Sexual expression, physical disability and professional practice

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ABSTRACT

The asexualisation of disabled people was first documented in the 1970's. This prompted an international drive to improve the education of health and social care practitioners working with disabled people, to ensure inclusion of sexual expression within rehabilitation and care. Yet research within some professions indicated practitioners lacked competence and confidence and little progress was apparent.

Increasingly health and social care are delivered through multidisciplinary teams. Uniquely, this research investigated the professional practice of three community disability teams toward the sexual health of their service users when disability impacts on intimate relationships and sexual expression. The study was developed in collaboration with disability organisations and disabled people. It was conducted within a contemporary, critical theory paradigm using focus groups and interviews. The teams, all based in south-east England, provided services for physically disabled people (including some with multiple sclerosis) who lived in the community. Thirty practitioners participated, (10 occupational therapists, 7 physiotherapists, 4 nurses, 4 speech and language therapists, 3 psychologists, and 2 support staff).

Findings indicated that sexual expression was a very uncertain area. There was a theory practice divide. All but one participant said sexual expression should be within their team's remit, yet it was either not addressed or very difficult to address in practice. Professional roles were ambiguous: none of the five professions consistently included, or excluded, sexual expression from its remit. The psychodynamic processes that deterred practice were explored. Themes, developed from in-vivo coding, were organised into five subsets: enculturation of the individual prior to training; professional socialisation; the affective component; professional practice; team working & the wider context. This new understanding reveals why simplistic changes to education are insufficient. Recommendations have been made that reach beyond the team to the NHS, professional bodies and health care education. Given such uncertainty, community disability teams need to take responsibility to ensure holistic practice, encompassing sexual needs, is offered to all service users. A new practice model to support them, appropriate to all disciplines, has been proposed.
ACKNOWLEDGEMENTS

This research would not have been possible without the kindness, support and generosity of so many. I am indebted to the organisations and individuals in the preliminary inquiry who shared their experiences of disability. I hope I have done full justice to their valuable contributions. I also owe a huge thank you to the participants from the four disability teams who so generously gave their time and shared with great candour their thoughts and feelings. I am grateful too for the support given by the Hospital Savings Association Charitable Trust and The Health Foundation. Above all else though, I wish to acknowledge the love and forbearance of my friends and family, especially during the darker times. This includes my three sons Christopher, Laurence and Jonathan, who have all successfully travelled the doctoral road before me. Shining above all is Chas, without whom this study may never have begun and certainly, without whom, it would not have been finished!

AUTHOR'S DECLARATION

This dissertation was prepared in 2007 for submission to the University of Brighton, United Kingdom for the award of PhD. My three supervisors believed it ready. The two examiners disagreed and sought major changes. I began working on the changes with a new supervisor however the changes, in my opinion, compromised the ethical integrity of the study. This especially concerned those who contacted me during the preliminary inquiry whereby they were becoming the subjects of the study. Additionally the analysis, which I had shared with the participants, was to be altered without recourse to them. Therefore I withdrew from the PhD process. Yet I am still asked for copies of this work. So here it is but you must read it on the understanding that you need to make your own judgement on the validity and reliability of the work.

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CHAPTER 1: INTRODUCTION

1.1 Prelude

'Policy and provision around disability often neglect to consider sexuality as one of the basic human needs. While housing, transport, education, and other needs are dealt with, albeit inadequately, consideration of social and sexual factors is not high on the welfare agenda. … This failure to prioritise matters which are highly significant to most adults, including most disabled adults, reflects a failure to consider disabled people as fully human. Just like elderly people, disabled people are not seen as having sexual needs, and provision consequently neglects this' (Shakespeare, Gillespie-Sells et al. 1996 p87).

This neglect of sexual expression is apparent in the few services that exist to meet the sexual and relationship difficulties experienced by disabled people (Disability Rights Commission 2003a; SPOD 2002). For the last thirty years, various authors have argued for change (Cooper and Guillebaud 1999; Davies 1988; Ducharme 1987; Greengross 1976; World Health Organization 1974). In their book 'The Sexual Politics of Disability', the authors included amongst the barriers to change -

'Government policies, professional ways of working, media representations and public attitudes' (Shakespeare, Gillespie-Sells et al. 1996 p182, italics added).

The research, presented here, investigated professional ways of working, looking particularly for tacit, often unconscious perspectives, in relation to the sexual expression of service users. The professionals concerned were health and social care personnel, working in teams, who provided interventions for people with physical disabilities living in the community: professionals considered to have expertise in disability. The findings have led me to reflect whether the care provided by some disability teams may unwittingly undermine the sexual health of disabled people and contribute to their sexual disenfranchisement.

This study is not about the sexual problems of disabled people but rather the difficulty disability professionals have in encompassing sexual expression within holistic practice. Increasingly, as the research progressed, I began to recognise that I did not hold a neutral place within it. I moved from seeking to elucidate professional practice to a

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1 In no way do I wish to imply physical disability is synonymous with sexual problems. Indeed some disabled authors indicate a richness and diversity of sexual expression, borne out of the necessity for good communication and creative problem solving, that many non-disabled people may not achieve (Shakespeare 2000; Shakespeare, Gillespie-Sells et al. 1996; Zilbergeld 2004).
contemporary critical theory paradigm which is concerned with issues of power, oppression and social justice (Forst 1996; Kincheloe and McLaren 2000; Lincoln and Denzin 2000a; Neuman 2003). My research question became: why is sexual expression of disabled people either not addressed, or so difficult to address in practice? What has emerged is that practice is frequently underpinned by largely unrecognised and unarticulated beliefs and values around, particularly sex, and disability too. These pervade professional education, practice and service delivery. Identifying this has enabled new levels of understanding of these difficulties.

My approach has been broad: team practice rather than a single profession; physical disability rather than a specific condition; sexual expression and intimacy not coitus. Others have, and will, focus on narrower aspects. At an international conference, for people with multiple sclerosis and professionals, eminent neurologists and urologists described innovative medical treatments for sexual dysfunction. Yet, it was a man with multiple sclerosis and his wife who received a standing ovation. David Golding spoke of what sexual expression meant for him. He said,

'It is not just erectile dysfunction. It is life giving and life affirming. In our relationship, it has been about having children but much more besides. For us it has meant affirmation, reconciliation, celebration and healing' (Golding and Golding 2001).

It is in this spirit that I have preserved breadth. However, focusing on only three teams has permitted a depth of exploration, not achieved before. My research has also been directly influenced by the lived experience of some disabled people who helped me form my initial research aims.

Reflection on the findings has led to detailed recommendations for individual, team and organisational change. I believe these changes are necessary to achieve an holistic approach to health and social care that encompasses sexual expression. Such an approach would enhance social inclusion and the quality of life of physically disabled people. This is in accord with the transformative endeavour of contemporary critical theory (Kincheloe and McLaren 2000; Lincoln and Denzin 2000b). The changes require placing the disabled person as a full human being, with sexual needs like all others, at the centre of service planning. In summary my recommendations include: -
• implementation of a new model of sexual health practice for disability practitioners
• changes to the pre and post registration education of health and social care personnel addressing attitudes, knowledge and skills in this aspect of care
• development of organisational policies, both at national and local level, to ensure health and social care services protect and support the sexual expression of disabled people
• the provision of guidelines and position statements by professional bodies to clarify roles and boundaries in work related to sexual expression
• raising awareness of the sexual needs of disabled people within specialist disability services across agencies
• raising awareness of the sexual needs of disabled people within sexual health and personal relationship services across agencies
• wider dissemination of relevant research into the mainstream of health and social care discourse

In keeping with a qualitative approach, I have chosen to write in the first person. This 'liberation of researcher voice' (Holliday 2002 p129) assists transparency thereby separating my thoughts and opinions from those of others, including participants, literary sources and experts in the field. I make no claim to reveal objective facts, rather I have tried to place before you, the reader, a complex reality which is mediated both by my interpretation (Holliday 2002) and by yours (Rolfe 2001b).

1.2 Orientation to the thesis

The research was conducted in two phases. During phase 1, the preliminary inquiry, I approached several disability groups and, through some of them, I made contact with a small number of disabled people. This was never intended to be a statistically representative sample but a determined pursuit of service user collaboration. The intention was to gain insights, from disabled peoples' perspective, to enhance the research. In phase 2, the main study, I investigated the professional practice of three
disability teams (four with the pilot study). This I did through focus groups and depth interviews, working with each team consecutively over a period of two years.

In this introduction, definitions are provided before proceeding to a rationale for the study, noting its potential contribution to health and social care. A distinction is made between professionals with expertise in disability and those with expertise in sexual health and personal relationships. The aims of the research are then outlined. I conclude the chapter with a reflexive account of my position within this research, thereby identifying my affiliations and how these may have impacted on the work (Kincheloe and McLaren 2000).

The conceptual framework, in chapter 2, highlights important themes underpinning the research. Connotations of disability are explored including the semantics of human functioning, impairment and disability. An historical overview indicates some of the complexity and sensitivity surrounding sexual expression. The terms, intimacy and sexual expression are reviewed. Finally a brief outline of what can be done when sexual problems arise, secondary to physical disability, is given.

A synopsis of the preliminary inquiry is given in chapter 3. It emphasised the need to frame the study within the social model of disability and indicated the importance of comprehending the richness and diversity of sexual expression. Too often problems with sexual expression are reduced to neuro-physiological impairment and, in particular, erectile dysfunction. It exemplifies the importance of seeing sexual expression 'as part of the total person as opposed to limiting it to the genital area' (Daniels 1981 p7).

Chapter 4, the review of literature, draws on a movie metaphor (Rudefstam and Newton 1992 p51). 'Long shots', give a broad overview of background research into sexual health and the general population. 'Medium shots' consider research into the impact of disability on sexual expression. In-depth critical appraisal, 'the close-up', is reserved for studies of disability professionals' education, roles, attitudes and skills around sexual expression, concluding with research into the practice of physical disability teams.

Methodology, chapter 5, recounts the thinking and decisions around the design of the main study, leading to the interpretive, qualitative approach taken within a
contemporary critical theory paradigm. Various frames of inquiry were considered but I explain why a pluralist stance had a better affinity with the research aims. Research strategies are evaluated and both rigour and ethics discussed. The chapter concludes with a specification of the actual design used, noting the influence of the pilot study.

Chapter 6, outline of data, is a factual account of information used in the main study. This includes a profile of the three disability teams and a numerical account of the fieldwork undertaken. It also outlines some serendipitous data, arising from electronic discussions held on the Internet, which were important and therefore included.

Data analysis in a team context, chapter 7, begins the process of interpretation. I have presented this as a narrative of each team. My aim was to provide a tangible sense of the teams and the group processes. Although most participants indicated that sexual expression should be included in practice, for the teams in this study, it was either not addressed or was very difficult to address.

The individual, chapter 8, begins a thematic analysis of deterrents to practice. It reveals some of the values and beliefs participants held as individuals before they embarked on pre-registration education to become a health or social care practitioner. Just talking about sex, for example, demands that a person crosses a learnt social boundary. Here, as in the next four chapters, the themes are discussed and related to the preliminary inquiry and to previous research.

Deterrents to practice, located in professional socialisation, constitute chapter 9. Interrogation of the data suggested deficiencies in pre and post-registration education. Many participants indicated that, in theory, sexual expression should be part of practice but there was little evidence of them engaging in a learning cycle to enable this.

The affective component is assigned to chapter 10. The emotional aspect of addressing sexual expression became a major theme that spanned the individual, their learning and their practice. Strong negative feelings were possibly the most significant deterrent to addressing sexual concerns.
In chapter 11, *professional practice*, role uncertainty is amongst the themes revealed. Additionally the unseen nature of sexual expression, and the specialness afforded to it, deterred participants. Mostly they only had their personal experience to guide their practice. Treatment priorities of the professional could relegate sexual expression to a non-essential activity: an optional extra that there was no time for.

In *team working & the wider context*, chapter 12, I consider the practice of the whole team collectively, its construction and the organisational culture. Deterrents to practice included: the nature of the service users; progressive disorders; having two clients rather than one; the lack of perceived support from the wider organisational context, and institutional asexualisation.

In chapter 13, I make *recommendations*. These are far reaching. Based on this research I have proposed a new model of sexual health. There are implications for pre and post registration education. I also urge the development of national & local policies as well as profession specific position statements. This is part of a broader strategy to raise awareness both within sexual health and disability services.

The thesis concludes with my *final thoughts* in chapter 14. I reflect how sexual expression of disabled people might move, as I believe it should, to an integral part of health and social care. 'For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled' (Medical Foundation for AIDS & Sexual Health 2005 p27). This includes disabled people. The chapter concludes with the limitations of this study and suggestions for future research.

1.3 Definitions

**Sexual expression**

Sexual expression has been used here to encompass three diverse terms: sexuality, sexual functioning and sexual health.

- **Sexuality** refers to an holistic concept of the individual as a sexual being incorporating role and gender identity (Woods 1984).
• **Sexual functioning** refers to specific physical and emotional behaviours through which an individual expresses sexual identity (Woods 1984).

• **Sexual health** has been defined as the physical, emotional, psychological, social and cultural well being of a person's sexual identity, and the capacity and freedom to enjoy and express sexuality without exploitation, oppression, physical or emotional harm (Royal College of Nursing 2000).

Sexual expression is an activity that can occur alone or with others. It is closely allied to intimacy and personal relationships and, throughout the study, I mean this to include heterosexual, gay, lesbian, bisexual and transgender relationships. I also consider it relevant to people not in a relationship as well as to those in monogamous and polygamous relationships.

Sexual expression, or more often problems associated with it, may be a primary or secondary focus of health care. In this study, it is the secondary focus, that is, where problems arise concomitant to physical disability, which is under scrutiny. This may be through illness, treatment or disability (Davies 1988). Disability may impact on sexual expression from neuro-physiological damage, psychosocial processes or from environmental barriers, both physical and social.

**Physical disability**

Physical disability is used here to include people whose physical impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities (Disability Rights Task Force 1999). This includes congenital or acquired disability, traumatic injury or the effects of long-term illness. The limitation to participation in activity may be due to individual incapacity or to social processes. This is developed later (see section 2.2 - Connotations of disability).

**Professional practice**

I have used the term professional practice in two ways. Firstly I have used it to indicate the practice of an individual who is employed in a health or social care role, both within their own professional role, or as a key worker. I have also used the term to indicate the combined practice of a group of professionals either employed within one agency, or networking across agencies, in a disability team.
**Disability team**

In this study disability team denotes a group of professionals who work together to provide services to people with physical disabilities (including those with a diagnosis of multiple sclerosis) who live in the community. The service may include activities such as rehabilitation, support or advice, with the specific aims of enabling people to remain living in their own homes, promoting independence or improving quality of life. The team's expertise is in the realm of physical disability. It was left to the teams to decide who their members were. Professions encountered in this study included:

- occupational therapy
- physiotherapy
- nursing
- speech and language therapy
- psychology
- support staff (employees working under the direct supervision of a speech and language therapist, physiotherapist or occupational therapist)
  - social workers and resource officers
  - dieticians

Social workers, resource officers and dieticians were identified as team members but no individuals from these professions elected to participate.

### 1.4 Rationale

'Our sexual health affects our physical and psychological wellbeing and is central to some of the most important and lasting relationships in our lives. It follows that protecting, supporting and restoring sexual health is important' (Dept. of Health 2001a p5).

This is as true for disabled people as for anyone else. It is closely allied to the human rights to privacy, a family life and living free from discrimination (Parliament 1998). Sexual health is about 'the enhancement of life and personal relationships and not merely counselling and care related to procreation or sexually transmitted disease' (World Health Organization 1974 p7).
The question is whether the professional practice of disability teams should protect, support and assist the restoration of sexual health for their service users. It could be argued that sexual health is not an appropriate concern for disability professionals and that it is more properly in the domain of sexual health staff. In providing a rationale for the involvement of disability teams (and thereby the study itself) I will establish the need some disabled people may have for disability specific sexual help. Then generic sexual health services and the management of sexual health within disability services are reviewed. Finally, the perspectives of disabled people are considered.

Establishing need
It is known that many disabilities and long-term conditions can impact on sexual expression (Bancroft 2004; Chandler 1999; Cooper and Guillebaud 1999; Davies 1988; Dechesne, Pons et al. 1985; Glass 1999; Morgan 1994; Woods 1984). Evidence of this has been shown in research; through the practice and experience of some disability organisations, and more recently in National Health Service (NHS) guidelines.

The research evidence is reviewed in detail in chapter 4. Briefly, studies have demonstrated the prevalence and severity of sexual dysfunction in specific disabilities, for example in: multiple sclerosis (Barak, Achiron et al. 1996; Borello-France, Leng et al. 2004; Dupont 1995; Nortvedt, Riise et al. 2001); head injury (Elliott and Biever 1996; Hibbard, Gordon et al. 2000); spinal cord injury (Linton 1990; Westgren and Levi 1999); Parkinson's disease (Brown, Jahanshahi et al. 1990; Wermuth and Stenager 1995); stroke (Carod, Egido et al. 1999; Korpelainen, Nieminen et al. 1999); amputation (Walters 1998), and motor neurone disease (Oliver and Gallagher 2000; Vincent and Rodriguez-Ithurralde 1997). Researchers have investigated the damaging impact of disability on body esteem and sexual attractiveness (Mona, Krause et al. 2000; Taleporos and McCabe 2001; Taleporos and McCabe 2002a; Taleporos and McCabe 2002b). Others have considered the harm of sexual dysfunction, caused by disability, on: intimacy and personal relationships (Chandler and Brown 1998; McCabe, McDonald et al. 1996); quality of life (Carod, Egido et al. 1999; Mattson 1995; Nortvedt, Riise et al. 2001; Walters 1998), and depression (Barak, Achiron et al. 1996; Carod, Egido et al. 1999; Nortvedt, Riise et al. 2001).
Evidence from user groups representing or supporting disabled people, is seen in advice booklets on sexual expression for their members, for example for those with: arthritis (Arthritis and Rheumatism Council n.d.; Arthritis Care 1999); multiple sclerosis (Foley 1999; Foley and Werner 1996; Hofreiter and Straub-Klinik 2001; Multiple Sclerosis Society of Ireland n.d.); stroke (Duddle 1996; Westcott 2002); motor neurone disease (Cooper n.d.); head injury (Coughlan and Morgan n.d.); spinal cord injury (Hooper n.d.-a; Hooper n.d.-b; Hooper n.d.-c; Hooper n.d.-d; Lobley 2003) and Parkinson's Disease (McGinley n.d.; Parkinson's Disease Society 2002; Parkinson's Disease Society n.d.). These booklets were written in response to needs identified by their membership.

Evidence of need is newly seen in NHS guidelines, for example in the management of multiple sclerosis. This recommends sensitive but thorough, systematic assessment, to consider any 'hidden' problem such as impaired sexual function (National Institute for Clinical Excellence 2003 p5). It proposes asking men and women if they experience any sexual dysfunction and, if so, whether it is a concern to them. The advice includes inquiring if the individual, or couple, has any difficulties in establishing and maintaining wanted sexual and personal relationships. Action includes sign posting to locally available counselling services and referral to a specialist practitioner with expertise in sexual problems associated with neurological disease. The impact of disability on partner and sexual roles is also noted in the National Service Framework (NSF) for Long Term Conditions (Dept. of Health 2005). The evidence reviewed in the NSF indicates that good quality, rehabilitation and social care incorporates provision of information, education and practical advice including access to family and sexual counselling if needed. Sexual issues are also being discussed in the development of the supporting competence framework for the NSF (Skills for Health 2005).

**Generic sexual health services**

The first national strategy for sexual health was almost entirely focused on control and treatment of sexually transmitted disease and provision of contraceptive advice (Dept. of Health 2001a). One of only two paragraphs given to sexual problems noted that 'a wide range of practitioners provide psychological and sexual dysfunction services in the private, voluntary and NHS sectors' (Dept. of Health 2001a p32). These included general practice, family planning and genito-urinary medicine as well as the psychosexual and personal relationship services in the private and voluntary sectors. It
could be argued these provide adequate services for disabled people. However, there may be two problems with this. Firstly they are themselves in crisis and secondly there does not appear to be universal recognition, or expertise, within these sexual health services of the needs of disabled people.

'Crisis' was the term used by the Health Select Committee in their report into sexual health services (House of Commons Health Committee 2003 p6). They noted that sexual health is not accorded the priority it deserves and described service provision as 'one of the poorest resourced, most stretched and least well-staffed areas of the NHS' (House of Commons Health Committee 2003 p7). Although primarily focused on sexually transmitted infections, contraception and unplanned teenage pregnancy, the report did mention treatment and services for sexual dysfunction. It highlighted the silent nature of this problem within society and indicated that specialist services were scarce. It criticised the government for dealing with sexual dysfunction as a lifestyle rather than a health issue, noting that the psychological distress can be profound. The government's response (Secretary of State for Health 2003) acknowledged the lack of priority and under investment over decades and stated its commitment to improving access to sexual health services, particularly for disadvantaged groups.

New recommended standards for sexual health services have been published (Medical Foundation for AIDS & Sexual Health 2005). This report recognises that provision of sexual dysfunction services has been fragmented and inconsistent. It does not directly address disability however it indicates that the sexual health needs for people with serious medical conditions are often ignored. It recommends that -

'people with medical conditions or receiving treatments, which effect sexual health or libido should have the opportunity to explore and address the impact of these on their sexual life' (Medical Foundation for AIDS & Sexual Health 2005 p40).

