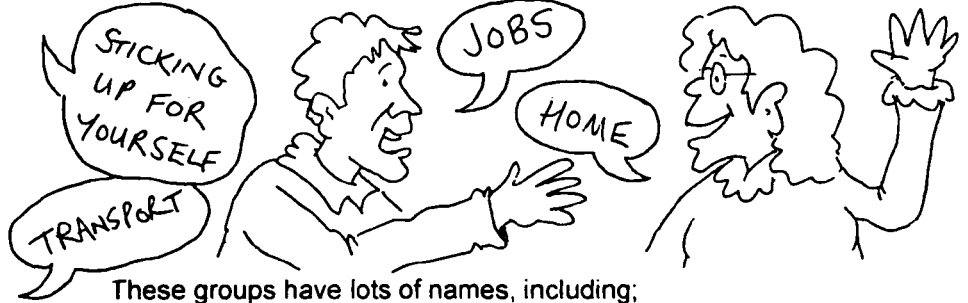
Danny Goodley

Danny Goodley

Self-Advocacy Survey

Could you please answer the following questions about your group.

(1) There are many groups in which people with learning difficulties can speak up for themselves and make decisions about their lives.



These groups have lots of names, including;

- ◆ trainee / student / resident committees
- ◆ trainee / student / resident councils
- ◆ Speaking for ourselves groups
- ◆ Discussion groups
- ◆ Consultative groups
- ◆ Action group
- ◆ Student's union
- ◆ self-advocacy groups
- ◆ People First groups
- ◆ Participation groups
- ◆ Self-help groups
- ◆ Consumer's groups
- ◆ Centre Panels
- ◆ Student's voice

(Taken from Bronach Crawley's (1988). *The Growing Voice - A Survey of Self-advocacy Groups in Adult Training Centres and Hospitals in Great Britain*. London: Values into Action)

What is the name of your group? e.g. London People First



(2) Who are the group members?



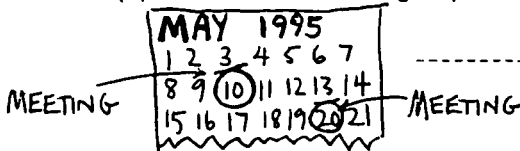
Number of students / trainees /
self-advocates / people with
learning difficulties

Number of staff

Number of parents

Any one else?

(3) How often does the group meet?



(4) Where does the group meet? e.g. in the local centre; arts centre;
school; town hall.

Address:



(5) How long has the group been running?



(6) Does the group have an Advisor? (Please tick box)



Yes

No

If yes, who is your advisor? (Please tick box)

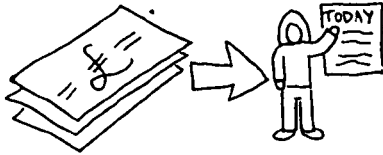


Parent

Member of staff

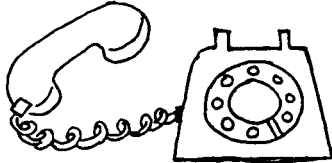
Other?

Does your advisor get paid or is he/she voluntary?



If it is **okay** could you please write down the name and address (or phone number) of your Advisor?





(7) Does your group have: (Please tick box)



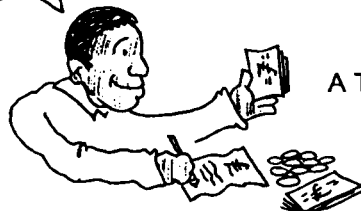
A chairperson

Yes

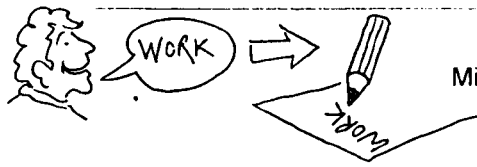
No



A Secretary



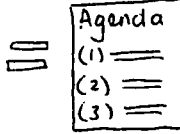
A Treasurer



Minutes

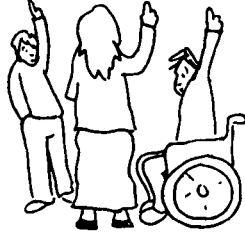
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TODAY'S MEETING
THINGS TO TALK
ABOUT.....



Agenda

--	--



Elections to get into
group

--	--

Elections for posts
within groups

--	--

(8) What sort of things does the group talk about?

.....

.....

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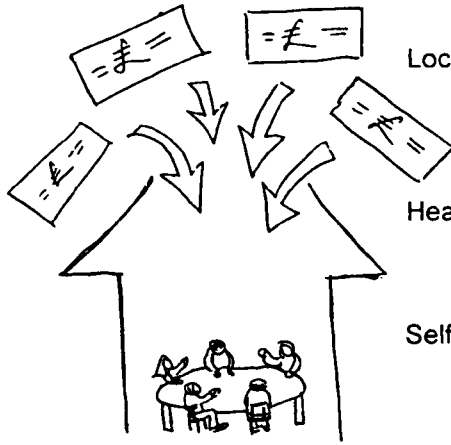
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(9) Who supports and funds your group? (Please tick box)



Local Authority

Yes

No

Health Authority

Self-funded

Charities

Any others?

Thank you for spending the time to complete this questionnaire. If you have any comments you would like to make, please write them down below:

Please put this finished questionnaire in the stamp addressed envelope provided, and send it back to:

Danny Goodley
Self-advocacy survey
30 Forres Road
Sheffield
S10 1WE

Please write down the group's name and contact address below;

Please could you tell me who filled in this form? (Please tick box):

Self-advocate / trainee / person
with learning difficulties

Advisor / supporter / staff
member

Both self-advocate & advisor

Other:

.....

THANKS!

.....

Appendix 2, 5

**Self-Advocacy Survey
SPSS Coding Sheet**

*The following coding schedule was used when entering information from each questionnaire into the data editor for SASURVEY.SAV. Various **Variable Names** were added to the data editor (e.g. Name ; Meeting) and in most cases **values** and **value labels** (e.g 1 = People First ; 1 = centre) were devised. Coding was completed by September 1996.*

(1) What is the name of your group? (Variable name 'NAME')

Value	Value Label	Group Name(s) and details
1	People First	People First groups e.g. Madeuptown People First
2	SAGroup	Self-advocacy groups e.g. Madeuptown self-advocacy group ; Self-advocacy in action
3	Committee	Generic label for groups entitled student or consumer or client or user or member / committee or council or group e.g. Madeuptown student council ; Member committee ; consumer group, etc, Attention committees
4	Selfhelp	Self-help groups e.g The Madeuptown self-help group.
5	Comm.Init	Primarily groups who identify themselves asCommunity initiatives. e.g Community Initiative ; Community Partners / Action.
6	Speakout	Names that centre around Speaking. e.g. Speak & Listen ; Speaking Out ; Speaking for Ourselves
7	Centrenam	Name groups e.g. Madeuptown Centre group ; Karl Marx group ;
8	Fancy	Groups with atypical and unusual names e.g. Act it Out Work it Out ; Friends ; You, me and us ; Daffodils ; Myself & Others ; Progression ; Reflected Images ; Our Vision, etc.
9	Advocacy	Advocacy without the self e.g. Madeuptown advocacy group.
11	Resident	Names to acknowledge Residential base e.g. Residents group ; Tenants committee ; residents committee

		meeting.
12	Men	Men's self-advocacy groups e.g. Madeuptown Men's group
13	Women	Women's self-advocacy groups e.g. Madeuptown Men's group
14	Council	Management committee and groups. e.g. MENCAP consultative group ; Management group.
15	Noname	Groups without a name. e.g. Don't know yet ; To be decided
16	Black	Black self-advocacy

(2) Who are the group members?

value	Variable names	No values or labels
Number of students / trainees / self-advocates / people with learning difficulties	'SELFADS'	<div style="border: 1px solid black; padding: 5px;"> Number entered NB : a value of '2000' - refers to responses of 'lots' / 'don't know' </div>
Number of staff	'STAFF'	<div style="border: 1px solid black; padding: 5px;"> Number Entered </div>
Number of parents	'PARENTS'	<div style="border: 1px solid black; padding: 5px;"> Number Entered </div>
Any one else?	<p style="text-align: center;">A written description was entered</p> <hr style="border-top: 1px dashed black;"/> <p style="text-align: center;">of 'others' e.g. '2 facilitators'</p> <hr style="border-top: 1px dashed black;"/>	

An additional question was asked when analysing the questionnaires : 'Are advisors / supporters / parents' perceived as members of the group?' (This gave rise to the Variable Name 'PERCEP')

Value	Value Label	Perception
1	No	No - advisors / supporters were not accounted for as members of the group in response to question 2
2	Yes	Yes - advisors / supporters were accounted for as members of the group in response to question 2. e.g. '3 staff members' was added to the staff box ; '2 facilitators' was added under 'any one else'.

(3) How often does the group meet? (Variable Name 'TIME')

Value	Value Label	Details of time of meeting
1	2+Week	Group meets two or more times a week
2	Week	Weekly meetings
3	Fort	Fortnightly meetings
4	3week	Meetings every three weeks
5	Month	Monthly get-togethers
6	2+month	Every two months
7	Split	Split times e.g. committee meetings every two months and informal get-togethers weekly

(4) Where does the group meet? e.g. in the local centre; arts centre; school; town hall (Variable Name 'MEETING')

Value	Value Label	Meeting place(s) and details
1	Centre	Group meetings take place in Social Education & Adult Training centres ; Resource centres ; Colleges.
2	Own Room	Groups meet in their own room in a centre
3	Rooms away	Rooms away from centres are used for meetings, ranging from; Church halls ; Convents ; YMCA ; Labour Clubs ; Council room ; town hall ; leisure centres ; Pubs ; cafes.

4	Independent	Independent organisations provide context for group meetings e.g. Citizen advocacy ; Community centres not specifically provided for people with learning difficulties ; MENCAP centre ; Disability consortium ; Skills for people ; Women's centre ; Building for organisations of disabled people; Spastic centre (sic)
5	Own office	Group boasts own office independent of centre (see 2) e.g. People First office
6	Initiative	Group meets in place as part of Mental Health Initiative
7	Home	Meetings in members home / place of residence e.g residential unit ; hostel
8	Village	Get-togethers in place of residence and work, namely 'villages' for people with learning difficulties
9	Charity	Office of large charity organisation e.g. MENCAP office for management committee
10	C&R	Meetings split between centre (see 1) and room outside (see 3)

(5) How long has the group been running? (Variable Name 'AGE')

No value or value label, age given nearest year as coded in September 1996

(6) Does the group have an Advisor? (Variable Name 'ADVISOR')

Value Label

Yes

No

Value

2

1

If yes, who is your advisor? (Please tick box) (Variable Name 'WHOAD')

Value	Value Label	Advisor Description
1	Staff	Members of Staff "college and centre staff"; "assistant senior social worker"; "social worker"; "staff facilitator".
2	Indep	Independent People "independent facilitator"; " independent person"; "independent advocate"; "volunteers"; "volunteer advisor"; "friends"; "staff from outside"; "freelance advisor"
3	Advoc	Member of advocacy / coalition "worker at local advocacy project", "member of coalition" ; "advocacy scheme worker" ; "staff from local advocacy organisation" ; Self-advocacy worker" ; "support worker from community forum" ; "support worker from skills for people" ; "advocate" NB : The response of "staff" was assessed alongside other information given on the questionnaire to assess for advocacy links
4	Gpsupp	Supporter managed / employed by group "self-employed advisor recruited on sessional basis" ; "group manages three support workers" ; "co-ordinator employed by group" ; "We employ our own advisor".
5	Coord	Coordinators "Coordinator of advocacy organisation" ; "coordinator" ; "project coordinator" ; "Full time salaried project coordinator"
6	Staf&vol	Staff members and volunteers "one volunteer and one social worker"
7	Staf&adv	Staff members and Advocacy support "staff & self-advocacy worker"
8	Coopf	Coordinator and People First supporter
9	Stlds	Staff and members with learning difficulties
10	Volad	Volunteers supported by advocacy organisations
11	Advol	Volunteers and advocacy organisation workers e.g "volunteer advisors are not paid but support workers are"
98	Many	Many advisors / supporters e.g. "Council voluntary service workers, MENCAP and citizen advocacy organisations"

99	Nowt	Not enough information provided to ascertain the description of the advisor
100	Noad	No advisor

Others in group? (Variable name 'OTHER')

Value	Value Label	Description of others in group
1	Indeps	"Independent" people
2	Advisors	Advisors and support workers <i>facilitators ; supporters ; helpers ; supporters and advocacy workers.</i>
3	Helpers	Helpers and volunteers <i>minibus drivers ; People First enablers</i>
4	Guests	Guest speakers and others groups <i>students and guests ; police ; placement officers ; invited guests ; management committee.</i>
5	Managers	Centre managers invited along to meetings
6	Trainees	Trainees / 'clients' from day centre invited to group as part of 'open meeting'
7	Staff	New members of staff invited along to the meeting
8	adhelp	Combination of advisors and volunteer helpers
99	None	No others mentioned

Does your advisor get paid or is he/she voluntary? (Variable Name 'PAID')

Value	Value Label	Advisor Description
1	Paid Staff	Paid Staff - self-advocacy as part of staff members' job. <i>e.g. Self-advocacy workshop running in centre as part of curriculum</i>
2	Vol Staff	Voluntary® Staff - self-advocacy is offered by a staff member voluntarily. <i>e.g. A careworker from the centre supports a group that meets in the local pub in his / her own time</i>
3	Vol Indep	Voluntary® Independent(s) - Independent person / people offering support voluntarily. <i>e.g. A student decides they want to get involved with self-advocacy and is accepted by a local group as advisor</i>
4	Paid Indep	Paid Independent(s) - independent advisor paid to support group (i.e. workers from MENCAP, citizen advocacy, Independent Living organisation, Disability Coalition) <i>e.g. As part of a county-wide advocacy project, three workers from the project set-up and support a self-advocacy group that meets in a local church hall.</i>
5	Paid Independent (gp)	Paid (by group) Independent(s) - the group pays an independent person / people to be their advisor. <i>e.g. the group receives money from a charity and with it employ a support worker to help them in their activities</i>
6	PS + VS	Paid Staff & Voluntary® Staff <i>e.g. A key-worker facilitates a self-advocacy forum as part of the centre curriculum. An interested social worker comes in in their own time to offer further support</i>
7	PS + VI	Paid Staff & Voluntary® Independent(s) <i>e.g. A key-worker supporting a 'trainee committee' enlists the help of an interested student from the local University</i>
8	VS + VI	Voluntary® Staff & Voluntary® Independent(s) <i>e.g. A self-advocacy group, supported voluntarily by a local day-centre manager, enlist the help of a young enthusiastic unemployed women</i>
9	PS + PI	Paid Staff & Paid Independent(s) <i>e.g. A tenants group are supported by one of the staff members in the house and an outsider from the local advocact project</i>
10	PI + VI	Paid Independent(s) & Voluntary® Independent(s) <i>e.g. Workers from an Advocacy organisation along with volunteers enlisted through an advert in the local newspaper, support a group for women with learning difficulties</i>

11	PI + P(G)I	Paid Independent(s) & Paid by group Independent(s) <i>e.g A self-advocacy group has just moved into their own offices. Their two employee support-workers (financed through donations from charities) are joined by an advocate from the local citizen advocacy offices, in helping the group to increase its independence</i>
12	PS + PI + P(G)I	Paid Staff, Paid Independent(s) & Paid by group Independent(s) <i>e.g. A working group in a day centre is facilitated by one of the care-workers. In addition members also meet on Wednesday night and are supported by a worker from the local advocacy</i>
98	NA	Not applicable - no advisor
99	NE	Not enough to say. Although group responding have an advisor, little or no information is provided

* Advisors are still classed as voluntary even if expenses are covered by the group. 'Paid' supporters receive a salary.

(7) Does your group have: (Please tick box)

Variable Name Value		Value Label &	
		Yes	No
CHAIR	A chairperson	2	1
SECRETAR	A Secretary	2	1
TREAS	Treasurer	2	1
MINUTES	Minutes	2	1

AGENDA	Agenda	2	1
ELEC1	Elections to get into group	2	1
ELEC2	Elections for posts within groups	2	1

NB : Some respondents cited advisors as treasurer (2 groups) and secretary (1 group). Others 'rotate' roles for each meeting - especially chairperson.

(8) What sort of things does the group talk about?

[See Coding Schedule for group discussions later]

(9) Who supports and funds your group? (Please tick box)

Variable Name	Value	Value Label &	
		Yes	No
LOCAL	Local Authority	2	1
HEALTH	Health Authority	2	1
SELF	Self-funded	2	1
CHARITY	Charities	2	1

Any others? (Other sources of funding, Variable Name OTHFUND)

Value	Value Label	Description of other funding sources
1	Adv	Advocacy organisation support <i>e.g. 'Agency assists'</i>
2	Fund	Fund-raising efforts by group <i>e.g. 'subs'; 'raffles'; 'sponsored silence'; 'money we got from sale of our 'Start!' video (Video made by group on how to set up a self-advocacy group)</i>
3	Firms	Donations from local firms & businesses
4	Services	Support from services <i>e.g. 'centre funds our conferences'; 'Our day centre helps'; 'local authority'; 'health authority'</i>
5	Policy	Direct support from policy initiatives <i>e.g. 'county planning team support'; 'All Wales strategy'; 'Department of Health'.</i>
6	Charities	Details of Charity support given <i>e.g. 'MENCAP'; 'Charity pays for our advisor'; 'Applying for money from National Lottery'</i>
7	Carer	Donations from parents and carers
8	Grants	Grants awarded to groups
9	Many	Responses which include many sources of funding <i>e.g. 'subs, local money, MENCAP, raffles, advocacy support.'</i>
99	None	No additional sources of funding cited

NB : Sometimes in completing the questionnaire respondents did not consider funding with respect to the group's advisor. Consequently an additional source of funding was coded for under Variable Name FUNDAD:

Value	Value Label	Description of funding sources with respect to the group's advisor
1	local	Meaning that the group receives funding indirectly from local authority / health authority / social services, etc when (one or more of) the advisors is a staff member and their support is part of their job <i>e.g. A social worker at a Social Education Centre starts up a</i>

		<i>workers' committee</i>
2	Indep	Meaning that the group receives funding indirectly from various independent organisations / advocacy projects / MENCAP, etc when (one or more of) the advisors supports the group as part of their job <i>e.g. A worker from citizen advocacy spends a day of her working week supporting a self-advocacy group in a group home</i>
3	Nofund	The group receives no indirect funding as their advisors are voluntary or the group pays for their support themselves out of existing funds <i>e.g. A group receives a grant from the local authority. They decide to pay for an advisor themselves</i>
4	locind	A combination of 1 & 2 - independent and service support through the paid independent and paid staff supporters.
99	Noen	Not enough information given

Thank you for spending the time to complete this questionnaire. If you have any comments you would like to make, please write them down below:

Variable Name	Value	Value Label	
'COMMENT' made given	1	No	No comments
	2	Yes	Comments

NB : Comments were then noted down

**Please could you tell me who filled in this form? (Please tick box):
(Variable Name 'RESPOND')**

Value Label		Value
Selfad	Self-advocate / trainee / person with learning difficulties	1

Adviser	Advisor / supporter / staff member	2
Both	Both self-advocate & advisor	3

Coding schedule for group discussion themes

Value Label @	Examples of labelled theme from responses
sadvoc	<i>sticking up for yourself. working together, helping each other. Help the less able. Being diplomatic. Speaking up for ourselves and to each other. About us. Where to go for help if you are not happy. Independence and assertiveness. Helping each other to speak for ourselves</i>
personal	<i>problems we share (people calling names behind our backs). meeting new friends. Building confidence. Things we feel good about, things we have achieved. I have a dream</i>
Leisure	<i>All things to do with sport and Leisure. Coffee mornings, outings, holidays. fish & chip suppers. Drama, cooking, making cards, bowling. Painting. Christmas lunch and shows. Social activities</i>
Running	<i>Getting a new supporter. Planning adverts. Should we have a chair in the meeting. Discussions regarding the group process, i.e. choosing chairperson. Elections. Committee members and their roles.</i>
Training	<i>Hopefully this group could be linked to the Open University Equal People course. co-ordinating the activities of many affiliated independent advocacy groups. Hosted conference on self-advocacy</i>
Centres	<i>Things that we want to do at the centre & things we want to change. Anything that goes on at centre, and what changes they would like to see and follow up complaints from other users not on committee.</i>
Cendosh	<i>protests against day charges. The unfairness of having to pay to come to our day centre. Opposition to day centre charges.</i>
Profess	<i>reviewing case managers. Interviewing for staff. Staff change with no consultation. Enquiries</i>
Rights	<i>Finding out / standing up for your rights. Access to buildings for disabled people. Rights and responsibilities. Freedom and choices. Laws about rights. Votes, jury service. You and your rights. Things we are not allowed to do. Moving into the community. Rights, independence in all areas</i>
Services	<i>social services plans / policies. activities of other organisations such as social services. Who should get services. Social services. Problems with the health authority. Transport. Bus passes.</i>

work	<i>Wages. Work experience. Benefits. Treatment by other workers. Day-time occupation. Work and support. Talk about work. Office work. Employment problems. Organising a petition about wages.</i>
housing	<i>Resettling back into the community after living in a large 'mental' hospital. Independent living. Moving people in and out of hospital. Local institution closing. housing and staff support.</i>
funding	<i>How to get money to keep going training. Funding (or lack of it) AD INFINITUM. Raising money for our group.</i>

@ a value of 2 was given if this theme was explicitly mentioned in the responses.

