AN INVESTIGATION INTO THE ADVOCACY ROLE OF
THE LEARNING DISABILITY NURSE

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Abstract

This study explored the advocacy role of learning disability nurses. Specifically its objectives were to find out whether nurses advocate for their clients with learning difficulties and, if so, how they do this; to explore any problems which nurses have with the advocacy role and to consider their advocacy education and educational requirements in this field.

The study adopted a mixed method approach within a grounded theory methodology, augmented by situational analyses and mapping. It took as its foundation definitions of advocacy and their advocacy needs obtained from people with learning difficulties. The definitions were considered by learning disability nurses and expanded by them. Nurses also discussed their received education in advocacy and their requirements for education, training and support in their advocacy practice. This information was incorporated into a questionnaire survey addressed to all learning disability nurses grades D-G working in NHS settings in Wales.

Results found that the advocacy role of learning disability nurses is constantly evolving and varies according to the specific needs of their clients, their work situation, the availability of independent advocacy services and nurses' willingness to access these. It is strongly influenced by nurses' adherence to either the individual(medical) or the social model of disability. Advocating according to the latter is generally more compliant with the expressed requirements of people with learning difficulties, but nurses may be drawn towards the medical model by resource issues, the influence of their qualification period and experience, or by their perception of the nature of their clients' disabilities.

All learning disability nurses in the study advocated for their clients and there was an awareness among nurse informants of several different levels of advocacy. Nurses were also conscious of problems which could affect their advocacy role in all but the most mundane situations. Despite this, many nurses felt they had a 'duty' to advocate for clients in the absence of any suitably trained alternative and had specific and definite requirements for ongoing education and support in their advocacy practice.
Acknowledgements

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Finally, my thanks to my family for their encouragement, and especially to my husband David for his expertise and willingness to provide practical support during the writing of the thesis and for his patience, support and encouragement throughout the period of my studies.
Author’s Declaration

I declare that the work in this thesis was carried out in accordance with the Regulations of the University of Glamorgan/Prifysgol Morgannwg. The work is original except where acknowledged or indicated by special reference in the text. No part of the thesis has been submitted for any other degree.

Any views expressed in the thesis are those of the author and in no way represent those of the University of Glamorgan/Prifysgol Morgannwg.

The dissertation has not been presented to any other University for examination in the United Kingdom or overseas.

SIGNED

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People with Learning Difficulties: Naming not Shaming

The 1913 Mental Deficiency Bill defined four types of ‘mental defective’: idiots, imbeciles, feeble minded and moral imbeciles. These denigrating names for people with learning difficulties persisted until well into the second half of the twentieth century, gradually giving way to ‘mentally retarded’ and ‘mentally handicapped’. By 1992 the Secretary of State for Wales acknowledged difficulties with the term ‘mental handicap’, and that service users preferred the terms ‘learning difficulties’ or ‘learning disabilities’, but continued to use ‘The All-Wales Mental Handicap Strategy’ as the title for the ‘Framework for Development of Services’ (Welsh Office, 1992). He argued that this gave the Strategy a ‘clear identity, and a focus on the needs of those with severe handicaps’, but stressed that it was ‘no more than the title of the Strategy’ and that, in contact with service users, their own preference would be used (Welsh Office, 1992.11). Since the start of the new century, the terms ‘intellectual disability’ or ‘intellectually impaired’ have been increasingly used, indicating the requirement of (mainly) academics for internationally acceptable terms for the wide range of difficulties and disabilities experienced by people so labelled. Historically, literature has used all these terms for people with learning difficulties and, where such works are referenced, I remain faithful to the texts. Service providers, including nurses, use the terms ‘learning disabilities’ or ‘intellectual disabilities’ and these are reflected in this work. Service users themselves, particularly self advocates, have expressed a preference for the designation ‘learning difficulties’ and, while acknowledging them as people first, it is as ‘people with learning difficulties’ that I refer to them throughout this thesis.

Note on naming nurses

I am aware that the designation ‘learning disability nurse’ is not internationally recognised, and it is also the case that a very small minority of nurses who took part in the study, all of whom were working with people with learning difficulties when the research took place, trained and qualified in other branches of nursing. Thus, in order to be strictly accurate, all nurse participants and respondents in the research should be referred to as ‘nurses working in learning disability services’. However, in the interests of brevity, I have used the term ‘learning disability nurses’ for all the nurses who took part in the study.
Introduction
Int.1 Background to the study
Many people with learning difficulties have moved, within a period of less than ten years, from a position in which they have been 'socialised into believing that their own views are not important' (Ward and Flynn, 1994.37) to one in which they are being urged to 'play a full role in decisions surrounding and affecting their lives' (Welsh Assembly Government, 2004). To understand and become closely involved in government and local government policies which may prove life changing would be a considerable undertaking for people who are not intellectually impaired, but for many people with learning difficulties it could seem frighteningly unrealistic (Llewellyn, 2004). Different ways of providing assistance have been suggested and the Learning Disability Advisory Group (LDAG), in its Report to the National Assembly of Wales, proposed that it may be necessary for people with learning difficulties to make extensive use of advocacy services in order to assist their active participation in individual planning processes, and to ensure that their views on their own lives are properly represented, understood and taken into account (LDAG, 2001.59).

Int.2 Definitions of advocacy and advocates
Although advocacy has been acknowledged as the ‘way forward’ for people with learning difficulties in their aim to gain respect and to have the same chances as everyone else to lead a full and interesting life (Department of Health (DoH), 2001), the concept is not straightforward and there are many different explanations of the term. The dictionary definition 'one who pleads for another' (Fowler and Fowler, 1963.20) refers, in general, to paid, professional/legal advocates who offer advice and support to anyone who actively seeks their help. This could be vastly different from addressing the more specialist concerns of people who have learning difficulties, and there are more relevant descriptions specifically concerned with advocacy for this client group. Simons (1993.2-4) offers separate explanations of 'self advocacy', 'citizen advocacy', 'independent professional advocates' and 'class advocacy'. All these different models of advocacy have their own aims and assumptions, but there are also common themes. None are without problems. Successful advocacy, whether generic or specialised, always necessitates gathering information, sometimes with and usually about the client, and always relating to her or his aspirations and goals.
Self advocates may be individuals, but are usually groups of people who have learning difficulties who meet together regularly, supported by a coordinator or facilitator, to share concerns and experiences. As a group, they acquire information about services, and voice their individual and collective opinions. Some self advocacy groups have had a continuing and significant impact on policies (Whittell et al, 1998). Nonetheless, groups are not available in all areas and their funding is usually tenuous (Snell, 2002). In addition support may be variable (Goodley, 1998) and, due to the nature of their activities, many potential self-advocates may be excluded; group members tending to be people with mild to moderate learning difficulties and a reasonable facility for verbal communication (Walmsley and Downer, 1997).

Citizen advocates do not generally have learning difficulties themselves, but are volunteer 'ordinary' citizens, who gather information about and from their partners who have learning difficulties in the course of developing supportive one to one relationships. Being volunteers, they tend to be in short supply and, even when they are matched with a partner, it may take a long time to build up a satisfactory relationship (Brooke, 1998). Citizen advocates aim to offer friendship and protection, if necessary, to vulnerable partners and to discover and facilitate the achievement of their personal goals (Simons, 1993). Citizen advocacy is increasing, but is not available everywhere, and although many long lasting and satisfactory partnerships are established, some volunteer advocates lose interest, become disheartened, or simply move on, leaving their partner who has learning difficulties without an advocate and possibly with a long wait before a new partner can be acquired.

Unlike citizen advocates, independent professional advocates are paid for their work, either by services, or occasionally, at least in the UK, directly by their clients. They may work exclusively with people who have learning difficulties, typically gathering information about both their clients and relevant agencies, and offering advice and negotiation to enable clients to realise specific targets or ambitions (Simons, 1993). Despite stressing the importance of independent advocacy services, the Welsh Assembly Government (2002) acknowledge that they are not always available, being readily accessible in some areas and not available at all in
others. When such services are obtainable, the likelihood is that referral will be a protracted process, possibly dependent on finance and on managerial personnel, who may be far removed from the client. Even after referral, there may be a long waiting list, and the activities of independent (paid) advocacy services will probably be restricted to short term crisis situations, rather than the more prolonged association required when a person with learning difficulties wishes to become involved in taking control of her or his own life.

Class advocacy is quite different, and does not involve advocates forming partnerships with individual clients. Rather it entails established organisations gathering information and then campaigning for what they believe are the interests of the collective which they support. The work of Mencap is typical of this type of class advocacy, claiming to speak for the needs of people with learning difficulties and their families. In response to recommendations by self advocacy groups, Mencap has invited a proportion of people with learning difficulties onto its ‘National Assembly’ and its local committees (Mencap, 2005), but is still open to the challenge that ‘charities’, controlled and run mainly by non disabled people, are not best suited to speak on behalf of all those people with learning difficulties whom they supposedly represent (Simons, 1993).

**Int.3 Nurses as advocates**

None of these examples relate specifically to learning disability nursing or, more particularly, to nurses’ possible advocacy role. Nurses differ from any of the advocates previously discussed as they are salaried employees, trained and contracted specifically to work with people who have learning difficulties, who are frequently dependent on the services provided by the nurses’ employing Health Trusts. Statutory regulation of nursing occurred in the early twentieth century and, between then and the present, the responsibilities of learning disability nurses have altered considerably. The first learning disability nurses, most of whom worked in large institutions, exercised considerable power and control over their ‘patients’. Although some nurses obviously did advocate for the people with learning difficulties in their care, those who stood up for the rights of their clients were often penalised by the ‘system’ which employed them (Oswin, 2000).
The shift away from institutionalisation and towards inclusion of people with learning difficulties into mainstream community life in the early 1990s released nurses from authoritarian and sometimes custodial care (Mitchell, 2000). Although there is still a considerable power differential between themselves and their clients, learning disability nurses increasingly work towards enabling and empowering the people with learning difficulties whom they support. Many learning disability nurses now have well established, long term relationships with their clients, based on mutual respect and trust. Most nurses have also, through necessity, learned to negotiate on behalf of service users for a fair share of available resources (O'Brien and Towell, 2004).

These facts might lead to the conclusion that learning disability nurses are ideally suited to advocate for their clients, and it has been widely understood that they have a professional responsibility to take on the advocacy role (UKCC, 1998). Indeed some nurses have implied that advocacy is one of their major responsibilities (Pennington, 2000). Despite this, nurses have varying understandings of the term advocacy and what their advocacy role might entail. Although there is a wealth of literature concerning nurse advocacy (e.g. Gates, 1994, Willard, 1996, Mallik, 1997), there is very little empirical evidence (Snowball 1996), particularly in the field of learning disability nursing which has, historically, been under researched (Parahoo et al, 2000). Blackmore (2001) highlighted a specific deficit when, prior to her small scale qualitative study, she found no previous research concerning advocacy in this field. She concurred that there is a lack of clarity amongst nurses regarding the term ‘advocacy’, which was described by participants in her study as several different activities, some underpinned by the desire to increase clients’ autonomy, others by a concern to represent clients’ wishes and yet others by an aspiration to act in the ‘best interests’ of clients. Blackmore conceded that her research findings were too small to be of great significance, and suggested further research using concepts identified by nurses in her study. This exemplified the argument that the failure of researchers to ask the right questions makes much contemporary research in the field of learning disabilities irrelevant (McConkey, 1998). Learning disability nurses, who assume the role of advocates for their clients, must necessarily know how advocacy is defined by those who are to receive this service i.e. people with learning
difficulties, and what those people require from anyone advocating for them. Without this knowledge, attempts by learning disability nurses to advocate for clients might be seen by the latter as an imposition and could be viewed as not only disempowering, but as the antithesis of the principles which underpin advocacy.

If learning disability nurses are to take on the role of advocate for their clients, in addition to knowing what people with learning difficulties mean by advocacy and what they require from an advocate, they must also be clear how they themselves define advocacy. Learning disability nurses might consider that they advocate for their clients in every day matters, for example, supporting them in choices about what to eat or what to wear, but, although these undertakings may be life-enhancing, they are more likely to be amongst the multifarious pursuits encompassed by the 'broad range of caring, counselling and helping activities' which constitute day to day nursing care (Goble, 2002.75). Many nurses will realise that there is a difference between supporting clients to make every day choices within the confines of services, and advocating with or for them to challenge the security and order of these services and enhance their lives through building new relationships and activities (Collins and Dawson, 2003). Nurse advocates involved in such pursuits with clients may find it imperative to undertake activities which go far beyond their everyday role. These might necessitate confronting the power structures fundamental to services, a task requiring considerable forethought and planning, and made particularly difficult for nurses, due to their status as employees within the systems they may seek, on behalf of their clients, to criticise or change (Goble, 2002, Brooke, 2001).

Jenkins and Northway (2002) accept that there may be problems for learning disability nurses, but argue that, despite these, on some occasions nurses do have 'a clear responsibility to advocate 'directly' on behalf of their ...clients'. They suggest that nurses might also advocate 'indirectly' by assisting their clients in self advocacy, working to reduce or eliminate barriers encountered by self advocates and ensuring the views of self advocates are heard and acted upon (Jenkins and Northway, 2002.10).


Int.4 Significance of the research
This study addresses the significant gap in empirical research concerning learning disability nursing (Parahoo et al, 2000) by investigating the advocacy role of the learning disability nurse. The one small qualitative study which specifically explored advocacy in learning disability nursing (Blackmore, 2001) took no account of the ways in which people with learning difficulties defined advocacy, nor what they required from anyone who might advocate for them. Conversely, the foundation of this research was built from definitions of advocacy which were obtained through focus groups with people with learning difficulties, and their ideas were crucial to the design of the only large scale questionnaire survey into the advocacy role of learning disability nurses to have taken place in Wales and, arguably, within the UK.

Most adherents to grounded theory methodology adopt a positivist/post-positivist stance (Glaser and Strauss, 1967; Charmaz, 1983) which does not attempt to capture the subjective views of participants nor consider the position of the researcher as creator of the text. Clarke’s (2003) method of ‘situational analyses’ expands and adapts traditional grounded theory and offers an original interpretation which takes account of these. The method is new and, having been briefly explained in a journal article (Clarke, 2003), seemed particularly appropriate for research among a range of very different participants. Communication with the author resulted in the acquisition of a draft copy of the ‘how to’ chapter, due for publication in 2005 (Clarke, 2005, in press). Subsequent personal communications confirmed its suitability for this research and some advice was offered by the author regarding utilisation of the method. In this study it facilitated the analysis of data acquired through multi site and multi method research. It also offered innovative ways of providing explanations for all the diverse activities which constitute the advocacy role of learning disability nurses, and their many different requirements for education, support and training in advocating for their clients.

Int.5 The context of the study
This research was initiated and sponsored by a Welsh University and took place in Wales. This was particularly appropriate as Welsh learning disability services have
operated in a distinct policy context since the launch of the All Wales Mental Handicap Strategy in 1983. Since devolution and the inauguration of the Welsh Assembly in 1999, subsequent policies have built on the Strategy in a Wales wide context (Welsh Assembly Government, 2004) which is different from that in the rest of the United Kingdom. Wales also has its own specific framework for the development of learning disability nursing (Welsh Assembly Government, 2002a.8-10) which requires nurses to 'recognise their role in advocating for the client'. Nurses are expected to 'seek the views of clients' and to 'develop partnerships' with them. This study addressed these obligations. It also sought the views on their advocacy role of learning disability nurses working in several different situations, within widely different areas and with clients with very varying needs, all within a relatively small geographical region.

**Int.6 Aim of the research**
The overall aim of the study was to explore the advocacy role of learning disability nurses. There have been many conflicting opinions as to whether or not advocacy is part of the nurse's role, (e.g. Mallik, 1997, Willard, 1996, Teasdale, 1998), but few of these relate directly to learning disability nursing, and a literature search found no studies which enquired whether people with learning difficulties want nurses to advocate on their behalf. Williams, who himself has learning difficulties, stressed the importance of advocacy, but suggested that the role of learning disability nurses may lie primarily in teaching clients about their rights and how to claim them, and in assisting their clients to develop self advocacy skills (Williams & Schultz 1982). Agreeing that self advocacy is important, Borland and Ramcharan (1997) argued that, for people who have historically been excluded from public life, the advocacy process itself might help to combat this rejection. They also acknowledged that for some individuals, in some circumstances, advocacy and substitute decision making might be required, and proposed that how these are organised is likely to be a key challenge for the future.

The organisation of advocacy for people with learning difficulties by any of the means discussed above, demands a common understanding of the term by potential advocates and those for whom they take on the advocacy role. It would be easy to assume that people who have learning difficulties are all guided by the
same definition of advocacy and have similar advocacy requirements, and that these concur with notions held by learning disability nurses. It would also be easy to assume that people with learning difficulties require assistance to advocate and that, at least those who have contact with learning disability nurses on a regular basis, expect the nurse to advocate for them or to support them in self advocacy. These assumptions are unlikely to be safe. People who have learning difficulties might have very different ideas about what advocacy entails, possibly affected by their life history, their present situation, the degree of their intellectual impairment and their own, very different, personalities. They might also have definite ideas about the circumstances in which they would require advocacy support and assistance; who could advocate for them or support them in self advocacy; and how this might be done. Similarly, learning disability nurses are likely to have varying ideas concerning their definitions of advocacy and their advocacy role, perhaps relating to the clients with whom they work; their area of work; their training, years of experience and seniority. These may or may not correspond to the ideas and definitions of people with learning difficulties. Conceptual differences between the parties involved may pose limitations on both advocacy and on people who might act as advocates (Aspis, 2002), and this could have a profound bearing on any possible advocacy relationship between nurse and client and on the advocacy role of learning disability nurses.

This research addresses some of the points set out above, and relates the findings to the advocacy education and training of learning disability nurses and to their ongoing requirements for support in advocating for their clients. Specifically the research questions addressed by the study were:

- What do people who have learning difficulties mean by advocacy?
- Do people who have learning difficulties want learning disability nurses to advocate for them?
- Do learning disability nurses have a role in helping people with learning difficulties to advocate for themselves?
- What do learning disability nurses understand by advocacy, and is this similar to the meaning given by clients?
- Do learning disability nurses advocate for their clients? If so, in what way do they do this?
- Are there specific problems concurrent with nurses' advocacy role?
What are the implications of the above for the education, ongoing support and practice of learning disability nurses?

Int.7 The research design

If research into the advocacy role of learning disability nurses is to have any validity, it must be guided by the voices and ideas of those most concerned by the activity, i.e. people who have learning difficulties. The study was thus designed to take place in three distinct stages using a grounded theory approach. This explicitly involved generating theory and doing social research as part of the same process, theories evolving during the research through a continuous interplay...
between analysis and data collection (Strauss and Corbin, 1998). Figure 1 illustrates both the design of the research and the structure of the thesis, showing how each stage drew on information gained in the previous stage(s); information from people with learning difficulties in the first stage thus forming the cornerstone of the research.

Stage one aimed to determine what people who have learning difficulties meant by advocacy and to enquire whether they wanted learning disability nurses to advocate for them and/or whether they thought nurses had a role in teaching or supporting them to advocate for themselves. Taking the definitions of advocacy given by people with learning difficulties as a base, the second stage enquired how a small number of learning disability nurses from different work settings defined advocacy, and considered whether their definitions were similar to those given by people with learning difficulties. Expanding on this information, stage two also enquired whether nurses were undertaking advocacy for their clients, and, if so, in what way and explored with them any problems concurrent with their advocacy role. Nurses were also asked about their education in advocacy and their possible educational, training and support needs in this area.

The design of the postal questionnaire survey which formed stage three of the research was based on information gained in stages one and two of the study. The questionnaire, consisting of closed questions, but with space for additional comments, was distributed to the whole population of learning disability nurses grades D-G (i.e. the ‘hands on’ nurses) working in the NHS in Wales, in order to both test and develop the emergent theories from stages one and two of the research. The overall intention was to acquire, from information gained in all three stages of the research, a comprehensive picture of advocacy in the working lives of learning disability nurses; to explore their received education in advocacy and to make recommendations concerning their educational and training requirements and their need for ongoing support in this field.
The structure of the thesis

Int.8 Historical background
If research is to be meaningful, it must offer some definition of the reference system from which it arises (Melucci, 1989). Chapter one of the thesis thus gives a brief historical background to the lives of people who have learning difficulties and to learning disability nursing. It demonstrates how the rights and voices of people with learning difficulties were subdued or lost during the massive increase in institutionalisation and segregation of people with learning difficulties which began before the 20th century and continued until well into the 1950s. It suggests that Goffman’s book ‘Asylums’ in 1959 and the various hospital scandals and subsequent enquiries in the late 1960s were instrumental in the initiation of the NIMROD project in South Wales (Welsh Office, 1978); the commissioning of the Jay Report of 1979; and the All Wales Strategy (Welsh Office, 1983). All these laid the foundations for a slow recognition by society that people with learning difficulties had equal rights to ‘An Ordinary Life’ (King’s Fund, 1984). The first British self advocacy conference ‘Speaking for Ourselves’ in 1982, also demonstrated that people with learning difficulties were prepared to speak out in support of their claims; leading to new opportunities for advocacy in their lives, and new expectations that professionals might have a role in advocating for them.

Int.9 Methodology and methods
Following this brief incursion into history, methodology and methods are examined in chapter two, particularly the qualitative/quantitative debate in relation to the whole study and decisions surrounding the specific methodology which would guide all stages of the project. Phenomenology, concept analysis and ethnography are considered and rejected, as is action research, although not before acknowledgement of its possibilities for future research. The grounded theory approach, which has been used successfully in many nursing studies (e.g. Knight, 1996; Premji and Chapman, 1999), is acknowledged as offering maximum potential for this research. There are several conflicting opinions on how best to implement this methodology (Glaser, 1992; Strauss and Corbin, 1990; Charmaz, 1983, Clarke, 2003). Some of these are outlined briefly, before a more detailed exposition of ‘Situational Analysis’ (Clarke, 2003) is offered, explaining why this
method was particularly suitable for multi site research, aiming to reveal the varying perceptions regarding the advocacy role of learning disability nurses.

The ways in which a researcher displays her/his commitment to inclusion and empowerment of people with learning difficulties during the research process is likely to be affected significantly by the nature of the project as well as by the people involved (Walmsley, 2003). This research is primarily concerned with investigating the advocacy role of learning disability nurses, but acknowledges that, without people with learning difficulties, there would be no role, nor would there be any learning disability nurses. The views of people with learning difficulties were thus of primary importance in the study, and the methodology section discusses the merits and pitfalls of emancipatory, participatory and inclusive designs as a means to prioritise their voices in the research.

Throughout the thesis the advice of Wolcott (1992.18) is heeded that ".....the most appropriate place for examining the literature seems to be in consort with the analysis of new data". There is therefore no conventional, single chapter devoted to a formal literature review. Instead, literature searches were carried out specific to either methodology and methods, or to emergent themes in the research. These are described in the relevant chapters, and a variety of pertinent literature is acknowledged and discussed appropriately within each section of the thesis.

**Int.10 The first stage of the research**

Following the discussion of methodology, in chapter three, methods of data collection are scrutinised and reasons given for the choice of focus groups with people who have learning difficulties in stage one of the research. A commentary is offered concerning the way in which people with learning difficulties, from three very different settings, were accessed for participation in the study and the ethical issues involved in this activity are explored. A description of the implementation of the stage one methods includes a comparison of focus groups in the various settings, the use or otherwise of focusing exercises and the occasional problems posed by staff delegated to support participants during the sessions. Following this there is a discussion of the analysis of the focus group data, illustrating how NVivo coding was combined with situational analysis and mapping (Clarke, 2003)
in order to capture the 'fundamental elements' (Clarke, 2005) of advocacy and advocating as experienced by people with learning difficulties. Chapter three ends with a presentation of the results which, in accordance with grounded theory methodology, informed the design of focus groups for nurses in the second stage of the research.

**Int.11 The second stage of the research**
Chapter four begins with an explanation of how, complying with the grounded theory methodology, definitions of advocacy and the advocacy requirements of people with learning difficulties formed the basis of the second stage of the research i.e. focus groups with learning disability nurses. This precedes a discussion of the design of the focus groups themselves and the development of goals, which were influenced by the views obtained from people with learning difficulties, and allowed for their expansion to include the concerns of nurses about their advocacy role. The chapter continues with a discussion of the problems relating to accessing nurses to participate in the study, mentioning the necessity to vary the use of focus groups with individual interviews. An appraisal of the implementation of both focus groups and interviews in stage two follows, and there is a brief discussion on the analysis of the data obtained, again using NVivo coding, supplemented by situational analysis. Finally there is a presentation of the important findings which emerged from this stage of the research.

**Int.12 The third stage of the research**
Strauss and Corbin (1998a.28) propose that 'combining [qualitative and quantitative] methods can be done [within the grounded theory methodology] for supplementary, complementary, informational, developmental and other reasons'. Chapter five begins by demonstrating how, in compliance with this view, the questionnaire, which comprised stage three of the research, was designed around data previously obtained from stages one and two (the qualitative stages) of the study. A brief description of the submission of the final stage of the study to the Multi-centre Research Ethics Committee (MREC) precedes a discussion concerning the distribution of the questionnaires and reminder letters and comments on their return. Preparation for analysis of the questionnaires using the
Statistical Package for the Social Sciences (SPSS, version 11) is briefly discussed before the actual analysis of the data is described in some detail. Chapter five concludes with a presentation of the results of the survey.

Int.13 Discussion and critique of findings
In chapter six, data from each of the three sections is brought together for more detailed comment and critique of the findings. Clarke’s approach to grounded theory uses situational maps and analyses to make the ‘usually invisible and inchoate social features of the situation more visible’ (Clarke, 2003.572), and was particularly suited to the investigation of the complex phenomenon which is advocacy. Rather than reducing the data and attempting to pinpoint just one ‘important’ issue; situational and positional maps are used to illustrate the many situations and interrelations concerning advocacy, as well as the social arenas in which they took place and the discursive positions of some of the key actors involved (Clarke, 2005). The chapter concludes with an evaluation of the use of mixed methods within the specific approach to grounded theory adopted in this study, and uses a project map to illustrate the main conclusions drawn from the data.

Int.14 Conclusions and recommendations
All research projects have some limitations and the final chapter of the thesis acknowledges these before bringing together conclusions regarding the conduct and results of the research. Recommendations are offered regarding the advocacy practice and education of learning disability nurses and suggestions are made for further research. The thesis concludes with observations on the value of the research and comments on its dissemination.

Int.15 Writing the thesis
The innovative social scientist Richardson confessed that she has ‘yawned’ her way ‘through numerous supposedly exemplary qualitative studies’ and that, perhaps more worrying:

“Coming out” to colleagues and students about my secret displeasure with much of qualitative writing, I found a community of like-minded discontents. Undergraduates, graduates and colleagues alike say they have found much of qualitative work – yes – boring.

(Richardson, 2000.924)
She argues that the reason for this is that research writing, in its efforts to impress academically, suffers from 'acute and chronic passivity'. The audience for a thesis of this nature is likely to be diverse. The work might have some interest for a range of people including academics with an interest in curriculum design; but also 'hands on' lecturers, service managers, learning disability nurses, students and self advocates. This necessitates explanations and discussions of varying degrees of complexity. Thus, although the academic/methodological issues bow to convention and are presented mainly in the passive voice, results and presentation of the data are proffered in the first person, with voice given at every opportunity to those who participated in the study. Many of these informants have expressed an interest in the results of the research. Most lead busy lives with little time to sit and puzzle over complex and difficult reports. Theoretical jargon has thus been kept to a minimum throughout the thesis. When the work is completed, short reports will be provided for Learning Disability Directorates, Educational establishments and participants who have expressed an interest in the findings of the study.
Chapter one

Changing expectations: A brief history of the support given to people with learning difficulties in the twentieth century.
1.1 Introduction
This short history traces the development of care and support for individuals with learning difficulties from the middle of the nineteenth century, through the rise in the eugenics movement in the early 1900s, and their consequent powerlessness within a climate of forced institutionalisation, until the present. It suggests that events in America and Scandinavia, various hospital scandals, the White Paper 'Better Services for the Mentally Handicapped' (Department of Health and Social Services (DHSS), 1971), the 1979 'Jay Report' and the 1980 King's Fund Report 'An Ordinary Life' were catalysts leading to the closure of large, long stay hospitals. It describes the importance of the NIMROD (New Ideas for the Care of Mentally Retarded People in Ordinary Dwellings) project as a pilot study for community care throughout the 1980s, and discusses its influence on the development of the 'All Wales Mental Handicap Strategy' which was launched in 1983 and is still extant. The history then explores the development of advocacy, which paralleled changes in social policies affecting people with learning difficulties and public perceptions of them. It contends that changes in the education and training of nurses working with people who have learning difficulties, which took place after the Jay Report, reflected the move from a philosophy of control to one of facilitation and enablement. The chapter concludes by proposing that advocacy and nurse advocates have a continuing role to play in the lives of people with learning difficulties.

1.2 Institutionalisation
Until the onset of the industrial revolution, despite the widespread misunderstanding and distrust shown towards them by other members of society, most people with learning difficulties spent their whole lives living at home with their families. The vast majority of people in Britain worked on the land (Giddens, 1993) and people with any sort of disability were usually found some task commensurate with their physical and intellectual capacities, through which they could, at least to some extent, earn their food. However, the development of industry and the introduction of complex technology into the workplace meant that most people with learning difficulties could no longer be integrated into any kind of work. Neither could many of them be supported by their families, who were
themselves dependent on employment by 'masters' of industry. They were thus 'left alone, locked up or turned out onto the streets' (Ryan and Thomas, 1987.101).

The first schools and asylums were set up towards the middle of the nineteenth century with the aim of improving, educating or even 'curing' people with learning difficulties; the expectation being that after residential training for perhaps a couple of years, 'idiots' would return to their families and be able to take up some useful occupation. However, despite some positive reports on the results of this regime, the hope was seldom realised, suggested reasons ranging from the non realisation of the expected improvements; to families of inmates becoming 'scattered and untraceable or unable to accept back an idiot member' (Ryan and Thomas 1987.98). Consequently asylums increased in number and changed, becoming much larger in order to accommodate life-long residents as well as mounting numbers of new admissions.

Ryan and Thomas illustrate how this situation typified an individual/medical model of disability:

Failure of the first schools and asylums in not returning all their inmates to some kind of normal life outside has... been attributed to the hopeless nature of the idiots themselves, as well as to the allegedly unrealistic ideas that their educators had about improvements. In fact ....the early educationalists' real failure was in not sufficiently appreciating the nature of a society that created the growing need for asylums and that made it extremely difficult for so many people, let alone idiots, to survive. Their mistake was not so much in the content of their ideas about education, as in their belief in the power of these ideas, divorced in their implementation from either social reality or social action.

(Ryan and Thomas, 1987.102)

The growth of asylums saw a change in emphasis from one of education of people with learning difficulties and alleviation of their solitude and isolation, to 'mass organisation of their daily life and the denial of individuality' (Ryan and Thomas, 1987.99). By the beginning of the twentieth century educationalists had given way to doctors, who were in undisputed charge of asylums, and officials concluded that people with learning difficulties were not worth expenditure or resources on education or training, and were unable to live anything but a segregated and
custodial life. The eugenics movement, which had gained prevalence at this time, bred widespread fears that the national genotype would be contaminated if people of low intelligence were allowed to breed unhindered. Thus increasing numbers of people with learning difficulties were segregated in ever larger institutions, usually in rural areas, inaccessible to the ‘temptations’ of more densely populated towns and cities (Felce et al, 1998). Work, social and leisure opportunities considered ‘typical’ by most members of society were denied to these people as a direct result of official concern to prevent procreation. The Mental Deficiency Act of 1913 saw compulsory certification of people admitted to institutions as mentally defective. They were excluded from welfare and social agencies, as well as from the general education system, and were classified within the act according to their perceived degree of handicap as either ‘idiots’, ‘imbeciles’ or ‘feeble minded’. After the First World War, many more asylums were built, and between 1918 and 1931, the number of places in institutions registered under the Mental Deficiency Act nearly tripled (Felce et al, 1998). In the eight years that followed, it nearly doubled again, to reach 32,000 by 1939 (Felce et al, 1998).

1.3 Resettlement
In 1948, ‘asylums’ were incorporated into the newly formed National Health Service and became known as Hospitals, with some of the attendants employed therein becoming nurses. However, by the 1950s the fears of the eugenics movement were less in evidence, possibly as a consequence of the horrors of the holocaust in World War 2, and segregation was no longer viewed as the only, or even necessarily the best, option for people with learning difficulties (Felce et al, 1998). In America it became a ‘rights’ issue and there were many successful legal cases against segregation (Felce et al, 1998), while, in Scandinavia, Denmark passed its ‘Mental Retardation Act’ in 1959 with the stated aim of creating ‘an existence for the mentally retarded as close to normal living conditions as possible’. Also in 1959, Goffman’s book ‘Asylums’, was published. This discussed the disastrous effects of ‘total institutionalisation’ on residents of large, long stay hospitals and was soon followed by other academic critiques of institutional life (e.g. Blatt and Kaplan, 1966, Oswin, 1971). By the late 1960s, following the Scandinavian initiative, de-institutionalisation had gathered pace in
the USA, and soon Wolfensberger’s (1972) principle of normalisation became its guiding philosophy (Felce et al, 1998).

Doctrines of normalisation, integration and, later, social role valorisation have had a profound and continuing influence on the care and support of people with learning difficulties for over thirty years. Hughson and Brown (1992) explain that:

The principles of ‘normalisation’ reflect a very important shift in the goals of human services. The critical function.... is now perceived as using culturally valued means to enhance the social role of individuals who might otherwise be viewed negatively by society. How a person is perceived affects how the person will be treated....

Hughson and Brown, 1992.306)

Following the publication of Goffman’s book and events in the USA and Scandinavia, public awareness was further raised in 1971 by the publication of the ‘United Nations Declaration of the Rights of Mentally Retarded Persons’ (1971), the first clause of which stated:

The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.

(United Nations, 1971)

In response to this, a pressure group for change was formed. The Campaign for Mentally Handicapped People (CMH, now VIA), was founded in 1971, with the innovative and, at the time, radical aim of:

....finding out what mentally handicapped people want for themselves, and giving them and various professionals a chance to meet on equal territory.

(CMH, 1973.1)

Members of the public, who might have disregarded early signs that the treatment of many people with learning difficulties, who had been segregated in hospitals, should give cause for concern, could no longer plead ignorance when a spate of enquiries into conditions in ‘mental handicap’ institutions was highly publicised by the national press. The ‘Ely Hospital Inquiry’ in 1969, was followed by that at Farleigh Hospital in 1971 (Brown, 1992.109); both of which highlighted the appalling conditions in which some people with learning difficulties were being
forced to live. Even after the resultant White Paper 'Better Services for the Mentally Handicapped' was published in 1971, other incidences continued to emerge, suggesting that mistreatment and exploitation of 'patients' in these hospitals had become endemic. The White Paper aimed to address the problem and focused on services for children, the provision of multidisciplinary community teams, improvements to day centres and residential services, with extra money being invested in institutions. Nonetheless, the majority of people with learning difficulties living in these places were forced to remain there, having lost touch with their next of kin after many years of obligatory and stigmatising segregation, and being otherwise homeless.

Problems surrounding the provision of care for people with learning difficulties, and efforts to integrate them into their local communities, and to change the emphasis from medical to social and educational care continued, and were addressed more fully in 1979 by the Report of the Committee of Enquiry into Mentally Handicapped Nursing and Care (The Jay Report). This report 'provided a programme that permeated mental handicap policy throughout the 1980s' (Brown, 1992:112), leading to radical changes in the training of learning disability nurses, although not the complete transfer to social work first envisaged by the report; and heralding the move to care for people with learning difficulties in smaller residential settings within the community. The new philosophy was addressed specifically in 1980 when the King's Fund launched their paper 'An Ordinary Life' as a focus for rethinking the opportunities and support which should be available for people with learning difficulties in the UK. The paper stated that:

Our goal is to see mentally handicapped people in the mainstream of life, living in ordinary houses in ordinary streets, with the same range of choices as any citizen, and mixing as equals with the other, and mostly not handicapped, members of their own community.

(King's Fund, 1980:6)

The following year the NIMROD project was instigated in Cardiff. 'New Ideas for the Care of Mentally Retarded People in Ordinary Dwellings' was a fore runner of the All Wales Strategy and was one of the first attempts to bring together intensively and minimally staffed residential accommodation in ordinary housing, professional services, a volunteer service and an administrative base, which also
housed an information and resource library. The project also provided individual and family support services for the 80% of people with learning difficulties still living at home, but usually stigmatised and marginalised within society. A number of houses were purchased in North Cardiff and between twenty and thirty people with learning difficulties, whose origins were in the area, were relocated from large institutions, becoming the forerunners of an eventual major resettlement policy. NIMROD received national attention as a pilot study in the implementation of community care throughout the early 1980s and had considerable influence on the development of the All Wales Strategy (AWS). The All Wales Advisory Panel (AWAP) was set up in 1981, the same year that NIMROD became operational. It reported in 1982 and the All Wales Mental Handicap Strategy (AWS) was launched in 1983, based on similar principles to those of the Jay Report published four years earlier:

- People with a mental handicap have a right to ordinary patterns of life within the community
- People with a mental handicap have a right to be treated as individuals
- People with a mental handicap have a right to additional help from the communities in which they live and from professional services in order to enable them to develop their maximum potential as individuals

(Welsh Office, 1983.1)

Although the Strategy envisaged an eventual change in the nature of residential provision, neither its launch, nor the NIMROD project, signalled the immediate or even the imminent closure of institutions in Wales. Portending a move away from the medicalisation of learning disability, Social Services were given ‘lead agency’ status in the provision of care and support for people with learning difficulties and the Strategy proposed the development of multi disciplinary teams of health and social service professionals, which were to be established locally. These would act as a single point of contact for individuals, families and generic services, and would be the focus for local planning and the collation of individual needs, which could be fed, through the teams, into each county’s planning system. Resettlement of people with learning difficulties from large institutions into smaller residential settings was not seen as an urgent priority, although there was a commitment that ‘new purpose built hostels, hospitals or units shall not form part of
the new patterns' (Welsh Office, 1983.6). The role of the existing hospital services was still seen as essential. They would 'continue to care for mentally handicapped people until such time as community services have been successfully developed to take over the whole job' (Welsh Office, 1983.6).

Despite this assertion, many parents and carers felt threatened by the All Wales Strategy, having fought to keep hospitals open, even when severe problems were revealed by the various enquiries. Anecdotal evidence suggests that some parents feared that hospital closures would result in their son or daughter returning to the family home, and that they would be unable to cope in that situation. There had been considerable improvements made to institutions in terms of extra staff and equipment after the enquiries, and many parents, particularly those who were now elderly, were happy with the care that their (adult) progeny received, and feared this may be less satisfactory in small settings, possibly run by social services where, for instance, medical help might be less readily available.

1.4 Advocacy
By the late 1980s 'the emphasis on achieving typical and valued lifestyles... and roles in society had increased' (Felce et al, 1998.167). Most services in Wales had adopted the ‘Five Essential Service Accomplishments' developed by O’Brien (1987) and the achievement by clients of ‘community presence', ‘competence’, ‘choice’, ‘participation' and ‘respect' became an essential aspect of their mission statements (Felce et al, 1998). Nonetheless, people with learning difficulties were still being admitted to long stay hospitals, albeit in ever decreasing numbers, even in the early 1990s, and were themselves seldom, if ever, consulted about potentially life changing policies. Participants in this study who were living in a large institution in the 1980s recalled their powerlessness in the face of the authoritarian regime under which they lived at that time:

| John       | We had to get up at 5 to go to work. JJ was in charge... We used to cut down trees and carry them on our backs. 100 tons of chippings every day... |
| P          | If you didn’t want to do it would that have been OK? |
| John       | I doubt it. Saying no to JJ - not highly recommended! He’s one of those people who said 'when you jump, just don’t come down boy' |

(Parkview, group 1)
It was not until the review of the Strategy (Welsh Office, 1991) that plans were required to reduce the size of hospitals, with one of the core priorities being the provision of accommodation for adults in ordinary housing with a range of support. There was also an obligation to show how resources obtained through the closure of ‘inappropriate facilities’ such as hostels and long stay hospitals would be used to increase community services (Welsh Office, 1991). By 1990 housing provision had increased, but the majority of the places were taken up by people with learning difficulties who had been living either at home or in hostels. Hospital closure, with Health Authorities rather than Social Services as the lead agency, became a dominant factor only from the early 1990s onwards (Felce et al, 1998).

While the AWS moved slowly forward, elsewhere the rumblings of change in public perceptions of people with learning difficulties, and in their perceptions of themselves, was gathering pace. Taking a lead from America, a group of self advocates based at the London office of Mencap held a conference: ‘Speaking for Ourselves’ in 1982. People First in London and Thames was founded in October 1984 and hosted an International Self Advocacy Conference in 1988 and the inaugural UK People First conference took place in 1990 (Hersov, 1992). Shearer (1986) quotes delegates at meetings of various self advocacy groups, who stated definite views on this issue:

We have the right to be treated like any other human being, without being labelled retarded or subnormal.

We should do more things with people who are not handicapped so that they can get to know us.

(Shearer, 1986.182)

This new development was also noted by the International League of Societies for Persons with Mental Handicap (ILSMH) in their paper of 1984, which stated:

A new voice is beginning to make itself heard in our midst and demanding that we should listen. It is the voice of persons with a mental handicap.

(Shearer, 1986.177)
In hospitals also, residents with learning difficulties were finding their voice. 
Atkinson and Williams (1990) recorded the following instance where residents 
were dissatisfied with the meals provided for them:

W I just don't like the food....
D ...you've got to sort it out and discuss it with the people 
what lives up there... Then one of you has to ...speak to 
the staff. Make arrangements for a meeting...
(Atkinson and Williams, 1990.164)

Of course this type of advocacy must, by its very nature, be a two way process 
and the nursing regime in hospitals for people with learning difficulties, which had 
previously been 'essentially social and supervisory' (Mitchell, 2000.127), with 
individual nurses having 'considerable control over their own areas of work and 
significant power over the people with learning difficulties within those areas' 
(Mitchell, 2000.127), was gradually being replaced. Many learning disability 
nurses within the emerging system, possibly taking a lead from the Jay Report, 
saw their role as less authoritarian and more as enabling and supporting clients to 
speak out for themselves and to exercise the maximum choice possible, albeit 
within the confines of a bureaucratic system.

1.5 Nurse education
The new philosophy was reflected in changes in the syllabus of nurse education 
which took place at the time. Prior to this, the first 'mental deficiency' nurses had 
qualified in 1913 with an award from the Medico Psychological Association (MPA) 
and subsequently learning disability nurses qualified either through the MPA or 
through the General Nursing Council (GNC) (Mitchell, 2002.207). By the late 
1940s, with the NHS firmly in charge of hospitals for people with learning 
difficulties, the Royal Medico-Psychological Association relinquished any control 
over nurse training, which passed completely to the GNC (Mitchell, 2002). 
Between then and 1982, as learning disability nurses sought to define their role 
within the nursing profession, the emphasis of training for nurses working with 
people with learning difficulties was on 'patients' in hospital, and followed the 
medical model. The syllabus in place in 1970 (GNC, 1970.8) stressed 'the 
problems of the mentally handicapped' and the nurses' role in 'treatment', 'training' 
and 'management of behavioural patterns'. Counselling received a brief mention
under the section labelled 'psychological methods of treatment', but advocacy by
or for clients, with its implications of citizenship and equality was not officially on
the training agenda. As one nurse in this study remarked when asked if she had
received education in advocacy:

I trained in 1974 – need I say more?
(Pam group 1)

and another remarked that:

...it was unheard of when I did my training in the late 1970s.
(Paula, interview 1)

The recommendations of the Jay Report signalled the design and implementation
of a new syllabus of training for learning disability nurses, which marked a
'significant break from a medical to a social developmental model of care' (Brown,
1992.115), encompassing the notion that people with learning difficulties are
disabled 'less by their impairment than by the prevailing social, economic, cultural
and political climate. The implications of this for practice led to a shift in training
placements away from hospital to community settings (Brown, 1992.116). The
new syllabus was approved by the GNC and was implemented by the English and
Welsh National Boards, but, despite being known as the 1982 syllabus, it was not
introduced in all schools of nursing for some time after that date. In a move
possibly designed to overcome 'the worst effects of a traditional medical model of
treatment for those who were not ill' (Brown, 1992.116), the preface to the
syllabus, even in the changing climate of the times, was seen as radical. It
reflected the principles of the Jay Report (1979) and the All Wales Strategy (1983)
stating:

This syllabus is based on a philosophy of care that recognises and
accepts that people with a mental handicap have the same human
value as anyone else within society. Implicit in this statement are a
number of important principles that are reflected in the syllabus:

THE FIRST principle is that people with a mental handicap have the
same rights and, as far as possible, the same responsibilities as other
members of the community.

THE SECOND principle is that people with a mental handicap have a
right and a need to live like others in the community and to receive
services that meet their changing needs.
THE THIRD principle is that people with a mental handicap should receive additional help from professional services to allow the full recognition and expression of their individuality.

(General Nursing Council, 1982)

The preface went on to explain that the syllabus had been developed as a consequence of 'the rapid development in the care' of people with learning difficulties over the preceding decade, specifically to prepare student nurses to 'meet the demands implicit within the [new]...philosophy'. It took as its benchmark a version of Henderson's (1960) definition of nursing, specifically adapted for nurses working with people with learning difficulties:

The function of the nurse for people with a mental handicap is directly and skilfully to assist the individual and his (sic) family, whatever the handicap, in the acquisition, development and maintenance of those skills that, given the necessary ability, would be performed unaided; and to do this in such a way as to enable independence to be gained as rapidly and fully as possible, in an environment that maintains a quality of life that would be acceptable to fellow citizens of the same age.

(adapted for the 1982 syllabus from Henderson, 1960)

Thus, for the first time in the history of 'mental handicap' nursing, the 1982 syllabus placed considerable emphasis on clients' rights and their need for support from nurses in gaining these. Student nurses training during this period were required to be able to distinguish between clients 'needs' and their 'rights', including their 'right to be represented informally and legally' (p.18); to understand the concepts of a 'named person', a 'key worker' and 'advocacy'; and to demonstrate that they were able to 'represent people who are mentally handicapped' to acquire the 'same range and quality of services that are available to other citizens' i.e. to advocate for clients.

Since the 1982 syllabus there have been other changes in the education and training of learning disability nurses. The Project 2000 (P2k) syllabus reflected a move towards a more academic education and required all nurses to undertake a common 'core' during the first eighteen months, pursuing their chosen specialist areas mainly during the second half of their training. This syllabus has also been superseded, in Wales by the 'Fitness for Practice' syllabus, which commenced in
April 2002, and for which the Quality Assurance Agency benchmark states that ‘learning disability nurses’ work is underpinned by the concepts of inclusion, partnership and advocacy’ (QAA, 2001.8).

Social policies for people who have learning difficulties have also moved on. The Department of Health White Paper ‘Valuing People’ claims to be a ‘new strategy for learning disability for the 21st century’ (DoH, 2001), but applies only to England, while ‘Fulfilling the Promises’ (LDAG, 2001) is the equivalent paper in Wales, supposedly reviewing and building on advances made since the All Wales Strategy was initiated in 1983. Both these documents propose that people with learning difficulties must be at the heart of planning to improve their lives, suggesting the important role that advocacy and advocates might have both now and in the future.

1.6 Conclusion
This short history has illustrated how the circumstances of both people with learning difficulties and learning disability nurses have changed since the late 1970s, and are continuing to change. Expectations for both self advocacy and advocacy support, have burgeoned and continue to develop, and people with learning difficulties are increasingly eager to speak out. This research sought ways to give voice to them and to learning disability nurses about their experiences of advocacy and advocacy support. The following chapter discusses the methodology and methods involved in realising this intention.
Chapter two

Finding out: Methodology and methods
2.1 Introduction

The preceding chapter depicts the changing expectations of people with learning difficulties concerning advocacy. It also explains how learning disability nursing has moved from a situation in which nurses were expected to exert considerable power and control over people with learning difficulties and would seldom, if ever, be called upon to advocate for them; to their present role as facilitators of clients' independence. The account illustrates how learning disability nurses might now be expected, or even required, to advocate for their clients or to support and assist them in self-advocacy.

The naissance of advocacy for people with learning difficulties provided the rationale for this research, the overall aim of which was to explore the advocacy role of learning disability nurses. This chapter begins with a formal theoretical discussion of the methodologies which guided the design of the study. The qualitative/quantitative debate is outlined and the decision to use a mixed method approach is defended. A comparison of qualitative methodologies follows, and concludes that a grounded theory approach was best fitted for this particular study, offering the potential to incorporate the views of people with learning difficulties as the cornerstone of the research. The chapter continues with a comparison of different methods of implementing the grounded theory approach and concludes with an appraisal of Clarke's (2003) 'situational analyses' which:

....supplement basic grounded theory with situation-centred approaches that can enrich research by addressing and engaging important post-modern theoretical and methodological concerns about differences and complexities of social life

(Clarker, 2003.558)

and which offered a valuable method of explaining the varied and complex endeavours of advocacy in learning disability nursing.

Research among disabled people has been criticised as contributing to their oppression (Abberley, 1987; Oliver, 1992) but efforts are being made to combat this. The chapter continues with an exploration of issues surrounding the power differential in research with people who have learning difficulties, before
consideration is given to how guidelines for emancipatory, participatory and inclusive research impacted on the study design.

The second section of the chapter moves from an exploration of methodology to a discussion of methods. This signals a change from a formal, theoretical exposition in the third person, to a more practically based first person explanation of methods of data collection. Several possible approaches are compared before reasons are given for the choice of focus groups to obtain information from participants in stages one and two of the research. The practical aspects of choosing and accessing participants for stage one are discussed, and consideration is given to the ethical and practical issues surrounding the provision of information to participants with limited literacy skills, and also to obtaining their informed consent to participate in the research. Different ethical issues are discussed in connection with the stage two groups with learning disability nurses, in which information giving and obtaining informed consent were straightforward, but arranging for sufficient participants to attend the groups was considerably less easy. Where appropriate, reference is made to occurrences in the actual research although more detailed appraisal of the methods will take place later, within the presentations of each section of the study. The chapter continues with a discussion of the rationale for choosing to conduct a questionnaire survey and some practical issues relating to its implementation. In conclusion, it demonstrates how both qualitative and quantitative data, obtained through the questionnaire, further developed the grounded theory; completing the research on the advocacy role of learning disability nurses.

2.2 The qualitative/quantitative debate
The starting point in the design of the study was to find ways to capture the information which would answer the main research questions (section Int.6). Plans centred on using definitions of advocacy and their advocacy requirements, obtained from people with learning difficulties, as a basis for exploring the advocacy role of learning disability nurses. Participants in the study would therefore have a wide range of intellectual abilities. Those in the first stage would have a variety of learning difficulties, while those in subsequent stages would be qualified nurses with a span of grades ranging from D to G.
Initial decisions surrounding the design of the study centred on the quantitative/qualitative debate. Quantitative research involving the design of a questionnaire for use as the single research tool would have posed a problem, as there is very little published information concerning the advocacy role of the learning disability nurse on which questions might have been based. McNally (2002.191) discusses some specific limitations of survey research with people who have learning difficulties. These revolve around their possible problems with literacy which would almost certainly have made it difficult for them to understand and respond independently to a questionnaire. McNally also points out that, in survey research, ‘the researcher may be relying on ...supporters to convey the information about the study’ to potential participants. Even without potential barriers due to literacy problems, the study required to address, rather than subscribe to, issues relating to this type of overt power differential within the research process. A qualitative approach to stage one thus seemed most likely to acknowledge the particular expertise of participants with learning difficulties, without involving them in potentially difficult situations caused by lack of literacy skills.

Stage two of the research aimed to build on the data obtained in stage one, and to question nurses closely about their definitions of advocacy, their advocacy role and their educational needs concerning advocacy. Again a qualitative approach offered the maximum potential to do this. Nurses could discuss the definitions obtained from people with learning difficulties in stage one. They could compare and expand these with their own definitions and could consider their educational needs concerning advocacy both individually and within their employment groups.

Quantitative methods in the form of a questionnaire survey, which could be designed around the data obtained from stages one and two, offered the optimum chance of taking this information forward for consideration by a large number of learning disability nurses. The research thus became a three stage study with stages one and two following a qualitative methodology, while stage three relied on a mainly quantitative approach. The questionnaire, designed around the data obtained from stages one and two, allowed nurses to compare their own definitions of advocacy with those obtained from participants in the early stages. It
also facilitated the testing of tentative theories developed from stages one and two and the expansion of these theories with the inclusion of new data.

2.3 Choosing a methodology
Following these decisions, it was necessary to decide on a specific methodology for the qualitative stages of the research. The descriptive approach inspired by phenomenology, with its lack of assumptions about the existence or causal powers of social structures (Abercrombie et al., 1994) was unsuitable to an investigation in which the background of participants seemed likely to have a major effect on their views; and the dearth of available literature on the advocacy role of learning disability nurses indicated that the formal linguistic procedures of concept analysis would be unworkable. Ethnography, with its reliance on participant observation, and its concern with explanations of specific cultures (Hammersley and Atkinson, 1995) did not seem likely to satisfactorily address research questions involving several different cultural scenes. Action research, which involves ‘taking action to improve practice and systematically studying the effects of the action taken’ (Streubert and Carpenter, 1999.251), could be useful in future research concerning the advocacy role of learning disability nurses, but would be premature when the definitions of advocacy were not yet clear. The grounded theory approach, used successfully in many nursing studies (e.g. Knight, 1996; Premji and Chapman, 1999), seemed to have the most potential. It is particularly useful where previous research is sparse, can include various methods of data collection, and allows continuing verification of ideas and concepts throughout the research process (Strauss and Corbin, 1998, Munhall, 2001). Most importantly, the views of people with learning difficulties on advocacy and advocates could form the starting point on which the whole study would be built.

2.4 Grounded theory
Developed by Glaser and Strauss in 1967, grounded theory ‘challenged the hegemony of the quantitative research paradigm in the social sciences’ (Charmaz, 2000.511) current at that time. It differs from other research methodologies in that, rather than aiming to confirm or refute an existing theory i.e. hypothesis testing; it is ‘emergent’ (Glaser 1978), setting out to discover a theory (or theories) which can account for the subject of the research (Dick, 2004). A literature search using the databases Cinahl, Embase and Medline and the search terms ‘grounded
theory' and 'nursing research' revealed 457 records in the five years between 1999 and 2004. A further search using the 'Applied Social Science Index and Abstracts' (ASSIA) database, and the search terms 'grounded theory' and 'nursing' revealed sixty records in the same period, seven of which were specifically about the use of grounded theory in nursing research, rather than reports of studies in which the method had been used. These demonstrated some of the many different approaches to the method. Even Glaser and Strauss developed their ideas substantially from the original, and ultimately their approaches diverged (Glaser, 1992). More recently, grounded theory has been questioned, Glaser's version for its 'traditional positivism' (Charmaz, 2000.510) and both Glaser (1992) and Strauss and Corbin (1990) for their assumption of objectivity (Charmaz, 2000) and their commitment to 'the erasure of context, variation and complexity' (Clarke, 2003.556).

The main methodological question in research is concerned with how the enquirer should go about acquiring knowledge (Mathbor, 2002). It is thus dependent on the ontological and epistemological positions of the researcher. Grounded theory has its base in a symbolic interactionist ontology in which individuals define their situation in a variety of different ways, all of which are 'real' to the persons involved. Meaning is not assumed to be intrinsic to an object or idea, but is inter-subjective, being constructed through the interactions of people involved (Swingewood, 1991). Charmaz (2000.513) proposes that, in its original form, grounded theory endorsed a 'realist ontology and positivist epistemology' in which reality, as a true state of affairs, could be discovered by the enquirer, with the researched 'object' being independent of the researcher (Annells, 1996). Backman and Kyngäsi, (1999) disagree, arguing that grounded theory was always closer to the 'post positivist' inquiry paradigm, in which reality is considered to exist but can only be probabilistically discovered, although objectivity is still the epistemological ideal (Annells, 1996).

Glaser and Strauss (1967), Glaser (1978, 1992) and Strauss and Corbin (1990), concentrated their efforts on discovering 'reality'; maintaining that any intrusion of the subjectivity of the researcher into the research should be minimised. To achieve this ideal, Glaser insists that the researcher should not attempt to develop
theoretical sensitivity prior to entry into the field of research, but should be sensitised only by the actual data, which must then be allowed to speak for themselves, thus minimising researcher subjectivity (Heath and Cowley, 2004). Strauss and Corbin (1990) disagree, proposing that:

...researchers have learnt that a state of complete objectivity is impossible and that in every piece of research ....there is an element of subjectivity. What is important is to recognise that subjectivity is an issue and that researchers should take appropriate measures to minimise its intrusion into their analyses.

Strauss and Corbin (1990.43).

They recognise the problems for researchers of maintaining objectivity while also developing theoretical sensitivity, but argue that if objectivity is maximised research findings should be 'a reasonable, impartial representation of the problem under investigation' (Strauss and Corbin, 1990.53).

In both the positivist approach of Glaser and the post positivist approach of Strauss and Corbin there may be very little connection between the researcher's thinking and the experiences of the people who are involved. The tendency is to at least attempt to treat participants as objects to be investigated. The researcher is assumed to be capable of studying the 'object' while exercising minimal influence on it, and also being minimally influenced by it. Thus findings are expected to be value free (Mathbor, 2002).

Contemporary moves towards postmodernism have led to criticisms and reassessments of the positivist/post-positivist assumptions of grounded theory, by 'new paradigm' researchers, typified by that of Clarke who argues that:

Most research has relentlessly sought commonalities of various kinds while evading and avoiding representations of the complexities, messiness and denseness of actual situations and differences in social life

(Clarke, 2003.556)

They challenge the positivistic, technocentric ideas of 'modernist' researchers and their belief in 'linear progress, absolute truths ...and the standardisation of knowledge' (Harvey, 1990.9). They argue that research must be transactional and
subjectivist, with the values of the researcher inevitably influencing the research; and that, rather than seeking objectivity, good research is both reflexive and inclusive (Mathbor, 2002). Practically, these criticisms have led many social researchers away from grounded theory, but others (e.g. Kools et al, 1996; Freshwater and Avis, 2004; Eaves, 2001) have developed and enhanced the methodology bringing fresh ideas, particularly to the analysis of the data, (Eaves, 2001; Clarke, 2003), its interpretation, (Freshwater and Avis, 2004) and the incorporation of reflexivity and relationality between researchers and participants in the study (Hall and Callery, 2001).

The process of analysis is central to all approaches to grounded theory, which depend for their success on constant interaction between the researcher and the data driving the research forward. In their original conception of grounded theory, Glaser and Strauss (1967) concentrated their analytical efforts on ‘building scientific facts’ (Glaser, 1992.30) from data which were treated as ‘reproductions of reality’ (Hall and Callery, 2001.258). The method relies on constant comparative analysis (Figure 2).

![Figure 2: Glaser and Strauss (1967) – Emergent Model](image)
Data is coded by asking the questions ‘What is the situation?’ ‘How is the person managing the situation?’ Data set is compared with data set and later compared to the emerging theory (Dick, 2004.6). Categories emerge which make sense of what informants have said and, in time, one, or sometimes more than one, category will be mentioned with higher frequency than others. If it is also well connected to the other categories, this becomes the core category (Dick, 2004). Coding and categorising are supported by memoing and, as categories emerge, they are strengthened by theoretical sampling which defines the properties of categories and explains the relationship between them. Saturation is achieved when data is adding nothing to what is known about a category, its properties and its relationship to the core category. When all categories have saturated, coding ceases and the accumulated memos, codes and categories will capture the different aspects of the theory which has emerged from the data (Dick, 2004).

Stressing the simplicity of this method, Glaser remarked that:

Using the constant comparative method gets the analyst to the desired conceptual power quickly, with ease and joy. Categories emerge upon comparison and properties emerge upon more comparison, and that is all there is to it.

(Glaser, 1992.43)

He espoused the view that Strauss and Corbin’s methodology entailed ‘forcing’ the data rather than allowing a grounded theory to emerge (Melia, 1996). Certainly the analytical methods (figure 3) of Strauss and Corbin (1990) are much more complicated and prescribed than those of Glaser and Strauss (1967). Where the starting point for Glaser is ‘What do we have here’, Strauss asks ‘what if...?’ and considers any possible contingency that might relate to the data, whether it appears within the data or not (Stern, 1994.220). This departure from the original formulation of grounded theory led Glaser to refer to Strauss and Corbin’s methodology as ‘full conceptual description’ (Glaser, 1992.123) rather than grounded theory; and there has been considerable debate concerning the merits of the different approaches.

The starting point for Strauss and Corbin is open coding and, following the development of preliminary basic categories, the method proceeds with axial
... is a complex process of inductive and deductive thinking... making comparisons and asking questions... [the]... procedures are focused, and geared toward discovering and relating categories ...

(Strauss and Corbin, 1998.114-5)

Figure 3: Strauss and Corbin (1990) – Full Conceptual Description Model

Categories are formed from previously coded data that seem to 'cluster' according to obvious fit (Streubert and Carpenter, 1999.110) and further development of the grounded theory depends on theoretical sampling of 'information rich' participants to focus on specific gaps or possible misapprehensions in the developing theory. Systematic analysis of the resultant data forces the researcher to make changes to the theory so that new phenomena can be incorporated (Seale, 1999). Streubert and Carpenter (1999.110) suggest that, at this stage, 'three major steps expand and define the emerging theory: reduction, selective sampling of the literature and selective sampling of the data'. The reduction of many clusters of
categories into broad themes, and their comparison with concepts selected from carefully scrutinised and relevant literature and from elsewhere within the data, refine and integrate the major categories, enabling the various schemes to merge into a major theory (Strauss and Corbin, 1998). Selective coding, which represents the final step of the analysis, is defined by Strauss and Corbin as:

> The process of selecting the core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development.  
> (Strauss and Corbin, 1998.116)

It may be necessary at this point to choose between two or more significant phenomena, but Strauss and Corbin (1998.121) insist that this is essential 'in order to achieve the tight integration and the dense development of categories required of a grounded theory'. They propose that the criteria for developing this 'core' category should not only 'fit and describe' the phenomenon, but should also be 'broad enough to encompass and relate, as subsidiary categories, to all the other categories'. The core category, they insist, 'must be the sun, standing in orderly, systematic relationships to its planets' (Strauss and Corbin, 1998.124).