This is to be done as part of the care received for the condition. It proposes sexual health services should contribute to the training of these condition specific staff, to ensure they are able to promote sexual health. It indicates that creating the right environment which permits exploration enhances the opportunity for early self-referral to specialist sexual health services where required.
These proposals are welcome but until now accessing sexual health services within the NHS, private and voluntary agencies, have been problematic for disabled people. Barriers frequently include the physical environment, inaccessible information and staff attitudes (Disability Rights Task Force 1999; Earle 2001; NHS Executive 1999; SPOD 2002). Also, research, funded by the Department of Health (SPOD 2002), revealed that psychosexual health services are limited in the support they can give to disabled people because they have little experience or expertise in disability. For many of these organisations, physical disability falls outside their area of competence (SPOD 2002).

**Management of sexual health within disability services**

The primary voluntary organisation that existed to address both sex and disability, the Association to Aid the Sexual and Personal Relationships of People with a Disability (SPOD) closed during 2003. It was founded in 1972 initially as the committee on Sexual Problems Of the Disabled (Christopher 1991; SPOD n.d.-c). It was formed to act as a pressure group to address the asexualisation of disabled people and to encourage disabled people to express the sexual aspects of their lives and personalities. It provided a confidential telephone counselling service for disabled people and information and support for health and social care professionals and personal assistants. It closed despite continuing demand by professionals and disabled people. The reasons for its closure are considered later (see section 2.5 - Sex as a taboo topic).

A six-month analysis of their telephone inquiries, concluding in 2000, revealed that calls from professionals were twice those from disabled people (SPOD 2000a; SPOD 2000b). SPOD's experience indicated that many professionals felt unskilled when dealing with the combined issues of sex and disability. 'With few notable exceptions, help, support and advice is still not available in mainstream health care services, which in reality denies disabled people freedom of choice' (Long 2000 p3). Before its demise, SPOD had intended to raise the awareness of health and social care professionals who work directly with disabled people -

'to affect a real shift in the importance of supporting disabled people in this aspect of their lives. Training those at the 'coal face' who support and have most contact with disabled people is the first and most effective way to bring about a real change in peoples' lives' (Parritt 2001 p3).
Health and social care professionals who approached SPOD included (in descending order of frequency of contact): social workers, nurses, counsellors, care workers, occupational therapists, doctors, psychologists, support workers, rehabilitation managers and physiotherapists (SPOD 2000a; SPOD 2000b). These are some of the many professionals, at the 'coal face', who work closely with disabled people. They could be in a position to sensitively and non-intrusively enable service users to discuss their concerns. These same people may be able to provide limited counselling and support. Where necessary they could facilitate access to mainstream sexual health or relationship services. Yet, there is no evidence that they do work to protect, support or restore sexual health where problems arise due to disability.

Only very limited research is available into the attitudes and skills of some disability professionals in addressing sexual expression as part of professional practice (Conine, Christie et al. 1979; Couldrick 1998; Couldrick 1999; Guest and Kopp Miller 1997; Haboubi and Lincoln 2003; Hoddy 1999; Kuczynski 1980). This is developed in the literature reviewed in chapter 4. Most notably the Royal College of Nursing (RCN) published a discussion and guidance document on sexuality and sexual health in nursing practice (Royal College of Nursing 2000). This followed studies that highlighted sexual expression as a neglected component of nursing care (Howlett, Swain et al. 1997; Penman 1998; Webb 1994). The RCN stated that the sexual health of patients is a legitimate domain of professional concern. The document includes a case study set in a physical rehabilitation context, requiring an inter-professional approach from nursing, physiotherapy and occupational therapy.

There is no similar statement from the College of Occupational Therapists or the Chartered Society of Physiotherapy. Indeed the occupational therapy literature is ambivalent with some authors stating that clients' sexual expression must be part of the therapist's practice (Friedman 1997; Summerville and Kryss 1998). In opposition, a leading occupational therapy academic, Professor Gary Kielhofner, explicitly excludes sexual expression from the role of occupational therapy (Kielhofner 1993). A few studies have highlighted the concerns of other professional groups in approaching sexual issues including: psychotherapy (Parritt and O'Callaghan 2000), social work, psychology and medicine (Katz and Aloni 1999) and counselling (Clarkson 2003). No
research into professional role and sexual expression of disabled people was found in the speech and language therapy literature.

**The perspective of disabled people**

The government has identified the patient voice as a key strategy in improving health and social care (Dept. of Health 1997; Dept. of Health 1998b; NHS Executive 1996) particularly sexual health services (House of Commons Health Committee 2003). Most information related to physical disability and sexual expression has been provided from a professional perspective. Therefore, I have included here two sources of information from a disability perspective. The first is literature from authors who are themselves disabled, or who draw extensively from the lived experience of disability (Bullard and Knight 1981; Gillespie-Sells, Hill et al. 1998; Shakespeare, Gillespie-Sells et al. 1996). The second is from the collaboration undertaken during the preliminary inquiry.

The concerns raised by disabled writers are extensive. No doubt, some will argue that these concerns apply equally to non-disabled people. However the authors indicate, from their experience, that these concerns are greatly exacerbated by physical disability. They include issues of self-identity and fears of not being desirable or loveable (Daniels 1981). There are barriers, both physical and socio-economic, reducing the opportunities to form intimate relationships (Davies 2000; Shakespeare, Gillespie-Sells et al. 1996). In an age when we are exposed to an almost continuous output of sexual information, disabled people cannot obtain the specific sexual information they require (Gillespie-Sells, Hill et al. 1998). This includes, for instance, appropriate sex education for disabled children (Blackburn 1994; Gillespie-Sells, Hill et al. 1998; Shakespeare, Gillespie-Sells et al. 1996), or information on the effects of specific disabilities on sexual function in adulthood (Daniels 1981; Davies 2000). Popular culture reinforces a stereotype of sexual attractiveness equating with the young and beautiful (Gillespie-Sells, Hill et al. 1998; Shakespeare, Gillespie-Sells et al. 1996). This may have a negative impact for many non-disabled people but it is seen as especially damaging for those with disfiguring impairments.

In summary, these authors highlight that often the major problems associated with sexual expression for disabled people are frequently the outcomes of social exclusion, prejudice and discrimination (Bullard and Knight 1981; Gillespie-Sells, Hill et al. 1998;
Shakespeare, Gillespie-Sells et al. 1996). One disabled woman forcefully expressed this when she said -

'Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about - and formulate strategies for changing - discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction' (Finger 1992 p9).

I undertook a preliminary inquiry to help develop the research agenda. Detailed coverage of this collaboration with disabled people is given in Chapter 3. The findings must be read with caution given the small number involved (18 organisations and 40 individuals) and the inherent bias of those who responded. That is, only individuals comfortable in discussing sexual issues, or who placed it as a high priority may have contacted me. That said, the information gathered from individual disabled people, their partners or the user groups that represent them overwhelmingly supported undertaking this research (Couldrick 2001). From their perspective, sexual expression was a neglected component of health and social care. The vast majority believed that someone to talk to about sexual issues was, or would have been, the best method of providing help. Respondents said that experts in disability (doctors, nurses, therapists, social workers) overall did not address the psychological impact of disability and did not enable discussion on sexual expression. For some disabled people, the most positive help was from external agencies providing counselling and psychotherapy but these services, they said, lacked knowledge of disability.

My presupposition

All adults can experience problems in sexual expression and intimacy. My contention is that, for disabled people, gaining appropriate, disability specific information, support and advice, and accessing mainstream sexual health services is more difficult. Yet, they are potentially subject to a greater number of difficulties due to physical impairment and the less tangible, but extremely pervasive, negative effects of prejudice and discrimination.

Disabled people may see a range of professionals, at different times and for different purposes, for example the community physiotherapist, the multiple sclerosis nurse and the local authority occupational therapist. These professionals, with expertise in
disability, frequently are part of a disability team. The composition, leadership, management structure and remit of teams may vary quite considerably. Some are formed as outreach teams from an acute hospital. Some are focused on specific client groups, for example a stroke team. Some are unified around rehabilitation and some are based within local authorities and focus on environmental adaptation. I reasoned that physical disability teams could fulfill an important role in helping to protect, support and assist the restoration of sexual health of their service users, where physical disability has impacted upon sexual expression. I do not imply this should be *instead* of sexual health services, but that the skills of experts in disability could compliment and enhance accessibility to more specialised services.

There were several reasons for investigating the practice of disability teams rather than individual professions. Within a team, one person rather than one profession may be ascribed expertise in managing sexual issues. Alternatively, one team member may not address sexual expression believing this to be in the professional realm of other team members. Also, a service user may only see one member of the team, probably the team member most relevant to the presenting problem. Sexual issues, because of their private nature, are unlikely to be the presenting problem (Annon 1974; Ross and Channon-Little 1991). Within a team of professionals, there will be some skills unique to certain health or social care roles. There will be shared skills common to many professions. There will be specific expertise acquired, for example, through personal experience or additional training.

Knowledge about these complex issues is limited. Thus, I believe it was important to research the service provided through the combined working of the different disciplines and people who constituted a disability team. No similar research has been published.

1.5 Aims of the research

My aim was the rigorous investigation of the professional practice of disability teams toward the sexual health of their service users where disability impacts on intimate relationships and sexual expression. The original intention was to provide rich ethnographic description of team culture to illuminate professional ways of working.
As the study has progressed, my focus has subtly changed. (Or the unconscious aim has moved to consciousness). From a contemporary critical theory position I have sought explanation of why sexual expression of disabled people is either not addressed or is difficult to address in practice. From this perspective, the task was to reach beyond espoused roles, skills and attitudes to a deeper analysis, deconstructing what disability teams actually did in practice. Deep exploration of the psychodynamic processes that underpin team members’ actions has assisted understanding. I have used the findings to indicate potential consequences for disabled people when this area of practice is ignored. I have also made recommendations with the goal of transformation of practice.

Several attributes are indicated in the literature if sexual issues are to become part of any professional’s practice (Davies 1988; Neistadt 1993; Ross and Channon-Little 1991). They include: the ability to sensitively raise the issue whilst respecting the individual’s privacy; provision of limited counselling and support within professional boundaries, and facilitating access to specific specialist services appropriately. I used these attributes to identify objectives against which the teams could be critically appraised. This formed the basis of the first level of interpretation, presented through rich narrative descriptions, given in Chapter 7. (Chapters 8-12 deal with the second level of interpretation, which enables a more profound awareness of the conscious and unconscious processes guiding team practice.) These objectives included:

- ascertaining if the team believed intimacy and sexual expression was a legitimate area for service provision
- outlining which professions were seen by the team as appropriate to deal with issues of intimacy and sexual expression
- verifying which practitioners addressed sexual issues in practice
- establishing the team’s confidence and competence to non-intrusively, enable service users to discuss their concerns
- establishing the teams confidence and competence in providing limited counselling and support
- detailing what support, guidance and referral resources were available for the emotional impact of disability on intimacy and sexual expression
- detailing what support, guidance and referral resources were available for the bio-mechanical impact of disability on intimacy and sexual expression
- exploring shared, unique or specialist skills within the team
- outlining professional development and support systems for this aspect of care

On entering the field, there was no previous research into the collective professional practice of a disability team toward the sexual expression of their service user.

1.6 Reflexive awareness

‘Whereas traditional researchers cling to the guard rail of neutrality, critical researchers frequently announce their partisanship in the struggle for a better world’ (Kincheloe and McLaren 2000 p291).

Others have outlined the importance for qualitative researchers to be open about their values and assumption (Holliday 2002; Kincheloe and McLaren 2000; King 1996) indicating that credibility can only be assessed by ‘showing the workings’ of the research process (Holliday 2002 p47). I have valued this when done by other researchers (Annon 1974; Bancroft 2004; Shakespeare 1997) especially when dealing with matters sexual. Thus, my aim here is to introduce my position as the researcher and to consider the possible effects I may have had upon the study. To do this I will endeavour to recount some of my own values and assumptions: that is, my subjectivity. I will describe relevant motivations that led to this study. My inter-relationship with the participants and my position as an insider or outsider are then discussed.

Subjectivity

As a starting point, I return to the shift of research aim. Instead of wanting to illuminate practice, I became aware of seeking a deeper understanding of why sexual expression of disabled people presents such difficulties. In my contact with teams, I endeavoured to present acceptance of all views including that it should not be part of practice. Yet, my core belief is that it should be. Awareness of this bias does not in itself remove it. However I can disclose my personal and professional development that underpins my belief and consider what effect it has had on the research.
In 1985, as a local authority occupational therapist, working with physically disabled people living in the community, I attended a course run by SPOD on Sexual Issues for the Disabled. Although short, the impact was enormous. Before this, I would tentatively introduce the subject with heterosexual couples under forty! It made me realise that my practice was insensitive to diversity and based on ignorance. I also had the opportunity in 1988, to attend two four-day courses organised by Relate on Sexual Issues in Counselling (parts I & II). Understanding the developmental milestones in my own sexual identity was integral to the training. As part of my broader education as a counsellor, I also explored the influences of my family, society and culture. This challenged many of my ethnocentric assumptions arising from fitting most stereotypical norms of English society: white, Anglo-Saxon, protestant, heterosexual, serially monogamous, middle aged and middle class. This helped me to recognise and value the diversity of family forms and the different ways people engage in intimate relationships. All these factors have made me more comfortable in considering sexual expression.

Unlike many of the respondents in the disability teams, I have also been immersed in the narratives of disabled people and their feelings around sexual expression. I have been extremely moved by the literature written from the lived experience of disability (Bullard and Knight 1981; Davies 2000; Finger 1992; Gillespie-Sells, Hill et al. 1998; Shakespeare 2000; Shakespeare, Gillespie-Sells et al. 1996). My PhD advisor, Dr Michael Rogers and his wife Elizabeth have been influential in describing their experiences of introducing sexual expression into patient and staff education at Stoke Mandeville Hospital, he as a person with quadriplegia and she as a former nursing sister in the hospital. Also, I heard, first hand, the personal testimonies of those disabled people who telephoned, emailed or wrote to me in the preliminary inquiry.

These influences have contributed to my belief, that acknowledging human sexuality, and addressing concerns around it, should be part of practice. Despite my endeavours to moderate this position in focus groups and interviews, it must impact on the study. Where appropriate, in writing up the results, I have included my responses in the verbatim transcripts. The question is: did it stop professionals renouncing a professional role in supporting their service users’ sexual health? Despite my efforts to validate both positions (sexual expression should AND should not be part of the disability teams’ remit) it may have contributed to the theory / practice divide (many
suggested it should be part of practice but in reality they did not raise the subject).

Some respondents will have colluded with me. Another consequence, on my part, was an underestimation, of the profound influence of the participants’ own personal experience of sexuality. The research strategies may have encouraged respondents to provide sanitised accounts of workloads, protocols and professional boundaries, rather than to focus on their own discomfort when confronted with other people’s sexuality. These thoughts are developed later both in the critique of methodology and in the developing analysis.

**Motivation**

There are two aspects of motivation: the drivers that spurred me to do this study and those pushing me to seek an academic qualification. This research arose from an earlier study, undertaken in part fulfilment of an MSc in Advanced Occupational Therapy (completed in 1996). It was a small qualitative study to consider if client’s sexual expression was a legitimate domain of concern of the occupational therapist (Couldrick 1996). I worked in forensic mental health services at the time, where sexual issues were discussed in the team. Alongside other professions (nursing, psychology and medicine), I had facilitated patient groups, in the regional secure unit, based around different aspects of sexual awareness and health. The research topic also allowed me to draw on the SPOD and Relate courses. It explored generic practice and focused on the fit with professional values. The findings demonstrated a need for a more in depth study to understand the powerful emotive forces that might explain why sexual expression was not regarded like any other activity of daily living. It also revealed the importance of team contexts and the fit of sexual expression with other professional roles.

Later, I moved into pre-registration occupational therapy education and I had to consider if sexual expression should be introduced into the curricula of the college. Should occupational therapists learn how to work with service users in a sexually affirming way? I could present my research and my personal view to students. Beyond that, I recognised the ambivalence in the profession and felt I had no mandate to insist that sexual expression should be part of professional practice. I saw more research as necessary to gain a clearer understanding.
In terms of motivation for an academic qualification, the overt reason is simple. It was an aspiration identified to meet the service needs of the college. However, with a change of employment, the PhD was no longer required. The academic accolade was unnecessary but ethically and morally, the research needs finishing: so many people have contributed to it. This would not have been possible without academic support.

I have also had the opportunity to talk with experts in the field such as Wendy Greengross, Roy Green, Simon Parritt, Dominic Davies, Penny Pepper and Tuppy Owens. Wendy Greengross (1998 & 2003 personal communication) suggested that very little progress had been made for disabled people in promoting sexual health since 1970. My concern is no longer limited to occupational therapy but more generally health and social care. I am motivated by the thought that this study may transform practice (Neuman 2003). At the project’s inception, I thought, at the very least, if the task of addressing sexual health for service users is beyond the scope and competence of disability professionals, this should be made explicit to service users.

**Insider / outsider**

In reflecting on my position within this research, the two phases of the study must be born in mind: the first with disabled people and the organisations that represent them, and the second with health and social care practitioners who were working in the field of physical disability. Likewise, there are two aspects of being inside or outside: how I perceive myself and how others perceive me.

Throughout this research, I have placed great value on the perspective of disabled people because I am an outsider. Nothing in my experience can give an understanding of lived experience of disability. In the preliminary inquiry, I think most perceived me as a researcher. *Researcher* may have connotations of being an expert. This may have limited some people’s responses. However, I suggest that it was in fact an advantage and that people disclosed more because of the authority invested in that role.

In terms of the disability teams in the main study, I have an ambiguous position being both insider and outsider. I hold professional qualifications as an occupational therapist, counsellor and educator; additionally my role in the project is as a researcher. I have worked within multidisciplinary teams and specifically physical disability teams in the
NHS and Social Services. Until recently I was the training and development consultant to five local authority teams, four of which are occupational therapy teams focused on environmental adaptation for people with a physical disability. The fifth team has a specialist social care workforce, whose role is assessing and commissioning services for people with sensory impairments. Some may regard me as an insider. I do not identify with this, as my practice experience in health is dated, or focussed on mental health, and my experience within local authority is parallel, not identical, with the teams under scrutiny in this study. Moreover, members in the teams were more likely to see my role as a researcher or educator, thereby potentially an expert. If this is so, it may have biased responses because it is possibly harder for someone to disagree with the person they see as having greater knowledge, however erroneous.

In terms of individual professions, I do acknowledge an insider role as an occupational therapist registered with the Health Professions Council and as an accredited senior practitioner with the Association of Counsellings and Psychotherapy. (I use a psychotherapeutic model of counselling from the humanistic and psychodynamic schools (Couldrick 1992; Thorne 1992)). Occupational therapy was the largest professional group in this study and psychotherapy was encompassed within the work undertaken by one of the psychologists. Values are often tacit, making the insider position particularly helpful. I do have a deeper understanding of the philosophical values of occupational therapy, counselling and psychotherapy plus greater knowledge of models of practice and of key figures in these professions. I routinely screen literature from these professional bodies. However, I am an outsider to the other professions within the research, which must at least; translate into less understanding for the roles and values of physiotherapy, nursing and speech and language therapy.

From the perspective of the participants in the main study, I believe only one professional recognised my counselling credentials. Therefore, I have presumed my position as a counsellor, did not significantly alter responses. On the other hand, my role as occupational therapist is problematic. I knew some of the occupational therapists either through work links or via occupational therapy education. This is explored later (see section 6.3 – Disability Team A). I may also have been known both through publications and conference presentations perhaps as a non-conformist, or a maverick pursuing this research for personal motives. Where this has been owned by a
participant, it has been open to discussion, and considered in the results (see section 9.3 – Deficiency of educational programmes). I cannot know the impact on the study where views such as these remain undisclosed.

1.7 Conclusion

This introduction has provided a rationale for, and a signpost through, the thesis. Definitions have been given. I argued that this research was necessary because disabled people may experience sexual problems secondary to their disability and that practitioners, with expertise in disability, those at the ‘coal face’, are in a position to help. I do not mean instead of sexual health services but complementary to them. The aim of the research, the rigorous investigation of the professional practice of disability teams toward the sexual health of their service users, was discussed. This included the deep exploration of psychodynamic processes that might explain why the sexual expression of disabled people is either not addressed or is difficult to address in practice. Locating the research in contemporary critical theory has led me to consider the potential consequences for disabled people when this area of practice is ignored. I have also made recommendations with the goal of transformation of practice. Finally, I have introduced myself as the key protagonist in the study. I have explored my subjectivity, motivations and position in relationship to the participants.
CHAPTER 2: CONCEPTUAL FRAMEWORK

2.1 Introduction

‘Human sexuality is a complex phenomenon, pervading every aspect of our being. It is a source of pleasure, even peak experience. Sexuality can also be a source of great pain. It is vulnerable to the vicissitudes of stress and strain and of daily living and illness’ (Woods 1984 piv).

This acknowledgement of the intricate, personal and fragile nature of sexuality introduces some of the complicated issues that underpin this research. Sexuality, and by inference sexual expression, may be a source of great joy or distress: of supreme importance or of little significance. Similarly, attitudes to disability are neither universal nor consistent. Is it about functional limitations or barriers constructed by society? A major function of a conceptual framework is to place me, the researcher, in relation to the research (Holliday 2002). By aligning key elements, something of my ideological position, within such complex phenomena, is revealed.