Section 3 – Life story Appendices



Appendix 3.1. Introductory handout

Tel: 0114 282 6321
Fax: 0114 276 8125

E-mail: Sociological.Studies@Sheffield.ac.uk

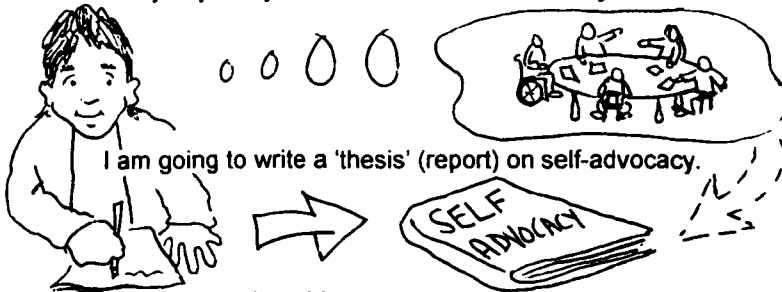
Chair of Department: Alan Walker, D.Litt., FRSA, Professor of Social Policy
Deputy Chair: David Phillips, M.Phil., Senior Lecturer in Social Policy

© SHEFFIELD HIGHER EDUCATION

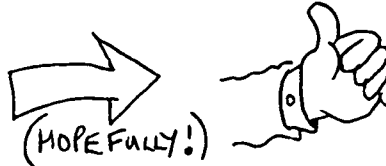
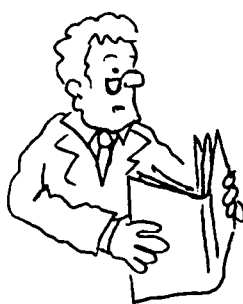
Danny Goodley
PhD Research Student
University of Sheffield



I am a research student at the University of Sheffield. A year ago I was lucky enough to get some money from the University to help support my study. My study will look at the **self-advocacy movement** in Great Britain.

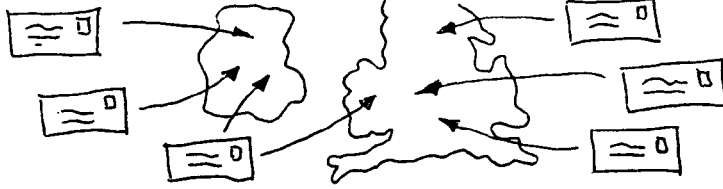


In two years time this thesis will be marked by examiners. If the examiners feel that it is good enough (and I hope they do) then I will be awarded the qualification of 'PhD' by the University of Sheffield.

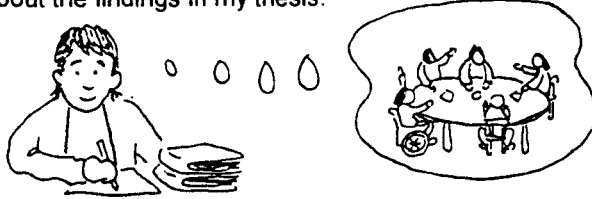


To help me understand self-advocacy and write my 'thesis' I have done a number of things.

First, I have sent a 'questionnaire' to groups in Great Britain.



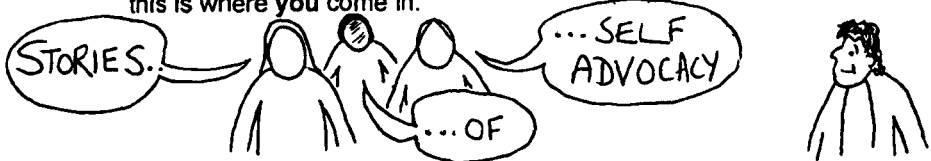
From this I will be able to see what groups are like in Great Britain. I will write about the findings in my thesis.



Second, I am going to visit a small number of groups to see how self-advocacy works. I will be talking to self-advocates and supporters in these groups.



Third, I want to hear about the stories of a number of self-advocates - this is where you come in.



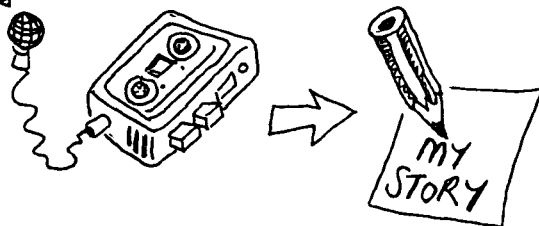
I think that when people read these stories they will understand what self-advocacy is about.



I would like to hear your story.

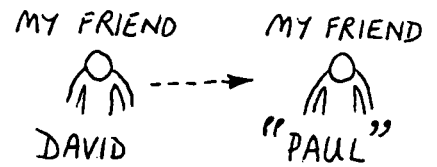
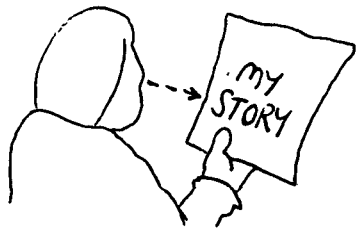


If you do not object I will **tape-record** our chats.

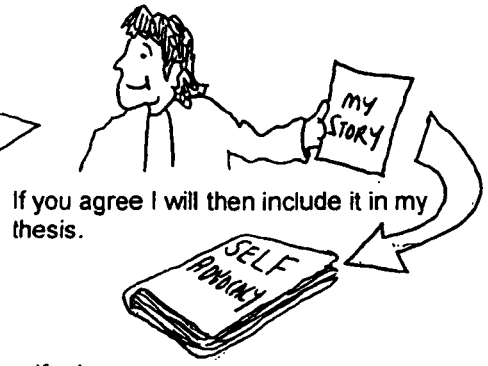
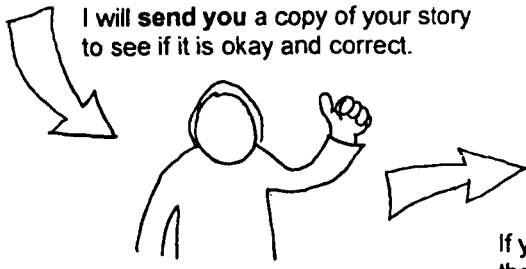


When you have told me your story I will **write** this down.

Because other people will be reading your story I will **change** the names of people and places.



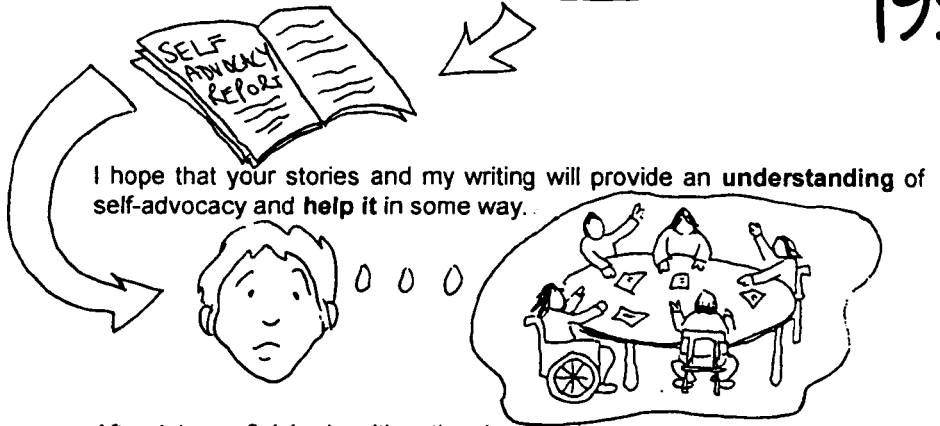
I will **send you** a copy of your story to see if it is okay and correct.



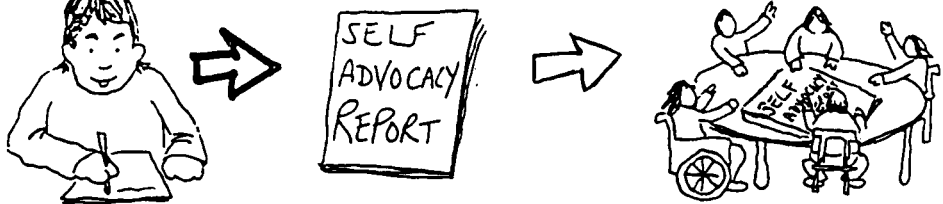
If you agree I will then include it in my thesis.

Your stories will help me write about self-advocacy.

My thesis will be handed into the University of Sheffield in 1997.



After I have finished writing the thesis I hope to write a report of my findings for self-advocates. I expect this to be finished in 1998.

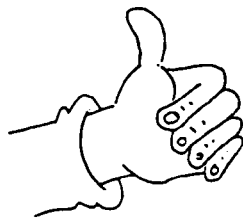


If you do agree to share your story then you will be helping me in a big way as your story will help me write my thesis.

But I aim and hope to make sure that self-advocacy is helped in some (small) way by my work.

Thankyou for your time.

Danny Goodley



THANKS!

Appendix 3, 2 : Talking to top self-advocates questions to be considered

Starting off

Where did you hear about People First / self-advocacy?

When did you get involved?

What were you doing before hand?

Where was the group / who was in the group / was there a supporter?

What the group did

What did you talk about at meetings?

Can you remember things that the group did?

Did people use the term mental handicap?

Did you ask for it to be changed?

Any meetings with staff / centre manager / parents?

Complaints about things?

Conferences - international / national / local.

The role of supporters / advisors

What is the role of the advisor in the group?

Do supporters have a say in the running of the group?

Is the supporter paid? Is this okay?

Should supporters be members of staff or independent?

The meaning of self-advocacy

What does speaking up / self-advocacy mean to you?

How has it affected you?

Why do you like being in People First?

What would you say to others that might want to get involved?

Future of self-advocacy

How do you see your future?

What are your ambitions?

How do you see People First in the future?

Is England people First a good idea?

How can self-advocacy develop in the future?

Friends and family

What do your friends and family think about you being in People First?

What did they say when you first became involved?

Appendix 3, 3 : Selections from Annotated Narratives

Below are extracts from the five finished *annotated* narratives, highlighting the textual strategies outlined in chapter 8.

Jackie Downer

“

[I was in] special schools [up to the age of] 16. Funny buildings, you were *labelled* as soon as you got there ...[I] changed colleges because I couldn't get a job [not even] basic stuff like shop assistants, rejection upon rejection. [It] starts [to make] you feel small. I stayed at home and was depressed for a year. I wanted a job. I thought about [myself] as a black woman with learning difficulties. People look at your disability and not you as a person - that's a common experience {9} ...

... Parents think they don't know about sex - they find it hard to talk about things. [It's] harder even now because I'm grown up [and] I need a life. I sat down and talked with my Mum. [I told her] "there's things I've got to do, I'm one of the lucky one's, others have more severe learning difficulties". "I'm 29", *///dir* I told her she's gotta let me [go] and she found it hard *///dir*. Some parents won't want their kids to do things and they need to have their own support group *///dir discarded sentence here ///dir* ...

... *\\con* Everyone [from the] health minister [to] professionals goes to certain groups but they need to network with other PF organisation *\\con*. *///dir* Certain groups *///dir* get mega bucks [but they] need to delegate to others. [It's] unfair if other groups want to have, [say], a mini-conference and the chance to talk about things. *///dir* With some groups *///dir* everything is me, me, me - [they think] they can do everything. [They] need to network, need to share work. *///dir* One or two groups *///dir* can't do everything, if you think this you are treading on dangerous ground {5}. [What do I think of England People First?]{6} Who's England People First? Who are they? Who's in control? *///dir* At the start I didn't know but now they're trying to get people with learning difficulties in control *///dir*. *///dir* Supposed to be people with learning disability *///dir*. People with learning difficulties are in control when they delegate work amongst themselves. If one group does it, [they're] not uniting together, no network. [There's] always one People First group, one organisation taking the power - we need to share things out. {6}

”

Lloyd Page

“

I was in day centre[s] for 17 years {23}. [In those places I didn't do] a single thing {6} . Everybody kept sitting around doing nothing, just sat on their backsides - *doing nothing* - like I was doing {6} . We [used] to get 75 pence {23} [for a day's work in the centre] {23} - that's a pittance {23} ...

... [I came back from the conference] {3} and [helped] set up [a] group{3}. [At the time our] group was called People First and [now] there is another group which is a spin-off ||_{mum} {3} . [There were] over twenty people {3} [in the group at the start and] I was link person there {3} . [I was also secretary] {5} for quite a while {5} . [At the start] we'd meet in peoples' houses but now [the group] meet[s] {5} [in] ||_{mum} a community hall that's let out once a fortnight - it's a regular thing ||_{mum} {5}. [We would talk about] transport, day centres, holidays and because we were losing our four pounds pocket money, [the *pittance*, that] we used to get from the centre {23}. [Right from the start people were] {23} very chatty {23} [because they'd been given the chance to speak] {23} ...

... They told [me] that the next international conference was going to be in Canada ||_{mum} {3} . ||_{mum} [To get me over to Canada my mother] and about four [of her] friends fund-raised for four years. [They] got four thousand three hundred pounds and that meant we could send four self-advocates and one ||_{mum} {4} supporter ||_{mum} to Canada ||_{mum} {4}. [When you're at these conferences] {4} you go and visit places and you go and have chats {4}. I don't know what to think about [it] {28} . [A good or bad thing?] {28} You've got to weigh up the balance between England People First and the other groups as well. There's a question of money and if it runs out it's a difficult question to answer {28}. [I would like to see England People First] {28} getting in contact with groups {28} [- getting groups together]{28}.
||_{dir} Our group is a much better set-up in all the groups really and it's much more central than others as well. We have got five paid supporters and ten voluntary workers. The self-advocates don't get paid but are given their expenses back. I cannot be paid because I'm on benefits. We need supporters for everywhere we want to go and the money we charge for supporting groups and carrying out workshops goes to the office. This all helps us to keep going. At first I did think we should be paid but this is not possible I am really pleased to be part of all this so don't mind for not getting paid ||_{dir} . In ten years time I'd like to go onto much bigger things, do some more work for Universities and stuff {27} [like that]

”

2

Joyce Kershaw – ‘Danny’s story’

“

[I went to a boarding school for children with epilepsy] {2}. They used to wake us up about 5 o'clock in the morning. There used to be a night-nurse on and she used to come and give us a pill and then at 5.30 we used to have to get up and get washed and dressed, clean us teeth and everything {1} ...

... At nine o'clock [we'd go to school]. [It] \\con was \\con like a proper school, we used to have a teacher there [and] then we'd come home for \\con our \\con dinner [and] go back until four {2}. We had \\con our \\con tea then we'd [do different things], it just depended what day it was. On Friday we used to do darning. They used to sit us down and [we'd] darn \\con our \\con black socks and mend sheets, we used to have to do \\con the \\con little girls' sewing {2}. On a Wednesday we'd have bath nights. We used to bath the little ones and sometimes would clear the cupboards out {2} ...

... [People] could come and visit you every month. I had about one visitor all the time I \\con was there \\con. \\con My \\con mum] said she'[d] try and send someone to take me out. I soon got used to it, get[ting] dressed up {1} \\con ready to go out \\con. Every year you could come home for a fortnight and then you had to go back after[wards]. [It] \\con was \\con nice coming home] {2} oh it was. I used to stand there and get dressed up when I thought they were coming for me and look out the window. \\con I'd see \\con everyone else going out and there \\con was \\con me with tears running down \\con my \\con eyes. \\con Of course \\con I was only 13 then and when I was 14 I got used to it {2} ...

... ♦ [People] have got a learning difficulty in anything they do. If mine wasn't epilepsy it might be arthritis or I might be \\con really \\con slow at reading, slow at writing, you don't know ...

... ♦^{new} \\con Once when I was talking to \\con students I said " you want to come and see some of \\con them \\con working [in the centre] and I bet they'd have to teach you how to do it". \\con Because we were making \\con masks and you used to have two little buckles, some elastic, you used to have to cut the elastic, thread it through, then put a mask on, so it \\con could \\con go just over your head. And I told those students "I bet you'd get mixed up doing them buckles. Come and try and do our work and you'll soon find out if you've got a learning difficulty or not" {14} ...

”

3

Anya Souza

“

I was born in Hampstead in 1962 and in those days it was Mongol. When my mum had me she was 44, which [is] quite old actually to have a baby. When the doctors had me in their hands to hand me over to my mother, she [asked] them “is my daughter okay?”. The Dr said “no she's not okay, she'll be mentally and physically handicapped for the rest of her life”, basically. My mother [couldn't make] head nor tail of that initially. She was shocked {1} ...

... From primary I went onto a mainstream comprehensive school and made some more friends. I came out with 3 CSEs I did French, Drama and housecraft. I did grade 3,4 and 5 in all of them. I also did an exam in typing so I know how to type, and I also had piano lessons. I learnt the piano for about ten years and after that I played the guitar too. My mum paid for the lessons which was good for me. I was there for 5 years instead of 6 years. I made some good friends, but then I get this thing after five years from the headmistress saying to my mother behind my back “Why is this Mongol person in my school?”. I felt really angry, very angry. Well the moment my mother heard that, bloody hell, she went to the high court *///dir* of justice *///dir* and we won, the headmistress lost - because you don't say those kind of words really. I think we sued her, because my mother didn't want that saying about me really [The headmistress' attitude was that I shouldn't be there] {1} but what was I doing there [for] five years? Going off to France because I was learning French, you know and all that, and I get that at the end of it {1} ...

... [I left for a number of reasons. It's difficult for me to tell you. I can't give the details] (((*tel* I said something I shouldn't have. I meant to say one thing but another thing came out of my mouth)))*tel*. *That was my mistake.* I did that, but we all make mistakes. [I was only worried for the members of the group]. (((*tel* Other people over-reacted)))*tel*. My second mum June said [they used me as a scapegoat] {7} *///dir* and gave me abuse *///dir*. (((*tel* They did. Nasty piece of work)))*tel*. [Then there was] all this stuff with another member of the group {8}. (((*tel* They accused me of doing something that I didn't *///dir* do *///dir* ... (((*tel* Even now when I bring things up about self-advocacy I tell them about my old group, but I do tell them not to mention my name)))*tel* ...

”

4)

Phillip Collymore

“

I haven't had an awful lot of opportunities for work but I have done work in the past. Clearing up, dusting and all that business. I've done household work, gardening and farm work. There used to be a farm where I lived which they're pulling down now. They're using the land for houses {1} ...

... It was run by a charity. They had an awful lot of farm land there and we used to look after it. There was me, Tommy, Peter, Arthur, about 5 or 6 of us. I was there for 30 years {1}. They [ran] it how they want[ed] to run it. They [didn't] let you have a say about how it should be run. It [was] for people with learning difficulties and some of them [were] really bad with learning. [The staff] really took over - "you can't have this, you can't have that" ...