### 2.5 The synthesis technique

There have been attempts to simplify the methods of Strauss and Corbin (1990), to update grounded theory methods and to address the inconsistencies noted in published reports purporting to use grounded theory (e.g. Eaves, 2001; Clarke, 2003). Eaves (2001) addressed the possibility that complicated explanations relating to practical methods, and consequent shortcomings in the use of grounded theory, may have become equated with weaknesses inherent in the method. Her synthesis technique for data analysis, is based on the work of five established grounded theorists – Glaser and Strauss (1967); Charmaz (1983); Chesler (1987) and Strauss and Corbin (1990). Despite its complex appearance (figure 4), the technique is relatively simple, although Eaves emphasises that, unlike a diagrammatic representation, the method is not linear and that 'at any one time the grounded theorist is in various stages of the process' (Eaves, 2001.657). The method lends itself to the use of qualitative data analysis software packages such as NVivo, for coding and reduction of the data into categories, and the substantive theory is certainly 'emergent' (Glaser, 1992).
Nonetheless, the synthesis technique adheres to modernist aims of simplification, homogeneity, regularity, generalisation and permanence (Clarke, 2003) in qualitative research and does not address post-modern concerns as to how the complexities and disarray of contemporary social life might be satisfactorily represented by research.

2.6 Situational Analysis
These issues are the focus of Clarke's (2003) situational analyses and mapping. Clarke states her goal as being 'to renovate and regenerate the grounded theory method toward new approaches to grounded theorising' (Clarke, 2003.558).
She aims to do this mainly by:

Supplementing the traditional grounded theory analysis of a basic or key social process (action) with multiple alternatives centred on cartographic situational analyses emphasising:

- Maps of key elements of the situation, variations and differences
- Maps of social worlds and arenas in meso level discursive negotiations
- Maps of issues and discursive axes focused around difference(s) of positionality and relationality.

(Clarke, 2003.559)

Figure 5: Clarke (2003) - Situational Analysis Model

Clarke, (2003) argues that although Strauss and Corbin's (1990) model of grounded theory attempts to engage the researcher in consideration about how contextual elements affect what is going on in the research situation, their reductionist methods of doing this are 'inadequate to the task'. Her mapping technique aims to supersede their approach and to 'offer instead the considerably
more elaborate situational analysis’, in which ‘the situation itself is a key unit of
analysis’ (Clarke, 2003.559).

Clarke’s approach (figure 5) can be used with coded or uncoded, but carefully
read, data. She stresses that ‘the maps produced are not necessarily intended to
form final analytic products…. Their most important outcome is provoking the
researcher to analyse more deeply’ (Clarke, 2003.560). Once the maps are made,
the researcher asks questions about each item by taking each element in turn and
relating it to all other elements on the map. This can be accomplished mentally or
literally by drawing connecting lines between the elements and ‘specifying the
nature of the relationship between the elements by describing the nature of that
line’ (Clarke, 2003.569).

Figure 6 illustrates how one such map acted as a guide to analytical thinking and
demonstrates why the method was particularly suited to the analysis of data in this
study. Rather than reducing relationships within advocacy to the ‘most important’
and subsidiary categories, the map acts as a tangible illustration of the nature of
all relationships mentioned in the research and gives examples of their effects
within the context of the nurse/client advocacy situation.

As in previous grounded theory methods, ongoing, simultaneous, memoing is
-crucial, and can be used to answer theoretical questions or to suggest new
questions, possibly leading to theoretical sampling. Saturation occurs when:

You have worked with your map many, many times….You can talk at
some length about every entry and its relation to …other entries….You
don’t think you have missed anything….You think these are the most
important elements….The final test is this: If some disaster wiped out
your computer files and your notes, and all you had left was this piece
of paper, could you work your way back into all the major stories you
want to tell about this situation?

(Clarke, 2003.571)
Clarke (2003) compares situational mapping with the Pompidou Centre in Paris in which all the utilities, rather than being concealed between the inner and outer walls are clearly discernable, attached to the exterior of the building. She explains that the maps make the ‘usually invisible and inchoate social features of the situation more visible’ (Clarke, 2003.572). Rather than reducing the data and
‘pinning it down’ to just one or perhaps a small number of ‘important’ issues, the maps and subsequent analyses reveal all the complexities of the phenomena of interest: their situation and interrelations, the specific social arenas in which they take place and the discursive positions of all the key actors involved. This made Clarke’s approach particularly attractive. The definitions and opinions about advocacy obtained from people with learning difficulties in many different circumstances, and those of learning disability nurses from a wide range of work situations, subjected to constant comparative analysis at each stage of the study, could be brought together figuratively and literally, making it easier to grasp the convoluted nature of the advocacy role of learning disability nurses.

2.7 The place of literature in grounded theory

Just as there have been, and continue to be, disagreements regarding the analysis of data, so there are similar disagreements, sometimes between the same protagonists, about the place of literature in grounded theory. As the method, in all its forms, is inductive, it does not rely on proving some hypothetical theory, and Glaser (1978) proposes that the researcher should therefore have as few preconceived ideas about the research phenomena as possible, to minimise the risk of a biased interpretation of the data. Strauss and Corbin (1990.48) comment realistically that researchers will probably have a background of ‘professional and disciplinary literature’ before commencing the study, and are likely to discover numerous other sources of literature as the research proceeds. They argue that, while it is not necessary or advisable to ‘review all the literature in the field beforehand’ (Strauss and Corbin, 1990.49), some prior knowledge of pertinent writings will expose salient problems and can also increase theoretical sensitivity. Cutcliffe (2000.1480) speculates that this depends on the starting point of the research. He proposes that if the position is “what do we know about this phenomenon?” initial gathering of relevant literature can identify gaps in knowledge, or help provide a rationale for the research. Alternatively, if, as in this study, the starting point of the research is recognition of a dearth of knowledge concerning the phenomenon i.e. the advocacy role of learning disability nurses; there may still be value in reading literature which can assist in conceptual clarification i.e. literature about advocacy in nursing generally. This might help the researcher to reach conceptual density, enhance the richness of concept
development (Strauss and Corbin, 1990) and aid the process of theory development (Cutcliffe, 2000).

Strauss and Corbin (1994) and Glaser (1978) agree that a second review of the main literature is necessary but disagree about when this should take place. Glaser (1978) argues that it should be kept in abeyance until the theory has emerged from the data, but Strauss and Corbin suggest that selective sampling of the second body of literature should be woven into the emerging theory during the 'concept development' stage of the study (Strauss and Corbin, 1990). McCann and Clark agree that this gives certain key benefits:

- It is a useful secondary source of data
- It gives rise to questions about the data
- It aids validation of the emerging theory
- It is an important means of theoretical sampling

(McCann and Clark, 2003)

Clarke (2003) concurs with this view and considers literature to be important to grounded theorising. She views literature as a research site and includes it in her situational mapping, stressing that 'multisite research' is very much part of her research design which, in addition to transcripts and field notes, might also include 'discursive textual, visual and archival historical materials and documents'. These will, she argues 'more fully take into account the sea of discourses in which we are continually awash in the post-modern era' (Clarke, 2003.559).

In this study, literature relevant to advocacy in nursing generally was reviewed prior to writing the research proposal and presenting it for registration to the School Committee. This gave some background to the study; and was repeated during the transfer process from MPhil. to PhD. A literature search using the databases CINAHL, Embase and Medline with the search terms 'advocacy' and 'learning disability' revealed 120 references in the ten year period between 1992 and 2002, but only 16, some of which were small news items, over the same period when the search term was narrowed to 'advocacy' and 'learning disability nursing'. In the main, relevant literature was accessed as part of the 'theoretical
sampling' which is very much part of a grounded theory study. Literature was chosen that:

Illuminates, supports or extends’ the proposed theory.... Through its correspondence with the real world, [it] ... establishes an essential connection between theory and reality.  
(Hutchinson and Wilson, 2001.233)

The databases CINAHL, ASSIA, Medline and Embase were used extensively for theoretical sampling of the main themes which emerged as the study progressed. The searches generally covered the five years between 1999 and 2004 with search terms reflecting the relevant themes, for example: ‘power and empowerment’, ‘relationships’ and ‘advocacy education’. Following the advice of Strauss and Corbin (1990) and Clarke (2003), pertinent samples from the literature were woven into the discussion, thus expanding the emergent theories.

2.8 Theoretical sampling
Literature is not the only source of theoretical sampling. Strauss and Corbin define the latter as:

Data gathering driven by concepts derived from the evolving theory and based on the concept of ‘making comparisons’, whose purpose is to go to places, people or events that will maximise opportunities to discover variations among concepts and to densify categories in terms of their properties and dimensions.  
(Strauss and Corbin, 1998.201)

Theoretical sampling differs from purposeful sampling which takes place before the researcher has begun to collect and analyse data, at a time when there is no evolving theory which can act as a guide (Cutcliffe, 2000). It is a fundamental strength of inductive methods, allowing questioning of the initial data and encouraging development of a dense description of the particular areas under consideration. Clarke (2005) suggests that a ‘very very important’ direction for theoretical sampling consists of pursuing ‘sites of silence’ which seem to be present in the data, but have not been overtly articulated. This may involve re-interviewing informants considered to be particularly ‘data rich’, and, without putting words into their mouths, finding ways to uncover the situations of concern. There can be problems with this, particularly in research which, due to the nature
and/or situation of its participants, must be approved, perhaps by Ethics Committees, before its commencement. In such circumstances, the researcher must build into the study design the possibility of accessing participants, who may be unknown at the outset of the study, and interviewing them outside the confines of the original interview settings.

2.9 Reflexivity in grounded theory
Gaining access to suitable informants is just one of many problems which may affect the researcher-participant interaction during the study. Hall and Callery propose that:

Reflexivity, which addresses the influence of investigator-participant interactions on the social process, and relationality, which addresses power and trust relationships between participants and researchers, have the potential to increase the validity of the findings in grounded theory studies.

(Hall and Callery, 2001.258)

This has not always been considered to be the case. Glaser and Strauss (1967) and later, Strauss and Corbin (1990) acknowledged ‘the investigator’s vital and creative role in the production of grounded theory’ (Hall and Callery, 2001.259), but also stressed the importance of objectivity, and did not extend their view to include the implications of the interaction between researcher and participants on the production of the data. Subsequent critiques of grounded theory have recognised the necessity to move on from this positivist/post-positivist view and have emphasised the importance of reflexivity on grounded theory studies.

Lincoln and Guba define reflexivity as:

The process of reflecting critically on the self as researcher…. It is a conscious experiencing of the self as both inquirer and respondent…. as the one coming to know the self within the processes of the research itself.

(Lincoln and Guba, 2000.183)

They express the opinion that objectivity is a ‘chimera: a mythological creature that never existed, save in the opinion of those who believe that knowing can be separated from the knower’ (Lincoln and Guba, 2000.181). Clarke agrees and her
situational analyses acknowledge the acceptability of reflexivity in social research. The focus is on post-modern 'problematics' concerning the 'political nature of research practice and its interpretation; and on enhanced reflexivity on the part of researchers, and increasingly, on the part of those researched' (Clarke, 2003.555). Clarke also addresses the 'crisis of representation' and the de/repositioning of the researcher 'from all knowing analyst to acknowledged participant in the production of always partial knowledge'.

These points were particularly relevant when research informants had learning difficulties and were unaccustomed to participation in research, which could have been daunting for them. Lincoln and Guba succinctly summarise the advantages of 'new paradigm research' in which:

...control is a means of fostering emancipation, democracy and community empowerment, and of redressing power imbalances such that those who were previously marginalised now achieve voice.

(Lincoln and Guba, 2000.175)

Giving voice to participants in grounded theory research shows a definite move away from the objective 'scientific' research reports of early grounded theory researchers and towards 'messy texts' which 'seek to break the binary between science and literature' (Lincoln and Guba, 2000.184).

Increasingly grounded theorists are turning their backs on:

strict separation of method from findings and findings from interpretation; strict accounting of steps followed for data collection and analysis, and recurring appeals to significance and validity.

(Sandelowski, 1994.53)

Confirming this, Frank (2004) argues that it is not possible for research to arrive at the truth, but that research reports must aspire to telling a truth. This may be difficult, and may require persuasion that:

The post-modern sense of truth does not require an explanation that counts as a solution; post-modern truth sees too many perspectives to accept the closure of an explanation.....

(Frank, 2004.439)
Nurse advocacy is constantly developing and changing and research could not result in one finite explanation, but messy and complex reports require creativity from their author if they are to be acceptable to those entrenched in academic positivism. Overcoming fear of complexity is no small thing, but it results in gaining ‘the power to see what is and to say what is’ (Frank 2004:439). In this study, the intention guiding the use of grounded theory, following a post modern philosophy and augmented by situational analyses and mapping, was that researcher and participants should share this power.

2.10 Addressing the power differential: emancipatory, participatory and inclusive research

Traditionally, the power differential in research among disabled people, whatever their impairment, tended to contribute to their oppression, taking place according to the positivist tradition in which a powerful distinction was drawn between researcher and researched. The researcher, assumed to have specialised knowledge and skills, decided what topics should be researched and controlled the whole process of research production, from design right through to dissemination (Oliver, 1992). (S)he thus took up a super-ordinate position in relation to the informants, who were viewed simply as passive objects, lacking in expertise, to be acted upon in the course of the research (Park, 1993). Within disability studies the positivist research paradigm reinforced the medical model of disability, asserting that social phenomena could be satisfactorily explained only in terms of ‘facts’ about individuals. Disability was regarded as a ‘personal tragedy’ in which ‘problems’ were firmly located within the disabled individual, rather than in the failure of society to adapt to the needs of disabled people (Oliver, 1992).

Despite, or possibly because of its wide use, the value of positivist research amongst disabled people has been questioned, mainly by disabled academics who have, of course, interests in both the research process and its outcomes. Oliver (1992) argues that, according to the ‘social engineering’ paradigm, the publication of ‘facts’ obtained through positivist disability research, (for example, that x percentage of disabled people live in poverty), should force politicians to introduce policies for improvement (for example, provision of a ‘disability income’),
but this supposition has not proved justified. As Park (1993) argues:

Knowledge produced by traditional [i.e. positivist] social sciences ignores the fact that humans gain social knowledge through interaction as co-members of society, and it is therefore not likely to be valid in the instrumental sense of being practically useful. This undoubtedly is the reason why social sciences have been dismally unsuccessful in predicting and controlling social phenomena...

(Park, 1993.5)

Such harsh criticism has led to widespread opposition to the positivist approach, voiced by (mainly physically) disabled people. They argue that research following a positivist methodology is irrelevant to them, taking no account of the real, lived experiences of people with impairments, or of the social restrictions imposed, not by their disability, but by society. They propose that positivist research has neither acknowledged nor met the needs of disabled people and has failed to provide either understanding of, or adequate solutions to, their problems (Oliver, 1992).

Realisation of the deficits of positivist research led social scientists towards an interpretative methodology which those responsible for disability research were initially, possibly due to the persistence of the 'medical' account of disability, slow to adopt. The concept is based on an inductive model which stresses the significance of interpretation and understanding to research involving the social world (Hamilton, 1994), and recognises that people's reality is governed by society in which they hold multiple social roles (Felske, 1994). Objectivity and distance, which are the goals of positivist research, are replaced by face to face interaction between researcher and informants, with the researcher attempting to engage as fully as possible with the minds of participants in the study (Lofland and Lofland 1995). Interpretative research is largely based on ethnographic methods, namely interviews and participant observation and has led to a significant rethink away from the 'personal tragedy' model of disability and towards a definition of disability as the social exclusion of people with impairments (Goodley, 1999). Despite this, it has seldom resulted in practical improvements and still relies, although in a somewhat muted way, on the traditional power differential between researcher and researched in which 'only the researcher, the expert, learns, while the people who make the learning possible are left empty-handed' (Park, 1993.3).
Abberley (1987.7) proposes that any analysis of the oppression of disabled people involves ‘pointing out the differences between their lives and those of other sections of society, including those who are in other ways oppressed’. Such differences are evident amongst disabled people themselves. As Walmsley (2001) points out:

Disabled people, like others, vary in the degree of power they may wield, and most people with learning difficulties are particularly disadvantaged, even in comparison with other disabled people. (Walmsley, 2001.199)

As people with physical impairments increasingly speak out against oppressive practices, a ‘hierarchy of disability’ has become apparent, in which people who have learning difficulties are seen as different, and therefore lesser, by many people who have physical disabilities (Deal, 2003). Research among ‘wheelchair’ athletes (Llewellyn, 1995) demonstrated their discriminatory and scornful attitudes towards athletes who were different by virtue of their learning difficulties, and personal experience has demonstrated that, while clubs, sports centres and even churches frequently welcome physically disabled members, they have, often on the flimsiest of grounds, denied membership to people who have learning difficulties.

Possibly because of this type of discrimination, the inclusion of learning difficulties into the arena of disability studies is a comparatively recent occurrence. Walmsley suggests that the development of normalisation during the 1970s eventually supplied ‘the conditions to make speaking out [by people with learning difficulties] possible’ (Walmsley, 2001.188). These conditions were enhanced by the widespread replacement, in the 1990s, of the term ‘mental handicap’ by ‘learning disability’, or ‘learning difficulty’ (Walmsley 2001), encouraging disability researchers to see learning disability as a fit subject for their studies (Walmsley 2001.89), and to align themselves with other disability groups in asserting the need for research specifically based on the experiences, expertise and ambitions of disabled people. Goodley (1999) explains that:

Disability research should be about research with rather than for or on disabled people, if research is not constructed through participation it
will confirm rather than challenge existing social constructions (italics in original).

(Goodley, 1999.27)

This was a major turnabout from more traditional research methodologies. Its proponents noted the similarities with feminist research methodologies, which aim to subject the power structure of a patriarchal society to question and, by revealing hidden areas of dominance within society, subject these to direct and public scrutiny and challenge. Like feminists, many disabled people acknowledge that it is their differences from other members of society that lead to discriminatory practices. In the field of learning difficulties, self advocates are particularly aware of this. Self advocacy groups support people with learning difficulties to work towards overcoming their oppression by increasing public awareness and making their presence felt within their communities in a positive manner.

Emancipatory, participatory and inclusive research methodologies in disability research enable disabled people to make a positive contribution to knowledge. They aim, not only to question the structure of standard research practices, but also to acknowledge and respect the particular expertise and experience of disabled people. The methodologies highlight and transform the unequal power relationships inherent in both positivist and interpretative research, and also those which exist between disabled and non disabled people in contemporary society (Stone and Priestley, 1996).

The goals of this research were framed using the social model of disability mentioned in the previous chapter (section 1.5). Socially constructed barriers were removed by using definitions of advocacy and the perception of their advocacy needs, obtained from people who have learning difficulties, as the crucial starting point for an exploration of the advocacy role of learning disability nurses, with a view to informing their advocacy education and practice. However, despite the fundamental nature of the information gained from people with learning difficulties in relation to the rest of the study, for reasons which are explained in the following chapter (section 3.2), the research fell far short of the conditions required to fulfil either the emancipatory or participatory ideals.
Walmsley allies participatory research with the principles of normalisation and uses the term 'inclusive' research to describe a participatory approach specific to research with people who have learning difficulties. She agrees that, in the emancipatory model, the expectation is that disabled people should be in full control, but argues that, in participatory/inclusive research and 'in normalisation terms, the non-disabled researcher has a legitimate role as ally or advocate' (Walmsley, 2001.197). Walmsley argues that:

...the key issue here is power. Whilst disabled people can and do conduct their debates without reference to members of the oppressing groups [i.e. the non-disabled], people with learning difficulties still rely on a team approach, and few have been able to argue that without this team approach, people with learning difficulties would be in a position to research and publish.

Walmsley, (2001.200)

The reference to publishing might be seen to imply a somewhat narrow focus on the production, through research, of technical knowledge, but Park (1993) argues that 'instrumental knowledge' such as that produced by conventional research, can be complemented by interactive knowledge which is accomplished by 'conversations in which we talk with personal feelings and listen with interest and supportiveness' (Park, 1993.6). Participatory/inclusive research complies with this and also addresses situations in which the 'non-initiated' are unable to take part in research due to their lack of the 'specialized language of argumentation' (Park, 1993). Studies following this methodology entail the researcher and researched being involved as equal partners, but not necessarily in the same way, in the research. Thus the expert knowledge of people with learning difficulties on their condition can be shared on an equal basis with the expertise of the researcher, resulting in critical knowledge (Park, 1993) and, possibly, action towards the common good.

Kiernan (1999.45) proposes that the differences between emancipatory and participatory research are 'more a matter of emphasis than kind', and both models involve the intention to raise the profile of people with learning difficulties participating in research. However, emancipatory research suggests complete control by disabled people which would not have been possible in this research,
where they were equal partners, rather than sole participants in the study. Inclusive research, which acknowledges the particular expertise of people with learning difficulties having experience that can only be acquired by those with impairments living in a disabling society, enabled them to share their definitions of advocacy and their ideas concerning their advocacy requirements. Used as the foundation for further research with (non-disabled) nurses these provided a crucial element to the study and challenged the assumption of ‘the problem’ of learning disability. They should also enhance the status of people with learning difficulties amongst those to whom the results are disseminated, which might contribute to their fight against discrimination and oppression.

Data collection: Stage one

2.11 Rationale for choosing focus groups
Having considered the methodological issues relevant to this research I shall now turn to the more practical concerns surrounding data collection from the participants in the study. My intention when aiming to adhere as closely as possible to an inclusive ideal within the grounded theory approach to the first stage of this study was that I should gain a thorough and verified understanding of what advocacy means to people with learning difficulties, which would drive the research forward. Choosing a suitable method of data collection demanded some deliberation. Participant observation requires an element of ‘sameness’ between the observed and the observer and the presence of the observer in ‘data-yielding’ situations. Where I could perhaps have used this method to explore situations where advocacy was used by participants, their initial definitions of the concept, which were to be the cornerstone of the research, required a more explicit investigation. One to one interviews, which could have yielded useful information, might be daunting to participants who were unfamiliar with both me and the research process. In my role as Board Member of a Housing Association I had gained satisfactory, if limited, experience of focus groups with people who have learning difficulties, and, after studying the literature, I chose this as my preferred method, with the possibility of back up through informal interviews if necessary.

Focus groups are a particular form of group interview, which rely less on the alternation of the researcher's questions and the responses of group members,
than on interaction between participants; the synergistic effect of the group setting often resulting in the production of data and ideas that might not have been uncovered in individual interviews (Stewart and Shamdasani, 1990). Experience has shown that focus group members are likely to feel relatively empowered and supported by the group dynamic, and may be more likely to share feelings and insights in the presence of people they perceive as being like them in some way (Farquahar (with Das) 1999.47). Relevant to my research, focus groups have been found to be especially useful when working with categories of people who have historically had limited power and influence (Morgan and Krueger, 1993.15). They have been effectively used with people of varying intellectual abilities (e.g. Kerr et al, 1997; Pavis et al, 1996) and also specifically with people who have learning difficulties (e.g. Ippoliti et al, 1994; Fraser and Fraser, 2001; Barr et al, 2003).

In order to obtain several, possibly different, perspectives on advocacy and advocates, I decided to conduct three sets of focus groups: the first with residents at a long-stay hospital for people with learning difficulties, the second at a day centre and the last with members of a self-advocacy group. Morgan and Krueger (1993.6) suggest that there has been an 'overly rigid restriction' on running focus groups with participants who know each other, due to the possibly inhibiting effect of existing relations between group members. However, Kitzinger and Barbour (1999.8) point out that the 'naturally-occurring group, is one of the most important contexts in which ideas are formed'. For participants with learning difficulties, unused to the methods of research, and to whom the researcher may be unknown, the familiarity of participants with each other seemed more likely to be an advantage than to 'breed contempt'. I anticipated that it would decrease my need to constantly ask questions to encourage them to give opinions, thus lessening any perception of a power differential between myself and the focus group members; this being already considerably less obvious in a group situation than in observably researcher-led one to one interviews.

2.12 Ethical issues and accessing participants
Having decided to use focus groups for data collection with people who have learning difficulties, I needed to address ethical issues concerning the choice of
participants, accessing them through 'gatekeepers', providing them with information, obtaining their informed consent to both the process and the specifics of the research and maintaining their confidentiality. Due to the design of the study, participants needed to have a reasonable degree of conventional verbal communication skill and some knowledge of advocacy. I considered this to be an unavoidable limitation of the research design. People with severe and profound learning disabilities and very limited or alternative communication skills may have had a great deal to offer, particularly in terms of their own need for advocacy. However the development of sufficient accurate understanding of such individuals would have taken both a degree of specialist skill and a huge amount of time not available to me. After much heart searching, I decided that an attempt would be made to gain some understanding of the possible status of advocacy in the lives of people with severe communication difficulties by asking participants with learning difficulties if and how they became involved, as advocates, for their peers who do not speak. I would also recruit nurses who worked specifically with this client group for focus groups in stage two of the study.

Gaining access to potential participants with learning difficulties was a three tier process. Formal approval for the research was initially agreed by the School Ethics Committee and later, after a somewhat convoluted process, by the Local Research Ethics Committees of the two Health Authorities covering the areas in which the participants lived. Negotiations then involved approaches by telephone and letter to professionals within the research settings i.e. a senior nurse manager in the appropriate NHS Trust, the manager of the day centre and the facilitator of the Self Advocacy Group. The phone calls outlined the purpose and methods of the study to the 'gatekeeper' in each setting. When they expressed interest, an information pack was sent, containing a copy of the research proposal, several copies of the information booklet about the study (appendix 1) and a copy of the consent form which the LREC required from each participant (appendix 2). The pack also contained a copy of the appropriate confirmation letter from the LREC. I requested a meeting with possible participants, so that I could explain the research to them in more detail and ask them if they would be willing to take part. Using gatekeepers in this way had the disadvantage of my reliance on professionals to determine who might be potential participants, and could be seen as diminishing
the autonomy of people with learning difficulties. However, individual service users were unknown to me, and I did not assume that obtaining an introduction to possible participants and permission to proceed from relevant professionals automatically meant that individuals with learning difficulties would consent to take part in the study.

Stalker (1998.8) notes that although gatekeepers do not usually assume that individuals with learning difficulties will take part in research, they do have power to block access to certain clients. My first approach to the suggested professional in the hospital met with a negative response but, after taking advice, a second attempt, to a different professional, yielded the names of four potential participants who, in an echo of Stalker's (1998.8) experience, the gatekeeper assumed, even before my meeting with them, would agree to take part. From the outset, the manager of the day centre did not assume that any of the day centre clients would be willing to take part, but arranged meetings for me to meet clients who were then free to decide whether or not to participate. My approach to the coordinator of a People First group also met with willingness to arrange a meeting for me to meet the self advocates, who could then decide whether or not they would participate in the study.

The information booklet which I provided for all potential participants with learning difficulties (Appendix 1) was specifically designed with simple text and illustrations in a manner described by other researchers in this field (e.g. Goodley, 1999; Bashford et al, 1995; CHANGE, 1999). It was piloted, after some bureaucratic problems (Llewellyn, 2002) (appendix 13) by an acquaintance with learning difficulties, to ensure that it would be accessible to those participants who might have literacy problems. As the study would follow a grounded theory methodology, it was not possible to provide more than an overview of the research at this stage. The booklet therefore concentrated on the task focused partnership between me (the researcher) and the potential participants. If they agreed to meet me, I could then elaborate on the information already provided, answer any questions that arose and, if they were agreeable, arrange dates, times and the venue of focus group meetings.
The information booklet was used by gatekeepers as a basis for preliminary discussions between themselves and potential participants. Introductory meetings were then arranged between those who were interested and myself. Using the booklet as a framework, many of the prospective informants asked pertinent questions and we were able to discuss the conduct and timing of the groups and consider possible venues. The introductory meetings gave me a chance to assess the verbal communication and social skills of the group members. I was able to decide in advance how the group should be seated to gain maximum interaction and also to consider the intellectual level at which questions should be posed, and whether the use of focusing exercises would be appropriate. I also felt that potential participants, having discussed the provided information with both the 'gatekeepers' and with me, could decide on a truly informed basis whether or not they would like to take part in the study.

In qualitative research, and particularly in studies following a grounded theory approach, some of the necessary information regarding the conduct of the study will emerge during the research rather than being known in advance. Initial informed consent can thus only be consent to the process of the research itself (Behi, 1995). The consent form (Appendix 2) was designed in 'tick box' format with simple statements which could be read by or to the participants, who could then indicate agreement by ticking the appropriate boxes on the form. Unlike the experience of Rodgers (1999), the LREC had agreed that the participants themselves could indicate their consent to participate on the approved forms, and, beyond the courtesy of informing consultants in the hospital that the research had been approved and would take place there, no other professional was actively involved in the consent process. Where possible, individual participants were asked to sign the consent form, but, if they were unable to do this, with mutual agreement, their supporter signed the form in their presence and on their behalf. Ongoing informed consent to the research was sought verbally before the start of each focus group session. Participants were reminded what had been discussed previously and told what the focus of the impending session would be. They were asked if they were still willing to participate and reminded that there was no compulsion to do so. Prior to each session, permission was also sought to tape record the proceedings and participants were reminded of their duty of
confidentiality within the group. This was reiterated at the end of each session, when the proceedings were summarised and participants were reminded that they could withdraw any untoward comments from the report of that group meeting.

2.13 The participants
Fraser and Fraser (2001) suggest that, in focus groups where people may have speech and comprehension difficulties, a relatively small number of participants is most likely to yield a satisfactory outcome. Following this advice, and after discussion with others experienced in the focus group method, I decided on a maximum of six members at each session. This would afford enough opportunity for all individuals to participate actively in the group. It would also give me a chance to preserve a balance between uncommunicative and over talkative members and to dissuade group members from straying from the point under discussion. Six members is an ideal however, as is a mix of gender, age and ethnicity. As I was reliant on gate-keepers to introduce me to potential participants from the different service settings I had very little idea or control over who the prospective members would be until the introductory groups took place. All the participants were white and the majority of group members in all the sessions were male. Jackie Downer, (who herself has learning difficulties) has said that in her attendance at self advocacy groups 'men are shouting the loudest' (Walmsley and Downer 1997.38) and, ostensibly, this could have been borne out by these sessions. All the participants in the hospital groups, chosen (by a gatekeeper) to participate in my study, were men. Of the group members at the day centre, most of whom belonged to the Service Users Committee, only one woman came to all the sessions, although two others participated in one or more of the three focus groups there. There were, however, more men attending on a regular basis. At the first focus group at the self advocacy group, only one participant, the chairperson, was female, and at the second session all eight participants were men, as the chairperson was away on holiday.

Walmsley has suggested that:

There is ... a danger that as self-advocacy grows in importance, its leading figures will represent the interests of white men with mild
learning difficulties and other groups of people with learning difficulties will not be seen or heard.

(Walmsley and Downer, 1997.38)

Despite the majority of the participants in the focus groups being 'white men', they were not necessarily, or in fact, the 'leading figures' in this stage of the research. It was very noticeable that, where women did take part, most of them were assertive and ready to take the lead, in contrast to many of the men, who needed encouragement to speak. The elected (female) chair-person of the self advocacy group kept order at the meetings in exemplary fashion and was confident and articulate when expressing her opinions and the women in the day centre were also very keenly involved in the sessions, one in particular following everything that was said, and proffering opinions voluntarily and frequently.

2.14 Arranging the meetings
Focus groups are grounded in 'the human tendency to discuss issues and ideas in groups' (Albrecht et al, 1993.54) and are social events involving interaction between participants for the purpose of examining and shaping opinions and modifying ideas. The dynamics of different groups vary according to factors which include the nature and mix of the participants, their relationship to each other, the skill or otherwise of the moderator and the subject under discussion. I decided on four group meetings with each set of participants with learning difficulties: an introductory meeting, followed by two focus groups and a concluding session. Before the sessions began, I enlisted the help of an assistant, experienced in the focus group method, who offered both moral support and practical assistance with tape recording and note taking during the groups. Theoretically, the introductory session would give all participants including myself and my assistant, the group members who have learning difficulties and any supporters they might bring, a chance to introduce ourselves. The timetable and purpose of the forthcoming focus groups could be discussed and participants could be asked to sign the consent forms required by the LRECs.

Vaughn et al (1996.38) propose that establishing the purpose of any focus group is essential to its success and argue that it is necessary to write a 'general purpose statement that reflects an overall summary of the researcher's interests'.

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The general purpose statement which I wrote to clarify the purpose of the ensuing groups was as follows:

The purpose of the focus groups is to establish what the participants understand by the term advocacy. I am particularly keen to gain their own definition of advocacy, rather than some definition suggested by myself or other professionals. I want to find out whether group members advocate for themselves. I would like to discover whether, and, if so, in what circumstances, participants feel the need for someone else to advocate for them, and who that person, or persons, might be. I would also like to find out whether participants have problems with advocating for themselves and whether they have had, or would like to have, training in advocacy.

Before each focus group I developed a moderator guide for the session, loosely based on this statement. There are no specific rules for this, but I followed the advice of Vaughn et al (1996) and Krueger, (1994) and prepared a short introduction, a warm-up activity, ideas for questions and/or focusing exercises, and lastly a wrap-up, member check, and closing statement.

Bloor et al propose that:

Focusing exercises are an attempt to concentrate the groups' attention on a particular topic (without reversion to a question-and-answer group interview format) by requiring the group to undertake a group task which requires the group to interact on the study topic.

(Bloor et al, 2001.56)

As the hospital participants experienced lack of choices and opportunities in their day to day lives, and also had some difficulty discussing abstract concepts, I decided to use two focusing exercises in the sessions there. The first consisted of a selection of pictures of advocacy and advocates in action, taken from a variety of sources (appendix 3). Participants were asked to talk about these and give reasons why they did or did not think they were good representations of advocacy. This stimulated interaction between the participants and reduced the need for a 'question and answer' interview format as well as providing useful data. The second exercise consisted of two short questionnaires (appendix 4) one headed 'What is advocacy?' and the other ‘What is an advocate?’ Each questionnaire gave a list of possible answers with a tick box next to each one. The men were
asked to discuss the definitions with their supporter, or, for those who could read, to consider each definition, and to mark the boxes appropriately. This activity, which took place over a coffee break, resulted in a fruitful discussion of how the participants perceived both advocacy and advocates.

Despite this success, I did not use the focusing exercises at the Day Centre, where they would have severely disadvantaged one of the (most vocal) participants who was severely visually impaired; or at the self advocacy group, where the participants were very vocal and needed no extra encouragement to proffer their opinions. I shall discuss the conduct of the groups, the data analysis and the results of this endeavour in the following chapter.

Data collection: Stage two

Data from the stage one focus groups yielded many different definitions of advocacy and illustrated how, and in what situations, people with learning difficulties advocate for themselves. They also revealed circumstances in which they required support from others, either to self advocate or to advocate for them; what type of support they might need and the qualities they might require in their supporters. Following a grounded theory methodology, much of this information was used in the design of focus groups with learning disability nurses in stage two of the research.

2.15 Rationale for using focus groups

Focus groups had been my preferred method of data collection with people who have learning difficulties in the first stage of the research, and I considered they had worked well and enabled the collection of useful information. In the interests of parity between all the participants, focus groups were also my method of choice for data collection from learning disability nurses in stage two. They have been used successfully in many other nursing studies (for example, Wallace et al, 1999; Balfour and Clarke, 2001). Directly relevant to the exploration of nurse participants' views on advocacy and their advocacy role, focus groups enable researchers to explore the different perceptions and meanings that participants have for a concept. They can also demonstrate the normative understandings used by groups to reach their collective judgements (Bloor et al, 2001).
Practically, focus groups would allow several nurse participants to be interviewed at the same time, and the stimulus of the group setting should encourage prioritisation and decision making about the aspects of advocacy under discussion. Typically, participants in focus groups articulate ideas which can be censored, opposed and changed during the interaction (Barbour and Kitzinger, 1999), all of which, given that my enthusiasm should counteract my still limited experience as a moderator, would generate useful data.

2.16 Ethical concerns
Having decided at the outset to use focus groups for data collection in both stages one and two of the research, it was possible to submit my proposals for the two stages to the Local Research Ethics Committees (LREC) simultaneously. The design of both the information sheet (appendix 6) and the consent form for nurse participants (appendix 7) was straightforward and permission to conduct the focus groups had been obtained in advance from the head of a Learning Disability Nursing Directorate, who had also recommended gatekeepers through whom participants for the groups could be contacted. Neither of the LRECs had any queries related to stage two of the research and both approved my application.

As with the focus groups in stage one, nurses were provided with an information sheet (appendix 6) in advance of the sessions and were asked to sign a consent form (appendix 7) signifying their willingness to participate in the groups. Before the commencement of the first session with each set of nurses, participants were asked to fill in a ‘personal information’ sheet (appendix 8), giving details of their qualification(s), grade, experience, the communication skills of their clients and their key worker responsibilities, all of which would aid the eventual analysis of the data. In the interests of anonymity the nurses were not required to give their names, but chose and used pseudonyms, which were also used in the transcription and analysis of the ensuing data. Permission to record the ‘business’ of the groups was sought at this stage, and nurses were reminded of their duty of confidentiality.

2.17 The design of the groups
In accordance with the advice of Vaughn et al (1996), as well as writing a general purpose statement for each session, I listed the information which I did and did not
want to obtain from the focus groups with learning disability nurses. The lists were similar for all the groups and related either specifically to the research questions, to their particular client group, or to background literature (Gadow, 1989; Blackmore, 2001) of which I had become aware when writing the research proposal:

**Do want to know:**
- What the nurses understand by advocacy
- Is there a difference between advocacy in their personal and professional lives?
- How do their ideas about advocacy compare with those of people with learning difficulties?
- Is there a consensus as to what advocacy means?
- Do they advocate for their clients?
- How do they know what their clients actually want?
- Do they differentiate between advocacy and 'best interests'?
- What happens if what the client wants is not thought to be in her/his best interests?
- Do nurses have problems advocating for clients?
- Are there some situations where advocacy is seen as particularly necessary?
- If so, can they be more specific about these?
- How do they see their role as nurses?
- Do they think education about advocacy would be useful, if so at what level e.g. pre or post registration?
- What should the education cover?

**Do not want to know:**
- How nurses think other individuals (outside the group) understand advocacy.
- How nurses feel about their work in general (e.g. gripes about pay, hours etc.)
- What they think about the present system of nurse training.

I wrote a 'moderator guide' of open ended questions loosely based on these lists for each group, to remind myself of the order of events for each session. This included a ranking exercise, based on the twenty five different definitions of advocacy obtained from the groups with people who have learning difficulties in stage one, all of which had been verified by group members in the final sessions with the different participants. Some of the twenty five were specific to membership of either the Self Advocacy Group or the Service Users Committee at
the day centre concerning, for example, attending meetings or speaking at conferences, and thus seemed only marginally relevant to the nurses’ advocacy role. Others, being very similar, were merged into single definitions. This left nine definitions which were used in the ranking exercise, all of which had been corroborated by people with learning difficulties in a specially arranged ‘feedback’ session at the self advocacy group (appendix 5). I expected the ranking exercise to serve three purposes:

1. To give participants a break from the intensive talking within the group setting.
2. To facilitate discussion on how nurses advocate for their clients and allowed them to evaluate some of the ideas generated by stage one participants.
3. In accordance with grounded theory methodology, to use data from the previous stage as a base from which theories should emerge.

A more detailed discussion of the nurse participants, the conduct of the focus group sessions, the analysis of the data obtained and the results will take place in chapter four.

Data Collection: Stage three

2.18 The decision to conduct a survey
This research was initially proposed as a two stage qualitative study with the aim of providing a greater understanding of the advocacy role of learning disability nurses. Miller and Crabtree (2000,619) propose that researchers should conceptualise their own particular study before creating an original design ‘from the full range of data collection and analysis tools’. It was during this process, which took place some time after the proposal for a qualitative study had been accepted, that the suggestion to conduct a Wales-wide questionnaire survey of learning disability nurses, in addition to the qualitative work, was first discussed. There have been few, if any, large scale surveys of learning disability nurses, but, as the ultimate aim of the study was to provide a greater understanding of their advocacy role and to inform and support their advocacy education and practice, it seemed appropriate to include, as informants, as many nurses as possible who might be affected by the outcome of the study.
Initially, I had reservations on two counts. The first concerned my total lack of quantitative research experience, which I recognised could only be addressed by ‘doing’ such research. The second concerned whether or not qualitative and quantitative methods could be combined within a grounded theory methodology, due to the intransigent positions which are often taken in favour of either qualitative or quantitative research. The argument of two well known arbiters of grounded theory methodology, Strauss and Corbin (1998) was reassuring. They proposed that ‘useful research’ can be accomplished with various combinations of both qualitative and quantitative procedures (1998.31) and argued that it is possible to:

...view the research paradigms as complementary. Each adds something essential to the ultimate findings, even to the final theory if that is the aim of the particular research project.

(Strauss and Corbin, 1998.28)

Greene and Caracelli, (1997.7) suggest that the 'rationale for mixed-methods research] is to understand more fully, deeply and broadly knowledge claims that represent a wider range of interests and perspectives'. I could appreciate that:

...quantitative methods [might] extend and inform ...qualitative methods, just as ...qualitative methods [could] extend and inform ...quantitative methods [and that]...the quantitative and qualitative methods [could]... work reciprocally to extend and inform each other.

(Langhout, 2003.229)

I was keen to obtain, as the foundation of the research, definitions of advocacy and their advocacy requirements from people with learning difficulties. Their probable difficulties with literacy had made qualitative methods the best option for this first stage of the research and I had decided to follow this with similar qualitative work involving learning disability nurses. However, nurses working in different employment areas e.g. rural mid Wales and urban South Wales; and in different work situations and those working with different clients, were likely to have different ideas as to what constituted the advocacy role of learning disability nurses. It also seemed likely that these and other issues would affect their requirements for education and support in advocacy. Qualitative work could thus
inform the design of a questionnaire survey aimed at the population of ‘hands on’ learning disability nurses in Wales.

In addition to developing the questionnaire from data gained from the focus groups in stages one and two, information from the qualitative stages might also clarify and expand some of the positions taken by respondents in the survey. The consequent theories, grounded in the interaction between all three stages of the research (figure 7), should represent the views of learning disability nurses throughout Wales on advocacy and their role as client advocates, and might inform the development of their future advocacy education.
2.19 Population issues
Before making an irrevocable decision to conduct a survey Trochim (2002) suggests points for consideration regarding the target population. These include the ability to enumerate respondents, their literacy, possible language problems and the likelihood of their cooperation. Wales was chosen for the survey as it has its own distinct framework for learning disability nursing (Welsh Assembly Government, 2002) which brings together “current Welsh Assembly Government policy initiatives, which will effect learning disability nursing and nursing service delivery” (Welsh Assembly Government, 2002a.3). The numbers of learning disability nurses grades D-G, i.e. qualified nurses who were likely to be working everyday in ‘hands on’ contact with clients, rather than in office based, managerial positions, were easily obtainable through the Learning Disability Nursing Directorates. As all were qualified nurses it seemed reasonable to assume that they would be able to complete the questionnaire, and I anticipated that all the respondents, including those who used Welsh as their everyday language, would adequately understand all the given information in English. The ability of research participants to use a common language was important, due to its influence on ways in which they might conceptualise advocacy, and also to ensure their meanings would be comprehensible to myself as a non Welsh speaker, without being jeopardised by the use of translation services. Nonetheless, I accepted that failure to provide a bi-lingual version of the questionnaire had the potential to affect the cooperation and consequent response rates of nurses who spoke Welsh as a first language.

Targeting the whole population of interest for a questionnaire survey can be prohibitively expensive and impractical (de Vaus, 1996.60), but selecting a sample brings complications of representativeness, and the results may not allow a statistical generalisation from sample to population (May, 1997.85). The total of learning disability nurses grades D-G working in the NHS in Wales was only 466 and it was possible to minimise costs by arranging distribution of the questionnaires internally in each of the six Health Trusts involved. The survey could thus be addressed to all the individual nurses and it was not necessary to select a sample from the population.
2.20 Designing the questionnaire

Having assessed the suitability of the target population, the next stage was to design a questionnaire which would adequately fulfil the initial aims of the survey. These were primarily to verify and extend the tentative theories which had emerged from the focus groups in stages one and two of the research. Participants with learning difficulties in stage one had proffered numerous definitions of advocacy, many of which had been discussed by nurse participants in the second stage of the study. Some of these had been the subject of heated exchanges between nurses with opposing ideas. Participants with learning difficulties had also discussed situations where they might require an advocate, and the qualities they would require in that person. In addition to considering the definitions of advocacy and the requisites for a successful nurse/client advocacy partnership proposed by people with learning difficulties, nurses in stage two had reflected on their own advocacy role, their attitude to independent advocates and their advocacy education. Data from stages one and two had been verified by participants with learning difficulties and by learning disability nurses and detailed analysis, using NVivo and situational mapping, had resulted in many points of interest which would benefit from a more extensive investigation. These were used in the design of questions for the survey.

The questionnaire consisted mainly of a mixture of Likert-style scaling questions and 'yes/no/don't know' checklists, with space for respondents to make additional comments if they so desired. de Vaus (1996) explains that a scale is 'a composite measure of a concept, a measure composed of information derived from several ....indicators'. Building on data gathered and analysed in the qualitative stages of the study, scaling questions were developed around definitions of advocacy proposed by people with learning difficulties and by learning disability nurses. Other, similarly formatted, questions were based on items resulting from the analysis of data from stages one and two and viewed as important to satisfactory nurse/client advocacy. The scaling questions invited nurses to consider the relevance of individual definitions of advocacy, while the overall scores gave an indication of how relevant they considered advocacy to their practice. Summated scaling also allowed comparisons between the relevance of definitions generated
by people with learning difficulties and those produced by nurses, and the comparison of different definitions.

Variants of the Likert scale exist, consisting of any number of response points between three and ten (Joppe, 2004). Simplicity dictated use of the most commonly used five point scale, recommended by many experts in research methods (for example, Mogey, 1999; de Vaus, 1996), with respondents being given the alternative of selecting an additional 'no opinion' box (Joppe, 2004). There are some disadvantages of the scaling method. Respondents may interpret the scales differently e.g. the meaning of 'important' may vary considerably from one respondent to the next. Respondents might also circle the same option throughout the scaling questions, or they may circle what they consider is the 'best' option, rather than that which describes their actual practice (Strauss and Corbin, 1998). Nonetheless, a range of scaling questions, using a “formalised and systematic version of the way in which impressions are formed by people in everyday life” (de Vaus, 1996.249), allows a 'composite picture' to be built of the concept being explored. Practically, and relevant to maximising response rates, scaling questions are relatively simple and not too time consuming for potential respondents to complete.

Other items in the questionnaire adopted a 'yes/no/don't know/can't remember' checklist format asking nurses about their education in advocacy and their educational requirements. Throughout the questionnaire, most items were supplemented by an option inviting nurses to extend or explain the opinions proffered. These were analysed as a qualitative extension of both questionnaire and focus group data and also contributed to positional maps (Clarke, 2003) in the eventual grounded theories. The final section of the questionnaire, reflecting the possibilities for data analysis, asked respondents for relevant personal/professional information e.g. grade, work area, year of qualification etc.

2.21 Piloting the questionnaire

de Vaus (1996.57) argues that ‘there is no ideal way of determining the validity’ of measures used within a questionnaire survey and proposes that, if there are no established theories which use the concept which is to be validated, it is best to
obtain the opinions of other people. The questionnaire was thus submitted to an experienced statistician, who approved the measures used, before a small pilot survey was conducted. There are three elements in pilot testing. The first asks pilotees to check the questions for understandability, variation between questions, appropriateness of scaling and the likelihood of response. The second invites them to evaluate the whole questionnaire by considering its flow and layout, noting the time taken to complete it and assessing the ability of the questionnaire to hold the respondents’ interest. The last element consists of polishing the questionnaire in the light of feedback from the pilotees and ensuring it is comprehensible and unambiguous before distribution to the target population (de Vaus, 1996). de Vaus proposes that:

As far as possible, pre-testing should be conducted on people who will resemble the types of people to whom the questionnaire will finally be given.

(de Vaus, 1996.103)

Many learning disability nurses work in similar residential settings and take on similar roles to those working for the target Health Trusts, but in the private sector. Pilot copies of the questionnaire were sent to several of these nurses, and also to a number of academics who had expressed an interest in the study. Pilotees were asked to answer all questions on the questionnaire, comment on both the questions and the questionnaire as critically and constructively as possible and to indicate how long they had taken to complete the task. The questionnaire was modified in the light of their comments before ethical approval was sought for its distribution.

2.22 Ethics

The submission of the questionnaire survey for ethical approval was a convoluted process (figure 8). The Research Governance Framework for Health and Social Care in Wales (National Assembly of Wales 2001a.26) requires that the person in charge of the research ensures that:

The Chief Executive of the care organisation(s) involved and/or any other individual(s) with responsibilities within this framework are
informed that the study is planned, and that their approval is given before the research commences.

(National Assembly for Wales, 2001a. 26)

Figure 8: Ethical procedures preceding questionnaire distribution

Prior to seeking ethical approval for the survey from the Multi-centre Research Ethics Committee for Wales (MREC), authorisation was sought and obtained from each of the six target Health Trusts, who also approved named contacts who would distribute the questionnaires to potential respondents within each Trust. This enabled the questionnaires to be completely anonymous. Although nurses were asked for personal details (qualification date, grade etc.) they were not asked to supply any personal identification. Each respondent was also supplied with a prepaid reply envelope so that the distributor of the questionnaires would not be aware whether or not individual nurses had responded to the request to participate in the research. The disadvantage of this procedure was the inability to specifically target non respondents. A reminder letter, again distributed through named contacts within each Trust was sent to every potential respondent after the
stated date for return had passed, apologising if they had already responded, and inviting them to do so if they had not (appendix 12).

The survey, including the information sheet (appendix 6) and questionnaire (appendix 11), was approved, without modification, at a meeting with the MREC. Nonetheless, there were considerable delays before commencing this stage of the study. Administrative problems, due to the implementation of new research governance arrangements within individual Trusts, caused setbacks lasting between five weeks and five months in registering the research in some areas. Distribution of the questionnaires was therefore, of necessity, staggered over a period of several months.

2.23 The pros and cons of questionnaire surveys
The decision to conduct a survey was influenced by the relative ease of its administration to nurses over a wide geographical area and the considerable savings in both time and cost over conducting interviews or focus groups with learning disability nurses from all the Health Trusts in Wales. A survey avoided the need to recruit unknown interviewers while the use of postal questionnaires also circumvented any possibility of interviewer bias (May, 1997). Of course the questionnaire survey had disadvantages. Advance warning of the survey had been given to senior nurse managers, all of whom had expressed their support and had also agreed to make arrangements for the distribution of the questionnaires within their own Health Trusts. This had guaranteed the anonymity of individual respondents, but had the disadvantage that, in some cases, questionnaires passed through many administrative and managerial hands before being distributed to nurses. Inevitably some questionnaires did not reach their intended recipients and others were distributed to nurses not included in the survey. Reply paid envelopes and a final date for return of the questionnaires were provided and, in a further effort to maximise responses, reminder letters were sent immediately after this date had passed. Despite these precautions, a very small number of questionnaires were returned too late to be included in the research and the overall response rate was comparatively low. As with all questionnaire surveys, there is a chance that those who responded had a particular interest in the subject of the research, but it was not possible to check
whether the characteristics of those who responded differed in any important way from those who did not.

2.24 Preparation for analysis
As I had no experience of conducting quantitative research and limited knowledge of statistics, it was necessary for me to prepare for the analysis of the questionnaire data. I was able to enrol on a statistics course at the University in which both basic statistical theories and the use of SPSS for analysis were explained and practical advice was offered relating to students' individual projects. I was also fortunate to enlist the support of a statistician, who was willing to check my questionnaire before distribution and to verify my analyses of the subsequent data. Due to the lengthy distribution period, return of the questionnaires extended intermittently over several months, reminder letters being sent to some Trusts before the initial distribution took place in others. As the questionnaires returned, quantitative data was entered into SPSS (version 11) for analysis. Comments made by respondents were entered into NVivo in parallel with the qualitative data from the focus groups in stages one and two. This data was coded and memos written and stored for use as clarification of the positions of nurses. This data also extended nurse participants' views on questions which may not have been adequately covered in stage two.

The qualitative and quantitative data from the questionnaires, together with data from the earlier stages, contributed to situational mapping (Clarke, 2003) and to the grounded theories which would emerge from the research.

2.25 Conclusion
In this chapter I have described and justified my decision to use both qualitative and quantitative methodologies within a post modern approach to the grounded theory method in this research. I have detailed some of my problems with emancipatory and participatory research paradigms and explained how an inclusive ideal informed the design of stage one of the study with people who have learning difficulties. I have explained decisions surrounding the collection of data during each of the three stages of the research including ethical concerns and
accessing participants for the study and have briefly mentioned the analysis of data which will be discussed in more detail in the appropriate chapters.

Clarke (2005) suggests that 'project maps' may be used to 'explicate particular aspects of a specific project to intended audiences' and may use elements from other maps which have been used in the analysis of the project. Such maps 'provide an accessible background to help audiences understand the intersectional character' of the research. The project map (figure 9 overleaf) details those decisions which have most direct bearing on the collection of data in stages one, two and three of the study. I describe these stages in detail in the following chapters.
Figure 9: Project map – Decisions regarding methodology and methods
Chapter three

Focus groups with people who have learning difficulties
3.1 Introduction

I have previously discussed the theoretical and practical issues relating to the methodology and methods employed in this study and shall now consider the actual conduct of the first stage of the study. This chapter begins with a short assessment of the design of the study, illustrating how, despite my desire to minimise the power differential, neither emancipatory, nor participatory research paradigms were achievable within this particular setting. It demonstrates how the first stage of the research was guided by the inclusive approach described by Walmsley (2001), and discussed in detail earlier in this work (section 2.10). Useful and thought provoking data were thus produced which acted as the foundation of subsequent stages of the study, emphasising the crucial contribution which people with learning difficulties made to this research.

The rationale for using focus groups as my preferred method of data collection has already been discussed, as have ethical issues surrounding the arrangement of the sessions, the recruitment of participants, the provision of information and their informed consent. Grounded theory relies on the gradual emergence of categories during analysis of the data, but as some starting point was necessary, the data from stage one of the study was analysed initially under the broad headings which guided the design of the focus groups i.e. choice (section 3.3); advocacy (section 3.4); barriers to advocacy (section 3.5); advocates (section 3.6) and nurses (section 3.7). The enquiry was aided by the computer aided qualitative data analysis package NVivo (version 2) and by Clarke’s (2003) system of situational mapping described earlier in this work (section 2.6). Results of the analyses are presented and discussed, and demonstrate how the support afforded to different groups of people with learning difficulties can affect their confidence to advocate in everyday situations and their consequent sense of empowerment. A short evaluation of the focus group method as used in this stage of the research follows and the chapter concludes with a summary of the key points from this stage which informed the design of focus groups for subsequent stages of the research with learning disability nurses.
3.2 Assessing the research paradigm

The goals of emancipatory disability research are quite explicit in their aim to both expose and overcome the shortcomings of traditional methodologies. Stone and Priestley propose that the model has six key principles:

1. The adoption of a social model of disablement as the epistemological basis for research production.
2. The surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self emancipation.
3. The willingness only to undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers.
4. The evolution of control of research production to ensure full accountability to disabled people and their organisations.
5. Giving voice to the personal as political whilst endeavouring to collectivise the political commonality of individual experiences.
6. The willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people.

(Stone and Priestley, 1996.706)

Measured against these standards stage one of this research could not aspire to be emancipatory for people who have learning difficulties, although the social model of disability was used to frame the goals of the research. Participants with learning difficulties were encouraged, within the focus group setting, to talk subjectively about their own experiences, particularly in the context where advocacy may or may not have been useful to them. Their experiences were compared to the 'political' in the form of the provision of advocacy, in order to gain a comprehensive understanding which may contribute to future advocacy training programmes for nurses. However, the subject of the research was not chosen by people with learning difficulties, although my own views and ideas changed considerably in response to discussions with participants. I was committed to working with people who have learning difficulties and hoped, through my research, to give voice to their personal experiences and to support their empowerment. However, as a research student, I had my own agenda, which included writing a thesis on a subject of both interest and concern to me, but with the ultimate aim of gaining a PhD. As such I was also subject to a power differential. I received a bursary from the University to conduct my research which
was overseen by my Director of Studies, my supervisors and ultimately by examiners, all of whom influenced the way in which the research was conducted.

Although the views of participants with learning difficulties shaped the subsequent data collection from learning disability nurses, it is doubtful whether any of the participants in phase one of my study would have chosen to do research. Many of them were interested in advocacy and in their own advocacy needs but had little overt interest in the advocacy role of learning disability nurses. In the hospital, nurses were perceived by people with learning difficulties to have considerable authority. The participants expected them to be bosses, carers, judges, jurors, counsellors and even friends. Amongst the day centre participants and the self advocates, nurses were perceived as quasi medical. In neither setting was their advocacy role seen to be of great import. As a researcher, participants equated my status with that of nurses (in the hospital), and with their various visiting speakers (in the day centre and the self advocacy group). Although keen to participate, none of the participants had any expectation of input into the research beyond answering my questions, telling me about advocacy in their everyday lives and possibly discussing the research findings prior to any report which I might write. Research as a means of empowerment was, at least for the duration of this study, outside the realm of their imagination. There was little I could have done to alter these perceptions. I listened to the views of participants with learning difficulties with interest and respect. These shaped the design of subsequent focus groups with learning disability nurses, but the participants themselves were not, and did not expect to be at the ‘apex of the research hierarchy’ (Ramcharan and Grant, 1994) in a way deemed necessary for emancipatory research.

Assessment of my study also found grave difficulties with any aim to pursue a participatory ideal as defined by Cocks and Cockram (1995):

- The researcher must take up and act upon a value position.
- The researcher must have close involvement with the researched community.
- The approach is problem centred.
- The participatory research process is conceived as a two-way educational tool between the researchers and the constituents.
Participatory research stipulates respect for the capability and potential of oppressed groups to produce knowledge and analyse it.

(Cocks and Cockram, 1995.34-5)

Taking up and acting on a value position demands subjectivity and reflexivity by the researcher and, during the course of the study, I became less definite in my own views on the advocacy role of learning disability nurses and much more receptive to the suggestions of different groups of people with learning difficulties. This contributed to lessening any perceived power differential between myself and the research participants. However, equality of power and influence between researcher and researched demands continuous close involvement and active engagement. This entails dialogue between the researcher and participants on equal terms, challenging the marginalisation of disabled people and the supposition that they are incapable of articulating their own needs (Cocks and Cockram, 1995). While I definitely did not subscribe to the marginality of people who have learning difficulties, the proviso of 'close involvement' was a major stumbling block in my desire to enact the ideals of participatory research.

To explain further, I need to elaborate on my circumstances in relation to the study. I am a qualified nurse for people with learning difficulties. My post-registration experience was in supported housing, first with elderly people who had learning difficulties and then with people who had profound and multiple disabilities and no conventional verbal communication skills. Many of these people, with whom I established considerable rapport, have since died. After only three years I was forced into a career change by the ongoing health needs of my elderly mother, and my nursing experience continued in private nursing homes for elderly people with physical and mental infirmities. At the commencement of this study, I therefore had limited experience of working with people who have learning difficulties. Of those with whom I had had ongoing relationships of trust and friendliness, only one remained. Early on in the research it therefore became obvious that, due to my own lack of contacts, I would have to enlist participants through 'gatekeepers' who had day to day contact with people who have learning difficulties.
Gatekeepers who do not know potential researchers, and who have the power to give or withhold access to potentially vulnerable people, require confirmation from an LREC that the study is worthwhile and that the researcher will fulfil certain ethical responsibilities. LRECs, before considering a research protocol, demand considerable detail regarding the conduct of the proposed study, including overtly ethical issues, but also concerning the methods of collection and analysis of the data and its eventual dissemination. Thus, because access to the potential participants cannot be agreed prior to LREC approval, unless the researcher has had a prolonged period of time before the research commences in which (s)he can develop links with possible participants, the study must be designed by the researcher without consultation with potential informants. Approval (or otherwise) is then granted for the research in that form, and any deviations must be further approved by the LREC. Even if access has been approved in principle before submission of the proposal to the LREC, it is only after approval has been obtained that access to likely participants, through appropriate gatekeepers, can be negotiated. This excludes the involvement of participants in decisions about the content and design of the study, and in major decisions regarding the 'products' of the research, which have already been submitted to the LREC. It thus confines their participation to contributing information, involvement in the extraction of themes from the collected data, and approval of the final research reports.

I have previously mentioned Walmsley’s (2001) use of the term ‘inclusive research’ which describes a participatory ideal specific to the needs of people with learning difficulties (section 2.10). Despite problems with the participatory model, inclusivity seemed attainable and I evaluated the first phase of this study as a participatory/inclusive project using four questions adapted for this purpose from Zarb (1992):

1. Who controls what the research will be about and how will it be carried out?
2. How far will it go in involving disabled people in the research process?
Control of the research was shared within the constraints of being a PhD student and the limits set by the necessity to gain LREC approval, which I have already mentioned. The subject of the study was not initially of my own choosing but my interest, at least in advocacy, was shared by the participants who were all eager to take part in the focus groups. Data gained from these groups definitely impacted on the direction of the research, although the actual process was influenced by the need for LREC approval. At the end of each session, we discussed the findings of the study to date and participants put forward their own ideas as to their importance. Some of the participants verified my findings from stage one of the research, and had some input into the focus group questions for stage two of the study. The product of the research will eventually be disseminated to interested parties within schools of nurse education, again after some consultation with participants with learning difficulties. Self advocacy groups and citizen advocacy projects as well as other organisations known to people who have learning disabilities may have an interest in the research. Publication of the research report in a format accessible to people with learning difficulties, and with full acknowledgement of their involvement in its production, should encourage self empowerment and play at least a small part in raising the profile of people with learning difficulties within the wider research community.

I have already discussed the arrangement and composition of the focus groups in stage one of the research with people who have learning difficulties, and mentioned the need for innovation in order to reveal how participants with learning difficulties defined advocacy. Data obtained through the focus groups were subjected to constant comparative analysis using NVivo and supplemented by situational analyses (section 2.6). Key findings will now be discussed under the broad headings derived from the design of the focus groups and used in the initial analysis.
Findings from focus groups with people who have learning difficulties

3.3 Choice

One of the problems in attempting to gain definitions of a concept from participants in a research setting is that, if the researcher advances her/his own ideas for discussion, the participants may concur with these, rather than advancing their own definitions, even though these may be different from those of the researcher. This seemed a very real problem when the concept under discussion was advocacy and the participants had learning difficulties. Websites of self and citizen advocacy groups had yielded many different definitions of advocacy and these, in their turn, were vastly different from legal and 'dictionary' definitions of the concept.