So, here I explore definitions, models and classifications of disability. This includes the medical and social models, which reveal the interplay between the private and public domains inherent in this research. The disability language used in this dissertation is also clarified. I will then explain why I believe sex is a complex subject. Partly this is because everyone’s personal, social and cultural experience not only shapes different attitudes to sexual expression: it contributes to its actual social construction. This is exemplified through a very brief history. Also, complexity is partly due to the taboo of sex. This is explored along with the possible effects taboo may have upon the study. The relationship between intimacy and sexual expression is then considered. The chapter concludes with a summary of contemporary thinking on what can be done, by disability professionals, to support the sexual health of their service users. This was the received knowledge available on entering the field. I have since, as a direct consequence of the findings of this study, proposed a new model of sexual health practice (see section 13.2 – A sexual health practice model for disability practitioners).
2.2 Connotations of disability

Disabled people have been described as one of the most disadvantaged groups in society (Disability Rights Task Force 1999). The definition provided earlier (see section 1.3 – Definitions: Physical disability) was developed from the Disability Discrimination Act (Parliament 1995; Parliament 2005). The Act defines people as having a disability where they have a physical or mental impairment that has (or will have) a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. For pragmatic reasons, I have focused on the health and social care provided for people with a physical impairment. This in no way seeks to minimise similar concerns about professional practice for those working with different client groups. Other authors have raised parallel issues in learning disabilities (Brown 1996; Craft and Craft 1982; Holmes 1998; Murray and Minnes 1994; White and Barnitt 2000; Wolfe 1997; Wolfe and Blanchett 1997), in sensory impairment (Berman, Busby et al. 1981; Hicks 1981; Job 2004; Straw 1981) and in mental illness (Crawford and Shaw 1998; Ferguson 1994; Grant 2003; Penna and Sheehy 2000; Sladyk 1990). However, to consider the totality of disability, and the professional practices related to it, was too daunting.

Models of disability

In 2001, the World Health Organization published the International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2001). This represents a major revision of their former tripartite International Classification of Impairment, Disability and Handicap (ICIDH) (World Health Organization 1980) which was a cornerstone of the individual or medical model of disability. In the ICIDH, impairment was defined as any loss or abnormality of psychological, physiological or anatomical structure or function. Disability was defined as any restriction or inability, resulting from an impairment, to perform an activity in the manner or within a range considered normal for a human being. Handicap denoted any disadvantage, resulting from the interaction between a person’s impairment or disability and their environment, which limited or prevented them fulfilling a role, normal to them.

The ICIDH was not universally adopted. The political mobilisation and social protest of disabled people, which I have summarised as the disability movement, was forging
another view. They preferred a twofold classification that distinguished simply between impairment and disability (Barnes, Mercer et al. 1999; Oliver 1996; Priestley 2003). Impairment in this sense corresponds broadly to the ICIDH’s definitions of impairment and disability. The term disability, for the disability movement, is more akin to ICIDH’s definition of handicap but with a subtle shift in emphasis. ‘For the World Health Organization it is the individual who is ill-adapted to fit into the environment, whereas for the disability movement it is the environment which is ill adapted to accommodate the individual’ (Low 2001 p4). This is the social model of disability (Marks 1999; Oliver 1996; Oliver 1999a; Priestley 2003; Thomas 1999).

Traditionally the medical model has dominated academic understanding of disability especially in the therapeutic literature (Priestley 2003). From this perspective disability is seen as a problem for the individual caused by impairment. The individual requires treatment to reduce the impairment or to help them adjust to their disability. The disability movement has increasingly, and vociferously, rejected this concept in favour of the social model of disability. This sees disabled people as –

‘disabled or oppressed by society that expects its members to conform to the yardstick of able-bodied normality and whose physical and social environments penalise any ‘misfits’ (Bochel and Bochel 1994 p82).

That is, disability is a social problem caused by social processes (Oliver 1996). The disabled is not an homogenous group with a unified voice. However, protagonists of the disability movement argue that disabled people do share a common experience, to a greater or lesser extent, of discrimination and inequality of opportunity (Barnes, Mercer et al. 1999; Marks 1999; Millington and Mottram 1999; Oliver 1996; Thomas 1999).

Having worked in both health and social care, where the alternate models dominated each context, I know first hand, how difficult it is to perceive both models simultaneously. It is as though the two models cannot co-exist. Yet, each may leave something important out. From a medical model perspective, oppressive environmental barriers (both social and physical) may not be seen. From the social model perspective the personal subjective experience of impairment may be ignored (Crow 1996).
Public versus private domains of disability
Some disabled people in the preliminary inquiry stressed the importance, to them, that this research was framed within the social model of disability. I too felt this was essential because the collective practice of physical disability teams has the potential to contribute to oppressive practice. This is the public domain, the wider picture. However, I felt my research could not ignore individual impairment. The aim was to investigate the practice of health care professionals whose role is specifically to work with individuals, normally at their direct request, to enhance their function and extend their skills. Their service users were seeking, to a greater or lesser extent, alleviation of their impairment. This is the individual domain and in terms of sexual expression is normally regarded as private. At the heart of this research, is the need to unravel the individual, medical and often private, from the social, environmental and public factors. Unless we have a shared understanding of holistic rehabilitation for the individual, inclusive of sexual expression, we cannot acknowledge the more global oppression caused by its omission.

International Classification of Functioning
The ICF was written to address the criticisms of the ICIDH. It is intended as a synthesis of the medical and social models of disability and provides a taxonomy to describe health and health-related states for all people (not just those who experience disability) from the perspective of the body, the individual and society (World Health Organization 2001). The revised language emphasises function rather than condition or disease. The utility of the ICF to this study is that it prioritises relationships, including intimate sexual relationships, as important to health, on a par with communication, mobility and self-care. It also recognises sexual expression as a health-related contributor to quality of life. The category descriptor is ‘creating and maintaining close or romantic relationships between individuals, such as husband and wife, lovers or sexual partners’ (World Health Organization 2001 p163). It is sub-divided into romantic, spousal, sexual and other intimate relationships. Additionally, in classifying environmental factors, the attitudes of health professionals are separated from societal attitudes.

My difficulty with the ICF is its positivistic and reductionistic approach to classification of function. Whatever its purport, it seems to encourage professionals to take an expert approach, meticulously classifying problems without recognising the disabled person as
the expert on his or her experience. This is especially important in sexual expression. The ICF has also been criticised for classifying people according to their differences and assuming the power to judge normality and thereby deviance (Hammell 2004a).

**Language of disability in this study**

In this study the term, *disabled people* is used to refer to the potential service users of a physical disability team. My use is from the social model perspective: that is people disabled by society’s barriers (Employers’ Forum on Disability 2005). For those who find the term objectionable, on the ground that it implies non-normality, I apologise and distance myself from this interpretation. I do not intend it to indicate one end of a spectrum that is *disability*, with the other end assumed to be *ability*. I also accept that some people do not identify themselves as *disabled* despite having a severely incapacitating disease (Scullion 1999). When I use the term *disabled people* I include people with: congenital disorders such as cerebral palsy and spina bifida; disease processes such as multiple sclerosis and rheumatoid arthritis, and impairment due to trauma such as cerebrovascular incident or spinal cord injury.

I have also extended my gaze to the disabled person’s social context. This includes family members and carers who have experience, from their own perspective, of the effects of disability. For an individual, sexual expression may include the experience of masculinity or femininity; solitary sexual activity such as fantasy, cyber-sex, erotica and masturbation; or lifestyle choices like celibacy. More often, it is closely allied to relationships and family life. The effect of disability on sexual expression may be as profound for a partner as it is for the individual. Parents may be concerned about the potential sexual risks for their disabled adolescent. Or a carer may be offended by finding pornography in the home. So, in the preliminary inquiry and in my reflections in the main study, I have taken a broader view than the disabled person and have encompassed partners, family and paid carers.

Before leaving the language of disability, it is important to acknowledge the uniqueness of the experience of disability for the individual, especially when aligned to its impact on sexual expression. For one person it is the experience of a sudden catastrophe. For another, it may have a slow, insidious onset. The preliminary inquiry revealed broad differences between people who had: congenital or early onset disability; acquired a
disability before sexual competence was achieved; or acquired a disability after achieving sexual competence (Couldrick 2001). For those with a congenital disability, all relationships will be established within this experience, whereas others may have established intimate relationships prior to impairment. Thus, issues for the person with spina bifida will be totally different to the person with a traumatic spinal cord lesion, despite comparable damage to body structure.

In summary, by using the term, disabled people, I imply the service users of a physical disability team and their family members and carers. In investigating physical disability, sexual expression and professional practice, I have had to consciously engage with both the individual and social models of disability. This involves focusing on the individual, often private issues; the microcosm where intimate relationships develop and sexuality is expressed. It also involves refocusing on the wider picture, including the social and physical environment, which includes political and public domains.

2.3 **Sex as a complex subject**

Fundamental to this study is the multifarious nature of sexual expression. Increasingly my reading has moved me toward a social constructionist view of sexuality whereby sex cannot be seen as a simple biological phenomenon but socially and culturally shaped (Evans 1998; Foucault 1978; McLaren 1999; Rivers 1998; Weeks 1992; Weeks 2000; Weeks and Holland 1996). This results in differing, changing and conflicting views. These ‘conflicts of opinion and values surrounding human sexuality reflect the inherent complexity of the issues’ (Bancroft 2004 p9). Weeks revealed something of this when he described what might be encompassed when thinking of sexuality.

‘We think of reproduction, which has traditionally been seen as the main justification of sexual activity, and with which western cultures at least have historically been the most preoccupied. We think of relationships, of which marriage is the socially sanctioned, but far from being the only, form. We think of erotic activities and of fantasy, of intimacy and warmth, of love and pleasure. We relate it to our sense of self and to our collective belongings, to identity, personal and political. But we also think of sin and danger, violence and disease’ (Weeks 2000 p163).

Thus, it can be seen as the ultimate creative act, pleasurable, benign and life enriching. Simultaneously it may be viewed as destructive, risky, threatening and dangerous. This conceptual framework provides a fleeting view of the cultural and historical background
to this unstable territory. Others have provided more detailed histories (Bullough 1994; Christopher 1993; Foucault 1978; McLaren 1999; Tannahill 1992; Weeks 2000). First, I introduce sexual story telling.

**Sexual stories**

I have found Plummer’s (1996) concept of sexual story telling helpful in comprehending the social constructionism of sexuality. It builds on Foucault’s (1978) treatise on the relations of power and social control inherent in sexuality. Plummer outlined the cultural changes occurring toward the end of the last century that permitted the present proliferation of sexual stories. With the expansion of the media (like newspapers, radio, chat shows and the Internet), telling sexual stories has become part of the currency of modern consumerism, but *hearing* the story changes. He suggests that the coming out stories of gay men and lesbian women would not have been heard before the 1970s. Although now seen as empowering and liberating for the gay person, in a previous era, homosexual tales were heard as morbid and pathologising.

Plummer (1996 p38) argues that ‘specific stories have their specific times’: the moment in history when they can be heard, and he outlines the necessary steps for this to happen. These steps move the story from a private world to a public one. The inner world of experiences and feelings has to be articulated. Growing awareness is required of the languages ‘that mask, hide, deny, or erase experience’ (Plummer 1996 p42). Then different groups, or as he terms them ‘social worlds’, must identify with and hear the story. Finally, these social worlds come together around the story, providing a power that creates a culture of public concern, moving the story from a limited social world to an ‘array of arenas of public discourse’ (Plummer 1996 p44).

Reviewing cultural and religious influences, confirms ‘that sexuality is not a unified domain’ (Weeks 1992 p232). There is no comfortable agreement about what constitutes normal acceptable sexual behaviours. Put another way, sexual stories are conflicting or contested. Behaviour valued and accepted in one society, in one moment of history, may be considered abhorrent to another. Examples include homosexuality (Rivers 1998; Smith, Bartlett et al. 2004) and masturbation (Engelhardt 1992) both previously classified and treated as diseases. But difference also exists within ostensibly the same cultural groups (Sedgewick 1993). Plummer (1996 p49) suggests one strategy used to
manage this difference is to ‘create a silent pact’. He provides a homosexual example: many people who identify as gay may simply avoid ‘coming out’ while others elect to ignore it, thereby ‘life goes on and nobody is (too) threatened’ (Plummer 1996 p49).

So differences, despite sometimes being self evident, are little discussed. For example, the meaning, priority and significance attached to sexual expression and sexual identity varies between people (Sedgewick 1993). Likewise, for some people it is important that sexual expression is located in a loving relationship, invested with meaning and connectedness (Hammell 2004b; Sedgewick 1993). For others, this is unimportant or even undesired (Sedgewick 1993). The traditional binary divisions of sex and gender (women/men: male/female) are now contested because they are seen to exclude people whose gendered embodiment is outside these categories (Archer and Lloyd 2002; Parlee 1998). This leads to a dichotomy whereby society is pre-occupied by the sexual (Evans 1998; McLaren 1999) and yet, to manage difference, it is not discussed.

I have found it helpful to conceptualise the recognition of physically disabled people as fully human, inclusive of sexual identity and needs, as a sexual story. It seems to me that this is a story articulated over nearly forty years, but only heard in limited ‘social worlds’. It awaits the power of a wider social audience. It is a story couched in terms of sexual disenfranchisement (Bullough 1994; Milligan and Neufeldt 2001), or the sexual and intimate citizenship of disabled people (Evans 1998; Plummer 1996) and thereby framed as the sexual politics of disability (Shakespeare, Gillespie-Sells et al. 1996). Others have discussed why sexual rights have not been at the forefront of the British disability movement agenda (Disability Now 2005; Finger, Stack Hall et al. 1992; Shakespeare 2000). This study considers its place in the professional practice agenda.

2.4 An historical overview

**An early split between west and east**

In the western world we are ‘heirs of a Christian tradition’ (Weeks 2000 p131). Historically the Christian influence on thinking integrated lust and sex with the doctrine of Original Sin (Bullough 1994; Tannahill 1992). The writings of St. Augustine appear particularly influential (Augustine 419/1887; Bullough 1994). These indicated that the
purpose of sex was procreation. Therefore, sexual intercourse should be undertaken only within marriage and exclusively with that purpose in mind. All other sexual activities were sinful. The only proper act was penis/vagina penetration, and the use of any other orifice was condemned (Augustine 419/1887). This contrasts to eastern societies where sexual expression was linked to Taoism and Tantra. In medieval China, instead of being sinful, sex was a sacred duty that should be performed frequently and conscientiously to achieve harmony with the Way, Tao (Tannahill 1992). Many cultures across China, India and Arabia were polygamous. Historically, eastern cultures saw sex as part of the pattern of life, to be encouraged and promoted and, in its perfected form, it led to an expansion of the spirit (Tannahill 1992).

Morals or science
Bancroft (2004 p4) suggests that, ‘compared with most other areas of human behaviour, the study of sex has lacked scholarship’. This he attributes to the widespread opposition to scientific inquiry. This made me reflect on other areas of human function. In 1628, William Harvey published his thesis on human circulation. His dissertation was the result of considerable scientific research identifying, for the first time, the heart as a pump (Porter 1997). That was almost four hundred years ago and it parallels other huge advances in the scientific knowledge of human functioning. In contrast, the first empirical studies into the human sexual response were not undertaken until almost the mid twentieth century and are epitomised in the works of Kinsey et al (1948 & 1953) and Masters & Johnson (1966). It appears that until the last century, sexual expression was not in the domain of science but of religion: ‘more a matter of morals than physiology or psychology’ (Bullough 1994 p2).

Sex in the 20th century
The century opened to the essentialist theories of the new sexologists (Rivers 1998; Winton 2000) like Richard von Krafft Ebing (Krafft-Ebing 1886) Henry Havelock Ellis (Havelock Ellis 1905; Havelock Ellis 1937) and Magnus Hirschfeld (Hirschfeld 1932; Hirschfeld n.d.). This nascent science re-framed much thinking around sex and sexuality, often replacing religious thinking with a medical approach of classification and pathologisation. Thus, for example, homosexuality was no longer the sinful behaviour of an individual but a malfunction or disease (Havelock Ellis 1905; Krafft-Ebing 1886). Freud was developing his theories of sexual development, sexual
motivation (or libido) and unconscious processes (Freud 1905). Birth control was becoming available with the first clinic opening in 1921 (Eugenics Society Members List 2006). This was instrumental in not only reducing the birth rate, but also separating sexual expression and reproduction (McLaren 1999). Additionally, two world wars brought ordinary people face to face with other cultural values.

These were also the formative years of eugenesics (Galton 1892), the science of the production of fine offspring that spread through non-Catholic Europe and North America (Craft and Craft 1980; McLaren 1999). In England, in part, this was about addressing the perceived unbalancing effects of contraception with the lower social orders continuing to have large families (Bullough 1994; Carter 1962; Weeks 2000). In a policy of positive eugenics, the state aspired to encourage the reproduction of the healthy (McLaren 1999) and ‘the more capable in society’ (Anon 1984 p111). The Eugenics Society (founded as the Eugenics Education Society in 1907 (Wellcome Library 2006)) also argued for forms of negative eugenics such as detention and voluntary sterilisation to restrict the ‘reproduction of the unhealthy’ (McLaren 1999 p126). In the UK voluntary sterilisation was legalised for those ‘believed to be a carrier of, a grave physical disability which has been shown to be transmissible’ (Departmental Committee on Sterilization 1934 p57).

After World War II came the revolutionary Kinsey reports (1948 & 1953). These were the first large-scale studies (5300 men and 5940 women), conducted in the United States, into human sexual behaviour. They demonstrated that many activities including masturbation, homosexuality, oral sex, pre and extra marital sex, previously regarded as abnormal, immoral or illegal, were in fact being practised by many people (Kinsey, Pomeroy et al. 1948; Kinsey, Pomeroy et al. 1953). This was followed by the groundbreaking research of Masters and Johnson (1966) who were the first to investigate the physiology of the human sexual response. They observed over 10,000 acts of intercourse in 382 women aged 18-78 years of age and 312 men aged 21-89 years of age during the 1950’s. Facts were replacing myths and assumptions.

Thus began a profound change in western thinking, crystallised in what became known as the permissive society of the 1960’s. It was marked by the judicial separation between what is allowed in public and what is tolerated in private (Home Office 1957).
Censorship laws were challenged (O'Higgins 1972). The oral contraceptive pill became available giving women reliable control over their fertility (Christopher 1993). Homosexual acts between consenting adults were legalised (Parliament 1967b) and the criteria for legalised abortions were broadened (Parliament 1967a).

The 1970’s signalled a new concern: to disseminate better understanding of human sexual functioning. Dubbed the ‘genital years’ (Christopher 1993 p291), workshops on sexuality and related issues proliferated with an ‘evangelical zeal to clear away ignorance and prejudice’ (Christopher 1993 p291). Family planning clinics were incorporated into the NHS. People, and especially women, were beginning to consider their right to enjoy sex and have orgasms (Hite 1976). There was an explosion of literature on how to obtain sexual pleasure (Comfort 1972; Devlin 1974; Zilbergeld 1978). Same sex relationships began to be accepted as a valid expression of a person’s sexuality and Gay Liberation was launched (Christopher 1993; Weeks 1992).

This was also the decade when the story of the sexual disenfranchisement of disabled people was first told. In 1972, in the United Kingdom, SPOD was convened (Christopher 1991; SPOD n.d.-a). In 1974 the Sex Information and Education Council of the United States (SIECUS) published its first lead article on sexuality and the handicapped (Calderone 1981). Seminal works such as ‘Not Made of Stone’ from Holland (Heslinga, Schellen et al. 1974) and ‘Entitled to Love’ in England (Greengross 1976) were published. These organisations and publications highlighted the endemic asexualisation of disabled people and campaigned for the recognition of disabled people as sexual beings entitled to express their sexuality. Adding impetus to the tale were the large numbers of young men injured in the Vietnam War (Knight 1992). I suggest young men are allowed to be more overtly sexual. This would have helped them in acquiring a powerful voice in demanding sexual rights, reflected in popular films like ‘Coming Home’ (United Artists 1978) and ‘Born on the 4th of July’ (Universal 1989).

However by the 1980’s, a significant backlash towards the liberalising attitudes of the 1970s was occurring. Christopher (1993) argues that the darker side of sexuality, like rape and sexual abuse, was revealed because of the increased openness and understanding. Permissiveness was attacked as it was seen to undermine the family; challenge gender roles; devalue heterosexuality, and induce children to unacceptable
sexual behaviour (Weeks 1992). These concerns were emerging at the same time as a
new and frightening infection: the Human Immunodeficiency Virus (HIV) and Acquired
Immune Deficiency Syndrome (AIDS) (Garfield 1994; Winton 2000).

The 1990s saw sexual expression, as a determinate of health and well being, entering
NHS policy (Dept. of Health 1992). Training institutions for health professionals were
charged with providing adequate information about the importance of sexuality in
human relationships, alongside counselling skills and self awareness so that they may
address ‘problems posed by sexuality in every day practice’ (Jacobsen, Smith et al.
1991 p261). The decade also saw the introduction of new drug treatments for
impotence. In July 1999, Viagra became available on the NHS for men with specific,
listed, clinical conditions including multiple sclerosis, Parkinson’s disease, spinal cord
injury and spina bifida (Dept. of Health 2000). However, increasing concern about the
rise in sexually transmitted disease and unwanted pregnancies appears to have taken
precedence in the development of the government’s sexual health strategy (Dept. of
Health 2001a).