... It was for men like ourselves with (((tel.hospital staff)))_{tel} looking after us. The (((tel.hospital staff)))_{tel}, they could be a bit on the 'bent side' - if you know what I mean. That was a problem. They took it out on the lads [who] were there. That's why the majority of men don't like the (((tel.hospital staff)))_{tel}. We took them to court over a few things as well. They got fined for what they were doing. They're not running here any more they've gone abroad [but] they'll be doing exactly the same over there. I moved there in 1966. [Living there it was hard] {2}. I got knocked left, right and bloody centre. That's why I [was] afraid to speak up. It [was] very hard for me to say anything I wanted to say because if you're not big enough to fight then you'll get a hammering. And if you're big enough to have a fight, you're all right. If you can stick up for yourself, you're okay, if you can't, then watch out. Sometimes I couldn't stick up for myself at all. Every day I was getting beaten. There was not a day missed out without me getting a good hiding. Then I would be getting raped and all that business. People don't realise it. It is true. I know it is. The people out there experiencing it they'll tell you [that its] true. Others will say it isn't. But these days you've got to look at it. People who have been in homes all their lives will tell you it is true. The outside people have never been in - [they won't] {2}. [Now] I know they're the ones who are in the wrong not us {3} ...

... [I'd like someone to say] here's 20 grand to keep us going. If we're still there then we're all right. What do we think of this generation. How is this next generation going to go? Will they tag along with us? I want to see their ideas. It's just a question of whether we'll last. If it does I hope so. I think it will {8}.

”

5

Appendix 3, 4 Correspondence with 'Top' Self-advocates

All five self-advocates were sent the following cover letter with the introductory handout 'Self-advocacy Stories':

Danny Goodley

Dear Jackie / Lloyd / Joyce / Anya / Phillip

I am a research student at the University of Sheffield, looking at the self-advocacy movement in Great Britain.

I got hold of your address from ----- / I recently saw you in the video ---
- / I read the chapter you co-wrote for the book ----- .

Part of my research presents **the stories** of self-advocates. I gathered that you have been involved in self-advocacy for a number of years. **I would really like to hear your story.**

I was hoping we could meet up for a chat just after christmas / soon / in the next month or so. Would it be okay for me to come to -----?

I would be grateful if you would let me know so that we can fix up a date. In the mean time I enclose more details of my research with this letter.

Hoping to hear from you soon,

Best wishes,

Danny Goodley.

In addition to this letter, details of other written correspondence with each narrator is outlined below.

Jackie Downer

A meeting was arranged by telephone and interview undertaken by November 1995.

Dear Jackie,

5th December 1995

Many, many thanks for spending the time to talk with me a couple of weeks back.

I will be writing your story down around Christmas time and will send you a copy for you to read and add, change or correct anything. You had so many important things to say and it was good to hear about your experiences.

Thanks again for your time and I hope everything is fine with you in -----.

Best wishes,

Danny.

First draft of life history written up.

Dear Jackie,

February 1996

How are you? I hope everything is well in ----- and you are as busy as ever (not too busy!). Please find with this letter your **life story** that I have written based on what you told me in our interview. Sorry it has taken so long to send it to you - I have also been very busy. I hope that you like what I have written and that you feel it gets your story across.

Please feel free to:

- Change words that I have used
- Add anything that you would like to be included in your story
- Take out parts of the story that you would rather not be in.

When you feel the story is okay could you please post it to me in the stamped addressed envelope? Then if you still agree I will use it in my report ('thesis'). I hope that people who read your story will be able to really see what self-advocacy is all about. Thanks again for your time.

Best Wishes,

Danny.

*Telephone conversation held to discuss changes Jackie wanted.
Second draft written up.*

Dear Jackie,

April 1996

Please find enclosed a copy of your life history that includes the changes we spoke about. I hope you find it okay.

Good luck with the new job and perhaps the next time I'm in ----- we could meet up for a chat.

Thanks again for your time, Best wishes

Danny

Final draft accepted and sent back by Jackie with following note attached:

Danny

It would be nice to meet up some time.

Jackie.

Lloyd Page

A meeting was arranged and interview undertaken by November 1995

Dear Lloyd,

5th December 1995

Many, many thanks for spending the time to talk with me a few weeks back. I will be writing your story down soon and will send you a copy for you to read and add, change or correct anything. You had so many important things to say and it was good to hear about your experiences.

Now, you asked me to find out some **University Addresses** so that you can send them some details about the **Equal People** course you are involved with. Well after lots of searching I think the best thing to do is to write to the following organisation:

c:\append7\sadlets.doc

3

UCAS (The Universities and Colleges Admissions Service)
Fulton House
Jessop Avenue
Cheltenham
Gloucestershire GL50 3SH

Telephone: 01242 227788

They have a list of **all the universities in Great Britain** - so I am sure that they are your best bet. Hope that helps, speak to you soon and thanks again for your time.

Best Wishes,

Danny.

First draft of life history written up

Dear Lloyd,

5th March 1996

How are you? I hope everything is well in ----- and you are as busy as ever (not too busy!). Please find with this letter your **life story** that I have written based on what you told me in our interview. Sorry it has taken so long to send it to you - I have also been very busy. I hope that you like what I have written and that you feel it gets your story across.

Please feel free to:

- Change words that I have used
- Add anything that you would like to be included in your story
- Take out parts of the story that you would rather not be in.

When you feel the story is okay could you please post it to me in the stamped addressed envelope? Then if you still agree I will use it in my report ('thesis'). I hope that people who read your story will be able to really see what self-advocacy is all about. Thanks again for your time.

Best Wishes,

Danny.

Telephone conversation held to discuss changes Lloyd wanted. Soon after Lloyd sent back a section of the life history which he wanted to be replaced with text outlined in his letter:

March 1996

Our group is a much better set-up in all the groups really and it's much more central than others as well. We have got five paid supporters and ten voluntary workers. The self-advocates don't get paid but are given their expenses back. I cannot be paid because I'm on benefits. We need supporters for everywhere we want to go and the money we charge for supporting groups and carrying out workshops goes to the office. This all helps us to keep going. At first I did think we should be paid but this is not possible I am really pleased to be part of all this so don't mind for not getting paid.

Dear Danny

Thank you very much for sending me the report and it is excellent. I have made the changes that I have spoken to you about and look forward to seeing th final draft. With best wishes to you and the success on your thesis,

Yours sincerely,

Lloyd Page

Second draft written up in accordance with changes set-out.

Dear Lloyd,

March 1996

Please find enclosed a copy of your life history that includes the changes we spoke about. I hope you find it okay.

Thankyou for the copy of the newsletter - I thought your article was excellent (front page eh?). Next time I'm in ----- we will have to get together for a coffee and a chat. Thanks again for your time,

Best wishes Danny

Joyce Kershaw

A meeting for early 1996 was arranged by telephone. Joyce and I met up and we went through the introductory handout 'Self-advocacy Stories together'. It was a while before I finally typed up the first draft of what became 'Danny's story':

Dear Joyce,

July 1996

Please find with this letter your life story that I have written based on what you told me in our interview. Sorry it has taken so long to send it to you - I have also been very busy. I hope that you like what I have written and that you feel it gets your story across.

Please feel free to:

- Change words that I have used
- Add anything that you would like to be included in your story
- Take out parts of the story that you would rather not be in.

When you feel the story is okay could you please post it to me in the stamped addressed envelope? Then if you still agree I will use it in my report ('thesis'). I hope that people who read your story will be able to really see what self-advocacy is all about. Thanks again for your time.

Best Wishes,

Danny.

Telephone conversation arranged meeting to talk about first draft. Changes Joyce wanted were outlined at this meeting (July 1996). Then, a second draft of 'Danny's story' was sent to Joyce but again she was unhappy when speaking to me on the phone. Another meeting was arranged (November 1996) at which she handed me 'Joyce's story'. I typed this up and sent it back to her:

Dear Joyce

December 1996

Here is the story you wrote typed up. I have typed up everything you wrote, changed the spelling mistakes as you asked, and changed the names of the following people:

- ----- (centre manager) is now called "Mr Jones".
- ----- is now called "Stuart"
- ----- your key worker is now called "Lesley"

I have also put the paragraph about ----- in the story where you directed me.

I have now added 'your story', and 'my story' that I wrote, to my report as you said I could. Keep writing your diary we could perhaps do something else with that later. Best wishes for Christmas and the New Year

Danny

Correspondence with Anya Souza

A meeting was arranged and interview undertaken in January 1996. The first draft was not sent off to Anya until November.

Dear Anya.

November 1996

Well Anya here is the story, see what you think. I have made a number of name changes:

- Your friend ----- is called "Jennifer"
- -----, who poured custard down you at school is called "Brenda"
- ----- are called the "speaking out group"
- ---- and ----- are now called - "Shaun and Kerry"
- Other members of ----- : ----- = "Julie"; ----- = "Peter"; ----- = "Jane"; - ---- = "Carol"; ----- = "Rebecca".
- And finally from the ----- video : ----- = "Julie" and ----- = "Chris".

Hope that's okay, now for the story

Anya sent back the life story with various changes made but no accompanying letter. I changed the life history and sent back the final draft:

Dear Anya,

December 1996

Well Anya here is the new story, re-written in the ways you asked. see what you think. I have also changed ----- to "James" and ----- = "Luke" as you told me.

Thank you for sending me a conference report of 'Not just painted on'. Absolutely excellent. Next time I'm in ----- we will have to get together.

Thanks again for your time.

Best Wishes for Christmas and the New Year,

Danny.

Phillip Collymore

A meeting was arranged and interview undertaken in May 1996. It was not until November of that year that the first draft of the life history was sent to Phillip with an audiotaped version of the narrative. On the tape the following letter (which was sent with the text and tape) was read out:

Dear Phillip,

November 1996

Happy New Year. Well I have finally typed up your life story. With this letter you will find have:

- a typed up version of your story
- your story read out aloud by me on tape.

Would you please listen to the story, see what you think and give me a ring back? Hope you like it.

I have changed some names, so that people who read your story will not know the identity of others. ----- from your group I have called "Rachel" and ----- is now "Guy". Also ----- the supporter is now called "Wendy" in the story.

I'd like to thank you again for spending time with me and sharing your story.

Best Wishes,

Danny.

After meeting with police investigating Phil's claims of sexual abuse, Phil asked that I change his name and the name of the abusers. The final draft was sent to him with this letter:

Hi -----

Here is your story re-written as you asked. Sorry I haven't tape-recorded it - my tape is broken (again). Your name is, as we talked about on the phone, Phillip Collymore. I have also changed the names of ----- to 'hospital staff'. Hope that's okay.

Take care of yourself, I will ring you soon

Best wishes
Danny

⊗ Phillip's keyworker read out his story to him.

Appendix 3, 5 - Danny's story - Joyce Kershaw's life story written by Danny Goodley

From boarding school to married life

I went to a boarding school for children with epilepsy. They used to wake us up about 5 o'clock in the morning. There used to be a night-nurse on and she used to come and give us a pill and then at 5.30 we used to have to get up and get washed and dressed, clean us teeth and everything. There were two dormitories, one for little ones and at 13 you went in the big dormitory. Down for breakfast for 7.30, with porridge, which was, like slush or sometimes, if your parents sent you something, you could have that. Mum didn't send me much she was too poor.

After breakfast we used to have to clean the dormitory with like a big 'dummy', like a duster on a stick. At nine o'clock we'd go to school. It was like a proper school, we used to have a teacher there and then we'd come home for our dinner and go back until four. We had our tea then we'd do different things, it just depended what day it was. On Friday we used to do darning. They used to sit us down and we'd darn our black socks and mend sheets, we used to have to do the little girls' sewing. On a Wednesday we'd have bath nights. We used to bath the little ones and sometimes would clear the cupboards out. After we'd done that we'd have a game, either monopoly or table tennis or anything like that with the nurses. Every Sunday we'd go to church. That's where I got confirmed.

People could come and visit you every month. I had about one visitor all the time I was there. My mum said she'd try and send someone to take me out. I soon got used to it, getting dressed up ready to go out. Every year you could come home for a fortnight and then you had to go back afterwards. It was nice coming home, oh it was. I used to stand there and get dressed up when I thought they were coming for me and look out the window. I'd see everyone else going out and there was me with tears running down my eyes. Of course I was only 13 then and when I was 14 I got used to it.

I left school at 16 and came back home to my Mum and Dad's. My father went to Woolworths with me and he explained to this manager that I had epilepsy and that I hadn't had a fit for a long time, for two years. It was a lady manager and she said she'd give me a trial. She was all for people like us, like people who had a learning difficulty, so I went to work in the stores. I met my husband there, he was a soldier. He was on leave. He came into Woolworths and asked if there was a picture place about. I told him there was one. He said " because I've come

from Oldham, I'm just on leave and I don't know where it is". He was based in Germany, he used to come home on leave. He was a cook in the army, he'd just come over to town and he didn't know his way round - so he said! Anyway he went away but came back again and asked me if I'd show him, if I'd come out with him to pictures, and I said "yes". Then he went away and he came back and asked me if I'd show him, if I'd come out with him to pictures, and I said "yes". Then we started seeing each other. I remember We used to go out on a tandem together every weekend. When he was away with the army, I used to write a letter every night and he used to write to me and that. I was married when I was 18 and we had a little house. He left the army, started on the buses as a bus conductor, and eventually ended up as driver. I stopped working at Woolworths and went in an office for a while until we broke up, me and my husband. He went with my best mate, we'd been mates ever since we were kids. Aye, I was upset.

Caring at home

I'm not frightened of living on my own now but when my husband left it seemed a bit strange. I'd never been on my own before. I'd always been in somebody's company, my mother's or my sister's or someone else's. Even at the boarding school there used to be a lot of girls there and nurses and they were really nice. So my mother and my sister came and took me down to live with them at my mothers. It was a bit weird being at my Mum's after seven years away.

After a while my mother and I went to live with my brother because his wife left him. We used to look after his two lads who were four and ten, my sister's lads who were two and ten, and of course my brother and my sister's husband. We'd have tea ready for them all in the evening. I took the kids to school when they first started and I'd do all the washing. Nothing like the washers are now, scrubbing all the necks of the shirts in a tub. My mother used to bake lovely buns. The children would come in and see the buns on the side that had just come out of the oven. Then when my mother was sat in the living room they'd say "can we wash our hands Grandma?" and go into the kitchen. After a while my mother went into the kitchen to see what the kids were up to and all the buns had gone! My sister was taken poorly with cancer. She used to live in a prefab but they've pulled all them down now. When she died I brought her children up to our house and put them in bed with the others. Around that time I went into hospital myself to have a cyst taken off and when I came back my mother was taken poorly. I was with her for over a year. I slept on a two seated couch and I used to be up and down the stairs seven or eight times a night to see her. She'd be rattling the legs of the bed with her walking stick, shouting "Joyce" at the top of her voice. One day I was vacuuming the living room. My mother was sat in her chair watching me and all of a sudden she said she wanted to go to bed. I said that I'd help her when I'd finished cleaning up. When I did finish she had already died. Do you know, I could hear her shouting my name for years after.

2

My Dad used to visit me and my brother every week. One day on his way back home his legs went. He was in hospital for eight weeks and the Doctor said that he couldn't live on his own. He would either have to live in a home or with us. Well my brother said that no way would we leave Dad in a home and he came to stay with us. Soon after moving in he had a stroke in my arms. I ran up and got my brother and it took both of us to get him in the chair. There I was running up and down to the neighbours in my nightie shouting "can you phone the doctor!". When he was dying, the day he died, the Doctor said "he's really poorly". I said, "I've been telling you that all week". All he gave me were these prescriptions so I gave him them back.

I was at the centre then. I started when my mother had already died and I've been going ever since for 21 years. I stopped working to be at home, to help with the kids, and then my father got poorly. Before he got really poorly he said I could do with someone to help me, so he went somewhere, and these people used to come and see me. They got me into this place, the centre.

The centre and staff

You used to have to call the staff by their last name but they used to call us by our first names. Also when we went for our dinner there used to be two members of staff stood up and three rows of us. They used to say "this row" and that row used to get up and go off. And if people were talking they used to say "right this row go because your talking". Also the staff used to go in a little room for dinner. I asked the centre manager "aren't we good enough to eat with?" and he said that of course we were. So I asked him why the staff ate in a separate room and he told me that it had always been like that. So I said that we thought they should eat with us, that it didn't look right. It was as though we weren't good enough to eat with. And he told me he'd bring it up at the next meeting. Also I wanted us to be able to call them by their first names. So I went round all the staff asking them if we could. At first some said no so I told them they could call me Mrs Kershaw from then on. And when they called me Joyce I wouldn't answer them.

The centres were bad then. We didn't used to get jobs or group homes. They started getting group homes when we started to say where we'd like to live. I've got my own house but some lived in the old institutions, others with their mothers, foster carers and like that, but they were mostly in these hostels. In the centres they used to play hell with you if did anything wrong. I used to take no notice of them but some used to cry. There was one girl called Julie, her and Mary got a house together, and there was one lad Pete and he was always picking on her. I told her that the more she took notice of him the more he could

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see that he was upsetting her, and the more he saw that he was upsetting her the more he'd do it.

Some staff were all right with you others weren't. If I was talking to one of the staff another one of the staff would come up and interrupt me. It was all right for them to interrupt us but if we did it, even if it was something important that we needed to say, even if we said excuse me, they'd say "we're talking it's ignorant to interrupt when we're talking". So once when I was talking to one of the staff another one of the staff, who always used to be interrupting, came up and started talking. I said "excuse me do you mind I'm talking - it's ignorant to interrupt when people are talking". Well he couldn't say anything because he was the one who'd said that to me the day before!

Also if we pushed in the queue for dinner the staff would send us to the back. One day one of the staff was at the front of the queue, I was watching him, and he was just about to push in so I went down to him. I told him that we had been waiting and he had only just come in. He said that he was talking to his mate but he had a plate in his hand. So I said "you won't be needing this then", took the plate off him and sent him to the back of the queue. Another time these two staff came into the games room and these two lads were playing table tennis. They couldn't play properly, they were quiet, they weren't bothering anybody and they were fair having fun playing their little game by themselves. Then one of the staff said, "right can we have a go now", and the lads gave them the bats and sat down. Anyway the next day me and this lass were on the table and these two staff came up and said "can we have a game?". I told them we were playing a game and that they could have a go after we'd finished. So they sat down and when we'd finished one game they got out their seats. But I made my friend play another game, and then another, and the staff were getting fair annoyed. They kept getting up every time they thought we'd finished and then sitting down again. I only did it to teach them a lesson. I kept my eye on the clock and we finished just before it was time to go back to our groups. I said "oh look at the time we'll have to stop, anyway it was good that" and they looked and went "tut". I was doing it so they wouldn't do it to other people. I said to them "it's how you ask, 'can I have a go' not 'can I have a go after you've finished please. You act like you do when you're telling people to do something - 'do that', not 'will you do that for me please'. You don't ask properly you frighten them, they give in to you. That's why I played Ping-Pong like that from side to side because I've seen you do it". One of them said "Oh, I thought I hadn't seen you playing Ping-Pong before" and I told them it was surprising what I can play when I have to! Since then they've asked if people can go to the shop, and asked if people can do this, and they've found them jobs.

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Starting People First

I've always stuck up for myself even before People First. I stare them in the eye as long as they stare me in the eye. I started our People First group. At the centre all week we used to go round every one in the centre asking if they had any news. There used to be six of us and we used to write down what people said : if they'd won at bingo, or been on holiday, got some new clothes, or had a fight with their husbands. We used to put it all down. Then on a Friday we used to read it out to one of the key workers and he used to take it home and type it up. He would give us all a page to read and then at dinner time it used to come over the loud speaker for everyone to hear. Once one of the staff had been on holiday and she'd bought some new thermal underwear and we put that over. Some of the staff said "oh let's have a look then!".