Rather than present the participants with a list of definitions of advocacy, none of which would have been generated by them, I decided to explore their opportunities for expressing choice, in the hope that this would facilitate a gradual revelation of their own definitions of advocacy. Choice, advocacy and empowerment are closely connected. For people who have learning difficulties choice can be a key to independence. Without choice they are in the thrall of others and have very little, if any, power over how their lives are run. People who have learning difficulties may have limited opportunities for choice. They may make choices themselves, or it may be necessary for choices to be presented to them. When they have made a decision between the alternatives, they may need to advocate, either independently or with support, for that choice. Speaking up for oneself or for another, with or without support, encourages confidence and assertiveness, possibly the first steps on the pathway to independence and empowerment.

Situational analysis and comparison of the choices available to participants in the focus group sessions revealed the differential opportunities offered to clients in the different settings. At my initial meeting with the staff at Parkview Hospital who had agreed to support participants at the focus groups, one of the nurses remarked that, in the eyes of the residents, the relationship between themselves and the nursing staff was one of complete inequality, with nurses undeniably in a position of power. Kieffer (1984.15) argues that powerlessness can be seen as 'an
experience embedded in and reinforced by the fabric of social institutions’ in which individuals lose their sense of control over social relations through their submersion in the system. The ‘system’ in Parkview decrees that the senior nurse on duty, identifiable to residents by the task of administering the daily drugs, is ‘in charge’ on that shift. (S)he has power, within the confines of the system’s regulations, over how the residents spend their day, what and when they should eat, whether there will be trips ‘off campus’, and if so, by whom and for what purpose. In short (s)he controls most aspects of the residents’ daily lives.

The disempowerment of the participants and their lack of control over their day to day lives became obvious in the discussion of choices during the first focus group at Parkview. Jim was only able to suggest ‘cleaning’ as a choice if he was offered a day off from his usual work, and all the participants suggested home based activities which reflected their lack of leisure opportunities. The men spent weekdays in the hospital workshop doing repetitive work outsourced from large companies. When asked if they could choose from the work on offer John replied ‘No, no, we just get told to do it’. One of the supporters, possibly in an attempt to improve this negative image of workshop policies, suggested that the participant, Jim: ‘is an entrepreneur, he does something that he started up himself’. Jim, in fact, dealt with the shredding and disposal of paper from a nearby business establishment. On being asked how he had come to embark on this venture Jim seemed bemused, and, after some thought, replied ‘Well, he just told me to do it and I done it’. His engagement in this task thus seemed to demonstrate the ‘empty ritual of participation’ (Arnstein 1969) rather than the empowered choice of the ‘entrepreneur’ identified by his supporter. It also reinforced my own impression that Jim, like the other participants from Parkview, was still on the very bottom rung of the ladder (Arnstein, 1969) leading to power and control over his daily activities (for further explanation of Arnstein’s ladder, see section 6.6).

The lack of choice in their daily work routine, experienced by the participants from Parkview, was, surprisingly, also the case with most of the members of the self advocacy group. Some, but not all, of these participants did, however, have opportunities for a choice of leisure activities at evenings and weekends. The focus group members from Downtown Day Centre were able to choose from the
variety of activities on offer either at the centre or arranged by day service staff, usually at the request of the Service Users Committee. Many of these took place outside the centre and some took up a large proportion of the participant's working week. A minority of these participants also spoke of a variety of leisure activities in the evenings and at weekends. Probably the major lack of choice that they experienced was in their daily attendance at the segregated day centre. However, where this might once have been a problem, the participants obviously did not perceive it as such at the present time. Most of group members had been attending the Centre for many years and had seen their opportunities for choice and control escalate during that time. They also had close friends amongst the members and good relationships with day centre staff. Members of the Service Users Committee were constantly advocating for increased funding for the centre and saw their attendance there as similar to that of non-disabled people attending their place of work daily.

3.4 Advocacy
Coding the data from the focus groups for 'definitions of advocacy' and then subjecting the coded data to constant comparative analysis and later, to situational analysis revealed many different definitions of advocacy. These depended mainly on the environment and the consequent opportunities afforded to focus group members, and I was able to group them broadly into reactive and proactive advocacy at three levels which I termed micro, meso and macro levels (figure 10). Except for micro-level advocacy, the majority of the activities defined as advocacy relied on professionals for either facilitation or support.

Micro level advocacy is reactive and was practiced by all participants in the focus groups, who described speaking up for themselves in minor disputes with their peers and in routine negotiations with their immediate supporters. Several of the participants also described advocating at this level for their peers who experienced problems with verbal communication.

Meso level advocacy is also reactive and was described by participants as involving them in discussions with persons closely concerned with them, but outside their circle of immediate associates. In this context, they mentioned
advocating to service managers, general practitioners, and others who, although not well known to the participants, were perceived to have some authority and control over certain aspects of their lives.

Figure 10: Hierarchies of advocacy

At this level advocacy was reliant on a negotiated partnership between the intending advocate(s) and a supporter who would be prepared to become involved in the advocacy attempt, initially by listening to clients' requests or complaints, then following this by arranging meetings and supporting clients to voice their concerns to appropriate managers or bureaucrats.
Only participants from the day centre and the self advocacy group engaged in proactive, macro level advocacy. This included explaining to non-disabled people what it is like to have a learning difficulty (the self advocates) and taking part in interviews for staff members (the day centre).

Participants from Parkview lived protected, institutionalised lives, so their opportunities for advocacy on a wide scale were extremely limited. Practically, advocacy by these men was purely reactive and at micro level. They advocated for themselves in disagreements with fellow residents, or possibly in disagreements with staff members about local issues i.e. what job they were asked to do in the workshops. They might ask a staff member to advocate for them in local situations in which they felt they were being treated unfairly. Of the four participants, only John had experience of self-advocacy outside the hospital, and he seemed to consider this a political activity far removed from his day to day life. Neither he, nor any of the other participants, had any expectation that they themselves, nor any staff member, would be able to advocate for them in matters relating to large scale hospital policies.

When I asked these participants outright for a definition of advocacy, John was the only one who volunteered an answer and had obviously given this some thought prior to the focus group:

"Advocacy is a group of people who want to speak up for themselves and all that, get our points through and all that....like talking about the Disabled Bill and all that and Equal Rights with people like you, and um... just live like ordinary people."

John, Parkview)

Calling on his experience in a self-advocacy group, he suggested that advocacy was an external group activity and saw it in the nature of a class where people went who wanted to learn to speak for themselves on a political level, rather than about smaller local issues. There were 'bosses' who were non-disabled and, at least in John's view, were very much in charge. He said that advocacy gave a small number of people from the hospital an opportunity to go on trips away from
home, and obviously saw this as an ego boost for them as well as a change from
the ordinary life of the hospital.

Atkinson and Chant (2002) suggest that people who live in hospitals do not get
enough information about advocacy, and this was borne out by the participants at
Parkview. There were two advocates working on the hospital site whose role
concerned resettlement. Despite the imminent closure of the hospital and the
advanced plans to resettle the four participants, only John had met them. He was
able to say that they worked in an office, but had little idea what their role was. He
proudly told the group that he had been an advocate before they came to the
hospital and talked about a protest meeting that he had attended in London.
Apparently, during the demonstration that followed, some disabled people had
chained themselves to the railings at 10 Downing Street as a political protest.
Although he had found this event exciting and interesting, John seemed to find it
totally disconnected from his 'real life'. He obviously did not consider that
advocacy at this level was at all relevant to him personally, or to his experiences
within the hospital. He seemed to accept that major changes in his life would
occur with minimal consultation and although this made him cross, he did not
translate his frustration into an ability to do anything about it or to get someone
else to do it for him. He seemed, as did all the participants (and many of the staff
to whom I spoke), to dismiss hospital policies and procedures as decided by an
unnamed 'they' and incontrovertible. They were thus considered to be outside the
realm of mediation or representation from either the clients or their immediate
nursing or support staff.

Similarly to Parkview, Downtown Day Centre is also a segregated service which
many of the participants had attended for twenty years or more. Unlike Parkview,
it exemplifies Rappaport's (1985.18) proposal that 'organisations can be
empowering... because they provide settings for individuals to feel in control of
their own lives'. The present regime is very facilitative and members were
expected, in most circumstances, to advocate for themselves. Like the men from
Parkview they were encouraged to sort out their own internal disputes, although
they could get help from staff if necessary. Unlike the hospital based participants,
they took some responsibility for many practical aspects of the everyday upkeep of
the centre. They were also encouraged to advocate for themselves to relevant, sometimes senior, officials in matters concerning the centre. While they obviously relied on staff to bring some of these matters to their attention and then to introduce them to appropriate bureaucrats, day centre users were prepared to advocate for themselves and obviously felt they played a major role in the everyday running of the centre.

Dowson (1997.106) proposes that there is a culture within services for people with learning difficulties that 'staff have higher status than users', a situation which may be compounded by the superficial knowledge which service users have of the specific roles of different staff members (Goble, 1999.449). This was certainly the case at Parkview. Conversely, at Downtown, the participants obviously did not feel subservient to staff. They knew which staff members were in charge of health and safety; to whom they should report any concerns and how soon their problems should be resolved. Any culture of inequity had been further ameliorated for some members of the democratically elected Service Users Group who had successfully completed courses on interviewing staff. They had been involved as interviewers on panels which appoint staff for the centre, a task which involved knowing exactly what would be required of the staff appointed to fill the positions. The development of the skills necessary to take part in the interviewing process and its satisfactory conclusion had led to the personal empowerment of those members involved. They were proud to define this activity as advocacy.

Parkview is, of course, a residential facility, and Downtown is a segregated Day Centre which most of the participants in the focus groups attended daily, although they participated regularly in a variety of out of Centre activities. The Self Advocacy Group had an official meeting only once each month, although some of the self-advocates spent several hours each week doing voluntary work in the People First offices. There were also regular (monthly) meetings for clients of the local day centres, held in the offices of the self advocacy group and facilitated by the advocacy coordinator. Thus the participants from Parkview all lived in close proximity, and those from Downtown were in regular, sometimes daily, contact with each other and with staff involved in their services. In contrast, the participants from People First did not meet each other as self-advocates on a daily
basis, although some met regularly at their various day services. Nor did they meet the group facilitator, except at their monthly and other occasional meetings.

These facts obviously affected the advocacy agendas of the different groups of participants. The hospital residents were only concerned about day to day issues in their institutional environment. Participants from the day centre experienced advocacy mainly around service-centred issues, although this did result in their meeting with a wide variety of officials, managers and bureaucrats, and in a very positive sense of empowerment among members. Members of the self-advocacy group, although concerned with similar issues surrounding their day services, living accommodation and health provision as the other groups, were able to view these problems from a broader perspective when attending self-advocacy group meetings. With the support of their coordinator they were able to search for solutions which were less dependent on internal or structural changes to the services involved. The Downtown group usually relied on day centre staff to alert them to problems at the centre and to bring in appropriate professionals to whom they might advocate. Similarly, the self-advocates relied on their coordinator either to act as an independent advocate for them or to suggest and facilitate long term political solutions to their difficulties. In consequence, some of them were able to consider and work towards the possibility of moving out of services completely and enjoying a more independent life.

Atkinson (2002) proposes that:

Self-advocacy is .... about identity, in contrast to normalisation, where the emphasis is on conformity and denial of difference, people in self-advocacy groups are more likely to acknowledge their identity as people with learning difficulties. (Atkinson, 2002.122)

The participants from People First spoke quite openly about their lives as disabled people. They also spoke with pride of a proactive advocacy project which had been extremely successful. This started when a few self-advocates visited an infants school and talked to the children about what it was like to have a learning difficulty. As a result of this, they were asked to go into other schools and to the local Further Education College, which they visited regularly to talk to the students.
Some of the participants had gained a teaching certificate for this work. Some members had also taken part in 'Diversity Training' where they made links with the police and the fire service to raise awareness of people with a learning difficulty. The aim was to encourage people to be aware of the needs of people with learning difficulties and lessen or prevent bullying and unfair discrimination. This proactive advocacy has had a major impact on the group members who take part. They particularly mentioned that, during their participation in these projects, they were treated like 'ordinary' people i.e. as adults with opinions, rather than children. Several members spoke of developing greater confidence and many had addressed local and national meetings of self advocates. This had resulted in a sense of empowerment, within the group, which surprised even those experiencing it, when they compared their present selves with their pre-self-advocacy group persona.

This far reaching and non service oriented approach to advocacy evidenced by the proactive 'schools' and 'community' projects run by the People First group promoted the rights of people with learning difficulties and could definitely be considered as advocacy outside the range of ordinary day to day activities (Goble, 1999). It appeared to have very positive results for both the self advocates and their audiences. Nonetheless, although the People First members spoke of having power and gaining in confidence and assertiveness, and this was undoubtedly true in dealings with their peers, what I have described as the 'meso layer' of advocacy was missing for them. Members spoke of being able to address some of their immediate personal problems, but did not seem capable of advocating for themselves on a regular day to day basis about, for instance, problems in their day services, or when visiting health professionals. While they were happy to confront some of these issues in a group setting, they did not have confidence individually to face up to their perceived problems. Despite the frequent mention of advocacy giving him 'power' and helping him to be more 'assertive', Jim described a visit to his G.P. and expressed the wish that he could speak to the doctor on his own, rather than being accompanied by his father. This apparently resulted in the consultation taking place between the G.P. and Jim's father, rather than between Jim himself and his doctor. Jim was confident and able, at meetings of the self advocacy group, to speak up for himself and did not hesitate to let the others know
when he wanted to speak or be spoken to by the co-ordinator. Asked why, in view of this, he did not feel able to ask the doctor to speak directly to him, rather than to address his father, Jim explained the difference between his feelings of empowerment within the group and his individual feelings in other circumstances:

Donna: I'd feel like saying 'look, I'm an adult, talk to me'
(coordinator)

Jim: I can talk to you like a grown up

Donna: You could talk to the doctor like that too

Jim: There was one day it happened, but I started to cry
(Jim and Donna, People First)

This appeared to have been caused less by fear of asserting himself to the doctor than by doing this in front of his father, who obviously assumed that he would speak for Jim and did not expect his paternal stance to be challenged.

My own experience as a learning disability nurse has demonstrated how some parents of adults with learning difficulties are prone to regard their (adult) offspring as children, and that consequently these adults tend to display non typical childish dependency when they are with their parents. Despite his resentment, and his experience as a self-advocate, Jim's accustomed servitude towards his father would not allow him to actually verbalise his request. Lack of support and encouragement to self advocate on an individual, rather than a group basis, resulted in Jim and the other self advocacy group participants appearing less empowered overall than the participants from Downtown Day Centre, who, despite their service oriented experience of advocacy, had achieved what they obviously perceived to be satisfactory control of their lives.

Kieffer (1984.31) proposes that empowerment is a 'long-term and continuing process of adult development'. Developing confidence in their ability to advocate can lead to empowerment for people with learning difficulties, although this may be dependent on their environment, their opportunities and their support. The participants in Kieffer's research relied 'extensively on the assistance of an external enabler' and this was true for the people with learning difficulties in this study. In all except micro advocacy situations participants relied on some degree of external support which, depending on the situation of the person with learning
difficulties and the context of the advocacy attempt, may or may not have been from learning disability nurses.

3.5 Barriers to advocacy

Although all the participants were able to discuss 'successful' advocacy activities, they also experienced barriers to advocacy. Sometimes these were explicit, but at other times they were 'sites of silence' (Clarke, 2003) which emerged during the focus group discussions, even though the participants did not overtly articulate them. In a classic definition, which still holds true after almost half a century, Seeman defined powerlessness as:

...the expectancy or probability held by the individual that his (sic) own behaviour cannot determine the occurrence of the outcomes ....he seeks.

(Seeman, 1959.784)

At Parkview, the residents experienced powerlessness in anything more than micro advocacy due to their institutionalised life. They were subjected to life under a medical model of disability, through which they, rather than their environment, were required to adapt to meet the ongoing demands of 'the system'. Participants thus encountered barriers when staff, who might otherwise have facilitated advocacy at a higher and more empowering level, worked to this model and accepted the 'system' as all powerful. One of the support staff demonstrated how staff let it be known, albeit sometimes covertly, that it was outside the remit of their positions as paid members of the organisation to even attempt to change it:

Melvin There are lots of jobs that people don't like doing up there [in the workshops] but ...it's been instilled into everyone that work equals money equals leisure. That sort of philosophy, do you know what I mean?

John I hate doing the cardboard. One day I had to stay back and do two hundred and fifty boxes. I was late coming home....

Melvin Yeh, but you know the difference between working for money and doing nothing and not getting anything?

John No work no pay innit?  

(John and Melvin, Parkview)

These barriers seemed unequivocal. The barriers to advocacy for the other participants were less straight forward. Unlike the residents in Parkview, who
relied for support only on their immediate staff, at Downtown, the participants were able and encouraged to advocate for themselves at meso level. Support staff facilitated meetings which enabled service users to meet external officials so that they could advocate for increased funding for the centre:

Arthur: The mayor wants to help us out to get more money for the centre.
P: So how did you decide to go and see the mayor?
Arthur: At the meeting yesterday. The mayor, he's going to improve our services, the centre and all that.
P: So were you able to tell him what you wanted?
Arthur: Yes, we told him we needed another minibus.
Judy: We told him could we have a new minibus because we want one. The grey one's breaking down all the time.
P: So you were able to tell him it was breaking down all the time.
Arthur: Yes and we are going to have a new bus.

(Arthur and Judy, Downtown)

Staff also facilitated advocacy at the proactive level of enabling clients to engage with appointing new staff for the centre. Despite being employed within the system, support workers have encouraged the members to take a high degree of control over the day to day routine of the centre, and this was further facilitated by an independent advocacy worker who attended the Centre each week to coordinate the Service Users Group. The consequent sense of service user empowerment was demonstrably carried into some aspects of their lives outside the centre.

Nonetheless, there were barriers to advocacy for these participants, although they were less obvious than those experienced by participants from Parkview. All the advocacy opportunities which were facilitated by support staff, with the possible exception of interviewing for new staff, were at meso level. Most of them were reactive and all of them concerned the internal organisation and funding of the centre. A more proactive approach to advocacy might have aimed at the closure of the segregated day centre, with the clients moving either to, possibly supported, full time paid work or employing individual support staff for their own choice of educational/leisure activities. If clients had wished to consider this it would have been put to the Service Users Group, and discussed by clients only in the
presence of their independent coordinator, ensuring that all the clients’ views would be taken into account. Nonetheless, barriers to closure of the Centre could come from the day centre staff, who were supportive and facilitative towards service users but for whom the closure of the centre would, of course, result in loss of jobs, although they could obtain work as individual supporters for their clients. Probably a more powerful barrier to advocacy involving moves towards the closure of the day centre would come from the parents of the service users, many of whom were apparently elderly; and, possibly more importantly, from the day centre clients themselves. Kieffer (1984.19) argues that the catalyst for taking empowering action must be a ‘sense of outrage or confrontation’ by those who are to take the action. The participants from the day centre obviously did not even feel aggrieved by their attendance there. It was their accepted way of life. They were perceptibly contented with the inclusive regime at the centre and undoubtedly felt empowered by their sense of being ‘efficacious participants in ....local decision making’ (Kieffer 1984.32).

Parents and carers could also be a barrier to macro level advocacy by the self advocates from People First. Some of the members there were involved in protracted discussions in an effort to gain Direct Payments and thus move out of the oppressive environment of their day services. The successful administration of Direct Payments must to some extent involve people with learning difficulties, their parents and carers in taking steps into unknown territory. It is obviously a leap of faith from the protected environment of the day centres, however oppressive, to employing and directing an individual supporter to facilitate daily activities. Many parents and carers have said that they are not prepared to take this risk. The coordinator was hoping that, if Direct Payments proved a successful way forward for a small number of self advocates, others would follow, or perhaps the authoritarian management at the day centre would, as service users voted with their feet, move from the oppressive towards a more facilitatory and inclusive regime.

Macro level advocacy took place on a regular basis when People First members went into schools and colleges to explain to pupils and students what it was like to have a learning difficulty. The self advocates involved in this were considerably
empowered by their experience. They were also able to advocate for themselves at micro level and had confidence to speak at meetings with other self advocates and in low level disputes involving support staff in their homes. Nonetheless, although the self advocates repeatedly recited that ‘advocacy gives us power’ (Sylvia, Ted), they were usually led in this by the coordinator, and it seemed to be more a reminder to themselves of how things ‘ought’ to be, than a statement of fact. Although those group members involved in the community projects doubtless felt empowered during that experience, the meso level of empowerment through advocacy was missing for them. The participants demonstrated that they were unable to advocate for themselves on a day to day basis about the many problems they experience in their day services:

Mike  I wanted to go on the farm to work
Donna  So it’s up to you isn’t it, to tell the managers cos they don’t always know best... Is it easy to tell A (day service manager)? Does he really listen?
Jim    No, he listens like a brick wall!!
Mike    He doesn’t listen, he tries to change the subject
John   G L (another day service manager) is the same, he have’s his hair off and takes it out on us then
Mike    Yes he does
Sylvia  If he says you’re not going, you’re not going and that’s the end of it

(Mike, Jim, Sylvia, John and Donna, People First)

The coordinator of the self advocacy group was able to act as an independent advocate for the members in negotiations with officials about Direct Payments and Therapeutic earnings (i.e. macro level solutions), but, because she was outside the service, was less able to facilitate advocacy within the day centre. Participants complained that day centre staff treated them like children and did not allow them any say in the running of the centre or the activities which took place there. They obviously found this situation deeply disempowering. Moving from micro-level advocacy straight through to advocating on a macro level meant that the self-advocates missed out an important developmental stage in their ‘empowerment through advocacy’ experience. This severely affected their confidence, causing them difficulties in advocating for themselves at meso level in other situations in their every day life.
3.6 Advocates

Analysis of the data revealed that exactly what is required of advocates by the participants with learning difficulties depended largely on their advocacy ambitions which were, in turn, influenced by their day to day circumstances. Coding for ‘advocates’ also demonstrated that in each of the three settings, people who have adequate verbal communication were prepared and able to advocate for their peers who do not speak. The self advocates explained:

<table>
<thead>
<tr>
<th>Name</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donna</td>
<td>Sometimes you speak up for....</td>
</tr>
<tr>
<td>Sylvia</td>
<td>People who can’t speak up for themselves</td>
</tr>
<tr>
<td>Mike</td>
<td>We speak up for their rights</td>
</tr>
<tr>
<td>John</td>
<td>Yes we do</td>
</tr>
<tr>
<td>Sylvia</td>
<td>Cos if people can’t speak up for themselves we’ve got to do it on their behalf, we’ve got to do what we think they would like to do</td>
</tr>
</tbody>
</table>

(Sylvia, Mike, John and Donna, People First)

Most of the focus group members felt that they could speak up for themselves in minor matters, but in most other situations they relied on facilitation and support in their attempts at advocacy. The participants from Parkview took part in a focusing exercise in which they were asked to complete, with the help of their supporters, two questionnaires, one with definitions of advocacy and the other asking ‘what is an advocate?’ All the definitions on the questionnaires had been taken from various advocacy websites (appendix 12). All the men ticked all the definitions on both questionnaires. I suspected that two of the participants ticked them before they fully understood what they were about, as they both like to demonstrate their writing skills. Paul was sitting next to me and certainly understood all the definitions and entered into some discussion with his supporter before ticking them. John read them himself and ticked them all too. None of the definitions were patently inappropriate. There was space at the end of the sheets for the men to put their own ideas about who might help them to advocate. All the men chose Jenny (staff nurse) as their ideal advocate, obviously seeing their relationship with her as more than simply one between hospital resident and nurse:

P Paul, I think this is yours isn’t it. You chose Jenny and Tanya as people who could do things for you. Are Jenny and Tanya your key workers?

Paul Tanya’s one, for when I move, Jenny’s my friend
P let's see who else. That's Ron's is it? you wrote Alan and Jenny. Are they your key workers?
Ron No, Alan is my key worker, Jenny is my friend
(Paul and Ron, Parkview)

Bogdan and Taylor argue that:

It has always been common for some people working in the human services to form genuine friendships with their clients, relationships that transcend the boundaries of their occupational obligations.
(Bogdan and Taylor, 1987.36)

Jenny had apparently formed what the hospital participants saw as a special relationship with them over many years. Two of them referred to her as their friend and all four were in no doubt that she would advocate for them in any circumstance they could imagine, even if this caused problems for her. They saw their relationship with Jenny as reciprocal:

Paul If something happens to Jenny, you know M down the house? I said to M, if you go for Jenny I said, I'll break you
P Right, it's a two way thing. You support Jenny and Jenny supports you?
John Mmm.
(Paul, and John, Parkview)

 Nonetheless, they all accepted that their relationship with her would be unlikely to continue when the hospital closes and they move to various community based settings away from both Jenny and the hospital.

It was interesting to note that John put his key worker as a second choice despite having previously remarked that he could never sit down and talk to his key worker because the latter was ‘always on his mobile phone’. I suspect that, in this, John, who throughout the focus groups was obviously mindful of the presence of supporting staff, complied with what he assumed would be their expectations. Further exploration revealed that the participants from Parkview practiced advocacy only in micro situations and relied on nurses who are immediately available to support them in internal disputes which they could not solve by themselves. They also expected nurses to speak for them at intermittent meetings which concerned them and to support and speak for them at occasional events
outside their immediate environment. Paul, for example, felt vulnerable on a visit to hospital for tests, and had refused to be admitted unless the staff nurse who had accompanied him would stay with him and support him. The participants defined all these activities as advocacy. Asked about the qualities they required in an advocate, all four of the men thought that a long relationship was ‘very important, extremely important’ (John, Parkview). When asked if an external independent advocate might not be more dispassionate than a nurse, and thus more useful as an advocate, John was adamant:

I wouldn’t like a stranger to be coming up to me and saying ‘I’m going to be your advocate’. I wouldn’t like it at all. Cos a) he doesn’t know me, b) I don’t know him and c) we might not have a good relationship with each other.

(John, Parkview)

When asked why this was important he replied:

I want someone I know, someone I get on well with and someone I can make a friend of as well.

(John, Parkview)

The advocacy support required by the participants from Downtown Day Centre differed from that in Parkview in many respects. Although they were not residential, and therefore had a much wider circle of possible supporters, clients of the day centre relied, to a large extent, on facilitation and support by staff who were immediately available. The advocacy support required by these clients fell into three categories: First, and similarly to the residents of Parkview, in micro level situations they might ask staff to advocate for them in difficult internal disputes with peers:

When Teddy hits me, I tell George cos he can sort it out.

(Paul, Downtown)

Second, and moving to a meso level not experienced by the hospital participants; when matters concerning the centre required attention, they relied on staff to arrange meetings with appropriate people and to enable the service users to speak in support of what was required. Arthur and Judy explained:

P So how do you find out who to talk to?
Sometimes meetings were initiated by service users noticing, for example, the state of the centre's mini bus. On other occasions clients' attention was drawn to potential problems by the day centre manager, who would then encourage and support them to advocate for whatever was required.

At a proactive macro level, classes had taken place so that service users could be part of the interviewing process for Day Centre staff. Tess explained how staff had facilitated their presence on interviewing panels.

We had mock interviews so that people could learn what to do. We interviewed staff but we called them Mr A, Mr B, Mr C and Mr D then we practised asking them questions, so that the service users can sit on interview panels and will know what to do

(Tess, Downtown support staff)

This type of facilitatory advocacy obviously relied heavily on the ability and willingness of staff and on their relationship with clients and this was clearly dependent on the ethos of the day centre. Downtown was recommended by a social services manager as being the most likely day centre in the locality for me to recruit willing participants for my focus groups. This was mainly due to the very active Service Users Committee which has become an important part of the Downtown culture. My first introductory meeting with service users at the day centre was conducted almost entirely by the clients, who listened to my presentation, asked questions afterwards and then took a few days to discuss my request and get back to me. This exemplified the way this particular day centre is conducted. The clients expected to speak for themselves in almost all service oriented situations. They relied on staff to bring some, but by no means all, of these to their attention and to facilitate meetings between them (the service users) and appropriate officials. They defined these activities as advocacy and, similarly
to the participants from Parkview, felt that the relationship between themselves and the staff was of major importance:

Paul: It's important that we know [the day centre staff]... well.
P: Do you think that's important too Arthur?
Arthur: Yes I do, it's important that we know them well. I get to know them all. We're a good team now.

(Paul and Arthur, Downtown)

Arthur's 'good team' included both clients and staff with the expectation that they would work equitably together, at least on day service matters, to ensure the smooth running of the service.

The participants from People First also worked together as a team and were dependent on their coordinator for support and facilitation in advocacy situations. Like the other participants they usually felt able to speak up for themselves in disputes with their peers. Unlike the participants from Downtown, they were subject to a very perceptible power differential in their day service, over which they had apparently no control and no immediate advocacy support. They relied on the coordinator of the self advocacy group to advocate for them in day service disputes by calling a meeting of people who might help and attempting to solve the problem. This was sometimes satisfactory, but there appeared to be a tendency for people at these meetings, including the coordinator, to unthinkingly assume a deficit in the person with learning difficulties, rather than focusing on their ability (Goodley, 1998). This was illustrated by Roy when he explained how he had been told by his day centre manager that he could no longer do voluntary work at the People First offices:

Donna And when you came up to People First what did we do? We sat down didn't we? Who was there?
Roy My mother and my social worker.
Donna and we told them didn't we, that you wanted to go on coming up. And they went to Alan and told him you were to go on coming up.

(Roy and Donna, People First)

The coordinator encouraged Roy's mother and his social worker to 'sort out' his problem for him, rather than assuming they would support him to self advocate to 'Alan', and despite knowing that Roy had spoken as a delegate at a national
People First conference before several hundred people. Advocacy at People First functioned well in 'representing the interests of [a group] of people' (Cocks and Duffy, 1993.51) for example, concerning Direct Payments or the Schools Project, but seemed less successful on the individual level. Advocating was easier for the participants from Downtown, where the emphasis was on the capability of each client and the support staff were readily available, than it was for individual members of the self-advocacy group.

3.7 Nurses
Towards the end of the focus group sessions with the three different sets of participants, I asked each group of informants how they perceived the role of the learning disability nurse. Of the three groups, only the hospital participants had regular sustained access to learning disability nurses. They had all lived in the hospital for many years. Their lives were bounded by hospital activities and they had few if any, social contacts and extremely limited access to anyone, other than staff members, most of whom were learning disability nurses or nursing assistants. When we discussed the role of nurses in the hospital they obviously saw this as based on an individualist (medical) rather than a social model. Ron and John saw nurses as somewhat authoritarian, 'they watch us if we’re fighting or something' (Ron); they 'keep an eye on us' and 'look after us' (John). Jim thought their main role was quite mundane – they 'get the boys up in the morning' and Paul needed prompting to come up with any ideas as to the nurse’s role. A leading question reminded him about his previous assertion that Jenny would support him in hospital, where he felt vulnerable among strangers in a strange environment, and he agreed that this was indeed part of the nurse’s role.

Wolfensberger and Zauha (2002) differentiate between instrumental advocacy, which is specific, short term and outcome driven, and expressive advocacy which they describe as relationship based, long term and non specific. The hospital participants saw nurses as having an advocacy role which is a mixture of these. They felt able to depend on nurses for their short term needs, but also stressed the importance of continuity in their relationship with them and felt that this meant that nurses knew them really well and that at least some of the nurses would always stand up for them if they were in trouble. However, they also saw nurses
as being very much in authority, ordering their day to day lives, watching over them and telling them what to do.

In contrast to the hospital participants, those from Downtown Day Centre, who live in a variety of settings, but none in a large institution, did not see learning disability nurses as particularly relevant to their daily lives. They perceived nurses as an adjunct to doctors, mainly in the context of practice nurses at their GP surgery, flu jabs, blood tests and other quasi medical procedures. Paul spoke of regular visits from a social worker who, he said, helped him ‘sort out problems’, but, although I had been told that learning disability nurses did visit the centre, none of the participants at Downtown appeared to have regular contact with nurses from the Community Team for People with Learning Difficulties.

Participants from People First also perceived nurses almost entirely in medical terms. Ted spoke about regular visits from the district nurse to have an ulcer on his leg dressed and others spoke of nurses in the context of physical accidents. Jim spoke about being looked after at home by a nurse after a car accident and Roy spoke about nurses in the context of his mother’s recent surgery. When it was suggested that nurses could speak up for them about medical treatment, Jim, who had epilepsy and therefore had probably the most contact with both doctors and nurses, thought this would be a good idea, although he had remarked that the nurse whom he saw regularly (who may be a learning disability nurse) only spoke to him after first consulting with his mother. Asked whether there were circumstances when a nurse might advocate for them, the participants were doubtful. Tom had previously remarked that nurses ‘have to look after you when you are bad’ but ‘only in hospital’. The coordinator of the group asked them whether, if they were in hospital, a nurse might advocate for them. In their reply the importance of the client/advocate relationship mentioned by both the participants from Parkview and those from Downtown recurred again:

Donna Sometimes a nurse could speak up for you as well as you speaking up for yourself.
John Like sticking up for you
Donna Yes. What would the nurse need to be like?
Mike She'd need to understand us. She'd have to trust us and we'd have to trust her.
(John, Mike and Donna, People First)

3.8 Evaluation of the focus group method for participants with learning difficulties

Research would be unusual if all arrangements went smoothly, and neither the introductory groups at the hospital nor those at the day centre went as planned. Two introductory groups were deemed necessary by the gatekeeper at the hospital, the first between me and the staff who would support the participants, and the second between me and the participants themselves. The timetabling of the meetings had been arranged in advance by the manager/gatekeeper, taking account of staff shift patterns and other organisational issues. At the first meeting I outlined to the supporters the form the meetings would take and their expected role, i.e. as supporters of the participants rather than participating in the groups themselves. This meeting proved something of a waste of time as the support staff who eventually came to the focus groups were usually different from those who had attended this meeting, with, at least in one case, somewhat unfortunate results. At the second meeting I met the potential participants, all of whom agreed to take part and signed the consent forms. There were also two introductory groups at the day centre, one for the Service User Group, who then became my gatekeepers at the centre, and the other for members of the debating circle. Some of the potential participants attended both. Once again the dates and times of meetings had been arranged in advance by the Service User Group and staff, in order to take account of organisational issues and also of the Christmas festivities occurring at the centre. The introductory group at the self advocacy group went as planned and the timetable for the focus groups was agreed without any problems.

These pre focus group meetings were useful, allowing me to assure the participants of their confidentiality within the study, again, with somewhat unexpected results. One member of the day centre group was adamant that he should not be referred to by a pseudonym in reports of the research. He explained that he was proud to be taking part in the study and required recognition of his contribution. The other members were happy with his decision, which, as only fore
names would be used in the reports, seemed unlikely to compromise the anonymity of the day centre. Members of the self advocacy group agreed on the use of pseudonyms and decided that they should each choose their own. A hilarious few minutes ensued as some bizarre suggestions were chosen and rejected before each participant finally settled on a suitable nom de plume for use in reports of the research.

Albrecht et al (1993) propose that focus group interactions include three distinct social processes by which opinions may be formed and articulated: compliance, identification and internalisation. Awareness of these by the moderator may be particularly relevant where the participants have learning difficulties, as, without skilful handling, they may threaten the validity of focus group data. At the hospital, compliance was not a major issue, but identification did occur when participants, throughout the research, sought approbation of their views from supporters and were unwilling, without persuasion, to discuss issues which may have been seen as contentious. Internalised opinions are potentially the most valuable, but also the most difficult to access as they are often subject to psychological and communication barriers. In the hospital groups, one member attempted on more than one occasion, to articulate his 'deeply felt thoughts and opinions' (Albrecht et al, 1993) by using metaphorical examples. He was twice interrupted by a supporter, on the second occasion breaking off and refusing to continue, possibly from concern about the consequences if he did so. Internalisation demands specific skills by the group moderator and I felt powerless to address this situation. It was not possible to dispense with the supporter assigned to our meetings due to the hospital policy that the four participants must be accompanied by a male staff member in the presence of women. The other two supporters attending the sessions were female. As I had initially requested, the latter did not volunteer any information, but were active in assisting the participants to read and understand the small questionnaire which was part of a focusing exercise in group two.

A further critique of the focus group method with this particular group of participants, must acknowledge that, except during the focusing exercises, there was a lack of sustained interaction between the men, so that the format tended to be more akin to a group interview than a focus group proper. Nonetheless, I felt
that interviewing all four men together was useful. Two of the participants were
certainly more confident in the presence of the others and from my own
perspective it was definitely helpful for obtaining relevant information, despite the
imperfections of my own technique as a facilitator. Several times I described
imaginary scenarios and asked the men how they would respond to these. Two of
the participants were able to do this, but the others had trouble with the abstract
idea of expressing their possible reaction to imagined situations. They were
helped by one group member who more than once rephrased my questions so
that the participant could give a simple yes or no answer.

The groups at the day centre followed a similar format to those at the hospital,
except for the use of focusing exercises, which seemed inappropriate as one
participant was severely visually impaired. I was however, able to incorporate
some of the ideas gained from the hospital groups into new questions about
advocacy and advocates. The confidence of these participants was apparent
during the focus groups. They very seldom sought approbation of their ideas from
the supporting staff member. In turn the single supporter at each meeting was
very facilitative. Beyond very occasionally interrupting to give background
information to what someone was saying, they did not interfere. The participants
were free to discuss their ideas in a facilitative and comfortable atmosphere and
obviously felt at liberty to talk about the faults as well as the strengths of the
service at the day centre. Possibly because all the participants belonged to
established groups within the centre, the interaction between them was better than
it had been between the hospital participants and, despite being arguably less
intellectually able, they were both more assertive and much more forthcoming with
their ideas.

I met the participants from the self advocacy group at their pre-arranged, monthly
meetings. The groups followed a similar format to those at the day centre, but
were held at monthly rather than weekly intervals. I had thought this might prove a
problem, but, after running through the main points from the previous meeting(s),
the participants at each session had no problem in picking up the threads and
were confident in giving their opinions. Most of them spoke of the power they felt,
due to their membership of People First. Jack explained that:

Power enables people to speak out. If you see someone suffering from injustices, it means you can speak out and advocate for that person. If they can’t do anything about it, then you can speak up for them. We could do that if we wanted to.

(Jack, People First)

Note here that Jack said ‘if we wanted to’, as if he was covering himself against the times he may not want to, perhaps because of lack of confidence, inability to be assertive, fear of reprisals or whatever. The participants had a very easy relationship with the coordinator of the group, but she was prone to prompt them into giving positive opinions about their experience of self advocacy. When they recited their piece about advocacy giving them power, this seemed more like a mantra recited for her pleasure, than a statement of truth. Despite their confidence as a group making interaction between them in the focus group setting very useful, this obviously did not translate into individual ability to confront the lack of consultation and choice apparent in many aspects of their day to day lives.

3.9 Emerging themes
Two main research questions guided the design of the first stage of the research and were specifically addressed in the focus groups with people with learning difficulties. The first asked ‘What do people with learning difficulties mean by advocacy? and the second enquired whether people with learning difficulties want learning disability nurses to advocate for them or whether they think nurses have a role in helping people with learning difficulties to advocate for themselves. Analysis of the transcripts of the focus groups revealed twenty five different definitions of advocacy:

1. Speaking for themselves and others
2. Interpreting for others
3. Being treated like an ‘ordinary’ adult person.
4. Proactively getting to know people in the community and encouraging other people to get to know people with learning difficulties
5. Receiving understandable information
6. Having support to complain
7. Learning about rights and using this knowledge to fight for particular issues, local or national
8. Standing up for one's rights
9. Having responsibilities as well as rights
10. Learning about democracy
11. Representing one's case to appropriate people
12. Presenting opportunities to meet influential people
13. Expressing emotions
14. Power
15. Finding opportunities for work etc.
16. Working together as a group
17. Working in collaboration with other people
18. Solidarity
19. Confidence building
20. Respecting other people and gaining other people's respect as well
21. Gaining independence
22. Getting out and about to conferences etc.
23. Learning how to behave at meetings
24. Having confidence to speak up in meetings and in public
25. Using the group + supporters to represent all members

Some of these were specific to certain participants; the last four applied particularly to the participants from People First, while 11 and 12 were only articulated overtly by the day centre participants although the self advocates did refer, in passing, to meetings with officials regarding Direct Payments and Therapeutic Earnings. Definitions 7, 8 and 9 were the result of interactions between participants and their supporters and although these were verified enthusiastically by participants from People First at a special post focus group meeting, were generated more by professionals than by the people with learning difficulties themselves. Definitions 1 and 2 were common to all the participants and number 3 was emphasised by both the day centre participants and those from People First. The first nine definitions on the list were discussed at some length by many of the participants and were thus taken forward as a ranking exercise to the focus groups with nurses which will be discussed in the following chapter.

Only the participants from the hospital had regular, direct contact with learning disability nurses and their opportunities to exert control over their lives were minimal. They were, however, adamant that nurses were the best, if not the only people who should advocate for them in situations where they required advocacy
support. There was very little direct data from the focus groups at the day centre and the self advocacy group in relation to the possible advocacy role of learning disability nurses. Nonetheless, a great deal of information emerged concerning ways in which people with learning difficulties conceptualise advocacy and their requirements of support to either advocate for themselves or from someone who would advocate for them. All of this was relevant to the advocacy role of learning disability nurses and contributed to subsequent investigation of this role in the ensuing stages of the research.

After analysis of the focus group data, several tentative theories emerged. One concerned the significance that people with learning difficulties placed on their relationships with anyone who might advocate for them or support them in self advocacy. Although the day centre participants and the self advocates apparently did not have regular contact with learning disability nurses, their views on relationships with supporters and the models of the advocacy support which they received would be very relevant to nurses taking on the advocacy role. ‘Power’ was much emphasised by self advocates, and was experienced by some of them in specially arranged situations where they had adequate support, but was not a reality for most of the participants, who encountered disempowerment on a day to day basis. Empowerment was a ‘site of silence’ (Clarke, 2005) not overtly articulated by the clients at Downtown, but becoming increasingly evident as the groups there progressed, and attributable to the eagerness and ability of staff at the day centre to support clients in self advocacy. Although the staff were not nurses, the ways in which they encouraged and enabled their clients to self advocate were certainly worthy of further investigation.

Facilitation by supporters as an advocacy activity was highlighted in both the People First groups and the Downtown groups, and the promotion of activities endorsing the community presence of people with learning difficulties was seen as crucial to the advocacy role of professionals, particularly in the self advocacy group. Differences between advocating according to an individual (medical) model and a social model were another ‘site of silence’, revealed as the analysis progressed which will be expanded in the presentation of stages two and three.
In conclusion, the project map (figure 11, overleaf) summarises the major themes generated by the focus groups with people with learning difficulties and illustrates some of the conditions which emerged from the data as influencing advocacy by and for people with learning difficulties. Both the major themes and their influences informed the design of the stage two focus groups and interviews with learning disability nurses. They also impacted on the design of the questionnaire survey which formed stage three of the research.
Situation of participants

Availability of opportunity

Attitude of supporters

Nature of advocacy attempt

Availability of support

Availability of funding and resources

Definitions of advocacy
25 different definitions (section 3.3), some very similar, some specific to certain client groups. Some generated by participants and others by participant/supporter interaction. Reactive and proactive
3 levels:
1 = micro, 2 = meso, 3 = macro level
1 + 3 - 2 = limited empowerment
1 + 2 + 3 = empowerment through advocacy

Available support

Systems and organisations

Relationships
Long term relationships seen as vital. Need for understanding and trust between client and advocate.

Models of support offered
Medical/Individual model
Social model

Ethos of support system

Power and empowerment
Negligible for hospital participants
Clearly demonstrated in day centre
Articulated but not demonstrated as 'every day' reality for self advocates

Opportunity

Attitude of supporters

Facilitation to self advocate
Dependent on varying degrees of support

Community presence
Not available to hospital participants
Seen as crucial by other participants
Requires varying degrees of support

Dependence on other organisations

Figure 11: Project map illustrating main themes from stage 1

KEY

Main themes from stage 1
Influences

113
Chapter four

Focus groups with learning disability nurses
4.1 Introduction
The previous chapter described the use of focus groups with participants who have learning difficulties to discuss the concept of advocacy and their requirements for support, either to advocate for themselves or from someone who might advocate for them.

| 1. Definitions of advocacy |
| 2. Relationships |
| 3. Power and empowerment |
| 4. Facilitation to self advocate |
| 5. Community presence |
| 6. Individual (medical)/social model of disability |

Table 1: Major themes from stage one

Results from each session were confirmed by the relevant participants as the research progressed and some of the most important findings were collated into a ‘feedback’ report (appendix 5) which was verified by participants with learning difficulties from the self advocacy group at the end of stage one. Following a grounded theory methodology, six major themes resulting from the analysis of data from the focus groups in stage one (table 1) were incorporated into the design of the second stage of the research i.e. focus groups with learning disability nurses.

Four research questions were addressed specifically in this stage of the study:

1. What do learning disability nurses understand by advocacy?
2. Is this similar to the meaning given by people with learning difficulties?
3. Do learning disability nurses advocate for their clients? If so in what way do they do this?
4. If learning disability nurses do advocate for their clients what are the problems concurrent with their advocacy role?

The intention to consider the implications of the above for the education and ongoing support of learning disability nurses also required acquisition of some
information about the participants' received education in advocacy and their requirements for education and training in this field.

I have already discussed the rationale for using focus groups (section 2.15), the design of the groups (section 2.17) and ethical issues concerning this stage of the research (section 2.16). In this chapter I discuss those characteristics of the nurse participants which were relevant to stage two and mention the problems I encountered in accessing nurses for some of the focus groups, resulting in conducting one to one interviews with two nurse participants. As in the first stage of the research, I analysed data from the focus groups and interviews in stage two using NVivo supplemented by situational analyses (section 2.6). I present and discuss the main points from the data, before evaluating the focus group method as a data collection tool with learning disability nurses in this stage of the research. The chapter concludes with a summary of the main themes and their implications for the design of the survey which comprised stage three of the research.

4.2 The participants
As I was unable to include people with learning difficulties and minimal or no conventional verbal communication in stage one of my study, I had decided, in an effort to give these people some representation, that the nurse participants should be grouped according to the communication skills of the clients with whom they worked. I considered that it would only be necessary and practicable to run two sessions with each group of nurses. In the first session I intended to explore the nurses' advocacy role, using the second session, with the same nurses, for feedback and review and for theoretical sampling to fill in any obvious gaps in the data.

Thus my intention was to run two groups with nurses working with people who do not verbalise, two groups with community nurses whose clients have the whole range of communication skills and two groups with nurses working with clients whose verbal communication can be understood by most people. I hoped for a representative mix of grades, gender and ethnicity. Once again, I was reliant on gate-keepers and, although I achieved my aim of a mix of grades D to G, these
being the ‘hands on’ nurses; of a total of eighteen participants all were white British and only three were male.

<table>
<thead>
<tr>
<th>Group 1 &amp; 2</th>
<th>Communication skills of clients</th>
<th>Grade</th>
<th>Qual. year</th>
<th>Exp. with present or similar clients</th>
<th>Key worker</th>
<th>Female/Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pam</td>
<td>non-verbal</td>
<td>E</td>
<td>1974</td>
<td>5 years+</td>
<td>4 clients</td>
<td>F</td>
</tr>
<tr>
<td>Debbie</td>
<td>non-verbal</td>
<td>E</td>
<td>1979</td>
<td>5 years+</td>
<td>1 client</td>
<td>F</td>
</tr>
<tr>
<td>Peter</td>
<td>non-verbal</td>
<td>E</td>
<td>1982</td>
<td>3 years+</td>
<td>1 client</td>
<td>M</td>
</tr>
<tr>
<td>Liz</td>
<td>non-verbal</td>
<td>E</td>
<td>1996</td>
<td>3 years+</td>
<td>1 client</td>
<td>F</td>
</tr>
<tr>
<td>Group 1 only Janet (Deputy Manager)</td>
<td>non-verbal</td>
<td>F</td>
<td>1987</td>
<td>5 years+</td>
<td>No</td>
<td>F</td>
</tr>
<tr>
<td>Jane</td>
<td>non-verbal</td>
<td>E</td>
<td>1984</td>
<td>5 years+</td>
<td>1 client</td>
<td>F</td>
</tr>
<tr>
<td>Group 3 Graham</td>
<td>whole range from non-verbal to adequate</td>
<td>G</td>
<td>1978</td>
<td>5 years+</td>
<td>N/A</td>
<td>M</td>
</tr>
<tr>
<td>June</td>
<td>as above</td>
<td>G</td>
<td>1989</td>
<td>5 years+</td>
<td>N/A</td>
<td>F</td>
</tr>
<tr>
<td>Interview 1 Paula</td>
<td>as above</td>
<td>G</td>
<td>1984</td>
<td>5 years+</td>
<td>N/A</td>
<td>F</td>
</tr>
<tr>
<td>Interview 2 Carol</td>
<td>as above</td>
<td>G</td>
<td>1988</td>
<td>5 years+</td>
<td>N/A</td>
<td>F</td>
</tr>
<tr>
<td>Group 4 Polly</td>
<td>adequate verbal</td>
<td>E</td>
<td>1996</td>
<td>5 years+</td>
<td>2 clients</td>
<td>F</td>
</tr>
<tr>
<td>Kelly</td>
<td>adequate verbal</td>
<td>D</td>
<td>2002</td>
<td>1 year</td>
<td>1 client</td>
<td>F</td>
</tr>
<tr>
<td>Group 5 Jo</td>
<td>mainly adequate verbal, occasionally non-verbal</td>
<td>E</td>
<td>1993</td>
<td>5 years+</td>
<td>2 clients</td>
<td>M</td>
</tr>
<tr>
<td>Karen</td>
<td>as above</td>
<td>E</td>
<td>1993</td>
<td>5 years+</td>
<td>2 clients</td>
<td>F</td>
</tr>
<tr>
<td>Group 6 Mary (Manager)</td>
<td>one non-verbal three adequate verbal</td>
<td>G</td>
<td>1990</td>
<td>5 years+</td>
<td>No</td>
<td>F</td>
</tr>
<tr>
<td>Nia (Deputy Manager)</td>
<td>as above</td>
<td>F</td>
<td>1989</td>
<td>5 years+</td>
<td>No</td>
<td>F</td>
</tr>
<tr>
<td>Jane</td>
<td>as above</td>
<td>E</td>
<td>1979</td>
<td>3 years+</td>
<td>1 client</td>
<td>F</td>
</tr>
<tr>
<td>Sara</td>
<td>as above</td>
<td>D</td>
<td>2004</td>
<td>Newly qualified</td>
<td>No</td>
<td>F</td>
</tr>
</tbody>
</table>

Table 2: Characteristics of Nurse Participants – Stage 2

The first focus group included six nurses, all of whom worked, in two small residential settings, with people who have profound learning difficulties and no conventional verbal communication (table 2). Five were E grade staff nurses and
the sixth was an F grade deputy manager. Only one of these participants was male. All the nurses had over three years experience with this client group and two of them had worked with these or clients with similar needs for over twenty years. Four of the nurses had a range of post registration education at diploma or degree level. All except the F grade deputy manager, who had administrative responsibilities in addition to her ‘hands on’ work with clients, had key worker responsibility; four for one client only and the other for four clients. Two of the nurses were unable to attend the second group, which thus had four E grade nurses, one of whom was male.

Despite the gate-keeper’s suggestion that I should be able to access a minimum of ten participants, the groups of community nurses, who worked with clients with the whole range of communication skills, proved much more difficult to arrange. The first group consisted of only two participants, one male and one female, both G grade nurses with over five years experience (table 2). Both held the post registration Diploma in Community Nursing Studies. As it had proved so difficult for these nurses to attend the sessions, rather than have a second meeting, data from the first group was summarised and sent to each nurse for their comments and approval. This proved very satisfactory and paved the way for similar action with all the remaining nurse participants, with theoretical sampling occurring in subsequent groups of nurses, rather than with the same participants. Fortunately, the LREC had agreed that I could conduct individual interviews with participants if this proved necessary, so, having failed to arrange a joint meeting with the two other community nurses who had volunteered to participate, I interviewed them individually at their separate office bases. Both were female and were G grade nurses with over five years experience. They each had post registration education at Diploma level and one had a post graduate degree (table 2).

The final group, with nurses working with people who have learning difficulties but are able to verbalise adequately, was arranged, again through a gatekeeper, to have seven nurse participants. After some difficulties due to work commitments and sickness, the group was split into three separate sessions with a total of eight nurses taking part (table 2). The two nurse participants in the first group and the four in the last group worked in two different long term residential settings with
clients who may challenge services. The two nurses in the middle group worked in an assessment unit, with similar clients who were typically in a situation of behavioural crisis and expected to stay only temporarily in the unit. Although most of the clients in these settings had adequate verbal communication skills, the nurses in group six reported having one client who did not speak and the verbal communication skills of clients from the assessment unit were described as varying from adequate to non verbal. Amongst the nurses, there was a good mix of grades D-G, one of the two D grade nurses being newly qualified and the other having just twelve months experience. Of the four E grade nurses, one had worked with these or clients with similar needs for three years and the others, similarly to the F and G grade nurses, had over five years experience. The two D grade nurses had no post registration education, while that of the six others ranged through none to courses at Diploma and Degree level. Only one of the eight nurses in the three groups was male. Neither the newly qualified D grade nurse nor the F grade deputy manager and the G grade manager had key worker responsibilities, both the latter having administrative as well as 'hands on' responsibilities for clients. Of the other five nurses, two acted as key worker for one client each and the other three each had key worker responsibility for two clients (table 2).

4.3 The design of the groups
I have already discussed the design of the groups based around a general purpose statement (Vaughn et al, 1996) which I had written for the purpose. Following the grounded theory method, I transcribed the data soon after each focus group and interview had taken place, and did an initial analysis, giving me a tentative overall picture of the views of the different participants. The main points were then summarised and submitted to the relevant nurses for their approval. The transcripts were coded using NVivo, initially taking as broad headings the main subjects around which the groups had been designed i.e. advocacy, advocating; barriers to advocacy; advocacy education; the role of the learning disability nurse, and as sub topics, within the first three headings, the major themes from the stage one focus groups (figure 12). Additional lines of enquiry were revealed as the transcription and analysis of the stage two groups progressed. Thus, in addition to the broad headings already mentioned, I
investigated issues relating to independent advocacy and advocates and searched in more detail the categories of 'relationships' and 'power and empowerment'. I also looked for more detailed evidence that, as well as advocating for their clients, nurses might facilitate self advocacy for them, and explored the data for evidence that nurses might be guided by different models of disability.

**Findings from focus groups and interviews with learning disability nurses**

![Diagram showing various social worlds and arenas affecting learning disability nurses']

Figure 12: Social worlds/arenas which might affect learning disability nurses' advocacy role
4.4 Advocacy

Before presenting the findings from the focus groups and interviews with learning
disability nurses, I offer a simplified map of the social worlds/arenas which might
impinge on their advocacy role (figure 12). Clarke (2005) points out that many of
the boundaries in such a map are porous and it is this porousness which gives the
analysis of social worlds/arenas its flexibility. She also calls attention to the
overlapping nature of multiple social worlds, proposing that ‘some people and
collectivities are participating in more than one’ (Clarke, 2005, in press) at any one
time. Nurses’ advocacy roles may be affected by any or all of the worlds depicted
as the outer (black) ring on the map. They will also be influenced by the nurses’
employment situation, the intellectual abilities of their clients, their clients’ support
systems (shown in blue on the map), and the circumstances in which the nurses
are called upon to advocate. For example, advocacy for a client with profound and
multiple disabilities who is unable to speak and who lives in long term
accommodation, supported by nurses, is likely to be vastly different from advocacy
for a client with mild learning difficulties participating in supported employment and
living in the family home.

Many of these differences were demonstrated by nurses in the focus groups. The
first question in each session with different participants asked the nurses to give a
formal definition of advocacy. Comparison of the different definitions reflected the
varying intellectual abilities of the clients with whom they worked. Nurses working
with clients who have profound and multiple disabilities and do not verbalise,
emphasised the importance of advocating for the legal and moral rights of their
clients. They also suggested that advocacy was about encouraging their clients,
who live in NHS ‘continuing care’ settings, to make what choices they can, while
prioritising their ‘best interests’. The participants demonstrated an awareness of
the complexities of defining advocacy, suggesting that ‘true advocacy’ might
involve situations leading to ‘conflicts of interest’ and an inability to represent
clients, due to nurses’ employment by the Trust which has overall responsibility for
them.

Illustrating the overlap between the advocacy definitions given by nurses in very
different employment situations, the concept of ‘best interests’ was also included in
the definitions given by the community nurses. Two of these participants agreed that advocacy entailed:

Speaking or acting on someone else's behalf, with their best interests in mind and with their agreement if possible.

(June, group 3)

Another expanded the definition, adding the proviso that clients should be given adequate information to enable them to make informed decisions if possible. In addition, and reflecting differences due to the mixed abilities of her clients, this nurse proposed that advocacy meant ensuring clients' rights are upheld as well as:

...making sure that people have a voice, particularly people who aren't able to communicate effectively.

(Carol, interview 2)

The fourth community nurse thought long and hard before giving a definition which reflected concern for the varied abilities of her client group and also made reference to the 'different' social world of their carers:

It's actually about being a facilitator... trying to be the person that enables things to happen for that person, who is unable to speak for themselves, or for the families of those people who might find it difficult to do that. It's quite a complex role. It's not as simple as just speaking for someone. It's more about liaison, facilitation, making phone calls on behalf of somebody... to enable something to happen for them.

(Paula, interview 1)

The community nurses all mentioned clients' rights and agreed that advocacy entailed both providing information and speaking for clients. Nurses working in residential settings with clients who have adequate verbal communication demonstrated a common dimension in their understanding of advocacy but also expanded on the definitions of the other nurses. Possibly acknowledging a measure of paternalism within her advocacy role, one of the nurses argued that:

It's not just about information .... You can give them all the information but you need to be sure that they can adequately understand it. They need to do that before they know what choice to make... I suppose it's informed guidance.

(Nia, group 6)
So for these nurse participants at this initial stage in the research, advocacy was about speaking for clients after giving them, and sometimes their families or carers, comprehensible information and supporting them to make decisions. There was an implicit understanding, communicated overtly by some of the nurse participants, that these should be based on the nurses' view of the 'best interests' of the client. The way in which information was given and the necessity to provide informed guidance was largely dependent on the intellectual ability of the clients and nurses' relationship with them. In addition, and introducing a potential for incompatibility with the concept of 'best interests', nurses defined advocacy as being about recognising clients' rights and making sure that other people recognised them also.

4.5 Relationships
The relationship between clients and potential advocates had been considered highly important by participants with learning difficulties in the stage one focus groups. Many of them had mentioned being able to advocate for peers with impaired communication skills and felt this was due to their long relationship with each other, either in their residential settings or in day services.

In order to probe the nurse participants' views on the importance of relationships, I questioned them about possible differences in advocating for their clients and for family members, for example children or elderly relatives. Most of the nurses agreed that the main difference was in actually deciding whether or not to advocate for clients, where this would probably not be an issue for their children or elderly relatives. They agreed that the reasons, emotions and conflicts involved in making this decision would be different on a personal than on a professional level, largely because of the relationships involved. As in the stage one focus groups relationships were demonstrated to be an issue of great importance to the nurse participants in stage two. Nurses have a different relationship with their own family members than that which they have with their clients. With the latter, they must also take into account the relationship between clients and their families, between clients' families or carers and nurses and between nurses and their employers.
The attitude to relationships varied according to the employment areas of nurses and the abilities of their clients. One community nurse perceived a danger in becoming too emotionally involved in her relationships with both clients and their families, rather than retaining a more objective professional role:

I think there are big differences between personal and professional advocacy because of the huge difficulties that can arise if you were to become too familiar, because you can't be a friend. You can't be a paid friend because obviously you've got your professional role and it can be difficult at times, but I think there's clear boundaries where you should be, how much information you should give and how close you get to people.

(Carol, interview 2)

Community nurses have, of course, limited time to spend with each of their clients, and Carol, who had clinician only responsibility, unlike some of the nurses working in other settings, did not appear to find it difficult to keep her relationship with clients on an objective, professional, footing. Nurses working in residential units with people who have profound and multiple disabilities and no conventional verbal communication counted the close relationships they are able to forge with their clients as one of the major 'positives' of the closure of the institutions, where many of them had previously worked, and as contributing towards a successful nurse/client advocacy role:

Pam We advocate more for our clients than general nurses do
Peter Yes it's all about the ability to form relationships
Debbie Yes it's about relationships and the small numbers, if you've got four clients, you can do much more for them than if you've got forty on a ward
Pam Yes and even twenty
Debbie It wouldn't have been possible to advocate for each of them as a person before, but now we can

(Pam, Peter, Debbie, group 1)

Forming relationships with clients in these settings was associated with the professional need for time in which the nurses could learn to understand the gestures, signs and other communication attempts of people who do not verbalise. Possible conflicts due to 'friendships' between nurses and their clients were not explicitly considered as an issue.
The development of trust in relationships with clients was considered of primary importance by nurses working in long term residential settings with clients who have adequate communication skills, but may challenge services. Nurse participants working with this client group did however recognise the potential conflict between forming good relationships with clients and the possibility that clients would then consider the nurse to be a friend rather than a professional with loyalties to her/his employer:

P What sort of relationship would you aim for ideally with your clients?
Polly You need a good rapport, but it does have to remain professional. I know I made that mistake in my early career thinking you can be a friend of all the people you work with, but that can cause problems.
P Can you say a bit more?
Polly Yes... it comes down to the conflict of interest. When you work for a service with service constraints and try to be a friend of a client. Sometimes you do have to say 'No' or 'I can't be with you to do that particular thing'. If you can't do something because of service constraints and you have to back off suddenly, then that's not a friend. A friend is there for as long as that person wants. You can't progress much if you’re the only person they’ll do things with. And we can’t be their friends. We are told to create a homely atmosphere but within that you have to remain professional. It’s a nursing skill to do that, and one with a cost as well. Because sometimes you do get really attached to the clients and when you know something’s gone wrong you worry about it and when you go home it’s hard to switch off. (Polly, group 4)

Even in the assessment unit, where clients were residential, but were not expected to stay for a prolonged period of time, relationships with the clients were seen as important and the possibility was recognised that nurses might suffer psychologically by advocating unsuccessfully for a client with whom they had formed a close relationship:

Karen It’s a working relationship. It’s a fundamental part of our work to know the clients well and to speak for them.
Jo That’s not saying that things in work don’t upset you
Karen It’s not true to say they don’t. Sometimes in work you do get very heavily involved with people.
In summary, good, possibly long term, relationships with clients were seen as important by all the nurses, as was a recognition that keeping the relationship on a professional basis, although ideal, was not always attainable. Nurses recognised the potential problems caused for both themselves and people with learning difficulties by becoming too emotionally involved with their clients. They felt able to acknowledge that these did occur but were reasonably confident that their professional training enabled them to deal with the problems which would not be allowed to compromise their advocacy role.