The same decade also saw the passing of the Disability Discrimination Act (Parliament
1995) which was implemented incrementally. This provided legal support for disabled
people’s demands to equal civil rights (Disability Rights Task Force 1999).
Additionally the 1990’s saw greater recognition of the increasing diversity of the
population.

What of the 21st century?
As the millennium dawned, Weeks (2000) identified three dominant themes in the
current social construction of sexuality: the secularisation of sex; a liberalisation of
attitudes, and the challenge of diversity. The progressive detachment of sexual values
from religious values means that sexual matters are increasingly governed by individual
choice. He suggests the debate is now ‘about the legitimate limits of choice, not about
the legitimacy of choice itself’ (Weeks 2000 p169). This is accompanied by an
expansion of liberal attitudes, for example surrounding co-habitation, illegitimacy and
the transformation in power relationships between men and women. The challenge of
diversity is the acceptance of choice and difference including different family forms;
different ways of sexually relating and even different gender divisions.
This diversity in sexuality is echoed in a wider political climate of equality and inclusion. There has been a raft of anti-discriminatory legislation providing protection, on the grounds of race, ethnic or national origins; sexual orientation, and religion or belief (European Community 2000; Parliament 2003a; Parliament 2003b; Parliament 2003d). The Disability Rights Commission, an independent body, was set up in 2000 to enforce rights and promote equality of opportunity for disabled people (Disability Rights Commission 2003b). The incremental implementation of the Disability Discrimination Act (Parliament 1995; Parliament 2005) has kept disability issues in the forefront of many people’s minds. The government’s 20-year vision for disabled people has been published, with policy development co-ordinated across departments by the new Office for Disability Issues (Cabinet Office 2005). By 2025 disabled people should have full opportunities to improve their lives and ‘will be respected and included as equal members of society’ (Cabinet Office 2005 p4). Diversity awareness training is now customary as organisations consider how they address institutional barriers, promote access and develop inclusive practices. All this may provide the moment when the story of the sexual politics of disability may be heard.

2.5 **Sex as a taboo topic**

The Concise Oxford Dictionary defines taboo as

- a system or the act of setting a person or thing apart as sacred or accursed
- a prohibition or restriction imposed by social custom

Both are applicable to sexual expression, yet neither conveys the affective component of a taboo. I contend that a taboo creates an emotional reaction. It is not enough to be open to diversity in sexual expression. It is necessary to appreciate the power of feelings engendered by sexual behaviours that fall outside our own understanding and moral codes. As examples two behaviours are considered: homosexuality and extra marital sex. In 2003, after a ‘firestorm of opposition’ the Archbishop of Canterbury withdrew his acceptance of Jeffrey John, a celibate gay clergyman, as assistant Bishop of Reading (Religious Tolerance 2004 p6). This was part of an on-going impassioned debate surrounding same sex relationships and Christianity. Similarly in 1998, the
United States presidency teetered on Bill Clinton’s sexual behaviour with Monica Lewinsky leading to his impeachment for perjury and obstruction of justice (Watkins 1998). Intense feelings about morality and integrity led to denial, cover up, accusation and attack. The feelings aroused in these two examples represent considerably more than an opinion on the acceptability of same sex or extra marital relationships. I suggest that they are the powerful emotions of taboo.

Despite the increasing acceptance of diversity, SPOD closed in 2003. I believe this is linked to the emotive nature of sexual expression and physical disability. A statement, in an early leaflet explaining why the organisation was formed, says

‘The founding committee members felt that the area of sexuality and personal relationships of disabled people was at best overlooked and at worst actively suppressed’ (SPOD n.d.-b p1 italics added).

This sentiment was echoed thirty years later in a letter to the membership calling an Extraordinary General Meeting in March 2003. The management committee was experiencing a real sense of marginalisation both by the Department of Health, and from their landlord Islington Council (Parritt 2003 personal communication). There may be other explanations for the withdrawal of funding and lack of building maintenance but subjectively it was experienced as active suppression of the organisation and its aims.

How we manage our emotions aroused by the taboos surrounding sexual expression and disability are closely woven into this study, particularly uncomfortable feelings like hostility and fear. I have, at times, been advised to relate this study to explanatory psychological theories. For example, Freud’s work on psychoanalysis introduced into common language, a raft of defence mechanisms to manage this often unconscious conflict (Carlson, Martin et al. 2004; Freud 1946; Freud 1924). Or Festinger’s theory of cognitive dissonance considers how people resolve discrepancy between attitudes and behaviour (Carlson, Martin et al. 2004; Festinger 1957). Although both have relevance, I have chosen a systems perspective to try and understand the real world complexities embedded within the context of professional practice (Heylighen and Joslyn 2006; Laszlo 1995). That is, the affective component of taboo is only one aspect of this study. My emphasis is on understanding the inter-relationship of the individual within the context of professional practice within a wider organisational context. However, some reflexivity on the effects of taboo on this study is required.
Inference for participants
In chapter 1, I considered how the practitioners in this study might hide negative feelings, like disgust, in sanitised accounts of professional boundaries and roles (see section 1.6 – Reflexive awareness: Subjectivity). Hide implies a conscious intent but they may have a whole world of feelings and experiences that they are unaware of and that are repressed, projected, masked and denied. This is their inner world which they may be unable, or unwilling, to share in a public domain of research. I return to this theme in the methodology chapter, where I discuss respondents as defended subjects (see section 5.4 – Strategies of investigation: Free association narrative interview). The participants may have defended themselves from the dissonance created by the taboo nature of the subject. But it is not just their feelings to be considered.

Inference for the researcher
Throughout my research, I have endeavoured to reflect deeply on my attitudes to sexual expression and the emotional reactions that it evokes in me. A good example arose with Earle’s continuum of facilitated sex and my initial personal abhorrence at the inference that masturbation of patients might be included as part of nursing practice (see section 2.7 – What can be done by experts in disability). I am also aware, during the course of the study, of some profound changes in my feelings for example increasingly I regard sexual surrogacy as a positive option. The importance of these disclosures is to convey that my attitudes are socially constructed, dynamic and are unique to me.

Also, I have recorded a sense of my own marginalisation as a researcher. It is what I have called in my research journal the ‘so what’ factor. So what that sex may be compromised for a disabled person: does it matter? So what if health professionals don’t like to raise the subject! I perceive so what statements as indicating that this research is unnecessary or not quite respectable. Colleagues have alluded to sex being a natural phenomenon that should not be investigated. I do not know if I have been cast as deprived or depraved (Lee 1993). On the other hand, I have experienced difficulty getting conference papers accepted. I sense also that this study falls outside the traditional research arena of the university and, in my darker moments, is regarded as of lesser importance. This is not unique and has been identified by others researching human sexuality (Lee 1993; National Centre for Social Research 2003; Poole, Giles et
al. 2004; Weeks 2000; Weeks and Holland 1996). Lee (1993 p9) noted stigmatisation by colleagues, academia and students implying it might pose a risk to career development. Poole et al (2004 p83) indicated evidence of damaging consequences for the researcher, both personal and professional, in carrying out sexuality research for example to psychological health, career and academic reputation.

**Inference for the reader**

From me I move to you the reader and your feelings. In the process of writing I am striving to present disparate elements in a way that explains what I believe is happening and to explain my subjective experience of it. It does not end with writing. There is the de-construction of this text by you and the reconstruction of my words mediated by your subjective experience (Rolfe 2001b). This ‘re-authoring’ is also subject to the emotions raised in you by the taboo nature of the topic.

**Language of sex**

Another factor resulting from the taboo of sex, is the lack of common language (Weeks 2000). In one breath, sex is talked about all the time yet it is not discussed like other aspects of daily life (Evans 1998). This is evident in the hundreds of euphemisms used for sexual behaviours. Additionally, the language used alters according to context. Thus, the words used in romantic literature are very different to those of the medical school, the church, courts of law, the pub and the playground. Words acceptable to one group of people may give considerable offence to another. An example was the first AIDS campaigns of the 1980’s where ‘the words that those most at risk might understand were judged unsuitable and offensive’ (Garfield 1994 p26).

### 2.6 Intimacy and sexual expression

Intimacy and sexual expression are not synonymous. Intimacy can exist without sex and sex without intimacy although, for many, the two are inextricably linked (Weeks 2003). Intimacy has been described both as a need for, and a capacity to, experience emotional closeness to another human being, and to have that closeness reciprocated (Esmail, Esmail et al. 2001). Intimate relationships ‘foster perceptions of value and competence, connecting and belonging’ (Hammell 2004b). Shakespeare (2000 p164)
indicated a danger in overstating the importance of sex as opposed to relationships, suggesting that most people are not seeking sex per se but ‘intimacy, warmth, validation and connectedness’. I am sure this is true but I believe there is a corresponding risk to focusing solely on intimacy, in that it avoids the very essence of the problem: the contested arena of sex. It may also negate the importance some people place on physical sexual intimacy to the development and maintenance of emotional intimacy (Bancroft 2004; First and Tasman 2004; Rollo 1969).

For me there are two issues here, of importance for all people, firstly to remain grounded in reality rather than the unrealistic expectations of media hype and secondly to recognise diversity in sexual expression. Few people are having great sex all the time (see section 4.2 – Sexual health and the general population). Also, people are different. Some people, single or partnered choose celibacy. Some have celibacy thrust upon them (Donnelly, Burgess et al. 2001). Celibacy is not the same as asexuality. Some people select sexual partners with whom they have no emotional intimacy. For others, emotional intimacy is an essential pre-requisite to sexual intimacy. For some coitus is necessary to sexual expression but not for all. Sexuality is uniquely personal (Crouch 1998) and is expressed in a rich variety of behaviours which may include giving and receiving pleasure (Spero 2003; Tepper 2000; Zilbergeld 2004).

2.7 What can be done by experts in disability

This conceptual framework concludes with an outline of what can be done by disability professionals to support the sexual health of their service users. I begin by considering sexual dysfunction per se, and its relevance to disability, before reviewing potential approaches for practitioners who are not sexual therapists. The three approaches reviewed are those currently reported in the literature but, as a consequence of undertaking this research, I shall return to the subject later, to recommend a new model of practice (see section 13.2 – A sexual health practice model for disability practitioners).
Classification of sexual dysfunction

Identification of the physiological phases of the human sexual response, in both men and women, led to new classifications of sexual dysfunction and thereby new therapy options (Masters and Johnson 1966). The four phases identified were; excitement, plateau, orgasm and resolution (Masters and Johnson 1966; Masters, Johnson et al. 1995). Kaplan (1974) added to this, seeing desire an important factor. This has led to the taxonomy: desire, arousal and orgasm. With the inclusion of pain as a category, this taxonomy now broadly frames the two most widely accepted medical classifications of sexual dysfunctions: the International Classification of Disease (ICD-10) American Psychiatric Association 2000) and the Diagnostic and Statistical Manual (DSM IV) (World health Organisation 1992). These are summarised in table 2.1 below.

<table>
<thead>
<tr>
<th>Problems of desire</th>
<th>ICD-10</th>
<th>DSM IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack or loss of sexual desire</td>
<td>Hypoactive sexual desire</td>
<td></td>
</tr>
<tr>
<td>Excessive sexual drive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual aversion and lack of sexual enjoyment</td>
<td>Sexual aversion disorder</td>
<td></td>
</tr>
<tr>
<td>Problems of arousal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Failure of genital response</td>
<td>Female sexual arousal disorder</td>
<td>Male sexual arousal disorder</td>
</tr>
<tr>
<td>Problems of orgasm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Orgasmic dysfunction</td>
<td>Female orgasmic disorder</td>
<td>Male orgasmic disorder</td>
</tr>
<tr>
<td>Premature ejaculation</td>
<td>Male orgasmic disorder</td>
<td>Premature ejaculation</td>
</tr>
<tr>
<td>Problems of pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non organic vaginismus</td>
<td>Vaginismus</td>
<td></td>
</tr>
<tr>
<td>Non organic dyspareunia</td>
<td>Dyspareunia</td>
<td></td>
</tr>
</tbody>
</table>

*Table 2.1: Classifications of sexual dysfunctions*

The ICD-10 and the DSM IV are essentially classifications of mental and behavioural disorders. However these diagnostic categories can be applied when the 'sexual dysfunction is judged to be exclusively due to the direct physiological effects of the general medical condition' (First and Tasman 2004 p1075). The differential diagnostic label is then: <Sexual Dysfunction> due to a <general medical condition>.

Treatments for sexual dysfunction

The treatment of sexual dysfunction is no longer seen to necessitate prolonged analysis to address deep-rooted psychodynamic conflict (Kaplan 1974; Masters, Johnson et al.)
1995). Nowadays psychological treatments often include brief therapy offering a combination of behavioural, cognitive and psychodynamic approaches such as the sensate focus (Masters, Johnson et al. 1995), re-education and improved communication. There are professional organisations supporting skilled intervention for sexual dysfunction (and the wider relationship issues often implicated). These include the Institute for Psychosexual Medicine\(^1\), the British Association for Sexual and Relationship Therapy\(^2\), the Association of Psychosexual Nursing\(^3\) and Relate\(^4\).

There is also now a range of direct medical treatments and devices (Christopher 1991; Cooper and Guillebaud 1999; Masters, Johnson et al. 1995). These include:

- medication for erectile dysfunction applied either by injection into the shaft of the penis (intracavernosal) or introduced into the urethra
- oral medication such as sildenafil (Viagra) and tadalafil (Cialis)
- surgically implanted penile prosthesis
- vacuum pumps to obtain an erection
- sex aids (sex toys) including externally worn penile prostheses, artificial vaginas, masturbators and vibrators (FP Sales 2005)

**Limitations of sexual dysfunction diagnoses**

There are problems in using these classifications of sexual dysfunction. Firstly, it may be very difficult to establish the aetiology of dysfunction. Even with substantive physical impairment, it may be impossible to separate what is due to psychosocial factors. Next, classifications of dysfunction are phallocentric. That is they revolve around penis / vagina penetration with orgasm as the goal of sexual expression. It implies a norm of heterosexuality. In disability especially, it is important that other orientations are recognised as disabled people have described less acceptance of their gay and lesbian identities (Dept. for Work & Pensions 2003; Gillespie-Sells, Hill et al. 1998; Guter and Killacky 2004; Shakespeare, Gillespie-Sells et al. 1996).

\(^{1}\) For further details see www.ipm.org.uk
\(^{2}\) For further details see www.basrt.org.uk
\(^{3}\) For further details see www.psychosexualnursing.org.uk
\(^{4}\) For further details see www.relate.org.uk
It is also necessary to challenge 'fucking ideology' (Coble 1997; Shakespeare, Gillespie-Sells et al. 1996 p97) because many disabled people may be labelled sexually dysfunctional inappropriately. The man unable to have an erection or the woman unable to have an orgasm, due to physical impairment, by these classifications have a sexual dysfunction even though they may have rewarding and satisfying sexual lives. Sexual satisfaction may be relatively independent of sexual function (Di Giulio 2003; Read, King et al. 1997; Tepper 2000). For example, painful intercourse ceases to be a problem for those who enjoy non-penetrative sex. Intervention therefore may be better focused, not on the reduction of sexual dysfunction, but on increasing the subjective experience of pleasure and satisfaction. As one man with multiple sclerosis said,

'Sex can be a wonderful reason to keep going when everything else seems bleak. It can be a way of connecting with someone we love, of giving our bodies attention, of relaxing, even of mild exercise. It is good for fatigue and excellent for pain relief. And there really is no disability that makes sex impossible, if we define sex not as intercourse, but as physical contact for the purpose of sharing intimacy and pleasure' (Spero 2003 p1).

Finally, for disabled people sexual dysfunction may not be the issue at all. As identified earlier (see section 1.4 - Rationale: The perspective of disabled people) problems may be much more to do with identity, social exclusion and discrimination. For example, it seems to me to be essential that the social opportunity for the development of intimate relationships is included when considering sexual expression. This is because disability is persistently reported to affect finding a partner and forging relationships (Dept. for Work & Pensions 2003; Esmail, Esmail et al. 2001; Milligan and Neufeldt 2001; Taleporos and McCabe 2003). For some people the issue of establishing an intimate relationship is more important than sexual performance (Shakespeare 2000).

The role of disability professionals
Over the years, recommendations have been made about the skills required by generic health workers (as opposed to sexual health workers or sexual therapists) to promote the sexual health of their patients (Annon 1974; Earle 2001; Jacobsen, Smith et al. 1991; National Institute for Clinical Excellence 2003; World Health Organization 1974). Here I review the World Health Organisation's (1974) recommendations and two models of practice, PLISSIT (Annon 1974) and the Continuum of Facilitated Sex (Earle 2001). These are related to the practice of professionals with expertise in disability.
The World Health Organization (WHO) (1974) proposed three skills needed by all health workers: to be able to give sex information; carry out elementary sex counselling and to refer more complex cases to specialised staff or institutions (World Health Organization 1974). It was anticipated that all health staff would have sufficient knowledge of sexual development, human reproduction, sexual behaviour and health to be able to advise. They were also to have positive attitudes toward sexuality for objective discussion of sexual matters. I suggest that, as counselling has become increasingly professionalised, *elementary sex counselling* is better conceived as the use of counselling skills. That is skills to enhance communication and explore issues with the client but without taking on the role of their counsellor (British Association for Counselling 1989). The WHO proposal presumes a minimum level of education, particularly around knowledge and attitude formation, has been given to all health workers. Additionally it supposes health workers regard sexual health to be within their role. In many ways, these assumptions are at the heart of my research.

A practice model, **PLISSIT**, developed by Annon (1974), is the most referenced in the literature (Ekland 1997; Esmail, Esmail et al. 2001; Herson, Hart et al. 1999; Morrissey and Crouch 1998; Rubin 2005; Tepper 1997b; Weerakoon 1994; Weston 1993). It has four levels of action: Permission giving; Limited Intervention; Specific Suggestions and Intensive Therapy (P-LI-SS-IT) (outlined in table 2.2). The first three are considered appropriate levels of intervention for the generalist health and social care professional. The fourth falls within the sexual therapist's domain of expertise.

In this model, the disability professional's role begins with providing permission for the disabled person to explore sexual expression. It includes provision of disability specific information, addressing what fits within their existing role and referral on. This may be to counselling, psychotherapy or sexual health services where issues fall outside the disability practitioner's competence. Its advantage is that it sets out what can be done before a specialist sexual health practitioner is needed. However this model again presumes disability practitioners accept that sexual expression is part of their role and that they have the skills not only to provide permission but also to explore issues raised and to develop treatment goals.
<table>
<thead>
<tr>
<th>PLISSIT Model for Sexual Counselling</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Permission</strong></td>
<td>Permission</td>
</tr>
<tr>
<td>The practitioner brings up the topic of sexuality thereby validating sexuality as a legitimate health issue and giving the client permission to discuss sexual concerns now and later in their programme</td>
<td>Most clients need permission to raise their sexual concerns. Rehabilitation professionals may lack the confidence to discuss sexuality with their clients, however the majority have adequate skills and knowledge to provide this level of service</td>
</tr>
<tr>
<td><strong>Limited Information</strong></td>
<td>Limited Information</td>
</tr>
<tr>
<td>The practitioner addresses specific sexual concerns and attempts to correct myths and misinformation</td>
<td>Much of a health professional's knowledge and training can be applied to sexuality. At this level the practitioner's primary role is that of an educator and therefore should focus on basic sexual information applicable to their area of practice. Many clients would benefit from this level of intervention</td>
</tr>
<tr>
<td><strong>Specific Suggestions</strong></td>
<td>Specific Suggestions</td>
</tr>
<tr>
<td>The practitioner compiles a sexual history or profile of the client: 1. define the problem 2. determine the course of the problem 3. treat the problem 4. formulate ideas about causes and develop appropriate goals and treatment plans</td>
<td>Fewer clients require this level of intervention and fewer practitioners are qualified to provide this degree of service. The practitioner should possess counselling skills as well as appropriate information and treatment skills in order to provide treatment at this level</td>
</tr>
<tr>
<td><strong>Intensive Therapy</strong></td>
<td>Intensive Therapy</td>
</tr>
<tr>
<td>The practitioner completes a full sexual history of the client and provides specialised treatment</td>
<td>This level has the smallest clientele. Requires specialist skills of a sex therapist or other appropriate professional</td>
</tr>
</tbody>
</table>

Table 2.2: The PLISSIT Model (developed by Esmail, Esmail & Munro 2001 p276 from Annon 1974)

More recently, Earle (2001) considered the nursing role in the holistic care of disabled patients. Rather than a model, she has proposed a Continuum of Facilitated Sex, which she likens to other forms of assistance with activities like washing and dressing. She is not suggesting nurses undertake all activities on the continuum (outlined in table 2.3). However, she indicates that they should be aware that some patients may have benefited from such facilitation or may wish to explore it as an option.
The continuum | The role of the nurse: examples
--- | ---
Providing accessible information, advice and services | Arranging for information to be available in Braille, large print & audio tape
Fostering an environment which allows intimacy | Acceptance & acknowledgement of patient's sexual needs
Offering and observing the need for privacy | Closing door, providing curtains
Encouraging and enabling social interaction | Arranging suitable transportation
The procurement of sexual goods | Purchasing or arranging the purchase of pornographic magazines
Arranging paid for sexual services | Assistance with arranging, or information on how to arrange, paid-for sex; willingness to discuss this as an option for the patient
Facilitation of sexual intercourse with another party | Undressing, or helping to undress, patient
Facilitation of masturbation | Assisting patient with positioning and technique
Sexual surrogacy | Assistance with arranging, or information on how to arrange a sexual surrogate

Table 2.3: The continuum of facilitated sex (taken from Earle 2001 p 437)

I see her proposal as more relevant to nursing and social care staff working in residential settings rather than with service users who live in their own homes. Facilitation of intercourse by undressing the service user would seem outside the role of the participants within this study. That said, the continuum does challenge the boundaries of actions that may or may not fit within a professional role. For example, a service user who was unable to masturbate due to physical impairment may seek a solution. Apparently, some personal assistants employed under the Direct Payment Scheme have informally agreed to undertake this service (Pepper 2003 personal communication). There is also an example in the literature of an occupational therapist enabling a woman to masturbate, by providing adapted equipment (Evans 1987). Earle (2001) acknowledges that her continuum raises difficult legal and ethical issues. Sexual surrogacy is not available in the UK and procurement of a prostitute is presently illegal. So the continuum challenges thinking but, I suggest, without a supported opportunity for reflection, it may act more as a deterrent than a help to professional practice.
2.8 Conclusion

This chapter has built on my earlier definitions, providing a deeper understanding of the position I have taken to both disability and sexual expression. My intention in this research has been to capture the breadth of issues. It requires connecting both with the public domain of disability and the political context of practice, plus the private domain of individual impairment and the intra-personal experience of practitioners and service users. Far from sexual expression being the most natural thing in the world, it is socially and culturally constructed. This adds to the complexity of the subject and contributes to the powerful negative emotions of taboo. With the current emphasis on diversity and inclusion, plus the secularisation of sex, I suggest we may be entering a moment when the story of the sexual disenfranchisement of disabled people may be heard.