One day the centre manager showed me this leaflet he had. It was about people with learning difficulties, like advocacy groups and that. So I asked to have a look and saw the address of a group nearby. I decided to write to them and ask if they could help us. This chap got back in touch with me and I told him that we wanted to start a group. I asked him what they were called and he said that some were called People First groups, some were advocacy groups, but theirs was called a People First group. So we asked one of the staff if she'd do it with us and she said she'd be our advisor. Then we went and found the centre manager and he told me that there was a room at the COOP we could hire for meetings for four pounds. So I went and saw the manager there. I told him that we didn't get paid so he let us have it for free!

At first there were about ten members. I went round asking them all in the centre if they'd like to come. They didn't understand what I was talking about. I said that it was about being independent and sticking up for yourself. I only told them what this fella had told me. I said "it's about sticking up for your rights against these big-nobs who put you down, when they make you feel small you can make them feel small" - which I have done to a lot of them. That's why they never argue with me.

At the first meeting we were wondering what to do. At first people were nervous but they soon got into it. The advisor used to write down everything that had happened at the meeting, and there used to be so many that would go on a Tuesday night to arrange what kind of fund-raising we could do. It wasn't the big meeting it was a little group and we used to write letters to people and post them off and read other letters. When we started we used to ask for help from other groups. I suggested to the advisor one day that we should have someone to keep the group in order. So I was chairperson at the start.

On advisors

Our first advisor was one of the staff from the centre. She used to make us all feel nervous. We always used to be having five mile walks to raise money. I

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couldn't do it and a lot of others couldn't. So I started thinking of something we could all do like sponsored dominoes and I went and asked all the members if they'd do it and they said they would. So I told them to put their hands up when we voted for it at the next meeting. When it came to the next meeting I mentioned the sponsored dominoes but the advisor thought a walk would be better. "Hands up who agrees with me and hands up who agrees with Joyce" she said. She used to stick her hand up and look at them. Gradually she would stare at them and there was only me and another who didn't put our hands up. Then she said "so hands up who disagrees" and I said "well there aren't many more - you've frightened them all into putting their hands up. You frighten them into it instead of explaining, you just to take it all on your own. The group isn't for you, this is for people with learning difficulties, it isn't for your benefit so you can go on a walk, it's for what we can do". Every meeting we'd have an argument over something. She'd always be onto somebody and I'd be sticking up for them, telling her off. I got a card from her when she was on holiday and on it she said how sorry she was about one of the meetings and how it showed I could stick up for myself. I thought "aye, I wish a lot more would speak up".

She wanted it all her own way. She always wanted to be the top dog, she wanted the top job at work. She's left now and is the boss of a home. She got what she wanted. I think there's a problem with advisors who are staff because you see them every day. She was always watching you. It was like when people were shown round the centre and the manager would say "this is Joyce typing up wage slips", I said "I can't do it while people are watching I can feel you at the back of me". I think the members saw her first as a staff member. They thought if they said anything wrong she'd take it out on them at work. They found it very difficult to say yes and no. They agreed with her so she wouldn't play hell with them at work.

We like the advisor we've got at the moment. He doesn't tell us what to do, he'll tell us what he's found out but it's up to us whether we want it or not. We have hands up, whereas the other advisor would say "I think we should do this". Our advisor now lets everyone have a say. He wants everyone to have a part, something to do in People First, so that every one feels wanted. Whereas before there was only secretary which was me, treasurer which was me, and an advisor. Now we have lots of officers.

The advisor is there to explain things. People put letters complicated sometimes and we don't understand. They have all these long words so I fold it up and put it away until the advisor comes and we ask him to explain it. The members run the group and they ask the advisor to find out things. If I thought the advisor were taking over, I'd tell him that I don't want him to take over because it's our group. It goes on what we want and say. If you can find out anything we'll listen to you, but it's up to us - you don't do it on your own. Now with England People First they'd already decided and voted themselves in in Canada and the advisors are

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taking over. England People First should be run by people with learning difficulties with people helping them, advising them, like our advisor's helping us, but they should have the last say what should be done, not the advisors. If it was run by a person with learning difficulties then they'd get more people helping them. But they were doing it and not letting people know what was being said. If you can't read then you should have pictures, like with our feedbacks from the meetings. But with England People First we never heard a word from them. I think they could do a lot for us, get to know a lot of things for us, but if they'd only just do the feedbacks. Not all of us can go to meetings.

Conferences

The first conference I spoke at I was scared stiff. I asked the advisor to write me something down to say, I had two or three pages of notes. It was at a University. They were students and they wanted to know about people with learning difficulties because they were going to be social workers. I went in and they were all looking. There was like a big room and I went up to the front, looked down at my notes and then looked up again, and then when I looked down again I'd lost me blummin' place! I thought "flippin' find it", so I told everyone "I'm sorry but I've lost my place. That's that then, terrible writer!". Well they all burst out laughing and when they did that I felt a bit of confidence. Then I just said what I felt, what came out of inside, not what the advisor wanted to say but what I wanted to say. So I chucked away the notes that she had written and everybody laughed and clapped and I just started saying what I thought. I said "people with learning difficulties won't bite you they're just human beings like yourselves". They all came up to afterwards and said they'd fair enjoyed my speech and wanted to know how I did it without any paper. When I was leaving someone gave me a bag of money, they'd had a collection for me they'd enjoyed it so much.

At the 1993 International Conference in Canada, the Canadians sent all the advisors out. They said "if you're not a person with learning difficulties you're to go out". Then one got up on stage and he had been falling out with his girlfriend and it had upset him but he was talking rubbish. He was going on because he didn't have his advisor with him. As long as they see the advisor they're not frightened to say anything, when they're put on their own they lose all confidence.

Asking people with learning difficulties

I got asked to do a book. This researcher told me I'd get a thousand pounds afterwards. At first I said that I was too busy but I thought about it, spoke to a few friends and decided to do it. It lasted for three weeks and there were two of us with learning difficulties. We interviewed people one by one in their houses and

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asked them about their experiences. How they liked it, whether they chose the home, chose the furniture and everything, whether they had a say in anything. That was the first time that anything like that had been done by people with learning difficulties. I asked if they had had a say in the house but they hadn't. People with learning difficulties were not being given a say in their lives

I told the centre staff that when we get a new keyworker we should be allowed to sit in and pick one we like. Because its us who have got to live with it. People might not like such 'n' such a person whereas they might take to someone straight away. Nothing has come of it. The Centre staff said they were going to break us all up and put so many of us into one centre and others into another. They asked us what we thought about it and at first I thought it wasn't a good idea, because people have just learnt how to go on the bus themselves, how to do new jobs, and now we are just having to go back to the beginning. I mean for a start you'll have to show them all again where to catch the bus from. I told them its not on, it's not fair. Not only that, we've been with one another all these years, we don't want to go and meet some new people we don't know. We're always the last to know when we should be the first to know. It's our lives not theirs. You must ask us what we want , some people are asked but there's still a long way to go.

Talking properly

There's still people who use the word mental handicap and if I hear them I'll pull them up about it. Even if I'm at a conference or a meeting and they use *that word* I'll say " do you mind not using that word. Next time you come to it can you use 'learning difficulties' please". Learning disabilities - I don't like that, disability makes you believe that we are in wheel chairs and we can't do anything for ourselves, when we can. We've got jobs now, we've got paid jobs. Like I said when I made that first speech we've all got learning difficulties. I said to everyone you have, you have, you have. You talk posh and all that, it's all right all these big words but you want to say what you mean and talk proper English. Can't people talk proper English?

People have got a learning difficulty in anything they do. If mine wasn't epilepsy it might be arthritis or I might be really slow at reading, slow at writing, you don't know. Men wouldn't like to do a woman's work they'd find it hard. Groups of kids, when we were going for our buses, they used to say "Oh look they're mental", I used to be bloody heart broken. "Crackers", "are you going back home", "is your green bus waiting for you?" It used to fair upset my friends and I told them once "just walk straight pass, they used to say it to me, but they don't now because I walk straight pass them".

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People First teaches you how to stick up for yourself and we do, you don't hear half as many people calling us now. One time Me and two friends were having a drink in a café. We were just sat talking, having our drink waiting for the bus and there were these two lads and these two lasses. They just kept looking at us grinning. I noticed them and the girlfriends started saying to the lads "shhh" but they kept on looking and laughing. So I said to my friends "come on let's sit over there I don't like sitting where babies are, lets have a proper grown up talk". And they looked at us, I just looked at them, they looked, I looked, and one of the lads' girlfriends said "come on Jean they're showing us up" and they just walked out!

I don't know why people say those things. They either see it on the telly or they here their mothers say something like "don't go near that". Because there used to be some houses for people with learning difficulties and no one would live near them. The TV sometimes has people with learning difficulties on and sometimes it has people who act you funny, and these men go and knock him about and his brother or father will come up and look after him. I think it frightens people. This woman had put in the local paper "mentally handicapped are simple and happy people". I read it and thought the cheeky so-and-so. There was a meeting about it and I went up to her and said "what do you think about what they put in the paper". I didn't let her know that I knew she had written it. She said "Oh I don't know I'll have to go I've got another meeting". After a few times of me asking and her refusing to answer me I followed her down the steps and I said "Excuse me but do you think it's right because I'm one of your simple happy people". I said "I'm not always happy and I'm not simple, some of you lot might be by thinking that". I told her that we all have our off days and we're happy other days. I think people with learning difficulties should be on the TV or in the newspaper to make a speech talking grown up, telling others what we do.

Once when I was talking to students I said " you want to come and see some of them working in the centre and I bet they'd have to teach you how to do it". Because we were making masks and you used to have two little buckles, some elastic, you used to have to cut the elastic, thread it through, then put a mask on, so it could go just over your head. And I told those students "I bet you'd get mixed up doing them buckles. Come and try and do our work and you'll soon find out if you've got a learning difficulty or not".

I think if you talk to people properly, not baby talk, I think people understand. There was this girl with learning difficulties in the café of the bus station. They'd let her out and she was crying. She said that she'd lost her way home and didn't know which bus to catch. I asked her where she had come from and she told me, and I said "oh dear love don't cry". So I went and told the woman at the counter to phone up for a bus or an ambulance. I sat with her until they came, telling her about myself. She was fair sobbing away but as she listened to me she forgot

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about it. I missed two buses! Eventually a woman from her home turned up and said "come on love" and as soon as she saw her she wasn't frightened anymore

Two or three meetings where I've gone and spoke and I've made centre managers look small and there's been folk who talk posh I've said "can you tell us what you mean instead of using these big words?". It was the same when I spoke about sex at a university, and this chap said to me "you come straight out with it". The younger they tell people with learning difficulties about things like that the better. Because the father might do something to them and tell them they're good girls but not to tell their Mams because it's 'their secret'. The staff could do it, in these homes, and tell them they're good and they wouldn't know any different. A woman in the centre came to me and said "I'm pregnant Joyce". I said "what are you talking about?" and she said "well Andrew kissed me". So I said "yes go on", and she said that her boyfriend had kissed her so she would be pregnant. I said "you're pregnant because he kissed you? Who told you that?" and it was her mother. She were fair frightened and she's forty something years old. I said "well if you get pregnant like that then I must have a load of children all over the place!". I asked her if she kissed her mother good night, which she did, and said "next time tell her you can't because you might get pregnant". Then I sat down and I told her the facts of life, she was surprised.

Reflecting on People First

I used to be right quiet. When I say that I used to be right quiet and frightened, you know when I was a child, that my brother used to stick up for me, people don't believe it. Oh I wish I'd have known about People First when I was young. Oh I wish I had, I wish I'd have known then. I mean the nurses at the boarding school used to tell us to stick up for ourselves. We need People First for when younger babies come into the world that have got a learning difficulty then they won't be frightened of speaking up for themselves. They've heard of us and they won't be frightened. We've stuck up for ourselves and you can. Babies who haven't been born yet or who have just been born when they grow up and they're frightened of speaking up they can join a People First group and it'll teach them about independence and how to stick up for yourself. Like I said to the centre manager "is there a People First in our town?" - he said "no" and I told him "well there is now!". People First is getting stronger every year. More and more people with learning difficulties are sticking up for themselves. All these books are coming out showing what we have done, how we've got on and put people down. They'll be frightened, raise your voice and not be frightened of them and stick up for yourself.

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Appendix 3. 6 : Details of access negotiated with top self-advocates

In October 1995 I wrote to **Lloyd Page**. He replied soon after telling me how interested he was in my research and how happy he would be to talk. I was told to meet him at his group's office where we would then go on to his home. His mum would be cooking tea. Lloyd did make a point about my use of the word 'thesis' being a "jargon word". His own involvement with many research projects meant that he was familiar with the notion of research. I also gave a copy of my research introduction to Lloyd's mother. She read it briefly without commenting. When I first spoke to **Jackie Downer** on the telephone she was sceptical of my research. She insisted that my research should not be yet another case of the researcher "getting a book out of other people's experiences" when so often they "get left on the shelf". She wanted to know what self-advocates would get out of the research - something to which we would come back to in our meeting. I told her my plans to produce a report accessible to self-advocates. We agreed to meet up soon afterwards in late 1995.

I originally wrote to **Phillip Collymore's** self-advocacy group with the aims of talking to a well-renowned senior member. The group had recently filmed a video on self-advocacy and are staunch supporters of moves towards a national movement. I received a letter from the group some weeks later (see Appendix 3, 4), written by a support worker, offering two volunteers. As it turned out Phillip was the most easily available to meet up and a time was arranged in mid 1996. I wrote to **Anya Souza** early in the new year of 1996 and received a letter from her soon afterwards. In it she started to tell me about the conferences she had attended, problems with the self-advocacy group she was involved in and her anger at the treatment she and others with Down's Syndrome have received. She gave me dates which would suit her and after a telephone conversation we arranged to meet in late January.

In contrast to the other informants, at the time of our interview (November 1995) I had known **Joyce Kershaw** for about six months, through my involvement as volunteer in her self-advocacy group. After one of the meetings I briefly mentioned to Joyce my interest in her experiences as a self-advocate and asked if I could give her a ring later in the week to talk some more. We arranged to meet up after her group's next meeting, made our way to a near-by cafe, and went through my introductory handout together.

Appendix 3, 7 : Details of meetings & interviews with top self-advocates

Lloyd and I met up around lunch-time and made our way to the train station. He said a number of times how happy he was to see me and thanked me for coming down. I reiterated to him throughout the journey how I should be the one thanking him for his time in talking to me. He asked if I could help his work by sending him addresses of Universities that might be interested in the new course that he is involved in preparing. I said that I would be happy to do so. On the train Lloyd made the ideal guide, pointing out various local landmarks out of the window of the train. We eventually got to Lloyd's house where his mother and 15 month old nephew were waiting. His mother welcomed me in and we all sat in the living room. The dining room was arranged for the tea, Lloyd's bedroom was full to over-flowing with People First material, so we had the interview in the living room. With his nephew being present Lloyd's mother was quite preoccupied although she did take part in the interview. The interview was fairly formal, and we chatted for a good hour and a half. In it, he showed me photographs, mementoes he'd picked up on his travels and various leaflets advertising projects he is involved in. I got the impression Lloyd had had enough when he put on a Walt Disney film he had just bought. As the tape was switched off the interview ended and we soon went into the dining room for tea. An hour later I thanked Lloyd and his mother for making me welcome and left to catch my train.

Jackie and I conducted the interview in the local Pizza Hut near to her work. I was to later find out that Jackie has a lot of her meetings here - she was due to meet with someone else later that day. I had been waiting for about 15 minutes before she turned up. She eyed me sitting by the door and asked my name. Confidently poised she directed me to the table she normally sits at. On first name terms with the waiters and waitresses, Jackie organised our food and we got down to the necessary business of eating, conversation flowing over the next two or so hours.

Anya asked me to meet her at home. I got there on a fresh winter morning. I rang the buzzer on the main door and she shouted to me to come up. Her door was already open and she welcomed me in as applied the finishing touches to her lipstick. Her boyfriend Paul was present and we shook hands on the landing whilst Anya made the coffee. He left soon afterwards and for the next four hours Anya and I were engrossed in conversation. I had posted down the introduction of my research though it was a good half hour before we got down to any serious 'formal' interview. From the moment empty coffee cups were placed down on the table before us, we got to work. Anya was especially humorous and has an incredibly infectious laugh. We looked at photographs, discussed documents from her last self-advocacy groups and finished many

cups of coffee. Listening to the tape later on, you could tell we got on. I had a good time.

In May 1996 I met up with **Phillip** in the offices of his group. The support worker, 'Murial' was already present and we spent about an hour together chatting before Phillip turned up. He apologised for being late, he'd slept in. I thanked him for giving up his time. Phillip had a lot to say, much of it traumatic. I was left feeling what a strong character he is to have come out of such a dysfunctional transition from childhood to adulthood. Here, as with all the self-advocates was a person who had couched out a sense of self in the face of such atrocities which he faced. He was a survivor not only of sexual abuse but of the everyday experiences of discrimination he faces as an Irishman and a person with learning difficulties. Though these experiences were daunting he has lost none of his sense of humour. The support worker was present throughout and only had some minimal input.

Over egg and chips in a local cafe **Joyce** started to tell me about her life. She observed my chain-smoking and advised me to give up - she had and she'd been a heavy smoker for years. The cafe was empty apart from one couple sat nearby. They looked over in a puzzled manner at the tape-recorder which was placed on the table between Joyce and I. After about an hour and a half and numerous cups of tea and coffee we got the bus up to her house. Back at her home we sat in the kitchen, I put the kettle on. She had brought along a copy of a book in which one chapter summarised the study she had co-researcher. She said I could borrow it. Joyce was proud to have her name to her story and understood other names would be changed. For the next three hours Joyce continued to present her life history from childhood to the present day.

Other Issues

About research applications and dissemination of findings, **Jackie** pressed me a number of times, both in our initial telephone conversation and throughout our meetings. I was told to consider my role as a white, able-bodied male researcher and the effects this could have on my understandings of the stories that I obtain. She suggested that I should involve people with learning difficulties as co-researchers. **Phillip** insisted that I should listen to and write up his experiences of abuse. "I want people to hear" he told me. He arrived to the interview later than we had planned to do so and ended it when he'd had enough - "you've talked it all out of me". **Anya** moved attention away from my probes about her self-advocacy experiences to talk about other issues of significance to her. While I was wary of imposing my own framework on the interview, I found I often had to wrestle my way into conversations, to ask questions I wanted to ask! Many times I interrupted **Joyce** with a question, she would ignore it, continue with her anecdote and come back to my query later if she so-wished. Here was not a passive informant responding affirmatively to prods and inquisitions. The power of the informant was less so, perhaps, with **Lloyd Page**. Although he disclosed a number of experiences he undoubtedly considered as significant, I think I could have helped him a bit more, by being patient. Whereas some would put down his stifled responses to impairment, an honest appraisal would put it down to researcher inexperience.

Section 4 – Ethnography Appendices

Appendix 4.1. Introductory handout to gain access to groups

The University of Sheffield



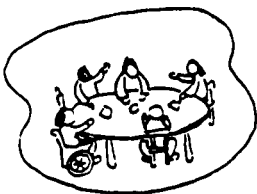
Department of Sociological Studies

Elmfield, Northumberland Road, Sheffield S10 2TU, UK

Tel: 0114 282 6321
Fax: 0114 276 8126

Chair of Department: Alan Walker, D.Litt., FRSA, Professor of Social Policy
Deputy Chair: David Phillips, M.Phil., Senior Lecturer in Social Policy

Danny Goodley
PhD Research Student
University of Sheffield



Finding out about self-advocacy



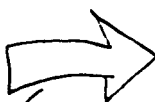
I am a research student at the University of Sheffield. A year ago I was lucky enough to get some money from the University to help support my study. My study will look at the **self-advocacy movement** in Great Britain.



I am going to write a 'thesis' (report) on self-advocacy.



In two years time this thesis will be marked by examiners. If the examiners feel that it is good enough (and I hope they do) then I will be awarded the qualification of 'PhD' by the University of Sheffield.

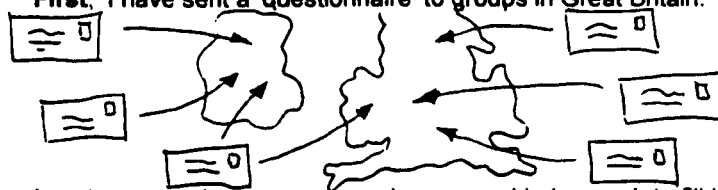


(HOPEFULLY!)