4.6 Ranking definitions of advocacy
The stage one focus groups had generated twenty five definitions of advocacy, some broadly similar and others widely different. Some of these had been initiated by the participants themselves and some had been the result of interaction between the participants and their supporters. All had been verified by group members in the final sessions with the different participants. Bloor et al (2001.43) propose that ranking exercises “lay bare the background assumptions that underlay the groups’ responses”. Accordingly the twenty five definitions of advocacy were narrowed down to nine which were printed on cards and introduced as a ranking exercise for the nurses in each focus group (section 3.9). Participants were asked to rank the definitions in order of their relevance to the nurses’ current practice. In compliance with the grounded theory method this facilitated comparison between the nurses’ ideas and the definitions of advocacy gained from people with learning difficulties in stage one. It also encouraged the nurses to discuss their reasons for their rankings as the exercise proceeded.

Bloor et al (2001.43) argue that “the discussion about the rankings serves to illustrate the deep differences (along with some important similarities) in the tacit understandings of each group”. Table 3 illustrates that this was indeed the case.
Interpreting for others
Speaking for others
Treating people as adults...
Working with individuals...
Promoting the rights of.....
Encouraging decision making...
Encouraging people to take responsibility....
Supporting clients to complain....
Proactively getting to know people...

<table>
<thead>
<tr>
<th>Definition</th>
<th>Group one</th>
<th>Group three</th>
<th>Interview one</th>
<th>Interview two</th>
<th>Group four</th>
<th>Group five</th>
<th>Group six</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpreting for others</td>
<td>2</td>
<td>6</td>
<td>4</td>
<td>2</td>
<td>8</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Speaking for others</td>
<td>2</td>
<td>6</td>
<td>4</td>
<td>7</td>
<td>Not ranked</td>
<td>9</td>
<td>2</td>
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<td>Treating people as adults...</td>
<td>1</td>
<td>4</td>
<td>6</td>
<td>7</td>
<td>4</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Working with individuals...</td>
<td>5</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Promoting the rights of.....</td>
<td>6</td>
<td>8</td>
<td>7</td>
<td>1</td>
<td>3</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Encouraging decision making...</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Encouraging people to take responsibility....</td>
<td>Not seen as applicable</td>
<td>5</td>
<td>1</td>
<td>2</td>
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<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Supporting clients to complain....</td>
<td>Not seen as applicable</td>
<td>2</td>
<td>8</td>
<td>2</td>
<td>6</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Proactively getting to know people...</td>
<td>7</td>
<td>Not seen as applicable</td>
<td>Not seen as applicable</td>
<td>Not seen as applicable</td>
<td>7</td>
<td>7</td>
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Table 3: Ranking order of definitions of advocacy generated by focus groups in stage one

‘Encouraging people to make their own decisions’ scored in the top four in the rankings of all groups. The nurses in group one spent some time explaining how they both encourage and teach their clients, who do not verbalise, to express their own likes and dislikes and how staff learn to recognise these decisions and try to adhere to them. All the nurses also scored ‘working with individuals to ensure their rights are respected and upheld’ in the top five of their rankings. Polly, who ranked it in first place, expressed the opinion that this was:

...one of the core principles of the nursing role. You can advocate for people but only as much as they know what they should be having... so part of advocacy is bringing people up to that level.... so that they know what they are entitled to.

(Polly, group 4)

In the stage one focus groups, participants with learning difficulties from the day centre and the self advocacy group had placed a great deal of emphasis on the importance of interaction with (mostly non disabled) people in a variety of community settings. For the self advocates, their work in the 'schools project' and in 'community awareness' schemes was a major source of empowerment, while the day centre clients had gained self confidence due to their successful
negotiations with a variety of community based officials and their presence on interview panels with non disabled people. Despite its importance to people with learning difficulties, 'Proactively getting to know people in the community and encouraging people in the community to get to know people with learning difficulties' scored very low with all the nurse participants, not even seeming particularly relevant to those nurses who worked in residential units. They talked about visiting local pubs and restaurants, but not actively encouraging any real interaction or relationships between their clients and neighbours or other people outside the service.

'Supporting clients to complain if they think they are being treated badly or if they think something is unfair' was one of the most interesting definitions discussed. Reflecting adherence to a 'medical model' of disability, nurses who worked with clients who do not verbalise thought it not applicable to their clients. It was ranked second by the community nurse group and one of the community nurse interviewees, the other ranked it last, giving the 'negative connotations' as her reason, rather than it not being something she would do in her professional role. One community nurse started by ranking it last 'because it only looks at the negatives', but after some discussion about his own practice, rather than just about definitions of advocacy, changed his mind because:

if they're unhappy with something, you have to give them 100% just as you would if they were pleased

(Graham, group 3)

This apparent failure to relate the definitions to their current professional practice was also a problem for nurses in group four. Polly suggested that 'supporting clients to complain...' was something they did 'at face value' but suggested that:

.... there are so many bad connotations about advocacy... that that is all advocacy is about... I wouldn’t want that in any of my definitions of advocacy, but then, I suppose... it is part of it.

(Polly, group 4)

From which I gleaned that Polly thought advocacy was positive and wanted to present it in the best possible light, rather than consider it's 'warts and all' definitions which she might find useful in her practice.
Jo, from the assessment unit, was adamant that they 'would bring someone in' if a client wanted to complain. He had previously explained that, probably because of the locally unique service they offer, clients in the assessment unit had relatively easy access to independent advocacy services. In a different group, Nia remarked that in seventeen years she had only given a complaint form to one client and helped her to fill it in. She suggested that this was because:

We support them to complain about services that we're not providing... but not to complain about us, individually or as a team

(Nia, group 6)

Lukes (1974.23) proposes that one of the most effective uses of power is when potential ‘issues’ are kept off the agenda by ‘institutional practices or through individuals’ decisions’ to prevent conflict arising and Mary confirmed this. She explained that clients did not complain because they were not given information, due to staff being:

... in a position of power. So we advocate from a very uneven position because... we have the power to say 'yea' or 'nay'. We've got the power to give them some, but not all, the information... With our clients, not giving them some information because we know it triggers very difficult behaviours is a temptation .... and we do do it.

(Mary, group 6)

This lack of information includes clients having very little knowledge about the roles of staff and therefore not being in a position to complain about their treatment by staff or about staff behaviour. In an effort to counteract this and other concerns, three of the four clients in the house which Mary manages have independent advocates. The nurses involved considered that this service was 'tokenistic' (Nia, group 6), a view centred around relationships, which had already evolved as a major theme in this study.

Mary explained that:

Sometimes the individuals don't choose that person to advocate for them. They say they want an advocate and that person is selected. Sometimes the commitment isn’t there.

(Mary, group 6)
In the case discussed by the nurses, one advocate works with all three clients and seemingly makes no effort to form any relationship with them, a situation which the nurses (and apparently the clients also) viewed as unsatisfactory. Mary expressed the opinion that the best volunteer advocates are people who have formerly had some role (e.g. physiotherapist; O.T.) in the person's life, as they will have formed a relationship, and are more likely to have good personal commitment to the client.

There was general consensus in group six that 'Promoting the rights of people with learning difficulties at local and national level' should be ranked first because:

> If you don't do it from the top down, no-one's going to do it from the bottom up are they?  
(Sara, group six)

This view was not shared by all the nurses, even those who worked in similar specialties. Community nurse Carol agreed with Sara and ranked it at number one, but Graham, also a community nurse, ranked it last, explaining that he thought this was:

> ...a citizen advocacy, self advocacy role. If we get the opportunity to do it obviously we will, but I think it's more for people with learning difficulties themselves.  
(Graham, group 3)

Graham's argument seemed apposite, although Carol, in her clinician role, gave examples of fighting for the rights of her clients, mainly within health care settings. None of the nurses from residential units proffered examples of occasions where they explicitly promoted the rights of their clients at local or national level.

'Speaking for others' and 'Interpreting for others' resulted in a wide range of rankings. The nurses in group five (whose clients generally have adequate communication skills) ranked 'speaking for others' last, arguing that:

| Jo     | I don't think I'm there to speak for others |
| Karen  | No, I don't either                        |
| Jo     | I think it's disabling to do that         |

(Jo and Karen, group 5)
Polly and Kelly (group 4) agreed and threw ‘speaking for others’ out of their ranking altogether, suggesting that it was not ‘what advocacy is’. Both these groups also put ‘interpreting for others’ low on their list, probably reflecting the adequate verbal communication of their clients.

When asked at the start of the focus groups to give a definition of advocacy, two of the community nurses agreed that it entailed ‘speaking or acting on someone’s behalf’ (June and Graham, group 3) and a third suggested it was about ‘making sure people have a voice’ (Carol, interview 2). Despite this, when faced with ‘speaking for others’ in the ranking exercise, the community nurses did not see it as a hugely important part of their role. June and Graham ranked it in joint sixth place with ‘interpreting for others’ and Carol ranked it last on her list, although her rankings were compromised by the individual format of her interview. All the community nurses argued that they preferred to encourage their clients, where possible, to speak for themselves.

Nurse participants who worked with clients who have no verbal communication had a very spirited discussion before ranking ‘interpreting for others’ and speaking for others’ joint second on their list, with the proviso that they should always be considered together because:

- Peter: ‘...If you’re speaking for others you might be giving your own opinion instead of their’s.’
- Jane: ‘...but if you’re interpreting for them you can tell by their actions what they want.’
- Janet: ‘If you learn to interpret, then you can speak for someone cos you know what they want.’
- Peter: ‘Yes, it’s their views then and not ours.’

(Peter, Jane and Janet, group 1)

Although ‘speaking for others’ was bottom of the rankings by nurse participants in group five and was thrown out of the rankings altogether by nurses in group four it was high on the list of group six, who worked with clients with similar needs; being ranked in joint second place. Mary returned to the issue of power when she explained:

‘...we do speak and interpret for them... because they are not empowered in the venues that we are empowered in, so when it...’
comes to meeting other individuals we do this. We do it with their parents, we do it with professionals...

(Mary, group 6)

'Treating people like adults....' was seen as crucial by the people with learning difficulties from whom the definitions came, but received a wide range of rankings from the nurses. Nurses from group one had placed this definition behind 'interpreting' and 'speaking for others' at their first meeting, but moved it into first place after reconsidering it in the second focus group. Debbie felt that 'we couldn’t really speak for them unless we treated them like adults and consulted with them' and the others agreed. Many of the other nurses ranked this definition on a par with others, rather than suggesting that it stood out as of particular importance to their practice.

Two of the community nurses ranked ‘Treating people like adults...’ jointly with ‘Encouraging people with learning difficulties to take responsibility for themselves...’. This definition received rankings from one to five from nurses who worked with clients who had either adequate or a mix of verbal communication skills, but was not ranked by the nurses who worked with clients who had minimal or no verbal communication. Pam explained:

I think it’s important but it’s not something that our clients would really be able to do. They are just unable to take responsibility for themselves because of their disabilities.

(Pam, group 1)

A view which reflected Pam’s long experience with this client group and the consequent ‘taking for granted’ of received thinking concerning people with profound and multiple disabilities who do not speak. It may also have reflected her training. Pam qualified thirty years ago in an era when the ‘individual/medical’ model of disability was prevalent and the ‘social’ model had not yet evolved.

4.7 Barriers to advocacy
Although all the nurses agreed that they do advocate for their clients, they were also very aware of potential problems concurrent with their advocacy role. Conflicts of interest with their employing Trust were mentioned by all the participants, although a minority of them felt that they were able to address these
by adopting a multi-disciplinary team approach when advocating for clients against Trust policies. However, team advocacy was not always positive or even practicable for at least one community nurse, who suggested that the ‘team’ itself was a major source of conflict, being headed by Social Services rather than by the local Health Trust (June, group 3). Health and safety regulations imposed by Trusts were frequently mentioned as a source of conflict of interest by nurses wishing to advocate for clients to be supported to take an (assessed) element of risk in the course of life enhancing activities; and resource allocation was another frequently mentioned source of conflict with employing Trusts. This particularly affected the community nurses. As a clinician, Carol has to advocate for what she considers are essential aids for clients, but explained:

... it's resource led so there's a conflict. I've identified some need and they're saying the money isn't there. I just keep bringing it up at every opportunity.

   (Carol, interview 2)

Graham, with a dual case-manager/clinician role was adamant that the client's needs are paramount, even when the Trust requests concessions:

... it's when you are asked to compromise... about financial things. You're not going to dumb the assessment down, but you might be asked to do that.

   (Graham, group 2)

Conflict between nurses and families was a key issue for many of the community nurses, mainly in cases where the client had made an informed choice about, for example, moving out of the family home, or forming a relationship with another person, and the family, usually the mother, was adamantly against this decision. Individual community nurses offered different opinions on coping with such circumstances. Graham would always advocate for the clients wish, but, returning to the issue of relationships, Paula felt that keeping the family in touch with the community team took priority because:

If you start challenging that powerful mother about the rights of their son or daughter.... They have been known to say 'don't come back here'. So you are at risk of throwing away the relationship [between the nurse and the client with learning difficulties].

   (Paula, interview 1)
The power of families over their adult children with learning difficulties was seen as very much an issue here, as it had been in the focus groups in stage one (section 3.4). The community nurses agreed that assisting the client to self advocate to their family is the best solution for all concerned. This is not always possible however. In a reflection of the problems experienced by a self advocate in the stage one groups, Carol described supporting a client to self advocate to her mother about her wish to have a relationship with a male friend. Even though the client had decided what she wished to say and Carol had written down the list of the points for her and had been present to support and prompt her if necessary, the client had still not been able to self advocate satisfactorily to her mother.

Attitudes to family as advocates varied amongst the groups. Several of the nurses had very positive experiences, but others suggested that, similarly to nurses advocating for their own family members, the emotional involvement between clients and family members sometimes led to lack of objectivity which could hinder satisfactory advocacy. Paula felt that families were particularly good at representing their sons or daughters with profound and multiple disabilities. She argued that most community nurses, herself included, lacked both time and skill to advocate adequately for these clients:

"People who are deaf and blind with profound learning disabilities.... even if we make every effort to find alternative means of communication. How do you communicate complex issues about changes in their package of care or lack of staff maybe? I think we tend to rely on .... families who are more in tune with that person to communicate with them. Myself, I know I'm not very good at it."

(Paula, interview 1)

Paula thus accepted that the long term relationship with their families or carers was important for advocacy with these clients, echoing the views of nurses in the first focus groups in this stage of the study.

4.8 Independent advocates.

Moving on from family to independent advocates, data revealed that the attitudes of individual nurse participants varied, as did attitudes among the groups. Relationships were again seen as an important issue. One of the nurse participants in the first group was adamant that the intimate knowledge that nurses
have of their clients who have profound and multiple disabilities made them more suitable than 'outsiders' to act as advocates for people with the particular needs of this client group. She stressed that forming relationships that would enable some understanding of the likes, dislikes and possible choices of clients with multiple disabilities who do not verbalise, is both demanding and time consuming. She felt it was therefore better suited to those working full time with these clients than to independent advocates, who are likely to be involved on an irregular basis and be unfamiliar with the special skills involved in communicating with these people. However, illustrating the different views of nurses working with the same clients, another participant in the same group had had very positive experiences with independent advocates:

I've worked with advocates .... And they could go that one step further, because they could say what the service deficiencies were

(Janet, group1)

Whilst accepting the importance to successful advocacy of close relationships built up over a period of time, because the clients 'haven't got the strength or the ability to fight for themselves', this nurse suggested that there could be short term 'crisis' situations, such as mistakes in the assessment of a client's benefits, which could be dealt with by a 'crisis advocate' who did not need to have a long-term relationship with the client. She thought it might also be possible for a staff member who had a close relationship with a client to pass on 'to somebody outside what they needed to know and then they could act for that person if it was something really controversial' i.e. something in which the nurse, possibly because of conflicting interests, could not become involved. While conceding that this was a possibility, another nurse in the same group was worried that the advocate would then be acting more for the nurse than for the client, and this revealed some confusion amongst some of the nurses, concerning the actual function of external advocates. Some of them obviously perceived that if the role of independent (volunteer) advocates was to be constructive, they should be of some assistance to nurses. Pam illustrated this with a short narrative concerning a client with whom she had once worked:

I remember one lady with very challenging behaviour, and sometimes she wouldn't do what we wanted, you know, what we thought was best
for her at the time, and then there would be uproar ... and then she’d get on the phone and speak to her advocate then she would calm down. The advocate was a good influence, she would listen to the advocate where she wouldn’t listen to us.

(Pam, group 1)

Another nurse mentioned ‘teaching’ a citizen advocate to be compliant with the nurses’ assessment of a client’s needs and judged an advocate to be ‘very good’ when he supported the client to behave according to the wishes of staff.

Most of the community nurses felt that some citizen advocates played a positive role in their clients’ lives. Only Paula disagreed, having suffered a difficult personal conflict with a citizen advocate in the past, which had obviously coloured her rather negative perceptions. Carol mentioned a citizen advocacy partnership with a client with unusual and very specific needs which was working extremely well and had greatly enriched the client’s life. Citizen advocacy was seen as less positive by a nurse working in residential services with people who have adequate communication skills but may challenge services. Sara explained that, in her experience, citizen advocates tended to have an unrealistic view of what was possible for some clients:

...they say ‘yeh, you can have anything you want, you can go about it any way you want’. Maybe they don’t look at it very realistically...the way that everybody lives their lives... not just people with learning difficulties. So sometimes they over emphasise people’s rights.... without being very practical.

(Sara, group 6)

Unlike nurses from the earlier groups, nurse participants who work with clients whose behaviour may challenge services had relatively easy access to paid independent advocacy services, usually for specific problems such as representation to the Mental Health Act Tribunal. The nurses had mixed views about the service. Most of them did not feel that their clients had found advocates particularly helpful and relationships were again mentioned as an issue. Nurses felt that in many cases, the provision of an independent advocate was perfunctory. They argued that clients would prefer to rely on nurses, with whom they have formed a relationship of trust, to advocate for them. Nonetheless independent advocates were seen as extremely important in some complex cases. Mary
mentioned a client who was being denied certain rights, against her will, in a deliberate effort to help her control her behavioural problems. Mary, as nurse manager, had referred the client to independent advocacy services for support to claim the rights being denied her, because:

….we’re fighting for one side and she needs someone to fight for her in decisions which we perceive to be in her best interests but are not what she wants.

(Mary, group 6)

Similar cases were mentioned by other nurse participants, particularly those from the assessment unit and, despite their reservations, all the nurses could visualise at least some circumstances in which the services of an independent paid or volunteer advocate could benefit their clients.

4.9 Advocacy education

Many of the questions and points for discussion in the focus groups with nurses had evolved from the stage one data. The exploration of nurses received education in advocacy and their educational and training requirements opened a new avenue of enquiry demanding a new set of focus group questions specifically aimed at learning disability nurse participants in stage two of the research.

The advocacy education and training received by the nurses tended to vary according to their year of qualification rather than with their grades or seniority within the system, although these were somewhat interrelated. None of the most experienced nurses had received any formal advocacy education, although some of them had received post registration training sessions from independent advocacy services or had received an ‘advocacy training pack’ to read for themselves. All thought advocacy education would be useful. Pam expanded on this, remarking that pre qualification advocacy training should include:

The legal aspects of advocacy and the ethical aspects …. because if you have a critical incident…. not just the every day advocacy we do as part of our role…. You see something you think is wrong… then you need to know the legal and the ethical aspects. So if you’re speaking proactively for a client, you’ve got the ammunition to back the client up.

(Pam, group 1)
The separation of 'every day' advocacy from advocacy in 'critical incidents' was interesting, and was an important issue for nurse participants from the assessment unit. It added a new dimension to the definitions of advocacy which nurses had previously discussed, and also extended the concept of advocacy education to include nurses as educators in advocacy. One of the nurses explained that unqualified nursing assistants working with clients with learning difficulties are expected to know about advocacy. He anticipated, in his role as an assessor for the National Vocational Qualification scheme (NVQ), that he would supervise carers in the day to day advocacy which Goble (2002.72) refers to as 'advocacy with a small a'. He expressed the opinion that the NVQ scheme for carers had put advocacy firmly on the training agenda. Nurses are now likely to find themselves participating in advocacy training sessions for carers, who might then get involved in advocating for clients, at least in everyday situations.

Qualified nurses as well as advocating in mundane circumstances, frequently became involved in advocacy and decision making at a very different level, which sometimes concerned issues which could be life changing for their clients. One of the participants cited the nurses' role in decision making in connection with specialised drug treatment for clients. Advocacy in these cases may involve ensuring the client has sufficient information to give informed consent to the proposed drug regime, or, if the client does not wish to comply, finding an independent advocate and making sure that that person has sufficient unbiased information to represent the client's view to the medical team. One of the nurses explained the intricacies of issues around informed consent for these and similar clients and how they might affect both the advocacy role of the nurse and her/his advocacy education:

There are a lot of rules about consent and a lot of guidelines, so if we get a client in with something we are not quite au fait with, we all do a bit of research ...it becomes quite a teaching process in the end for everybody. That widens our knowledge, then the more knowledge you've got, the more you advocate for people.

(Karen, group 5)

So advocacy education for these nurses had a much wider remit than that of nurses who expected only to represent their clients concerning more routine
issues. Nurses were also able to request education about issues of special concern on an individual basis:

Jo  We have written recorded supervision sessions with our line managers so that we can bring things right to the fore
Karen  Yes on a regular basis
Jo  and if there are issues that come up that you need to know about you have the opportunity to raise them
Karen  and if you need any further guidance, you can get it
Jo  It's also part of the Trust's policy that you can request supervision sessions when you feel you need them
P  and would you do that in an advocacy situation?
Jo  If I thought it was big enough, yes

(Jo and Karen, group 5)

One of the community nurses had qualified in 1984 and remarked that education in advocacy at any level was 'unheard of in those days' (Paula, interview 1). She had recently done some teaching during which she did sessions on advocacy with student nurses in which she:

... went through the theory of it, and talked about self advocacy groups, and then used scenarios to consider the advocacy role of the nurse'

(Paula, interview 1)

The other community nurses had had some post registration training around advocacy which they had found useful and informative.

The two D grade nurses, both of whom had been qualified for twelve months or less, had attended lectures on advocacy during their training and one had worked with an independent advocate and her client during one of her placements. She had not felt her education in advocacy had been particularly satisfactory because although she had attended:

... quite a few lectures about what it is.... and the outcomes.... I don't think we did enough about how you go about it. We did lots about what it is and why we do it and why it's so good, but I don't think there's enough there about how you actually do it.

(Sara, group 6)

This concern was echoed by Janet (group 1) who argued that there is a difference between learning about advocacy and learning how to advocate, and raised
doubts about whether it is possible to learn the latter. She considered that the ability to advocate satisfactorily came with experience, rather than formal education or training. This issue was later endorsed by participants in group three, who thought learning about advocacy should include issues around the nursing ‘Code of Conduct’ (Nursing and Midwifery Council, 2004) and about potential role conflict. Learning how to advocate was seen as being more dependent on experience and confidence:

... when you’re starting up you have no confidence. You need to know about possible conflicts in work and also about personal conflicts. It’s easy to have a set idea about something, but you have to be neutral. You need to be able to say that, if you have definite views about something, you may not be the right person to advocate about that thing.

(Graham, group 3)

Mary (group 6) had had no formal teaching in advocacy but ‘lots of belt and braces experience’ of advocating for clients. Asked if she thought it was feasible to be taught how to advocate, or whether the ability only came with experience, she thought that advocating could certainly be taught, and returned to her concerns about the power inequity in attempts by nurses to advocate for clients:

I think there are definite skills in it. I think you need a lot of self awareness of being in a position of power, supporting someone who isn’t in a position of power, and how you can offer people support in situations where you might not be encouraged to offer people that sort of support.... I think being supported to be reflective and to be confident enough to encourage people to challenge decisions you’ve made when you’ve spoken on behalf of people. Yes, I think you can be taught to do it.

(Mary, group 6)

Suggestions for how this might be done included role play and discussions with people with learning difficulties who have been the subjects of advocacy attempts. The community nurses proposed that specific training on the Human Rights Act (1998) would be useful and relevant to advocacy, and this suggestion was endorsed by participants in all the subsequent sessions.

4.10 The role of the nurse
Participants in the focus groups for people with learning difficulties had viewed the role of learning disability nurses as either supervisory or quasi medical. So,
towards the end of each of the stage two focus group sessions the discussion was
directed towards nurse participants’ perception of their role. They all agreed that
learning disability nursing and the skills of learning disability nurses were difficult to
describe. The nurses working in residential units saw their role differently from the
community nurses, but the latter also differed in their individual perceptions of their
role. As Paula argued:

It's a contentious issue really, particularly now we've merged with
other geographical areas, because I think if you asked a community
nurse from say R, I think she might see her role in a very different
way from the way we operate here.
(Paula, interview 1.)

Paula saw her work as very family oriented arguing that:

...if a client is living at home with family and there's nothing on the
horizon about them moving out or somebody else providing
accommodation, you have to tread quite carefully. You could make
things a whole lot worse for them if you stand up for what you believe
to be their rights. Particularly if you know it's going to be in direct
opposition to what the carer wants...
(Paula, interview 1)

The other community nurses described a role which was less family and more
client oriented, and discussed ways of assisting clients to self-advocate in familial
disputes. Graham described a proactive, preventative role, and Carol, who has
clinician only responsibilities, sees her role as:

.....concentrating on people with complex health needs and making
sure they get treatment and assessment..... it's all about screening.
We have health screening for people with Down syndrome, we do
dementia screening and all that stuff...
(Carol, interview 2)

All the community nurses found that the relatively new requirement to time limit
particular pieces of work caused immense problems, particularly concerning the
ability to form trusting relationships with their clients. Those who occupied a dual
care manager/clinician role also experienced some conflicts of interest, usually
resource oriented, between the two.
Amongst the nurses working in residential settings, there was general agreement that, unlike the custodial, task oriented care provided by learning disability nurses in the past, today’s nurses expect to offer a service which is much more ‘person centred’. Assessment and planning were mentioned as ‘high priority’ aspects of care as were facilitation, coordination and organisation, much of which involved some form of advocacy. Newly qualified Sara expected to play:

...a big part ...[in]...coordination and organisation. Making sure [the clients’]... most simple needs are catered for, maybe making sure they are clean; to their most complex needs, maybe medication or maybe needs conducted by another professional, maybe psychology or something. I see coordination as a big part and it’s not just health. It’s across the board: health, financial, social and economic. We do the lot..... and if we can’t do it, we communicate it to a person who does, or can.

(Sara, group 6)

Most of the nurses from residential settings worked in ‘continuing health care’ services, and Mary summarised their expectations neatly:

....for our individuals we cater for all their needs. So you couldn’t just define it as their health input requiring x number of injections a week. It’s not just medical, it’s their social wellbeing too. So our greatest measure in terms of health is not in the absence of illness, but in the whole of their quality of life. That would be our greatest impact in terms of health workers....We understand that it is about the full package, we deal with every aspect. It is about the complete picture.

(Mary, group 6)

This ‘complete picture’, in the case of all the nurse participants included an awareness of the rights of people with learning difficulties and a willingness to either advocate for them or to facilitate some form of self or external advocacy in an attempt to obtain these rights.

4.11 Evaluation of the focus group sessions
At the outset of the study, I had considered possible disadvantages to the use of focus groups with nurses in stage two. Foremost was the potential difficulty in arranging the attendance of nurses. I was fortunate to obtain the contact details of gatekeepers who put me in touch with nurses from each of the work areas that I wished to include, and also to find suitable venues for the focus groups. Convening nurses for the first groups caused minimal difficulty but later, it proved
very difficult to find suitable dates and times for the sessions, especially where nurses were called to hastily arranged, but urgent, meetings and failed to attend, leaving the focus group denuded of members with no time or opportunity to find replacements. Nurse participants were however, enthusiastic about the study and some agreed to unconventional times and venues for the (rearranged) groups. I was made welcome at a Day Centre, a Community Team base and on the night shift at the Assessment Centre.

I had been concerned when I discovered that some of the nurse participants were known to me, but this did not impede the interaction in the groups, tending instead to contribute to the friendly atmosphere and the eagerness of nurses to become fully involved in the sessions. I had also been concerned that less experienced nurses would be reluctant to air their views in the presence of more senior colleagues and that nurses' familiarity with each other would lead to them using jargon which would be outside my vocabulary. In the event, neither the D grade nor E grade nurses were reluctant to state their views, and I soon refamiliarised myself with jargon from my 'hands on' nursing days.

Assessing the conduct of the groups, a similar format was used satisfactorily in all the sessions and my confidence as moderator increased with experience. The ranking exercise proved a source of rich data, but worked best when there were at least three members in the group. The six participants in the first group, all of whom were familiar with each other, entered into some spirited discussions, arriving at consensus on some definitions and agreeing to disagree about others. Attempts to use the ranking exercise in the two interviews with community nurses were much less successful, as the participants had no colleague with whom to discuss their opinions, necessitating a 'question and answer' format between myself and the individual participants to examine the reasons for their choices. Nonetheless in both focus groups and interviews the ranking exercise yielded useful information.
Bloor et al propose that:

.... Focus groups ... have an advantage in researching topics relating to group norms, the group meanings that underpin these norms, and the group process whereby these meanings are constructed. (Bloor et al, 2001.99)

Evaluating the focus groups in the light of the data obtained, I felt that the sessions had achieved my aim of exploring how learning disability nurses perceived advocacy and their role as advocates for their clients.

4.12 Conclusion and summary of key themes
I had initially analysed the data from the stage one focus groups under the broad headings used in the design of the groups i.e. choice; advocacy; barriers to advocacy; advocates and nurses. As the work progressed, constant comparative analysis and situational mapping both expanded these themes and revealed others. The ranking exercise on definitions of advocacy, many of which had been generated by the stage one groups, would certainly form the basis for further exploration in stage three of the research and some new definitions were also significant.

Early consideration of definitions of advocacy in the focus groups prompted the nurses to discuss conflicts in advocacy which became a new and important topic. Relationships had emerged as a major issue in advocacy in stage one and had been considerably expanded in stage two. It now included not only relationships between clients and potential nurse advocates but also between clients and independent advocates, nurses and independent advocates, nurse advocates and families and even between clients and their peers. Self advocates in stage one had forged links with schools, colleges and other community based services, to the evident advantage of both parties, but it was interesting that 'community presence', another 'relationship-based' theme, which was of considerable importance to people with learning difficulties in stage one seemed of significantly less interest to the nurses in stage two.

Much has been written about the advantages of independent advocacy over nurse advocacy for clients (e.g. Goble, 2002; Brooke, 2001); but many nurse participants
spoke of difficulty in accessing independent advocacy services and also doubted their efficacy. Thus nurses' ability and willingness to facilitate independent advocacy for their clients became a new theme and a major issue, as did their attitude to external (paid or volunteer) advocates and their expectations of client/independent advocacy partnerships. Participants in the day centre groups in stage one of the study, had grown in confidence and ability due to the willingness of support staff to facilitate their efforts at self advocacy. Evidence of similar endeavour was sought from nurses in the stage two groups. Exploration of this phenomenon in relation to 'supporting clients to complain', resulted in power and empowerment, already an emergent theme from stage one, being expanded into a major theme in the stage two groups.

Analysis of the data from stage one had suggested that, on occasions, advocacy attempts by both nurses and support staff appeared to be guided by an individualistic (medical) model of disability. This was confirmed by some of the nurses in stage two, particularly those who had been long qualified and worked in residential settings. This, along with the other emergent themes just discussed, warranted further exploration in the final stage of the study.

Several new themes particularly relating to nurses' education in advocacy evolved from stage two of the study. There was a possible correlation between nurses' qualification year and their receipt of advocacy education which repaid further investigation, as did the possibility that nurses required ongoing training and support in advocacy, relevant to the client group with whom they worked. Nurse participants in stage two also thought training in the Human Rights Act (1998) would be relevant to their advocacy role. All these are included in the project map (figure 13) which illustrates major themes from stages one and two of the study and which informed the design of the questionnaire survey which became the third and final empirical stage of the research.
Definitions of advocacy
- Ranking exercise-differences in relevance of definitions between stage 1 participants and nurses in stage 2
- Differences and similarities between groups of nurses concerning relevance of advocacy definitions
- 'Best interests' - important new concept

Relationships
- Many different relationships in nurse advocacy.
- Maintaining a professional relationship viewed as important.

Community presence
- Seen as considerably less relevant to nurses than to people with learning difficulties

Facilitation to self advocate
- Some nurses illustrated the importance of this activity, particularly within families

Power and empowerment
- Inequity in power accepted as a problem by some nurses
- Empowerment of clients seen as desirable by most nurses

Individual (medical) vs social model
- May depend on resources, intellectual ability of clients and nurses' perceptions

Barriers to advocacy
- All nurses experienced barriers:
  - Advocating to multidisciplinary team
  - Obtaining independent advocacy
  - Encouraging self advocacy

Independent (paid and volunteer) advocacy
- Variable accessibility and willingness to use services
- Variable attitudes to independent advocacy
- Mutual education required concerning roles

Education, support and training (including Human Rights Act)
- Received education very variable.
- All nurses required ongoing support and education
- Interest in Human Rights Act

Figure 13: Project map illustrating emergent themes from focus groups and interviews in stage 2
Chapter five

The questionnaire survey
5.1 Introduction

The suggestion to conduct a questionnaire survey of all the learning disability nurses grades D-G (i.e. the ‘hands on’ nurses’) working in the NHS in Wales was made in the early stages of the research design and the opportunity to conduct a relatively large scale survey amongst learning disability nurses presented an interesting challenge. From the outset, I had been keen to use the views of people with learning difficulties as the foundation of my research. Taking forward their definitions of advocacy and their requirements for support either to advocate for themselves or from someone who might advocate for them, had already enabled useful comparisons to be made between their views and those of the small number of learning disability nurses in the stage two focus groups. Used as the core of a Wales-wide questionnaire survey, the ideas of people with learning difficulties would be available to a much larger population of nurses and would give them a chance to assess their own advocacy practice according to the stated requirements of their clients.

Data obtained from the focus groups in stages one and two thus influenced the design of the questionnaire survey which sought the opinions of a large number of learning disability nurses. I anticipated that the report which followed the conclusion of the research might increase nurses’ knowledge of advocacy, inform their advocacy education and support their advocacy practice. I also envisaged it raising the profile of people with learning difficulties by demonstrating the important contribution they had made to the study.

The project map (figure 13) in the preceding chapter (section 4.12) summarised the key themes which emerged from the analysis of data from the stage one focus groups with people who have learning difficulties and the stage two sessions with learning disability nurses (table 4). Either explicitly or more covertly, these themes informed the questionnaire survey which comprised stage three of the research. The questionnaire (appendix 11) was designed with four main sections: ‘advocacy’; ‘advocates’; ‘advocacy education’ and ‘the advocacy role of learning disability nurses’ (section 2.20).
This chapter consists primarily of a descriptive analysis of the quantitative data from the questionnaires, supported by some inferential statistics. In cases where nurses made additional comments on the questions, a similarly descriptive analysis of their observations is appended. Throughout the analysis an attempt has been made to depict the definitions, relationships, concerns and educational attainments and requirements which comprised the nurses’ experience of advocacy.

5.2 Note on presentation of results
Responses to the questionnaire resulted in a large number of ‘category variables’ (Rowntree, 2000) sometimes necessitating the use of a statistical test to determine whether there was a significant association between two or more of these. The chi square ($\chi^2$) test compares the expected figure for each category (i.e. the figure obtained assuming the null hypothesis to be true) with the obtained value, in order to determine whether the difference between the two is too large to have arisen simply from sampling variation. Statistical significance occurs when the p value (obtained from tables showing the distribution of chi square) is 0.05 or less, that is, when the difference between the categories would occur five times or less in one hundred samples if the null hypothesis were true. p values of .05; .01 and .001 thus provide increasingly strong evidence that the null hypothesis can be rejected and that it is reasonable to conclude that there are associations between the categories subjected to the chi square test.

One of the rules of the chi square test concerns the number of items appearing in each cell in the expected category, obtained in the computation stages, which must be at least 5 (Clegg, 1990). Where this was a potential problem in analysing the data, categories were grouped into broad divisions. For example, in cases
where there are 5 categories e.g. 'extremely relevant', 'relevant', 'undecided', 'not relevant' and 'not at all relevant', data has usually been grouped into two broader categories i.e. 'relevant and extremely relevant' and 'undecided, not and not at all relevant', to enable accurate calculation. Similar steps have been taken where the categories were, for example, 'yes', 'no', 'unsure' and 'can't remember' and the broad groupings were 'yes' and 'no, unsure, can't remember'. In cases where cells have been merged in this way in order to obtain counts greater than five this has been made explicit in the tables and/or the text.

Where data has been presented in tables, blanks have been used appropriately rather than zeros as this better depicts the absence of possible numbers in the particular categories involved.

**Results: Stage 3 – The questionnaire**

5.3 Analysis of questionnaire returns

![Bar chart showing questionnaire response rates for different Health Trusts](image)

**Figure 14: Total questionnaire response rates**

5.4 Questionnaire returns by Health Trust
The numbers of learning disability nurses employed by the six Health Trusts targeted by the survey varied from below 40 to over 200. 466 questionnaires were distributed with a total return of 37% (n=173). The largest number of returns was
from Trust 1 and the smallest from Trust 6 (figure 14). To preserve the anonymity of the Trusts, percentages rather than figures have been used in the analysis of relevant questions.

<table>
<thead>
<tr>
<th>employing Health Trust</th>
<th>questionnaire returns</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes %</td>
</tr>
<tr>
<td>One</td>
<td>41.1</td>
</tr>
<tr>
<td>Two</td>
<td>33.8</td>
</tr>
<tr>
<td>Three</td>
<td>27.3</td>
</tr>
<tr>
<td>Four</td>
<td>33.3</td>
</tr>
<tr>
<td>Five</td>
<td>37.0</td>
</tr>
<tr>
<td>Six</td>
<td>42.9</td>
</tr>
</tbody>
</table>

Table 5: Questionnaire returns by Individual Trust

Trust 6 had the highest percentage return rate and Trust 3 the lowest. A frequency table of returns from individual Health Trusts indicated return rates of between 27% and 43% (table 5).

5.5 Questionnaire returns by grade
Analysis of questionnaire returns by grade showed that only 28% of the questionnaires sent to D grade nurses were returned but this went up to 44% of those sent to G grade nurses (table 6). Return rates by grade were not found to be statistically significant.

<table>
<thead>
<tr>
<th>grade</th>
<th>questionnaire returns</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes %</td>
</tr>
<tr>
<td>D</td>
<td>27.8</td>
</tr>
<tr>
<td>E</td>
<td>37.7</td>
</tr>
<tr>
<td>F</td>
<td>32.5</td>
</tr>
<tr>
<td>G</td>
<td>43.7</td>
</tr>
</tbody>
</table>

Table 6: Questionnaire returns by grade
**Personal information of nurse respondents**

Personal information’ was the last section of the questionnaire. The results are discussed here to give background to the findings relating to nurse advocacy.

### 5.6 Qualifications of nurse respondents

The majority of nurse respondents held the RNLD qualification. Those listed as ‘other’ were usually enrolled nurses who had converted to RNLD (table 7).

<table>
<thead>
<tr>
<th>qualification of respondents</th>
<th>frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>reg. nurse (learning disabilities)</td>
<td>156</td>
</tr>
<tr>
<td>reg. nurse (mental health)</td>
<td>2</td>
</tr>
<tr>
<td>reg. nurse (adult)</td>
<td>1</td>
</tr>
<tr>
<td>enrolled nurse</td>
<td>8</td>
</tr>
<tr>
<td>other</td>
<td>4</td>
</tr>
<tr>
<td>not given</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>173</td>
</tr>
</tbody>
</table>

**Table 7: Qualifications of nurse respondents**

### 5.7 Qualification period

For ease of manipulation, the qualification years of respondents were divided into three periods, corresponding to different training syllabi. The earliest qualification year given was in the early 1960s, so the first ‘qualification period’ considered was 1960-1985. By 1986, nurses trained under the ‘1982’ syllabus were qualifying, so the second period was 1986-1994.

<table>
<thead>
<tr>
<th>qualification period</th>
<th>count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1960-1985</td>
<td>53</td>
</tr>
<tr>
<td>1986-1994</td>
<td>69</td>
</tr>
<tr>
<td>1995+</td>
<td>43</td>
</tr>
<tr>
<td>totals</td>
<td>165</td>
</tr>
</tbody>
</table>

**Table 8: Qualification period of respondents**

The third period included nurses trained under the ‘Project 2000’ syllabus, introduced in Wales in 1992. Nurses starting their training in 1992 would have
completed in 1995, so the third qualification period considered was from 1995 to the present (table 8). The largest percentage of respondents (42%, n=69) qualified between 1986 and 1994. 32% (n=53) qualified between 1960 and 1985 and 26% (n=43) qualified in or after 1995 (table 8).

5.8 Grade of respondents

<table>
<thead>
<tr>
<th>grade</th>
<th>count</th>
</tr>
</thead>
<tbody>
<tr>
<td>D</td>
<td>22</td>
</tr>
<tr>
<td>E</td>
<td>72</td>
</tr>
<tr>
<td>F</td>
<td>25</td>
</tr>
<tr>
<td>G</td>
<td>52</td>
</tr>
<tr>
<td>totals</td>
<td>171</td>
</tr>
</tbody>
</table>

Table 9: Grade of respondents

Of the 171 respondents who gave their grade, the highest percentage were E grade nurses (42%, n=72). 30% (n=52) were G grade nurses and a much lower percentage of the respondents were F grade (15%, n=25) and D grade (13%, n=22) (table 9).

5.9 Sex of respondents

<table>
<thead>
<tr>
<th>work area</th>
<th>grade</th>
<th>sex of respondents</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>male</td>
<td>female</td>
</tr>
<tr>
<td>hospital</td>
<td>D</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>E</td>
<td>10</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>F</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>G</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>other residential</td>
<td>D</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>E</td>
<td>8</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>F</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>G</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>community</td>
<td>D</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>E</td>
<td>3</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>F</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>G</td>
<td>12</td>
<td>26</td>
</tr>
<tr>
<td>totals</td>
<td>46</td>
<td>125</td>
<td>171</td>
</tr>
</tbody>
</table>

Table 10: Sex of respondents
73% (n=125) of the respondents to the questionnaire were female and 27% (n=46) were male. The percentage of males and females in the three work areas was similar. 28% (n=13) of the men and 28% (n=35) of the women worked in hospitals, 26% (n=12) of the men and 25% (n=32) of the women worked in 'other residential' settings and 46% (n=21) of the men and 47% (n=58) of the women worked in the community (table 10).

The proportion of men to women by grade saw 18% (n=4) men and 82% (n=18) women at D grade, 29% (n=21) men and 71% (n=51) women at E grade. The proportion of men at F grade was slightly higher (32%, n=8) with 68% (n=17) women and at G grade 25% (n=13) were men and 75% (n=39) women (table 10).

5.10 Work area
46% (n=79) of respondents worked in the community, but answers to some of the questions encouraged the supposition that some nurses who worked in residential units in community settings classed themselves as working in 'the community' rather than in 'other residential' settings. 26% (n=44) classed themselves as working in 'other residential' units and 28% (n=48) worked in hospitals (table 11).

<table>
<thead>
<tr>
<th>Work area</th>
<th>percentage</th>
<th>number</th>
</tr>
</thead>
<tbody>
<tr>
<td>hospital</td>
<td>27.9%</td>
<td>48</td>
</tr>
<tr>
<td>other residential</td>
<td>25.6%</td>
<td>44</td>
</tr>
<tr>
<td>community</td>
<td>46.5%</td>
<td>80</td>
</tr>
</tbody>
</table>

Table 11: Work area of respondents

5.11 Communication skills of clients

<table>
<thead>
<tr>
<th>Communication skills of clients</th>
<th>count</th>
</tr>
</thead>
<tbody>
<tr>
<td>non/limited verbal, limited signing</td>
<td>36</td>
</tr>
<tr>
<td>adequate verbal</td>
<td>28</td>
</tr>
<tr>
<td>all or various</td>
<td>107</td>
</tr>
<tr>
<td>totals</td>
<td>171</td>
</tr>
</tbody>
</table>

Table 12: Communication skills of clients
There were 171 valid answers to the question ‘what are the communication skills of your clients?’ Only 16% (n=28) of respondents worked solely with clients who have adequate verbal communication skills i.e. they can be understood by most people. The largest percentage (63%, n=107) worked with clients with a variety of communication skills. 21% (n=36) worked with clients who have either no or limited conventional verbal communication (table 12).

5.12 Period working with these or similar clients
The time periods were chosen at 3 year intervals on a somewhat arbitrary basis to correspond with the duration of nurses' pre qualification training. A high percentage (68%, n=117) of respondents had considerable experience, having worked with the same or similar clients for over 6 years (table 13).

<table>
<thead>
<tr>
<th>work period</th>
<th>frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>less than 1 year</td>
<td>9</td>
</tr>
<tr>
<td>1-3 years</td>
<td>27</td>
</tr>
<tr>
<td>4-6 years</td>
<td>19</td>
</tr>
<tr>
<td>longer than 6 years</td>
<td>117</td>
</tr>
<tr>
<td>not given</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>173</td>
</tr>
</tbody>
</table>

Table 13: Work period with these clients or clients with similar needs

Some of the respondents stated that they had been qualified for less time than they had spent working with particular clients. There are two possible explanations for this. It is not unusual for nurses to have worked as unqualified nursing assistants for several years before commencing nurse training, nor is it unusual for nursing students to spend long periods during their training working with clients with the same or similar needs.

5.13 Key worker responsibility
69% (n=102) of respondents had key worker responsibility for up to 10 clients with 31% (n=45) being responsible for more than 10 (table 14). The relationship between nurses' work area and having key worker responsibility for eleven or more clients was analysed using chi square. The value of chi square was found to be significant at the 0.001 level ($x^2 = 54.169$, df =8). This was extremely strong
evidence for the conclusion that community nurses were more likely to have key worker responsibility for eleven or more clients than nurses in other work areas.

<table>
<thead>
<tr>
<th>work area</th>
<th>grade</th>
<th>1-10</th>
<th>11-21+</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>hospital</td>
<td>D</td>
<td>12</td>
<td></td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>E</td>
<td>25</td>
<td></td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>F</td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>G</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>other</td>
<td>D</td>
<td>6</td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>residential</td>
<td>E</td>
<td>24</td>
<td></td>
<td>24</td>
</tr>
<tr>
<td></td>
<td>F</td>
<td>4</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>G</td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>community</td>
<td>D</td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>E</td>
<td>13</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>F</td>
<td>4</td>
<td>14</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>G</td>
<td>6</td>
<td>23</td>
<td>29</td>
</tr>
<tr>
<td>totals</td>
<td></td>
<td>102</td>
<td>45</td>
<td>147</td>
</tr>
</tbody>
</table>

Table 14: Number of clients for whom nurse respondents hold key worker responsibility

5.14 Additional comments on questionnaire questions
Twenty four items on the questionnaire attracted a total of 881 additional comments from respondents (table 15). Section 4 (the advocacy role of the learning disability nurse) attracted the most comments overall, a mean of 107 comments for each of the two questions. Except for section 5, which asked nurses if they wished to make any additional points not covered by the questionnaire; section 2 (advocates) attracted the least comments per question, a mean of 28.6 for the ten questions. The individual question which attracted the most comments was from this section i.e. ‘Do you consider that members of clients’ families can advocate satisfactorily for them?’ Section 1 (advocacy) attracted a mean of 33.4 comments for the five questions and section 3 (education) attracted a similar mean of 33.3 comments for the six questions in the section (table 16).
Q2e Do you consider that members of clients' families can advocate satisfactorily for them? 120
Q4a Do you consider that advocacy is an important role of nurses working in learning disability services in the present... climate of nursing? 114
Q3c2 What should be included in nurses' advocacy education? 100
Q4b Has the advocacy role of the learning disability nurse changed since you qualified? 100
Q1b Would you consider advocating in your personal life the same or different from advocating for clients? 67
Q2d Where your clients have experienced independent advocacy, do you consider they have found it satisfactory? 66
Q2f Do you consider that clients who have an advocate get better services than those who do not? 41
Q1d10 In what additional situations might you advocate for clients? 41
Q3a4 Give brief details of what your advocacy education included 33
Q1a List any definitions of advocacy you think relevant to learning disability nursing 28
Q3b Do you consider there is a difference between learning about advocacy and learning how to advocate? 26
Q3d1 Do you consider nurses should receive education on the Human Rights Act? 20
Q3c1 If you think advocacy education would be useful to nurses, who should provide it? 19
Q2c What additional situations might warrant a referral to paid independent advocacy services? 19
Q1f What might militate against satisfactory nurse advocacy? 17
Q2a4 Would you encourage clients to join a self advocacy group? 17
Q1e What makes a satisfactory advocacy partnership between nurses and client? 14
Q5k Have you any further comments on the advocacy role of the learning disability nurse? 14
Q2a2 Would you encourage clients to have a citizen advocate? 11
Q2a1 If any of your clients have a citizen advocate, do you consider this to be a positive relationship? 7
Q2a3 Would you expect staff to benefit from a client/citizen advocacy partnership? 2
Q2b Do your clients have access to paid independent advocacy services? 2
Q3d Have you received education on the Human Rights Act (1998)? 2
Q2a Do any of your clients have a citizen advocate? 1

Table 15: Number of comments from nurse respondents attracted by individual questions on the questionnaire

Some of the comments repeated information given in answer to the questions, but many gave relevant and thought provoking additional information.

<table>
<thead>
<tr>
<th>Section</th>
<th>Number of questions</th>
<th>Number of additional comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>one (advocacy)</td>
<td>5</td>
<td>167</td>
</tr>
<tr>
<td>two (advocates)</td>
<td>10</td>
<td>286</td>
</tr>
<tr>
<td>three (education)</td>
<td>6</td>
<td>200</td>
</tr>
<tr>
<td>four (advocacy role)</td>
<td>2</td>
<td>214</td>
</tr>
<tr>
<td>five (comments overall)</td>
<td>1</td>
<td>14</td>
</tr>
</tbody>
</table>

Table 16: Breakdown of additional comments by section.
Analysis of section 1 – Advocacy

5.15 Definitions of advocacy
The first question in the advocacy section of the questionnaire listed thirteen definitions of advocacy (table 17) and asked respondents to score each definition on a scale of 1 to 5 by its relevance to their current nursing practice, 1 being equal to not at all relevant and 5 being extremely relevant. The definitions were an extension of the nine definitions used in the ranking exercise for the stage two focus groups. Two new definitions were added, number 9: ‘Ensuring clients have information they can understand’ had evolved from further analysis of the focus groups with people who have learning difficulties, and number 11 ‘Enabling things to happen for clients’ was generated by nurses in stage two. Numbers 8 and 13, the ‘community presence’ definitions, had appeared as a single entity in the ranking exercise as had numbers 2 and 12 which related to clients being supported to complain. These definitions were split following feedback from the pilot study, giving two ‘community presence’ definitions and two relating to supporting clients to complain.

<table>
<thead>
<tr>
<th>Definitions of Advocacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Working with individual clients to ensure their rights are respected and upheld</td>
</tr>
<tr>
<td>2 Supporting clients to complain if they think they are being treated badly</td>
</tr>
<tr>
<td>3 Treating clients as adults and consulting them about things that concern them</td>
</tr>
<tr>
<td>4 Promoting the rights of people with learning difficulties whenever possible</td>
</tr>
<tr>
<td>5 Speaking for clients</td>
</tr>
<tr>
<td>6 Encouraging clients to take responsibility for themselves and their actions</td>
</tr>
<tr>
<td>7 Interpreting for clients</td>
</tr>
<tr>
<td>8 Proactively supporting clients to get to know people in the community</td>
</tr>
<tr>
<td>9 Ensuring clients have information they can understand</td>
</tr>
<tr>
<td>10 Encouraging clients to make their own decisions</td>
</tr>
<tr>
<td>11 Enabling things to happen for clients</td>
</tr>
<tr>
<td>12 Supporting clients to complain if they think something is unfair</td>
</tr>
<tr>
<td>13 Encouraging people in the community to get to know people with learning difficulties</td>
</tr>
</tbody>
</table>

Table 17: Definitions of advocacy in question one

Scores for each respondent were totalled in order to find whether questionnaire respondents were ‘pro’ or ‘anti’ advocacy. None of the nurses scored every
definition as not at all relevant or not relevant. Only 1% (n=2) of the respondents were undecided or indicated that advocacy was not or not at all relevant to their current practice. The scores of 18% (n=31) of the respondents signified that they thought advocacy relevant and the scores of 81% (n=140) indicated that they thought advocacy was extremely relevant to their practice (table 18).

<table>
<thead>
<tr>
<th>Relevance of advocacy</th>
<th>percentage</th>
<th>number</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all/not relevant/ undecided</td>
<td>1.2%</td>
<td>2</td>
</tr>
<tr>
<td>relevant</td>
<td>17.9%</td>
<td>31</td>
</tr>
<tr>
<td>extremely relevant</td>
<td>80.9%</td>
<td>140</td>
</tr>
</tbody>
</table>

Table 18: Relevance of advocacy to current practice of nurse respondents

The line graph (figure 15) illustrates the range of opinions concerning the relevance of the various advocacy definitions. All the questions attracted a proportion of ‘extremely relevant’ scores.

Figure 15: Relevance of advocacy definitions

These ranged from 83.2% for question 4: ‘Promoting the rights of people with learning difficulties whenever possible’, to 30.6% for question 13: ‘Encouraging
people in the community to get to know people with learning difficulties’. Nurses were least divided on this question which had the lowest percentage of respondents thinking it extremely relevant (31%) and the highest percentage (17%) thinking it either not at all or not relevant to their practice.

The other community presence definition, question 8: ‘Proactively supporting clients to get to know people in the community’ also secured a high level of agreement, but was considered of low relevance. 9% of the respondents found this not at all or not relevant, with only 45% thinking it extremely relevant to their practice. Question 4: ‘Promoting the rights of people with learning difficulties whenever possible’ had the widest disparity with 83% thinking it extremely relevant and less than 1% thinking it not at all or not relevant to their practice. A similar inconsistency related to question 3: ‘Treating clients as adults and consulting them about things that concern them’. 81% classed this as extremely relevant and less than 1% thought it not at all or not relevant to their advocacy practice.

<table>
<thead>
<tr>
<th>Question number</th>
<th>Client generated definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Speaking for clients</td>
</tr>
<tr>
<td>7</td>
<td>Interpreting for clients</td>
</tr>
<tr>
<td>3</td>
<td>Treating clients as adults and consulting them about things that concern them</td>
</tr>
<tr>
<td>8</td>
<td>Proactively supporting clients to get to know people in the community</td>
</tr>
<tr>
<td>13</td>
<td>Encouraging people in the community to get to know people with learning difficulties</td>
</tr>
<tr>
<td>2</td>
<td>Supporting clients to complain if they think they are being treated badly</td>
</tr>
<tr>
<td>9</td>
<td>Ensuring clients have information they can understand</td>
</tr>
<tr>
<td>12</td>
<td>Supporting clients to complain if they think something is unfair</td>
</tr>
</tbody>
</table>

Table 19: Definitions of advocacy generated by people with learning difficulties and by learning disability nurses

<table>
<thead>
<tr>
<th>Question number</th>
<th>Client/supporter generated definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Working with individual clients to make sure their rights are respected and upheld</td>
</tr>
<tr>
<td>4</td>
<td>Promoting the rights of people with learning difficulties whenever possible</td>
</tr>
<tr>
<td>6</td>
<td>Encouraging clients to take responsibility for themselves and their actions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question number</th>
<th>Nurse generated definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Enabling things to happen for clients</td>
</tr>
<tr>
<td>10</td>
<td>Encouraging clients to make their own decisions</td>
</tr>
</tbody>
</table>
Eight of the advocacy definitions in this question came from focus groups with people with learning difficulties and five either from the interaction between support staff and people with learning difficulties in the stage one groups and/or through focus groups and interviews with learning disability nurses (table 19). A comparison was made between the relevance for each nurse respondent of the definitions generated by the two groups. Each nurse’s responses to the definitions were categorized into either ‘nurse definition’ or ‘definition by people with learning difficulties’. Totals were made for both categories and a mean for each category was calculated for every respondent. The number of respondents scoring a mean of four and over (i.e. relevant or extremely relevant) for the nurse generated definitions was 157 with only 16 scoring below 4. For the definitions given by people with learning difficulties the number of respondents scoring a mean of 4 or over was only 104 with 69 nurses scoring below 4 (i.e. undecided, not or not at all relevant) (table 20).

<table>
<thead>
<tr>
<th>Relevance</th>
<th>nurse definitions</th>
<th>relevance</th>
<th>definitions by people with learning difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all/not relevant/undecided</td>
<td>16</td>
<td>not at all/not relevant/undecided</td>
<td>69</td>
</tr>
<tr>
<td>extremely relevant/relevant</td>
<td>157</td>
<td>extremely relevant/relevant</td>
<td>104</td>
</tr>
<tr>
<td>Total</td>
<td>173</td>
<td>total</td>
<td>173</td>
</tr>
</tbody>
</table>

Table 20: Comparison of relevance scores – definitions by nurses and by people with learning difficulties

The relationship between respondents’ scores for nurse generated definitions and definitions by people with learning difficulties was analysed using chi square. The value of chi square was found to be significant at the 0.01 level ($x^2 = 9.067, df = 1$) and it was concluded that respondents were considerably more likely to score nurse generated definitions of advocacy as relevant or extremely relevant than definitions generated by people with learning difficulties.

11 nurses found at least one of the advocacy definitions not at all relevant to their practice and sixty four nurses found at least one definition not relevant (table 21). The six definitions which attracted ‘not at all relevant’ scores had been given by people with learning difficulties. Of the ten definitions which attracted ‘not relevant’
scores, three were generated by nurses and the remaining seven by people with learning difficulties. Two nurse generated definitions ‘Working with clients to ensure their rights are respected and upheld’ and ‘Encouraging clients to take responsibility for themselves and their actions’, attracted no scores indicating they were considered either not or not at all relevant (table 21).

<table>
<thead>
<tr>
<th>Definition</th>
<th>not at all relevant</th>
<th>not relevant</th>
<th>definition</th>
<th>not at all relevant</th>
<th>not relevant</th>
</tr>
</thead>
<tbody>
<tr>
<td>q1a1. Working with clients....</td>
<td></td>
<td></td>
<td>1a8. Proactively supporting clients to get to know</td>
<td>1</td>
<td>15</td>
</tr>
<tr>
<td>q1a2. Complain if treated badly</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>q1a3. Treating as adults</td>
<td>1</td>
<td></td>
<td>q1a9. Understandable information</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>q1a4. Promoting rights</td>
<td></td>
<td>1</td>
<td>q1a10. Encouraging decision making</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>q1a5. Speaking for clients</td>
<td>1</td>
<td>8</td>
<td>q1a11. Enabling things to happen</td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>q1a6. Encouraging responsibility</td>
<td></td>
<td></td>
<td>q1a12. Complain if things unfair</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>q1a7. Interpreting for clients</td>
<td>2</td>
<td></td>
<td>q1a13. Encouraging people in the community.....</td>
<td>6</td>
<td>24</td>
</tr>
</tbody>
</table>

Table 21: Definitions of advocacy showing those seen as not at all or not relevant by some questionnaire respondents

The two ‘community presence’ definitions attracted the largest number of ‘not at all’ or ‘not relevant’ scores from respondents. ‘Proactively supporting clients to get to know people in the community’ was scored as not at all relevant by one and not relevant by 15 nurses, and ‘Encouraging people in the community to get to know people with learning difficulties’ was scored as ‘not at all relevant’ by 6 nurses and ‘not relevant’ by 24 nurses (table 22).

<table>
<thead>
<tr>
<th>work area</th>
<th>proactively supporting clients to get to know</th>
<th>encouraging people in the community</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>not at all relevant</td>
<td>not relevant</td>
</tr>
<tr>
<td>hospital</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>other</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>residential</td>
<td></td>
<td></td>
</tr>
<tr>
<td>community</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Totals</td>
<td>1</td>
<td>15</td>
</tr>
</tbody>
</table>

Table 22: Relevance of definitions –proactively supporting clients to get to know people in the community and Encouraging people in the community to get to know people with learning difficulties.
A high proportion of community nurse respondents reported the ‘community presence’ definitions as ‘not at all’ or ‘not relevant’ to their practice, but no statistically significant relationship was found between respondents’ work area and these definitions (table 22).

<table>
<thead>
<tr>
<th>work area</th>
<th>supporting clients to complain (bad treatment)</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>not at all relevant</td>
<td>not relevant</td>
<td>undecided</td>
<td>relevant</td>
<td>extremely relevant</td>
</tr>
<tr>
<td>hospital</td>
<td>1</td>
<td></td>
<td>3</td>
<td>7</td>
<td>37</td>
</tr>
<tr>
<td>other</td>
<td>1</td>
<td>3</td>
<td>13</td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>residential</td>
<td>1</td>
<td>5</td>
<td>16</td>
<td>57</td>
<td></td>
</tr>
<tr>
<td>community</td>
<td>1</td>
<td>2</td>
<td>11</td>
<td>36</td>
<td>121</td>
</tr>
<tr>
<td>totals</td>
<td>1</td>
<td>2</td>
<td>11</td>
<td>36</td>
<td>121</td>
</tr>
</tbody>
</table>

Table 23: Relationship between nurses’ work area and their perception of the relevance of the advocacy definition ‘Supporting clients to complain if they think they are being treated badly’

The vast majority of nurses (92%, n=157) thought that supporting clients to complain if they think they are being treated badly was either relevant or extremely relevant to nurse advocacy, but this left 6% (n=11) undecided about this and 2% (n=3) thinking it either not or not at all relevant to their current advocacy practice (table 23).