This is the conceptual framework underpinning my investigation into why sexual expression remains one of the most sensitive, challenging and marginalised elements in the work of health care practitioners (Heath and White 2002). I have also introduced helping strategies outlined in the literature that are suitable for use by disability practitioners. This includes PLISSIT, as the accepted model of practice although I will return to critically appraise this in the light of my research findings.
CHAPTER 3: PRELIMINARY INQUIRY

3.1 Introduction

'The point is often made within the disability movement that disabled people have, historically, not been allowed to speak for themselves, either as individuals in the community or within organisations and institutions' (Millington and Mottram 1999 p374).

This apparent denial of the voice of disabled people had implications for my research because, although I intended to investigate the practice of professionals, it was also a transformative endeavour. That is, the ultimate purpose was the improvement of services for disabled people. I was aware of the growing body of evidence indicating that involving the people who use services leads to research that is more relevant, more reliable and more likely to be used (Couldrick 2000). The NHS has been promoting service user involvement, both in research and policy development\(^1\), for over a decade (NHS Executive 1996). It established a national advisory group (NHS Executive 1998) which has now evolved into INVOLVE\(^2\). INVOLVE, funded by the Department of Health, promotes and supports service user involvement in NHS, public health and social care research (Hanley, Bradburn et al. 2003). That is not to say that service user involvement has yet reached mainstream practice (Hanley 2005). However here, where I was looking at professional practice in a very personal and private area of care, I believed it was essential to collaborate with disabled people to hear their views.

I saw several advantages in collaboration. It acknowledges the importance of disabled people's experience and expertise, as users of health and social care, recognising -

'That living with disability creates insights that most able-bodied people – even those trained in therapy and rehabilitation – overlook or find hard to conceive (Harrison 1999 p382).

I was also concerned whether, what I had identified as important, was in fact important to disabled people. It was possible that disabled people did not want sexual expression to be shared with their health or social care team, or that sufficient, adequate services

\(^1\) A mandate for service user involvement can be seen in government white papers (Dept. of Health 2006), standards (Medical Foundation for AIDS & Sexual Health 2005) and guidance (Cabinet Office 2005). For example in Improving the Life Chances of Disabled People it states, 'new arrangements should be established for securing participation of disabled people in policy design and delivery at all levels' (Cabinet Office 2005 p169).

\(^2\) For further details see www.invo.org.uk.
are available. Collaboration helped to ensure that this research was relevant to them and thereby to health and social care as a whole (Hanley, Bradburn et al. 2003). My reading had led me to consider how disabled people could be involved in all stages of the research from inception to dissemination, not as subjects but as partners (Couldrick 2000). I believed this to be particularly important in the formative stage prior to developing the proposal. I wanted to hear their opinions on the general area of research before formulating my research questions. I wished to ensure an agenda for action that captured and reflected their perspective (Hanley 2005).

I gained ethical approval from the university to approach disability groups as part of a preliminary inquiry (appendix A). The work spanned January 2000 to September 2001. Groups were chosen either because they: campaigned on behalf of disabled people (e.g. RADAR); or represented particular disabilities (Spinal Injuries Association); or illnesses (Arthritis Care), or they promoted the sexual and personal relationships of people with disabilities (e.g. SPOD & Discern). Some of these groups spoke on behalf of their members. Others invited a more direct contact with their membership. This chapter provides a synopsis of this preliminary inquiry indicating its contribution to the main study. A full account is available as an unpublished report (Couldrick 2001).

Before proceeding, I wish to sound a note of caution. The preliminary inquiry was conducted in collaboration with disabled people. They were not the subjects of the research. Anyone expecting to see a matched, representative sample or analysis of response rates to ensure statistically verifiable conclusions will be disappointed. The number of disabled people represented in this preliminary inquiry is insignificant when compared to the estimated 11 million disabled adults in the UK (Cabinet Office 2005). That does not make their voice less valuable. Shakespeare et al (1997) noted the small number of disabled people (only 44) involved in the study that culminated in the book 'The Sexual Politics of Disability' (Shakespeare et al 1996). Like him, I felt the important thing was not to be statistically representative but to give disabled people a voice. I saw it as important to connect the professional domain under investigation in the main study with the lived experience of some disabled people.

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1 The preliminary inquiry was used by INVOLVE as an exemplar of how collaborative practice can assist in the prioritisation of research topics (Hanley, Bradburn et al. 2003 p24).
3.2 The first approach to user groups

After discussion with the supervision team, a final group of 19 national organisations, representing a wide spectrum of physically disabled people, was approached (see table 3.1). Each organisation was sent a letter providing information and requesting their assistance. This was followed with a telephone call. In some organisations I spoke with the Chief Executive or Director, in others I was referred to the Research, Policy, Development Information or Welfare Officer. After this first contact, three groups were excluded.

<table>
<thead>
<tr>
<th>User groups initially contacted who contributed</th>
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</thead>
<tbody>
<tr>
<td>Age Concern</td>
</tr>
<tr>
<td>Arthritis Care</td>
</tr>
<tr>
<td>Association for Spina Bifida &amp; Hydrocephalus (ASBAH)</td>
</tr>
<tr>
<td>BackCare</td>
</tr>
<tr>
<td>British Council of Disabled People (BCDP)</td>
</tr>
<tr>
<td>Disability Living Centres Council (DLCC)¹</td>
</tr>
<tr>
<td>Discern</td>
</tr>
<tr>
<td>Headway</td>
</tr>
<tr>
<td>Motor Neurone Disease Association (MNDA)</td>
</tr>
<tr>
<td>Multiple Sclerosis Society (MS Society)</td>
</tr>
<tr>
<td>Parkinson's Disease Society (PDS)</td>
</tr>
<tr>
<td>Royal Association for Disability and Rehabilitation (RADAR)</td>
</tr>
<tr>
<td>Scope</td>
</tr>
<tr>
<td>Spinal Injuries Association (SIA)</td>
</tr>
<tr>
<td>SPOD</td>
</tr>
<tr>
<td>Stroke Association</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>User groups initially contacted who did not contribute</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability Alliance</td>
</tr>
<tr>
<td>Disability Information Trust</td>
</tr>
<tr>
<td>Disabled Living Foundation</td>
</tr>
</tbody>
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<th>Subsequent User groups approached</th>
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<td>Gemma</td>
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<td>Outsiders</td>
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<td>Regard</td>
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Table 3.1: List of organisations contacted in the preliminary inquiry

¹ In 2005 DLCC became Assist UK
where they saw their role (financial or equipment advice) as outside the proposed remit of the study. Three more were identified and added (although it proved impossible to make contact with one, Regard). Thus, 18 groups participated.

I began telephone conversations with some standard questions to develop a dialogue and to establish whether a project such as this was seen as relevant to their membership. I asked if they knew of any allied research and sought their suggestions and ideas. Some people answered from their personal knowledge of the membership. Others spent time researching help line inquiries, etc. Some organisations invited a face-to-face interview and some directed me to specific individuals recognised as either experts or campaigners in the field. Thus, I discussed the project with 34 people directly or indirectly representing these 18 disability groups.

Additionally, from my approach to the Multiple Sclerosis Society of Great Britain (MS Society), I was invited to attend, and speak at, an international conference. This was for professionals and people with multiple sclerosis, organised by the European Multiple Sclerosis Platform, on intimacy and sexuality (European Multiple Sclerosis Platform 2001). It included facilitated workshops to identify what people with multiple sclerosis would like to see researched in the field of sexual dysfunction.

### 3.3 An invitation to approach members

Some user groups encouraged direct contact with their membership. Within the time available five different avenues for this contact were established. The Disability Living Centres Council (DLCC), Headway and the Spinal Injuries Association (SIA) each published a 'flyer'. The DLCC sent it out with their quarterly mailing, not to members but to each of their Disabled Living Centres. Headway circulated it electronically through their network of email user groups. The SIA published it in their bimonthly magazine, Forward, sent to members. The Motor Neurone Disease Association (MNDA) accepted a slightly shorter version for their quarterly magazine, Thumbprint, sent to all members. Finally, a 50-word advertisement inviting people to request a Project Information Sheet was placed in the magazine, Disability Now. From these opportunities, 46 people made direct contact with me.
Arthritis Care, Gemma, the MS Society and the Parkinson's Disease Society (PDS) also supported direct access to their members. With the first three groups, this was not possible due to time constraints. The PDS asked me to consider focus groups with some local branches. However, it became apparent that the written flyer, sent to the chairs of local branches did not get through to the membership. In one branch, I discovered that only two members were sent the flyer: the two judged by the chairperson as being young and fit enough that they might still be sexually active! In another, it was decided not to circulate the flyer, as their members would not wish to discuss such personal issues with someone they did not know. Interestingly, a member of Outsiders had indicated, from her research experience, that reaching disabled people could be problematic, because of protective censorship by others in their organisation.

**Making contact**

I arranged multiple methods of contact including letter (standard and large print), electronic mail and telephone. (Audiotape was indicated but not used). Some individuals made only one contact with me. Others made several contacts. The most frequent method of first contact was by email and the second was a telephone message, left at the Clinical Research Centre at the University of Brighton, asking me to telephone them. Over half those contributing had access to electronic mail. Some began with an email but would follow this with an invitation for me to telephone.

At the first contact, I established the best method of communication for the respondent. This involved three hierarchical issues: practicalities, confidentiality and trust. I had to take account of the practical issues related to their disability. Some were unable to write. Others, with speech or hearing difficulties, preferred to write. At another level, it concerned confidentiality especially using a variety of communication equipment. When an email arrives, it cannot be assumed the sender is the sole viewer of a reply. Likewise, one woman asked me not to telephone as she used a loud speaking phone. Respondents were also concerned about trust, epitomised by one man who became involved once he was assured that I 'was genuine and the work worthwhile'.

I responded to all correspondence in an open way that I hope conveyed a personal presence. I thanked each person for his or her involvement and I paraphrased the
information given into general research statements. The contributor was then asked to confirm if I had responded accurately. This approach is akin to first stage counselling skills. It acknowledged their contribution without putting confidential information in jeopardy. It also permitted confirmation, or correction, ensuring I had understood them, and it encouraged people to add further information.

I used a similar pattern of paraphrasing and reflecting in telephone calls. I did not devise an interview schedule, as I believed it was important for the contributor to lead the discussion and to raise what, for them, were the essential issues. Many were not certain what to expect and would ask to be sent 'the questionnaire'. Where a degree of trust needed to be established the caller was invited to give some information on their disability. Gradually they would be asked, in terms of their experience, should sexual expression and disability be researched? And what were the important issues surrounding sexual expression that should be researched? I asked no direct questions about their orientation or sexual practices. All information of this nature was volunteered. Where possible, notes were taken during telephone calls with some key phrases recorded verbatim. I also recorded my reflections after all contacts.

**Individual people with individual stories**

The range of information from each person varied hugely. A few sent a formal list of research ideas, with no personal information. Others included specific research questions within their correspondence. The majority sent details about their personal experience and the effects of disability on their own sexual health, leaving it to me to ascertain the research questions inferred by the information. Some provided a brief description of their functional ability but many summarised this into diagnostic labels, for example 'I am a c5/c6 tetraplegic following a diving accident that occurred in 1986'. Some described their journey through health and social care while others rarely mentioned it, choosing instead to describe the intra-personal experience of their disability. Most spoke about themselves although occasionally a contributor would speak more generally for disabled people.

Strategies to manage this diverse information became imperative. Firstly I gave every individual (and where applicable, their partner) a pseudonym. These are used here to help separate what was said by an individual from that said by a person representing an
organisation. Management of information was ethical, methodical and meticulous. I repeatedly read the letters, emails and telephone notes, seeking themes, patterns or uniqueness. At every stage one question dominated: what does this person wish to see researched? I endeavoured to hear the individual and understand his or her perspective.

**Demographic summary of the individuals**

Forty-six individuals made contact with me. Some initial inquiries could not be followed through or their contribution arrived too late, therefore information was used from 40 respondents. Of these, 34 people were disabled and seven contributors were (or had been) partners of a disabled person. There were 29 men and 11 women. Geographically the contributors were spread throughout England, Scotland and Wales. Their ages ranged from 24 to 76 years old with a median of 50 years. One disabled person did not give her age. Of the other 33 disabled contributors: 3 people were in their twenties; 6 in their thirties; 5 in their forties, 12 in their fifties; 6 in their sixties and 1 in his seventies. The majority (26) were people who had experienced a spinal cord injury. Diagnoses for the others included: head injury, motor neurone disease, cauda-equina syndrome, growth disorder, multiple sclerosis, polio or spina bifida. Between them, they represented a wide experience of disability: from congenital and childhood onset; both recent and long-standing traumatic injury and those with progressive conditions. They included single, married and co-habiting people as well as heterosexual, lesbian and gay people.

### 3.4 Is this research necessary?

**What the user groups said**

BackCare was not aware of sexual expression being an issue within their membership, whereas all the others saw it as relevant to their membership and an important area for research. Some indicated a preference for research specific to their membership. Others felt research across a spectrum of disability was appropriate. The need for research into sexual aspects of disability had been identified as high priority via members' conferences in Headway and by Different Strokes, the younger section (under

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1 One was both a disabled person and the partner of a disabled person.
55) of the Stroke Association. The European MS Platform conference had been convened in direct response to member need. Other groups were aware of concerns via help line inquiries and requests for literature. It was not a priority research area for Scope although their research spokesperson suggested this might be because discussion of sexual issues had not been enabled within the organisation. Likewise, the Stroke Association indicated that sex may be important for their older members but it was culturally harder for them to raise. Both the Association for Spina Bifida and Hydrocephalus (ASBAH) and SPOD noted a particular dearth of research, or information, on physical disability as opposed to learning disability.

The response of the individuals
Without exception, every individual respondent wished to see aspects of sexual expression, physical disability and professional practice researched. 'It was a pleasant surprise,' said Patrick, 'to read in Thumbprint that somebody is investigating this major problem'. Similarly, others said 'I just feel this is so important'; 'your study is long overdue'; 'it's a big, big subject, but a very important one'; 'It should be investigated, people have ignored it for too long'. Despite its perceived relevance to quality of life and positive self-concept, sexual expression was seen as a subject 'not on the health care agenda'. Clare noted health professionals wanted to talk about her bowels but she asked 'why couldn't anyone talk to me about sex?' Similarly, Hazel described how health professionals focused on her physical function overlooking her sexual needs. She wrote, 'There seems to be therapists for most aspects of life except for this one problem'.

3.5 What should be researched?

The following paragraphs are a synthesis of what groups and individuals felt should be included within the research. All items influenced the study particularly in broadening my understanding but some, as I will indicate, had a more specific result. All these issues must be set against the diversity of the lived experience of disability. Each individual told a unique story and had different priorities. There were significant differences for those with an early onset disability and those becoming disabled before or after achieving sexual competence. There were essential differences for those who became disabled when they were, or were not, in a significant relationship. There were
also differences for those with static or progressive disorders. Some individuals pointed out that many issues would be similar for non-disabled people, however non-disabled people were seen to have greater avenues for information, advice and support.

**Importance of a positive sexual identity**

Contributors said the research agenda had to include an understanding of the relationship between positive sexual identity and self-esteem. The DLCC also saw sexual expression as essential to quality of life. The overall sense given by individuals was of the integral nature of sexual identity to person-hood, confidence, psychological well being and quality of life. For example Gail, who had recently been widowed, said

"Sex was very important to us and to the quality of our life. He was made to feel important. His person-hood stayed intact. Sexual intimacy was a big part of that."

Similarly, Clare wrote,

"Before my accident I had an active sex life. As I enjoyed it and it is essential to my sense of well being, I wanted this area of life to continue."

In a later conversation, she described the importance of her sexual identity, seeing it as

"A measure of my worth as an individual that I am attractive to some men. Not to everyone, but that I should be seen as sexually attractive at 49 & now at 55"

William, who had described the very close link for him between psychological well being and sexual identity, added

"When you lose your dignity, self-esteem and confidence, of course you are less able to deal with a disability's physical problems"

Sexual identity included positive concepts of masculinity and femininity. RADAR exemplified this noting that, if masculinity was seen as strength and power, or femininity expressed in mini skirts and heels 'all this gets impaired by disability'. Fay described her partner's deepening depression when his spinal stimulator broke down. No longer able to maintain an erection he was convinced he was never going to be a 'real man' again. Dawn said she 'didn't feel like a real woman any more' due to the loss of genital sensation and catheter use. The development of a positive sexual identity begins in childhood and Eva described how this could be impaired with an early onset disability. Those with a disability acquired in adulthood indicated they would have valued professional help to adapt to their new identity in a radically different body. A
positive sexual identity was separate from impaired sexual function. Lack of a positive sexual identity was seen as an important contributor to the negative perceptions of disabled people.

**Asexualising attitudes**

Contributors sought research that addressed asexualising attitudes toward disabled people. Almost universally, individuals and user groups confirmed that, from their direct experience, asexualising attitudes existed. These, they said, pervade literature, drama and the media. Kate, a partner of a disabled man, said

"It's as though if you are in a wheelchair it doesn't really matter any more because you can't feel anything anyway. Its as though you have no need for sex."

Allied to this, some noted the lack of positive sexual role models for disabled people, especially for women. As Clare said, the only occasional stories are of men who 'marry their physios or nurses'. She had never seen any role models for disabled women, 'possibly a little on women having children but not sex'. Some people reported asexualising attitudes within their family. Eva was four when she contracted polio. She was born in the 1930's and her experience was that

"If you are disabled sex is not for you. … My parents would say. 'Of course we hope you will get married.' But I knew they didn't mean it"

Others demonstrated internalised asexual attitudes. Like Zac who was certain no one would want him, based on 'his own pre-accident prejudices'.

Age Concern, Gemma and Outsiders, plus three individuals, specifically reported ageism and heterosexism in health and social care. This added to asexualising attitudes and increased the problems experienced by older disabled people, and gay, lesbian and bisexual disabled people.

The British Council of Disabled People (BCDP) noted how sex is

"Pushed into the background by professionals who perpetuate the image that the disabled are not supposed to be sexual beings"

Asexualising attitudes of disability professionals were also evident in the experiences reported by many individuals. Sometimes this was historical with individuals drawing on their experiences 20 or 30 years ago. For example, Karl's experience of a spinal injuries unit in the 1970's was of being
"Surrounded by young women. At ward rounds I would be stark naked, no curtains. I ended up very confused. I'd be having spontaneous erections and everyone would be ignoring it. The implication is that you were no longer sexual".

Often the sense of asexualisation came from what was not done rather than what was done. Ray's experience in the 1970's both of a spinal injuries unit and from attending a national college for physically disabled people, was that nobody talked about sexuality or sexual expression. He interpreted this omission as 'sex isn't done by disabled people'.

From the contributions of individuals, it appears that regional spinal injuries units over the last five years or so have improved. However outside these units, disability professionals were consistently described as projecting asexualising attitudes. Eva, who was involved in disability awareness education of medical students, said,

"Professionals are amongst those who are adding to this negative image. There is an enormously asexual way that health care is delivered to disabled people. Professionals continue to add to asexualising images and it messes up self concepts and acceptance of oneself as a sexual person"

This 'asexual way health care is delivered' may not be unique to disabled people. It may apply equally to general medical and surgical patients too. However, here the important issue is the experience of disabled people and the cumulative impact of health care when combined with a lack of role models and negative social and family attitudes.