To help me understand self-advocacy and write my 'thesis' I have done a number of things.

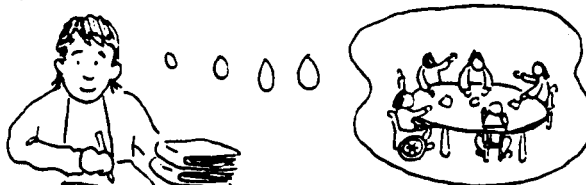
First, I have sent a 'questionnaire' to groups in Great Britain.



I sent a survey to your group and you were kind enough to fill it in and send it back to me



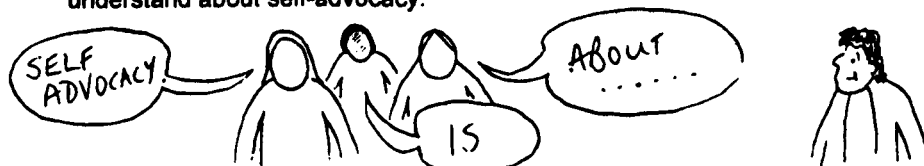
When I get all the surveys back from groups, I will be able to see what groups are like in Great Britain. I will write about the findings in my thesis.



Second, I am going to visit a small number of groups to see how self-advocacy works. I will be talking to self-advocates and supporters in these groups.



This is why I would like to visit your group. I would like to chat with self-advocates and supporters in your group - so that you can help me understand about self-advocacy.



c:\field\intro2.doc

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I will meet a number of groups and will write about these visits in my report.



Because other people will be reading my report I will change the names of groups, places and people mentioned:

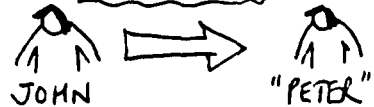
In the report I will not give the names of the groups I visit.



I will not say in which town the groups are.



I will not give names, self-advocates supporters and others.



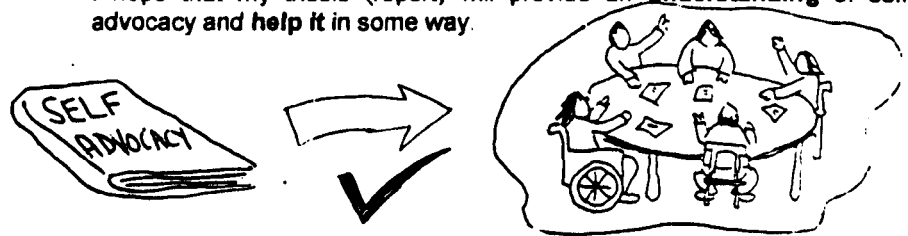
By writing about the groups I visit I hope that people who read my report will get to understand what self-advocacy groups are about.



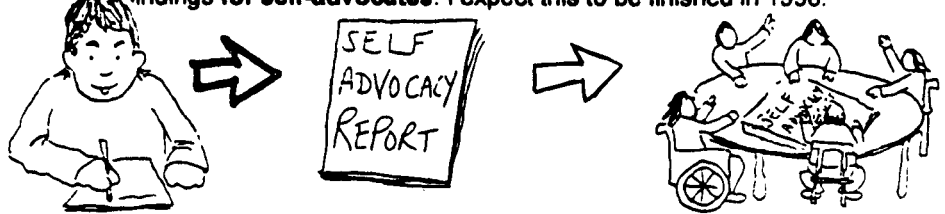
My thesis will be handed into the University of Sheffield in 1997.



I hope that my thesis (report) will provide an **understanding** of self-advocacy and **help** it in some way.



After I have finished writing the thesis I hope to write another **report** of my findings for **self-advocates**. I expect this to be finished in 1998.

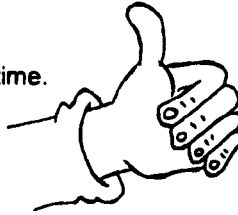


If you do agree to let me visit your group then you will be **helping me** to write my thesis.

But I **aim** and **hope** to make sure that **self-advocacy** is helped in some (small) way by my work.

Thankyou for your time.

Danny Goodley



THANKS!

Appendix 4. 2. Introductory handout for group discussions

The University of Sheffield

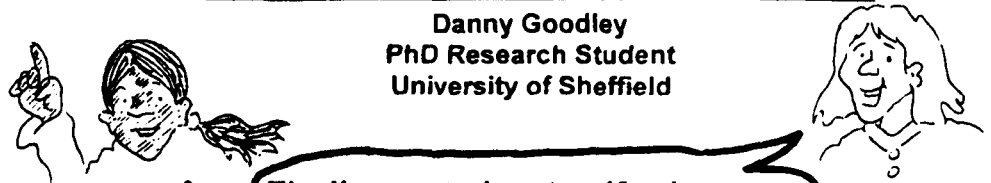


Department of Sociological Studies
Elmfield, Northumberland Road, Sheffield S10 2TU, UK

Tel: 0114 282 6321
Fax: 0114 276 8125

Chair of Department: *Alan Walker, D.Litt., FRSA, Professor of Social Policy*
Deputy Chair: *David Phillips, M.Phil., Senior Lecturer in Social Policy*

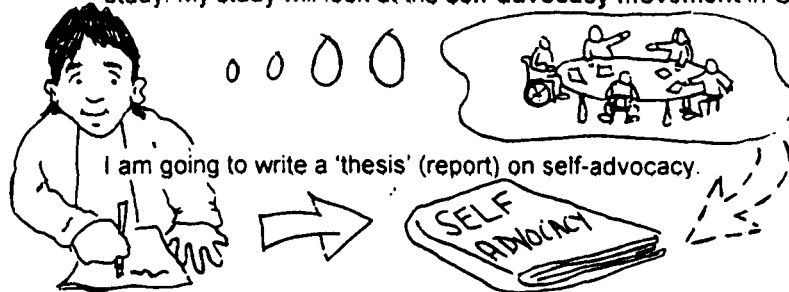
Danny Goodley
PhD Research Student
University of Sheffield



Finding out about self-advocacy Your Group

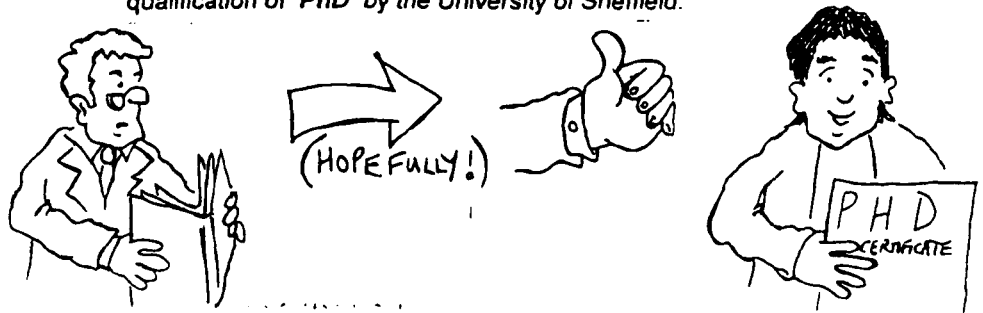


I am a research student at the University of Sheffield. A year ago I was lucky enough to get some money from the University to help support my study. My study will look at the **self-advocacy** movement in Great Britain.



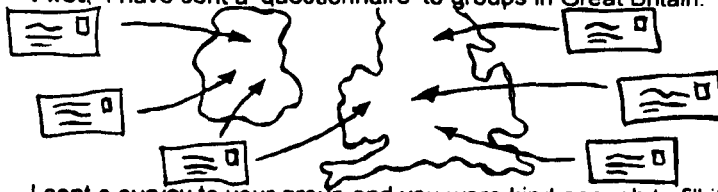
I am going to write a 'thesis' (report) on self-advocacy.

In two years time this thesis will be marked by examiners. If the examiners feel that it is good enough (and I hope they do) then I will be awarded the qualification of 'PhD' by the University of Sheffield.



To help me understand self-advocacy and write my 'thesis' I have done a number of things.

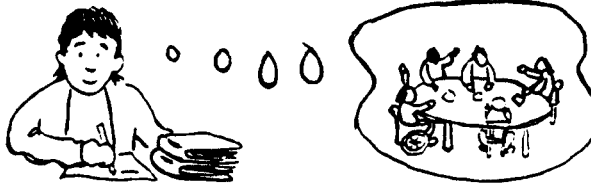
First, I have sent a 'questionnaire' to groups in Great Britain.



I sent a survey to your group and you were kind enough to fill it in and send it back to me



When I get all the surveys back from groups, I will be able to see what groups are like in Great Britain. I will write about the findings in my thesis.



Second, I am visiting a small number of groups, including your group, to see how self-advocacy works



I will be talking to self-advocates and supporters in these groups - to help me understand about self-advocacy.



Third, I want to **speak to self-advocates in these groups** - this is where your group comes in.

You! 



I would like to hear what you **all** have to say about being in your group



If you do not object I will **tape-record** our chat.



SPEAKING OUT...

When you have spoken to me I will write this up in my thesis



Because other people will be reading what you say I will **change the names of people and places.**

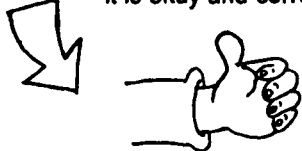


I will send you a copy of what you all said. You can check if it is okay and correct.



MY FRIEND

MY FRIEND

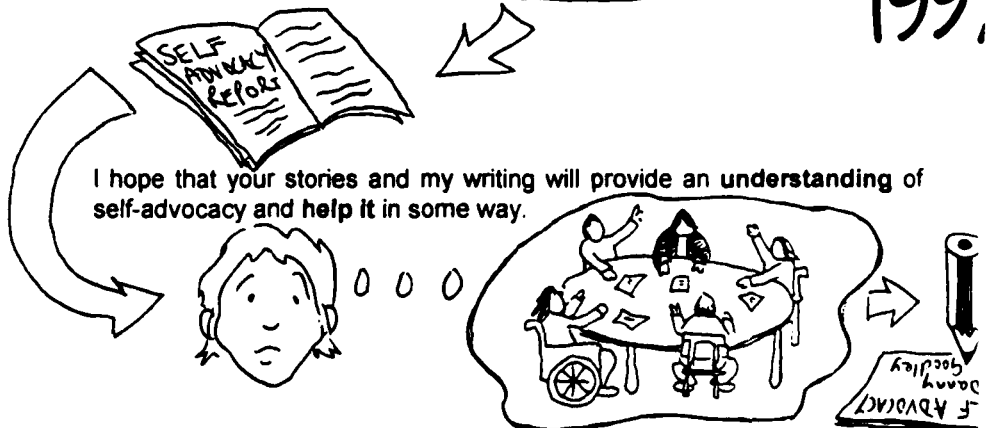


If you agree I will then include it in my thesis.

My thesis will be handed into the University of Sheffield in 1997.

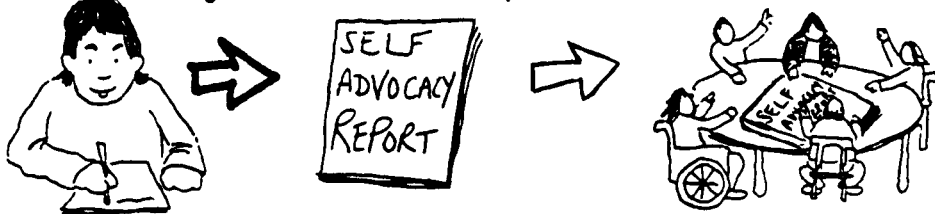


I expect some of my thesis to be published



I hope that your stories and my writing will provide an understanding of self-advocacy and help it in some way.

After I have finished writing the thesis I hope to write a report of my findings for self-advocates. I expect this to be finished in 1998.

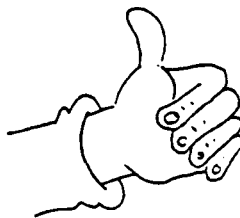


If you do agree to share your story then you will be helping me in a big way as your story will help me write my thesis.

But I aim and hope to make sure that self-advocacy is helped in some (small) way by my work.

Thankyou for your time.

Danny Goodley



THANKS

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4

Appendix 4.3. Group Discussion Prompts - 'So what do you get out of self-advocacy?'

Starting off

Where did you hear about the group? Who told you about the group? How did you find out?

How did you get involved with the group?

What was it like the first time you came along to meetings / to the group?

The things the group has done

What events or activities has the group been involved in?

Any meetings with staff / centre manager / parents?

Complaints about things?

Training / social events / trips away

Conferences - international / national / local.

The meaning of the group and self-advocacy

Why do you come to the group?

What does speaking up / self-advocacy mean to you?

How has it affected you?

Why do you like being in the group?

What would you say to others that might want to get involved?

What advice would you give other people with learning difficulties if they were thinking about getting involved with your group / self-advocacy (speaking out)?

Friends and family

What do your friends and family think about you being in People First?

What did they say when you first became involved?

Do your friends and family understand / encourage 'speaking out'?

The role of supporters / advisors

What is the role of the advisor in the group?

Do supporters have a say in the running of the group?

Is the supporter paid? Is this okay?

Should supporters be members of staff or independent?

The meaning of self-advocacy

Future of individuals and the group

How do you see the future?

What are your ambitions? Group ambitions?

How do you see the group in the future?

How can groups in general develop in the future?

Appendix 4.4. In-depth introduction to research (for *Advocacy Supported* group)

- Interested in Speaking Out groups or self-advocacy groups - I am sitting in four different groups
- Sitting in groups to get a picture of Speaking out groups in action
- Like to sit in this group - until September if that is okay with you
- By sitting in this group will help me write a report which will allow others to see what self-advocacy is all about:
 - what speak out groups talk about
 - what things get changed - like the car parking that you mentioned
 - what people with learning difficulties can get out of speak out groups
- People who read about your group will understand what speaking out is all about
- Feedback my findings to the group and also write a report - use pictures so people who cannot read can understand
- Confidential - all names will be changed, the group, people's names

c:\field\h&dintro.doc

Appendix 4. 5. General Correspondence with Groups

Master Letter for groups to accompany *Group Discussion Feedback reports*

Dear *Social / Centre / Advocacy group*

Here is the **discussion report** that I promised you. I have put down what you all said about being in the group. I hope you like it and make use of it in the future. Also you will find another report I have written about **voting**. Members of the group that I support were interested in the next general election. However some had never voted and did not know how to. I wrote this report for them and they have told me that they think it is useful. I hope that you also like it. Any comments you have - I would like to hear. I hope we can keep in touch. In the meantime take care of yourselves and keep speaking up.

(No written reply from social / centre groups)

Reply *Advocacy Supported Group* -----

Dear Danny,

November 1996

The group has asked me to thank you for copies of the discussion report. They had a couple of comments which I have written on the enclosed copy. Guy wanted confirmation that you will change the names of the group when the report is published. He also wanted you to have a copy of the minutes he produced, Best wishes,
John.

My Reply *following changes made to report* -----

Dear Advocacy-Supported group,

January 1997

Thank you very much for sending back discussion report with the changes you asked me to make. Enclosed with this letter is the new-improved version whihc I hope you prefer. Can I just take this chance to assure you that ***all names will be changed*** when it comes to writing up my report. So no one will be able to identify the group or any of you the members.

Thanks again for sparing your time with me last year. Happy New Year for 1997

Best wishes Danny

Letter accompanying feedback report for *The Independent Group*

Dear Robert (chairperson)
1996

July

Please find enclosed with this letter the following:

- A report for the group entitled : '**The Independent Group : what members get out of being in a self-advocacy group**'. This is basically what people said at the group discussion on ----- July which I have typed up to form the report. I hope that you find it useful and pass it on to other members.
- **Feedback of comments from 'Do it Now' and Blaketon College** who I spoke to on the phone. As you will see the comments are very positive indeed.

I have now completed the 'evaluation report' for the County Council. In it I have fed-back *some* of the comments that were made at the meeting. Please note that unlike your report, I have *changed all names* in the Council's evaluation report. So they will not not know who said what! Also some comments that members made have not been included and the reasons for this we can talk about when we next meet (although I have mentioned to Norma why certain comments were left out). Finally the feedback that the group got from 'Do it Now' and Blaketon College has been included in the report.

Hope this is clear if you have any questions give me a ring. Best wishes to you and all the group,
Danny.

Reply from Independent group-----

The Independent Group
Dear Danny,

August 1996

Thank you for your reports, it was very helpful and useful as we can use it for other things. We are having our AGM on the ----- at Blaketon library and you are welcome to come. The times of the AGM runs from 11am to 3pm. Please let us know in advance if you want to come. You

are also welcome to come to group meetings but please let us know beforehand that you are coming. With best wishes

Yours sincerely
The Independent Group.

Other correspondence

Letter of Apology to Centre Group ----- 26th April 1996

Dear Centre group,

Many apologies for having to call off our meeting on the 3rd May. The reason I cannot come that day is because another self-advocacy group that I am meeting with are moving offices. I will be helping them move their stuff to their new premises.

If you the group decide it is okay I will come down on the 17th May. Again my apologies for being absent and I look forward to seeing you all on the 17th.

Best Wishes Danny.

Follow Up letter to groups April 1997 -----

Dear *Social / Centre / Advocacy / Independent group*

Just a short letter to say hello! I am writing up my findings at the moment and having a great time remembering my time sitting in your group. I hope to finish writing up my report in August and hopefully get my qualification of 'PhD'.

Once again thanks for the time that you gave me in 1995 - 1996, I really enjoyed it. Take care and best wishes to you all
Dan Goodley

Reply from centre group -----

The Centre group April 1997

Hi Danny,

Thank you for your letter. We hope you are well. We have a new advisor now his name is ----- He works at the centre and should as well. Hope you come and see us soon. (S.Z)

Love from

{Signatures of each group members}

The Centre group

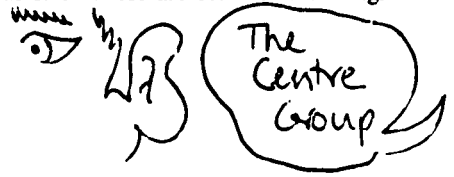
Appendix 4.6. Group Discussion Feedback report (Centre group)

What members get out of being in a self-advocacy group

Some members of *the Centre group* had a discussion about the group in August 1996. Danny Goodley wrote down what was said. These are some of the things members said.

- **The beginnings of the group**

How people heard about the group



Simon : Somebody asked me about it ... the centre manager mentioned it to me and the last advisor we had she told me about the group.

David : The manager asked me and I got voted in by the users. That took place in the dining hall. There were photos of each candidate and they put their vote in a box.

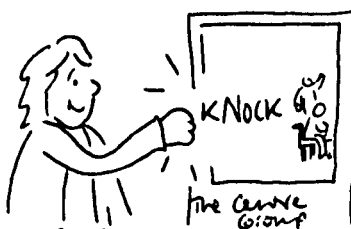
Lesley : I got voted in - it depended on the amount of votes you got.

Paul : I started the group with the last advisor. It was nice from the start.

Carol & Sally : We were voted in.

Stan : I used to walk past the room and see the group inside. I asked Lesley "what's the group about?" and she said it was the user group. I started to come along a bit after that.

What it was like at the start?



Simon : It was nerve-wracking at first but I got more confident as time went on.

Sally & Carol : It was fine from the start.

Paul : I started the group when we had the last advisor. It was quite nice at the start. I stayed behind for a staff meeting. We used to do role plays and learn Makaton. I quite enjoyed it.

Lesley : We used to do role plays, all different ones. I had to chair the meeting, had to open it. Someone helps me to write down the agenda, because I'm a non-reader. Since I've joined its progressed

• Activities and events - 'things the group has done'

Learning new things & helping others



David : Learn how to do Makaton. We wrote a book about abuse. Learn how to ask others for help. We make posters and put them on the wall. We also get trainees together to talk about their problems.

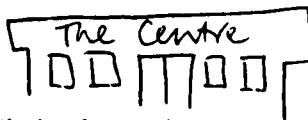
Simon : We tape-record our meetings.