<table>
<thead>
<tr>
<th>Work area</th>
<th>supporting clients to complain (things unfair)</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>not at all relevant</td>
<td>not relevant</td>
<td>undecided</td>
<td>relevant</td>
<td>extremely relevant</td>
</tr>
<tr>
<td>hospital</td>
<td>1</td>
<td></td>
<td>8</td>
<td>7</td>
<td>31</td>
</tr>
<tr>
<td>other</td>
<td>1</td>
<td>5</td>
<td>17</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>residential</td>
<td>1</td>
<td>7</td>
<td>22</td>
<td>50</td>
<td></td>
</tr>
<tr>
<td>community</td>
<td>1</td>
<td>3</td>
<td>20</td>
<td>46</td>
<td>102</td>
</tr>
<tr>
<td>totals</td>
<td>1</td>
<td>3</td>
<td>20</td>
<td>46</td>
<td>102</td>
</tr>
</tbody>
</table>

Table 24: Relationship between nurses’ work area and their perception of the relevance of the advocacy definition ‘Supporting clients to complain if they think something is unfair’

A slightly smaller, but still very large, percentage of respondents (86%, n=148) thought that supporting clients to complain if they think something is unfair was relevant or extremely relevant, but 12% (n=20) were undecided and 2% (n=4) thought it not or not at all relevant to their current practice (table 24).
While acknowledging the small numbers of nurses who did not think ‘supporting clients to complain’ was relevant to their practice, issues from the focus groups with nurses made further analysis of these results appropriate. 28.5% (n=4) of the respondents who were either undecided about the relevance of the definition ‘supporting clients to complain if they think they are being badly treated’ or who thought it not or not at all relevant, worked in hospital. The percentage was similar (28.5%, n=4) for those working in ‘other residential’ settings, but a higher percentage of community nurses (43%, n=6) were also either undecided about this definition or thought it not or not at all relevant. The highest percentage of those who were either undecided about the relevance of ‘supporting clients to complain if they think things are unfair’ or who thought it not or not at all relevant worked in hospital (42% n=10) with 25% (n=6) working in ‘other residential’ settings and the remaining 33% (n=8) working in the community. A chi squared test did not find a significant relationship between nurses’ work area and their perception of the relevance of supporting clients to complain if they think they are being treated badly or if they think something is unfair.

<table>
<thead>
<tr>
<th></th>
<th>No response</th>
<th>Yes</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>complain if treated badly &gt;&gt;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>not at all relevant complain if things unfair &gt;&gt;</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>not relevant</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>undecided</td>
<td>4</td>
<td>7</td>
<td>11</td>
</tr>
<tr>
<td>relevant</td>
<td>20</td>
<td>16</td>
<td>36</td>
</tr>
<tr>
<td>extremely relevant</td>
<td>56</td>
<td>66</td>
<td>122</td>
</tr>
<tr>
<td>totals</td>
<td>83</td>
<td>89</td>
<td>172</td>
</tr>
</tbody>
</table>

Table 25: The relationship between nurses perception that unequal nurse/client power relationships might cause problems for nurse/client advocacy and the perceived relevance to advocacy of supporting clients to complain if they think they are being treated badly or if they think something is unfair

Some of the nurse participants in the focus groups suggested that the reason why they did not support clients to complain, particularly in relation to their treatment by service providers, was related to the inequity in power between nurses and their clients with learning difficulties. This was reiterated by 52% of the respondents
who thought that supporting clients to complain if they think they are being treated badly or if something is unfair was less than relevant to their current practice who also thought that unequal power relationships might cause problems for satisfactory nurse/client advocacy (table 25).

95% (n=163) of respondents reported ‘Treating clients as adults and consulting them about things that concern them’ as relevant or extremely relevant to their current practice. 8 nurses from a variety of settings were either undecided or thought this definition not at all or not relevant to their current practice.

62% (n= 108) of nurses who thought interpreting for clients was relevant or extremely relevant thought the same about speaking for clients (table 26).

<table>
<thead>
<tr>
<th>speaking for clients</th>
<th>interpreting for clients</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>not at all/ not relevant/undecided</td>
<td>24</td>
</tr>
<tr>
<td></td>
<td>relevant/extremely relevant</td>
<td>31</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>34</td>
</tr>
</tbody>
</table>

Table 26: The relationship between the advocacy definitions: speaking for clients and interpreting for clients

This relationship was analysed using chi square. The value of chi square was found to be significant at the 0.001 level ($\chi^2 = 29.372$, df = 1). It was therefore concluded that nurses who thought speaking for clients relevant or extremely relevant were significantly more likely to think the same about interpreting for clients (table 26).

The nurses who argued most persuasively in the focus groups that speaking for clients should only be in the context of interpretation of the clients’ wishes were those who worked with clients who had no or very limited verbal communication, nonetheless, no statistically significant relationship was found between the advocacy definition ‘speaking for clients’ and the communication skills of clients.

13% (n=6) of hospital nurses and 11% (n=5) of those working in ‘other residential’ services were either undecided about the relevance of the definition ‘ensuring
clients have adequate information' or thought it not or not at all relevant to their advocacy role, but this percentage dropped for community nurses of whom only 1% (n=1) thought it not relevant while 99% (n=79) thought it relevant or extremely relevant to their advocacy role (table 27).

<table>
<thead>
<tr>
<th>ensuring clients have understandable information</th>
<th>work area</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>residential</td>
<td>community</td>
</tr>
<tr>
<td>not at all/ not relevant/undecided</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td>relevant/extremely relevant</td>
<td>81</td>
<td>79</td>
</tr>
<tr>
<td>totals</td>
<td>92</td>
<td>80</td>
</tr>
<tr>
<td>% totals</td>
<td>53.5%</td>
<td>46.5%</td>
</tr>
</tbody>
</table>

Table 27: Comparison of relevance scores for nurses working in residential and community settings for the definition 'ensuring clients have adequate understandable information'

This relationship was analysed using chi square. The value of chi square was found to be significant at the 0.05 level ($\chi^2 = 7.604$, df = 2) and it was concluded that community nurses were significantly more likely to think it relevant or extremely relevant to ensure their clients received understandable information than nurses working with clients in residential settings.

An unequivocal 95% (n=165) of respondents thought that working with individuals to make sure their rights are respected and upheld was relevant or extremely relevant to their present practice. No-one thought this definition not at all or not relevant to their current practice. A similar percentage of nurses (94%, n=163) agreed that promoting the rights of people with learning difficulties whenever possible was relevant or extremely relevant to their advocacy role, although in this case 1 (G grade, community) nurse thought this not relevant to his/her current practice.

Despite the assertion by some nurse participants in the focus groups that their clients' degree of impairment made encouraging them to take responsibility for themselves irrelevant, none of the respondents classed this as not at all or not relevant to their present practice (table 28). 25% (n=9) of those working with clients with no or limited verbal communication were undecided about the relevance of encouraging clients to take responsibility. 11% (n=3) of those
working with clients with adequate verbal communication were also undecided, as were 5% (n=5) of those working with clients with a variety of communication skills.

<table>
<thead>
<tr>
<th>Communication skills of clients</th>
<th>Encouraging clients to take responsibility</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>undecided</td>
<td>relevant</td>
</tr>
<tr>
<td>non/limited verbal/ limited signing</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>adequate verbal</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>all or various</td>
<td>5</td>
<td>22</td>
</tr>
<tr>
<td>Totals</td>
<td>17</td>
<td>39</td>
</tr>
</tbody>
</table>

Table 28: Relevance of advocacy definition ‘Encouraging clients to take responsibility for themselves and their actions’

95% (n=102) thought encouraging clients to take responsibility for themselves and their actions was relevant or extremely relevant to their present practice.

<table>
<thead>
<tr>
<th>grade</th>
<th>work area</th>
<th>Encouraging clients to make decisions</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>not relevant</td>
<td>undecided</td>
</tr>
<tr>
<td>D</td>
<td>hospital</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>E</td>
<td>hospital</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>F</td>
<td>hospital</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>G</td>
<td>hospital</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Totals</td>
<td></td>
<td>1</td>
<td>13</td>
</tr>
</tbody>
</table>

Table 29: Advocacy definition: ‘Encouraging clients to make their own decisions’

For 92% (n=157) of the respondents, ‘encouraging clients to make their own decisions’ was relevant or extremely relevant. No-one thought it not at all relevant and only one (D grade) nurse working in ‘other residential’ services thought it not relevant to her current practice (table 29).
Only 18% (n=31) of respondents thought the definition 'Enabling things to happen for clients' was less than relevant to their practice. No statistically significant relationship was found between nurses' perception of the relevance of this definition and their work area.

Chi squared tests comparing each of the advocacy definitions with answers to the question 'Are you a key worker?' failed to establish any statistically significant relationships.

Additional comments on question 1a – Definitions of advocacy
Respondents accepted that clients require advocacy support. Speaking for clients, acting on their behalf and/or assisting them to speak for themselves were threads that ran through most of the additional comments provided by nurses, which supplemented the quantitative data in the first question. Several nurses mentioned supporting clients to obtain an independent advocate. Encouraging clients to support each other in self advocacy was also alluded to by several respondents. There was considerable emphasis on giving clients information which they could understand and then supporting them to make choices from the available options. Related to this, and also to Person Centred Planning, was the realisation that advocacy might be necessary if clients are not to be directed to use services 'because they are already there' (5.4). Relationships, which had emerged as a theme from the focus groups were also seen as an issue by respondents, many of whom mentioned the need for an understanding partnership between nurses, independent advocates and clients. One respondent put this particularly succinctly, arguing that 'Nurses and advocates should work together and support each other as well as the client in providing an effective service' (1.5).

One respondent referred to different levels of advocacy previously acknowledged in the focus groups. She commented that, as a nurse, (s)he would advocate 'regarding daily living'; but would refer clients to an independent advocate for 'more difficult/delicate issues'. Other issues mentioned were advocating for health care, which was proffered by several respondents, and representing clients at Legal Tribunals to uphold their rights under the Mental Health Act and other legislative frameworks.
5.16 Nurse respondents’ experiences of advocating

In order to introduce the concept of relationships in advocacy, nurses were asked to compare their experiences of advocating in their personal lives with advocating for clients. 50% (n = 85) of the respondents thought advocating in their personal life would be the same as advocating for clients. 43% (n=73) thought it would be different and 7% (n=13) were unsure.

Additional comments on question 1b – Do you consider advocating in your personal life is the same or different from advocating for clients?

67 respondents supplemented their answer with additional information. Of these, only one thought advocacy would be the same in her/his personal and professional life, giving a seemingly hypothetical reason ‘we should aim for the best for our clients as well as our family’ (4.1). Many of the respondents suggested that advocacy in their personal lives was guided by personal involvement and emotional attachment, but there was disagreement whether this was a help or a hindrance. On the one hand, one nurse suggested that ‘personal involvement and emotional attachment affects the ability to advocate effectively’ [for family] (2.2) and others suggested that because there is less emotional attachment to clients, ‘ability to advocate [for them] may be more effective’ (2.16) and they would be ‘more persistent if failure is initially encountered’ (2.10). On the other hand some respondents argued that they may have ‘more commitment’ when advocating for family members (1.5) because there is ‘more emotional involvement’ (1.29) and also because ‘family members, especially children, are totally your own responsibility’ (1.41) and that there are ‘less restrictions in personal life’ (2.1).

Restrictions on advocating for clients, which are not present in the family situation, were frequently mentioned, with ‘conflict of interests’ featuring in the comments of many respondents. Policy and procedures were seen as a curb on satisfactory advocacy by most of the nurses, and others mentioned ‘fear of litigation’ (5.17) as a restraint. However, some respondents felt that ‘the system’ was there to give guidance, that advocacy was made easier by the necessity to ‘abide by Trust policies and procedures’ (4.23) and that their professional advocacy practice could
be 'guided by rules and protocol' (4.14). Other differences between family and client advocacy related to 'the need to make assumptions when advocating for clients, due to the degree of mental impairment' (1.7) and the aim of overcoming the additional burden imposed on people with learning difficulties of being 'stigmatised and undervalued' (4.9) by their communities. Some respondents expected that, as their children matured, they would take on the responsibility of advocating for themselves, but that as nurses, they expected to stay involved with clients, although the ultimate goal would be for them 'to self advocate, but with support' (5.16). One nurse opined that as a 'paid person' (s)he could not be a 'true advocate' for clients, but made 'every attempt to advocate within the constraints of the work environment' (1.60). Echoing this, and acknowledging the limited availability of alternatives, others proposed that advocacy was part of their job, 'a duty of care' (4.13).

5.17 Situations in which nurse respondents might advocate for clients
Respondents were asked to indicate whether they might advocate for clients in any or all of the situations listed on the questionnaire (appendix 11).

<table>
<thead>
<tr>
<th>employing Health Trust</th>
<th>work area</th>
<th>might you advocate for clients regarding problems with day services?</th>
<th>No response %</th>
<th>Yes %</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>hospital</td>
<td>25.0</td>
<td>75.0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>15.6</td>
<td>84.4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>12.1</td>
<td>87.9</td>
<td></td>
</tr>
<tr>
<td>Two</td>
<td>hospital</td>
<td>14.3</td>
<td>85.7</td>
<td></td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>40.0</td>
<td>60.0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>7.7</td>
<td>92.3</td>
<td></td>
</tr>
<tr>
<td>Three</td>
<td>other residential</td>
<td>100.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>100.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Four</td>
<td>hospital</td>
<td>5.6</td>
<td>94.4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>100.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>25.0</td>
<td>75.0</td>
<td></td>
</tr>
<tr>
<td>Five</td>
<td>hospital</td>
<td>100.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>33.3</td>
<td>66.7</td>
<td></td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>18.2</td>
<td>81.8</td>
<td></td>
</tr>
<tr>
<td>Six</td>
<td>hospital</td>
<td>100.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>100.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>25.0</td>
<td>75.0</td>
<td></td>
</tr>
</tbody>
</table>

Table 30: Might you advocate for clients regarding problems with day services?
Approximately 81% of respondents reported that they might advocate for clients regarding choice of leisure activities, relationships with others, disagreements with carers and applications for resources. A lower percentage said that they might advocate for clients about their housing options, but a chi square test did not find this statistically significant. 86% (n=146) of respondents reported that they might advocate for clients regarding problems with day services. 100% (n=9) of nurses from one Health Trust stated that they might do this. Percentages in the other five Trusts ranged from 83% to 88%. 82% (n=36) of respondents from ‘other residential’ settings said that they might advocate about problems concerning day services. This compared closely with the 86% (n=69) of community nurse respondents and 88% (n=42) of hospital nurses who might do the same (table 30). 57% of nurses might advocate for their clients concerning problems with benefits. Proportionally, similar percentages of hospital and community nurses reported that they might do this (hospital 54%, n=26; community 55%, n=44) and a higher percentage of nurses working in ‘other residential’ units (64%, n=28). A chi squared test did not find this difference to be statistically significant.

<table>
<thead>
<tr>
<th>employing Health Trust</th>
<th>work area</th>
<th>No response</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>hospital</td>
<td>6.3</td>
<td>93.8</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>6.1</td>
<td>93.9</td>
</tr>
<tr>
<td>Two</td>
<td>hospital</td>
<td>14.3</td>
<td>85.7</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>20.0</td>
<td>80.0</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>Three</td>
<td>other residential</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>Four</td>
<td>hospital</td>
<td>5.6</td>
<td>94.4</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>25.0</td>
<td>75.0</td>
</tr>
<tr>
<td>Five</td>
<td>hospital</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>Six</td>
<td>hospital</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

Table 31: The effects of Trust and work area on whether or not nurses would advocate for specialist health care for clients

94% (n=161) of respondents reported that they might advocate for specialist health care for clients. All the respondents from Trusts 3 and 5 said they might do
this, the 6% who did not coming from the other four Trusts involved in the study (table 31). A similar percentage of nurses from across the three work areas reported that they might advocate for specialist health care (hospital 96%, n=46; other residential 91%, n=40; community 94%, n=75) (table 31). 95% (n=141) of respondents who have key worker responsibility for clients also reported that they might advocate for specialist health care for clients (table 32).

<table>
<thead>
<tr>
<th>advocate for specialist health care?</th>
<th>are you a key worker?</th>
<th>total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No response</td>
<td>yes</td>
<td>141</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>19</td>
</tr>
<tr>
<td><strong>totals</strong></td>
<td></td>
<td>160</td>
</tr>
</tbody>
</table>

Table 32: Relationship between key worker responsibility and the likelihood of advocating for specialist health care for clients

The relationship between having key worker responsibility and advocating for specialist health care was analysed using chi square. The value of chi square was found to be significant at the 0.05 level ($\chi^2 = 5.302$, df = 1) and it was concluded that nurses who have key worker responsibility were significantly more likely to advocate for specialist health care for their clients than those who do not.

<table>
<thead>
<tr>
<th>employing Health Trust</th>
<th>work area</th>
<th>might you advocate for generic health care for clients?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>No response %</td>
</tr>
<tr>
<td>One</td>
<td>hospital</td>
<td>12.5</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>15.6</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>3.0</td>
</tr>
<tr>
<td>Two</td>
<td>hospital</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>100.0</td>
</tr>
<tr>
<td>Three</td>
<td>other residential</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>14.3</td>
</tr>
<tr>
<td>Four</td>
<td>hospital</td>
<td>16.7</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>16.7</td>
</tr>
<tr>
<td>Five</td>
<td>hospital</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>33.3</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>100.0</td>
</tr>
<tr>
<td>Six</td>
<td>hospital</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 33: The effects of work area and employing Health Trust on whether nurses might advocate for generic health care for clients

172
95% (n=76) of community nurse respondents said that they might advocate for generic healthcare for their clients with 90% (n=43) of the hospital nurses and 82% (n=36) of nurses from ‘other residential’ settings in agreement (table 33).

<table>
<thead>
<tr>
<th>advocate for generic healthcare?</th>
<th>are you a key worker?</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>No response</td>
<td>yes</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>totals</td>
<td>16</td>
</tr>
<tr>
<td>Yes</td>
<td>yes</td>
<td>134</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>totals</td>
<td>155</td>
</tr>
</tbody>
</table>

**Table 34: The relationship between key worker responsibility and the likelihood of advocating for generic healthcare for clients**

90.5% (n=134) of the respondents who have key worker responsibility for clients reported that they might advocate for generic healthcare for clients (table 34). A chi square test did not find a significant relationship between being a key worker and advocating for generic health care for clients ($x^2 = 0.014$, df = 1).

<table>
<thead>
<tr>
<th>would you advocate for clients in these situations?</th>
<th>Yes</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>specialist health care</td>
<td>162</td>
<td>11</td>
</tr>
<tr>
<td>generic health care</td>
<td>156</td>
<td>17</td>
</tr>
<tr>
<td>problems with day services</td>
<td>148</td>
<td>25</td>
</tr>
<tr>
<td>disagreements with carers</td>
<td>143</td>
<td>30</td>
</tr>
<tr>
<td>applications for resources</td>
<td>141</td>
<td>32</td>
</tr>
<tr>
<td>relationship with others</td>
<td>140</td>
<td>33</td>
</tr>
<tr>
<td>choice of leisure activities</td>
<td>139</td>
<td>33</td>
</tr>
<tr>
<td>housing options</td>
<td>120</td>
<td>53</td>
</tr>
<tr>
<td>problems with benefits</td>
<td>99</td>
<td>74</td>
</tr>
</tbody>
</table>

**Table 35: Frequency table – advocacy situations**

In order to explore whether nurses were more likely to advocate for the health care needs of their clients than for other needs a comparison was made between the number of respondents who reported that they might advocate for generic health care for clients (the lower scoring of the 2 health related options) and the number who might advocate for clients regarding problems with day services (i.e. the highest scoring non health related option (table 35). This relationship was analysed using chi square. The value of chi square was found to be significant at
the 0.05 level ($x^2 = 6.625, df = 1$) and it was therefore concluded that nurses were significantly more likely to advocate for health care for their clients than for non health related options (table 36).

<table>
<thead>
<tr>
<th>advocate for generic health care</th>
<th>problems with day services</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No response</td>
<td>Yes</td>
</tr>
<tr>
<td>No response</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Yes</td>
<td>19</td>
<td>137</td>
</tr>
<tr>
<td><strong>totals</strong></td>
<td><strong>25</strong></td>
<td><strong>148</strong></td>
</tr>
</tbody>
</table>

Table 36: The relationship between advocating for generic health care for clients and advocating about problems with day services

Additional comments on question 1d10 – In what situations might you advocate for clients?

Respondents were asked to list additional situations in which they might advocate for clients. Many of the respondents stated that they advocated ‘in all aspects of the service users’ life’ (1.59). This included ‘choosing meals, clothes, aspects of personal care’ (2.20) i.e. Goble’s (2002.75) ‘advocacy with a small ‘a’. Others mentioned advocating for generic health care due to the ‘lack of understanding of learning disabilities by generic health care workers’ (2.9) and advocating for clients against the imposition ‘of values/ideology which may not have resonance for the individual’ during the resettlement process (4.23).

One respondent proposed that in ‘relationships with others’ and ‘disagreements with carers’ (s)he would be more likely to act as mediator than advocate (5.9) and would expect clients to advocate for themselves in many of the listed situations. Respondents who were members of multi-disciplinary teams suggested that they might call upon social workers to advocate for clients in some situations. The care manager/clinician split was mentioned by several respondents, one nurse suggested that (s)he would advocate for clients concerning ‘relationships with others’, ‘disagreements with carers’, ‘applications for resources’ and ‘specialist and generic health care’ in her/his ‘nurse role’ and for ‘choice of leisure activities’ ‘housing options’ ‘problems with day services’ and ‘problems with benefits’ in her/his role as care manager (6.2). Advocating for clients at review meetings was
a situation additional to the given list, as were explaining the nature of a child’s behaviour to his/her school and advocating for educational options for children with learning difficulties.

5.18 Circumstances which might contribute to a satisfactory nurse/client advocacy partnership

Respondents were asked to indicate on a scale of 1 to 5 the importance of given items to a satisfactory advocacy partnership between nurse and client. Once again some of the items had been obtained from people who have learning difficulties in stage 1 and others from the nurse participants in stage 2.

<table>
<thead>
<tr>
<th>are you a key worker?</th>
<th>work area</th>
<th>How important is understanding clients’ communication?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>not important</td>
<td>undecided</td>
</tr>
<tr>
<td>Yes</td>
<td>hospital</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>hospital</td>
<td></td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>1</td>
</tr>
<tr>
<td>Totals</td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

Table 37: The influence of nurses’ work area and key worker responsibility on their perception of the importance to advocacy of understanding clients’ communication

97% (n=166) of respondents reported ‘understanding clients’ communication’ to be important or extremely important. Only one nurse found it not important and 2% (n=4) were undecided (table 37).

45% (n=77) of nurses were undecided about the importance of a long term relationship with clients to nurse advocacy and 9% (n=16) thought it not at all or not important. 46% (n=80) considered it important or extremely important. 58% (n=28) of the respondents who work in hospital thought a long term relationship with clients was important or extremely important with 42% (n=20) either being undecided or thinking it not or not at all important. Of those nurses working in ‘other residential’ settings 46% (n=20) thought it important or extremely important and 54% (n=24) were either undecided or thought it not or not at all important. Only 40% (n=32) of the community nurse respondents thought a long term...
relationship with clients was important or extremely important to a satisfactory advocacy partnership with 60% (n=48) being either undecided or thinking it not or not at all important (table 38).

<table>
<thead>
<tr>
<th>how important to advocacy is a long standing relationship with clients?</th>
<th>work area</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>hospital</td>
<td>other residential</td>
</tr>
<tr>
<td>not important</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>undecided</td>
<td>17</td>
<td>21</td>
</tr>
<tr>
<td>not at all important</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>important</td>
<td>12</td>
<td>9</td>
</tr>
<tr>
<td>extremely important</td>
<td>16</td>
<td>11</td>
</tr>
</tbody>
</table>

**Table 38:** The relationship between nurses' work area and their perception of the importance to advocacy of a long-standing relationship with clients

Fewer of those respondents who work with clients who have a whole range of communication skills from adequate to non verbal reported finding a long term relationship with clients important or extremely important than those who were undecided or thought it not or not at all important. Of the 107 respondents in this category, only 39% (n=42) thought a long term relationship important or extremely important while 61% (n=65) disagreed (table 39). Nurses who worked with clients who have adequate verbal communication reported the opposite with 61% (n=17) of them thinking a long term relationship important or extremely important.

<table>
<thead>
<tr>
<th>communication skills of clients</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>non/limited verbal, limited signing</td>
<td>adequate verbal</td>
</tr>
<tr>
<td>not at all/not relevant/undecided</td>
<td>15</td>
</tr>
<tr>
<td>relevant/extremely relevant</td>
<td>21</td>
</tr>
</tbody>
</table>

**Table 39:** The relationship between the communication skills of clients and nurses' perception of the importance to satisfactory advocacy of a long standing relationship with clients
The percentages were closer in the case of nurses who worked with clients who have no verbal communication. 58% (n=21) thought a long term relationship important or extremely important and 42% (n=15) were either undecided or thought it not or not at all important to a satisfactory nurse/client advocacy partnership. (Table 39)

The relationship between the communication skills of clients and nurses' perception that a long standing relationship is important or extremely important was analysed using chi square. The value of chi square was found to be significant at the 0.05 level ($X^2 = 6.549$, df = 2) and it was concluded that nurses whose clients had communication skills across the range from none to adequate were significantly less likely to think a long term relationship with clients was important or extremely important than nurses who work solely with clients who have either adequate verbal communication or do not communicate verbally.

67% (n=115) of the respondents thought a good relationship with carers important or extremely important with 33% (n=56) being undecided or reporting it not or not at all important to a nurse/client advocacy partnership.

<table>
<thead>
<tr>
<th>work area</th>
<th>good relationship with carers</th>
<th>total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>not at all/not relevant/undecided</td>
<td>relevant/extremely relevant</td>
</tr>
<tr>
<td>hospital</td>
<td>10</td>
<td>38</td>
</tr>
<tr>
<td>other</td>
<td>13</td>
<td>31</td>
</tr>
<tr>
<td>residential</td>
<td></td>
<td></td>
</tr>
<tr>
<td>community</td>
<td>34</td>
<td>46</td>
</tr>
<tr>
<td>totals</td>
<td>57</td>
<td>115</td>
</tr>
</tbody>
</table>

Table 40: The relationship between nurses' work area and their perception of the importance of a good relationship with carers to satisfactory nurse/client advocacy

The highest percentage of those respondents thinking a good relationship with carers was important or extremely important were hospital nurse respondents of whom 79% (n=38) took this view. Of the respondents working in 'other residential' settings 70% (n=31) thought a good relationship with carers important or extremely important, 25% (n=11) were undecided with only the remaining 5% (n=2) thinking
it not very or not at all important. Only 58% (n=46) of community nurse respondents thought a good relationship with carers important or extremely important, with 42% (n=33) either being undecided or thinking it not or not at all important to a satisfactory nurse/client advocacy partnership (table 40).

This relationship was analysed using chi square. The value of chi square was found to be significant at the 0.05 level ($x^2=6.701$, df=2) and it was therefore concluded that nurses working in the community were significantly less likely to think a good relationship with carers important or extremely important than nurses working in residential settings.

<table>
<thead>
<tr>
<th>items</th>
<th>how important are these items to a satisfactory nurse/client advocacy partnership?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>not important</td>
</tr>
<tr>
<td>mutal trust nurse/client &gt;</td>
<td>2</td>
</tr>
<tr>
<td>knowledge of clients' likes/dislikes &gt;</td>
<td>3</td>
</tr>
<tr>
<td>maintaining professional relationship &gt;</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 41: The importance to satisfactory nurse/client advocacy of mutual trust, knowledge of clients' likes and dislikes and maintaining a professional relationship

'Mutual trust between nurse and clients’, ‘knowledge of clients' likes and dislikes’, and ‘maintaining a professional relationship’ all attracted a high percentage of ‘important’ or ‘extremely important’ responses. None of these were thought not at all important and only 4% (n=7) of respondents were undecided or found them not important to their advocacy practice (table 41).

<table>
<thead>
<tr>
<th>work area</th>
<th>time to develop mutual understanding</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>not important</td>
<td>undecided</td>
</tr>
<tr>
<td>Hospital</td>
<td>6</td>
<td>18</td>
</tr>
<tr>
<td>other residential</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Community</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td>Totals</td>
<td>2</td>
<td>27</td>
</tr>
</tbody>
</table>

Table 42: The importance of time to develop mutual understanding between nurse and client
83% (n=142) of respondents reported 'time to develop mutual understanding' to be important or extremely important. 81% (n=63) of the community nurse respondents reported it as important or extremely important, 88% (n=42) of hospital nurse respondents agreed, as did 82% (n=36) of respondents working in 'other residential' services (table 42).

88% (n=42) of the hospital nurse respondents thought supporting clients to self advocate was important or extremely important, while 89% of both nurses from 'other residential' settings (n=39) and community nurses (n=71) agreed (table 43).

<table>
<thead>
<tr>
<th>work area</th>
<th>support to self advocate</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>not at all/not relevant/undecided</td>
</tr>
<tr>
<td>hospital</td>
<td>6</td>
</tr>
<tr>
<td>other residential</td>
<td>5</td>
</tr>
<tr>
<td>community</td>
<td>7</td>
</tr>
<tr>
<td>totals</td>
<td>18</td>
</tr>
</tbody>
</table>

Table 43: The influence of nurses' work area on their perception of the importance of supporting clients to self advocate

Additional comments on question 1e – ‘What makes a satisfactory advocacy partnership between nurse and client?’

Of the fourteen respondents who provided additional comments to the given list of items which might contribute to a satisfactory nurse/client advocacy partnership, the majority gave their views on relationships with clients and/or carers. In many cases, a long term relationship with clients was seen as useful, although some respondents pointed out that this did not necessarily mean a 'good' relationship. There was disagreement between two respondents about the virtues of a long standing relationship with clients. One nurse argued that (s)he 'did not need to know clients very well to advocate for them as long as (s)he is... aware of their wishes' (1.70). The other disagreed; commenting that '... I frequently find myself advocating for a client I barely know. This can prove very difficult' (1.74).

Several of the respondents mused on the fact that 'closeness and friendship emerge naturally in [long standing] nurse/client relationships' (4.23) and one
respondent had found that 'as one becomes closer to the client, boundaries between friendship and professionalism merge' and advocacy becomes 'inoperable' (2.20). Many respondents felt that objectivity is essential to satisfactory nurse advocacy and this could be compromised by a long standing relationship.

A good relationship with carers was deemed important, with the proviso that it focused mainly on the nurse/client relationship and the duty of the nurse 'to advocate correctly' for the client remained paramount.

Comments which did not relate to relationship issues highlighted the difficulties for nurses wishing to support clients with impaired communication skills to join a self advocacy group, and the 'clear need' for independent advocacy in some cases (1.2). The final comment issued a warning to nurses to consider the topic of the advocacy attempt before committing themselves to advocate for clients (1.5).

5.19 Problems for nurses taking on the advocacy role
The last group of questions relating to advocacy concerned potential problems for nurses taking on an advocacy role for their clients. Respondents were asked to tick those situations offered on the questionnaire which might cause problems, and to add any additional situations which might militate against a satisfactory nurse/client advocacy partnership.

<table>
<thead>
<tr>
<th>work area</th>
<th>conflict of interest with employer</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No response</td>
</tr>
<tr>
<td>hospital</td>
<td>14</td>
</tr>
<tr>
<td>other residential</td>
<td>13</td>
</tr>
<tr>
<td>community</td>
<td>26</td>
</tr>
<tr>
<td>totals</td>
<td>53</td>
</tr>
</tbody>
</table>

Table 44: The relationship between nurses' work area and their perception that conflict of interest with their employer might compromise nurse/client advocacy

Conflict of interest with employers was seen as a possible problem to successful advocacy for similar percentages of respondents in all work areas. 71% (n=34) of
hospital nurse respondents and of those working in 'other residential' settings (n=31) and 68% (n=54) of community nurses agreeing that this might be the case. (table 44).

There was more variation between nurses working for the different Health Trusts. 69% (n=120) of respondents felt that they might encounter conflict of interest with their employing Health Trust if they advocate for clients. Trust four had the lowest likelihood (53%) while Trust six had the highest probability (83%) (table 45).

<table>
<thead>
<tr>
<th>employing Health Trust</th>
<th>conflict of interest %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No response</td>
</tr>
<tr>
<td>One</td>
<td>28.4</td>
</tr>
<tr>
<td>Two</td>
<td>24.0</td>
</tr>
<tr>
<td>Three</td>
<td>33.3</td>
</tr>
<tr>
<td>Four</td>
<td>46.9</td>
</tr>
<tr>
<td>Five</td>
<td>25.0</td>
</tr>
<tr>
<td>Six</td>
<td>16.7</td>
</tr>
</tbody>
</table>

Table 45: The relationship between nurses’ employment area and their perception that conflict of interest with their employer might compromise a satisfactory nurse/client advocacy partnership

Key worker responsibility carried a high possibility that conflict of interest with employers might be perceived to cause a problem for nurse/client advocacy. 91% (n=107) of the respondents with key worker responsibility expressed this view (table 46).

<table>
<thead>
<tr>
<th>are you a key worker?</th>
<th>conflict of interest with employer</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No response</td>
<td>Yes</td>
</tr>
<tr>
<td>yes</td>
<td>41</td>
<td>107</td>
</tr>
<tr>
<td>no</td>
<td>12</td>
<td>11</td>
</tr>
<tr>
<td>totals</td>
<td>53</td>
<td>118</td>
</tr>
</tbody>
</table>

Table 46: Relationship between key worker responsibility and nurses’ perception that conflict of interest with their employer might cause a problem for satisfactory nurse/client advocacy

181
The relationship between having key worker responsibility for one or more clients and nurses' perception that conflict of interest might cause problems for a satisfactory nurse/client advocacy partnership was analysed using chi square. The value of chi square was found to be significant at the 0.05 level ($x^2 = 5.574$, df = 1) and it was concluded that nurses who have key worker responsibility are more likely to perceive conflict of interest with employers as a problem to satisfactory advocacy than those who do not (table 46).

Respondents had mixed opinions on whether unequal power relationships between nurse and client were a potential problem to nurse advocacy. 53% (n=87) agreed that this would be the case, and 47% (n=77) did not. This was obviously a personal perception. Neither work area; nurses' grade; qualification period; nor key worker responsibility was found to have a statistically significant effect on nurses' assessment of problems relating to unequal power relationships.

![Table 47: The relationship between nurses’ work area and their perception that responsibility for several clients might compromise nurse/client advocacy](image)

The hospital nurse respondents were the only group in which more nurses saw responsibility for several clients as a problem (56%, n=27) than otherwise. Only 44% (n=35) of the community nurses and 48% (n=21) of those in 'other residential services' saw this as a problem although many of the former had responsibility for at least twenty clients. The relationship between nurses' work area and their perception that responsibility for several clients might compromise efforts at nurse advocacy was not found to be statistically significant (table 47).
Of the 170 respondents who answered the question 'would inability to interpret clients' requirements militate against successful nurse advocacy?' 74% (n=126) thought this would cause a problem. The communication skills of the clients did not appear to affect nurses' opinions. Of the respondents working with clients with adequate verbal communication 71% (n=20) thought lack of ability to interpret clients requirements might be a problem and, surprisingly, only 69% (n=25) of those working with clients with no or limited verbal communication took the same view. Of the respondents working with clients with varying communication skills 77% (n=82) thought problems with interpreting clients requirements might cause difficulties for successful advocacy (table 48).

<table>
<thead>
<tr>
<th>work area</th>
<th>communication skills</th>
<th>inability to interpret clients' requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>No response</td>
</tr>
<tr>
<td>hospital</td>
<td>non/limited verbal</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>adequate verbal</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>all or various</td>
<td>5</td>
</tr>
<tr>
<td>other residential</td>
<td>non/limited verbal</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>adequate verbal</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>all or various</td>
<td>4</td>
</tr>
<tr>
<td>community</td>
<td>non/limited verbal</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>adequate verbal</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>all or various</td>
<td>16</td>
</tr>
<tr>
<td>totals</td>
<td></td>
<td>44</td>
</tr>
</tbody>
</table>

Table 48: Might inability to interpret clients' requirements compromise a satisfactory nurse/client advocacy partnership?

Lack of time was seen as a potential problem to satisfactory nurse/client advocacy by a high proportion of respondents (72%, n=124). 75% (n=60) of the community nurse respondents reported finding lack of time problem. 71% (n=34) of hospital nurse respondents agreed as did 68% (n=30) of those working in 'other residential' situations.

68% (n=112) of the respondents reported that lack of knowledge (e.g. legal, clinical) might be a problem to their advocacy role. 31% (n=35) of these had
qualified before 1985 and 69% (n=77) had considerable experience, having worked with the same or similar clients for over 6 years. 54% (n=61) of those reporting that lack of knowledge might cause a problem were D and E grade nurses (table 49).

<table>
<thead>
<tr>
<th>grade</th>
<th>period working with these clients</th>
<th>qualification period</th>
<th>lack of knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>No response</td>
</tr>
<tr>
<td>D</td>
<td>less than 1 year</td>
<td>1995+</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>1-3 years</td>
<td>1995+</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>4-6 years</td>
<td>1995+</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>longer than 6 years</td>
<td>1960-1985</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1986-1994</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1995+</td>
<td>1</td>
</tr>
<tr>
<td>E</td>
<td>less than 1 year</td>
<td>1960-1985</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1995+</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>1-3 years</td>
<td>1986-1994</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1995+</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>4-6 years</td>
<td>1960-1985</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1986-1994</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1995+</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>longer than 6 years</td>
<td>1986-1994</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1995+</td>
<td>3</td>
</tr>
<tr>
<td>F</td>
<td>1-3 years</td>
<td>1986-1994</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>4-6 years</td>
<td>1986-1994</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1995+</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>longer than 6 years</td>
<td>1960-1985</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1986-1994</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1995+</td>
<td>2</td>
</tr>
<tr>
<td>G</td>
<td>1-3 years</td>
<td>1960-1985</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1986-1994</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>4-6 years</td>
<td>1995+</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>longer than 6 years</td>
<td>1960-1985</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1986-1994</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1995+</td>
<td>1</td>
</tr>
<tr>
<td>totals</td>
<td></td>
<td></td>
<td>53</td>
</tr>
</tbody>
</table>

Table 49: The relationship between nurses' grade, qualification period and experience to their perception that lack of knowledge might compromise attempts at advocacy

54% (n=93) of respondents thought conflict with carers might be a potential problem to advocacy. Although 79% (n=38) of hospital nurse respondents and 70% (n=31) of nurses working in 'other residential settings had reported a 'good
relationship with carers' to be important or extremely important to nurse/client advocacy a much smaller percentage (hospital: 56%, n=27; ‘other residential’: 57%, n=25) perceived conflict with carers to be a potential problem. Responses to the two questions by community nurses were more consistent, 58% (n=46) reported a good relationship with carers important or extremely important and 51% (n=41) considered conflict with carers might be a problem for nurse client advocacy (table 50).

<table>
<thead>
<tr>
<th>work area</th>
<th>good relationship with carers</th>
<th>conflict with carers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>very/extremely imp.</td>
<td>undecided/not/no at all imp.</td>
</tr>
<tr>
<td>Hospital</td>
<td>38</td>
<td>10</td>
</tr>
<tr>
<td>other residential</td>
<td>31</td>
<td>13</td>
</tr>
<tr>
<td>community</td>
<td>46</td>
<td>33</td>
</tr>
<tr>
<td>Totals</td>
<td>115</td>
<td>56</td>
</tr>
</tbody>
</table>

Table 50: The relationship between nurse respondents' work area and their views on the importance of a good relationship with carers and whether conflict with carers might compromise nurse/client advocacy

60% (n=103) of respondents thought lack of experience might be a problem for nurse advocacy (table 51). Of those who had been working with the same clients or clients with similar needs for less than 12 months 88% (n=7) thought insufficient experience might cause a problem, and of those who had been working with the client group for between one and three years (58%, n=15) agreed. Of the nurses who had been working with their particular client group for between four and six years 74% (n=14) thought lack of experience might cause problems for an advocacy partnership with a client, but only 58% (n=67) of those who had worked with the same or similar clients for over six years agreed. 13% (n=22) of the respondents were D grade nurses. They were equally divided on this question with 50% (n=11) thinking lack of experience might cause a problem while the other 50% (n=11) disagreed. The highest percentage of those thinking lack of experience might cause a problem were E grade nurses of whom 71% (n=51) thought lack of experience might cause difficulties. The next highest percentage were F grade nurses, 64% (n=16) of whom thought lack of experience might be a problem. The G grade nurses reversed the trend. Only 48% (n=25) of G grade
respondents thought lack of experience might cause a problem for satisfactory nurse advocacy while a slightly higher percentage 52% \((n=27)\) did not (table 51).

<table>
<thead>
<tr>
<th>grade</th>
<th>period working with these clients</th>
<th>insufficient experience</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>No response</td>
</tr>
<tr>
<td>D</td>
<td>less than 1 year</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>1-3 years</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>4-6 years</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>longer than 6 years</td>
<td>5</td>
</tr>
<tr>
<td>E</td>
<td>less than 1 year</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>1-3 years</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>4-6 years</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>longer than 6 years</td>
<td>14</td>
</tr>
<tr>
<td>F</td>
<td>1-3 years</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>4-6 years</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>longer than 6 years</td>
<td>6</td>
</tr>
<tr>
<td>G</td>
<td>1-3 years</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>4-6 years</td>
<td></td>
</tr>
<tr>
<td></td>
<td>longer than 6 years</td>
<td>25</td>
</tr>
<tr>
<td>totals</td>
<td></td>
<td>67</td>
</tr>
</tbody>
</table>

Table 51: Relationship of nurses’ grade and experience to their perception that insufficient experience might compromise a satisfactory nurse/client advocacy partnership

The last question in this section asked nurses if lack of understanding of clients’ rights might affect their efforts at client advocacy. 59% \((n=101)\) of the respondents thought that this could compromise their efforts at advocacy. No statistically significant relationship was found between whether or not lack of understanding of client’s rights would be a problem to nurse/client advocacy and nurses’ grades, their qualification period or whether or not they had received education in the Human Rights Act (1998)

Additional comments on question 1f – What might militate against satisfactory nurse advocacy?

Conflict of interests, lack of resources, unequal power relationships and lack of knowledge, training and confidence were all cited as potential problems for satisfactory nurse advocacy. Some respondents also agreed with Brooke (2001), suggesting that advocacy ‘can be difficult if the nurse has a large caseload and each of them with many needs’ (2.19). One respondent highlighted the different

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aspects of advocacy and suggested that the nurse might encounter difficulties with 'undertaking a formal advocacy role' as opposed to advocating informally (5.9). Possible problems with independent advocacy services were also accentuated by a nurse who suggested that 'sometimes unique person-centred needs are over ridden' by an 'ideologically driven independent advocacy service' (4.23).

**Analysis of section 2 - Advocates**

Section 2 of the questionnaire investigated the availability and use of external advocacy services for clients, and explored nurses’ attitude towards them.

**5.20 Citizen advocates**

The first question asked respondents whether any of their clients had a citizen advocate. 52% (n=89) reported in the affirmative, 39% (n=66) did not and 9% (n=15) were unsure. More nurses from Trusts 2, 5 and 6, reported having some clients who had a citizen advocate than those reporting that clients did not. Of the 169 respondents, 48% came from Health Trust 1. Of these 45.6% reported that they did have clients who had a citizen advocate and an equal 45.6% reported that they did not. 9% were unsure.

<table>
<thead>
<tr>
<th>Health Trust</th>
<th>do clients have a citizen advocate?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes %</td>
</tr>
<tr>
<td>One</td>
<td>45.6</td>
</tr>
<tr>
<td>Two</td>
<td>75.0</td>
</tr>
<tr>
<td>Three</td>
<td>44.4</td>
</tr>
<tr>
<td>Four</td>
<td>37.5</td>
</tr>
<tr>
<td>Five</td>
<td>65.0</td>
</tr>
<tr>
<td>Six</td>
<td>100.0</td>
</tr>
</tbody>
</table>

*Table 52: The influence of employment area on whether or not the clients of nurse respondents have a citizen advocate (table showing percentages to conserve confidentiality)*

14% of the respondents were employed in Health Trust 2 and 75% of these reported having clients with a citizen advocate. 21% did not and 4% were unsure. 5% of respondents were employed in Health Trust 3 and of these only 44% had clients with a citizen advocate. 18% of the respondents were employed by Health Trust 4. 37% of these had clients who have a citizen advocate, 44% did not and
19% were unsure. 12% of nurses were employed in Health Trust 5 and of these 65% reported that they had clients who have a citizen advocate, 30% reported that they did not and 5% were unsure. 3% of the respondents were employed in Health Trust 6 and 100% of these reported that they had clients who have a citizen advocate (Table 52).

Additional comments on question 2a – Do any of your clients have a citizen advocate?

Only one nurse respondent commented on this question, making the seemingly paradoxical statement that her/his clients did not have citizen advocates but had the services of an ‘independent advocate employed by the Trust’ (2.14).

5.21 Relationships between clients and their advocates
Of the 103 respondents who reported having clients with a citizen advocate 60% (n=62) thought this was a positive relationship. Exactly half that number (30%, n=31) were unsure. Only 10% (n=10) thought the relationship was not positive. 32% (n=32) of the respondents worked in hospitals, 17% (n=18) in ‘other residential’ units and 51% (n=53) in the community. 59% (n=19) of the hospital nurse respondents thought the relationship positive, 10% (n=3) disagreed and 31% (n=10) were unsure. A similar percentage of the respondents working in ‘other residential’ settings (56%, n=10) thought the partnerships positive, 11% (n=2) disagreed and 33% (n=6) were unsure.

<table>
<thead>
<tr>
<th>work area</th>
<th>positive relationship between client and citizen advocate?</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>hospital</td>
<td>19</td>
<td>3</td>
</tr>
<tr>
<td>other residential</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>community</td>
<td>33</td>
<td>6</td>
</tr>
<tr>
<td>totals</td>
<td>62</td>
<td>11</td>
</tr>
</tbody>
</table>

Table 53: Is there a positive relationship between client and citizen advocate?

A slightly, but not significantly higher percentage of the 53 community nurses (62%, n=33) found the relationships positive with 11% (n=6) disagreeing and 27% (n=14) being unsure (table 53). The relationship between nurses’ work area and their perception that a client/citizen advocacy was or was not positive was not
found to be statistically significant.

Additional comments on question 2a1 – If clients have a citizen advocate, do you consider this to be a positive relationship?

The majority of respondents who commented on whether or not they thought the client/citizen advocate relationship was positive, were uncertain. In one case this was due to the brevity of the relationship, but in others nurses felt the advocate did not understand the client’s needs or confused the client by following their own, rather than the client’s agenda. Several nurses felt that negotiation between themselves and citizen advocates was necessary to clarify advocates’ entitlement to information about the client and access to meetings concerning the client. Objectivity was raised as an advocacy issue, one respondent suggesting that citizen advocates require ‘skill/knowledge into mental state/diagnosis of client to remain objective’ (5.5). One nurse echoed the concerns of Schwer (2002) when (s)he raised the issue of citizen advocates having ‘no understanding re capacity’ (section 6.3). This respondent also commented that (s)he had ‘some issues re experience of advocates and understanding of their role’ (5.9). Despite the uncertain attitudes of respondents towards client/citizen advocacy partnerships, 72% (n=118) said that they would encourage their clients to have a citizen advocate. Only 4% said they would not although 24% (n=40) were undecided.

5.22 Benefits to staff of client/citizen advocate partnership

66% (n=112) of respondents expected staff to benefit from a client/citizen advocacy partnership. Only 7% (n=12) did not, but 40% (n=45) were unsure. Similar percentages were found across each of the work areas.

Additional comments on question 2a3 – Would you expect staff to benefit from a client/citizen advocacy partnership?

Only two respondents commented on whether or not staff should expect to benefit from a client/citizen advocacy partnership. One emphasised her selection of ‘unsure’ with the comment ‘not always’. The other felt that staff would benefit from the lessening of ‘certain behaviours’ as the client would have more opportunity to do what he or she ‘would like to do’ resulting in ‘better understanding of the client’s need’ (3.2)
Additional comments on question 2a4 – Would you encourage clients to have a citizen advocate?

Two respondents, commenting on whether or not they would encourage clients to have a citizen advocate, gave a categorical 'no' due to 'negative' experiences in the past. Several respondents thought that citizen advocates 'have a hidden agenda which does not always operate in the client's interests' (2.20). One nurse suggested that citizen advocacy 'had lost all sense of direction' in her/his area (4.4) and another reported that clients had been discouraged from applying for a citizen advocate by the long waiting list (5.13). Two respondents commented in the affirmative with the proviso that 'the advocate .... works within agreed ground rules' (5.7) , and another thought it essential that the client should be able to choose 'the person they prefer, not have an advocate forced upon them' (2.1). Two respondents agreed in principle with clients having a citizen advocate, but thought this depended on clients' ability to self advocate or whether they had 'parents advocating for them' (1.63).

5.23 Self advocacy

<table>
<thead>
<tr>
<th>employing Health Trust</th>
<th>would you encourage clients to join a self advocacy group?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes %</td>
</tr>
<tr>
<td>One</td>
<td>82.5</td>
</tr>
<tr>
<td>Two</td>
<td>92.0</td>
</tr>
<tr>
<td>Three</td>
<td>100.0</td>
</tr>
<tr>
<td>Four</td>
<td>87.5</td>
</tr>
<tr>
<td>Five</td>
<td>90.0</td>
</tr>
<tr>
<td>Six</td>
<td>83.3</td>
</tr>
</tbody>
</table>

Table 54: Influence of employment area on whether nurse respondents would encourage clients to join a self advocacy group

Respondents were more certain about the benefit of clients joining self advocacy groups than about citizen advocacy services. 87% (n=149) reported that they would encourage clients to join a self advocacy group with only 4% (n=7) saying they would not and 9% (n=16) being unsure. 100% of respondents employed by
Health Trust 3 reported that they would encourage clients to join a self advocacy group. Percentages in the other Trusts were also high, ranging from 82.5% to 92% (table 54).

Additional comments on question 2a4 – ‘Would you encourage clients to join a self advocacy group?’

The majority of respondents who gave reasons why they would or would not encourage clients to join a self advocacy group said that they would; basing this on the positive experiences of clients who belong to such groups. Two nurses reported that self advocacy groups were not available. Only one nurse said she would not encourage her clients to join self advocacy groups, feeling that ‘self advocacy groups are biased towards those with self expression’ while her/his clients did not have verbal communication skills. Nurses who were unsure either felt that it was a matter of client’s personal choice, or that clients with good support networks would not benefit from membership of a self advocacy group.

5.24 Paid independent advocacy services
167 nurses responded to the question ‘Do your clients have access to paid independent advocacy services?’ 59% (n=98) reported in the affirmative.

<table>
<thead>
<tr>
<th>work area</th>
<th>access to paid independent advocacy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
</tr>
<tr>
<td>hospital</td>
<td>36</td>
</tr>
<tr>
<td>other residential</td>
<td>23</td>
</tr>
<tr>
<td>community</td>
<td>39</td>
</tr>
<tr>
<td>totals</td>
<td>98</td>
</tr>
</tbody>
</table>

Table 55: The influence of nurses' work area on the availability of paid independent advocacy services

76% (n=36) of the hospital nurses reported that their clients could access paid advocacy services, as did 55% (n=23) of those working in ‘other residential’ units and 50% (n=39) of the community nurses. Only 9% (n=4) of the hospital nurses reported that clients did not have access to independent advocacy services. 29% (n=12) of those in ‘other residential’ units did not, neither did 22% (n=17) of the clients of community nurses, although 28% (n=22) of these nurses were unsure
whether their clients could access paid independent advocacy. 16% (n=7) of those working in ‘other residential’ settings and 15% (n=7) of the hospital nurses were also unsure (table 55). The relationship between respondents’ work area and availability of independent (paid) advocacy services for their clients was analysed using chi square. The value of chi square was found to be significant at the 0.05 level \((x^2 = 11.539, df = 4)\) and it was concluded that respondents working in hospital were significantly more likely to have access to paid independent advocacy services for their clients than nurses working in other areas (table 56).

<table>
<thead>
<tr>
<th>work area</th>
<th>access to paid independent advocacy?</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
<td>no/unsure</td>
</tr>
<tr>
<td>hospital</td>
<td>36</td>
<td>11</td>
</tr>
<tr>
<td>other residential</td>
<td>23</td>
<td>19</td>
</tr>
<tr>
<td>community</td>
<td>39</td>
<td>39</td>
</tr>
<tr>
<td>totals</td>
<td>98</td>
<td>69</td>
</tr>
</tbody>
</table>

Table 56: The influence of work area on positive availability of paid independent advocacy services

Additional comments on question 2b – Do your clients have access to paid independent advocacy services?

Only two respondents made additional comments on whether their clients have access to paid independent advocacy services. One, who worked with children, reported that parents had access to independent advocacy on behalf of their child if necessary. The other commented that, in common with the rest of the population, her/his clients had access to ‘Citizens Advice and legal aid’ (5.4). The nurse did not comment on how clients would access these services and whether they would be able to represent themselves to obtain the advocacy representation they might require.

5.25 Situations which might warrant referral to paid independent advocacy services

Respondents were asked to indicate whether situations listed on the questionnaire might warrant a referral for paid independent advocacy services. A high percentage (84%, n=145) of nurses reported that they might refer clients to paid
independent advocacy services for legal purposes e.g. Mental Health Act tribunals. 63% (n=108) of respondents said they might refer clients for purposes of representation to the Trust. 59% (n=102) of respondents said that they might refer clients for financial reasons, and a higher (74%, n=128) percentage of nurses said that they might refer clients for independent paid advocacy regarding their residential concerns (table 57).

<table>
<thead>
<tr>
<th>reason for referral</th>
<th>No response</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>legal purposes</td>
<td>27</td>
<td>145</td>
</tr>
<tr>
<td>representation to Trust</td>
<td>64</td>
<td>108</td>
</tr>
<tr>
<td>financial purposes</td>
<td>70</td>
<td>102</td>
</tr>
<tr>
<td>residential concerns</td>
<td>44</td>
<td>128</td>
</tr>
</tbody>
</table>

Table 57: Might legal purposes, representation to the Trust, financial concerns and/or residential concerns warrant a referral for independent (paid) advocacy?

Additional comments on question 2c – What situations might warrant referral to paid independent advocacy services?

Most of the additional situations which respondents reported as warranting referral of clients for paid independent advocacy services were straight forward, concerning risk to clients caused by Health and Safety issues and quality of service provision. Several nurses suggested that they would refer clients to independent advocacy services in family disputes, to enable the client to make decisions independent of family pressures, and one reported a referral for paid advocacy services in a situation of perceived abuse of the client by carers. Several respondents would refer clients to independent advocacy services if they requested access to ‘inappropriate’ activities or items or made ‘inappropriate’ demands, but none of them enlarged on by whom or why these issues might be deemed inappropriate.

5.26 Client satisfaction with independent advocacy
Less than half the respondents (42%, n=70) reported thinking that their clients had found independent paid advocacy services satisfactory. 15% (n=25) of the nurses thought their clients had found the services unsatisfactory, and 43% (n=72)
reported either having no experience or being unsure. Opinions were evenly divided in all work areas.

<table>
<thead>
<tr>
<th>work area</th>
<th>satisfaction with paid independent advocacy services?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
</tr>
<tr>
<td>hospital</td>
<td>20</td>
</tr>
<tr>
<td>other residential</td>
<td>17</td>
</tr>
<tr>
<td>community</td>
<td>33</td>
</tr>
<tr>
<td>totals</td>
<td>70</td>
</tr>
</tbody>
</table>

Table 58: The influence of nurses' work area on their perception of whether or not clients have been satisfied with paid independent advocacy services

42% (n=20, hospital; n=17, 'other residential'; n=33, community) thought their clients did find partnership with independent advocates satisfactory, while 58% in each area (n=28, hospital; n=24, 'other residential'; n=45, community) either did not think clients found it satisfactory, had no experience or were unsure (table 58).

**Additional comments on question 2d – In cases where clients have experienced independent (paid or volunteer) advocacy, do you consider they have found it satisfactory?**

Several of the respondents were uncertain whether clients were satisfied with independent advocacy, mainly due to their clients’ lack of verbal communication skills. Despite the statistics, many of the nurses reported that, based on their experiences, client/advocate partnerships were very positive. Examples were given of successful outcomes to various service disputes and clients were reported to have gained self esteem and developed skills in relationship building. Other nurses cited the ‘extra voice’ which advocates gave to clients and clients having someone not compromised by service issues to fight for their individual rights.

Respondents who thought the advocacy relationship had not been positive usually based this on specific experiences. One had found a client’s advocate ‘hostile’ and several suggested that advocates lacked commitment, had their own agenda or were using the advocacy experience as a stepping stone to work. Respondents had found some advocates unwilling to accept advice based on the nurse’s
experience and knowledge of specific clients and one nurse suggested that the advocacy service was 'ideologically driven' and 'service led'. Some nurses had no experience of independent advocacy due to the lack of available services or long waiting lists which had led to clients losing interest before an advocate was found for them. One nurse explicitly stated that 'nurses advocate far more on behalf of people with learning difficulties' (4.7).

5.27 Clients' families as advocates
The penultimate question in section 2 asked respondents whether they thought clients' families could advocate satisfactorily for them.

<table>
<thead>
<tr>
<th>work area</th>
<th>can clients' families advocate satisfactorily for them?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
</tr>
<tr>
<td>Hospital</td>
<td>15</td>
</tr>
<tr>
<td>other residential</td>
<td>18</td>
</tr>
<tr>
<td>community</td>
<td>17</td>
</tr>
<tr>
<td>Totals</td>
<td>50</td>
</tr>
</tbody>
</table>

Table 59: The influence of nurse respondents' work area on their perception of whether clients' families can advocate satisfactorily for them

Only 27% (n=49) thought that they could. The largest percentage of nurses (36%, n=61) were unsure, 30% (n=52) thought they could not and 5% (n=9) had no experience. 28% (n=48) of the respondents to this question worked in hospital, 26% (n=44) in 'other residential' settings and 46% (n=80) in the community. Only 21% (n=17) of the community nurses thought that clients' families could advocate satisfactorily for them. The percentage of respondents reporting that clients families could advocate satisfactorily for them rose to 31% (n=15) of hospital nurses and 41% (n=18) of nurses working in 'other residential' services (table 59).

The relationship between respondents' work area and their perception of whether or not clients' families could advocate satisfactorily for them was analysed using chi square. The value of chi square was found to be significant at the 0.05 level ($X^2 = 4.436, \text{df} = 1$) and it was concluded that community nurses were significantly less likely to think clients' families could advocate satisfactorily for them than
nurses working in residential services (hospital plus 'other residential' units) (table 60).

<table>
<thead>
<tr>
<th>work area</th>
<th>Can families advocate?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
<td>no/no experience/unsure/not given</td>
</tr>
<tr>
<td>hospital/other</td>
<td>33</td>
<td>59</td>
</tr>
<tr>
<td>residential</td>
<td></td>
<td></td>
</tr>
<tr>
<td>community</td>
<td>17</td>
<td>63</td>
</tr>
<tr>
<td>totals</td>
<td>50</td>
<td>122</td>
</tr>
</tbody>
</table>

Table 60: The influence of nurses' work area on their positive perception of families as advocates

Additional comments on question 2e – Do you consider that members of clients' families can advocate satisfactorily for them?

The question 'Do you consider clients families can advocate satisfactorily for them?' attracted the highest number of additional comments from respondents. Many of these were unsure, some commenting that it depended on the issues, on individual families or on the particular needs and wishes of clients. Some respondents had experienced families advocating satisfactorily for clients in some circumstances but not in others. The majority of nurses commented that clients' families made unsatisfactory advocates for them. In some cases this was because families had lost touch with clients, or had only sporadic contact, and were felt to know very little about the client. Other reasons given included the supposition that close emotional ties were likely to restrict objectivity; families and clients experiencing conflicting interests, particularly around financial concerns; family members advocating for their own needs rather than the clients; and families treating their adult progeny with learning difficulties as an 'eternal child'.

Some nurses had very positive experiences of clients' families advocating for them and felt this was due to their long standing relationship and intimate knowledge of the clients. One respondent suggested that:

A lot of families have had to fight to be heard in the first place so they are not nervous of getting their relatives' views over.

(4.16)
Others argued that, while families could advocate satisfactorily for clients, they may need support to access consultants, educationalists etc. and perhaps also some assistance with determining the rights of their relative with learning difficulties in order to obtain the services they require.

5.28 Influence of advocates on service provision
The highest percentage (38%, n=65) of respondents thought that clients with access to some sort of external advocacy did get better services than those without. A slightly lower percentage (28%, n=48) thought not and 35% (n=59) were unsure (figure 16).

![Figure 16: Nurses' responses to the question 'Do clients who have an external advocate receive better services than those who do not?'](image)

**Additional comments on question 2f – Do you consider that clients who have an advocate get better services than those who do not?**

Very few respondents commented that clients who had an advocate did not get better services than those without. Two of those who did suggested that nurses/care managers were able to ‘provide [clients] … with a better quality of life and relay information to clients about services’ (1.42). One had had a negative experience with an advocate and another suggested that services were inconsistent everywhere, regardless of whether or not clients had advocacy representation. Nurses who were unsure argued that this depended on the attitude and experience of the advocate, but that advocates’ ability and willingness to ‘put up a good fight’ might lead to overall changes in the long term, with
subsequent benefits for clients. One nurse respondent who was unsure felt that:

Quality of training for advocates is an issue here.... often advocates do not understand the concept of 'capacity to consent' or whether clients understand the choices made or about how mental health problems can affect their decision making.

(4.20)

The majority of nurses who commented on this question thought that clients with an advocate were likely to get better services than those without, although some regretted this. One respondent argued that:

It seems an unfair system. In my experience the clients who are vocal and have family input and/or legal representation are also likely to have more advocacy input.

(4.27)

Another agreed, suggesting that clients:

who have an independent advocate do so because they are able to ask for one themselves and are therefore also capable of asking for better services.