**Damaging health and social care practice**

Contributors to the preliminary inquiry indicated a need to clarify what disabled people described as damaging health and social care practices to positive sexual identity. This, they said, can be through an act or omission. For example, focusing only on the medical or mechanical aspect of sexual function without regard to emotional aspects was experienced by several individuals as detrimental to a more holistic sense of sexual identity. Another example of potential damage was provided by SPOD

"Jo Bloggs quietly raises a concern with the nurse. The nurse raises it with the ward manager. A protocol is demanded and Jo Bloggs' intimate and private issue is now the property of a grand committee and consultation exercise"

The perceived lack of awareness amongst health and social care staff and having no one for the disabled person, or their partner, to talk to however was the priority concern raised by both individuals and organisations. Gail said,
“This was one aspect of our relationship that was never brought up or discussed. It was not discussed by anyone, not with the Motor Neurone Disease Association, anyone.”

Thus, the sexual needs in their relationship did not inform their care plan. The implied message, that she received, was that sex is not important and no longer matters.

## Priorities for treatment

A potential mismatch of treatment priorities between the professional and patient was identified for investigation. For example, a representative from the MS Society suggested that the importance of sexual expression for people affected by MS was 'more or less matched by its neglect'. Men and woman both described sexual expression as a high priority concern to them. For some, this was even at the point of trauma. For many, it was more important than other activities of daily living, such as walking, being able to transfer, feed themselves independently or write. Clare said,

"The first thing, within the first day or two (of the accident) I was saying to the surgeon 'How will it affect sex?' He said 'Be grateful you are not a man'. For me it was high priority. Even before my surgery at four in the morning, I was concerned and asking the doctor. I didn't ask if I would go to the loo independently. My immediate thought was how is this going to effect my sex life"

The depth of concern can be heard in Jeff's account. At the time of the accident he was

"Absolutely devastated. I just burst into tears at the thought of the loss of sex. You are concerned if you are not able to perform and satisfy your partner, that in itself was quite devastating to me. At the time (of the accident), I couldn't get it out of my mind. I'd see my wife in hospital every day but at night I'd lie awake worrying about not being able to work, not being able to walk and not being able to have sex."

Jeff was 48 at the time of his spinal injury, which occurred four years earlier.

Comparing his feelings then to now he said,

"My sex life was absolutely paramount to me. I had a very active sex life before this happened. Physically I have improved but not fantastically. Similarly sex is better but not as it was. After four years, I am still switched on in my head, sexually, as ever I was. Actual sex now isn't nil but it is greatly reduced. My sex life is just so important to me. … In terms of priority I know everything is so important, like walking but certainly my sex life would come very close to the top in my case"

But sexual expression is not a priority for everyone. Colin described the sheer effort to undertake the routine of daily living, indicating that this outweighed the pleasure saying,

"Able bodied people on a scale of 1 - 10 rate sex at 8 but for a wheelchair user it would be nearer 3. As the sex drive diminishes it tends to fade into the dim and distant past and becomes less important."
Also, priorities change as other life events claim greater or lesser attention. This is closely linked to loss, bereavement and the journey to acceptance described in several of the narratives. It also dovetails with concerns about timing of any help offered.

**An emotional rather than a mechanical perspective**

Without exception, individual contributors wanted the research to focus on the broad issues, understanding the sexual impact of a disability more from an emotional than a mechanical perspective. They said that although issues such as strategies, equipment and medication were relevant it was the wider concept of social functioning that was more important. Ray coined the terms ‘hard issues’ and ‘soft issues’. Soft issues included: emotional adjustment; social isolation; building and maintaining relationships, and moving them toward intimacy, much of which for non-disabled people, occurs in the subtleties of body language. It also included the emotional responsibility, felt by many men, for them and their partner to achieve sexual satisfaction.

Many contributors saw emotional adjustment to sexual change as the main issue for research. Owan, disabled 17 years ago, said the research agenda should include,

"The inner side, the inner feelings. No one actually sees that. No one spoke to me about that (sexual) side of life. I have found a book but no one to talk to."

Individuals recently admitted to a spinal injury unit did sometimes receive direct and useful intervention on sexual expression but several said it neglected the emotions of sex. This was epitomised by Jason who wrote

"My experiences from professionals have been mostly limited to the sexual health nurse at the spinal injuries unit. I have found her friendly and helpful with suggesting ways of achieving orgasm through artificial means. She does not, however, deal with the psychological / counselling side of things."

Josh too said, 'they discuss the clinical side - the focus is on the mechanics of sex'. Quentin described his progress since his disability and that he had now experienced several relationships. He was presently living with someone. He felt it was in dealing with the psychological aspects, in accepting himself as a disabled person, which made it

"Easier to make other people like me. I had to do it all on my own. I wonder how many people never get there and therefore never resolve the issues."

Len put it another way. He said,
Ben, Victor and Zac all described problems of social isolation caused by their disability. Hearing and visual impairments, restrictions on driving, and access to the built environment exacerbated this. For some like Ben, head injury meant relearning social skills. The user groups Gemma and Outsiders both saw social isolation and lack of opportunity as a particular issue for gay, lesbian and bisexual disabled people. Iris suggested this was not just about physical access 'with most gay clubs in basements' but also about the 'body conscious gay sub culture' which created greater barriers.

Contributors spoke of building and maintaining relationships. There was the fear, or for some the reality, of relationship breakdown. Quentin gave an example

"I was in a relationship at the time of the accident but the relationship did not survive. You are trying to rediscover yourself and your partner is also trying to rediscover you as you are now: a different person. And it doesn't survive. I don't blame her."

Also for some individuals, the problems associated with sexual expression were located in their inability to engage in the kind of body language that could test out a relationship and move it toward sexual intimacy. For example, Greg said

"It is so difficult for anyone in a wheelchair to form relationships: apart from transport, access and those sorts of things. It does act as a barrier. You have got to build up the natural steps: brushing arms; putting your arm round someone; finding out how they feel about you (by the way they react). The development of a sexual relationship mostly goes on in the subtleties of body language. In a wheelchair you have to take one step back and look at the practicalities."

Jack, married for 28 years, mirrored this. He wrote,

"For me I find the main problem is the physical contact that may, or may not be the preliminaries to sex. … I now use a rollator and a wheelchair and it is very hard to do the casual touching that married couples do. The casual, informal kiss, grope or whatever."

Joy noted, as the non-disabled partner, she now had to take the initiative. Thus the preamble of seduction, including undressing and caressing, which for many couples adds to the eroticism of the encounter, was now, at best, out of the disabled person's control and for some absent altogether.

Several men expressed a sense of responsibility within a relationship for providing sexual satisfaction, with the 'gold standard' being penis / vagina penetration. This
adoption of responsibility has been recognised in the general population (Zilbergeld 1978) but has to be of greater significance for a disabled man. Derek said

"I don't feel guilty about not being able to walk, but I do about not being able to maintain an erection"

Stuart wrote of his daydream of a new relationship

"I then stop day dreaming and come back earth. What if a relationship was to develop? I know what the outcome is going to be already when it comes to the sexual side of things. I won't be able to pleasure her as a fully functional male would. I will feel inadequate, frustrated, annoyed with myself and depressed, just like I have in the past with my wife."

Kate gave a partner's perspective.

"My husband still gets very upset about it (not being able to have an erection). He feels confronted by it. Now we don't have any sex. He feels inadequate that he cannot give me what I need. He is not prepared to try other things because we had a good sex life that worked on intercourse. So, he is not prepared to try other things with me. For my husband it feels a terrible loss of manhood."

Only one man, Victor, presented an alternative view. He felt sexual expression was an important aspect of disability to research because of the 'tremendous lot of unhappiness through ignorance'. He believed men needed to increase their understanding and he went on to describe how disabled men could enjoy an active sex life concentrating on satisfying themselves and women without penetration. Fay echoed this

"We had a very happy and active intimate life even though, there was minimal penetration. There are more ways than one to skin a cat! If you are open minded, get catalogues, buy some sex toys - penetrative sex is a bonus but it is not the only way."

**Current health and social care services**

Individuals suggested that the research should establish what current health and social care services are available for disabled people to promote sexual expression. The spokesperson from RADAR suggested a comparative study looking at the difference in provision in regional units, general hospital and community services. Differences were emerging in the accounts given. As noted earlier, sexual expression had begun to be addressed in regional specialist spinal injury units. Access to these specialist services though, was available only to a minority of disabled people. For people with a spinal cord injury before this time, and for all other conditions, there appeared to be no consistent provision of information or support.
There were examples of positive help. Jason's neurologist asked him about sexual function at a routine, regional, outpatient appointment and, from this inquiry, Jason was referred to the specialist sexual health nurse. Respondents, like Jason, referred to the specialist sexual health nurse, indicated this was possibly the greatest source of help and support. It was this nurse, usually, who was the only person willing to talk openly and in depth, however there was still the limitation, described earlier, of focussing on the mechanics rather than the emotional aspects. For Karl, a new district nurse heard his concerns and she put him in touch with a counsellor. A couple of people had discussed the matter in a helpful way with their GPs.

On the other hand, the RADAR contact described disabled people 'being blanked' by professionals when they had tried to raise sexual issues and several people described unsuccessful approaches to their consultant, GP or district nurse. When Stuart and his wife broached the subject with his GP, she dismissed them saying that they should be happy with the family they already had. Apart from Karl, no one else indicated that community nurses, physiotherapists or occupational therapists had any sort of enabling role around sexual expression. Jeff though did describe how he would joke with his physiotherapists, testing to see if he could approach them. Of occupational therapists, Greg said they only addressed 'their remit', which, from his perspective, did not include sex. However, the MNDA contact suggested occupational therapists may be the 'best placed' professional to consider sexual issues with their members. Despite the number of professionals involved in many people's care, Kate spoke for most when she said,

"You don't get anything unless you ask but that's not the case with sex because you don't know who to ask"

Quentin echoed this when he said 'nobody knows whose job it is'.

**Confidence and competence of disability professionals**

Research was suggested to outline the confidence and competence of disability professionals in this aspect of care. The experience of contributors indicated there was no clear avenue of advice and support. Apart from the sexual health worker now available in some regional units, they did not know whom they, or their partner, could talk to within statutory services. The disability professionals working with them (doctors, nurses, therapists, social workers) appeared not to address the emotional
sequelae of disability & did not enable discussion on sexual expression. This resonates with an issue identified at the EMSP conference: to improve health professionals' skills in enabling a person with multiple sclerosis to discuss their concerns.

Above all, the best method of providing help was seen to be having someone to talk to about sexual issues. Similarly, Headway's Information Officer, present at their members' conference when sex was raised, commented on the enormous relief she felt it was for the members to be able to talk about sexual concerns. In reality, for the majority of individuals, there appeared to be no one with whom they could discuss the impact of the disability on their sexual expression. It was never discussed. Eva spoke of the lack of any 'resources where it would have felt all right to explore these issues'. Some wished the subject had been introduced by one of the professionals involved in their care. Len spoke of the need for professionals to be 'proactive and not leave it to the patient' to speak out. This would have given him permission to discuss sexual issues and possibly have identified the professional with whom it was appropriate to talk. Beyond discussion, as Clare describes, contributors wanted information too.

"It is not a subject people are prepared to contemplate or discuss. I went to the spinal injuries unit but there was very little information. I raised it but nobody raised it with me. The first thing I needed was factual information. I needed detailed factual information. They provided me with information on lots of other areas, getting a job, applying for benefits, but not on sex. There was minimal information, negligible, two little booklets but nobody to talk to. I asked the nursing staff but they didn't know. There was nobody I could talk to. … since leaving the spinal injuries unit. … I haven't raised the issue with any body because I wouldn't know who to ask and nobody has asked me."

Both the organisation Discern and individual respondent Noel, a consultant physician, added a professional slant. Discern suggested discussion on sexuality set up 'all sorts of tensions' in the professional. Noel felt doctors were unable to discuss sex because it brought into question how they related to their own sexuality.

**Range of help and advice**

ASBAH, the EMSP conference, and many individuals wanted research that would explore and develop the range of help and advice available in statutory & non-statutory provision. Several contributors spoke of the equipment they had tried, reporting on its usefulness or uselessness. Body massagers and vibrators were seen as helpful. The erection aid vacuum pump generally received less favourable reports. Equipment was
expensive and information, including names and addresses of suppliers was difficult to obtain. Getting details on vibrators for example was less easy than on toilet seats or wheelchairs. For some, it felt furtive, as Derek described in his quest for information.

"SPOD is seedy unlike the 'above board' wheelchair clinic. It (feels like) the equivalent of a back street abortionist. In the same way vibrators are not advertised whereas mobility and cooking aids are quite different”

Sometimes, as Fay's partner found, other patients were the main source of information. Accessing information was enabling, allowing the disabled person to raise sexual issues with professionals. For example, the publicity given to Viagra enabled Stuart to speak to his GP. Individuals reported on two medications to aid erections, intracavernosal injections and the orally administered Viagra. Success and failures were noted for each. For Ray help was having a supra-pubic catheter fitted and Viagra.

Like many, Unwin received no information from professionals, he said,

"It was a matter of coming to terms with it yourself. Reading articles, Forward magazine, the Internet, trying to get more information.”

For those with a spinal cord injury, the main source of information was the SIA who produced booklets, videos and provided a telephone counselling service. There was no similar mention of Headway, the MNDA or the DLCC. At the time of conducting the preliminary inquiry SPOD's specialist telephone counselling service was available. However, the BCDP's spokesperson said SPOD was not highly regarded as it had a long tradition of using non-disabled counsellors. Many contributors did not know about SPOD, some had not found it helpful and others had wanted face to face contact. Derek had contacted SPOD but he felt the information he sought should have been available within the existing health services.

**Timing of help**

The research needed to consider the timing of any social or health care intervention aimed at promoting sexual expression. In part, this was because the importance, or priority, of sexual expression can change as other life events claim greater or lesser attention. For some people it was the first and most important concern, even at the point of trauma. For others, it only became relevant after their return to the community. This was epitomised by Beth whose husband Tim still had nursing and social care support.
“Tim went through the spinal injuries unit five years ago. Whilst advice was available, it was at the wrong time and totally wasted. There was so much else going on, rehabilitation, housing. … They talked of still being able to have a family. It was good to hear but I needed much more later. Yet, since leaving the spinal injuries unit there seems to be no way back into the service. … It took us a year to get the house adjusted. It's only this year that we have started to move on but there is no one around now when it would be helpful.”

Timing of help was closely allied to another recurrent theme: hospital versus community provision. RADAR and several individuals noted that sexual expression might be introduced during the rehabilitation phase in hospital (notably in regional spinal injuries units). This is a stage marked, for most, by lack of opportunity for sexual intimacy. Adjusting to disability often challenges existing relationships. For some individuals, it entailed the establishment of new relationships. Yet getting access to help and advice, once in the community, appeared very difficult. Additionally for those with progressive conditions there was often no hospital phase.

**Support is required for the couple**

The preliminary inquiry indicated the research needed to acknowledge that support is required for the couple as well as the disabled person. This was identified at the EMSP conference and by individuals. Terry, whose wife had a traumatic brain injury, wrote a long, detailed letter to give an understanding of what it was like for him as her partner.

"The stresses which this brings to a partner with a 'normal' sexual drive can be immense and there is little work available for reference or guidance as to what may or not be appropriate in the circumstances. … Now, some years after the accident, we have a personal and intimate relationship but, on my side, there remains a deep concern that it is my needs which are being served and not necessarily those of my partner. … I think that the partner as well as the disabled person needs to be helped and supported"

Others echoed this need including those married before the onset of disability as well as where the relationship developed afterwards. It was apparent that many couples wanted help to accommodate the changes within their relationship and had wanted to discuss this with an external person. For Beth and Tim, there had been no help available to them as a couple and they had begun to ignore the sexual difficulties in their relationship. Yet, she said, 'it is the issue that I have not been able to reconcile in any shape or form'. She felt help and advice should have been available within the existing services, someone who was part of their health care team. Gail also noted, for couples, a potential conflict between the role of carer and lover, which she had worked to avoid.
Sexual surrogacy

A few individuals indicated sexual surrogacy as an important issue that should be included on the research agenda. For example, both William and Ray noted how helpful such a service would have been to them, if it had been available in this country. They saw surrogacy as very different to prostitution. Importantly the surrogate was assumed to be experienced in, and understanding about, disability. Also, a legalised service was considered safer. Some individuals identified the complexities of learning how to manage a hoist, convene, catheter or stoma as part of their sexual encounter. Surrogacy was seen as providing a safe environment to practice and rehearse what is and is not possible. Confidence could be gained in a safe, non-threatening environment. Len confirmed this from his experience of using a surrogate sexual partner.

"I had my accident at the age of 17. I had had no prior (sexual) experience. Then when I was 26 / 28 I was going crazy. I became a recluse, shut in, nothing was talked about. I saw a programme. … They (the surrogates) know what limitations, what functions are lost. I made enquiries and went to Amsterdam. It was enjoyable and I came out less stressed, less anxious. It was a turning point, a liberating experience."

Although he was unable to have other surrogate partners in England, it did provide the increased confidence for him to move out of his parent's home into his own flat. He said research 'should be about pushing the boundaries forward for surrogacy'.

Barriers to services

Contributors also indicated that the research should identify barriers facing disabled people to services that are available to non-disabled people. Both ASBAH and Outsiders noted that many disabled people did not want specialist services but, from their experience, access and disability awareness was not good in mainstream services, including sexual health clinics. This was born out by several individuals, particularly around counselling services. As Colin noted

"If counselling and psychotherapy was more readily available - more user-friendly there is none round here that's wheelchair accessible"

Others like Karl and Beth had accessed counselling and described it as valuable but they both noted a limitation: the counsellor's lack of expertise on disability. As Beth said

"The counsellor was not experienced in disability issues. It was very good and better than any other help I got. … It helped me through the initial shock of it. But the counsellor was not experienced in sexual issues or disability issues."
Also, because she had only managed to get individual counselling, this work was not shared with her husband, the disabled partner.

Pornography and erotica too could be difficult to obtain. Additionally any that was available was based on non-disabled imagery. Len, Zac and Patrick had all considered using prostitutes but they were unable to do this independently and therefore could not use them privately. Although sometimes these barriers are about an inaccessible physical environment, more often, they were said to be about attitudes of other people including carers, families and professionals.

3.6 Outside the scope of this study

Four individuals, as well as the user group Scope, raised concern about fertility and parenting. People spoke of their desire to have children and the prejudices they had experienced. Again, it seemed that progress had been made in spinal injury services but there appeared to be little opportunity for others to discuss the impact of disability on fertility, pregnancy and parenthood. Access to family planning and fertility clinics were seen as problematic. One mother thought that her parenting skills were negatively judged because of her disability and avoided approaching Social Services fearing they might remove her child. Although I acknowledge the fundamental drive for parenthood, I have excluded it from the remit of this study, as it brings a tranche of other issues beyond the scope of this study.

3.7 How should professional practice be researched?

Some user groups and individuals made recommendations about the conduct of the study around language, disability models and the involvement of disabled people. Arthritis Care and the PDS noted that many of their members would not necessarily identify with the term disabled person. Yet, Ned objected to the inclusion of the word illness in the Project Information Sheet. Another key recommendation from the contributors was that the research should be framed in the social model of disability as this was seen to identify barriers faced by disabled people. The Discern representative urged a 'small and deep, not large and superficial' approach. Finally, and perhaps most
importantly, was the issue of service user involvement. The MS Society and ASBAH specifically, and other user groups more generally, appreciated this early collaboration. Likewise, individuals were pleased to assist in defining the research agenda. Some, like Adam, saw this as contributing to the improvement of services. Collaboration with disabled people as the research proceeded was considered. Nearly half the individuals indicated a willingness to remain involved. However, I was challenged as to whether I was the right person to conduct the study. Ned wrote

"Being a 'professional' you will always be tarnished with the 'professional' brush, and I think you need to consider your role in the data collection part of your study."

The BCDP also envisaged problems having a non-disabled researcher undertaking the study. However, Greg reassured me suggesting it was more important that the research is done, rather than insisting whom it is done by.

### 3.8 Completion of the preliminary inquiry

On completion of the preliminary inquiry, a formal letter was sent to the user groups thanking them for their contribution to the study. Letters (or emails where appropriate) were also sent to individuals involved in this study as well as to those whose response arrived too late to be included. Some six months later a summary was circulated to user groups and individuals (Couldrick 2001). In keeping with a collaborative approach, I also published short articles on the preliminary inquiry in: the BCDP newsletter; Headway News; SPOD's newsletter, and the MNDA's magazine, Thumbprint. Unfortunately, because of the time taken for analysis, the summary did not reach every individual. Some contact details had changed. Of the others, several replied: some wanting to remain collaboratively involved in the study; some to confirm the summary reflected their views, and some indicated their priorities for research. For example, Frank listed the four issues most pertinent to him in the summary I had sent: the emotional rather than mechanical perspective; timing; use of surrogate sexual partners, and identifying the barriers facing disabled people to services. He added

"It is a shame that any further study could not include all the points raised as they are all very valid and would lead to a more holistic view of the problems facing the disabled community. Social attitudes are changing for the better … but sex is the greatest taboo and, as such, is a topic most people don't think concerns those of us who are disabled. My hope is that a study like yours, and those like them, begins the slow process of breaking down these walls of ignorance."
3.9 A limitation of the preliminary inquiry

This collaboration had a profound influence on my thinking, and contributed to the development of the research proposal. What it revealed however cannot be attributed to all, or even to many, disabled people. This is because individuals in organisations cannot speak authoritatively for all their members and only a tiny fraction of individual members contacted me. It is probable that many disabled people may have read the flyer but did not make contact. I cannot know the views of those who did not collaborate. I can conjecture that some disabled people would not perceive sexual expression as a concern or would not desire the intervention of a health or social care professional. Others might view the project as irrelevant or offensive. Possibly, only those who had a level of confidence in speaking about sex may have approached me. In reality, of the individuals who contacted me, without exception, they supported the project indicating that sexual expression was an important issue that they wished researched. Seventeen organisations also saw it as a relevant research topic for their membership. My interpretation of this preliminary inquiry is that for some disabled people, sexual expression is a significant and a neglected area of health and social care.