Lesley : If anyone has problems they can come to the user group - like bullying, special diets for those with illnesses.

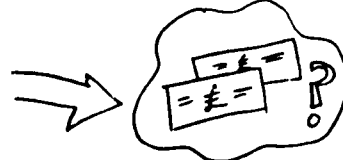
"they come to us if they have problems - they know what we're about".

"People ask about the meetings. We can help other people around the centre. We are going to have badges made so people know who we are".





Things to do with the day centre



Lesley : Leaflets were sent out to all the key-worker groups so they could decide what they wanted to eat at the Christmas meal. They had to tick which dinner they wanted. It's helping others to have a choice.

Carol : We help other users with special needs - the befriending scheme. I've also helped with security - make sure that we look after our things, so they can be locked up.

"We put together fund-raising ideas for the centre - like sponsored walking, car wash, organise events".

Being in the group seems to be about helping yourself and others

• The meaning of the group and speaking out

Why people come to the group



Lesley : I enjoy coming along - it's really good. My role is really good. I chair the meeting, anything the group wants to talk about I write it down.

Carol : To talk with friends. It lets you speak up.

Paul : It's interesting. You're with all your friends, any problems you have you can talk it over with the group and sort it out.

David : It's interesting - we made a book about abuse, you meet your friends. When you want to speak you put your hand up.

Simon : To help people if they have any problems. I enjoy coming along. Speaking up for yourself.



Stan : I like coming it's more fun, good to hear people what they're saying, you can have a cup of tea.

Sally : I like the group.

A place to talk



"Sometimes you can't tell people about problems. It made me feel lousy, I couldn't speak to other trainees. You can here".

Lesley : If its private you can't tell anybody else but you can say it in the group. We have a rule where anything you say stays in the room.

David : If you have a problem yourself you can tell the group. If you're in trouble you can tell the other people in the group. The group is fun, it's like a party.

What 'speaking out' means

Lesley : Speaking up for your rights. Speaking up for others who can't speak. It's difficult for shy people. You need to listen to what they say

Simon : Speaking out for yourself - help others to speak out for them - what they want.

David : Helps you listen, after all they listen to you.

Paul : Being assertive - they listen to you.

Carol : It's great.

Paul : being assertive.

Stan : It's good to speak to staff and trainees.

Sally : speaking up is good.



Helping yourself and others



Lesley : Other trainees get something out of the group. We can help others - find out what is wrong and how we can help them. It's great for me - if it wasn't for the other members I don't know where I'd be. The group helps you a lot.

Stan : The group is great. We try to stop people being violent.

Carol : The group helps me to speak up.

David : It helps you understand not to be rude, be more friendly.

Paul : It's made me more confident. I used to be shy and its got me out of me shyness. Yeah. I used to be shy at one time.

Sally : Sitting in the group helps.

• About the advisor - Louise



What advisors should be like

Simon : They start off the group. They support but do not run the group. Goes through things with you.

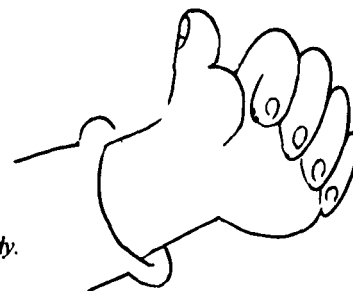
Sally : They make the tea and coffee.

Paul : Someone to turn to for advice.

"Remind people of things"

David : Help you to speak to others

Paul : Someone who gets on with everybody.



The members said the following about Louise



Carol : She's all right - she's coping!

Stan : Very good, she listens to what you have to say and helps you out.

Carol : She's fine, she's helping. She helps me to read, writes the poster, got pictures for a poster so I could colour it in.

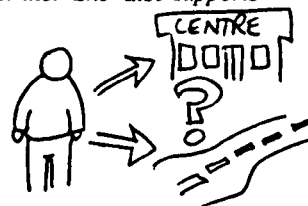
Paul : Doing a good job, quite good, can have fun. She gives advice if problems with anything.

David : Very good. If anyone is falling out she sorts it out. Makes us friends again. Helps us out with things.

Simon : She's very good at helping you with your relationships. She's a good friend. Takes you out sometimes and offers support.

Lesley : She helps me a lot, because he knows I have difficulties with my befriender. I have to give her up and I don't want to. I couldn't handle it. So I saw Louise and she said he'd have a word for me. She also supports me to write.

Independent supporters or staff from centres?



Simon : Staff are there to help you.

David : Staff understand you, how you talk. I'd be frightened to talk to a stranger.

Paul : We've had outsiders before. Now Louise is part of the staff, but it's easier to talk to some of the staff than it is outsiders.

Carol : Staff are better.

David : Staff are there if you want them, can go up to them and they can intervene.

Lesley : We had an independent advisor, she turned up one week and didn't come the next.

What the advisor Louise says:



The group was well organised before I started. It was already running smoothly. I can bring the staff side in but I don't have to butt in much. At the end of the day we 'gel'. Mind you it does help having a supportive centre manager.

• **Advice to others thinking about starting up a self-advocacy group**

Lesley : If they would like to see us then they should come along.

"You should have user groups"

Simon : I would help them

David : It's good to go to other centres.

The group agreed that users of centres should "go for it".



Finally **Danny** would like to say :



"The centre group is brilliant. Everyone helps one another out and you are not afraid to speak up. Keep speaking out for yourself. I have really enjoyed coming along to meetings. Thank you very, very much for letting me sit-in".

Appendix 4.7. Group Discussion Feedback report (Social group)

What members get out of being in a self-advocacy group

Some members of *The 'Social Group'* had a discussion about the group in October 1996. Danny Goodley wrote down what was said. These are some of the things members said.

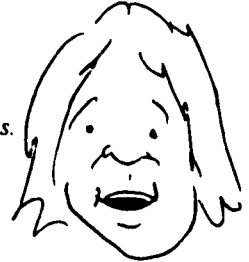
- **The meaning of the group and speaking out**



Why people come to the group

Karen : It's something to do - gets you out of the house.

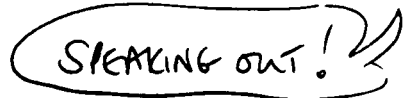
Ken : You can have a drink and talk about your problems.



Chris : To hear what others have to say.

Jarrod : I like it a lot. I like meeting people.

Andrew : Oh I like it a lot.



At *The 'Social Group'* you have a chance to talk, meet others and have a pint.

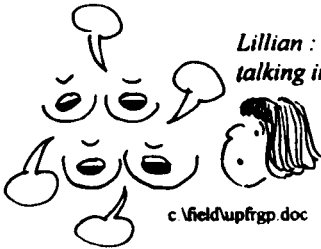


Sarb feels that the group could be better:

Sarb : I like coming but others talk rubbish. It's not a proper meeting. It would be better if people weren't shouting all the time.

Lillian finds it difficult to speak in a group:

Lillian : I like it a bit, not a lot. I can't get a word in edgeways. Its stressful talking in the group. I prefer talking to the advisor in the breaktime.



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1

Helping yourself and others



Chris : I like coming and hearing what other people have to say. I don't like bad-tempered people though.

Ken : You can explain your problems and speaking out helps you. It's very good.

Karen: Sometimes it helps, sometimes it doesn't - you can talk to people when you are stressed, away from the home.

Karen : You get to see good-looking men!



Jarrold : People make you laugh.

The group is:

comfortable.



fun
HA HA (smiling face) HA HA

a place away from home and the centre to talk
(an independent place)



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Finally **Danny** would like to say :

“The ‘Social Group’ group is great. Everyone helps one another out and you are not afraid to speak up. Keep speaking out for yourself. I have really enjoyed coming along to meetings. Thank you very, very much for letting me sit-in”.

Thanks
Danny



Appendix 4.8. Group Discussion Feedback report (Advocacy supported group)

(NB: CHANGES MADE BY GROUP LIKE SO)

What members get out of being in a self-advocacy group

Some members of the *Advocacy-supported group* had a discussion about their group in October 1996. Danny Goodley wrote down what was said. These are some of the things members said.

• The meaning of the group and speaking out



Why people come to the group

Bill : Talk about different things. Get people to help you.

Graham : It enables me to talk about my problems and to listen to other people's problems.

Guy : I like it because it gets you out the house. You can come here rather than be sat at home watching TV. I like new challenges. The group gives me a new challenge and responsibilities - like being the treasurer. It's made me realise what the treasurer's job is all about.



Rudi : I enjoy coming because it enables me to help other people. I like to help other people with learning difficulties, to help them and me to do a worthwhile job.

Rachel : [nothing but smiled when Rudi suggested that she likes coming]

Clive : I like to tell people about my news. I have been coming for the past 3 years.

Erica : I really like coming. I like talking to the other members and the advisors about my news.

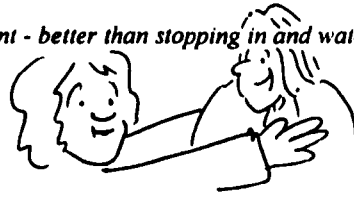
Becca : I like to come along all the time and talk about different things like my Dad. [part of this taken out ~ too personal]

Jane : Like to talk about news. The teachers are striking.

Bill : Yes. people like Jane tell us about things on the TV we might have missed.



Richard : It's good, it's brilliant - better than stopping in and watching the telly.



Helping yourself and others

Rudi : I've always wanted to help people with learning difficulties. I've been brought up in a good family and I can help people who haven't. I can tell people what it was like now [part taken out - too personal] It's important to me more than ever to help people who need help.

Clive : I like sharing my news with everyone. The group has got bigger and I've helped to get new members in.

Erica : I like talking and listening to all the members.

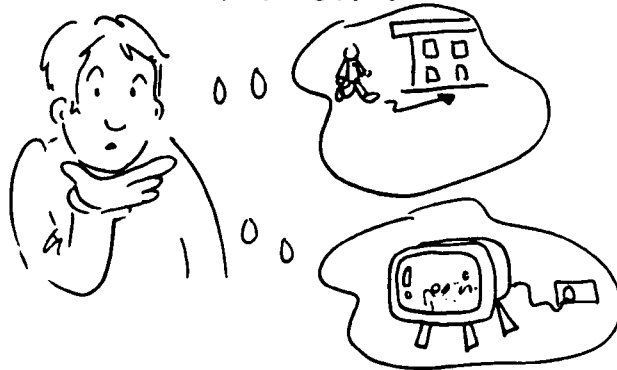
Becca : I like to share things.

Rudi : kindness goes a long, long way. It does you good to listen to other people.

People decide to come they are not made

Rudi: I've noticed that if people can't get to meetings they send their apologies.

Bill : no never we don't say anything if people don't come.



- **Advice to others thinking about starting up a self-advocacy group**

Members came up with some encouraging words for other people with learning difficulties who may be thinking about joining a self-advocacy group.

"come along"

"You would enjoy it".

"It won't do you any harm".

"We would decide what to talk about and put it on the agenda. We'd make sure it gets seen to".

"See how you like it. If you enjoy it then go for it".

"Go for it and come every time".



- **What the advisors say**

Paul and George like the group:



George : You all come along regularly. You make a real effort to come and are committed. People trust each other. I like coming to the group and am very, very happy that you're sticking together.

Paul : People are kind to one another and take turns to help. [advisor took out part he felt "he did not say"]



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Finally **Danny** would like to say .

“The advocacy-supported group is brilliant. Everyone helps one another out and you are not afraid to speak up. Keep speaking out for yourself I have really enjoyed coming along to meetings. Thank you very, very much for letting me sit-in”.

Thank you



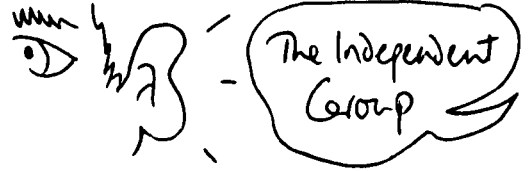
Appendix 4.9. Group Discussion Feedback report (Independent group)

What members get out of being in a self-advocacy group

Some members of *The independent group* had a discussion about the group in July 1996. Danny Goodley wrote down what we said. This was later used in the 'Evaluation Report' for the County Council. These are some of the things members said.

• The beginnings of the group

How people heard about the group



"from the employment centre, a worker there told me"

Imran : Everybody was going to the group. I heard from my friends, they said it was good. I love it coming here - it is my favourite friday

Ellen : A trainee at the centre told me. I decided to join

Andy : I was here at the start. A woman came down to the centre she said she had some money to start up a self-advocacy group. We already had a discussion group that we went to on Wednesday. Sometimes we talked about ground rules, day trips, like what we talk about now. She asked if we would like to start up a group outside. Quite a few people round the table were interested. Four or five us went to join

Colin : [before the group] The discussion groups in the centre helped. We were allowed to speak our minds

Jonny : My keyworker heard about it. He thought it would be a good idea to get me out of the centre. It's good to get out of the centre

Andy : The group did an introduction at one of the centres. Some people heard about us from that

Elizabeth : A worker at the centre told me about the group. I like it very much

What it was like at the start?



Robert : We started off going on Mondays and then that went to all week. We were meant to go in taxis but we walked down

Andy : At first I was nervous and had support from staff. They would do the bills but now we do it

Imran : I was fine when I started. well ... a bit nervous

Elizabeth : I was nervous I had never been there before

• Activities and events - 'things the group has done'

Moving to the new offices

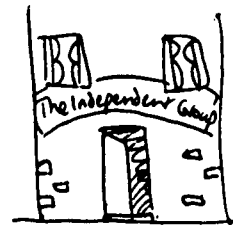
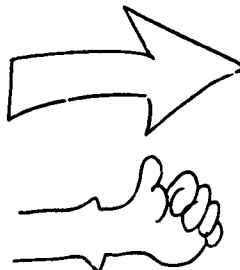
Robert : The first office we had was owned by the social services. It was only a temporary letting, but we didn't know that at first. We had to find another one or move upstairs. They gave us three months to move out. We chose this one and we love it

Andy : those at 'housing' have really helped us. They're great with people with learning difficulties

Other comments have been 'beautiful', 'lovely' and 'its our office' being heard.



OLD PLACE



BLAKETON

Training The group has offered lots of training sessions including:

"A training day on sexuality"

"training for workers"

"helping out at the college"

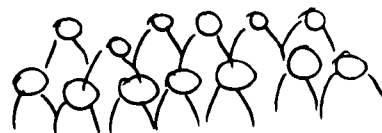


On training **staff** members said:

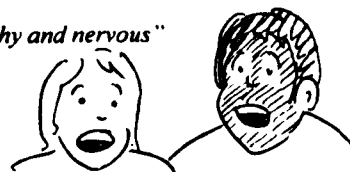
"At first it was nerve-wracking"

"After a while it's fine. Staff wanted us in their discussion groups"

"It was a bit difficult at first. I was shy and nervous"



But members can speak up for themselves:



Colin : Dad says that if I went in an old people's home I'd train them how to run the house!

Robert : I've spoken to loads of people from all over the country

Andy : It's a good chance to meet up with other self-advocacy groups. like People First



Helping others

Andy : I'm a volunteer for 'learning partners'. I help others

Colin : I'm working with this man who cannot speak or talk but he's a joy to work with

Petra : I told my friends about the group and got them interested

The independent group instead of the day centre



Colin : *You do what you want to do instead of what they want you to do*

Andy : *We could do with a few more buildings like our office. Everyone with learning difficulties should be able to join in*

Imran : *You don't have to pay here! You can choose what food you want to buy for your lunch*

• Supporters - Dennis, John and Matthew



What supporters should do

"to advise" "to do what we say"

"to help us do more, with support"



The members said the following about Matthew, Dennis and John

"They are very helpful, they can advise you"

"If you have a problem you can talk to them - they all listen"

"Dennis and John are filling out the national lotteries application for us"

"We like them a lot"

"Matthew is young but bright"

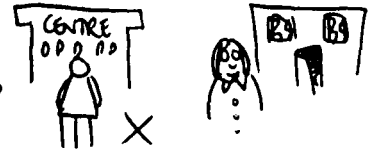
Paying supporters?



Andy : I think it's jolly good we pay them. they earn their money it's intense work

Robert : before we paid them they got paid by charities. Now we as a group pay them

Independent supporters or staff from centres?



Colin : I'm not keen on staff supporting us. It's better to come from outside to learn about it "

"it's better that we're independent we can run the group on our own "

Andy : if the supporters are staff they look down on you all the time

Colin : they get nosy asking "what you doing" all the time

Supporting together its not just supporters who support :

"we help too "

"all support each other "

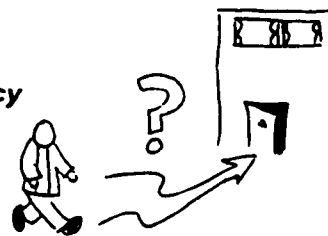
"we all have special skills "

Wendy : I get things from the shops



• **The meaning of the group and self-advocacy**

Why do you come to the group?



“To do work .. clean windows, whatever”

Imran : I like going on the telephone. My Mum and Dad don't let me use the telephone at home. I prefer the group to the centre. It's my favourite friday

Ellen : I like training people, shopping and meeting new people. I enjoy coming along

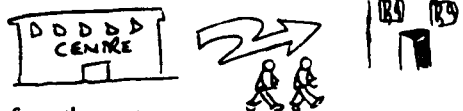
Share experiences and skills with others.

Andy : It's a good thing that you can come along. I used to have group experiences like this before and I've shared them with the group. I enjoy presentations and giving training. It breaks the week up, its a change of scene. If it folded I'd be upset

Petra : To share skills. I do lots of typing on the computer, typing up the minutes. I've been learning typing at tech

Colin : I've always spoke out for myself. I enjoy seeing other people get the chance to

To get out from the centre :



Wendy : I enjoy getting out from the centre

Elizabeth : I like getting out from the centre. When there's no work at the centre there's nothing to do. But you can come here and there's work for you

Jonny : Overall I enjoy the group more than the centre. It gives you something to do

Robert : Better than the centre, there's no work there. Here there's loads of things to do

What self-advocacy means



"getting things right that you want to say"

"being listened to" "independence"

"Tony Benn thought our group was great"

"Speaking out and shouting up. Doing things you want to do"

"speaking up for yourself and to people in authority"

"having your own rights"

But it might take time

Wendy : I was a bit nervous at the start but I'm not now

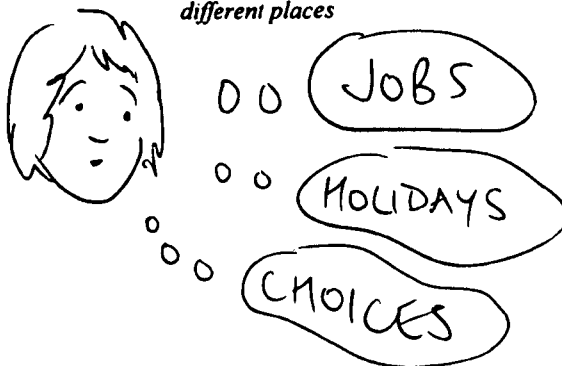
Choice

"Got a choice to go somewhere or not go somewhere"

"More choice here"

Peira : no freedom at the centre. Just sit there and got to sleep

Colin : With the centre - same places all the time. Here you get to go to different places



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Being in The independent group



Elizabeth : There's more friends here than at the centre, it's better than the centre

Andy : It helps you speak up in the community, so people can choose jobs, houses and transport. We run this group independently but with support and advice

Elizabeth : It's helped me become more independent

"it's helping me"

Colin : You do it not your parents

Imran : I get to use the phone here

• The future

Individuals



Ellen : to have nice holidays

"to go to Butlins"

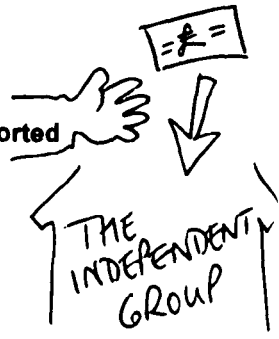
"to still be around"

For the group

Andy : to go from strength to strength

"to get bigger, have different groups, more groups"

Why The independent group should be supported



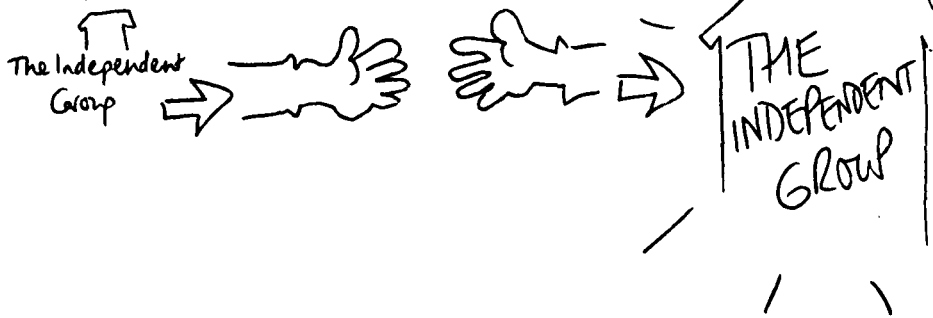
Colin : to help us out

Petra : because we're a small group and a nice group

Andy : to move onto bigger things ... to let us reach out

"help the group grow in size and to keep our building"

Jonny : to help people with learning difficulties take control of their own lives



The Independent Group



Appendix 4.10. Feedback report from organisations who have had contact with the Independent group (for group)

Introduction

The independent group gave Danny Goodley telephone numbers of organisations they have had had contact with. Danny phone two of these, The 'Do it Now' advocacy organisation and Blaketon College. This is what they said.