(4.9)

Most respondents gave more mundane reasons. Variations on the old adage '(s)he who shouts the loudest gets the most' were quoted by many respondents, one adding that having an advocate 'reinforces client's wishes' (5.15) and another that services gave 'greater recognition if the client has an advocate' (5.16).

Analysis of section 3 – Education

Section 3 of the questionnaire asked nurses about their received education and also about their educational requirements concerning their advocacy role.

5.29 Received education
The first question asked nurses whether they had received any formal advocacy education. The highest percentage (49%, n=84) reported in the affirmative. 46% (n=80) had not received formal education and the remaining 5% (n=9) could not remember. Of the 165 nurses who gave their qualification year, 82 had received advocacy education. 50% (n=41) had qualified between 1986 and 1994 i.e. had followed the '1982' syllabus; 29% (n=24) qualified since 1995 and 21% (n=17) had qualified before 1985 i.e. prior to the introduction of the '1982' syllabus. Of the 75
respondents who had not received advocacy education 45% (n=34) had qualified before 1986, 31% (n=23) between 1986 and 1994 and 24% (n=18) since 1995. Only 8 nurses reported that they could not remember whether or not they had advocacy education. 25% (n=2) of these qualified before 1986, 62% (n=5) qualified between 1986 and 1994 and 13% (n=1) qualified after 1995 (table 61).

<table>
<thead>
<tr>
<th>qualification period</th>
<th>formal education in advocacy?</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>1960-1985</td>
<td>17</td>
<td>34</td>
</tr>
<tr>
<td>1986-1994</td>
<td>41</td>
<td>23</td>
</tr>
<tr>
<td>1995+</td>
<td>24</td>
<td>18</td>
</tr>
<tr>
<td>totals</td>
<td>82</td>
<td>75</td>
</tr>
</tbody>
</table>

Table 61: The influence of nurses’ qualification period on their receipt of formal education in advocacy

The relationship between nurses’ qualification period and their receipt of formal education in advocacy (table 62) was analysed using chi square. The value of chi square was found to be significant at the 0.01 level ($x^2 = 9.836$, df = 2). It was therefore concluded that respondents who had qualified in the period 1986-1994 were significantly more likely to have received formal education in advocacy than nurses qualifying before 1986 or after 1995.

<table>
<thead>
<tr>
<th>have you received formal advocacy education?</th>
<th>qualification period</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>yes</td>
<td>17</td>
<td>41</td>
</tr>
<tr>
<td>no/can’t remember/not given</td>
<td>36</td>
<td>28</td>
</tr>
</tbody>
</table>

Table 62: The relationship between nurses’ qualification period and their receipt of formal advocacy education (grouping no, can’t remember, unsure and not given for analysis)

Proportionally more nurses who had qualified between 1960 and 1985 received advocacy education at post qualification level (76%, n=13). Very few of these nurses (6%, n=1) received formal education in advocacy at both pre and post qualification levels. A higher proportion of those who qualified under the ‘1982’
sylabus received their education before they qualified (44%, n=18), and also reported receiving advocacy education at both pre and post qualification level (27%, n=11), and this was similar for those qualifying under the Project 2000 syllabus (pre-qualification=63%, n=15; pre and post qualification=29%, n=7) (table 63).

<table>
<thead>
<tr>
<th>level at which education received</th>
<th>qualification period</th>
<th>totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>pre-qualification</td>
<td>3</td>
<td>18</td>
</tr>
<tr>
<td>post-qualification</td>
<td>13</td>
<td>12</td>
</tr>
<tr>
<td>both</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>totals</td>
<td>17</td>
<td>41</td>
</tr>
</tbody>
</table>

Table 63: The relationship between nurses qualification period and whether they received advocacy education at pre or post qualification level

For the vast majority of nurses who had received advocacy education (87%, n=73), this was about several types of advocacy or advocacy in general. 5% (n=4) had received education specifically and only about nurse advocacy. 7% (n=6) had received education only about citizen advocacy and 1% (n=1) only about self advocacy (figure 17).

Figure 17: Nurses responses to the question ‘What was your advocacy education about?’
Additional comments on question 3a4 – Give brief details about what your advocacy education included

Thirty two nurses provided details of what their advocacy education had included. Two had experienced 'self directed' learning as part of degree courses and one reported having 'very general and basic training' (4.24). Most of the others had experienced a mixture of lectures, workshops and role play. One had received training specifically around sexuality issues, two had had talks from people with learning difficulties, as well as from advocates and lecturers, and one had attended a three day advocacy workshop which incorporated 'lectures, discussion, role play, talks by advocates and their clients and practical advice and education' (5.5).

5.30 Practical advice on how to advocate

A large majority of nurses (94%, n=161) thought there was a difference between learning about advocacy and learning how to advocate but almost half the respondents who had received advocacy education (41%, n=38) claimed that they could not remember whether or not they had received practical advice on how to advocate.

Additional comments on question 3b – Do you consider there is a difference between learning about advocacy and learning how to advocate?

All the nurses who commented on the question ‘Do you consider there is a difference between learning about advocacy and learning how to advocate' answered in the affirmative. Most respondents agreed that:

Almost everyone can be taught about advocacy, however, not everyone can act as an advocate.

(1.4)

Nurses cited the need for ‘people skills' (1.67), ‘communication skills, patience and time' (2.19) in order to advocate. Other necessities included the ability to convey ‘impartial and unbiased information and to measure the outcomes of advocacy attempts' (2.24). Several respondents commented that learning how to advocate is ‘much harder' than simply learning the theory and others pointed out that nurses need to be aware that they might ‘open up a variety of issues, both ethical and professional' (6.2) when they put theory into practice. One respondent had found
his/her first experience of ‘facing an authority’ in an advocacy situation ‘quite daunting’ (1.66) and many respondents agreed that nurses ‘need formal instruction on how to advocate properly’ (1.54).

5.31 Required education

<table>
<thead>
<tr>
<th>grade</th>
<th>work area</th>
<th>would advocacy education be useful to nurses?</th>
</tr>
</thead>
<tbody>
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<td></td>
<td></td>
<td>yes</td>
</tr>
<tr>
<td>D</td>
<td>hospital</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>2</td>
</tr>
<tr>
<td>E</td>
<td>hospital</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>other residential</td>
<td>24</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td>17</td>
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<tr>
<td>F</td>
<td>hospital</td>
<td>2</td>
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<tr>
<td></td>
<td>other residential</td>
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</tr>
<tr>
<td></td>
<td>community</td>
<td>19</td>
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<tr>
<td>G</td>
<td>hospital</td>
<td>8</td>
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<td></td>
<td>community</td>
<td>36</td>
</tr>
<tr>
<td>totals</td>
<td></td>
<td>162</td>
</tr>
</tbody>
</table>

Table 64: Influence of grade and work area on nurses responses to the question ‘Would advocacy education be useful to nurses?’

Asked if advocacy education would be useful to nurses, (95%, n=162) of respondents claimed that it would. Only 1 (E grade, community) nurse disagreed. Of the 4% (n=7) respondents who were unsure, 2 worked in hospital (1 D grade and 1 E grade). 1 (E grade) nurse worked in other residential services and the remaining 4 nurses (2 E grade, 2 G grade) worked in the community (table 64).

Responding to the question ‘Who do you think should provide advocacy education?’ 80% (n=133) of respondents thought advocacy education should be provided by a variety of people. Only 9% (n=15) thought lecturers should be solely responsible and 86% (n=12) of these were D and E grade nurses. 3% (n=5) thought citizen advocates should be responsible and a similar percentage thought people with learning difficulties should teach advocacy to nurses. The remaining 5% (n=8) thought advocacy education should be provided by independent (paid) advocates (table 65).

202
who should provide advocacy education?

<table>
<thead>
<tr>
<th></th>
<th>number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>citizen advocates</td>
<td>5</td>
<td>3.0</td>
</tr>
<tr>
<td>people with learning difficulties</td>
<td>5</td>
<td>3.0</td>
</tr>
<tr>
<td>independent (paid) advocates</td>
<td>8</td>
<td>4.8</td>
</tr>
<tr>
<td>lecturers</td>
<td>15</td>
<td>9.0</td>
</tr>
<tr>
<td>a variety of people</td>
<td>133</td>
<td>80.1</td>
</tr>
</tbody>
</table>

Table 65: Nurse respondents’ suggestions as to who should provide advocacy education

Additional comments on question 3c1 – If advocacy education would be useful to nurses, who should provide it?

Several respondents who provided additional information on who they thought should provide advocacy education were specifically against lecturers taking this role. One nurse explained that in her/his view lecturers ‘only learn from citizen advocates, independent advocates and people with learning difficulties’ (2.3) implying that these people could therefore provide advocacy education first hand instead. The comments of all the nurses emphasised that their preference was for practical, rather than solely theoretical, education and that this should be provided by:

A combination of lecturers, citizen advocates, people with learning difficulties and independent (paid) advocates to provide an overview of advocacy (lecturers); and then real life examples of what advocacy is in practice.

(1.21)

One nurse added a coda to her/his choice of people with learning difficulties as teachers of advocacy, suggesting that they would ‘need to have the necessary skills to avoid tokenism’ (6.3).

Additional comments on question 3c2 – If you think advocacy education should be provided, what should it include?

Ninety nine nurses responded to the question ‘What should be included in nurses’ advocacy education?’ The responses were split between those who argued for a mainly theoretical education, those who proposed only practical training in
advocacy and those who favoured a mix of both theoretical and practical education. One nurse gave a response which was typical of those who felt advocacy education should be mainly theoretical, stating that education should be:

All about advocacy, legal framework, how it fits into our role as nurses, different forms of advocacy, where to access advocacy services in your area, exploration of nurses' attitudes and views and how these influence our ability to advocate for someone else.

(3.6)

Most respondents who argued for a mainly theoretical education mentioned definitions and also the legal and ethical aspects of advocacy. Several suggested that the historical background to advocacy services should be included, while others proposed that advocacy education should include exploration of clients' rights to benefits, residential and resource issues and 'appropriate adult' training within the definition of the Mental Health Act. Conflict resolution was mentioned as a possibility by several respondents, as was the use of risk assessments to promote new situations and experiences for clients.

Many of the nurses who opted for a mainly practical education in advocacy suggested using the case study approach, where people with learning difficulties could discuss their experiences with nurses, explore what they want from advocacy and review the ways in which they think nurses could advocate for them. Role play was another popular suggestion, possibly in conjunction with advocates and their clients talking about their advocacy experiences and the 'benefits/pitfalls/conflicts and other practical issues involved' (2.23). Several respondents suggested that practical training in advocacy required time and help with self reflection on the part of potential nurse advocates. Others argued for assertiveness training and education in counselling skills appropriate to advocacy, while one nurse suggested 'debating skills' would be an asset to practical education in advocacy (4.4). Possibly with their responsibilities as NVQ assessors in mind, some nurses thought they should receive information on how to teach advocacy skills to others.

The majority of nurses proposed that advocacy education should include both theoretical issues and practical training. Many nurses felt that education should
address the difficulties surrounding advocacy for clients with non verbal or alternative communication skills. One respondent covered the most prevalent issues in her response, arguing that advocacy education should include:

Nature of advocacy. Different types of advocacy. Role of nurse as advocate. How to advocate. Legal aspects. Most importantly, user involvement and how to ensure/help people to be empowered. Different ways of speaking.

(4.23)

Other suggestions included how to make a realistic assessment of the expectations of nurse advocacy; 'top tips'; 'who to approach' (4.13) and when it would be more appropriate for nurses to bring in independent advocacy services for clients.

5.32 Should advocacy education be at pre or post qualification level?
Of the 161 respondents who gave valid answers to the question 'should advocacy education be at pre or post qualification level?' 31% (n=50) had qualified before 1986. Of these 24% (n=12) thought advocacy education should be at pre qualification level, only 4% (n=2) thought it should be at post qualification level, 8% (n=4) were undecided and 64% (n=32) opted for education at both pre and post qualification levels (table 66).

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<thead>
<tr>
<th>qualification period</th>
<th>should advocacy education be at pre or post qualification level?</th>
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<tr>
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Table 66: The effect of nurse respondents' qualification period on whether they think advocacy education should be at pre or post qualification level

6% (n=4) of the respondents who qualified between 1986 and 1995 thought advocacy education should be at pre qualification level and no-one thought it should be specifically at post qualification level. 3% (n=2) were undecided but 91% (n=63) thought education in advocacy should be at both pre and post qualification levels.

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Just 2% (n=1) of the nurses who qualified post 1995 thought education in advocacy should be at pre qualification level and a further 2% (n=1) were unsure. 10% (n=4) opted for post qualification level education in advocacy and 86% (n=36) thought it should be at both pre and post qualification levels.

5.33 The Human Rights Act (1998)

62% (n=104) of nurses responded in the affirmative to the question 'Have you received education in the Human Rights Act (1998)?' 25% (n=44) had not and 13% were unsure. 36% (n=38) of those who had received education in the Human Rights Act were E grade nurses. Only 15% (n=15) were D grade nurses. 17% (n=18) were F grade nurses and the remaining 32% (n=33) were G grade nurses. 23% (n=25) of the nurses who had received Human Rights Act education worked in hospital, 24% (n=25) worked in 'other residential' units and the largest proportion (53%, n=54) worked in the community (table 67).

<table>
<thead>
<tr>
<th>Work area</th>
<th>grade</th>
<th>have you received education on the Human Rights Act 1998?</th>
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<tr>
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Table 67: The influence of nurse respondents' work area and grade on their answers to the question 'Have you received education on the Human Rights Act (1998)?
Additional comments on question 3d – Have you received education on the Human Rights Act (1998)?

Only two nurses gave additional comments to the question ‘Have you received education on the Human Rights Act 1998)?’ Both replied in the affirmative and both stated that their education had been self directed by ‘information sheets’ although one had also received information on the Human Rights Act ‘at meetings’ (5.15).

A large majority of respondents (96%, n=157) thought that nurses should receive education on the Human Rights Act (1998). The only nurses who did not or were unsure were 1 D grade nurse working in ‘other residential’ services, 3 E grade hospital nurses, 2 E grade nurses working in ‘other residential’ services and 1 F grade community nurse.

Additional comments on question 3d1 – Do you consider that nurses should receive education on the Human Rights Act (1998)?

Twenty nurses provided additional comments on the question ‘Do you consider that nurses should receive education on the Human Rights Act (1998)?’ Nineteen of these argued that such education should be provided for nurses. Comments included that this was ‘becoming a vital issue’ (1.52) ‘essential to practice’ (1.54) and ‘fundamental’ (4.7). One nurse considered that;

It will give [nurses]... more of an insight into learning disability needs, what people are entitled to etc. and how these can be achieved. 
(5.2)

Another respondent argued that Human Rights education should be provided for all nurses ‘as people with learning disabilities access other generic services’ (2.2). Possibly thinking around the conflicts of interest which may beset the nurse advocate one nurse suggested that Human Rights Education would be useful ‘if only to allow us to advocate for ourselves!’ (1.66). Two respondents proposed that they needed education in clients’ rights so that they could pass this on to others and another suggested that Human Rights Act education should be combined with ‘education in citizenship and the rights and responsibilities inherent in being a citizen’ (5.1). Two nurses proposed that nurses ‘have an obligation to update self
and help the service to educate’ (4.23) and one remarked that (s)he received ‘regular updates/refreshers’ on the Human Rights Act. Similarly one respondent suggested that ‘information around the Human Rights Act could be provided at team level through presentations by colleagues’ (1.2).

Only one respondent was unsure whether education on the Human Rights Act would be useful to nurses. Thinking more in terms of recrimination than the possible preventative aspects of such education (s)he argued that:

The legislation appears ineffective and is limited owing to victims need to provide clear evidence of breach/discrimination (1.7).

The recriminatory possibilities of the Act were also considered by a respondent who proposed that education in the Human Rights Act should be:

ongoing as our understanding of human rights increases and court cases bring up issues which have not previously been considered (4.20).

Analysis of section 4 – The advocacy role of the learning disability nurse

5.34 The importance of the advocacy role
92% (n=158) of respondents thought nurses’ advocacy role important only 2% (n=3) disagreed and 6% (n=11 were unsure.

Additional comments on question 4a – ‘Do you consider the advocacy role of the learning disability nurse is important in the present socio/political economic climate of nursing?’

A very high number of respondents made additional comments about the perceived importance of the advocacy role of the learning disability nurse. Only one of these did not consider the advocacy role important, arguing that nurses were ‘biased in their approach’, and that ‘advocacy could be spoiled by the context we work in and are trained by’ (5.14). Five nurses were unsure whether or not the advocacy role was important for nurses. One stated that (s)he had ‘no training and inadequate information’ to make a decision (1.14). Another was ‘unsure whether nurses are the appropriate people to provide’ advocacy (1.46), but did not
enlarge on this. Of the remaining three, one argued that nurses were appropriate advocates for clients ‘where the majority of needs are health’ but that otherwise ‘much better [advocacy]... comes from paid advocacy services’ (5.16). One of the other two mentioned possible conflicts of interests with the nurse advocate’s employer, while the other proposed that:

Frequently the role of the nurse conflicts with the clients wishes. Advocacy from an independent/ outside source can resolve issues without damaging therapeutic relationships.

(2.8)

Most of the respondents who thought the advocacy role was important in the current climate of learning disability nursing gave some reason for their opinion. In many cases these centred on the long term relationship and consequent trust between clients and learning disability nurses; the nursing goal of assisting clients to reach their potential; the vulnerability of clients and nurses’ specific training in the care and support of people with learning difficulties.

Two respondents saw advocacy in terms of ‘giving an added dimension’ to their role (2.9) and thus assisting nurses to ‘fight for their rights and their role as learning disability nurses’ (5.19). In this context, several nurses mentioned being at the forefront of learning disability services and therefore being ‘in a powerful position to make recommendations involving people with learning difficulties in all aspects of their lives’ (3.6). Empowerment was frequently cited, particularly in the context of supporting clients in Person Centred Planning to make choices about their lives and to overcome prejudices within their communities. One nurse suggested that ‘clients have access to a whole range of different services/service providers and methods of financing care including Direct Payments’ (4.13) and that advocacy was increasingly important as clients have ‘more political clout’ and may need support to use this (4.13). Other nurses commented that, although care in the community is ‘philosophically sound’ it may be ‘environmentally and socially fragile’ (4.23) and those ‘who have been institutionalised for years may find even positive changes stressful and challenging’. In these situations, nurses know ‘their clients best of all, and [can] advocate for them on a level and at a pace that they are able to cope with’ (4.19).
Despite the positive vein of many of these comments, several nurses mentioned the need for caution by nurse advocates, due to conflicts of interests with their employer, with bureaucratic organisations and with clients' families. Many respondents thought that, as a principle, nurses should advocate for clients in some situations and an independent advocate should be brought in to advocate in others. Many nurses pointed out that this would be an ideal as 'most people with a learning disability do not have an advocate and are unlikely to get one' (1.73), or that 'it is a small vocal minority that receives a service from independent advocates. Most people get nothing' (4.2).

The difficulties for those clients who do not speak were emphasised by many nurses who thought the advocacy requirements of these clients were particularly important. One nurse argued that:

I'm sure that the role of the nurse advocate increases in direct proportion to the ability of clients, i.e. the less able the client, the more he or she depends on the nurse/carer to advocate for them.

(2.20)

Nurses are frequently 'the only ones to speak up for clients' (1.48). They keep abreast of constantly changing services and many 'advocate on a daily basis both formally or informally, although the role probably goes unrecognised' (1.37). Several respondents thought their advocacy role was particularly important in the present climate of 'rationing' of health care, arguing that clients 'need someone to help them gain the necessary healthcare that they are entitled to'. (1.70). In this context, one nurse proposed that:

Part of our role is helping social integration. Access to health care is often facilitated by nurses. Links between us and primary and secondary health providers are paramount for our clients.

(1.66).

Advocacy was also considered to be important 'in other fields of nursing, but appears to be lacking' (1.11). Two nurses summarised the reasons why advocacy could be considered an important aspect of the role of the learning disability nurse:

People with learning disabilities have always been marginalised and although societal views are changing and, ideally, nurses should not
have to perform an advocacy role, we are often the only influential people in our service users' lives.  

Learning disability nurses are the only professionals that receive in depth training in the care and support of people with learning difficulties. This knowledge, experience and insight gives them a unique vantage point, putting them in a prime position to support and uphold the views of the client group with whom they work and making them ideally suited to advocacy.

5.35 Changes in the advocacy role
The last question asked respondents whether their advocacy role had changed since they qualified.

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Table 68: The influence of nurses' grade and qualification period on their answers to the question 'Has the advocacy role changed since you qualified?'

Of the 170 respondents who answered the question 60% (n=102) gave an affirmative answer, 25% (n=43) thought the role had not changed and 15% (n=25) were unsure. 163 nurses gave their grade and qualification period. Of these, 32% (n=52) qualified between 1960 and 1985, 42% (n=68) qualified between 1986 and 1994 and 26% (n=43) qualified in or after 1995. 15% (n=7) of the nurses who qualified between 1960-1985 thought their advocacy role had not changed or were unsure. Neither did 48% (n=32) of those who qualified between 1986 and 1994. 60% (n=26) of respondents who qualified after 1995 also did not think their advocacy role had changed (table 68). Only 13% (n=22) of respondents were D
grade nurses of whom 72% (n=16) had qualified since 1995. 81% (n=13) of these thought their advocacy role had changed since they qualified (table 68).

Additional comments to question 4b – ‘Do you consider the advocacy role of the learning disability nurse has changed since you qualified?’

Over seventy nurses responded to the question ‘Do you consider the advocacy role of the learning disability nurse has changed since you qualified?’ Six of these had been qualified for less than a year and did not consider their advocacy role had changed in that time. Eight had been qualified for over twenty years and gave this as their grounds for thinking that the advocacy role had changed, without expanding on their reasons. Nurses who argued that their advocacy role had not changed proposed that the principles of advocacy were the same even if the specifics had altered. Despite this many of these respondents supplemented their replies with comments. These included awareness that ‘the Human Rights Act has supported and underlined the need for advocacy for people with learning difficulties’ (2.16) and an appreciation of the increased financial, political and legal constraints on advocacy. Some of the nurses who declared themselves ‘unsure’ whether the advocacy role had changed had taken on a different nursing role in the period since they qualified, and felt that this might be the reason why their advocacy role had changed, rather than any fundamental shift in nurses’ advocacy role. Others felt that their own advocacy role had not changed despite changes in the emphasis and attitudes to advocacy of those around them. One nurse described advocacy as being a ‘hot topic’ when she qualified, but now seeing it as ‘part of my everyday job’. She accepted this despite the inevitable ‘conflict’ because ‘access to independent advocacy is extremely difficult’ (3.3).

The majority of nurses who commented thought their advocacy role had changed since they qualified. For many of these the major change had come with the closure of institutions and the consequent resettlement of clients into small residential units in the community. Nurses had different attitudes to the effect this had on their advocacy role. One respondent argued that:

Nurses are no longer protected within institutions. Their work is done in a much wider variety of venues and with individuals in their own homes. Expectations of what people with learning disabilities can
achieve are growing and nurses have new responsibilities in facilitating and embracing that growth.

While another proposed that:

Hospital policies protected people with learning difficulties. Now we have moved on and advocacy skills are more essential when working to integrate clients into community settings. The political and financial aspects of service provision have become more prominent, hence the advocacy role of the individual central to departmental policies has increased.

Issues around resources and fear of litigation were frequently mentioned as provoking change in the nurses' advocacy role, as was the increased awareness by clients of their rights which are 'emphasised but not always respected' by services or society in general (5.8). Many of the respondents mentioned the change in their role from caring for clients, to enabling and empowering them, and some thought this had led to a breakdown in barriers between staff and clients, with nurses more prepared to respect the wishes of their clients while 'promoting them as valued members of society' (1.74).

Several community nurses mentioned the naissance of multi disciplinary community teams, in which the nurse:

Has a central role in negotiation on behalf of the clients, but not necessarily in advocating for them.

Others felt that they did still advocate for clients but that the role had altered with changes in the way in which community nurses are expected to work. One community nurse commented:

I think most nurses recognise advocacy as essential. However, changes in structures of teams and ways of working mean we are less involved than previously. Team changes mean shorter pieces of work on focused referral issues i.e. we work on a particular problem for a short period of time (in theory anyway!). This means we get less involved advocating for the 'bigger picture'.
The advent of multi disciplinary community teams was also felt to have led to advocacy responsibilities being shared between health and social care staff (5.15) with nurse advocates being in a position to either facilitate or provide appropriate services within either agency, and ensuring these are satisfactory.

Increased availability of independent advocacy services was also suggested as causing a change in the advocacy role of learning disability nurses. One nurse respondent commented that:

The nurse was often the only advocate. Now there are different systems. Advocacy is still at the core of nursing but crucially we can check our judgements, draw in other agencies to ensure proper representation. In theory we can have a stronger voice.

(4.23)

Another respondent was more cynical about this development. Possibly highlighting the lack of training and experience of some independent advocates, (s)he commented that:

In my place of work there's more [independent] advocates than ever, yet some major issues are not being dealt with. They are happy to go on trips to view new houses, but tend to give up easily regarding problems with benefits or other 'thorny' issues.

(4.27)

Additional comments on the advocacy role of the learning disability nurse

Fourteen nurses made additional comments on the advocacy role of the learning disability nurse. Several of these argued that they needed more education, both theoretical and practical. As one nurse remarked:

We are constantly advocating for our clients within our role as nurses. We need to be able to do this correctly and to the best of our ability. Therefore training, discussion and knowledge should be integral to our work.

(1.63)

On the same theme, one nurse commented that education and training in advocacy should not be confined to qualified nurses (1.52), and another suggested that nurses in all fields would benefit, as would nursing assistants and support workers (1.11).
Education was also mentioned by nurses concerned about the lack of understanding of nurses' role by independent advocates and vice versa. One nurse had experienced 'advocates 'taking over' and making decisions for the client in the workplace without discussing the implications with the nurse in charge' (5.19). Another commented that (s)he had been subjected to 'bad experiences of advocacy in the hospital setting' and suggested that:

We need to work together as opposed to 'them' and 'us' which, unfortunately, has been the situation in the past. Education is surely the way forward for all concerned to have an understanding of each others' roles and to respect those roles.

(1.1)

One nurse proposed that education would demonstrate how advocacy could lead to 'valuing and empowerment of people with learning disabilities' (4.22), but another argued that in order to make the most of the advocacy role:

One needs to develop assertiveness to challenge the political climate that has engulfed the NHS... This develops with experience and a genuine desire to fight injustices in individual's lives.

(1.41)

Several respondents commented that 'ideally nurses wouldn't have to perform [the advocacy] role' (5.10) but felt that they had no alternative because of the lack of accessible independent advocates with time to build up 'trusting relationships' with clients (2.17). However others felt that 'advocacy led Person Centred Planning should be an excellent initiative' (4.23) and would serve to encourage clients to make choices about their lives while at the same time 'enhancing the advocacy role' of learning disability nurses (4.23).

5.36 Evaluation of the questionnaire survey
I have already discussed the problems which beset the distribution of the questionnaires, partly due to the lengthy period of time involved in registering the research with some of the individual Health Trusts employing learning disability nurses in Wales. Limitations on the time available to complete the research and my use of a senior manager in each Trust to distribute both questionnaires and reminder letters meant that I could only send one reminder to each of the targeted respondents. As the study progressed, I also became aware that some of the
questionnaires had not been distributed until after the final date given for their completion had passed and others were distributed to nurses whose grades did not fall within the range of the intended population (i.e. D-G). Despite these problems, the survey achieved an overall response rate of 37%, not unusually low in a postal survey (Chiu and Brennan, 1990), and well within the bounds deemed to be both acceptable and representative of the target population (Association of Law Teachers, 1993). Cummings et al (2001) propose that if the relevant characteristics of respondents and non respondents are similar, it is possible to feel confident about accepting the results of studies with comparatively low response rates. Thus, although I had no means of assessing the data from the returned questionnaires for bias, as the survey was addressed only to qualified learning disability nurses, and there was no statistically significant difference in response rates from any single grade or work area, the results seemed likely to be representative of the views of the population of learning disability nurses in Wales.

In designing the questionnaire, I had been anxious to give priority to the definitions of advocacy acquired from data obtained through focus groups with people who have learning difficulties. The first question thus offered thirteen definitions, the majority of which had been obtained from the stage one groups, for relevance scaling by respondents. With hindsight, two similar definitions could have been amalgamated, possibly resulting in more definite responses. During analysis of the data I also felt, without concrete evidence, that a small number of nurses ticked the same alternative for every definition without giving their answers adequate consideration. Had this question been located between questions which demanded more thought, I considered it possible that these respondents might have answered differently.

Because I had only been able to send out questionnaires as I was notified that individual Trusts had registered my research, the completed questionnaires were returned over a period of several months. This was not totally negative. It enabled me to enter the data into SPSS as the questionnaires were returned rather than dealing with a large amount of data at the same time. Despite my initial reservations, analysis using SPSS proved much less difficult and more interesting than I had anticipated and the quantitative data yielded many points of
interest. Many respondents had also written comments on some of the questions and these, together with the quantitative data, both verified and expanded the themes generated by analysis of data obtained in stages one and two of the research.

Overall, the postal questionnaire survey proved a very useful adjunct to the study. It enabled the collection of data from a much larger population of nurses than I could have interviewed in the time available and allowed me to verify and expand the emergent themes and to consider explanations for them. It also raised a satisfactory degree of interest in the study from several of the Health Trusts involved, which may eventually be translated into action concerning nurses' educational and training requirements in the field of client advocacy.

5.37 Conclusions and summary of themes for discussion
The mass of data from the questionnaire survey both expanded and enhanced the information gained from stages one and two of the study. Emergent themes from the earlier sessions were substantiated and some new themes became apparent. I now briefly summarise some of the main issues, before presenting a project map of the themes which warrant more detailed discussion in the following chapters of this work.

Almost 99% of respondents considered the majority of the given definitions of advocacy relevant or extremely relevant to their current practice. They were significantly more likely to score the nurse or client/supporter generated definitions in this way than those provided solely by people with learning difficulties. Definitions concerning advocating for the 'rights' of either individual clients, or people with learning difficulties generally, were consistently reported as relevant or extremely relevant, but may have been outside the experience of most of the stage one participants. Conversely, the 'community presence' definitions, seen as crucial to improving their quality of life by participants with learning difficulties were scored consistently low by nurses.

Most of the nurses in the stage two groups had mentioned 'speaking for clients' as an advocacy activity, but with the proviso that this was only in the context of
interpreting clients wishes. This was confirmed by the questionnaire data in which there was a highly significant association (p=0.001) between the definitions 'speaking for clients' and 'interpreting for clients'. Possibly reflecting the organisation of their lives by others which tends to be the norm for people living in residential services, community nurses were significantly more likely than nurses from the latter to consider it extremely relevant to ensure that clients have adequate understandable information. Conversely, they were less likely to both think clients' families could advocate satisfactorily for them, and to consider a good relationship with carers relevant or extremely relevant.

Nurses were significantly more likely to advocate for health care than for the socially oriented alternatives suggested on the questionnaire, with key worker responsibility carrying a particularly high likelihood of this occurring. Advocating concerning problems with day services attracted the highest affirmative scores amongst the social options. Nurses showed an awareness of different levels of advocacy, some suggesting that they would advocate for 'daily living' concerns but enlist the services of independent advocacy for 'more delicate' issues. Approximately half the nurses acknowledged the potential problem caused by unequal power relationships between nurses and their clients.

Long term relationships, seen as crucial to successful advocacy partnerships by people with learning difficulties, assumed much less importance for nurses. This was particularly so for nurses working with clients who have the whole range of communication skills. Some nurses suggested that long term relationships could hinder objectivity and thus obstruct advocacy. Many nurses also stressed the need to maintain a professional relationship with clients.

Data illustrated awareness by nurses of the problems which may occur in advocacy relationships. Conflicts of interest with employers, clients' families and independent advocates were mentioned, with key worker responsibility holding a significant likelihood of these occurring in the advocacy context.

Independent advocacy services were not available in all areas, although clients living in hospital were significantly more likely than others to have access to
(specialist) paid independent advocates. Nurses reported a whole range of attitudes to independent advocates, some very positive and others demonstrating signs of overt hostility. Nurses were uncertain about the relationship of citizen advocates with their clients, particularly where ethical issues such as client confidentiality became a concern. Despite their reservations, most nurses would encourage their clients to have a citizen advocate and/or to join a self advocacy group, where one was available. Nurses would also refer clients to independent (paid) advocacy services, although most, but not all, expressed dissatisfaction with these provisions.

Whether or not nurses had received advocacy education depended significantly on their qualification period. A very large majority thought advocacy education would be useful and nurses expressed many ideas as to what it should include, when it should take place and who should provide it. Respondents suggested that all nurses, rather than just learning disability nurses, would benefit from advocacy education, as would unqualified nursing assistants. Some nurses expected to teach advocacy to the latter and required appropriate training to do this. Many nurses had received education in the Human Rights Act, but felt this should be updated regularly. The vast majority of nurses thought their advocacy role important, a small number suggesting that it would enhance their role as nurses in addition to benefiting clients.

Changes in the nurses’ advocacy role reflected new patterns of services. Nurses mentioned those relating to the resettlement of clients into small residential units; the naissance of multi disciplinary teams; the move from ‘caring’ for clients to ‘empowering’ them and the resource led ‘situation specific’ referral patterns experienced by community nurses. Nurses acknowledged there were more independent advocates available but were somewhat cynical about this development. All respondents accepted that they have an advocacy role for their clients and many felt that this was an absolute duty in some situations.

The project map (figure 18) summarises and illustrates the main points from all three stages of the research. I shall discuss these in more detail in the following chapter.
Figure 18: Project map illustrating main points from stages 1-3 of the research
Chapter six

Findings, discussion and evaluation of methods.
6.1 Introduction

In the previous chapter, I presented the findings from the survey which completed the empirical stages of this study. Analysis of the survey data confirmed and expanded themes from stages one and two of the research and also revealed new areas of interest to the study. Respondents indicated that they were 'pro' advocacy and most were accustomed to taking on the advocacy role for their clients. Their definitions of advocacy were not always in accord with those of people with learning difficulties, although none of the 173 nurses who completed questionnaires found all the definitions obtained through the stage one focus groups not at all relevant to their current practice. One of the objectives of the research had been to investigate nurses' received education and their requirements for education, support and training in advocacy. These were considered in detail and confirmed as of great import to informants in the study. The chapter concluded with a project map illustrating the main themes which had emerged from the qualitative and quantitative stages of the research into the advocacy role of learning disability nurses (figure 18).

These themes are interwoven throughout this chapter which brings together data from the three empirical stages of the research with relevant literature and occasional reflections on my own nursing experience. Literature relating to grounded theory has already been discussed (chapter 2) including that elucidating Clarke's (2003) post modern situational analyses (section 2.6), used extensively in this research. Clarke's method facilitates multisite research and projects can include field-notes and literature as specific sites (Clarke, 2003). Accordingly, although literature specifically concerning advocacy and learning disability nursing is sparse, published texts pertinent to the main themes have been used as research sites for discussion within this chapter. My literature searches involved the electronic data bases Assia, Cinahl, Embase and Medline, using key words relevant to the themes under discussion, for example 'advocacy', 'people with learning difficulties/disabilities', 'conflict of interests' and 'teaching advocacy'. As attitudes and opinions change rapidly in the field of learning disabilities I generally searched only the five years between 1999 and 2004, although I have referenced earlier publications, often accessed through the 'snowball' effect of following up.
apposite works referenced in contemporary articles. In addition some texts were accessed via library catalogues and others recommended to me by tutors, friends and colleagues.

The chapter begins with a short résumé of my use of situational analysis and mapping before I demonstrate the similarities and differences in ways in which people with learning difficulties and learning disability nurses define advocacy. I emphasise the importance of advocacy support for people with learning difficulties, either in the form of encouragement and assistance to self advocate or from someone who might advocate for them. I then consider the problems inherent in these activities before discussing independent advocacy services in the context of both their availability and the attitudes to them of learning disability nurses. I reflect on the advocacy education received by nurses in the study before considering their requirements for education, ongoing support and training in advocacy and assessing the importance given by nurses to their advocacy role. The chapter continues with some reflections on the methodology and methods used in this research before concluding with a project map which summarises the key concepts revealed in this research into the advocacy role of learning disability nurses.

6.2 Using situational mapping and analysis
Munhall (2001) argues that:

Symbolic interactionism provides the philosophical foundations for grounded theory and guides the conduct of the research
(Munhall, 2001.211)

She suggests that the task of grounded theorists is to ‘discover and conceptualise the essence of complex interactional processes’ and to construct a theory which is ‘an entirely new way of understanding the observations from which it is generated’ (Munhall, 2001.212). Clarke (2003.558) expands this assessment by taking a post-modern stance against a single, over riding supposition and proposing that there is seldom one ‘substantive and formal’ theory which will explain a social process. Following this philosophy, as the research advanced, I progressively moved away from the prescriptive, reductionist approach to grounded theory, implied by Munhall and recommended by Strauss and Corbin (1998), and
increasingly used Clarke's (2003) situational analyses to explain the diverse complexities of the advocacy role of learning disability nurses.

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Figure 19: Situational Map - Exploration of the Advocacy Role of Learning Disability Nurses

Clarke proposes that the goal of situational mapping:

... is first to descriptively lay out as best one can all the most important human and non human elements in the situation of concern of the research broadly conceived

(Clarke, 2005 in press)
She suggests that abstract situational maps should ‘include all the analytically pertinent human and non human material and symbolic discursive elements’ of a particular situation as framed by those in it and by the researcher. I found this advice useful. Beginning with a ‘messy’ version, after initial coding of the focus group data from people with learning difficulties using NVivo, I randomly ‘mapped’ all those elements which seemed relevant to my exploration of the advocacy role of learning disability nurses. I persisted with this exercise as the research progressed; supplementing my original map with new elements resulting from the coded data from the focus groups with learning disability nurses and from the questionnaire data in stage three. The resulting map contained those elements which were conspicuously relevant to my study. These were organised into an ordered version of the situational map (figure 19) and served as a basis for my analytical thinking around the main questions addressed in the research.

Clarke (2005) argues that:

\[\text{....representing all positions on their own terms is a democratising move, a \textit{politics of the acknowledgement of presence} instead of a fascist denial and repression of diversity} \]

(Clarke, 2005 in press, italics in original)

While adhering to the philosophy of grounded theory, I realised that there would inevitably be multiple positions and contradictions rather than any single ‘truth’ concerning the advocacy role of learning disability nurses. In order to acknowledge rather than repress these and to give voice to some of the many informants in the study, I used positional maps to represent their different views. These maps:

\[\text{...seek to represent the full range of positions on particular issues. [They] ...allow multiple positions and even contradictions to be fully articulated.} \]

(Clarke, 2003.560)

In this discussion I use positional maps to illustrate the range of opinions about certain concepts articulated by many informants in the study. They offer a ‘snapshot’ of these views which can be pursued in more detail in the text of this
and the preceding chapters, and which contribute to a greater understanding of the advocacy role of learning disability nurses.

6.3 Definitions of advocacy
The starting point for my exploration of the advocacy role of learning disability nurses was a comparison between the concept of advocacy as understood by people with learning difficulties and of the same concept defined by learning disability nurses. The focus groups with participants with learning difficulties produced a limited number of outright definitions of advocacy but, as the sessions progressed, many different, although rarely mutually exclusive, understandings were revealed. A search of the literature, using the search terms ‘advocacy definitions’ and ‘learning difficulties/disabilities’ had failed to produce any definitions of advocacy generated directly by people with learning difficulties in the period from 1999 to 2004. However, a search of various self and citizen advocacy websites had generated eleven different definitions of advocacy, all of which confirmed or were similar to those definitions obtained through the focus group sessions. All definitions from the stage one focus groups had been verified by the participants before being included in the subsequent sessions with learning disability nurses and the questionnaire survey.

Nurse participants in the stage two focus groups, in addition to discussing the definitions proposed by people with learning difficulties, some of which were rejected as irrelevant by some nurses; expanded the list of definitions to include others. Some of these were of a ‘professional to professional’ nature, as for example, ‘enabling things to happen for clients’ and ‘promoting the rights of people with learning difficulties’; and although these were not expressly discussed by people with learning difficulties, they had been mentioned obliquely and were of obvious import. They were thus included in the questionnaire survey. Advocacy defined as ‘best interests’, was less explicit and, being seldom overtly articulated, was not included in the questionnaire. Nonetheless, as it was integral to several lengthier definitions given by nurses and also featured in the very limited literature concerned with advocacy in learning disability nursing (Blackmore, 2001) it warrants further discussion in this chapter.
Of the thirteen definitions of advocacy included as the first question in the survey, eight had been the result of discussions between participants with learning difficulties themselves and three had been generated during interactions by participants with learning difficulties and their supporters in the focus group sessions. The remaining two had resulted from discussions in the focus groups with nurses (table 19). Respondents to the survey were found to be significantly more likely to consider the nurse and nurse/supporter generated definitions as relevant to their practice than those definitions resulting directly from interactions between the participants with learning difficulties (p=0.01) (section 5.15).

Power, empowerment and advocacy are closely associated and Gilbert (1995.867) proposes that if nurses are to empower their clients they must realise that they themselves are the products of power. They also exercise power through ‘the social processes and supporting discourses whereby different categories of need are established’, and according to which they develop responses to particular situations. Gilbert refers to the work of Lukes (1974), whose ‘radical view’ of power stresses the importance of ways in which power operates to prevent conflict arising. Exemplifying this, nurses described as important ‘encouraging their clients to make their own decisions’, but also discussed withholding information which would make these decisions problematic, either for the nurse or for the other clients within the setting. Thus nurses tended to view advocacy as more relevant when the wishes of the clients could be compartmentalised into ‘categories of need’ (Gilbert, 1995) which complied with their view of what was suitable, attainable and convenient at that time and within that particular setting.

Guidance issued by the Welsh Assembly Government (2004.3) stresses various ‘rights’ of people with learning difficulties and two of the supporter/client generated definitions of advocacy also concerned ‘rights’. Nurse informants in stages two and three demonstrated that they advocated for their clients’ ‘rights related’ concerns to whoever was responsible. They discussed advocating for clients’ rights within day services, particularly for their right to choose the services they required rather than ‘fitting in’ with what was already available and, related to this, some nurses also mentioned advocating for clients’ rights during the transition from full time education to ensure they received appropriate adult services. Many of the
community nurses in the focus groups had discussed advocating for their clients’ rights to healthcare and this had also been mentioned by nurses in the other groups and in the additional comments appended to questions in the survey.

‘Promoting the rights of people with learning difficulties whenever possible’ was considered relevant or extremely relevant to their advocacy practice by most nurse respondents, but had led to considerable discussion in the focus groups with nurses, some of whom felt that this was not an activity in which individual nurses would become involved. One nurse was adamant that promotion of the rights of people with learning difficulties in general, rather than the rights of individual clients, was an activity for self advocacy groups or organisations such as Mencap, who would have a stronger voice and be able to reach a wider public. He did however agree that he would promote the rights of people with learning difficulties en masse, when any opportunity presented itself. No obvious explanation of how the great majority of nurse respondents would enact the definition was forthcoming, but, on a wider front, it was exemplified by the 100% support for a demand for equity in healthcare for people with learning difficulties by nurses at the 2004 RCN Congress.

Almost 90% of the respondents to the survey reported ‘Encouraging clients to take responsibility for themselves and their actions’ to be either relevant or extremely relevant to their advocacy practice, but this was reduced to 75% of those nurses working solely with clients who have little or no conventional verbal communication (section 5.15). Seeking an explanation of this from the focus group data revealed that nurses who worked with these clients had argued that they would be unable to take responsibility for themselves due to their profound and multiple disabilities. All six nurse participants in this session agreed, seeming to adhere to the individual (medical) model of disability. This model is exemplified by the World Health Organisation’s definition of disability as:

Any restriction of ability to perform an activity, as a result of an impairment, in a manner or within a range considered normal for a human being

(WORLD HEALTH ORGANISATION, 1980)
Professionals guided by this philosophy act upon the 'discourse of individual pathology of clients' (Goodley 1998.440), making the hegemonic assumption that people with profound and multiple disabilities who do not speak, are prevented by their impairments from making any truly participative contribution to society.

The individual/medical model of disability is essentially paternalistic and therefore does not encourage clients to self advocate. Paternalistic advocacy occurs when the nurse 'protects [clients] from harm and unnecessary worry' (Falk Rafael, 1995.25) and is guided by the principle of 'doing something for or to another.... on the premise that it serves that person's own good' (Haggerty, 1985.340). Nurses working to this model would not expect their clients to be able to take any responsibility for themselves and their actions, and would therefore not offer them the opportunity to do so; resulting in a vicious circle of almost total disempowerment (figure 20).

![Diagram showing the individual/medical model of disability.](image)

**Figure 20: Responsibility and empowerment – individual/medical model of disability**

Of course not all nurses are guided by the individual/medical model of disability, and many nurses may be directed by this model in some circumstances and by the social model in others. The social model has been redefined from its original
by Oliver (1996) and juxtaposed with the individual model so that it no longer denies:

.....the problem of disability, but locates it squarely within society. It is not individual limitations, of whatever kind, which are the cause of the problem, but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation.

(Oliver, 1996.31)

Nurses working within the social model would seek to find innovative ways, within the organisation of daily activities, to overcome barriers and to present their clients with opportunities to take responsibility for themselves if they so desired.

---

Figure 21: Responsibility and empowerment – social model of disability

Research on the meaning of independence (Rock, 1988.27) suggested that disabled people viewed independence as 'an infinitely variable self concept ...which concerns control and choice rather than absolute competence'. The
nurses who had expressed the view that their clients could not take responsibility for themselves or their actions had gone to considerable lengths to demonstrate how these same clients were encouraged, with support, to make choices in their everyday lives. If their choices are recognised and adhered to, even such mundane activities as choosing what to eat or what to wear, although they may seem of small import, lead to the assumption of responsibilities, which can be incremental. New opportunities may then be offered, both for choice and to undertake responsibility, leading to the increased empowerment of people with learning difficulties (figure 21).

Adherence to the individual/medical approach to clients’ disability was obvious when other definitions of advocacy were being considered, particularly when explanations of these were sought from nurses working with clients who do not speak. Compliance with the medical model for these nurses was often less through choice than because resources, management and current health and safety legislation caused a conflict of interests between nurses advocating for what they interpreted as their clients’ wishes and the regulations of their employing Health Trust. This was illustrated in discussions concerning the two ‘community presence’ definitions: ‘Proactively supporting clients to get to know people in the community’ and ‘Encouraging people in the community to get to know people with learning difficulties’. Tyne (1981) argues that:

...by working to make more and more people with handicaps (sic) participants in the lives of a variety of community members, they will begin to grow a network of relationships which not only provides support, but also changes the status of the person and the group he/she represents in the eyes of others.

(Tyne, 1981.28)

This was echoed in O’Brien’s (1987) five service accomplishments (section 1.4) and was the case for many of the stage one participants, who demonstrated how even relatively simple advocacy activities within community settings had imbued them with confidence and feelings of empowerment (section 3.4). Nonetheless, the ‘community presence’ definitions were reported as significantly less relevant by nurses than any of the other definitions of advocacy listed in the questionnaire (p=0.001). A positional map (figure 22) illustrates some of the different views expressed by people with learning difficulties and nurse participants.
Yes

Is encouraging community presence an important part of the advocacy role?

No

We talk to people in schools and we get them to do role play and rhymes and stuff like that. We tell them we've got feelings and can be hurt by bullying, and then they tell other people and the bullying should stop.

(Stage 1, group 10)

We make use of the local facilities but we don't always encourage people to get to know the clients or the clients to get to know other people. If it happens it happens but....

(Stage 2, group 5)

It's not part of our role to encourage people to get to know our clients because we'd hope to be getting their family involved in doing that, to keep that part of their lives ongoing.

(Stage 2, group 4)

We don't encourage people to get to know our clients. Because of the type of clients we work with they are quite isolated. They tend to use specialised facilities and there are restrictions to do with staffing and the times we can go places.

(Stage 2, group 1)

We don't really encourage our clients to get to know people in the community. We do go out and about but if they get to know people it only happens by chance. We don't even use the local buses or local services.

(Stage 2, group 6)

Since [my advocate] taught me to use the bus I've made more friends and become more independent and people treat me as a person, not with learning difficulties, but as an ordinary person.

(Stage 1, group 11)

Nurses working in the short term assessment unit were keen that their clients should remain involved with their lives outside the service, but those working with clients in long term 'continuing care' settings reported feeling unable to encourage their clients to forge links in the community. A Government Report argues that policies and practices concerning disabled people:

...focus on incapacity, inability or risk associated with impairment.... Responses to needs are often more likely to create dependency than enable people to participate in local communities...

(Prime Minister's Strategy Unit, 2005.60)

Nurse participants in the focus groups who worked with clients with profound and multiple disabilities and little or no verbal communication demonstrated this.
reported feeling unable to support their clients to get to know people in the community, or to encourage people in the community to get to know their clients because of health and safety regulations and also due to the specialist nature of most of their activities. They explained that the former precluded their clients from using even the specially adapted ‘wheelchair friendly’ public transport facilities, and that resource issues dictated the use of, amongst other examples, a hospital based hydrotherapy pool for swimming and a music therapist employed by the Trust; giving clients minimal opportunity to use community based facilities.

The Report stresses the need to foster independence and control by disabled people, and nurses were aware that their clients would benefit from partaking in activities within their communities, but had encountered difficulties when considering advocating to enable these to take place. They explained that because their clients lived in ‘continuing health care' facilities, rather than those run under the auspices of ‘social care’, activities run for people with learning difficulties by social services, which usually took place in community settings, were not available to them. The nurses were prepared, and even eager, to support their clients’ independence within a range of socially based activities, but were not prepared to risk the conflict of interests with their employer which might ensue. Some of the community nurses interviewed in the study had managed to obtain places on ‘social care' activities for profoundly disabled clients living in ‘health care’ situations, but this had been made easier by their employment in multi disciplinary teams of both health and social care workers. Advocating for clients within a team meeting with colleagues was obviously seen as less challenging than advocating directly to senior management within the nurses’ employing Health Trust, particularly when nurse advocates knew that they were contracted to provide twenty four hour support to clients across the whole range of health and social care activities.

Richardson (1997.1271) points out that ‘the social construction model of disability does not deny that health care needs can co-exist with impairment’ and most of the nurses working with people with learning difficulties were aware that socially constructed barriers often impinged on their clients right to health care. Advocating for their clients against such circumstances had been successful for
these and other nurses in relation to both specialist and generic health care, which will be discussed in more detail later in this chapter. Richardson (1997.1272) argues that 'nursing is traditionally associated with caring for dependent patients' and the 'dependency model' is deeply engrained within the medical profession. Confirming this, nurses in both the focus groups and the questionnaire survey reported that their status as nurse advocates was definitely useful in such cases. Doctors were more inclined to listen to them and consequently it had become less likely that their clients would be refused appropriate treatment from generic services because of the severity of their learning difficulties.

Nurses demonstrated that support for their clients did not consistently adhere to either the medical or the social model of disability. 13% of hospital nurses and 11% of nurses working in 'other residential' services were either undecided or reported that 'ensuring clients have information they can understand' was not relevant to their advocacy role. A possible explanation of this came from a nurse participant who worked with clients living in 'other residential' units whose behaviour might challenge services. Demonstrating that, in some situations, many nurses conformed to the individual model of disability, she contended that there was a widespread practice in the service of withholding certain information from these clients as it could trigger 'difficult behaviours'. These had the potential to disrupt the routine of the unit and might result in upset and even injury to other clients and staff present at the time. While it is easy to condone this utilitarian approach as leading to 'the greatest happiness for the greatest number', in my own experience, a more empowering approach encompassing the social model of disability might concentrate on seeking ways to manipulate the environment and prepare the client to receive the information, thus minimising the extent of the problematic behaviour.

Only three of the thirteen definitions of advocacy presented in the questionnaire survey received scores indicating that less than 70% of the nurse respondents thought them relevant or extremely relevant to their practice (table 69). Two of these were the 'community presence' definitions previously discussed, the third was 'Speaking for clients' about which 31% of nurse respondents were either undecided or reported thinking it not or not at all relevant to their advocacy role.
Definition | Generated by... | % of respondents finding definition extremely relevant or relevant
--- | --- | ---
Treating clients as adults and consulting them about things that concern them | Participants with learning difficulties | 95.4
Working with clients to ensure their rights are respected and upheld | Supporter/client interaction | 95.3
Promoting the rights of people with learning difficulties whenever possible | Supporter/client interaction | 94.2
Ensuring clients have information they can understand | Participants with learning difficulties | 93.6
Encouraging clients to make their own decisions | Learning disability nurse participants | 91.9
Supporting clients to complain if they think they are being treated badly | Participants with learning difficulties | 91.8
Encouraging clients to take responsibility for themselves and their actions | Supporter/client interaction | 89.6
Supporting clients to complain if they think something is unfair | Participants with learning difficulties | 86.1
Enabling things to happen for clients | Learning disability nurse participants | 82
Interpreting for clients | Participants with learning difficulties | 80.8
Speaking for clients | Participants with learning difficulties | 69.4
Proactively supporting clients to get to know people in the community | Participants with learning difficulties | 66.1
Encouraging people in the community to get to know people with learning difficulties | Participants with learning difficulties | 56

Table 69: Scores of ‘relevant or ‘extremely relevant’ associated with definitions of advocacy

The positional map (figure 23) illustrates that opinions on this differed between nurses. Nurses working with people with learning difficulties who had adequate verbal communication generally reported that speaking for their clients would be disempowering, and that they would prefer to facilitate and support self advocacy by these clients whenever possible. Nurses working with clients who do not speak recognised that ‘speaking for clients’ was essential to satisfactory advocacy, but were concerned that, unless this definition was considered in conjunction with ‘interpreting for clients’ they could be thought to be advocating for their own wishes rather than those of their clients. This perception was confirmed by nurse respondents to the questionnaire when a highly significant relationship was found between the two advocacy definitions ‘Speaking for clients’ and ‘Interpreting for clients’ (p=0.001).
Nurses in the study confirmed that definitions of advocacy generated by people with learning difficulties were relevant to their practice. They also discussed other aspects of their advocacy role. Before considering these I shall discuss the notion of advocacy as ‘best interests’. The concept was introduced in definitions of advocacy given by several nurse participants in the stage two focus groups and permeated many of the comments appended by nurse respondents to the questions in the survey. It features in the limited literature concerning nurse advocacy (Gadow, 1989; Baldwin, 2003) and in literature concerning the advocacy role of the learning disability nurse (Blackmore, 2001), and may have legal implications for intending nurse advocates (Bennett, 1999, Schwer, 2002, Department of Constitutional Affairs, 2004).

Blackmore (2001) argues that advocacy for people who do not communicate verbally must necessarily be paternalistic, i.e. that the clients’ best interests, decided on their behalf by others, must be the main aim of any advocacy attempt.
The nurses who worked with this client group did not agree. They affirmed Gadow's (1989) proposition that advocacy was about supporting clients for their legal and moral rights and thus involved finding out what individual clients want and supporting them. The nurses explained that an objective view of their best interests would only be the starting point of opportunities offered to clients. When the nurses spoke for these clients, the interpretation of their actual wishes and desires, gained through a detailed assessment over a prolonged period, was likely to be the focus of any advocacy attempt.

Attempting to interpret and act upon the wishes expressed by clients who do not speak has always been fraught with difficulties, particularly if nurses' interpretation of their clients' requirements has attendant risks, or is likely to be life changing. Bennett (1999.41) argues that nurses who attempt subjective advocacy in this way, 'approach an ethical minefield' because 'the translation [of the client's wishes] is fraught with uncertainty'. He points out that:

> .... nurse advocacy is not recognised in English law... nurses are not recognised specifically as fulfilling this role. If advocacy goes beyond the nurse acting in the [client's]... best interests, a universal definition and professional and legal accountability is required'.

(Schwer, 2002.6)

Schwer agrees, and her account of the skills and responsibilities required of an advocate is relevant both to Bennett's view and to the potential nurse advocate. Briefly, these demand:

- Effective communication with [the client]...
- Awareness of the legal test for capacity
- An ability to probe and test others' assumptions
- Good connections with experts in assessment of mental capacity

Both Bennett and Schwer assume that subjective appraisal and subsequent representation of clients' wishes will present nurse advocates with a situation which may lead to litigation, hinging on the assessment of the 'legal capacity' of clients to make choices in a court of law. Even in today's litigious society, this may be a small possibility, particularly when clients' best interests have been
considered; and should be even less likely when the Mental Capacity Bill (2004) becomes law. The concepts of both ‘capacity’ and of ‘best interests’ are clarified in the Bill, which aims to change the current situation in which the legal position of both professional and informal carers of people with severe or profound learning difficulties is uncertain in relation to many of the activities they might undertake for those whom they support (Wheeler, 2003.10). The Bill purports to enable persons who lack legal capacity to have the maximum possible control over decisions taken on their behalf as well as protecting them, their carers and professionals (Department of Constitutional Affairs (DCA), 2004).

The key principles are:

> An assumption of capacity: every adult has the right to make his/her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.
> Capacity is decision specific: an assessment of someone’s capacity must be based on the actual decision to be taken at the time it needs to be taken – no blanket label of incapacity.
> Participation in decision making: everyone should be encouraged and enabled to make his/her own decisions, or to participate as fully as possible in decision-making, by being given the help and support s/he needs to make and express a choice.
> Individuals must retain the right to make what might seem eccentric or unwise decisions.
> All decisions must be made in the person’s best interests: decisions made on behalf of people without capacity should be made in their best interests, giving weight to the decision being what they themselves would have wanted.
> Decisions made on behalf of someone else should be those which are least restrictive of their basic rights and freedoms.

Setting out the criteria for lack of capacity, the Bill stresses that this may be temporary and is likely to be situation specific, for example a person with severe learning difficulties may be able to decide between a choice of foods, but may not be capable of making a decision regarding a new care package or major surgery. It also details the decisive factors in assessing whether or not people are able to make their own decisions, emphasising the possible necessity to use alternative
means of communication to provide information; and stressing that:

The fact that a person is able to retain the information relevant to a
decision for a short period only does not prevent him (sic) from being
regarded as able to make the decision.
(House of Lords, House of Commons, Mental Capacity Bill, part 1, 2004)

The concept of 'best interests' is also defined, the Bill requiring that the person
determining the best interests of the client should:

...consider, as far as is reasonably ascertainable –

   a) the person’s past and present wishes and feelings
   b) the beliefs and values that would be likely to influence his (sic)
      decision if he had capacity, and
   c) the other factors he would consider if he were able to do so.
(House of Lords, House of Commons, Mental Capacity Bill, part 1, 2004.3)

It also highlights the need to take account of the views of 'anyone caring for the
person or interested in his (sic) welfare' (Mental Capacity Bill, Part 1, 2004).

The Bill provides the legal basis for a person (or persons), who may be a learning
disability nurse, to act on behalf of an adult who lacks capacity, and protects them
from liability when they act in what they believe to be the best interests of a person
who cannot consent (DCA, 2004.2). The British Institute of Learning Disabilities
(BILD), while broadly welcoming the Bill, draws attention to a 'serious weakness'
whereby the person acting on behalf of another is also likely to be the person
responsible for determining lack of capacity in that person. BILD suggest that, if
the person with authority does not offer opportunities for the other to engage in
decision making, deeming that person to be 'lacking in capacity', this is unlikely to
be contested by the person so deemed, resulting in a self fulfilling prophecy, which
would not be in that person’s best interest (BILD, 2004.2). This valid criticism was
exemplified in the study by some nurses who, adhering to the individual/medical
model of disability, failed to offer opportunities to enable the maximum decision
making potential of their clients to be realised (figure 20).
The Joint Committee on the Draft Bill suggested that independent advocacy is a very important part of the Bill which should receive further consideration, implying that advocates could act as decision makers for those deemed to lack capacity. However, while accepting that there should be more and better advocacy services, the Committee did not feel it would be practicable to make a law that everyone who required an independent advocate should have one (Joint Committee on the Draft Mental Incapacity Bill, 2004); suggesting instead that people should use the advocacy services already provided by Health and Social Services (Mental Incapacity Consultative Forum, 2003). They did not explain how those lacking in capacity would access these services or what provision would be made where they were not readily available; presumably accepting that nurses, other professionals and carers would continue to support their clients by either 'direct' or 'indirect' advocacy (Jenkins and Northway, 2002).

Nurse informants were very aware of the risk of litigation which may be mitigated by the enactment of the new Bill. They felt that, at present, the risk did interfere with their advocacy efforts, even where these were based on what nurses considered to be the best interests of their clients. They gave an example which concerned Health and Safety regulations. Local buses had recently been converted to make them wheelchair accessible, and nurses felt it would be in their clients’ best interests to travel this way whenever possible. The ‘All Wales Strategy’ (Welsh Office, 1992) endorses the value of an acceptable element of risk; clients would benefit from the experience of using ‘ordinary’ transport; they would develop their ‘community presence’ and would have increased freedom. However, the buses, although they have an accessible entry point and a designated wheelchair area on board, do not have wheelchair clamps. In consequence there is a small possibility that, in the event of the bus lurching or coming to a sudden stop, the wheelchair might tip, injuring the client. The nurses explained that, gaining support for this, or similar activities considered to have an element of risk, would entail advocating within a multi disciplinary meeting headed by the client’s consultant, to decide on the proper course of action for the client.

Multi disciplinary meetings, called in this way by a nurse advocate to make decisions on behalf of a client, exemplify Rose’s (1995) concept analysis of ‘best
interests' in which she explored five key themes:

1. Expert involvement - (the consultant)
2. Incompetence in the client - (the person with learning difficulties who does not speak)
3. Conflict - (between the nurse’s interpretation of the client’s wishes and the policies of the Trust)
4. Intention to do long term good - (by the nurse advocate and also, possibly at variance with the nurse’s view, by the Trust)
5. The wishes of clients - (as interpreted and expressed by the nurse advocate)

(Rose, 1995.150)

According to Rose, the expert uses the concept of best interests to resolve conflict (between Health and Safety regulations and the clients' wishes) and to justify whatever decision is made (which is not usually the wish expressed by or on behalf of, the client). The intention to do 'long term good' usually describes the initial intention, in this example, for clients to use a bus without wheelchair clamps; rather than the hoped for outcome of the intervention i.e. to benefit the client in the ways previously described. The meeting, led by the 'expert' is thus likely to consider 'best interests' in the utilitarian sense of preventing the possibility of litigation against the Trust in the event of an accident, and, in consequence, to refuse the advocacy request.