3.10 The influence of the preliminary inquiry on the main study

The preliminary inquiry underpins the main phase of my research. It influenced the final choice of research context for the main study: disability services provided through multi-disciplinary teams working with people living in the community. It also aided the research design, gave me a sense of personal authority and motivated me.

Although suggestions were made (and considered) for studies comparing settings, I chose to focus where most support was expressed as needed, and least appeared to be available: the community. The future direction of the NHS indicates that increasingly health and social care will be provided in the community (Dept. of Health 2006). Choosing a community setting also addressed issues of timing. A few people did receive some support during an acute in-patient episode but, for most, it was while they were in the community that help was required. People with progressive conditions often
received no acute in-patient care. Additionally while living in the community, disabled people were in touch with the realities of intimate relationships.

Generalist practice was also chosen. Although the majority of individuals who contributed had a spinal cord injury, those with progressive disorders appeared to be faced with greater difficulties. I did not wish to exclude people with spinal cord injury but an inclusion criterion was added within the study design: that the teams to be studied should take referrals from people with multiple sclerosis.

The preliminary inquiry confirmed the importance of researching the fit between professional roles. It had identified that many different professionals were providing health and social care. No single disability professional was consistently available to all. Apart from the sexual health nurse, service users were unaware 'whose job it is' and therefore did not know who to approach.

I felt the contact at Discern was right. The study needed to be small and deep. However, it also needed to accommodate the breadth of issues: asexualisation to surrogacy: emotional to practical. This confirmed the necessity of taking a qualitative approach. Service user involvement for the later stages of the study was not possible. This is explored in detail later (see section 5.3 - Frames of inquiry: Collaborative research).

During the fieldwork stages of the main study, I found this period of collaboration immensely valuable, especially in managing the half-truths. That is, when a practitioner says that sexual expression is a low priority to the service user, I know that may be true. However, I also know, with certainty, that it is not true for all. Thus, in focus groups I experienced a sense of authority arising from the preliminary inquiry that helped me evaluate better what was being said.

Additionally, towards the end stages of the study, I found this preliminary inquiry especially helpful in maintaining motivation. At the times of wanting to give up, the preliminary inquiry kept me going. Reflecting on the time and effort so generously given, and the contributors' trust in me, stopped me abandoning the project.
3.11 Conclusion

The contribution of disabled people, in establishing the research agenda, added immeasurably to my understanding of the issues in this study. It also assisted deciding the research context, refining the methodology and supporting my motivation. The expertise of disabled people was harnessed both via disability groups and through direct contact with some of their members. Individuals particularly, indicated a desire that their contribution would ultimately lead to service improvement.

Overwhelmingly contributors supported the project seeing it as relevant and worthwhile. Sexual expression for many was a high priority concern and it was closely allied with quality of life issues. However, apart from people recently admitted to regional spinal injury units, there was no clear avenue for advice and support: no one in the health and social care team to talk to. Disabled people suggested that the research should investigate asexualising attitudes in health and social care as well as professional practices that may damage sexual identity. Although practical advice, strategies and equipment were all needed, the emotional aspects of sexual expression were of the greatest importance. This included social opportunity to establish relationships and help maintain relationships, as well as emotionally adjusting to the sexual changes caused by disability. They highlighted issues around the timing of help, the need for work with the couple and the kind of help required. Some wanted sexual surrogacy included on the research agenda. Others suggested that the research investigate barriers to mainstream services. Importantly they established that for most, sexual expression of disabled people is not on the health and social care agenda.
CHAPTER 4: LITERATURE REVIEW

4.1 Introduction

Until the 'genital years' of the 1970's (Christopher 1993 p291) there was minimal information on sex and disability. Chigier (1981) outlined the early development of the field from initial awareness, through advocacy, to the need for research. 'We as health professionals, were very ignorant and needed to collect more facts' (Chigier 1981 p135). Thus, the decade provides a good starting point, to review research into the practice of disability professionals toward the sexual expression of service users.

Drawing on the film making metaphor (Rudestam and Newton 1992), the literature review begins with 'long shots', a cursory scan of the research into sexual health and the general population. 'Medium shots' investigate evidence of the impact of disability on sexual expression. Detailed analysis, 'the close-up', is reserved for studies into disability professionals' education, roles, skills and attitudes in this area of practice. The chapter concludes with in-depth critical appraisal of the minimal research into the inter-professional practice of physical disability teams around sexual expression.

4.2 Sexual expression and the general population

It is not relevant to review here the research into human sexual development. It is comprehensively covered by others (Bancroft 2004; DeLamater and Friedrich 2002; Masters, Johnson et al. 1995). In essence, human beings are sexual beings throughout their entire lives. Sexual functioning may change in later life but sexual interest and desire may continue until death. DeLamater and Friedrich's (2002) summary includes social research, like the importance of the mass media as a source of information about sex and intimacy. Similarly, research into gender and sex roles (Archer and Lloyd 2002) and heterosexism and homophobia in health and social care (Wilton 2000) is extensively covered elsewhere. Only two aspects of sexuality research and the general population are considered here: relationship patterns and sexual dysfunction.
Two large-scale surveys have been conducted in the UK: the National Survey of Sexual Attitudes and Lifestyles - Natsal 1990 (Johnson, Wadsworth et al. 1994; National Centre for Social Research 2003; Wellings, Field et al. 1994) and Natsal 2000 (Johnson, Mercer et al. 2001; Mercer, Fenton et al. 2003; National Centre for Social Research 2003). Both were carefully constructed and tested to gain sensitive information. This was enhanced in Natsal 2000 with computer inputting. Natsal 1990 surveyed almost 19,000, and Natsal 2000 almost 11,200 men and women, aged between 16 - 44, resident in Britain. They were asked about their sexual lifestyles and attitudes. The focus was patterns of HIV risk behaviour, partnership formation and sexual practices. The second survey was able to measure changes in sexual behaviour.

These two studies established normative trends in relationship patterns. Relevant findings from Natsal 2000 are summarised in table 4.1. They showed a wide variability in sexual lifestyles, by relationship status, age, gender, and residence within and outside London. Cohabitation had increased. Successive relationships rather than single

<table>
<thead>
<tr>
<th>Trends in relationship patterns</th>
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<tbody>
<tr>
<td>● the proportion of cohabiting respondents was higher, and that of married respondents lower, in Natsal 2000 than Natsal 1990</td>
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<tr>
<td>● 81.9% of men and 76.4% of women reported more than one lifetime partner</td>
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<tr>
<td>● 34.6% of men and 19.4% of women reported at least ten lifetime partners</td>
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<tr>
<td>● in the previous five years the mean numbers of heterosexual partners were 3.8 for men and 2.4 for women</td>
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<td>● 2.6% of men and women reported homosexual partnerships</td>
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<td>● 4.3% of men reported paying for sex</td>
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<tr>
<td>● 31.2% of men and 21.4% of women had formed new heterosexual or homosexual partnerships in the previous year</td>
</tr>
<tr>
<td>● the proportion reporting a new partner in the last year declined with age in both genders with the mean number of new partners in the previous year varying from 2.04 for single men aged 25-34 years to 0.05 for married women aged 35-44 years</td>
</tr>
<tr>
<td>● it was estimated that 14.6% of men and 9.0% of women had concurrent sexual partnerships</td>
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<tr>
<td>● the mean frequency of heterosexual sex (vaginal, oral or anal) in the previous 4 weeks among respondents with a partner was similar for men and women but declined with increasing age</td>
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<tr>
<td>● there was considerable variability in frequency of sex during the 4 weeks, the mean (6.4 for men and 6.5 for women) being consistently higher than the median (4 for both men and women)</td>
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Table 4.1: Summary of relevant findings of Natsal 2000 (Johnson, Mercer et al. 2001)
lifetime partners were the norm. Significant numbers of people had concurrent sexual partners and over 4% of men reported paying for sex. It must be remembered however that these surveys had a very restrictive upper age limit.

Natsal 2000 investigated sexual problems, using duration of problem and the avoidance of sex as indicators of severity (Mercer, Fenton et al. 2003). A total of 34.8% of men and 53.8% of women, who had had a partner in the previous year, reported at least one sexual problem lasting at least one month. Persistent sexual problems, (defined as lasting at least six months in the previous year) were less prevalent affecting 6.2% of men and 15.5% of women. The most common was premature orgasm for men and lack of interest in sex for women; indicating that problems of sexual function are relatively common but persistent problems much less so (Mercer, Fenton et al. 2003).

The survey questions were based on sexual dysfunction, as defined in the International Classification of Diseases, 10th Revision (ICD-10) (World Health Organization 1992). The results highlight the difficulty already discussed of classifying sexual dysfunction (See section 2.7 - What can be done by experts in disability: Limitations of sexual dysfunction diagnoses). The Natsal authors asked whether lacking interest in sex could be considered dysfunctional when it was reported (as a problem lasting at least one month) by almost 40% of women and 20% of men (Mercer, Fenton et al. 2003). Few people sought help for the dysfunctions identified, possibly signifying they were not seen as problematic. Alternatively, people may only seek help if they believe help to be available. For example, more men have presented with sexual problems at genitourinary clinics since the licensing of sildenafil (Mercer, Fenton et al. 2003; Ralph and McNicholas 2000). The Natsal authors highlighted the need to both re-appraise the nature of sexual dysfunction and raise public awareness of psychosexual services.

Despite their focus on the under 45s, these surveys do contribute to the understanding of the diversity of human sexual behaviour in the UK. Their quantitative design does not permit deeper exploration of sexual problems, nor expressed desire for help, but they do provide a general baseline (6.2% for men and 15.5% of women) for prevalence.
4.3 The impact of disability on sexual expression

Professional literature on the impact of disability on sexual expression consists largely of commentaries, literature reviews and practice based articles. Data based studies are reviewed here. I have divided them into either, studies of prevalence, or other correlates of sexual expression. Some address disability, some are condition specific. Others have noted the paucity of research (Elliott and Biever 1996; Foley and Iverson 1992; Graves 1993; Milligan and Neufeldt 2001) with particular neglect identified around female perspectives (Esmail, Esmail et al. 2001; Milligan and Neufeldt 2001) and the partner's experience (Dupont 1995; Esmail, Esmail et al. 2001). I found no studies related to gay, lesbian and bisexual disabled people. Most research has been into men with spinal cord injury (Graves 1993; Milligan and Neufeldt 2001).

Prevalence

Disabled people are subject to all the same sexual difficulties that non-disabled people can experience. Research indicates they may additionally experience sexual problems secondary to their disability. These studies are problematic and difficult to compare. Firstly, they investigate different things. Some measure sexual problems (Stewart 1979). Others measure sexual dysfunction (Brown, Jahanshahi et al. 1990; McCabe, McDonald et al. 1996), sexual change (Chandler and Brown 1998; Wermuth and Stenager 1995), sexual concern (Chandler and Brown 1998; McCabe, McDonald et al. 1996) or sexual satisfaction (Nosek, Howland et al. 2001). Different populations and methodologies are used and very few have a control group, for comparison with the general population. I have used generic studies and then, as exemplars, multiple sclerosis, Parkinson's disease, stroke and motor neurone disease research.

I begin with one of the earliest reported generic studies in the UK, conducted in 1975, by SPOD (Stewart 1979). Of the 212 disabled people living in the community who were surveyed over half, 54% experienced current and significant sexual problems. The respondents said these were directly, or indirectly, due to the disorder or were significantly worsened by it. In this study, sexual problems were defined as obstacles to the satisfaction of sexual need. Additionally very little attention (usually none) had been paid to these sexual problems within any treatment or rehabilitation provided.
Twenty-five years later, 70 disabled people participated in a quantitative study, utilising standardised measures, designed to ascertain how many people with neurological disability experienced sex and relationship dysfunction. They represented 18% of the potential study sample of outpatients attending a UK rehabilitation centre. Fifty one percent of respondents reported a negative change in their sexual function due to disability and 27% were concerned about this change (Chandler and Brown 1998). The authors concluded that 'if concern is taken as a indication of a desire for help more than one in four of this sample required help for sexual dysfunction' (Chandler and Brown 1998 p877). Although this study indicates increased prevalence of sexual problems, a skew is possible because those volunteering might be those most seeking help.

A US study with women did gather comparable data from a non-disabled group (Nosek, Howland et al. 2001). Over one thousand physically disabled women were recruited through independent living centres. Each was sent two questionnaires: one for herself to complete and one for her to give to a non-disabled friend, 946 women replied: 504 were disabled and 442 were non-disabled. The disabled women reported significantly lower levels of sexual activity, sexual response and sexual satisfaction but there was no difference between the groups in terms of sexual desire. Partly the difference was attributed to the difficulty that the disabled women experienced in finding a romantic partner. It again questions how sexual problems are defined because issues noted by the disabled women; for example, weakness, poor balance, hip or knee pain and spasticity were different to the non-disabled group. The authors recommended involving physicians and physical therapists to consider better management for these symptoms.

Comprehensive literature reviews on multiple sclerosis have summarised earlier research (Dupont 1995; Foley and Iverson 1992; Lundberg and Hulter 1996; Mattson 1995; Vermote and Peuskens 1996). They conclude that sexual problems are common with a prevalence of sexual dysfunction as high as 48% - 75% of men & 39% - 75% of women (Dupont 1995; Mattson 1995). The percentage of people reporting changes in their sex life since the onset of multiple sclerosis were 90% for men and 70% for women (Vermote and Peuskens 1996). Erectile dysfunction was often amongst the first clinical symptoms of the disease (Opsomer 1996). In a Norwegian study, prevalence of sexual disturbance in multiple sclerosis was correlated with incapacity status: 53% of
people with low physical disability status reported disease related sexual disturbance, rising to 86% for those with high disability status (Nortvedt, Riise et al. 2001).

Dysfunction is not however an indicator of sexual satisfaction. In McCabe et al's study (1996) of 74 women and 39 men with multiple sclerosis, 80% & 65% respectively had one or more sexual dysfunctions. Yet 53.5% were not, or only a little, concerned by this. The questionnaire design did not allow exploration of the subjective experience of participants. Better understanding emerged from a larger study, with a matched non-disabled group (McCabe 2004). This confirmed significantly higher levels of sexual dysfunction for people with multiple sclerosis compared to the general population. The women experienced higher levels of sexual dysfunction than the men did; however, they also experienced higher levels of sexual activity and sexual satisfaction. The women engaged in alternative sexual activity thereby experiencing sexual satisfaction despite dysfunction. The authors indicated that men with a sexual dysfunction tended not to engage in any sexual activity resulting in low levels of sexual satisfaction. This may resonate with the preliminary inquiry where some men identified feeling responsible to sexually satisfy their partner. Without emotional readjustment, men may find it easier not to engage rather than experience what they perceive as failure.

Another study, into relapsing and remitting multiple sclerosis, demonstrated the mixed aetiology of sexual problems. Clinical and psychological correlates were assessed with 32 women and 9 men (Barak, Achiron et al. 1996). Measures included anxiety, sexual dysfunction, and depression inventories plus a neurological examination and a magnetic resonance image brain scan. It showed that sexual dysfunctions were frequently encountered and that although depression was a prominent variable, the demyelinating process contributed, particularly to loss of libido and anorgasmia.

Two quantitative studies concluded that Parkinson's disease increased the prevalence of sexual dysfunction (Brown, Jahanshahi et al. 1990; Wermuth and Stenager 1995). Both studies focused on patients under 56 years of age. Brown et al (1990) used self-reporting questionnaires for 34 patients and 38 partners in the UK, whereas Wermuth et al (1995), in Denmark, investigated 25 patients only, using structured interviews and neurological examinations. Brown's study suggested that 65% of men and 34% of women experienced sexual dysfunction. Wermuth et al (1995) noted that 40% of men
and 70% of women reported changed libido and 33.4% of the men and 80% of the women experienced changed sexual activity. Wermuth et al's (1995) study excluded depression as a variable. An interesting finding of the UK study is that 52% of the men's partners also had a sexual dysfunction. The scores of the partner were taken as an indication of the psychological impact of Parkinson's disease on sexual function. It also highlights the importance of considering the impact of disability for the couple.

A Finnish study into sexual functioning among stroke patients and their spouses used a self-administered questionnaire to investigate their pre and post-stroke sexual function (Korpelainen, Nieminen et al. 1999). There were 117 male & 75 female patients (90% of the potential sample) and 21 male & 73 female spouses. Most of the patients (89%) & their spouses (93%) had been satisfied with their pre-stroke sexual life. Post stroke, 49% of patients & 31% of spouses reported moderate or complete dissatisfaction. There was a significant decline in libido, coital frequency and sexual arousal in both patients and partners. Half the respondents expressed interest in sexual counselling but few had received any. The authors surmised that rehabilitation professionals inhibited discussion on the topic and recommend that basic information on sexuality should be given to stroke patients and their partners. The findings of this study were supported by data in an unpublished survey conducted in Madrid (Carod, Egido et al. 1999) which noted a marked decline in sexual function (72.7% of female and 70.8% of male patients who were sexually active before the stroke) one year after the stroke.

One qualitative, Canadian study investigated how stroke changed sexuality for people with aphasia and their spouses (Lemieux, Cohen-Schneider et al. 2001). Six couples participated. Several themes emerged including: reduced frequency of intercourse for all couples; aphasia negatively affected sexuality; most couples wanted to be asked about their experience of sex after the stroke, yet none of the couples were asked during the rehabilitation process. Patients were not just seeking information on sexual dysfunction: they wanted disability specific information on the safety of sex, alternative positioning, and other compensatory strategies.

For motor neurone disease, samples in the three available studies were very small. A German study used 9 male & 7 female patients plus 9 male & 8 female partners (Wasner, Enody et al. 2001). In Uruguay, there were 25 male & 15 female patients.
(Vincent and Rodriguez-Ithurralde 1997) and 4 male & 2 female patients in the UK (Oliver and Gallagher 2000). In Wasner et al's (2001) study, 12% of patients and 6% of partners reported sexual problems before disease onset, increasing to 50% of patients and 35% of partners at the time of the survey. Only 11% of couples had been asked by their physician about problems in their sexual relationship. The authors concluded that the importance of sexuality is 'heavily underestimated' by health professionals (Wasner, Enody et al. 2001 p108).

Findings though were generally more positive than in other conditions with some patients reporting an improvement in their sexual relationships (Wasner, Enody et al. 2001). Vincent et al (1997) indicated a physiological preservation of sexual function with sexual activity becoming increasingly important for some. Five quadriplegic men in his study, under respiratory assistance and percutaneous endoscopical gastrostomy (PEG) maintained sexual function and like a further six women in 'very advanced evolution' of their disease, still regularly engaged in sexual activity (Vincent and Rodriguez-Ithurralde 1997 p93). Long lasting sexual difficulties that were reported contributed to anxiety, a negative self-image and depression (Vincent and Rodriguez-Ithurralde 1997). The UK study was the only one I found where three respondents (50%) did not want sexual expression routinely raised, leading the author's to advocate sensitivity to patients' wishes (Oliver and Gallagher 2000).

In summary, this research confirms that disability can affect sexual expression both for the disabled person and for their partner. Sexual dysfunction, as defined for example in ICD-10 (World Health Organization 2001), has limited utility. More important is the subjective experience for the disabled person and their partner. The presence of severe impairment does not preclude the importance of, and desire for, sexual intimacy. The research reveals a complex interplay of direct neurological damage, associated impairment and psychosocial issues. Foley proposed a tripartite classification of sexual dysfunction in multiple sclerosis that may be a useful model for physical disability.

- **primary sexual dysfunction** resulting from physiological changes directly impairing sexual response (e.g. altered genital sensation, erectile dysfunction)
- **secondary sexual dysfunction** refers to non-sexual physical changes indirectly affecting the sexual response (e.g. fatigue, spasticity, incontinence and pain)

**Sexual expression, physical disability & professional practice**
- **tertiary sexual dysfunction** refers to psychosocial and cultural issues (e.g. role changes, low self-esteem or communication difficulties)
  
  (Foley and Iverson 1992; Foley and Sanders 1997a; Foley and Sanders 1997b)

In addition, where it was asked in the studies, disabled people and their partners usually wanted sexual expression included in disability treatment or rehabilitation although one study indicated a need to be sensitive to individual patients' wishes.