Reports

Training : 'Do it Now' Advocacy Organisation

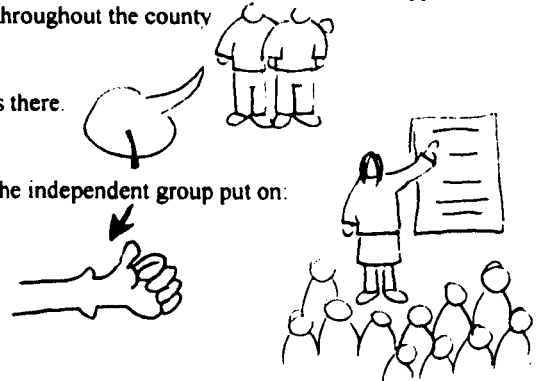
This advocacy organisation is based in the midlands and offers advocacy support for people with learning difficulties throughout the county

Danny spoke to one of the supporters there.

He said about the training day that The independent group put on:

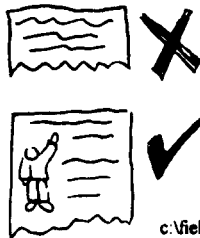
"a very good day"

"I took a lot away from it".



The independent group had made him think about his job as a supporter.

On the day of the training he remembers one session in which groups were expected to write down what they had been talking about. At the start of the day The independent group had asked people to communicate by pictures as well as written words. But in this last session the group had tended to use only words. He said that The independent group had challenged people in the group.

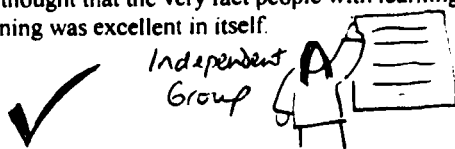


"they told us that they felt excluded, that we were using big words and not including them. This made me look at things again and had a massive impact upon me".

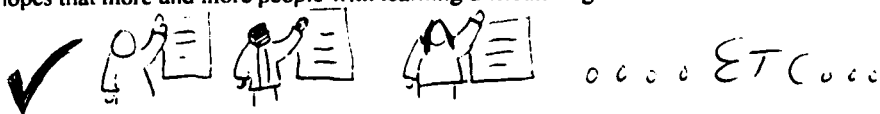
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He thought that the very fact people with learning difficulties were carrying out the training was excellent in itself.



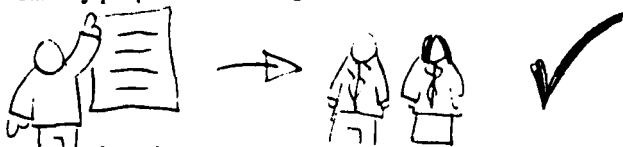
He hopes that more and more people with learning difficulties get the chance.



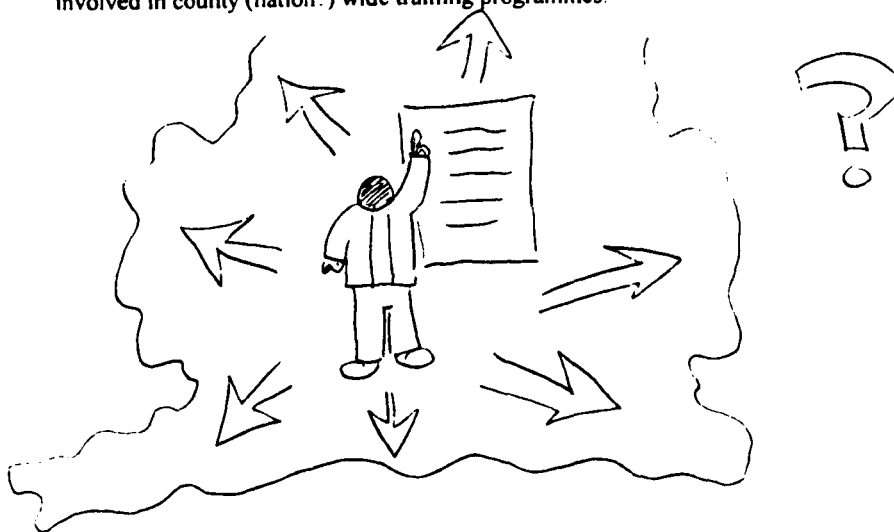
This suggests that *The Independent Group* have developed training packages which pack a punch.



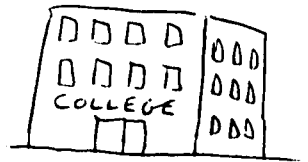
The training of staff by people with learning difficulties undoubtedly has a massive impact.



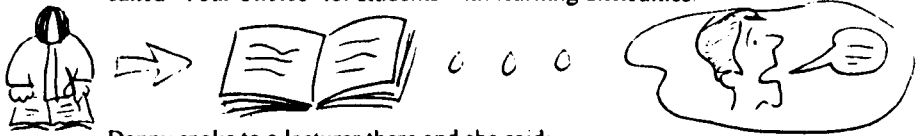
With support *The Independent Group* could increasingly become more and more involved in county (nation?) wide training programmes.



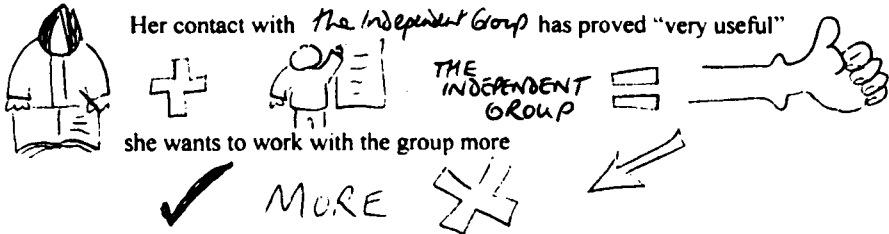
Consultation : Blaketon College



Blaketon college special needs department is developing a self-advocacy course called 'Your Choice' for students with learning difficulties.



Danny spoke to a lecturer there and she said:



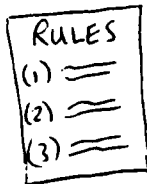
Her contact with *the Independent Group* has proved "very useful"

she wants to work with the group more

members of *the independent group* have told her about self-advocacy



Also the group's constitution has been used by *the lecturer* in staff training. She said that:



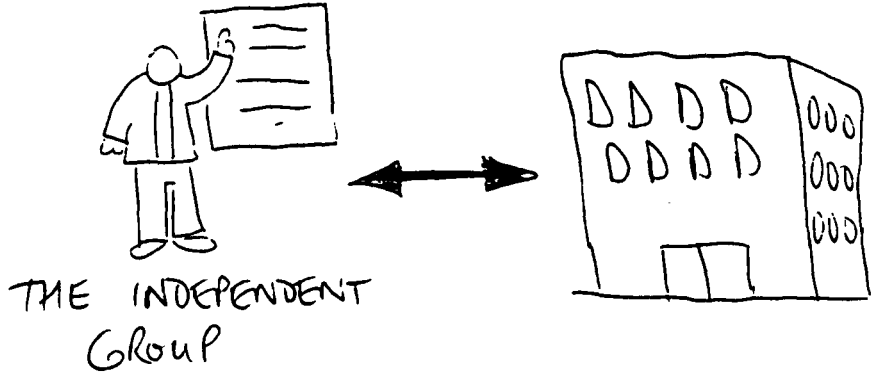
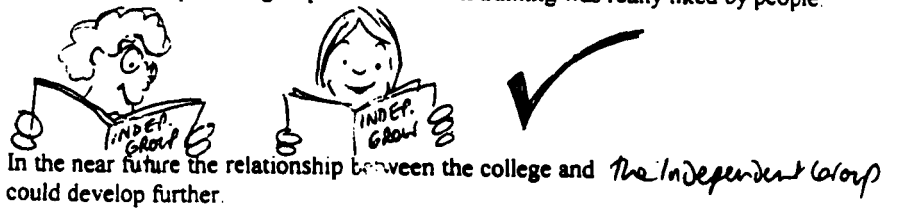
"the constitution was used as an example for staff. It recognises that we need to be aware of non-readers, people with visual and hearing impairments and those with transport difficulties. We need to be aware of individual needs if we are to consult with our students [with learning difficulties]. They are the experts".

She plans to work more and more closely with *the Independent Group*



"we are working in the same area towards the same ends. If we can build on that, buy them in, it would be brilliant".

She said that a report the group had written on training was really liked by people.



Appendix 4.11.
An evaluation of *The Independent Group*
A self-advocacy group for people with learning
difficulties

by

Danny Goodley
University of Sheffield

for Blaketon County Council

July 1996

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covering letter and reply.

Danny Goodley
13 Industry Street
S6 2WU

2nd August 1996

Margeret Snatcher
County Offices
Blaketon

Dear Margeret,

Please find enclosed my completed evaluation report of *The Independent Group*. You will find that the report includes members' comments, feedback from two organisations and suggested directions that the group could follow in the future

I have not spoken to the two centre managers that you named as I felt the issue of links between the group and centres is covered in members' comments. In addition I have spoken with *The Independent Group* regarding their factual report. They told me that a copy of the complaints procedure will be sent along with their final report

----- Reply -----

August 1996

Dear Danny, Thank you for your comprehensive report on *The independent Group*. This will be most useful as the basis for reports to committee about future funding. I have sent a copy to the group. Once again, thanks for this work.

Best wishes, yours sincerely

Margeret Snatcher.

Contents

This report outlines an evaluation of the self-advocacy organisation *the independent group* undertaken in late July 1996. The following sections make up the report.

1. **Member Views** - Feedback from members of *the independent group* obtained from a group discussion are presented. This outlines what 'users' feel they gained from their involvement. **pages 3 - 11**

2. **External feedback** - Feedback from organisations who have received training and consultation from *the independent group* is presented. **pages 11 - 12**

3. **Conclusions** - the report will conclude with some comments that tie the evaluation together. In light of the experiences imparted by members of *the independent group* along with feedback from other organisations, possible ways forward for the group will be presented. **page 13**

(1) "So what do you get out of self-advocacy?"

Members of the Independent group speak

Method

The group discussion took place in the main room of the group's office. Present were 10 members with one supporter. The following issues were introduced

- *Evaluation for County Council* - the primary reason for the meeting was reiterated, this being the collection of member's views on the independent group. Some members asked what 'evaluation' meant. I explained that this referred to the county council's aims to find out how the group was working and "whether or not people get anything out of it". I continued that as the council is giving the group money they want to find out if this money is being well spent in ways that benefit people with learning difficulties. The group were asked if it was okay for me to go through a few questions to see "what they and others get out of being in the group". They readily agreed.
- *Confidentiality* - members were given a pictorially presented handout which covers the issue of confidentiality (though I did not use this word). I asked the group if it was okay for me to write down what they said. They replied that this was fine. In addition I explained that any names that were mentioned, along with their own names, would be changed. Therefore anyone reading the evaluation report would not know the name of the commentator. Group members understand the issues involved here, with one member piping up "so I could be Fred?!". Another member mentioned that she had been involved in report writing herself and had to consider "confidentiality" (her words).
- *The group's own report* - I told the group that I would give them a typed copy of the notes I had taken. They responded positively to this and I suggested that maybe they could use the notes in training or other activities in the future.

A facilitative group discussion With the group briefed the meeting opened. Initially I started off asking questions to the group and went round each individual in turn. From then on the discussion was less structured with more themes emerging from members themselves. Members were very facilitative, asking peers what they felt. This was apparent in a telephone conversation I had with one of the members Andy¹. He had rung to tell me that the time I had proposed was fine and that people were looking forward to the discussion. Before putting down the phone he said;

¹ All names mentioned in the report are pseudonyms

"It would be good if you spoke to Elizabeth as well. She doesn't speak much but she's come on a lot. She hasn't half come on".

The themes that I had expected to be discussed were covered and this reflected members own interests and opinions. They themselves answered questions that I had anticipated asking. This highlights a methodological aim of mine to cover *issues of concern to self-advocates themselves.*

Self-advocates talking

• The beginnings of the group

Hearing of the group Members heard about the group from a number of sources

Wendy : from the employment centre, a worker there told me

Imran : Everybody was going to the group. I heard from my friends, they said it was good. I love it coming here - it is my favourite friday

Ellen : A trainee at the centre told me. I decided to join

Andy : I was here at the start. A woman came down to the centre she said she had some money to start up a self-advocacy group. We already had a discussion group that we went to on Wednesday. Sometimes we talked about ground rules, day trips, like what we talk about now. She asked if we would like to start up a group outside. Quite a few people round the table were interested. Four or five us went to join

Jane : [before the group] The discussion groups in the centre helped. We were allowed to speak our minds

Jonny : My keyworker heard about it. He thought it would be a good idea to get me out of the centre. It's good to get out of the centre

Andy : The group did an introduction at one of the centres. Some people heard about us from that

Elizabeth : A worker at the centre told me about the group. I like it very much

It would appear that self-advocacy can be publicised by self-advocates with learning difficulties, staff members and through projects initiated by groups themselves. The cases where staff passed on details of the group suggests a positive attitude amongst some paid workers to the principles of self-advocacy. In discussion everybody agreed that they had had some experience of self-advocacy and speaking up for themselves before joining the group.

What it was like at the start Members recalled the beginnings of the group with fondness and, in some cases, uneasiness.

Robert : We started off going on Mondays and then that went to all week. We were meant to go in taxis but we walked down

Andy : At first I was nervous and had support from staff. They would do the bills but now we do it

Imran : I was fine when I started, well ... a bit nervous

Elizabeth : I was nervous I had never been there before

Over time this nervousness seems to have disappeared reflecting confidence that can be gained in the group. One should also not underestimate the experience a number of members *already had* of self-advocacy gained through their involvement in centre-based discussion groups.

• **Activities and events - 'things the group has done'**

Moving to new premises The recent move to the new offices has proved to be a major event for the group.

Andy : We had to find another office. We chose this one and we love it

The group recognise the support they have received from others:

Robert : those at 'Enable Housing' have really helped us. They're great with people with learning difficulties

In other chats with members they have told me how happy they are with the offices. Comments such as 'beautiful', 'lovely' and 'its *our* office' have been noted

Training The group has offered lots of training sessions including;

"A training day on sexuality"

"training for workers"

"helping out at the college"

Perhaps of most interest is the training of staff members. This was followed up with the group at the discussion. People with learning difficulties training staff is an atypical interaction and not surprisingly members initially found this challenge difficult;

"At first it was nerve-wracking"

"After a while it's fine. Staff wanted us in their discussion groups"

"It was a bit difficult at first. I was shy and nervous"

Even when involved in such a radical context members seem to have been able to handle the pressure;

Jane : Dad says that if I went in an old people's home I'd train them how to run the house'

Robert : I've spoken to loads of people from all over the country

Andy : It's a good chance to meet up with other self-advocacy groups, like People First

Given the chance people with learning difficulties can be faced with the most difficult of audiences and, with support, put their opinions and views forward .

Helping others An issue that emerged from the discussions around training was that involving other people with learning difficulties. Training experiences are not kept simply within the confines of the group and with external organisations, but emerge in the relationships that develop with others so-labelled.

Andy : I'm a volunteer for 'learning partners'. I help others

Jane: I'm working with this man who cannot speak or talk but he's a joy to work with

Robert : I went into day centres to tell people about the group. Petra was there

Petra : I told my friends about the group and got them interested

The self-advocacy group as an additional context to the day centre was a major plus point of the group for a number of members. The unique nature of the group, through its funding and support from the county council, ensures that it exists as a major resource for people with learning difficulties in the locality.

Andy : We could do with a few more buildings like our office. Everyone with learning difficulties should be able to join in

Seeing a self-advocacy group as an additional day service highlights how radical and ground-breaking *The Independent group* really is.

• **The role of supporters & advisors**

Appraising supporters Group members were very sure about the role of supporters in self-advocacy groups. In response to what a 'supporter should do' responses included.

"to advise"

"to do what we say"

"Like with Imran, to help him buy things from the shop, to support him"

"to help us do more, with support"

In assessing the supporters in the group members were very positive.

"They are very helpful, they can advise you"

"If you have a problem you can talk to them - they all listen"

"Dennis and Julia are filling out the national lotteries application for us"

"We like them a lot"

"Matthew is young but bright"

Paying supporters? payment of supporters was viewed as a good thing. Tied in with this is the recent development which has seen the group take on the responsibility of paying supporters themselves. This comes out of the group's back account.

Andy: I think it's jolly good we pay them, they earn their money it's intense work

Robert: before we paid them they got paid by charities. Now we as a group pay them

Independent supporters? the group see the independent status of the supporters as a major strength:

Jane: It's better to come from outside to learn about it"

"it's better that we're independent we can run the group on our own"

This points to a general issue that independent supporters do not face the same kind of constraints experienced by staff members of other day services. *The Independent group* has supporters that are accountable only to this group.

But support from all A final point that emerged links into the notion of support in general:

"we help too"

"all support each other"

"we all have special skills"

Jim : I get things from the shops

Whilst the input of supporters is recognised, considered and appreciated, members also challenge a dominant belief that people with learning difficulties are incapable of support. Here the model of inter-dependence is fostered within the group.

• **The meaning of the group and self-advocacy**

Why do you come to the group? Members of the group obviously enjoy coming along. Linked to this is the notion of choice, took up in some more detail below, but important here with respect to membership. One should not pass over the fact that members *themselves choose* to come along to the group. Responses to the question 'why do you come along to group' were wide and varied. For some the group offers opportunities for work:

Wendy : To do work ... clean windows, whatever

Imran : I like going on the telephone. My Mum and Dad don't let me use the telephone at home. I prefer the group to the centre. It's my favourite friday

Ellen : I like training people, shopping and meeting new people. I enjoy coming along

For other members the group allowed them to share their experiences and skills with others.

Andy : It's a good thing that you can come along. I used to have group experiences like this before and I've shared them with the group. I enjoy presentations and giving training. It breaks the week up, its a change of scene. If it folded I'd be upset

Petra : To share skills. I do lots of typing on the computer, typing up the minutes. I've been learning typing at tech

Jane : I've always spoke out for myself. I enjoy seeing other people get the chance to

Again the group as an additional service to day centres was cited as a major reason for involvement.

Jim : I enjoy getting out from the centre

Margaret : I like getting out from the centre ... you can come here and there 's work for you

Other work or related activities included,

"paying the bills"

"Doing all the cleaning - I don't mind"

"Gardening ourselves, washing the windows"

The emphasis on people choosing to come along to the group, choosing to wash the windows and clean up, choosing to do the garden, rather than 'being volunteered into it', is salient here.