Advocacy in multi disciplinary meetings by nurses on behalf of their clients is deeply ingrained in residential services and seems unlikely to change, even when the new Bill becomes law. It is a paternalistic solution which can be doubly disempowering. Nurses can be disempowered by having their arguments on behalf of clients overridden by 'experts', who arguably know the client less well than the nurse advocate; and their clients can be disempowered by unsuccessful representation to a whole team of 'experts' with authority to overturn their wishes and to make binding decisions on their behalf, in the guise of their best interests. Such meetings exemplify compliance with the 'medical' model of disability, in which attention is directed to the client's impairment rather than to ways in which 'the wider environment interacts with their impairment' causing disability (Prime Minister's Strategy Unit, 2005.20). Nurses did not appear to have considered the
possibility of advocating directly to the local transport authority for buses to be fitted with wheelchair clamps. A course of action which would remove conflict between nurse and employer and might also benefit other disabled transport users.

The BILD response to the Mental Capacity Bill, accepts that several people may presume to hold authority for a client, and to make decisions concerning what each believe to be in her/his best interests, and is concerned about disagreements between the different parties. These may surface when nurses advocate for clients living at home with their families and any conflict of interests is less likely to be with the nurse’s employing Health Trust than with the client’s family, particularly the main carer (usually the mother). One community nurse described a situation in which her client had expressed a wish to leave home, which was opposed by her mother, who had come to see caring as the main job in her life. In such cases, Rose’s concept of ‘best interests’, relatively straightforward in small nurse-run residential settings, became complicated in the way BILD envisaged. The nurse was the client’s representative but was also the ‘expert’, and there were conflicting ‘intentions to do good’, certainly between the client and the nurse on the one hand and the main carer on the other, but also between family members where the father was able to consider the long term future of the client and the family, while the mother was unwilling to look further than the immediate present. In complicated situations such as this, the community nurse described mustering all her professional expertise in order to resolve the conflict of interests between what the client wanted and what she was also sure was in the client’s best interests, and the wishes of the main carer, who was also in conflict with other family members.

BILD recommends that the Code of Practice relating to the new Bill should ‘include advice on how different interpretations of ‘best interest’ among several persons, all with general authority, should be reconciled’ (BILD, 2004.2). This might alleviate circumstances where, even when they are certain that their advocacy attempts are focused on the wishes and best interests of their clients, nurses can be subject to internal conflict as well as conflicts of interest between themselves, their employers, colleagues and the families of clients.
6.4 Situations in which nurses might advocate for clients

In order to further explore the advocacy role of learning disability nurses, the questionnaire offered a list of situations and asked nurses to indicate in which of these they might advocate for their clients. The nine situations had been mentioned in either or both of the earlier stages of the study, some having been the subject of detailed discussions (section 5.17). Comparison of the responses revealed that nurses were least likely to advocate for housing options for their clients, possibly because over half the respondents worked with clients already settled in small residential units or in hospitals where independent advocates were employed in a role specifically related to client resettlement.

Mansell and Harris (1998) argue that health related skills are considered particularly appropriate to learning disability nurses, and nurse respondents were significantly more likely to advocate for health care than for the other seven (socially related) options on the list (p=0.05) (section 5.17).

Advocating for health related needs is important.

We have to advocate strongly so that our clients get the same health care as everyone else. (Stage 2, group 1)

I see it as my role to enable people to access not just specialist care but to access generic services as well. (Stage 2, interview 2)

Advocacy for health care is very important. We have to be strong and very assertive on the client’s behalf otherwise doctors only see the disability. They don’t look at what the quality of life could be if the intervention took place and was successful (Stage 2, group 2)

We support the client by speaking up for health care within the multi-professional team. (Stage 3, comment)

I advocated with the client’s sister to the consultant so that the client got appropriate treatment for the deterioration in her mental health. (Stage 2, group 4)

Because our clients come under ‘health’ they might even get treatment quicker than the general public. (Stage 2, group 3)

Health care has improved over the last ten years. Primary care is still patchy but there are some very good GPs out there and some good primary care teams who work well with clients and with paid and unpaid carers. (Stage 3, comment)

Figure 24: Positional Map - The importance of advocating for health related needs
Some of the self advocate participants in stage one experienced difficulties in articulating their health related needs to their GPs, particularly in the presence of parents or carers, and one participant in the hospital focus groups had related how, on a visit to hospital for tests, he had refused to be admitted unless his key worker would remain also. Apart from these instances, health care had not been mentioned as a specific need by participants with learning difficulties in the focus groups.

Opinions amongst nurses also varied. The positional map (figure 24) shows how some nurses felt it extremely important to advocate for equitable health care for clients, while others, particularly some of those working in 'continuing health care' situations were satisfied with the health care their clients received. This was not generally the case and responses to the questionnaire reflected the widespread acknowledgement that in Wales, as indeed throughout the United Kingdom, 'care in the community has not met the day-to-day healthcare needs of people with learning disabilities' (Matthews, 2002:40). A consultation draft on 'Fulfilling the Promises' (Welsh Assembly Government, 2004) states that:

There is strong evidence that people with learning disabilities have poorer health and more specific health needs than the general population. .....However, despite this increased need, there is evidence to suggest that people with learning disabilities do not always receive the health provision they require....

It goes on to suggest that:

Problems in providing adequate health care may arise from ........difficulties in accessing services that may be available, despite people with a learning difficulty having a right to the same level of service for physical and mental health services in primary and secondary care as any other individual living in Wales.

(Welsh Assembly Government 2004)

Several nurse respondents noted a lack of understanding of the health care needs of their clients by generic health care workers, and others noted difficulties for their clients when admission to hospital was proposed for what would normally be routine procedures.
Hannon, (2003) proposes that:

Learning disability nurses need to take a lead in getting the issue (of health care for their clients) on to the local agenda, and in strategic and operational health facilitation.

(Hannon, 2003.41)

Although nurses in the research had suggested that their status as nurses made it more likely that they would be successful in advocating for health care for their severely disabled clients, only one of the community nurses interviewed during the study seemed in a position to influence local health facilitation strategies. Unlike the other community nurses in stage two, she had clinician only responsibilities for her clients, and saw health related advocacy as one of her main tasks. As well as running health screening clinics, which required her to advocate to clients' families and to consultants on their behalf, she also spent considerable periods of time ensuring that clients were able to give their informed consent to various procedures, and to ensuring they were not disadvantaged in opportunities for either primary or secondary health care. For the majority of community nurses who had dual clinician/care manager responsibilities, advocating for clients' health needs was a less important part of their role, although having key worker responsibility for one or more clients made it significantly more likely that nurses would advocate for specialist health care for their clients (section 5.17).

6.5 Advocacy partnerships
All informants were asked for their ideas about what makes a satisfactory advocacy partnership between client and nurse or client and advocacy supporter (section 5.18). Nurse informants were also asked whether their experience of advocacy in their personal lives was the same or different from advocating in their professional role (section 5.16). Respondents were almost equally divided about this question and about the reasons proffered for their answers. Emotional involvement was considered helpful to family advocacy by some nurses and a hindrance by others; and the likelihood of persistence and commitment was seen as likely to be greater when advocating for family by some nurses, while others felt they would be more obdurate when advocating professionally for clients. Nurse respondents were also divided about the affects of adherence to the regulations
and policies of 'the system'. A minority felt these were a useful source of
guidance, but most nurses saw them as a potential source of conflicts of interest
and a restraint on attempts at advocacy for their clients.

<table>
<thead>
<tr>
<th>Importance of item</th>
<th>Item</th>
<th>undecided/not/not at all relevant</th>
<th>relevant/extremely relevant</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Understanding clients' communication</td>
<td>5</td>
<td>168</td>
</tr>
<tr>
<td>2</td>
<td>Mutual trust between nurse and client</td>
<td>11</td>
<td>162</td>
</tr>
<tr>
<td>3</td>
<td>Knowledge of clients' likes and dislikes</td>
<td>16</td>
<td>157</td>
</tr>
<tr>
<td>4</td>
<td>Willingness to support a client in self advocacy</td>
<td>18</td>
<td>153</td>
</tr>
<tr>
<td>5</td>
<td>Maintaining a professional relationship</td>
<td>21</td>
<td>150</td>
</tr>
<tr>
<td>6</td>
<td>Sufficient time to develop mutual understanding</td>
<td>19</td>
<td>143</td>
</tr>
<tr>
<td>7</td>
<td>Good relationship with carers</td>
<td>56</td>
<td>116</td>
</tr>
<tr>
<td>8</td>
<td>Long-standing relationship with clients</td>
<td>93</td>
<td>80</td>
</tr>
</tbody>
</table>

Table 70: Order of importance of listed items to a satisfactory nurse/client advocacy partnership

All except two (table 70: numbers 5 and 7) of the ‘partnership’ situations listed on
the questionnaire had been mentioned by people with learning difficulties and they
had discussed many of them at some length. They had laid considerable stress
on their need to be understood, for their likes and dislikes to be acknowledged and
for a relationship of trust between themselves and any potential advocacy
supporter. All these items were scored as important or extremely important by
well over 90% of nurse respondents to the questionnaire (section 5.18).

88% (n=150) of the nurse respondents considered the maintenance of a
professional relationship in their advocacy partnerships as important or extremely
important. The positional map (figure 25) illustrates the range of views on this
issue, some typical of participants with learning difficulties, who had few
acquaintances outside their institutional life; and others demonstrating the opinions
of nurse informants. Some of the nurses had encountered difficulties when clients
had come to view them as friends during an advocacy partnership which had
subsequently been unsuccessful, resulting in the nurse feeling (s) he had betrayed
the relationship. Many of the nurses, particularly those working in small residential
units had agreed that they found it difficult to maintain a professional relationship with clients, as they became very close to them in the course of their working lives and inevitably became emotionally involved.

Yes

There can be huge difficulties if you become too familiar because you can’t be a friend. You can’t be a paid friend because you have your professional role to fulfil and you can’t overstep the barriers.

(Stage 2, interview 2)

No

Maintaining a professional relationship with clients is important to nurse advocacy

We do get very heavily involved with clients but although there is a relationship there, the objectivity and professionalism you bring to the relationship is important too.

(Stage 2, group 3)

[Staff nurse] A is my key worker, [staff nurse] J is my friend. She has been with us from day one, she knows us better than all the other staff round here. She would always stand up for us. She’s a nurse and she’s a friend.

(Stage 1, group 2)

You can’t progress much if you’re the only person the clients will do things with. So if the client sees you as a friend that’s unhealthy. We can’t be their friends. We are paid to work with them. We’re not there because we want to be there every day, we’re there because we’re paid to be there.

(Stage 2, group 5)

Professional status is obviously important in effecting change but ‘closeness’ and friendship emerge naturally in some nurse/client relationships

(Stage 3, comment)

It’s important to recognise that some clients do have long standing worthwhile friendships with nurses.

(Stage 3, comment)

Figure 25: Positional Map - Maintaining a professional relationship with clients and carers is important to nurse advocacy

One of the respondents to the questionnaire suggested ‘over involvement’ could lead nurses to become possessive towards their clients, blocking their access to more suitable advocacy partners, who might assist them in service related issues where nurses would have a conflict of interests. The community nurses recognised the potential problems of being viewed as friends by clients or their families, but, possibly because of the short term nature of their involvement, appeared to find it less of a problem to maintain professional relationships.
All the participants with learning difficulties had agreed that an essential attribute of a satisfactory advocacy partnership was a long standing relationship with the advocacy supporter. This was confirmed by Gates (1994.76) who found that where client/advocate relationships ‘lasted beyond eighteen months, there was a high degree of flexibility and adaptability in the thinking and social behaviour of the advocate’. Surprisingly, in the survey, this item received a significantly lower percentage of ‘important or extremely important’ rankings than the seven other items on the list and was the only item about which more nurses were either undecided or viewed as not or not at all important than indicated otherwise (table 71).

Further investigation revealed that nurses who worked with clients who had a complete range of communication skills were significantly less likely than nurses working either solely with clients who did not speak or with clients who had adequate verbal communication to view long term relationships as important or extremely important within their present practice (p=0.05). These nurses also proved significantly more likely to work in the community than in residential units (p=0.001). This reinforced information given by some of the community nurse participants and confirmed by comments appended to questions in the survey.

The nurses explained that their advocacy role had been compromised by a relatively new requirement to include clients on their case load for only the length of time which it took to deal with the specific problem for which they had been referred to the community team. Literature confirmed the importance to satisfactory advocacy of building long term relationships. The mother of a disabled child, (Maxwell and Barr, 2003.58) commented that she was now ‘in the best possible situation’ as her son has ‘a key worker who visits when asked’ and who has taken time to build a good relationship with her ‘as an individual looking after [her] ....family’. Several community nurses reported that, due to the new system, they were no longer able to forge long term relationships with clients or their families and that ‘situation specific’ working meant they had difficulty seeing ‘the bigger picture’ of their clients’ lives, were unable to take a holistic view of their circumstances and were forced to work reactively, rather than in proactive ways which might prevent the occurrence of further problems and improve their clients'
possibly connected with this, community nurses scored the highest percentage of 'extremely important' rankings in the item 'supporting clients in self advocacy'.

6.6 Barriers to advocacy

This discussion has illustrated some of the barriers experienced by nurses attempting advocacy on behalf of their clients.

<table>
<thead>
<tr>
<th>Potential barrier</th>
<th>Yes</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Inability to interpret clients' requirements</td>
<td>129</td>
<td>44</td>
</tr>
<tr>
<td>2 Lack of time</td>
<td>125</td>
<td>48</td>
</tr>
<tr>
<td>3 Conflict of interest with employer</td>
<td>120</td>
<td>53</td>
</tr>
<tr>
<td>4 Lack of knowledge (e.g. legal, clinical)</td>
<td>117</td>
<td>56</td>
</tr>
<tr>
<td>5 Insufficient experience</td>
<td>104</td>
<td>69</td>
</tr>
<tr>
<td>6 Lack of understanding of clients' rights</td>
<td>102</td>
<td>71</td>
</tr>
<tr>
<td>7 Conflict with carers</td>
<td>94</td>
<td>79</td>
</tr>
<tr>
<td>8 Unequal conditions of power between nurse and client</td>
<td>90</td>
<td>83</td>
</tr>
<tr>
<td>9 Responsibility for several clients</td>
<td>84</td>
<td>89</td>
</tr>
</tbody>
</table>

Table 71: Nurses' responses to items as potential barriers to satisfactory advocacy

Nine potential barriers were listed on the questionnaire, all of which were derived either from discussions with people with learning difficulties or from nurse participants in the focus groups (table 71). Despite the assertion of Brooke (2001) that nurse advocacy can be compromised by the numbers of clients on the case load of learning disability nurses, only the item 'responsibility for several clients' was seen as a barrier to advocacy by less than 50% of nurse respondents to the survey. The range for the other items was from 75% reporting the straightforward 'Inability to interpret clients' requirements' as a barrier, down to 52% of nurse respondents who perceived the imbalance of power between nurses and their clients as likely to cause problems for nurse advocates (section 5.19).

Conflict of interest with employers, unequal power relationships and lack of appropriate education and training were most frequently cited in the comments appended by nurse respondents to this section of the questionnaire. The latter will
be discussed later in this chapter, but conflict of interests and barriers to advocacy due to the inequity in power between nurses and their clients will be discussed in more detail here.

No

If there is a conflict of interest we can bring in an independent advocate.
(Stage 2, group 4)

We would not have to advocate ourselves. We would take it to the multi disciplinary team and they would take it forward.
(Stage 2, group 3)

You might be asked to compromise about financial things. You might be asked to dumb the assessment down. I won’t go there and find there are needs and not put them down.
(Stage 2, group 3)

There can be conflict of interests with families because they think what we are doing is really their role as well.
(Stage 2, group 4)

I don’t think as nurses we can be true advocates because of the conflict. There is role conflict because we are employed by the Trust and there are other areas of conflict too.
(Stage 2, group 1)

Figure 26: Positional Map – Nurses are likely to find conflict of interest a problem for advocacy

69% of respondents to the questionnaire reported that conflict of interests with employers was a potential problem for nurse advocacy and a significant 91% of these had key worker responsibility for one or more clients (p=0.05), probably making them the most likely spokesperson in any advocacy attempt. 54% of the nurses also viewed ‘conflict with carers’ as a possible barrier. A search of the literature revealed that ‘conflict of interests’ was mentioned as a potential problem by the majority of authors discussing advocacy in nursing (for example: Blackmore, 2001; Brooke, 2001; Goble, 2002; Wheeler, 2000), and it was initiated for discussion at an early stage in most of the focus groups with nurses and considered at length. A positional map (figure 26) illustrates some of the different opinions of informants in stages two and three of the research. Many of the nurses
differentiated between what they viewed as everyday advocacy for their clients, in which conflict of interest with their employers was unlikely to cause a problem; and advocacy at a higher level, where it was frequently seen as a potential barrier. Nurses also experienced conflicts of interest when advocating for clients to their families and at least one community nurse discussed ‘treading a fine line’ between advocating for the wishes of her clients and risking the wrath of the main carer, which could result in the client being withdrawn from learning disability services, with obvious adverse effects.

Wheeler (2000.40) mentions the conflict which can arise over ‘assessment criteria’ and ‘the allocation and distribution of resources’. For the majority of community nurses in the study who had both care manager and clinician responsibilities for their clients, these were frequently encountered problems. These nurses also experienced conflict between the two aspects of their own role, which were often difficult to reconcile. Wheeler (2000.40) suggests that the nurse advocate risks ‘...being labelled as a troublemaker’ and ‘may also face being ostracised by colleagues’, and more than one respondent spoke of being ‘bullied’ or withdrawn from working with particular clients after making advocacy attempts on their behalf.

Many respondents to the questionnaire and some focus group participants spoke of ‘bringing in’ independent advocates where there was likely to be a conflict of interest between the nurse and his/her employer. This has been suggested as good practice by professional bodies (UKCC, 1998) and in the literature (for example: Brooke, 2001, Goble, 2002). Independent advocacy will be examined in detail later, but, while it was seen as a viable option by some informants, others reported a lack of independent advocacy services in their area, and many nurses expressed concern about their nature and efficacy, and felt that clients were not well served by these provisions. Some nurses referred their clients’ advocacy requirements to a multi disciplinary team if these were likely to cause a conflict of interest, and many of them were satisfied that problems would thus be dealt with justly. They did not always take account of the potential disempowerment of clients and possibly nurses also, resulting from this action.
Any discussion of disempowerment must revolve around the concept of power. The work of Foucault (1979) concerns the relationship between knowledge, truth and power and he identifies ‘disciplinary power’ as that which objectifies individuals through the effects of ‘hierarchical observation’, ‘normalising judgements’ and ‘examination’. According to this notion, people with learning difficulties are disempowered by their subjection to hierarchical observation through surveillance by professionals, who are themselves, as I demonstrate below, also subject to the ‘gaze’. Further disempowerment occurs when ‘normalising judgements’ are made by professionals, who measure the extent to which people with learning difficulties deviate from particular norms and classify them accordingly (Gilbert 1995); and then by ‘examination’ through which ‘judgement is achieved, interventions are prescribed and evaluations of these are recorded’ (Gilbert, 1995, 867). Mcintosh (2002) argues that:

Consciously or not, [nurses] ...are contributors to [this] diagnosis, classification and politicisation of the human condition of learning disabilities [through which] the individual is codified into a set of signs.

(Mcintosh, 2002.73)

and which, the research suggested, might result in their disempowerment within services.

Almost forty years ago, Arnstein (1969), in a paper still relevant to the power and empowerment of people who have learning difficulties, developed a typology, which she presented as a ‘ladder of citizen participation’ (figure 27). Each of eight rungs of the ladder correspond ‘to the extent of the citizen’s power in determining the end product’ (Arnstein, 1969.217) that is, for people with learning difficulties, in exercising control over situations which affect their lives, including those initiated by others.

On the first rung of the ladder, which Arnstein describes as ‘manipulation’, people with profound and multiple learning difficulties might, for example, be co-opted, as members, onto a resettlement committee, the expressed purpose being to inform and consult them about resettlement plans. In the event, no effort would be made to include them in any business, but their tokenistic membership of the committee
would satisfy bureaucratic demands for ‘inclusion’ in any subsequent monitoring exercise. Thus, although the publicised view is that profoundly disabled service users are being empowered to participate, they are being manipulated to present this appearance. In reality they are taking no part, and have little or no control over decisions which may affect their lives.

Figure 27: Arnstein’s ladder of citizen participation (1969.217)

For people on the second rung of the ladder, the purported objective is ‘therapy’, described by Arnstein as being ostensibly to ‘cure’ participants, who might, during the process, attend many specialist services. As nurses in the focus groups reported, this disingenuous move by professionals to ‘enable’ the participation of people with profound disabilities in community activities, is likely to be resource led, and may prevent their inclusion in other, more socially valued, pastimes. Both ‘manipulation’ and ‘therapy’ exemplify the medical model of disability in which professionals act upon the hegemonic assumption that people with learning difficulties are unable to participate in community life. As a result they are seldom offered real opportunities and are almost totally excluded.

People with profound and multiple disabilities are not alone in their disempowerment, although it is obviously difficult for them to reverse this trend.
Participants with learning difficulties who had lived in institutions for many years demonstrated that they had become inured to the powerlessness typified by the objectives of rungs three and four of Arnstein’s ladder, i.e. informing and consultation. In these stages, professionals give clients the opportunity to ‘hear and be heard’ but seldom give them any hope that their views will change their situation. The hospital based participants had been informed about plans for their imminent resettlement, but, despite their undoubted ability and willingness to express their opinions, neither they, nor the nurses who supported them, expected these to reach senior managers who made life changing decisions on their behalf. The clients consequently had no sense of participation and were disempowered within the resettlement procedure.

Arnstein describes the fifth rung of the ladder as ‘placation’. At this stage, clients being resettled may feel some sense of inclusion in resettlement plans. Participants described being ‘allowed’ some say in the furnishings being purchased for their new homes. However, even at this level, their participation seemed duplicitous. They had no control over the available budget and, had they chosen anything seen as unsuitable by staff, would certainly have had their choices overruled.

Informing clients of their rights, options and responsibilities, consulting them about their requirements and giving them a sense of inclusion need not be disingenuous and can be important steps towards full participation. Dawson (2002.7), demonstrates how perceptive support for clients with learning difficulties, even when they have no verbal communication, can enable them to participate in meetings and express their ideas. Staff supporters in the focus groups demonstrated a range of sensitivity to clients’ views. At least one supporter in the hospital groups occasionally interrupted participants aggressively, which certainly discouraged them from expressing themselves, although others encouraged clients in a more positive way. In the self advocacy group meetings, the supporter was over keen that participants should make a good impression and tended to put words into their mouths, which may not have been an accurate representation of their thoughts. The supporters in the Day Centre groups gave occasional background information and encouraged participants with verbal communication
difficulties, but otherwise did not interrupt the groups, ensuring that participants could convey their ideas freely and without restraint.

Depending on the support offered to people with learning difficulties, rungs six, seven and eight of Arnstein's ladder, i.e. partnership, delegated power and citizen control, can become available, although possibly in limited ways. Elements of all three were experienced by members of the Day Centre Service Users Committee, to their obvious satisfaction. They were also accessible, in a more limited way, to some members of the Self Advocacy Group, who demonstrated that it is possible to move up and down the ladder depending on the context of the participatory activity and the nature of the support offered. Arnstein argues that:


\[
\text{citizen participation is a categorical term for citizen power, It is the redistribution of power that enables the have-not citizens...... to be deliberately included in the future.}
\]

\(\text{(Arnstein, 1969.216)}\)

People with learning difficulties have historically been amongst the 'have-not citizens', but there are moves to reverse this, with advocacy at the spearhead of the endeavour. Most people claiming to support advocacy by, with, or for people with learning difficulties would assert that one of the main purposes of any advocacy attempt would be the empowerment of clients. Where advocacy supporters may not agree would be on a precise definition of empowerment and what this might mean to the people involved.

Servian (1996) in his research into empowerment in community care found that:


\[
\text{There was little evidence of a shared view of what empowerment is, or of a shared value of the importance of empowerment.}
\]

\(\text{(Servian, 1996.37)}\)

The desire for empowerment by both service providers and users presented an arena for possible conflict, reflected in this research. Senior management sought empowerment in the context of managing resources, nurses sought empowerment in freedom from bureaucracy and some supporters saw empowerment as assertiveness and as their ability to influence the views of users. For service
users empowerment entailed support when they needed it; their wishes being taken seriously; and access to information which they were frequently denied by bureaucracy and petty regulations (Servian, 1996).

People with learning difficulties are unlikely to attempt to explicitly define the concept of empowerment, but are no less likely than other members of the population to desire:

...a sense of control over [their] ...lives in personality, cognition, and motivation. Feelings of self worth [and of]... being able to make a difference to the world around [them]...

(Rappaport, 1985.17)

Participants with learning difficulties in the Day Centre were quite definite that advocating for themselves, with varying degrees of support, had given them an increasing sense of control over themselves and the day centre environment. Without specifically mentioning empowerment, they exhibited many features of Rappaport's classic definition. Members of the Service Users Committee, and some of the other clients demonstrated:

...a proactive approach to life; a psychological sense of efficacy and control; socio-political activity and organisational involvement.

(Rappaport, 1985.18)

Although participants from the self advocacy group explicitly mentioned power numerous times during the focus groups, they actually demonstrated a deep rooted lack of control over many areas of their lives. They expressed the opinion that:

Advocacy gives you power and lets you talk about the way you feel about things. ....when self-advocates work together, solidarity makes them powerful too.

(Sylvia, group 3)

But although they were confident as a group, and obviously felt considerably empowered during structured activities, organised and supported by the group coordinator, individually their social identities were considerably more fragile. In situations where they were without the support of the group coordinator, participants were frequently subjected to authoritarian controls which allowed them very little power or influence over their day to day lives.
This discussion has demonstrated that empowerment of people with learning difficulties is not assured by the presence of certain pre-defined circumstances, but is dependent on diverse environmental and human elements. The most important of these may be the real or perceived power of any supporters involved in advocating with or for people with learning difficulties; the context of the advocacy attempt and the willingness of supporters to encourage empowerment of their clients. Lukes (1974.24) develops previous theories of power (e.g. Dahl, 1961; Bachrach and Barantz, 1962) and offers a three-dimensional view of power which incorporates 'consideration of the many ways in which potential issues' remain outside the advocacy arena. It also makes reference to latent conflicts within the power relationship. These can occur when there is a contradiction between the interests of those exercising power and the real [but possibly unexpressed or even unknown] interests of those they exclude. Lukes argues that it is 'highly unsatisfactory' to assume that if people 'feel no grievances, then they have no interests that are harmed by the use of power' and this was demonstrated by the hospital participants. Although they were obviously capable and would benefit from autonomous decision-making, they have experienced, through years of institutionalised life:

\[\text{the...insidious exercise of power [which has prevented them]....from having grievances, by shaping their perceptions, cognitions and preferences in such a way that they accept their role in the existing order of things, ....because they can see or imagine no alternative...} \]

(Lukes, 1974.24)

Nurse supporters of the hospital participants, although they could presumably both see and imagine alternatives to the power of 'the system', were themselves subject to institutional disempowerment and appeared to accept their role within the existing order without dispute.

The Nursing and Midwifery Council (NMC) (2002.4) stipulates that nurses 'should be aware of the potential imbalance of power' in their relationship with clients and, if nurses are to empower people who have learning difficulties, it is essential that they understand how the hegemony of their clients' present situation has been produced (Gilbert, 1995. 870). Some understanding was demonstrated by one
group of nurses when 'supporting clients to complain' was discussed as an advocacy definition. They argued that, although they sometimes supported clients to complain about external services, they did not support them to complain about the services provided by nurses. The nurses explained that this was because, while clients might complain about, for example, their day services, they were not in a position to initiate complaints about staff as they did not have the appropriate knowledge concerning the roles of staff working with them. Research by Goble (1999) confirmed this as a problem. He found that participants with learning difficulties:

....had only superficial knowledge of staff identities and roles.... and consequently lacked the knowledge and awareness necessary to negotiate what these roles might be, or even that negotiation might be possible.

(Goble, 1999.449)

It may also have been confirmed by some of the 51% of nurses who were either undecided or reported that supporting clients to complain was not or not at all relevant as an advocacy activity, and who also viewed inequalities in power as a potential barrier to successful nurse/client advocacy (table 25).

The nurse who introduced the concept of power inequality as a problem for nurse advocacy explained that in her working life, she exerted power over her clients. In a different role, she had shared power equitably with a group of people with learning difficulties and had found this experience had increased her awareness of the problems caused by unequal power relationships. She discussed attempting to share power more equally with clients by giving them information about staff roles and responsibilities, but experiencing difficulties due to the ethos of the 'system'. This failed to facilitate a more open relationship between employees and service users, thus discouraging the empowerment of clients.

6.7 Advocates
This discussion has shown how, notwithstanding the efforts of some nurses, there were many areas of their lives over which clients exercised very minimal control, and nurses were frequently put in situations where to advocate for clients requirements, needs, or even their best interests, might have placed them in a
position where there was conflict of interest with their employing Health Trust, carers or even with both. Despite this, the positional map (figure 28) illustrates that nurse informants were divided about the merits of citizen advocacy; some having experienced very successful client/advocate partnerships and others expressing deep distrust of citizen advocates.

Figure 28: Positional Map - Nurses’ views on citizen advocacy

The Welsh Assembly Government (2004) propose that there should be a range of advocacy services available to people with learning difficulties, but despite this commonly held view, Brooke (2001) argues that advocacy is ‘a role too far’ for learning disability nurses. However, in his support for citizen advocacy services, Brooke is in danger of painting an unrealistic picture. He states that:

The major task of citizen advocacy is to take time to build up trust and communication that can often take up to six months to establish and two years before significant change is achieved... Because the partnership is one to one and takes place during the leisure time of the partner, all the necessary time is available.

(Brooke, 1998.19)
This is an idealistic account of the typical time invested in citizen advocacy partnerships by volunteer advocates. Nurses in stage two suggested that a weekly visit was probably the most that clients could expect, fortnightly the most common and even monthly not unusual. A representative request for citizen advocate volunteers confirmed this, suggesting that the time commitment could be ‘a few hours a week, a phone call a week, or an afternoon a month’ (People in Partnership, 2004). Nurse informants suggested that the difference between the contemporary role of learning disability nurses employed in community based residential units and their former role working in institutional settings, was the much smaller number of clients whom they supported, and the amount of time nurses were able to put towards building relationships with clients. Most respondents to the questionnaire and all the nurse participants in the focus groups, except those in managerial positions, which necessitated administrative as well as ‘hands on’ duties, had key worker responsibility. Those in small residential settings usually had specific responsibility for only one client, with whom they work on a one to one basis, whilst also being aware of and relating to the needs of other clients.

Crawley (1990.97) proposes that learning disability nurses ‘fear that, however well intentioned, advocates may harm individuals with learning disabilities’ and there was some evidence of this in comments made by nurses who worked with clients with profound and multiple disabilities. Most nurses were confident that by observing interactions and noting their clients’ preferred activities, they were in an ideal situation to build a composite picture of each client’s likes and dislikes, and to make an informed guess as to clients’ requirements. Contrary to Brooke’s view, nurses in the study reported that citizen advocates spent only limited time with clients, often lacked commitment, failed to take account of everyday events and activities in the client’s life and were consequently less able to forge understanding relationships with clients.

Brooke argues that healthcare workers can be vulnerable to power structures within their services, while citizen advocates, being independent of these, can bring dimensions to advocacy that professionals cannot. Most of the nurses accepted this suggestion, albeit with some reservations. Professional/client
loyalties can be a problem for nurses, as can family/partner loyalties be for citizen advocates, but nurses did report occasions when citizen advocates' independence of services could be an asset to their partners. Many nurses agreed that this independence enabled them to bring a fresh approach to collaboration with clients and conceded that citizen advocates might be more likely to obtain clients' requirements.

Jenkins and Northway (2002) suggest that nurses:

...need to examine their own feelings regarding independent advocates, and ensure that they are willing to work with them in an open and cooperative manner.... to provide support for the [independent] advocate when carrying out their role.

Jenkins and Northway, (2002.11)

This must however be reciprocal. A common bone of contention for some nurses was that, although they were willing to work alongside citizen advocates, neither they, nor citizen advocates, received clear guidelines about the responsibilities and requirements of the nurse/citizen advocacy partnership. In this context, the right of clients to confidentiality was frequently mentioned. Nurses contended that advocates expected to have access to their partners' records and to meetings called on their partner's behalf, but had been unwilling to accept advice or to give reciprocal information to nurses who were ultimately responsible for the client's wellbeing.

A further strand of Brooke's argument suggests that:

Professional staff may eventually move on; with luck, an advocate provides a constant human presence in what may be a bewilderingly changeable world for many people with learning disabilities.

(Brooke, 1998.19)

Of course nurses do move on for a variety of reasons, and possibly Brooke was considering the closure of institutions and the resettlement of clients into different residential settings. However, he seems to suggest that, when this happens, clients are left without support and representation. The study showed that this was not the case. Many informants had worked with the same or similar clients for
several years and there was no evidence that all the staff involved in working with a client were likely to be redeployed at the same time. Participants who were about to be resettled from hospital, demonstrated that, where clients were moving on, there was usually a lengthy period of introduction to new staff, with an overlapping phase during which clients worked with the latter in setting up their new accommodation. Conversely, when a citizen advocate moved on, nurses reported that there was frequently a long gap where the client was without external advocacy support, or even worse, a new citizen advocate could not be found. A typical advertisement for volunteer citizen advocates described the opportunity as a ‘fantastic experience for psychology students’, hardly suggesting long term commitment from the advocate (People in Partnership, 2004). Nurses were almost always replaced, but unfortunately this was not the case with citizen advocates and, being volunteers, their situation was much more precarious than that of paid staff.

Brooke (2001) proposes that nurse advocates are likely to be focused on healthcare issues to the detriment of other concerns. Certainly respondents to the questionnaire were significantly more likely to advocate for healthcare issues than for non health related concerns, but this did not preclude them from advocating for socially oriented options. 86% of nurse respondents reported that they would advocate for their clients regarding problems with day services and 67% were likely to advocate for any or all of the ‘lifestyle’ (Brooke, 2001) related options on the questionnaire (section 5.17). Despite the difficulties which some nurses encounter with citizen advocates, most nurse informants agreed with Brooke’s contention that:

any nurse who works towards ordinary life principles should find the citizen advocate a useful, if sometimes uncomfortable, ally.

(Brooke, 1998:19)

Only a small number of respondents who had clients with a citizen advocate reported thinking this was not a positive relationship. A majority of nurses reported that they would encourage their clients to have a citizen advocate, those who would not reporting that they either lacked experience of the service or that it was not available. Several nurse respondents bemoaned the latter situation, citizen
advocates were reported to be in very short supply, even in densely populated urban localities. This was confirmed by my own experience when my attempts to obtain advocacy partners for two profoundly disabled women moving from an institution to a small residential setting were met with incredulity by the local citizen advocacy administrator. I was left in no doubt that, as my clients were being supported by a group of nurses and paid staff, they would have very low priority on the waiting list for citizen advocacy partners; a situation which was echoed by several nurses in the study.

One of the nurse participants suggested that the quintessential advocate was one who had previously worked with the client, perhaps in a professional capacity, citing, as an example, a retired occupational therapist who now had a very satisfactory advocacy partnership with one of her clients. Nurses agreed that this was an ideal, but was rarely an available option and informants suggested that, in some situations where a long term citizen advocate was not available, they might ‘bring in’ a paid independent advocate. There were some difficulties with this suggestion as independent (paid) advocacy services are not always available. Paid independent advocacy services were reported as being easily accessible to people with learning difficulties still living hospital, but these were typically dedicated to resettlement issues, although legal representation (from different advocates) was usually available to clients detained under the Mental Health Act. Respondents reported that independent advocacy services were available to less than half of the clients living in small residential settings and to only one third of those living in the community (section 5.24). They suggested that, even after referral, there was likely to be a long waiting list and advocacy would probably be restricted to short term crisis situations.

People with learning difficulties, particularly those with impaired verbal communication, were also considered likely to experience difficulty forming the necessary relationships to enable this type of intervention to succeed (Mansell and Beadle-Brown, 2004). The use of paid independent advocacy could thus only be contemplated when nurses considered the client’s problem was likely to be short lived and could be solved to the clients’ satisfaction without the need for the development of a close relationship between the client and the advocate.
Symbolic interactionism as a basis for grounded theory 'directs our attention to the detail of interpersonal interaction, and how that detail is used to make sense of what others say and do' (Giddens, 1993, 716). The situational map (figure 29)
illustrates a range of relationships between nurses, their clients and independent paid or volunteer advocates. It also shows some of the situations in which nurses might interact with independent advocacy services on behalf of their clients. All but one of the questionnaire respondents could conceive situations in which they might wish to refer clients to paid independent advocacy services, the nurse who would not objecting on the ideological ground that advocacy services should be free for clients requiring their services.

<table>
<thead>
<tr>
<th>Situation</th>
<th>Yes</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Legal purposes (e.g. Mental Health Act)</td>
<td>146</td>
<td>25</td>
</tr>
<tr>
<td>2 Residential concerns (e.g. Resettlement; moving on)</td>
<td>129</td>
<td>42</td>
</tr>
<tr>
<td>3 Representation to the Trust (e.g. regarding clients' services)</td>
<td>108</td>
<td>63</td>
</tr>
<tr>
<td>4 Financial concerns (e.g. problems with benefits etc.)</td>
<td>102</td>
<td>69</td>
</tr>
</tbody>
</table>

Table 72: Situations warranting a referral to paid independent advocacy services

Table 72 illustrates that the likelihood of nurses referring clients for paid independent advocacy services may depend on their availability. 85% of respondents reported that they would refer clients requiring legal representation, and 75% would refer clients for residential concerns, both situations for which advocacy services had been reported as widely available. The percentage dropped to 63% of respondents who would refer clients to independent advocacy for representation to the Trust, possibly due to the reliance of nurses on advocacy within multi disciplinary teams. Only 60% of nurses would refer clients for financial concerns, many nurses reported that they were able to deal with these themselves or sometimes, where this was an option, enlist the services of the clients' citizen advocacy partner.

Where availability was not an issue only 42% of nurses who had referred their clients to independent advocacy services reported that their clients had been satisfied with the service. Explanations for this revolved around relationships. The hospital participants in stage one were adamant that they would not want 'strangers' to advocate for them and nurse participants who worked in residential settings confirmed this. They suggested that their clients would prefer nurses to
advocate for them, due to the relationship of trust formed between them when working together on an everyday basis. Crawley (1990) argues that the presence of advocates can make nurses feel ill at ease, giving them a feeling of 'being watched', and there was evidence of antagonism towards both citizen and paid independent advocates by some nurses in the study. There seemed thus to be a possibility that some clients' preference for a nurse advocate might have evolved from negative attitudes to independent advocates by nurses, expressed in the presence of clients who might receive their services. Several nurse informants mentioned complex situations where an independent advocate had been employed to represent the views of clients who were opposed to treatment they were receiving, but this tended to be viewed as tokenistic by nurses, who offered evidence that it had seldom been effective for their clients.

Encouragement to join a self advocacy group was viewed much more positively by nurse respondents (section 5.23), but accessibility of such groups was cited as a problem by many nurses, and several nurses working with clients who do not verbalise, taking the individual/medical view of their clients' disabilities, expressed doubt that membership of self advocacy groups would benefit their clients. The stage one focus groups belied this and demonstrated how participants supported their colleagues who had difficulty with comprehension and with impaired verbal communication. Participants waited patiently for the less verbal to express themselves and interpreted their sign language for the benefit of myself and their supporters. They also occasionally rephrased my questions for the benefit of others in the group.

Turning from independent advocacy to nurses' perception of the ability of clients' families to advocate for them, the positional map (figure 30) illustrates the range of opinions of nurse informants in the study. Comments on this question were made most frequently by community nurses, only one of whom, in stage two of the study, had expressed the view that 'the whole family' were her concern in her dealings with clients (section 4.7). She felt that, if there was no plan for the person with learning difficulties to move away from the family home it was essential to see any problems in partnership with carers and to consider their views as well as those of the client.
This nurse was not typical. Despite the instructions of the NMC (2004), that nurses must cooperate with others in the team including the client's family, 42% of community nurses were undecided about the importance of a good relationship with carers or considered it not or not at all important to their advocacy role. 51% of community nurses also reported that conflict with carers was likely to constitute a problem for nurse/client advocacy (section 5.27). Todd and Jones (2003) argue that:

...time needed to get to know and build trust is a key but lacking quality in [parents'] ...dealings with professionals.

(Todd and Jones, 2003:238)

and the comments of the community nurses acknowledged that, due to team policies, they spend only limited time with their clients, and that this meant they
had only partial understanding of the needs of the family, so that any decisions would be made based upon limited knowledge' (Todd and Jones, 2003.238).

Parents in Todd and Jones’s study wanted to advocate for the needs of their sons or daughters with learning difficulties, but felt that they risked alienating themselves from professionals, who were the key to services for their offspring. They also felt under constant scrutiny by professionals. Many of the comments in the survey reflected the value judgements by nurses of which parents in various studies (Todd and Jones, 2003; Shearn and Todd, 1997) were conscious. Although some community nurse respondents reported very satisfactory experience of family as advocates, the majority disagreed, frequently confirming the findings of Shearn and Todd (1997.294) that ‘standards of appropriate parenting were not shared’ between themselves and families of people with learning difficulties and that:

On the one hand, service workers criticised [mothers] for being overprotective, and on the other, expected them to fulfil the role of being the ‘always accessible’ parent when it was convenient for service workers.

(Shearn and Todd, 1997.294)

Todd and Jones (2003.241) argue that the ‘increasing involvement of parents in the professional network ...has led to further promoting and advocating for the rights of people with intellectual disabilities’ but that mothers continued to feel that they were ‘stereotyped, devalued and judged’. Many of the comments of informants seemed to validate this view. One community nurse remarked that ‘mothers are awful people really’ and others made derogatory remarks. Williams and Robinson, in their research on conflicts of interest reported that:

Many parents did feel strongly that they could interpret what their son or daughter wanted to do during the day [and] ... in the vast majority of cases this did not lead to conflict with the disabled person, but rather, with service providers, who might interpret the needs of the person differently

(Williams and Robinson, 2001.40)

Some of the community nurses demonstrated their unwillingness to value the knowledge of parents regarding their progeny with learning difficulties, and a sense of ‘believing they were right and that...parents .....should always do as they
suggested' (Maxwell and Barr, 2003.58). Neither did these nurses acknowledge the possibility, expressed by some participants in stage one, that, although there were some exceptions, most people with learning difficulties living at home, were accustomed to, and happy with their parents advocating on their behalf.

The opinions of nurses working in residential units were different, many of them valuing the contribution of relatives as advocates for their clients. Over 70% of these respondents had reported 'a good relationship with carers' to be important or extremely important to their advocacy role, a significantly higher number than that of community nurses (p=0.05) (section 5.27). Nurses from the short term assessment unit particularly welcomed the continuing involvement of their clients' families, acknowledging that they knew their offspring well and would usually be willing and effective advocates for them. Respondents working in long term residential units considered it unlikely that conflict with clients' families would impinge on their advocacy role, although the possibility was higher for those holding key-worker responsibility who were the first point of contact for families of clients living in these units.

<table>
<thead>
<tr>
<th>work area</th>
<th>can family members advocate satisfactorily for clients?</th>
<th>is advocating in personal life the same or different from advocating for clients?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
<td>no/unsure/no experience</td>
</tr>
<tr>
<td>hospital</td>
<td>15</td>
<td>33</td>
</tr>
<tr>
<td></td>
<td>31.3%</td>
<td>68.7%</td>
</tr>
<tr>
<td>other residential</td>
<td>18</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>40.9%</td>
<td>59.1%</td>
</tr>
<tr>
<td>community</td>
<td>17</td>
<td>63</td>
</tr>
<tr>
<td></td>
<td>21.3%</td>
<td>78.8%</td>
</tr>
</tbody>
</table>

Table 73: Comparison of nurses' opinions regarding advocating in their own personal lives (for example for children or elderly relatives) and the ability of clients' families to advocate for them

Comparing the views of nurse respondents on whether or not clients' families could advocate satisfactorily for them with their perception of whether advocacy in their own personal lives was the same or different from advocating for clients (table 73) revealed that 7% of nurse respondents had not experienced advocating
in both their personal and professional lives and 50% of nurses reported thinking advocacy would be the same in both roles (section 5.16).

Although almost half of the community nurses thought that their advocacy role would be similar both personally and professionally, presumably considering themselves able to advocate satisfactorily for both their clients and family members; only 21% considered that the families of clients' could advocate satisfactorily for them. 48% of nurses working in hospital thought advocacy would be the same personally and professionally, with only 31% considering clients' families would be satisfactory advocates, while in 'other residential' services the differential was less, with 52% considering they would advocate the same in both their roles and 41% viewing clients' families as satisfactory advocates for them. Many of the hospital nurses and those working in residential services reported that clients had lost touch with their families, either because they were elderly or because they had spent many years in institutions (section 5.28) and gave this as their reason why families would not make satisfactory advocates. However the comments of a minority of these respondents and of the majority of community nurses illustrated that, while they considered they could advocate satisfactorily for their own family members, they assumed the situation was different for families with a member who had learning difficulties and thus felt it unlikely that the families of clients could advocate satisfactorily for them.

Responding to the question 'Do you consider clients who have an advocate receive better services than those who do not?', several nurse respondents considered that clients with an advocate might receive preferential treatment, but regretted this. They argued that advocates were not available to all clients and some were much more effective than others. Clients who had an advocate were judged likely to be those capable of requesting one and would therefore, given appropriate information, be competent to advocate for themselves to improve their provision. Despite their varied views on advocates, the majority of nurses accepted that services in general responded more efficiently when clients were supported by external advocates (section 5.28).
6.8 Advocacy education

One of the prime purposes of this research was to consider the implications of the results for the education, ongoing support and training in advocacy of learning disability nurses. Foley et al (2002) found that empirical articles in the literature concerning nurse advocacy 'contain[ed] no mention of how advocacy is taught or how advocacy is learned' and Gates (1994.77) also points to the 'absence of relevant research on teaching and learning about advocacy'. Pertinent literature remains sparse, although websites of various advocacy organisations, for example 'People First' and 'People in Partnership' publish material relevant to their advocacy activities. A search of nursing data bases, using the keywords 'advocacy' and 'teaching' resulted in 19 references over the past five years, but only two articles in nursing journals since 1999, one of which was heavily biased towards nurses working in the American public health sector. The one relevant article exemplified the argument of Gates (1994.76) who questions 'the unproblematic portrayal of both the adoption and practice of advocacy by nurses' in the literature, which does not demonstrate the 'inherent tensions that a nurse may experience should she choose to act as patient advocate' (Gates, 1994.78). A useful narrative was provided, with accompanying case studies, on ways in which nursing students and junior nurses learn advocacy, but only passing reference was made to 'difficult situations involving interventions on behalf of patients' (Foley et al, 2002.185). Many of the nurse informants in this research reported receiving 'information packs' from various self and citizen advocacy groups as their only source of education in advocacy, and these also stress the positive aspects of advocacy and advocates.

Nonetheless, nurses were very aware of the potentially stressful conflicts inherent in advocating for clients. Over 70% of nurse respondents reported experiencing conflicts of interest with employers as a problem for nurse advocacy and this rose to 91% of those with key worker responsibility for one or more clients. 54% of nurses also suggested that conflict with carers could cause difficulties for a nurse/client advocacy partnership and many nurses reported both interpersonal and intrapersonal conflict in their advocacy roles (section 5.19). None of the nurses specifically suggested this as an area which should be addressed by
advocacy education, although it was implicit in their proposals concerning who should be involved in teaching advocacy and how this should be done.

Many of the nurses considered there was a big difference between learning about advocacy and learning how to advocate (section 5.30). They reported receiving quite detailed theoretical education about advocacy, but still feeling unprepared to actually take on the advocacy role for their clients. Foley et al (2002.185) found that nurses learned advocacy partly by 'watching other nurses interact with clients' and emphasised the importance of 'role modelling in how nurses deal with patients'. Informants in the research agreed this was important and some doubted whether nurses could be taught 'how to' advocate, arguing that competence came with experience, rather than with formal teaching (figure 31). Others disagreed and made many suggestions as to how and by whom the activity of advocating could be taught.

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Figure 31: Positional Map – The difference between learning about advocacy and learning how to advocate

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Gates (1994.79) proposes that 'nurse teachers [may] ...have lost touch with some....aspects of the profession which they teach'. Several respondents agreed, particularly specifying 'not lecturers' in their suggestions as to who would be suitable teachers of advocacy.

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Gates (1994.81)</th>
<th>Research informants</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>The various types of advocacy</td>
<td>Self-advocacy Citizen-advocacy Legal advocacy Collective/class advocacy</td>
</tr>
<tr>
<td>3</td>
<td>An analysis of a professional operating as advocate within a variety of contexts and of the inherent problems</td>
<td>Role stress and strain Multiple loyalties and conflict Dangerous and hostile environments</td>
</tr>
<tr>
<td>4</td>
<td>The use of networking agencies and other independent advocates</td>
<td>Effective inter-agency communication skills Assertiveness skills Negotiating skills</td>
</tr>
<tr>
<td>5</td>
<td>Dealing with conflict and seeking support during stressful periods</td>
<td>Recognition of conflict Interventions to reduce conflict Ability to maintain own health</td>
</tr>
<tr>
<td>6</td>
<td>Evaluation of advocacy schemes</td>
<td>The nature of evaluation Quantitative and qualitative approaches Summative and formative strategies</td>
</tr>
</tbody>
</table>

Figure 32: ‘Six dimensions and indicative contents for the teaching of advocacy’ (Gates, 1994.81) with additional contents as suggested by nurse informants in the study
Most respondents argued for a range of teachers, typically suggesting 'lecturers or independent advocates for the theory' and others for the practical issues. Several nurses included people with learning difficulties in their list of possible advocacy trainers, arguing that many self advocates were accomplished and eager speakers and could demonstrate how it felt to be 'at the receiving end' of nurse advocacy.

Gates (1994.81) offers six ‘proposed dimensions and indicative contents for the teaching of advocacy’. Most of these were confirmed as desirable by informants in the research. Nurses also made additional suggestions, some of which reflected the evolution of opinions in the ten years since Gates' work was published, and others emerged as empirical findings in the research. These have been appended to Gates' analysis of the six dimensions listed in figure 32.

Almost all the respondents agreed that there was a need for theoretical teaching, including legal and ethical issues surrounding advocacy. In this context, just over half the nurses had received education in the Human Rights Act (1998) but almost all agreed that it would be useful within the context of advocacy education (section 5.33). Relatively frequent and specific mention was made of the need for education about issues surrounding clients' 'capacity' to make choices and the designation of 'appropriate adults' within the definition of the Mental Health Act.

Foley et al (2002.185) argue that 'new learners...need specific situations and examples to better comprehend the concept of advocating'. While agreeing with this, the majority of informants in the study opted for a mix of theoretical and practical education and training, with case studies and role play being popular suggestions as to how the latter could be achieved (section 5.31). Some nurses suggested a need for ongoing support in advocacy relating to their specific clients, and several nurses argued that advocacy was not static and that legal judgements involving, for example, the Human Rights Act and the Disability Discrimination Act might affect their advocacy practice. These nurses suggested that, as relevant legal or ethical cases were publicised, it would be useful to have a forum where nurses who were interested, or who felt they might be affected by these issues could discuss them in an open and non confrontational manner, perhaps with senior management or with 'experts' brought in for this purpose. The forum could
also illustrate the connection between ‘text book knowledge and nursing skills’ (Foley et al, 2002.186), by featuring talks by nurses about specific situations in which they had advocated for clients. These could be used ‘to define and promote knowledge and skill’ (Foley et al, 2002.186) related to advocating for people with learning difficulties.

6.9 The advocacy role of the learning disability nurse

94% of the nurse respondents reported that the nurses’ advocacy role was important and a very high number of these appended comments in support of their views (section 5.34). Allmark and Klarzynski (1992) argue that:

...the role of the nurse and that of patient advocate are incompatible. ....the main sources of this incompatibility are the non mandated nature of the nurse advocate and the fact that the nurse is a member of the healthcare team that [provides the services] ...which the patient may desire to advocate against.

(Allmark and Klarzynski, 1992.36)

I have already mentioned potential problems concerning the non-mandated nature of nurse advocacy although this was not mentioned by respondents to this question. Five nurses who were unsure about the importance of the advocacy role cited unease related to possible conflicts of interest if clients wished to advocate against the services provided by their employing Trust. Only one nurse categorically stated that the nurses’ advocacy role was not important, arguing that unsuccessful advocacy by nurses might prevent a more satisfactory outcome being obtained through an independent advocate.

Smith and Godfrey (2002.301) in their study examining the perceptions of nurses concerning what it means to ‘be a good nurse and do the right thing’ identified ‘advocacy’ as one of the characteristics which were essential to this endeavour. Many of the respondents agreed with this. Nurses who had been with clients through the process of resettlement from hospitals to small residential units felt particularly strongly that, even though these were undoubtedly changes for the better, they were still stressful for clients. They appreciated that clients were likely to have positive views about nurses as their advocates, and to dislike the idea of independent advocates, with whom they did not have a relationship, advocating for
them. In order to do ‘the right thing’ these ‘good’ nurses felt they had a duty to advocate, working in partnership with their clients at a pace and intellectual level decided by their knowledge of each other and their established relationships.

Willard (1996.65) argues that pro-advocacy literature served the covert purpose of ‘discovering a specific and unique role for nurses...’ and Parrish and Birchenall (1997) argue that nurses’ advocacy role has been viewed as making them more valued. In contrast, Snowball found that nurse informants in her research:

...appeared quite clear that the cultural environment in which care is situated and advocacy occurs should be one which values all contributions equally and which puts the [client]..., rather than any member of the healthcare team at the powerful centre of care.

(Snowball, 1996.73)

Despite this contention, some of the respondents took the former view and, while agreeing that their advocacy role was important, viewed it more in terms of the ‘added dimension’ which advocacy might bring to learning disability nursing. They reported that, for them, advocacy was primarily an activity through which they could fight for their own rights and enhance the status of learning disability nurses, rather than, or at least in addition to, one from which their clients might benefit.

The majority of nurse respondents saw themselves ‘as part of a holistic response... to meeting the needs of people with learning difficulties’ (Daniel, 1994.8). Several nurses accepted the argument that:

...advocacy is regarded by professional organisations, nurse educationalists and the Welsh [Assembly]... as being an essential part of the role of the nurse...

(Wheeler, 2000.40)

They viewed their advocacy role as growing in importance, due to the changing needs and expectations of their clients and to the likelihood that they would be expected to respond, on behalf of their clients, to new political initiatives such as Person Centred Planning. Gates argues that:

...nurses can and should act as advocates in some circumstances. However, such a decision should be grounded in a full understanding
of the possible consequences of enacting such a role. Nurses should not be made to feel guilty and obliged to act as advocates when, for either personal or professional reasons to adopt the role would cause them distress. Rather nurses should recognise the importance of an independent advocacy scheme, to which they are able to make a referral.

(Gates, 1994.26)

Many nurses agreed with this assessment and were clear about the circumstances and reasons why they would advocate for clients. However, they were also aware of problems with accessing independent advocacy services, and commented that, as possibly the only professionals trained specifically in the care and support of people with learning difficulties, it was their 'duty' to advocate for the vast majority of their clients who might otherwise, in the present climate of rationing resources, fail to receive the health and social care to which they had a right.

The preceding discussion has illustrated how some nurses perceived that their advocacy role had changed and was evolving in the contemporary political environment. Only 25% of the nurse respondents to the survey did not think their advocacy role had changed since they qualified. Half of these had qualified since 1995, at least ten years after the philosophy of support for people with learning difficulties changed from one of authority and control to one of facilitation and enablement (section 5.35).

The positional map (figure 33) illustrates the changes mentioned by nurses. Opinions were divided as to whether or not there was an increased demand for nurse/client advocacy and this appeared dependent on informants' employment situation. Community nurses, working in the modern resource oriented 'situation specific' way now demanded of them, reported being more likely to advocate for their clients in 'crisis' situations, but less likely to advocate in long term, ongoing situations. Nurses working in small residential units or in hospitals cited changing political and environmental conditions as affecting their advocacy role. Almost all the nurses agreed that there was still a definite place and even, on occasions, a 'duty' for learning disability nurses to advocate for their clients.
There have been changes in the advocacy role. As we are now out in the community we are wholly responsible for our residents in their own home. The learning disability nurse is now responsible for clients' services, financial purposes, residential concerns, maintenance of property etc; daily care, medical care and regular contact with relatives. The nurse may need to advocate concerning any or all of these. (Stage 3, comment)

The advocacy role has changed. Political and financial aspects of service provision have become more prominent, hence the advocacy role of the individual central to departmental processes has increased (Stage 3, comment)

I'm unsure whether the advocacy role has changed. Advocacy was a 'hot' topic when I qualified, now it is part of my everyday job, however, there is conflict and access to independent advocacy is extremely difficult. (Stage 3, comment)

I'm unsure whether the advocacy role has changed. Most nurses recognise advocacy as essential but changes in structures of teams and ways of working mean we are less involved than previously in some aspects. In our area, we work less closely with support services and team changes are towards shorter pieces of work on focused referral issues. This means we get less involved in advocacy concerning the 'bigger picture'. (Stage 2, interview 2)

The advocacy role has not really changed. Nurses have always been required to contribute to advocating for a client as they often know the client well. Nonetheless there can be a conflict of interests due to professional status. This can never really change (Stage 3, comment)

No my role has not changed. I still believe in the same principles of practice as when I qualified and hope others do too, even though financial and political constraints exist (Stage 3, comment)

Figure 33: Positional Map – Perceptions of whether the advocacy role has changed since nurse respondents qualified

6.10 Reflections on the methods used
Reflecting on my study in terms of methodology and methods, I acknowledged some limitations of the research (section 7.2) but felt that the methods had enabled valuable knowledge to be accrued. Advice offered by Strauss and Corbin (1998) concerning mixed method work is to ‘think in terms of the interplay between qualitative and quantitative methods’. While data from stages one and two had inspired the design of the questionnaire, in its turn, statistical information from the survey expanded the qualitative data. Revisiting the qualitative data had then revealed explanations for some of the statistics obtained, thus completing the interplay described by Strauss and Corbin (figure 34).
Stage 1
People with learning difficulties suggest that long term relationships are extremely important to the nurse/client advocacy partnership.

Stage 2
Relationships discussed by community nurses who report that they now work in a short term 'situation specific' way with clients, rather than in a long term way that would facilitate relationships. Long term relationships are less attainable and are thus no longer considered of major importance to their work.

Stage 3
Design of question q1e2 in questionnaire: 'How important are long standing relationships with clients to a satisfactory nurse/client advocacy partnership?'

Stage 4
Statistical analysis finds that a significantly higher percentage of nurses working with clients with the whole range of communication skills were undecided about the importance of long standing relationships with clients or reported them to be not or not at all important, than nurses working with clients who have either adequate or no verbal communication. The former are also significantly more likely to work in the community.

Conclusion
Relating statistics from stage 4 to discussion of relationships in stage 2 reveals that the 'situation specific' work patterns of community nurses may cause problems for their attempts at nurse/client advocacy.

Figure 34: Example of interplay between qualitative and quantitative data

Situational maps 'are intended as supplemental approaches to traditional grounded theory analyses' (Clarke, 2003.554) and move away from the reductionist approach of the latter. The maps centre on:

...the key elements and conditions that characterise the situation of concern in the research project.... Situational analyses can deeply situate the research individually, collectively, social organisationally and institutionally, temporally, geographically, materially, culturally, symbolically, visually and discursively.

(Clarke, 2003.554)

The method proved a useful adjunct to the grounded theory approach and I used the maps extensively. Situational and world arenas mapping directed my thoughts and influenced more detailed analysis of the data; and positional maps enabled me to illustrate the varying positions taken by informants to different aspects of the advocacy role of learning disability nurses.
Slevin and Sines (1999) offer a ‘manifold of methods used to enhance research credibility’. These include:

- Use of a constant comparative method
- Internal consistency checking
- Convergent truthfulness evaluation
- Respondents and expert involvement
- Providing candid narrative accounts and an audit trail
- Utilising a reactivity analysis framework
- Transferability enhancement methods
- Providing rich and dense data

Elements of all these methods were used during this research and I was confident that participants’ views on all aspects of advocacy were valid and that the resultant representations of the advocacy role of learning disability nurses were credible. I did not expect to find one ‘all inclusive’ definition of advocacy, neither did I consider there would be a single explanation of the advocacy role of learning disability nurses. Mapping facilitated the integration of data from all the different research sites into the emergent theories from the research. It also enabled me to incorporate quantitative and qualitative data gained through the survey of a large number of learning disability nurses from across Wales into data generated by stages one and two of the study and to better explore the complexity of the advocacy role of learning disability nurses.

6.11 The project map
This complexity is demonstrated in the project map (figure 35) which illustrates and summarises the inferences derived from the mass of collected data. In the final chapter of this work I draw conclusions from these points and make recommendations both for possible areas of further research and for the furtherance of the advocacy role of learning disability nurses.
Support and supporters

Definitions of advocacy – People with learning difficulties
- Speaking for people
- Interpreting for people
- Treating people as adults and consulting them about things that concern them
- Supporting people to complain if they think they are being treated badly or if something is unfair
- Supporting people to get to know people in the community and encouraging people in the community to get to know people with learning difficulties
- Ensuring people have information they can understand

micro level advocacy = 1
meso level advocacy = 2
macro level advocacy = 3

1+3-2 = limited empowerment
1+2+3 = empowerment through advocacy

The ‘system’

Available opportunities

Learning disability nurses

Similarities and differences in definitions.
- May agree only with what is attainable.
- May see advocating for clients as a duty.
- Best interests.
- Rights – popular definition not overtly explicated.

Importance of support
- Models of disability/advocacy support (Goodley, 1998) Social model preferable but not always used. Medical model prevalent with clients who do not speak. May be directed by resources.

Training

Resources

Relationships

Crucial for people with learning difficulties; not seen as hugely important by nurses.
- With families, with independent advocates, with multi disciplinary team, with the ‘system’
- Community nurses - relationships with families

Work area + employment area

Barriers to advocacy

Conflicts of interest with employers.
Conflicts of interest with families
Inequalities in power relationships
Institutional disempowerment
Intra/inter personal conflict
Requirement for ‘situation specific’ working
Frequent link with resource issues

Education, support and training

Pre-qualification – theory and practice
Post-qualification – related to specific client group
- Variety of teacher/trainers, not necessarily academics
- Ongoing support related to legal, ethical and health issues
- Training related to relationships with independent advocates
- Forum for non judgemental discussions

Legislation

Figure 35: Project Map – Important elements of the advocacy role of learning disability nurses

KEY

<table>
<thead>
<tr>
<th>Important elements of nurses' advocacy role</th>
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<td>Influences</td>
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Conclusions and recommendations.
7.1 Introduction
The aim of this study was to explore the advocacy role of learning disability nurses. More specifically, there were six objectives by which this aim would be achieved:

1. To determine what people who have learning difficulties mean by advocacy.
2. To enquire whether they want learning disability nurses to advocate for them and/or whether they think nurses have a role in helping them to advocate for themselves.
3. To ascertain what learning disability nurses understand by advocacy and whether this is similar to the meaning given by clients.
4. To enquire whether nurses are undertaking advocacy for their clients, and in what way.
5. If learning disability nurses do advocate for their clients, to explore any specific problems concurrent with this role.
6. To consider the implications of the above for the education, ongoing support and practice of registered nurses (learning disability).

In addition to these, and of equal importance, was the intention to use definitions of advocacy and their advocacy requirements, obtained from people with learning difficulties, as the foundation of a grounded theory study.

As with most research the study had some limitations and, in this chapter, I acknowledge these before drawing conclusions and making recommendations based on findings from the study. The chapter ends with comments regarding the value of the study and the presentation and dissemination of the research findings.

7.2 Limitations of the study
As this study progressed, some deficits in the research design became obvious. I had been keen to obtain a variety of advocacy definitions and opinions about advocacy and advocating from people with learning difficulties, and to make this information the cornerstone of the study. I had thus selected three very different research sites for the first stage of the research, each in an accessible area where people with learning difficulties were willing and able to participate in the research. Participants from the hospital were supported by nurses and/or nursing assistants who were their main contacts, not only in advocacy situations, but in their
everyday lives. However, neither the day centre participants nor the self-advocates had regular contact with learning disability nurses, relying for their advocacy support on day service officers (in the day centre) and their coordinator (in the self advocacy group).

The research revealed many definitions of advocacy some of which were shared by participants from all the different sites (sections 3.4 and 3.5), and many of their requirements for advocacy support were also similar (section 3.6). Nonetheless, the ways in which different participants were supported, both within the focus groups and also in their everyday lives, were very different (section 3.9). In retrospect, it would have been useful to include at least one group of people with learning difficulties who had lived for a reasonable period of time in a community based ‘continuing health care’ setting, supported on a day to day basis by nurses. This would not have been easy as most local ‘continuing care’ units were not operational when I conducted stage one of the study, but it could be useful to focus on this area in future research of this nature.

The six Health Trusts involved in the research were in very different locations, some being in sparsely inhabited rural areas and others in densely populated industrial and commercial centres. Interesting comparisons could have been drawn between the advocacy role of learning disability nurses and also between the availability of independent advocacy services for people with learning difficulties in these different areas. These were precluded by ethical requirements to preserve the anonymity of the Health Trusts in the study.

I had few reservations concerning the use of Clarke’s situational mapping and analyses. The post modern approach seemed particularly useful in a multi-site project of this type (section 2.6). However, despite Clarke herself offering advice and being supportive of my endeavour (section Int.4), this was something of a ‘leap in the dark’, depending largely on my own interpretation of the method from the limited information I obtained. Unlike the grounded theory approaches of Glaser and Strauss (1967) and Strauss and Corbin (1990), the method has not been tested exhaustively, and this may be considered by some to be a limitation of the research. I would not agree. I found situational mapping and analysis exciting
and stimulating and consider that Clarke's method facilitated in depth, comprehensible explanations of the advocacy role of learning disability nurses as well as adding a dimension of originality to the study.

Conclusions

7.3 Conclusions about the conduct of stage one of the research
People with learning difficulties were very willing to take part in the research but their participation was affected by the support they received. This ranged from very minimal intrusion by supporters in the day centre groups, where the atmosphere was comfortable and the participants needed very little encouragement to express their opinions; to some quite aggressive intrusions by at least one supporter in the hospital groups. This had a stultifying effect on the participants, who were already disadvantaged by their institutionalised lives and lack of opportunities. The coordinator of the self advocacy group tended to encourage participants there to consider only the positive aspects of their advocacy experience and to discount their obvious disempowerment in some aspects of their lives (section 6.6). Despite these reservations, focus groups with people with learning difficulties were a very satisfactory method of data collection and resulted in a much wider picture of their experience of advocacy than would have been the case had one to one interviews been used. Participants illustrated how the availability of support which complied with the social model (Goodley, 1998), and was available on a day to day basis, resulted in confidence and a sense of empowerment for people with learning difficulties. Empowerment through advocacy was demonstrably 'developmental' (Kieffer, 1984) depending on the situation of participants and the nature of the support offered (section 6.6).

Some of the participants with learning difficulties took part in a 'feedback' session where they verified my interpretation of the data from stage one before it was incorporated into the design of the focus groups and interviews with nurses and the questionnaire survey. We met as partners and they showed great interest in the forthcoming stages of the study. I concluded that they had gained satisfaction from their participation in the study when I was invited to be their guest at the Annual General Meeting of the Area Self Advocacy Groups which took place after our meeting.
7.4 Conclusions about the conduct of stage two of the research
The focus groups and interviews with learning disability nurses were lively and enlightening. The standing of participants with learning difficulties was enhanced when the nurses showed great interest in their definitions of advocacy, obtained in the first stage of the study. Used as a ranking exercise, these definitions were the catalyst for animated and informative discussions in the focus groups (section 4.6). The ranking exercise was less successful in one to one interview situations, but the two community nurses involved nonetheless made very useful contributions to the study. One had a 'clinician only' role, very different from the other community nurses in the research, and her view of advocacy for her clients thus expanded the information gained in stage two.

7.5 Conclusions about the conduct of stage three of the research
This was my first foray into survey research and my first attempt at a mixed method study. It offered an opportunity to expand on the single empirical study into advocacy in learning disability nursing (Blackmore, 2001). With hindsight, I might have ordered the questionnaire and worded some of the questions differently. However, taking Strauss and Corbin's (1998) advice regarding the interplay between qualitative and quantitative data and extending their reductionist grounded theory approach with Clarke's (2003) situational analyses and mapping proved both innovative and interesting. It also yielded data which I consider has added significantly to the understanding of the advocacy role of learning disability nurses (section 6.10).

7.6 Conclusions about definitions of advocacy by people with learning difficulties
The definitions of advocacy gained from participants with learning difficulties formed a useful basis for the rest of the study. There was no dominant notion concerning advocacy, instead, definitions depended on the situation of the participants, the opportunities available to them and the accessibility, willingness and style of advocacy supporters. They ranged from purely reactive micro advocacy, through to advocacy at a proactive macro level. In all but the more mundane circumstances participants required advocacy support either from someone who would assist and support them in self advocacy or someone who would advocate for them (section 3.9).
Participants with learning difficulties had certain requirements of anyone who might act as their advocacy supporter. They considered relationships between themselves and any possible advocate to be of the utmost importance, and reported that these should preferably be long term, enabling the development of mutual trust and understanding, which they also considered vital to a successful advocacy partnership. Some people with learning difficulties have problems with verbal communication and looked to others with whom they were familiar for support and assistance (section 3.6). These were sometimes their peers with learning difficulties.

Supporters of people with learning difficulties living in community based situations worked with their clients according to either the medical or the social model of disability and sometimes alternated between the two. Clients of those who conformed with the social model were demonstrably more confident and displayed a sense of empowerment not obvious in those for whom support veered towards the individual/medical model. Participants with learning difficulties in the research, even some with severe disabilities and verbal communication problems, demonstrated that, if supporters adhered to the social model, showed confidence in their ability and provided appropriate support, they could advocate for themselves and achieve great satisfaction from this activity (section 3.4).

7.7 Conclusions about definitions of advocacy by learning disability nurses
Nurses validated all the definitions of advocacy obtained from participants with learning difficulties and extended them. They were significantly less likely to consider the definitions of advocacy offered by clients as relevant or extremely relevant to their practice than those generated by either nurses or by client/supporter interactions. This was particularly so in advocacy concerning the 'community presence' of people with learning difficulties, despite the undoubted evidence that this had greatly improved the lives of some clients. Participants with learning difficulties defined advocacy according to their own, sometimes limited, experiences, but nurses tended to view advocacy from a wider perspective. This included their aspirations for clients in terms of their individual rights and also for
the rights of people with learning difficulties in general (section 6.3). Clients’
definitions tended to be viewed as more relevant when they complied with nurses’
ideas as to what might be appropriate within a given situation. Some nurses
associated this with the inequity in power between themselves and their clients.

Despite the argument of Mitchell (2004.116), that the ‘image attached to nursing
contributes to the stigma of learning disability’; their designation as nurses was
viewed as extremely important by those advocating for health care for their clients.
They reported that advocacy between themselves and other health professionals
frequently resulted in treatment being offered to clients which might otherwise not
have been considered. Nurses were significantly more likely to advocate for the
health related needs of their clients than for the socially related options defined by
people with learning difficulties (section 5.17).

7.8 Conclusions about the ways in which nurses advocate for clients
Nurses demonstrated that they had many different advocacy roles. These varied
according to their work situation, the clients with whom they work and also the
availability of other agencies which could, if necessary, be called upon to advocate
for clients. Some nurses tended to advocate according to a paternalistic ‘best
interests’ model, although most viewed best interests only as a ‘starting point’ for
advocacy (section 6.3).

Nurses reported that they advocate for their clients in a multiplicity of
circumstances related to both health care and social situations (section 5.17).
Nurses with key worker responsibilities were extremely likely to advocate for the
former and also attributed their success in this field to their status as nurse
advocates (section 6.3).

Some nurses felt obliged to advocate according to the individual model of disability
due to the implications of adopting a different approach. This did not just occur
when socially based activities were unavailable to clients in ‘continuing health
care’ situations, but also in more insidious ways when community nurses were
obliged to work in a ‘situation specific’ manner which precluded long term
relationships with their clients (section 6.3).
7.9 Conclusions about problems with nurses’ advocacy role

Nurses accepted that there are different levels of advocacy Goble (2002). Most of them asserted that they advocated regularly for clients on a mundane, day to day basis. Many reported that they could not advocate in what they referred to as the ‘true’ sense, due to conflicts of interest between themselves and their employing Trust (section 5.19). Some nurses considered that advocating within a multi disciplinary team was a satisfactory answer to this, but did not reflect on the potentially disempowering effects of this approach. Others spoke of using independent advocacy services in these situations although the availability and efficacy of independent advocacy services is not uniform in all areas (section 5.24).

Many clients in residential units had lost contact with their families, and the latter were not seen as suitable advocates by all nurses. Community nurses were most likely to hold this view, often failing to recognise that the experience of families caring for a son, daughter or sibling with learning difficulties was likely to result in considerable knowledge of their needs and requirements (section 6.7).

Approximately half the nurse informants accepted that inequity in power between themselves and their clients constituted a problem for nurse advocacy. This was frequently demonstrated when nurses withheld information from clients either purposely or more insidiously. Attempts to address power inequalities by providing information about staff roles to clients had been adversely affected by the ethos of the ‘system’ which disempowered both staff and clients in some situations (section 6.6).

Several nurses spoke of advocacy as a ‘duty’, a ‘must do’, as they perceived an absence of other suitably trained and experienced persons who would represent their clients. In these circumstances they advocated for clients despite the possibility, mentioned as a reality by some nurses, that they might suffer recriminations from management and colleagues (section 6.6).

The effects of, and solutions to, conflicts in advocacy were dependent on the work area of nurses. Nurses working in residential units were unlikely to advocate for
'social' advantages for their clients, due to conflicts of interest between themselves and their employers (section 4.7). Community nurses found it relatively easy to advocate within their multi professional teams for 'social' benefits for their clients, as well as for the health related advantages associated with their clinician role. Conflict for these nurses was more likely to arise on an intrapersonal level due to clashes between the clinician and case manager aspects of their role and on an interpersonal level with the families and carers of their clients (section 6.7). Community nurses recognised the potential for conflict if they attempted to advocate to clients' families on their behalf. In these circumstance they tended to encourage and support clients to self advocate, rather than risk their own, sometimes apparently understandably, fragile relationships with carers (section 6.7).

Many nurses lacked knowledge about the availability of independent advocacy services in their particular area, how to access these and when it was considered appropriate to do so (section 5.24). They also reported concerns about confidentiality issues related to sharing information about clients with their citizen advocacy partners (section 5.20).

7.10 Conclusions about nurses' advocacy education
Whereas definitions of advocacy, advocacy relationships, nurses' advocacy role and problems for nurse advocates varied considerably according to the situation, the type of clients, nurses' work and employment areas and the availability of alternative advocacy services; nurses' views on education and their educational requirements were much more stable. 50% of nurse respondents had not had, or could not remember receiving any formal education in advocacy. The percentage was even higher in those who qualified prior to 1985. Nurses who qualified between 1986 and 1994 were significantly more likely to have received advocacy education than those who qualified before or after those dates (section 5.29).

The majority of nurses considered that advocacy education would be useful. Education about the theory of advocacy was felt to be appropriate at pre-registration level, but nurses also expressed a need for ongoing training in advocacy relating to the Mental Health Act (1983), the Disability Discrimination Act
(1995) and the Human Rights Act (1998) (section 4.9). Some nurses were involved in NVQ training and, in this context, suggested they would be teaching 'everyday' advocacy to unqualified support staff. Many nurses who had received formal education in advocacy were dissatisfied with their training in the functional aspects of how to advocate for clients (section 5.30). They felt that ongoing practical advice within their own work context would be useful both for their own advocacy practice and for the training needs of others (section 5.31).

Nurse educationalists were seen as appropriate teachers of the formal theoretical aspects of advocacy, mainly at pre-qualification level, but nurses felt that a variety of people, knowledgeable in the operational aspects of advocacy and advocates, including people with learning difficulties who have been at the receiving end of advocacy attempts, should be involved in their practical, usually post qualification, advocacy training (section 5.31).

**Recommendations**

Based on the conclusions above a number of recommendations for practice, education and research are appropriate:

7.11 **Recommendations about practice**

- Nurses must be aware of different models of disability and of advocacy support and should, whenever possible, adhere to the social model.

- Nurses need to remain aware of the health situation for people with learning difficulties in Wales, relate this to the needs of their particular clients and, where necessary, advocate accordingly.

- Nurses should ensure that any potential advocate has a good relationship with the client before advocacy support is offered. Nurses could usefully enlist the help of other people with learning difficulties from within the same setting as advocacy supporters for clients who do not speak.

- Nurses need to acknowledge the importance for clients of opportunities to increase and enhance their community presence. Nurses may need to advocate on their clients' behalf to facilitate these activities.

- Nurses should consider the possible disempowerment of their clients and/or themselves before advocating within a multi disciplinary team in cases
where there may be conflicts of interest.

- Nurses should be aware of the inequity in power between themselves and their clients and seek to minimise this. This might involve seeking acceptable ways to advocate against their own disempowerment by ‘the system’ within which they are employed.

### 7.12 Recommendations about advocacy education

- Theoretical training in advocacy should be provided at pre registration level. Practical advice should also be offered at this stage.

- Ongoing practical advice about advocating for clients should be available to practising nurses within their own work context.

- Education at all levels should not be provided only by nurse educationalists. A range of teachers of different aspects of advocacy should be provided.

- Information about the availability of independent advocacy services should be obtainable by practising nurses, who should be given details concerning when it is appropriate to access these services and how to do this. Training should be offered to nurses regarding their interaction with citizen advocates, particularly issues surrounding client confidentiality. Training should be offered to citizen advocates so that each would understand the role of the other.

- Where independent advocacy services are inaccessible, before deciding to advocate for clients, nurses should share any concerns with their peers and discuss both possible models of advocacy and other solutions to the lack of external advocates.

- Ongoing training should be provided at post registration level in legal issues which may impact on nurse advocacy.

### 7.13 Recommendations about research

This chapter has focused attention on some limitations of the research. Further research would be appropriate in the following areas:

- Research beginning immediately prior to the closure of one of the learning disability hospitals still open in Wales, and continuing through clients’ resettlement in the ‘continuing care’ sector and beyond, to uncover ways in which definitions of advocacy, participants’ requirements for advocacy support and the support styles of nurses change over time and in different situations.

- Research comparing differences in the advocacy role of nurses, the advocacy requirements of their clients and the availability of independent advocacy services in rural and urban areas in Wales.
Research to assess the impact of ‘situation specific’ working patterns on clients and their families, and on community nurses’ relationships with families and the ways in which they feel able to advocate for their clients.

7.14 Concluding comments
This research was guided by Clarke’s (2003) contemporary methodology whereby grounded theory is augmented by situational analyses and mapping. This innovative approach, rather than seeking a single over-riding explanation of the advocacy role of learning disability nurses, facilitated the disclosure of numerous important factors concerning advocacy and their advocacy requirements by people with learning difficulties and by learning disability nurses who might advocate for them or support them in self advocacy. All the informants in the study had definite views as to what advocacy and advocating entailed and, contrary to the dictionary definition, this proved to be not merely about one person (the nurse) speaking for another (the client with learning difficulties). Rather it encompassed a host of different activities, some of which proved empowering for both people with learning difficulties and nurse advocates.

As more and more people with learning difficulties become involved in or affected by Government Policy initiatives, advocacy and advocates will play an increasing role in supporting them to enhance their lives. In this scenario, nurse advocates are likely to assume increasing responsibility which will necessitate relevant, ongoing advocacy education, training and support. Reports on this research, built on the definitions of advocacy and the advocacy requirements of people with learning difficulties, will be disseminated to senior nurse managers and providers of nurse education as well as to self advocacy groups and others who have expressed an interest in the study. This should enhance the status of participants with learning difficulties, leave service providers in no doubt about the advocacy requirements of their users and inform the future education, training and practice of learning disability nurses who advocate for their clients.


House of Lords, House of Commons (2004) Mental Capacity Bill


Appendices
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Information
about the study on advocacy in nursing

Would you like to take part in this study?

This booklet will tell you what you need to know before you decide whether to take part in my study on advocacy in nursing.

Penny Llewellyn
School of Care Sciences
University of Glamorgan
Pontypridd CF37 1DL
Thanks to the 'CHANGE' Picture Bank (London 1999)

for most of the pictures in this booklet.
I am a research student at the University of Glamorgan.

Last January the University gave me some money so that I could study advocacy in nursing.

I am going to write a report (called a thesis)

It will be about advocacy and nurses.

In three years time somebody will mark my report.

If they think it is good enough, the university will give me a special degree called a PhD.

My report will be put in a library. Other people will be able to read it.
Before I can write my report I need to find out what people think that advocacy is.

I want to know if people like you and me advocate for themselves.

Or if they sometimes need help to advocate.

If they do need help, I want to find out who they think could help them to advocate and how they might do this.

I am looking for people to help me find out these things.

I would like you to help me but you do not have to.

No one will make you.
My work is about advocacy and nurses.

First I will come and meet you and tell you about my work. Then, if you are willing to help me, I will ask you to sign your name on a form called a consent form.

If you like, someone else can write it for you.

Meeting 1  Meeting 2  Meeting 3  Meeting 4

Then I will arrange four meetings with you and some other people from the self-advocacy group/day centre/hospital.

If possible, I would like the meetings to be at the place where you usually meet.

Each meeting will take about 2 hours

You can bring a supporter with you.
If you don't mind, I will tape record our meetings.

Later I will write down what you told me

Jack might be called Tom

Jane might be called Anne

Because other people will be reading what I have written, I will change the names of people and places.
Meeting 1

At the first meeting we will all get to know each other.

Meeting 2

At the second meeting we will talk about advocacy.

Meeting 3

At the third meeting we will talk about times when you might need help to advocate, and who might help you.

Meeting 4

At the last meeting, I will show everyone what I have written about our meetings, so that you can check that it is O.K.
Later I will ask lots of nurses about advocacy.

I will ask them if they think advocacy is hard and if they need special lessons to learn how to do it.

What you and all the other people tell me, will help me to write my report.

It will help me to write about advocacy and nurses

I will hand my report in to the University of Glamorgan in 2004

I also want to write about advocacy in magazines that nurses read.
The report and the stories in magazines will not use your real names.

You will be called by different names.

Reading the report about what you and the other people have told me should help nurses to understand advocacy.

It will tell them if they can help people like you and me to advocate and how to do this.

When I have finished the study I will write a report that advocacy groups can read.

I will also write a report for schools of nursing. This might help them to teach nurses about advocacy.

If you are willing to talk to me about advocacy, this will help me in a big way.

It will also help nurses to understand advocacy better, and to know if they can help people advocate and how to do this.
What you say will be an important part of my report.

I hope you will want to help with my study, but no one will make you if you don't want to.

If you do take part you can stop at any time. You do not need to say why. It will be O.K.

If you think of anything you want to ask me you can phone me.

My number at college is:

01443 483810

and my number at home is:

029 2021 3169

Thank you for reading this, I hope you will decide to help me.

THANKS

Penny Llewellyn
CONSENT FORM (stage 1 participants)

Title of Project: An Investigation into the Advocacy Role of the Registered Nurse (Learning Disabilities).

Name of Researcher: Penny Llewellyn

Please read each of the statements on the attached page and then tick the box [ ] if you agree.
I have read the information booklet about the study on advocacy and nurses.

I have been able to ask questions and I understand what is in the booklet.

I understand that no one will make me take part in the study unless I want to.

I understand that if I do take part I can stop at any time without telling anyone why.

I understand that I will be called by a different name in the reports about the study.

I understand that other people will read reports about the study.

I am willing to take part in the study.

(Signature of participant) (Name of participant and date)

(Signature of supporter (if needed) (Name of supporter and date)

(Signature of researcher) (Name of researcher and date)
Pictures 1 – For First Focus Group
Speaking up for yourself
Telling someone what you want and asking them to speak for you
Making choices
Telling people what you want and having help to get it.
Making sure people listen to you at meetings.
Showing people that we are all equal
Making links with your community and making friends
Being able to say NO
Pictures 2 - for Second Focus Group
Jerry and Martin choose where to live

Tim is being bullied
John doesn’t want an injection

Tom tells Mark what he wants
Bill chooses what to wear

James knows what he wants
Mike is at a meeting
John sleeps all morning
Ben eats lots of chips

Dan eats pasta
Questionnaire 1
What is advocacy?

Speaking up for yourself. ☐

Helping other people to speak up for themselves ☐

Helping people who can’t talk tell people what they want ☐

Making sure that important things are heard by the right people. ☐

Listening to what other people have to say and then making up your own mind ☐

Asking for what you want without getting upset or angry. ☐

Finding out about things like training and jobs. ☐

Finding out about things you could do in your spare time. ☐

Making choices and telling people what you have chosen and why. ☐

Gaining people’s respect and respecting other people’s ideas too. ☐

Making good relationships with other people. ☐

Any other ideas:
________________________________________________________________________
________________________________________________________________________

If you needed help to do any of the things on the list, who might you ask to help you? (You can choose more than one person).
________________________________________________________________________
________________________________________________________________________
Questionnaire 2
What is an advocate?

Someone who will speak up for you if you cannot speak up for yourself.

Someone who will find out what people want and try to get it for them.

Someone who will help you to meet people and make new friends.

Someone who will go out and about with you, perhaps shopping or to the pub or the pictures.

Someone who you can share things with.

Someone who will help you to speak up for yourself without getting angry.

Someone who might help you to get a job.

Someone who can help you to solve problems

Someone who will stand up for you and support you to get what you want.

Someone who will help you to make people listen to what you think and what you really want.

Someone who will help you to understand your money so that you know how much you've got and where it comes from.

Someone who will help you complain if you think you are being treated badly, or if you think something is unfair.

Someone who can help you find out about:

- Good places to go
- Good doctors and dentists
- Jobs
- Ways to keep healthy
- Colleges and training

Any other ideas:

Can you think of anyone who might do these things for you? Who would it be? You can choose more than one person
Feedback for Participants

Research about advocacy.

---------- Self Advocacy Group

and

Penny Llewellyn, University of Glamorgan.
Thank you

to all the self-advocates from the ------ Self Advocacy Group for helping me with my research.

Penny Llewellyn
The First Meeting on 20th March

What Penny is doing

Penny wants to find out about advocacy. She is going to write a report about advocacy.

She came to the meeting so that the group could tell her what advocacy means and if it makes a difference to their lives.

Penny wanted to know what group members thought that advocacy was, and whether members could advocate for themselves.

She recorded what everyone said on a tape recorder. She went away and listened to what the group had told her. Then she wrote down some of the things the group had said.
What the group said about advocacy

Group members said that advocacy meant a lot of different things. Here is a list of the things that they thought advocacy meant:

Power

Advocacy gives you power and lets you talk about the way you feel about things. When self-advocates work together, solidarity makes them powerful too.

Problems

Advocacy also helps people to sort out their problems.
Confidence

Advocacy is about being assertive and having confidence in yourself.

Speaking for others

Advocacy can mean speaking up for others or interpreting what other people say, so that they can be understood as well.

Independence

Advocacy can help you to be independent.
Being treated like adults

Self-advocates know how important it is to be treated like adults and to be asked about things that concern them, such as work, travel and pay.

Rights

In self-advocacy groups you can learn about your rights and then use what you have learned to fight for things such as Therapeutic Earnings or Direct Payments. Self-advocates can tell other people with learning difficulties about their rights too.
Responsibilities and respect

Advocacy doesn’t only teach you about your rights, it teaches you about your responsibilities as well.

It is also about respecting other people and having confidence so that you gain other people’s respect too.

Group work

Advocacy works well in a group. A few group members, with their supporter, can represent the whole group in meetings with powerful people. This is useful when you want to find out about things such as Direct Payments.
Meetings

Self-advocacy can be about learning how to run meetings. Self-advocates vote for their chair-person and other committee members. They have regular meetings and plan what they want to do.

Conferences

Some self-advocates go to conferences. Some have confidence to stand up and speak in front of lots of people.
Community links

Self-advocates make links with their community. They talk to children in schools and students in colleges. They also talk to the police and the fire service. They are not afraid to get to know people and to tell people what it is like to have learning difficulties.

Work

Being a member of People First has given some self-advocates the chance to work in the People First office. Some of the members have learned about editing the newsletter and others have learned about writing the minutes of meetings.
The Second Meeting on 10\textsuperscript{th} April

What we talked about

At the second meeting we talked about advocates and about nurses.

Penny wanted to know who might advocate for members of the group if they could not speak up for themselves.

She also wanted to know what people thought the job of nurses was.

What the group said about advocates

Most people said that they brought their problems to the People First group.

Sometimes, if someone has a problem, a meeting is arranged at People First with the people involved, to sort things out.
Day Services

Some people are not happy with their Day Service. Some group members are hoping to get Direct Payments. Then they could have their own support worker and could do things that they really want to do, instead of working at the Day Centre every day.

Learning together

It is hard to get Direct Payments, but group members are learning how to do it together.

If some people get a Direct Payment, others might also have confidence to do the same thing, and their lives should get better.
Nurses

Most people thought that nurses work in hospitals or with doctors and look after people who are ill.

One member of the group has his leg ulcer treated by a nurse and other group members had been treated at home by a nurse after coming out of hospital.

Some members of the group had been given injections by a nurse.

Having help to advocate

Group members thought that sometimes, as well as speaking up for themselves, someone else could speak for them too.
Appendix 5

Help from a nurse

If they were ill or in hospital, this other person might be a nurse.

If a nurse was speaking up for them, group members thought that it was important that the nurse should understand people with learning difficulties.

Getting to know a nurse

They thought the nurse would need to get to know the person with learning difficulties really well. They thought that the person with learning difficulties would have to trust the nurse, and also that the nurse would have to trust them too.
Appendix 6

RESEARCH INFORMATION SHEET FOR NURSES

Title of Research Project:
An Investigation into the Advocacy Role of the Registered Nurse (Learning Disabilities)

Name and contact details of researcher:
**Penny Llewellyn, research student,**
School of Care Sciences, University of Glamorgan, Pontypridd CF37 1DL
Tel: 01443:483810 (work) 029 2021 3169 (home)
Email: pllewellyn@glam.ac.uk, pjllewellyn@ntlworld.com

Who is sponsoring the research project?
The research is sponsored by the School of Care Sciences, University of Glamorgan.

What are the qualifications of the researcher?
B.ScEcon. Registered Nurse (Learning Disabilities)

What are the aims of the research?
1. To question whether clients want nurses to advocate for them and/or whether they feel learning disability nurses have a role in helping them to advocate for themselves.
2. To ask learning disability nurses whether they are undertaking advocacy for their clients, and whether there are specific problems attached to this role.
3. To consider the implications of the above for the education, support and practice development of Registered Nurses (Learning Disability).

How will the research be conducted?
The research will be in three stages:
1. Focus group interviews with people who have learning disabilities.
2. Focus group interviews with learning disability nurses.
3. Postal questionnaire survey

In which stage(s) of the research will I be involved?
I am hoping you will be able to participate in stage two of the research. You will also receive a postal questionnaire in stage three.

Who will be participating in stage two?
The participants for this stage will be learning disability nurses currently working within the health service. I aim to have three different groups, each with a maximum of eight nurses.

1. Nurses working with people who have profound or severe learning disabilities, who also have limited or no conventional verbal communication skills.

2. Nurses working with clients who have moderate or mild learning disabilities and are able to communicate verbally and make themselves understood by most people.

3. Nurses working with people who have a range of learning disabilities from mild to severe and profound, and a range of communication skills from conventional verbal communication to limited or entirely non verbal.

How many nurses will be participating in each focus group session?
There will be a maximum of eight nurses in each group, hopefully with a range of grades (D-G) and years of experience and employed by the learning disabilities directorate of the local NHS Trust.
Appendix 6

How many focus group sessions will there be?
There will be two sessions for each separate group.

What will be discussed?
In the first session we will focus on how nurses perceive their advocacy role, its problems and their educational needs regarding advocacy.
At the second session I will summarise the main points from the first meeting, which we will discuss together during the session. You can then add any further information and correct possible misunderstandings. We can also discuss the final analysis.

Where will the meetings take place and how long will each session last?
We can meet here at the university or at a venue negotiated between myself and the participants in each group. Each session will last approximately one and a half hours.

How will information be recorded? Will other people know that I have taken part in the study?
If there is no objection, I shall tape record the group meetings, for subsequent transcription and analysis. Recorded data will be destroyed after completion of the research. You will be asked to choose an alias name which will be used in the reports, data will be anonymised and computerised data is protected by password. All group members will be reminded of their duty of confidentiality to other participants at each session.

What happens after stage two?
The data resulting from all the focus groups will inform the final stage of the research in which a questionnaire survey about advocacy will be sent to all learning disability nurses employed by the National Health Service in Wales.

What will happen to the results of the research?
My thesis should be completed by mid 2004 and I hope to publish at least some of my findings. After my thesis has been handed in, I aim to write a report on my findings for schools of nurse education. This will hopefully inform the future education, support and practice development in the area of client advocacy of Registered Nurses (Learning Disability). I shall also write a report in accessible format for people with learning disabilities and an interest in advocacy (e.g. self advocacy groups). You will be able to have copies of the reports on request if you should so desire.
CONSENT FORM (stage 2 participants)

Title of Project: An Investigation into the Advocacy Role of the Registered Nurse (Learning Disabilities).

Name of Researcher: Penny Llewellyn

I confirm that I have read and understand the information sheet concerning the above study.

I understand that my participation is voluntary and that I am free to withdraw at any time without providing reasons.

I agree to take part in the above study.

(Signature of participant) __________________________ (Name of participant and date)

(Signature of researcher) __________________________ (Name of researcher and date)

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Pre-group self completion questionnaire. Stage 2

Please answer the following questions before the start of the focus group:

Fore name
(You need not put your surname)

Your designation and grade

Your year of qualification

How would you classify the communication skills of the clients with whom you work?
(Please tick any that apply)
- Non verbal
- Limited verbal
- Adequate verbal (understandable by most people)
- Other (please specify)

How long have you been working with these or clients with similar needs?
(Please tick)
- Less than 12 months
- 1 – 3 years
- 3 – 5 years
- Longer than 5 years

Do you have specific responsibility (e.g. as key-worker) for one or more clients? (Please tick)
- Yes
- No

If yes, for how many clients? (Please enter number)

Have you completed any post-qualification courses?
- Yes
- No

If yes, please give details with approximate dates

Thank you for answering these questions which will aid my analysis of the focus group data.

Penny Llewellyn
Dear Nurse,

Re: PhD Research: The Advocacy Role of the Learning Disability Nurse

I am a PhD. student based at the University of Glamorgan and am writing to invite you to participate in my research which is entitled ‘An investigation into the advocacy role of the learning disability nurse’. I have enclosed a questionnaire and a copy of the information sheet concerning my study.

This survey, which has been approved by the Ethics Committee, constitutes the third and final stage of my research and I am hoping that all nurses grades D-G working in learning disability services within the National Health Service in Wales will participate by filling in a questionnaire. In order to ensure your complete anonymity and confidentiality, I am not asking for individual names of nurses at this stage of the research, and your service manager has kindly provided me with details of a contact from whom you should have received this letter. Obviously, there is no compulsion that you should participate in my research, but I should be extremely grateful if you would take time to answer the questions and return the questionnaire to me by , in the attached pre-paid envelope.

If you have any queries regarding my research which are not covered by the information sheet, or if you would like to discuss any aspect of the study further, please feel free to contact me at the above address or by using the contact details on the front page of the questionnaire.

I should greatly appreciate your help with this final stage of my research, and look forward to hearing from you in due course,

Yours sincerely,

Penny Llewellyn
Appendix 10

RESEARCH INFORMATION FOR NURSE PARTICIPANTS

Title of Research Project:
An Investigation into the Advocacy Role of the Registered Nurse (Learning Disabilities)

Name and contact details of researcher:
Penny Llewellyn, research student,
School of Care Sciences, University of Glamorgan, Pontypridd CF37 1DL
Tel: 029 2021 3169
Email: pllewell@glam.ac.uk

Who is sponsoring the research project?
The research is sponsored by the School of Care Sciences, University of Glamorgan.

What are the qualifications of the researcher?
Diploma of the Society of Radiographers (Therapy) - 1964
Registered Nurse (Learning Disabilities) – 1993
B.ScEcon. (Sociology and Social Policy) - 1998

What are the aims of the research?
1. To question whether clients want nurses to advocate for them and/or whether they feel learning disability nurses have a role in helping them to advocate for themselves.
2. To ask learning disability nurses whether they are undertaking advocacy for their clients, and whether there are specific problems attached to this role.
3. To consider the implications of the above for the education, support and practice development of Registered Nurses (Learning Disability).

How is the research being conducted?
The research is in three stages detailed below. Stages 1 and 2 are now complete. I am hoping you will participate in the questionnaire survey which comprises stage three of the research (the final stage) by completing the questionnaire which accompanies this sheet.

1. Focus group interviews with people who have learning disabilities.
2. Focus group interviews with nurses working in learning disability services.
3. Postal questionnaire survey

Why is the study in three stages?
The study is based on definitions of advocacy and their advocacy needs, gained in the stage one focus groups from people with learning difficulties, which formed the foundation of the research. The information from these groups has been enhanced and supplemented by information gained, in stage two of the study, through focus groups with nurses working in learning disability services. The questionnaire which accompanies this information sheet constitutes stage three of the research and has been developed from data gathered during stages one and two and from relevant literature. Its aim is to provide a much more detailed and extensive picture of the advocacy role of nurses working in learning disability services. The results of the questionnaire survey will thus be tied into the previous work, resulting in an evidence-based theory concerning the advocacy role of the learning disability nurse.
Who will be participating in stage three?
The postal questionnaire survey is addressed to all nurses grades D-G working in learning disability services in the National Health Service in Wales. In order to preserve the anonymity of nurse participants, I am not, at any time, asking for individual names of nurses taking part. Thus it may be that you have already taken part in a focus group or interview in stage two of the study. Nonetheless, I would be extremely grateful if you would still fill in and return the questionnaire, enabling me to obtain as complete a picture as possible of the views of nurses working in learning disability services on their advocacy role.

What do I have to do?
It would be helpful if you would fill in the questionnaire according to the written instructions. When you have completed the questionnaire, I should be very grateful if you would return it directly to me in the enclosed reply paid envelope.

Do I have to take part in the research?
No. Although I am very much hoping that you will choose to take part in the survey, there is no compulsion on you to participate. The questionnaire is anonymous and neither myself, nor your service manager will know whether or not you have taken part. Your participation will be extremely valuable to me as researcher as I hope to gain as complete a picture as possible of the advocacy activities and educational requirements regarding advocacy of qualified nurses working in learning disability services throughout Wales.

Will other people know that I have taken part in the research?
The names of individual nurses will not be required in this stage of the study, neither will the names of employing Health Trusts be used in the reports. Even if you should wish to give specific information individually to the researcher at any time, neither your name nor that of your employer will appear in the report or in any published articles about the research.

What will happen to the results of the research?
My thesis should be completed towards the end of 2004 and I hope to publish at least some of my findings, and make presentations at nursing conferences. After my thesis has been handed in, I aim to write a report on my findings for managers of learning disability services and for schools of nurse education. This will hopefully inform the future education, support and practice development in the area of client advocacy of qualified nurses working with people who have a learning disability. I shall also write a report in accessible format for people with learning difficulties and an interest in advocacy (e.g. self advocacy groups). You will be able to have copies of the reports on request if you should so desire.
Questionnaire – The advocacy role of the learning disability nurse

This questionnaire is divided into five sections and I should be most grateful if you would complete each section, following the written instructions. I am hoping you will wish to expand on some of your answers by providing comments. If you do not have sufficient space to do this on the line(s) provided, please use the reverse side of the sheet, numbering your comment with the appropriate question number.

If you would like to discuss either the research or any particular question or aspect of the study further, please feel free to contact either myself (Tel: 029 20213169; email: pllewell@glam.ac.uk); or my Director of Studies, Professor Ruth Northway (Tel: 01443 483177; email: rnorthwa@glam.ac.uk) or write to me at the above address.

I should very much appreciate it if you would complete the questionnaire, and return it to me in the enclosed prepaid envelope by . I am most grateful for your assistance and thank you in anticipation of your reply.

Penny Llewellyn
Section One - Advocacy

q1a) Please read each of the following definitions of advocacy and circle the number which best indicates its relevance to your present professional practice

1 = not at all relevant; 5 = extremely relevant (place a cross in the box □ if you have no opinion)

q1a1) Working with individual clients to ensure their rights are respected and upheld
not at all relevant 1 2 3 4 5 extremely relevant □

q1a2) Supporting clients to complain if they think they are being treated badly
not at all relevant 1 2 3 4 5 extremely relevant □

q1a3) Treating clients as adults and consulting them about things that concern them
not at all relevant 1 2 3 4 5 extremely relevant □

q1a4) Promoting the rights of people with learning difficulties whenever possible
not at all relevant 1 2 3 4 5 extremely relevant □

q1a5) Speaking for clients
not at all relevant 1 2 3 4 5 extremely relevant □

q1a6) Encouraging clients to take responsibility for themselves and their actions
not at all relevant 1 2 3 4 5 extremely relevant □

q1a7) Interpreting for clients
not at all relevant 1 2 3 4 5 extremely relevant □

q1a8) Proactively supporting clients to get to know people in the community
not at all relevant 1 2 3 4 5 extremely relevant □

q1a9) Ensuring clients have information which they can understand
not at all relevant 1 2 3 4 5 extremely relevant □

q1a10) Encouraging clients to make their own decisions
not at all relevant 1 2 3 4 5 extremely relevant □

q1a11) Enabling things to happen for clients
not at all relevant 1 2 3 4 5 extremely relevant □

q1a12) Supporting clients to complain if they think something is unfair
not at all relevant 1 2 3 4 5 extremely relevant □

q1a13) Encouraging people in the community to get to know people with learning difficulties
not at all relevant 1 2 3 4 5 extremely relevant □
Please use this space to list any other definitions of advocacy which you think may be relevant to nurses working in learning disability services (optional)

q1b) Would you consider that advocating in your personal life (e.g. for children or elderly relatives) is the same or different from advocating for clients? (please tick)

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q1c) If different please say how:________________________________________________________

q1d) In what situations might you advocate for your clients? (please tick all that apply)

- q1d1) Choice of leisure activities
- q1d2) Relationships with others
- q1d3) Disagreements with carers
- q1d4) Applications for resources
- q1d5) Specialist health care
- q1d6) Housing options
- q1d7) Problems with day services
- q1d8) Problems with benefits
- q1d9) Generic health care
- q1d10) Other (please list)________

Comments (optional)__________________________________________________________________
**Appendix 11**

q1e) Please read the following and circle the number which, in your opinion, best indicates the importance of each item to a satisfactory advocacy partnership between a nurse and her/his client.

1 = not at all important; 5 = extremely important (place a cross in the box [ ] if you have no opinion)

<table>
<thead>
<tr>
<th>Item</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding client's communication</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Long standing relationship with client</td>
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<tr>
<td>Good relationship with carers</td>
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<tr>
<td>Mutual trust between nurse and client</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Knowledge of clients likes and dislikes</td>
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<td></td>
</tr>
<tr>
<td>Maintaining a professional relationship</td>
<td></td>
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<td></td>
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<tr>
<td>Sufficient time to develop mutual understanding</td>
<td></td>
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<tr>
<td>Willingness to support a client in self advocacy</td>
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</table>

**Comments (optional)**

________________________________________________________________________

________________________________________________________________________

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________________________________________________________________________

365
In your opinion, what circumstances might mitigate against satisfactory nurse advocacy for clients? (please tick all that apply)

| q1f1) Conflict of interest with employer | q1f6) Lack of time |
| q1f2) Unequal conditions of power between nurse and client | q1f7) Conflict with carers |
| q1f3) Responsibility for several clients | q1f8) Insufficient experience |
| q1f4) Inability to interpret clients’ requirements | q1f9) Lack of understanding of clients rights |
| q1f5) Lack of knowledge (e.g. legal; clinical) | q1f10) Other please list |

Comments (optional)

__________________________________________________________

__________________________________________________________

__________________________________________________________
Section 2 – Advocates (please tick one box for each question)

q2a) Do any of your clients have a citizen advocate?

Yes ☐ No ☐ Unsure ☐

q2a1) If yes, do you consider this to be a positive relationship?

Yes ☐ No ☐ Unsure ☐

q2a2) Would you encourage your clients to have a citizen advocate?

Yes ☐ No ☐ Unsure ☐

q2a3) Would you expect staff to benefit from a client/citizen advocacy partnership?

Yes ☐ No ☐ Unsure ☐

q2a4) Would you encourage your clients to join a self advocacy group?

Yes ☐ No ☐ Unsure ☐

Comments (optional)

q2b) Do your clients have access to paid independent advocacy services?

Yes ☐ No ☐ Unsure ☐

q2c) What situations might warrant a referral for paid advocacy services? (please tick all that apply)

q2c1) Legal purposes (e.g. Mental Health Act) ☐

q2c2) Representation to Trust (e.g. regarding clients’ services) ☐

q2c3) Financial purposes (e.g. problems with benefits) ☐

q2c4) Residential concerns (e.g. moving on, resettlement etc.) ☐
q2c5) Other (please describe briefly) __________________________________________

q2d) In cases where your clients have experienced independent (paid or volunteer) advocacy, do you consider that they have found it satisfactory?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>No experience</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

Please give reasons __________________________________________

q2e) Do you consider that members of clients’ families can advocate satisfactorily for them?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>No experience</th>
<th>Unsure</th>
</tr>
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<tbody>
<tr>
<td></td>
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</tbody>
</table>

Reasons __________________________________________

q2f) Do you consider that clients who have an advocate e.g. citizen advocate, independent volunteer advocate, paid independent advocate, family member; or those who attend a self-advocacy group, get better services than those without?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
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<tbody>
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</table>

Comments (optional) __________________________________________

368
Section 3 – Education (please tick appropriate boxes)

q3a) Have you received any formal education (e.g. courses, workshops) about advocacy? (if yes, please continue; if no, please go straight to question q3b.)

Yes □ No □ Can’t remember □

q3a1) If you have received formal education in advocacy, was this: (please tick one box)

pre-qualification □ post qualification □ both □

q3a2) Was it (please tick all that apply)

about citizen advocacy □ about self advocacy □ about nurse advocacy □ about advocacy in general □

q3a3) Did any education you received include practical advice on how to advocate?

Yes □ No □ Can’t remember □

q3a4) If yes, please give brief details as to what this included (e.g. lecture, role play etc.)

________________________________________________________________________

________________________________________________________________________

q3b) Do you consider there is a difference between learning about advocacy and learning how to advocate?

Yes □ No □ Unsure □

Comments optional)________________________________________________________________________
q3c) Do you consider that education about advocacy would be useful to nurses? (please tick one box)

Yes □ No □ Unsure □

q3c1) If you think advocacy education would be useful to nurses, who do you think should provide it? (please tick all that apply)

Lecturers □ Citizen advocates □ People with learning difficulties □ Independent (paid) advocates □

Other (please specify) ________________________________

q3c2) What should such education include? __________________________

q3c3) Should advocacy education be at pre or post qualification level? (please tick one box)

Pre-qualification □ Post-qualification □ Both □ Unsure □

q3d) Have you received education on the Human Rights Act (1998)?

Yes □ No □ Can't remember □

q3d1) Do you consider that learning disability nurses should receive such education?

Yes □ No □ Unsure □

Comments (optional) ____________________________________________

370
Section 4 – The advocacy role of the learning disability nurse.

q4a) Do you consider that advocacy is an important aspect of the role of nurses working in learning disability services in the present socio/political/economic climate of nursing?

Yes [ ] No [ ] Unsure [ ]

Please give reasons for your response: ______________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

q4b) Do you consider that the advocacy role of the learning disability nurse has changed since you qualified?

Yes [ ] No [ ] Unsure [ ]

q4b1 Please give reasons for your response __________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________
Section 5 - Personal Information

q5a) Name of employing Health Trust
______________________________
(this will not appear in any report)

q5b) What is your qualification? (please tick all that apply)

Registered nurse
(learning disabilities)

Registered nurse
(mental health)

Registered Nurse
(adult)

Registered nurse
(child)

Enrolled Nurse (please state specialism)

Other (please list)

q5c) In what year was your qualification obtained? (if you have more than one qualification, please state title and date of each)

q5d) What is your current grade
(please tick appropriate box)

D  E  F  G

q5e) Are you: Female  Male (please tick)

q5f) Where do you currently work? (please tick)

Hospital  Other residential  Community

Other (please specify)
Appendix 11

q5g) How would you classify the communication skills of the clients with whom you work? (please tick all that apply)

<table>
<thead>
<tr>
<th></th>
<th>Non verbal</th>
<th>Limited verbal</th>
<th>Adequate verbal</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>(understandable by most people)</td>
</tr>
<tr>
<td>Limited signing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adequate signing</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Other (please specify)</td>
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</table>

q5h) How long have you been working with these or clients with similar needs (please tick)

<table>
<thead>
<tr>
<th></th>
<th>Less than 12 months</th>
<th>1-3 years</th>
<th>4-6 years</th>
<th>Longer than 6 years</th>
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</table>

q5i) Do you have specific responsibility (e.g. as key-worker) for one or more clients? (please tick)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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q5i1) If yes, for how many clients? (Please enter number)

<p>| |</p>
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</table>

q5j) Have you completed any of the post-qualification courses listed below?

<table>
<thead>
<tr>
<th>q5j1) Diploma</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>q5j2) Degree(BA; BSc)</th>
<th>Yes</th>
<th>No</th>
</tr>
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<tbody>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>q5j3) Post graduate qualification</th>
<th>Yes</th>
<th>No</th>
</tr>
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<tbody>
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</table>
Appendix 11

q5j4) If yes, please give details:

<table>
<thead>
<tr>
<th>Title of course</th>
<th>Year completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diploma</td>
<td></td>
</tr>
<tr>
<td>Degree (BA; BSc)</td>
<td></td>
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<tr>
<td>Masters (MA; MSc)</td>
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<tr>
<td>PhD</td>
<td></td>
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</table>

q5k) Please use this space to make any further comments on the advocacy role of the learning disability nurse:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Thank you for completing this questionnaire. Please return it to me in the attached reply paid envelope. If you wish to make any comments or would like to discuss the advocacy role of the learning disability nurse, or if you would like a copy of the report on this study when it is completed, please contact me by letter, phone or email. My contact details are on the title page of this questionnaire. I am most grateful for your help.

Penny Llewellyn
Dear Nurse,

Re: PhD Research: The Advocacy Role of the Learning Disability Nurse

Some weeks ago, you received a questionnaire which formed part of my research into the advocacy role of the learning disability nurse. If you have already filled this in and returned it, many thanks. I am extremely grateful for your help with my study and would ask that you disregard the remainder of this letter.

If you have not yet filled in the questionnaire, I am very much hoping that you will still decide to do so. Your participation in my research will enable me to gain a comprehensive picture of what nurses working in disability services within the NHS in Wales understand by advocacy, what they consider to be their advocacy role in relation to their clients, and their educational needs concerning this role. The subsequent reports on my study will be offered to service managers and Schools of Nurse Education, who can then consider their implication for the education, ongoing support and training in advocacy of learning disability nurses.

If you have any queries regarding my research please phone me at 029 20213169 or email me at p llewell@glam.ac.uk . If you require another copy of the questionnaire or a reply paid envelope, please contact either myself or who will be able to supply these.

I do hope you will decide to take part in my research. It would be very helpful if I could receive your completed questionnaire by

Yours sincerely,

Penny Llewellyn
Copies of publications
Penny Llewellyn's pilot study involving people with learning difficulties highlighted paternalism in supported housing

The participants in the research I am conducting have learning difficulties. To ensure that they can give informed consent if they choose to participate, I designed an information booklet about the project. As I was keen to pilot the leaflet, I asked the manager of a community house where I had been a support worker if she would ask the residents there, all of whom have learning difficulties, if they would help me. She agreed and rang to say they would be delighted. But she later said her line manager wanted to seek approval from her line manager, who was on leave for several weeks.

I was astounded. The residents' decisions were apparently being overruled by managers who probably knew them less well than I did. I faced an ethical dilemma. I am occasionally approached to work relief shifts in the house and could have offered to work a 'sleep-in' – 14 hours with the residents would have been long enough to pilot my booklet without the involvement of any manager. This would have solved my problem, but I still felt uneasy. It had been my choice to contact the house manager, albeit only to ask if she would approach the residents on my behalf. I now felt some moral obligation to accept her decision, particularly if I was ultimately permitted to conduct my pilot study.

This eventually happened, but the experience confirmed what other researchers have found: that the autonomy and choice of residents in supported housing is severely constrained compared with that of typical people living in their own homes. It demonstrated that paternalism, as exercised by some managers, although supposedly in the best interests of the residents, overrides their autonomy. It assumes, possibly incorrectly, that their capacity to make informed decisions is automatically impaired by their disability.

Penny Llewellyn is a PhD student at the University of Glamorgan
nursing and advocacy in person centred planning

The recommendations of Valuing People (Department of Health (DoH) 2001), and more particularly A Framework for Person Centred Planning (DoH 2001a), have given added piquancy to debates surrounding the advocacy role of the learning disability nurse.

Some nurses, perhaps mindful of the possible risk to their careers, will be reluctant to advocate for their clients in the semi-public arena of partnership boards. Others, especially those who work with the most vulnerable groups targeted by the guidelines (DoH 2001b), may feel that in the absence of suitable others they have no option but to represent their clients. Yet other nurses will gladly embrace the advocacy role, feeling that their established relationship with clients makes them particularly suited to the task.

People with learning disabilities and severely impaired verbal communication who currently live in long-stay hospitals are among the groups primarily targeted by the DoH for person-centred planning (PCP) (DoH 2001). There are many reasons why learning disability nurses might feel called upon to advocate with or for these clients, but there are also conflicting opinions both for and against nurses taking on the advocacy role. These will be explored in this article.

A philosophical stance on the nurse advocacy debate (Gadow 1989) will be used to illustrate how learning disability nurses, who accept that all their clients have a right to self-determination, might discard objectivity and espouse subjective advocacy as the best option for clients who do not speak. In this form, nurse advocacy might be challenging and uncertain and not without risk, but may also result in clients with learning disabilities and severely impaired communication skills achieving their aspirations through PCP.

Why might nurses advocate?

The DoH guidelines (DoH 2002) suggest that priority for PCP should be given, among other groups, to people with learning disabilities still living in long-stay hospitals. Many of these people will have profound and multiple disabilities and/or behaviour which is considered challenging. Some will also have severe communication difficulties.

Among people with learning disabilities, these individuals, most of whom will have been ‘cared for’ by nurses for many years, are likely to have had fewer opportunities and be the least accustomed to making and expressing choices about their lives.
Building a ‘circle of support’ around such people to undertake PCP may be fraught with difficulties.

People who have been institutionalised may feel distrust and discomfort with people who are unknown to them. Their social networks will probably have been dominated by fellow residents and staff during years of hospitalisation, and their external contacts extremely restricted (Mansell and Beadle-Brown 2004). Citizen advocates who might support them are in very short supply and it may take a long time for possible supporters to learn ways to communicate with people who have substantial learning disabilities and severe communication problems.

In addition, people living in NHS accommodation are seldom seen as a high priority by hard-pressed citizen advocacy groups. Availability of independent (paid) advocacy services is patchy, being readily available in some areas and not at all in others (DoH 2001c). The likelihood that referral will be a protracted process for people living in long-stay hospitals, possibly dependent on finance and on senior managers who may be far removed from the client.

Even after referral, there may be a long waiting list, and the activities of these services will probably be restricted to short-term crisis situations, rather than the more prolonged association required for successful PCP. People with learning disabilities and severely impaired verbal communication are also likely to experience difficulty forming the necessary relationships to enable even this type of intervention to succeed (Mansell and Beadle-Brown 2004).

With all these barriers to self-fulfilment, people with learning disabilities and impaired verbal communication who are resident in long-stay hospitals are very likely to rely on learning disability nurses to support and advocate for them in the activities involved in PCP. Many nurses have well-established, long-term relationships with such clients, based on mutual respect and trust. They are also accustomed to listening, observing, thinking and acting creatively when consulting with clients, and to supporting them to meet their goals, whatever their disabilities.

Nurses have also, through necessity, frequently developed ways to circumvent deficiencies and to negotiate on behalf of service users for a fair share of available resources, as required by Valuing People (O’Brien 2004).

What is advocacy?

These facts could easily lead to the conclusion that learning disability nurses are ideally suited to advocate for clients during PCP. That is, exploring with them how they want to live and what assistance they require, and representing them, perhaps at partnership boards, in an attempt to achieve their aspirations. Nevertheless, before assuming the role of advocate in these situations, learning disability nurses must necessarily be clear in their own minds about how they define advocacy.

‘Before deciding to take on the advocacy role, nurses should consider their definition of advocacy and what it may involve, and reflect on the difficulties they may encounter’

Advocacy is confusing as a concept, and there are many different opinions about its meaning in the context of nursing. Conceptual differences between the parties involved may pose limitations on nurse advocates and on advocacy itself (Aspis 2002).

Learning disability nurses might consider that they advocate for their clients in everyday matters – for example, supporting them in choices about what to eat or wear and what activities to undertake. Although these activities are important and may be life-enhancing, they are more likely to take place within the nurse’s everyday range of ‘caring, counselling and helping activities’, referred to by Goble (2002) as ‘advocacy with a small “a”’. Many nurses will realise that there is a difference between supporting clients to make choices like these within the confines of services, and advocating with or for them to challenge the security and order of institutional life and to enhance their lives through building new relationships and activities in the wider community (Collins and Dawson 2003).

Nurse advocates involved in such life planning pursuits with clients who cannot express their values and choices verbally may find it imperative to undertake activities that go far beyond the therapeutic. These might necessitate confronting the power structures underpinning services, a task made particularly difficult for nurses due to their status as employees in the systems they may seek to criticise or change (Brooke 2001, Goble 2002).

Before deciding to take on the advocacy role, nurses should consider their definition of advocacy and what it may involve, and reflect on the difficulties they may encounter. Difficulties include:

- their relative powerlessness in the working environment (Hewitt 2002, Martin 1998)
- the possible effects on their own careers of taking on behalf of clients (Gates 1994, Mallik 1998, Teasdale 1998)
- perhaps most problematic, deciding how they might advocate for any individual client in a satisfactory way.

Learning disability nurses must also use their observation skills and intuitive knowledge to be clear in their own minds whether or not their clients who do not communicate verbally wish them to undertake the advocacy role. Without considerable conviction on this point, any attempt to advocate could be seen as an imposition and might be viewed not only as disempowering, but also as the antithesis of the principles which underpin advocacy.

There have been suggestions that advocacy on behalf of people who do not communicate verbally must necessarily be paternalistic (see, for example, Blackmore 2001), but Gadow’s (1989) analysis of advocacy for ‘silent patients’. in this case clients:
who are unable to express their views due to their learning disabilities and impaired verbal communication, disagrees.

Gadow proposes that, if advocacy is to be a ‘full-fledged moral position’, it must not only promote and defend the individualism of clients who already have a high degree of autonomy, but must also be a moral commitment to ‘illuminate the less accessible self of [clients]... whose subjectivity is all but invisible and inaudible’, and to enhance their self-determination.

Gadow differentiates between advocacy, utilitarianism and beneficence, suggesting that the last two are ‘particularly appealing’ when clients cannot express their views and choices. Utilitarianism ‘subtracts’ the client from the situation, allowing the interests of others (such as resource and resettlement officers, consultants and day service managers) to form the basis of decisions about the client. Beneficence gives precedence to the objective views of professionals, assuming that they know ‘with greater ... certainty than do [clients]... themselves what is in their best interest’ (Gadow 1989).

Advocating for clients who do not speak

Either of these positions would provide nurses with straightforward and clearly definable responsibilities towards their clients, but attempts to advocate for those with severely impaired communication offers special challenges. It ‘creates the greatest complexity’ for nurses committed to a perspective based on client self-determination (Gadow 1989). There are many practical implications for learning disability nurses who decide to take this option.

Nurses have traditionally been encouraged to be objective and to consider as sacrosanct the ‘best interests’ of clients who cannot communicate their wishes and needs. In choosing to advocate for such clients in PCP, nurses must make a substantial leap away from this position and, in so doing, may risk conflict with other nurses, their employer and even their profession (Dimond 1995).

Unquestionably, neither the objectivity of paternalism nor the utilitarian approach are meant by the DoH guidelines which clearly state that PCP is about ‘listening to and learning what the client wants from his/her life and helping him or her think about what (s)he wants now and in the future’ [my italics] (DoH 2002). Nurses must be prepared, if necessary, to defend this standpoint when taking on the advocacy role.

Gadow (1989) proposes that, where clients cannot express their views in a conventional verbal manner: ‘Advocacy involves learning to enter ... [their] worlds through embodiment; it requires infinitely personal devotion to the most mundane [activities]... Because it is experiencing, the moment of certainty associated with knowing will not exist ... but, after many days of physical involvement, the nurse [may]... slowly see where the boundary lies between harm and benefit in the [client’s] world.’

Learning disability nurses may feel that after long periods of involvement with a client group, they have a ‘head start’ exploring the aspirations of particular individuals. But advocacy for clients with learning disabilities and severely impaired verbal communication is necessarily a protracted and multifaceted process. It is also compelling, and involves the nurse in discarding the ‘traditional’ objective approach to client care and developing a close and empathetic relationship with the client.

Gaining the subjective views of the client will require the nurse to negotiate...
periods of one-to-one time in which nurse and client, in partnership, can subjectively explore a wide range of activities with many different people and in varying environments. It will entail the nurse becoming totally and subjectively involved in the experiences of the client in a way which may be seen by some as contrary to the 'professional role'.

It is only in this way that, through a process of trial and error, and drawing on all his or her creative and observational skills and those of others closely involved, especially the client's peers, a detailed picture can be drawn of the client's likes and dislikes, enthusiasms and aptitudes, and ambitions for the future.

The nurse consequently builds an account which he or she is satisfied is as close as possible to being a true reflection of the client's experiences as a prerequisite for piecing together the elements of a genuinely person-centred plan.

Conclusion

The emphasis in PCP is on people with learning disabilities making choices about their lives. Despite obvious differences in their ability to represent their views, no differentiation is made between people of varying intellectual abilities, nor between those who can and those who are unable to use conventional verbal communication.

‘Moving away from the perception of “best interests” may be extremely challenging for the nurse advocate, but is likely to have its own rewards’

People with severe and profound learning disabilities who do not speak may have very definite likes, dislikes and ideas about how they want to live their lives. They do not necessarily wish what others, usually professionals, judge to be in their best interests. Neither might they want decisions about their future to be considered on the basis of utilitarian concepts. Representation through advocacy may be vital for these clients in the context of PCP, and for many of them, learning disability nurses — known and trusted inhabitants of their world — will be the ideal, and perhaps only available, choice of advocate.

For a variety of personal and professional reasons, not all nurses will feel able to take on the advocacy role. But for those prepared to get involved, attempts to 'speak with the client's voice' necessitate working closely with clients to experience their pains and pleasure. This may be fraught with uncertainty, but will result in evidence based on firm foundations.

Possibly more controversially, nurse advocates must be prepared to defend the moral position that every client has the right to self determination. This may involve representing the client against colleagues and management who seek to adopt utilitarian or benevolent approaches. Moving away from traditions of objectivity and the perception of 'best interests' may be extremely challenging for the nurse advocate, but is likely to have its own rewards.

Nurse advocacy may help to transform the perception of PCP from being something that is 'done to' clients (Dowson 2004), towards its stated intentions of giving voice to all people with learning disabilities. It may also increase the autonomy of clients who have learning disabilities and severely impaired verbal communication skills and encourage their self empowerment in ways that will facilitate the fulfilment of their aspirations and ambitions for the future.

Penny Llewellyn BScEcon, RNLĐ, research student, School of Care Sciences Research Unit, University of Glamorgan

Keywords

- advocacy
- care plans and planning
- patients: empowerment

These keywords are based on the subject headings from the British Nursing Index. This article has been subject to a double-blind review.

References