The meaning of self-advocacy, personal and collective I asked the group what self-advocacy and 'speaking out' meant to them. Collectively a number of important themes were offered,

"getting things right that you want to say"

"being listened to"

"independence"

"Tony Benn thought our group was great"

"Speaking out and shouting up. Doing things you want to do"

"speaking up for yourself and to people in authority"

"having your own rights"

Though self-advocacy is understood in practical ways, achieving some of these self-advocacy skills may take time;

Jim : I was a bit nervous at the start but I'm not now

Self-advocacy and choice As the group chatted they identified an important element of self-advocacy. Knowing that choices are available and that we may act upon them occupied the thoughts of all members;

"Got a choice to go somewhere or not go somewhere"

"More choice here"

The effects of self-advocacy Linked in with the meanings of self-advocacy is its impact upon members. Many of the members felt that their involvement with the group had influenced aspects of their lives.

Elizabeth : There's more friends here than at the centre, it's better than the centre

Andy : It helps you speak up in the community, so people can choose jobs, houses and transport. We run this group independently but with support and advice

Elizabeth : It's helped me become more independent

Wendy : [who has just started] it's helping me

Jane : You do it not your parents

Imran : I get to use the phone here

• **Future of individuals and the group**

Personal ambitions Individuals were asked about the future. First, and a number of personal ambitions were identified;

Ellen : to have nice holidays

"to go to Butlins"

"to still be around"

Perhaps being in a self-advocacy group further encourages members to consider things they would like to do in their lives.

Collective ambitions members had strong beliefs and hopes for the future of the group:

Andy : to go from strength to strength

"to get bigger, have different groups, more groups"

This notion of collective ambition was picked up further when I asked the group "*why should this group be supported?*";

Jane : to help us out

Petra : because we're a small group and a nice group

Andy : to move onto bigger things... to let us reach out

"help the group grow in size and to keep our building"

Jonny : to help people with learning difficulties take control of their own lives

- **Conclusions that can be drawn from members' feedback**

The members of *the independent group* appraise their group in a practical, insightful and meaningful manner. It is apparent from the evaluative comments cited above that members have clear personal and collective reasons for coming along to the group. In terms of a self-advocates' appraisal, *the independent group* is fulfilling the expectations and aims set out in the service contract it has with the county council.

(2) Feedback from organisations who have had contact with The Independent group

Introduction

The independent group gave me telephone numbers of organisations they have had contact with. For two of these contact took on the form of training and consultation. Training in this case was offered to staff members of an advocacy organisation at a conference over a few days. Consultation was given by the group to the Special Needs department of the local College. Both organisations were contacted by telephone and the following reports were gained.

Reports

Training : 'Do it now' Advocacy Organisation

This advocacy organisation is based in the midlands and offers advocacy support for people with learning difficulties throughout the county. In view of the extensive support that is offered one could perhaps assume that staff will be highly experienced. One of the staff members, June Bloomfield, was at a training day offered by *the independent group*. She remarked that it was a "very good day" and that she had "taken a lot away from it". She told me that there was perhaps a tendency for advocacy workers like herself to think they are "doing the right thing" and to feel "rather smug with themselves". However the training offered by *the independent group* made her think more deeply about many aspects of her job.

On the day of the training she remembers one session in which groups were expected to write down what they had been talking about. At the start of the day *the independent group* had encouraged people to communicate by pictures as well as written words. Yet in this last session the group had tended to use only words. She told me that *the independent group* had challenged people in the group.

"they told us that they felt excluded, that we were using big words and not including them. This made me look at things again and had a massive impact upon me".

Ms Bloomfield thought that the very fact people with learning difficulties were carrying out the training was excellent in itself. She hopes that more and more people with learning difficulties get the chance. In conclusion she said that she really enjoyed the training offered by *the Independent group* and found it a valuable experience.

This suggests that *the independent group* have developed training packages which pack a punch. The training of staff by people with learning difficulties undoubtedly has a massive impact. With support the group could increasingly become more and more involved in county (nation?) wide training programmes.
national

Consultation : Blaketon College

Blaketon college's special needs department is currently involved in developing a self-advocacy course called 'Your Choice' for students with learning difficulties. I spoke to a lecturer there, Julie Bently, who is involved in the writing and presentation of the module. Her contact with *the independent group* has proved "very useful" and she is keen to acquire further input from the group. She is interested in the group acting on a consultation level and hopes to "buy them in" more and more in the near future.

In the past she said that members of *the independent group* had provided valuable information on self-advocacy in the classroom setting. Moreover, the group's constitution has been used by Ms Bently in staff training. She told me that;

"the constitution was used as an example for staff. It recognises that we need to be aware of non-readers, people with visual and hearing impairments and those with transport difficulties. We need to be aware of individual needs if we are to consult with our students [with learning difficulties]. They are the experts".

Ms Bently is well aware of current literature on self-advocacy and was very impressed with the group. She plans to work more and more closely with *the independent group*:

"we are working in the same area towards the same ends. If we can build on that, buy them in, it would be brilliant".

In addition, told me, a report that the group has written on training was very positively received. It would appear that educationally the group has much to offer. In the near future the relationship between the college and *the independent group* will develop further.

(3) Directions for the future

A number of directions that the group could follow emerge from my discussions with members of *the Independent group* and organisations they have worked with.

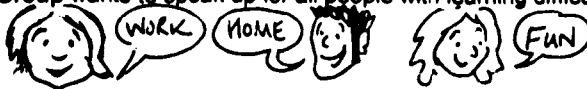
- **Continue to offer training** - particularly to staff would appear to offer an existing and ground-breaking way forward for the group. It would be possible also for the group to support other self-advocacy groups' training.
- **Continue to broaden training** - varying the training is something already recognised by the group. Small workshops, training sessions and conferences have all been offered. Allowing for two / three hour training sessions as opposed to one day / two day sessions would seem to be appropriate at this time. Specifically this would build up links with Blaketon College.
- **Continue to develop workshops** - members of the group have expressed wishes to start up smaller, specialised workshops. Such ideas include men and women's groups. The new office premises allow the space for such groups to meet
- **Learning in group** - members have appreciated the opportunities *the independent group* provides to try out new skills. Answering the telephone and word-processing the minutes for meetings are just some of the activities people said they enjoy. By continuing to allow for such opportunities the group will encourage the self-advocacy skills of its members to be developed further

Danny Goodley
University of Sheffield
July 1996

Appendix 4.12. Social group's 'constitution', introductory leaflet, covering letter and reply.

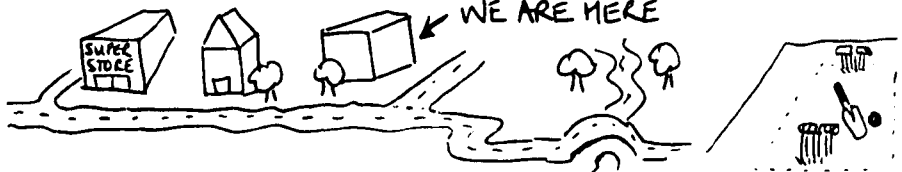
**The Social Club
Constitution (based on details given by advisor)**

The Social Group wants to speak up for all people with learning difficulties.



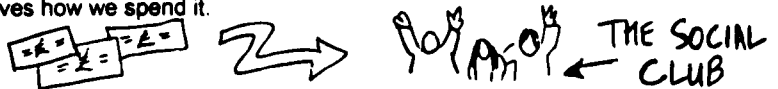
We are a group of people with learning difficulties who are interested in speaking out for ourselves, to show people that we can stand up for ourselves.

We meet once a month at 5pm until 7pm. We use a room at the Lawley Social club on the Lawley Street just up from Lawley Superstore.

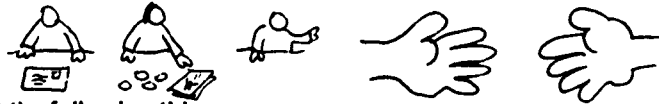


We are mostly interested in service users, but we are also adults who are interested in what goes in our lives.

We have been given grants to help us run our group. We are going to decide for ourselves how we spend it.



We have formed a committee to help run our group and we have some helpers for the moment to give us a hand with the running of the group.

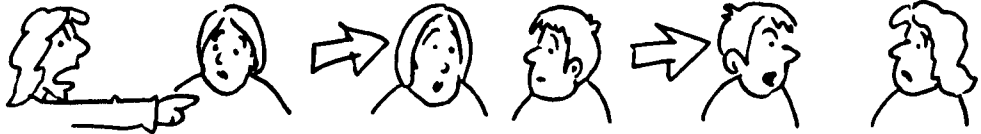


We want the following things:

- (1) All staff should treat us with respect



(2) If we are badly treated then there should be ways in which we can complain. People should listen to our complaints and take action. We are not trouble makers.



(3) We should be told about things that affect us.

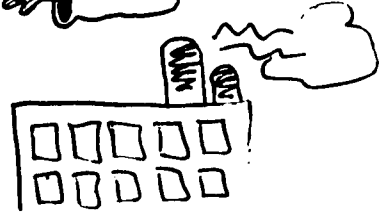


(4) We should have a keyworker or a close person who listens to what we want. Our keyworkers should be people we get on with.



(5) We want things to do with our time:

In the day



And at weekends.



We want to be given the chance to talk about all these things and report on their progress.



The Social Group

Introduction to Self-advocacy Newsletter

We are writing to introduce ourselves.



We meet every first ----- of the month at Lawley Social Club.



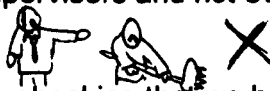
We go to different centres and have different jobs.



We talk about getting more money and having control of our money.



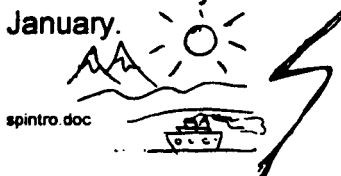
Some of us are being badly treated at work by supervisors and not everyone likes their jobs.



It's shocking that we have to pay for new services.



We like holidays and we all went out for a meal in January.



3

Letter re : the first group constitution I did for the social group this was rejected by the advisor Jurgen

9th November 1995

Dear Jurgen,

Many thanks for sparing time to chat with me this Tuesday. It was interesting to hear your views on self-advocacy and I thoroughly enjoyed the meeting. The members made me feel really welcome and I thought that they had many important things to say. I would love to pop along to the Christmas Party if that was accepted by you and the group - don't worry I promise that my Des O'Conner Xmas record remains here in Sheffield (but then again if you want me to bring it).

In the mean time please find enclosed the group aims that you gave me - in pictorial fashion and slightly re-written. I have made sure that I stuck to the original text but if you feel I am treading on any toes then of course you do not have to use my attempt. Hope to hear from you soon, Danny.

Reply -----

2nd May 1996

Dear Danny, any chance you can re-visit the work you did for the group? I'm going to make an application for funding (so that we don't have to always miss the expensive conferences). So I thought I could form a constitution of sorts out of our list of demands. I've jotted amendments down, etc. on the attached sheets, but the new text won't have illustrations unless you'd like to invent some. I'm sure pictorial consultation will be much more interesting to look at than a lot of legalistic writing. Our next meeting is May ---. We hope for a better turn-out than last time. This week we have recruited a new volunteer helper - an unknown who applied through the volunteers bureau. So if he comes, tell me what you think! Hope to see you next time, Jurgen.

This led to the formulation and group acceptance of the constitution show overleaf.

4

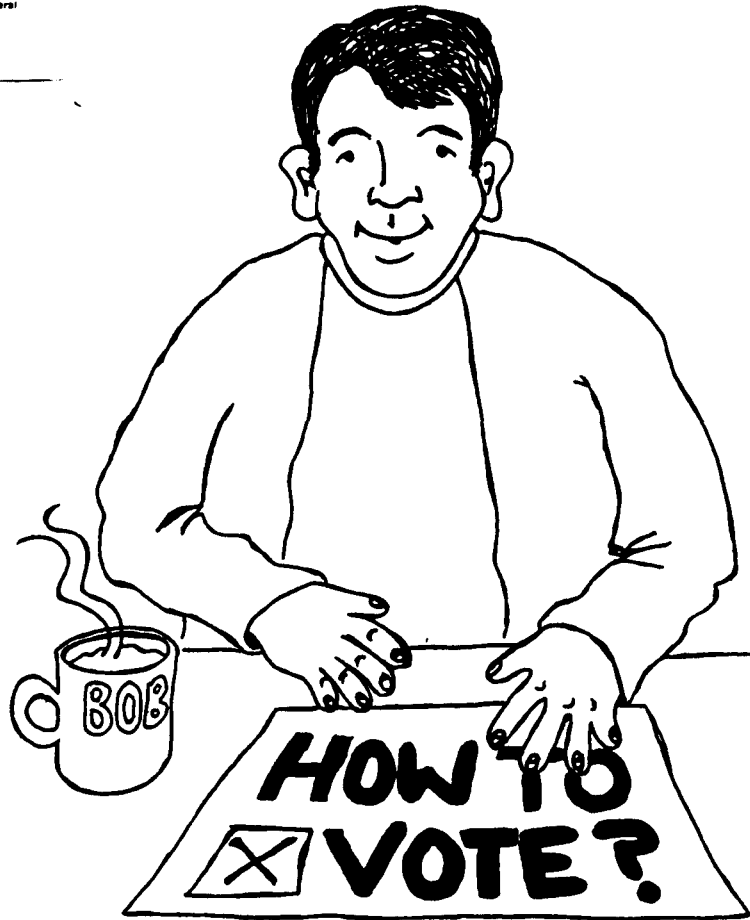


A story about a person with learning difficulties voting in a general election



A story about a person with learning difficulties voting in a general election

You can Vote



A story about a person with learning difficulties voting in a general election



A story about a person with learning



A story about a person with learn



Bob has learning difficulties.
With the **general election** coming up he wanted to have his say.

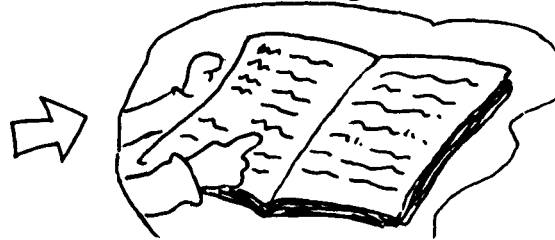


Like many people in Great Britain
Bob has the right to **vote**.
He can choose the political party
he would like to run the country
(the **government**).

Before Bob could vote he
had to make sure his name
was on a special list.
This list has a name,
it is called an **electoral register**

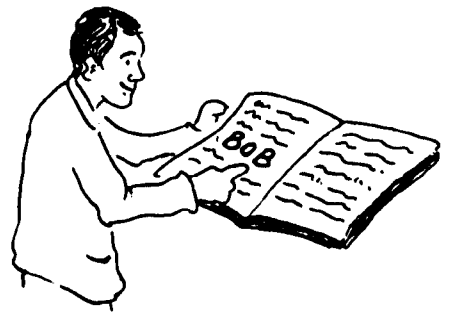


The staff in Bob's house
helped him fill in a form so
his name could be added to
the electoral register

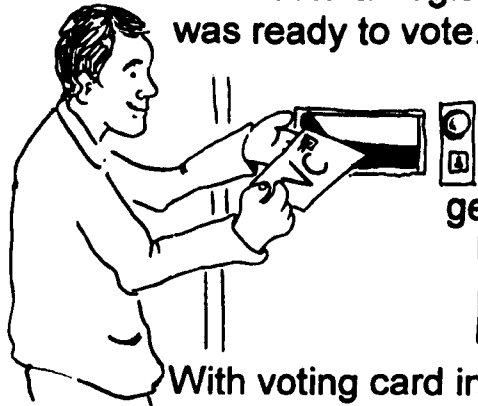




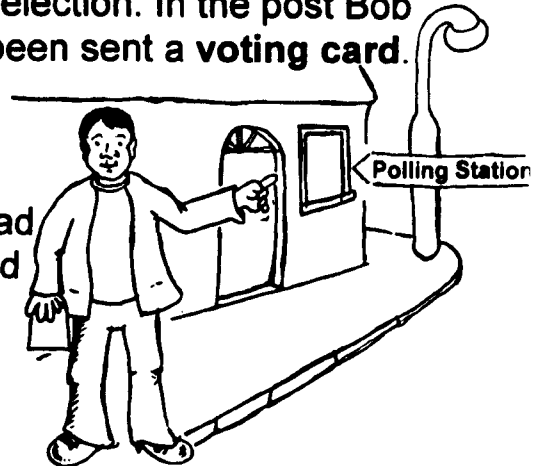
Now with Bob's name on the electoral register he was ready to vote.



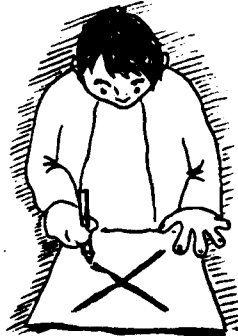
Then came the day of the general election. In the post Bob had been sent a voting card.



With voting card in hand Bob walked down the road to a place where he could vote. This is known as the polling station.



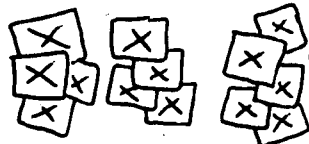
On a special form given to him at the polling station Bob wrote a X by the political party he wanted to have as the government.



Bob's vote was added to all the others in the country,



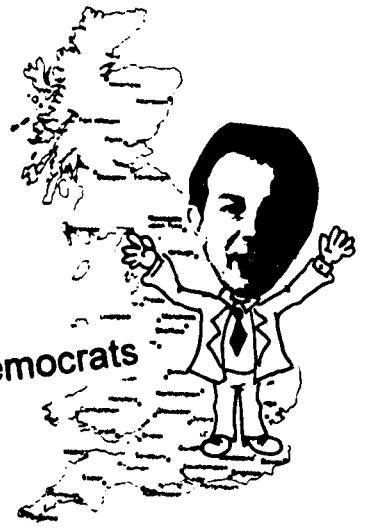
and they were all counted up.



Labour Tories Lib-Dems

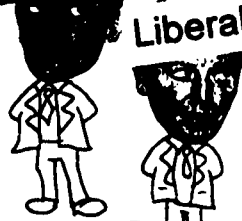


The party with the most votes won the election and became government.

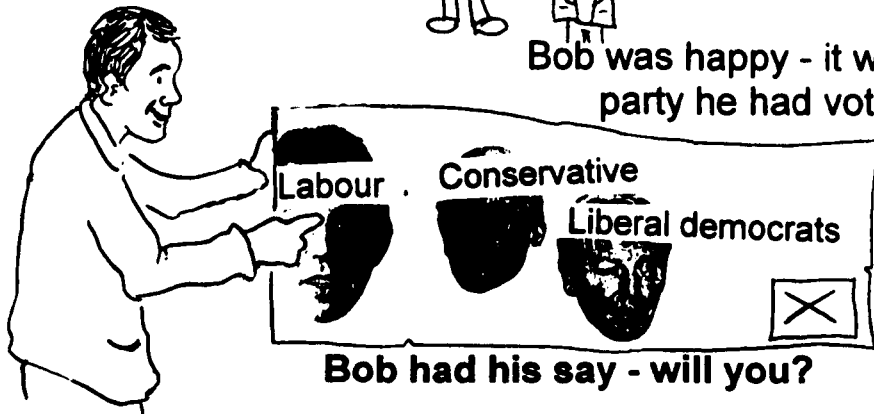


Conservative

Liberal democrats



Bob was happy - it was the party he had voted for!



Ask a member of your family, staff or a friend if your name is on the electoral register

You have the right to Vote

Appendix 4. 14 - Models of Disability

Individual model	Social model
personal tragedy (disability = impairment) personal problem	social oppression (disability = society) social problem
individual treatment (‘cure’) medicalisation	social action (social change) self-help
professional dominance (helping professions)	individual & collective responsibility
expertise (of non- disabled people)	experience (of disabled people)
adjustment	affirmation (increase public vis. of dis. peo)
individual identity	collective identity (of disability movement)
prejudice (attitudes) care	discrimination (acts) rights
control	choice
individual adaptation	social change
policy	politics

[Taken from Oliver, M. (1996) *Understanding disability - from theory to practice*. London : Macmillan (p34)].