**Other correlates of sexual expression and disability**

There has been some empirical investigation of the correlation between quality of life and sexuality (McCabe, Cummins et al. 2000), sexual satisfaction (Walters 1998) or sexual disturbance (Nortvedt, Riise et al. 2001). Again, these studies are not comparable, with each using different measures. In the US study, sexual satisfaction was found to significantly predict quality of life for people with amputations (Walters 1998). The authors concluded that sexual counselling should be included in the rehabilitation process. Similarly a Norwegian study into multiple sclerosis found that those who reported bladder and particularly sexual problems showed markedly lower quality of life scores (Nortvedt, Riise et al. 2001). They too recommended better identification and treatment for sexual issues to improve quality of life. These studies however contradict an Australian study that recruited participants with a congenital disability (McCabe, Cummins et al. 2000). They found a low level of association between sexuality and quality of life. The authors' interpretation was that the negative attitudinal environment in which respondents had grown up may have led to their denial of sexuality. This highlights the complex differences between disabled people.

Another finding in the McCabe et al (2000) study was the lack of knowledge and education for those with a disability. The respondents, disabled since birth, when compared to a matched non-disabled control group, reported low levels of sexual knowledge and experience, held negative feelings in relation to their sexuality and experienced high levels of sexual need including a high desire to know more about sexuality (McCabe, Cummins et al. 2000). This finding is supported by an extensive qualitative study undertaken in the UK into 95 young adults (16 - 25 years old) with spina bifida and or hydrocephalus (Blackburn 1994; Blackburn 2002). This identified that young disabled people received much less information on sex generally and almost
nothing on sex and disability specifically. A dearth of disability specific sexual information for people with acquired disability has also been identified (Milligan and Neufeldt 2001; Nosek, Howland et al. 2001).

McCabe and a disabled colleague Taleporos conducted a series of studies on body image and esteem (Taleporos and McCabe 2001; Taleporos and McCabe 2002a) culminating in the development and validation of the Physical Disability Sexual and Body Esteem scale (PDSBE) (Taleporos and McCabe 2002b). Thirty-five disabled people assisted in its development. Many described their own experience of feeling sexually unattractive (Taleporos and McCabe 2001). Feedback from the social environment was identified as a powerful mediator of body esteem suggesting that many participants had internalised negative social attitudes (Taleporos and McCabe 2001; Taleporos and McCabe 2002a). A US study, of almost 200 people with a spinal cord injury, found sexual self-esteem instrumental in predicting sexual adjustment (Mona, Krause et al. 2000). This led the authors to recommend 'close attention' to sexual expression as part of the rehabilitation process. In the UK, Disability Now, a magazine for disabled people, conducted an electronic survey to which 1,115 disabled people responded (Disability Now 2005). It showed that sexual self-esteem was very, or extremely, low in more than half of married and cohabiting respondents; and in 76% of single people and 80% of those who are divorced. A main finding of the study was that respondents wanted someone to talk to and there was a call for a dedicated disability psychosexual counselling service. This is two years after SPODs closure!

Sexual expression and intimate relationships have been investigated (Chandler and Brown 1998; McCabe 2004; McCabe, McDonald et al. 1996; Nosek, Howland et al. 2001; Richards, Lloyd et al. 1992; Taleporos and McCabe 2003). Chandler & Brown (1998) found that sexual dysfunction could be predictive of difficulties within a relationship indicating that services needed to address relationship issues as well as sexual health. A study using the PDSBE scale (with 748 physically disabled and 448 non-disabled participants) indicated that physically disabled people experienced difficulty establishing relationships (Taleporos and McCabe 2003). They were more likely to be single than non-disabled people were, and disabled men faced more barriers than disabled women did to forming intimate relationships. Not surprisingly,
relationship status was strongly associated with sexual wellbeing in people with and without a disability, with single people reporting lower levels of sexual satisfaction, sexual esteem and sexual activity. Yet disabled people who were married, reported lower levels of sexual wellbeing than did those in a relationship with a non-resident partner. One interpretation provided by the authors was the difficulty in maintaining a relationship with a person who is a primary carer (Taleporos and McCabe 2003).

A relationship study was conducted in spinal cord injury, to establish the efficacy of a pharmacological intervention for erectile dysfunction (Richards, Lloyd et al. 1992). The researchers had hoped to establish a control group from people on the waiting list who were willing to defer treatment. This proved impossible because, even with financial incentives, none were willing to wait. Seventeen men, and their partners, were assessed before and after starting an intracavernosal injection programme. Both patients and partners experienced greater overall relationship satisfaction after treatment. The men also reported improvements in sexual pleasure and self-acceptance.

Studies have shown a significant correlation between the presence of depression and sexual problems (Barak, Achiron et al. 1996; Carod, Egido et al. 1999; Hibbard, Gordon et al. 2000; Nortvedt, Riise et al. 2001). One large-scale study into traumatic head injury with a matched non-disabled group, found that the most sensitive predictor of sexual dysfunction was the level of depression (Hibbard, Gordon et al. 2000). Carod et al (1999) noted that libido decline was statistically correlated with depression but not with stroke aetiology or level of disability. Also, depression was not correlated with other sexual dysfunctions (Carod, Egido et al. 1999). In a multiple sclerosis study, those with depression reported a frequency of major sexual disturbance five times higher than did those without depression (Nortvedt, Riise et al. 2001). The authors concluded that sexual dysfunction induces depression. Yet, this highlights the multifactorial processes in sexual response because depression, of itself, can cause sexual dysfunction (Bancroft 2004; Masters, Johnson et al. 1995).

There is substantial evidence that society perceives disabled people as asexual: that is without sexual drives or needs, but this is based mainly on the subjective experience of disabled people (Kallianes and Rubenfield 1997; Milligan and Neufeldt 2001; Nosek, Howland et al. 2001; Sakellariou and Simo Algado 2006; Tilley 1996). A meta-analysis
of asexualisation, reviewed social and empirical evidence. Social evidence included not only personal testimonies but also culture, as portrayed in the media, and the 'historical absence of attention to matters of sexuality within professional rehabilitation settings' (Milligan and Neufeldt 2001 p93). Unavailability of measures in disability sexuality research (compared to availability for the general population) has been cited as evidence of researchers not valuing sexuality among disabled people (McCabe, Cummins et al. 1999). Studies investigating the attitudes of the general population have tended to use student cohorts (Milligan and Neufeldt 2001). In one from Australia, students were asked to complete matched sentences: one with and the other without a disabled woman for example buying contraceptives (Chandani, McKenna et al. 1989). Although old, it did indicate that students then held negative views of the sexuality of physically disabled women compared with non-disabled people. In summarising empirical studies, Milligan & Neufeldt (2001) concluded that, although the hypothesis has not been directly tested, there was considerable evidence of the asexualisation of disabled people.

4.4 Professional education

General health education

In 1974, the World Health Organization convened a conference to promote the training of generic health professionals in human sexuality (World Health Organization 1974). Problems in human sexuality were seen to be more pervasive and important to wellbeing and health than previously recognised. It suggested that professionals reluctant to be involved might unconsciously deny the sexuality of the patient. It therefore established learning objectives for all health care practitioners (see section 2.7 - What can be done by experts in disability: The role of disability professionals). In the UK, sexual health was identified as one of five priority areas in the health of the nation strategy (Dept. of Health 1992). Undergraduate and continuing education programmes for health professionals were urged to include adequate information on the importance of sexuality in human relationships (Jacobsen 1988). It proposed skills training to ensure practitioners could manage the diverse problems posed by sexuality in everyday practice. More recently health professionals' awareness of sexual health, and available services, has been identified as a key factor in facilitating improved access to, and uptake of, specialist sexual health services (Medical Foundation for AIDS & Sexual
Health 2005). One might assume that pre-registration education therefore includes basic preparation in human sexuality: to this could be added specific knowledge and skills on sexuality and disability for those working directly with disabled people.

**Developing training for disability professionals**

Personal accounts of the development of training programmes on sexuality and disability, stress the importance of taking a multidisciplinary approach and involving disabled people in the training (Bullard and Knight 1981; Ducharme 1987). They provide anecdotal evidence that professionals talk more often, and more easily, with clients about the sexual aspects of their care after training. Ducharme (1987) also considered the importance of working with systems, as well as individuals, thereby enabling whole services to better support clients' sexual concerns.

Others provide detailed specification of learning goals and curriculum content, for example in occupational therapy (Goldstein and Runyon 1993; Neistadt 1986; Neistadt 1993), nursing (Finger, Stack Hall et al. 1992; Katzman 1990), physiotherapy (Keall 1982) and for health care professionals (Tepper 1997b). One study is from New Zealand (Keall 1982) the others are from the US: they may have been overlooked in the UK. Each identified the neglect of sexuality in academic programmes. Tepper (1997a) decried the paucity of inter-professional training programmes, seeing them as essential for a rehabilitation team where collaborative care is necessary to meet the holistic needs of the service user. Professions in his programme included: nursing, psychology, occupational therapy, physiotherapy and recreational therapy. I found no published details of UK based programmes delivered to disability professionals.

More recently, one Australian team has been developing a scale to identify the training needs of rehabilitation professionals working in spinal cord injury (Kendall, Booth et al. 2003). The Knowledge, Comfort, Approach and Attitudes towards Sexuality Scale (KCAASS) was developed, evaluated and refined, based on a conceptual model encompassing staff knowledge, comfort and attitudes towards sexuality following spinal cord injury. Testing of construct validity highlighted the need to include an additional construct, that of personal approaches from clients.
Evaluation of training programmes

A Canadian undergraduate two-day programme in human sexuality, undertaken by medical, nursing, occupational therapy and physiotherapy students, was evaluated (Cohen, Byrne et al. 1994). Findings demonstrated that the training had positive effects on students' attitudes towards sexuality, their comfort with clinical situations involving sexual issues, and knowledge of human sexuality. The workshop occurred at the start of the occupational therapy and physiotherapy intensive, two-year, problem-based, learning programmes. Eighteen months later 81% of the original physiotherapy and occupational therapy cohorts were tested again (Hay, Byrne et al. 1996). Although this demonstrated that the positive results of the workshop were maintained, my concern is that this research did not measure the impact, if any, on the students’ actual practice.

Enhancement of practice was part of the evaluation of the multidisciplinary course described by Tepper (1997a). It was subject to a comprehensive battery of assessment tools to measure the objectives of the programme, including participant observation by a research assistant and a five-month follow-up. The outcome of the programme evaluation, undertaken by the 18 participants, demonstrated a statistically significant increase in knowledge, comfort and skills. It was the only study I found where the gains from the workshop were transferred into measurable, behavioural changes in the provision of sexual health care in the participants' work environments.

Inconsistency

Inconsistency in education on human sexuality has been reported (Karlen and Moglia 1995; Neistadt 1986; Tepper 1997b; Webb and Askham 1986). One study investigated the curricula in occupational therapy schools in the US (Payne, Greer et al. 1988). Chairs of all accredited programmes (67) were surveyed, 50 took part. Although 32 believed patient sexual expression was important to occupational therapy, 10 disagreed and five were undecided. Relevant course work varied considerably, suggesting that therapists' willingness to address sexual expression would depend on where they were trained. This variability in sex education training was similar to a study into the education of physical therapists by Siracusano & Corbin (1986) cited in (Payne, Greer et al. 1988). Although unpublished, Payne et al's (1988) study was repeated in the UK

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1 Despite an extensive search, the cited article could not be located for use as a primary source.
Of the 27 schools that offered a first-degree course in occupational therapy, 25 replied. Some level of coverage on human sexuality was included at all schools. This ranged between two hours to 20 hours with an average of eight hours.

A similar investigation into sexuality training for psychologists in the US found more than one third of programmes did not cover typical or healthy sexual function (Wiederman and Sansone 1999). One fifth provided nothing on the assessment and treatment of sexual dysfunction, or related issues. The authors found that the attention and priority given to sexuality training was driven by the staff expertise available to the programme. Pressures on an overcrowded curriculum were discussed. The authors indicated, given the affective component of the subject, that self-directed learning, post qualifying, was insufficient. They proposed that deliberate attention to sexuality during training was required for the development of the competent psychologist.

In reviewing nursing literature I found several opinion pieces suggesting that sexual expression 'is defined and taught in narrow terms' (Brogan 1996 p45) and that nurses are not adequately trained to manage sexual issues with confidence (Finger, Stack Hall et al. 1992; Medlar and Medlar 1990). This is sometimes attributed to the tutors not being sufficiently comfortable with issues of sexual expression to teach the topic (Brogan 1996; Gender 1992; Webb and Askham 1986; Weston 1993). Lewis and Bor (1994), who indicated that tutors needed to develop insight into their own attitudes, echo this. Teachers, they said, could provide positive or negative role models and that reluctant or obstructionist attitudes of staff members provided barriers to effective education (Lewis and Bor 1994). Webb & Askham (1986 p80) said the 'potential role that schools of nursing could play in dismantling traditional views on sexuality and sex-roles cannot be understated,' yet they too found omission and inconsistency in curricula.

Decline of sexuality education programmes

A US study on the education of health professionals, albeit focused on ageing, resonates with this inconsistency noted above. The authors suggested that professional education 'had stalled or slid backwards' (Karlen and Moglia 1995 p193). They surveyed 25 experienced educators, people who had been teaching human sexuality to health professions for at least ten years, and followed this with some interviews. Respondents had taught students in nursing, medicine, psychology, counselling, social work,
midwifery, physical therapy, public health and health education. The programs varied from two-day courses to modules with 20 - 40 hours of direct teaching. Only three respondents felt adequate education was now being provided. The findings suggested that relatively few health professionals were well informed about sexuality. It also indicated a worsening in the entire field of sexuality education with fewer hours being allocated, and of those, a shift in focus had occurred, to problem areas like HIV & AIDS, rape, sexual abuse and unwanted pregnancy.

Similarly, a UK opinion piece lamented the decline in matters sexual in the psychotherapy field compared to the 1970s, when 'there was a lot of training going on of counsellors and psychotherapists about sexuality and sexual health' (Clarkson 2003 p7). In her view, there is little evidence now that sexual issues are taught within psychotherapeutic courses, and it is absent from contemporary professional literature.

4.5 Professionals' roles, skills and attitudes

By the 1980's, books on rehabilitation were beginning to include information on sexual expression for disabled people, directed to the many disciplines that contributed to their health and social care (Davies 1988; Dechesne, Pons et al. 1985; Hamilton 1980; Stewart 1979). Stewart (1979) believed that all disability professionals had a responsibility to address the sexual needs of their client. He considered the fit with each of the professional roles and reflected on their involvement at that time. He saw occupational therapists as leading the way closely followed by the medical social worker. The interest and skills of physiotherapists and nurses he believed were less marked but both had a strong potential role and 'at the rear of the procession come psychologists' (Stewart 1979 p131). The literature emphasises the importance of a positive approach and of staff feeling comfortable with the subject of sexuality. I will review the research evidence on issues such as comfort, attitudes and knowledge for each profession plus the fit with the professional role as indicated in the literature.

Occupational therapy

I have previously identified an ambiguous picture for occupational therapy (Couldrick 1996; Couldrick 1998). In summary, articles outlining the role of occupational therapy
in sexual expression began to emerge from the US in the 1980's (Dahl 1988; Evans 1987; Kennedy 1987; Neistadt and Freda 1987; Sidman 1977; Trombly 1989). These placed sexual expression within the domain of occupational therapy and described a fit with professional values and skills. Specific service areas were highlighted for example in: spinal cord injury (McAlonan 1995; Miller 1984; Novak and Mitchell 1988; Summerville and Kryss 1998); low back pain (Ritchie and Daines 1992); burns (Cooper-Fraps and Yerxa 1984); stroke (Edmans 1998); physically disabled women (Zukas and Ross-Robinson 1991), rheumatoid arthritis (Haslam 1995) and children (Evans 1985). In the US sexual expression formally entered professional language alongside other activities of daily living (Uniform Terminology Task Force 1989) and it was incorporated into two models of practice (CAOT & Health Services Directorate 1991; Reed and Sanderson 1992).

This sense that sexual expression is part of an occupational therapist's role conflicts both with the dearth of research evidence and practice reports since the 1980s and with another widely used model of practice: the Model of Human Occupation (MoHO) (Kielhofner 1993). The only explanation for MoHO was Kielhofner's statement (the model originator) that sexual activities were not occupational in nature and therefore not within the domain of occupational therapy (Kielhofner 1993). There have been only three published UK based research or practice reports in the field of physical disability and sexual expression (Edmans 1998; Northcott and Chard 2000; Ritchie and Daines 1992). Interestingly Moores (1996) in undertaking his research, spoke with an officer of the College of Occupational Therapists. She stated that issues of sexuality were not part of the profession's core skills. In her opinion, it would be outside a British occupational therapists competence to practice in this area without post-registration training. The UK professional body has not published any statement or guidelines.

Additionally research evidence does not sustain a confirmed role in practice. Three linked postal surveys of occupational therapists working with disabled adults or children in north America revealed the majority did not participate in sexual habilitation and rehabilitation (Conine, Christie et al. 1979; Conine and Quastel 1983; Evans 1985). The methodology was weak, with all three drawing on a flawed questionnaire developed from nursing literature. It did not provide practitioners any opportunity to explore
underlying issues. Respondents felt inadequately prepared to address sexual issues citing a void of information in both pre and post-registration education.

In my MSc study, I considered if client's sexual expression is a legitimate domain of concern of the occupational therapist (Couldrick 1996). Using depth interviews this investigated generic practice and nine of the ten participants said sexual expression of the client should be a legitimate domain of occupational therapy\(^1\). It was seen to be compatible with the values of the profession. Views differed about the scope and limits of the role. It demonstrated a disparity between ideology and practice. There was evidence of powerful emotive forces, encompassing cultural, contextual and personal issues indicating that sexual activity was not regarded like other activities of daily living. The majority of participants felt they did not have the expertise or interpersonal skills to competently manage this within their practice. Only one therapist described satisfactory, pre-registration training. All worked in multidisciplinary services. Only in one setting was client sexual expression aligned to the occupational therapy role. In another, it fell to psychology. Otherwise it was not a role or task clearly attributed to a particular professional group. Where it was being undertaken, either routinely or occasionally, it appeared to be equally appropriate to all professions. Where it was not being undertaken, it was probable that all staff ignored it.

Researchers in the US have developed an attitudinal measure, the Survey of Attitudes toward the Sexuality of Adults with Disabilities (SASAD) (Guest and Kopp Miller 1997). They redesigned the attitude scale developed by Conine et al (1979). A three-part instrument was used to test reliability and validity. Part one elicited demographic information, part two was the SASAD and part three was a Sex Knowledge and Attitude Test (SKAT). SKAT consists of 35 attitude statements. The complete instrument was sent to 200 occupational therapists registered in the physical disability specialist section of the American Occupational Therapy Association: 68 replies were analysed. Based on a statistical comparison of the SASAD and SKAT the authors concluded the SASAD was a reliable measure of therapists' attitudes toward the sexuality of adults with physical disabilities. The authors deduced that there is agreement among occupational therapists to include sexual rehabilitation within practice. However, I contend scales

\(^1\) A paediatric occupational therapist did not consider sexual expression within occupational therapy, although a study limitation noted was not clarifying the altered role when working with children.
like the SASAD allow respondents to sanitise or intellectualise their responses. To explore this point I have listed three sample statements from the SASAD.

1. Sexuality is an important dimension of the health care and rehabilitation process
2. Information on sexuality should be made available to patients
3. Occupational therapy patients have questions related to sexuality and their disability or illness

I contend therapists could agree, or strongly agree, with each of these statements without considering whether they do include sexual issues in practice, or how they feel. A 'strongly agree' response to the third question for example may be given as a 'politically correct' response. It does not explore the therapist's affective domain. It gives no indication whether the occupational therapist enables all, some or no patients to voice their questions. It assumes a relationship between positive attitudes and actual practice. This is hypothetical and unproven.

Yallop and Fitzgerald (1997) sought to explore some of the factors that may contribute to an occupational therapist being comfortable dealing with clients' issues of sexuality. They used a multi-method qualitative design that included: a focus group; three informal interviews, and a scenario instrument. The scenario instrument was a particularly interesting aspect of the study and provided the richest information. Six scenarios were developed from the literature and clinical experience. This was given out to 20 willing participants to be completed in their own time and returned by post. Ten students and ten practitioners responded. All were women in the age range 20 - 28. The respondents were asked to rate their degree of comfort with each scenario on a five point Likert-type scale. This was followed by open-ended questions to help explore the reasons for their perceived level of comfort.

The study confirmed knowledge, experience and attitude are important to therapists' comfort, they also introduced two new concepts: issues of power & control, and role perception (Yallop and Fitzgerald 1997). If respondents had a sense of power and control over a situation, they felt more comfortable. In some scenarios, control could be gained through knowing how to access necessary knowledge and plan appropriate action. Professionalism also gave a sense of control over both self and situation thereby
helping to maintain an acceptable and comfortable power relationship between therapist and client. The authors' conjectured that some scenarios challenged personally held values, beliefs and feelings and connected some respondents to a decreased sense of control due to the historical power relationship between men and women.

Role perception was also an important finding (Yallop and Fitzgerald 1997). All respondents felt occupational therapists should have a role in dealing with sexuality however there was a large difference of opinions about exactly what that role entails. The largest discrepancy in role perception was revealed in scenarios that challenged the values and beliefs of respondents. It also changed according to participant's role within their team and the skills of others in the team. Despite the small sample size and its potential bias (that is only those with already higher levels of comfort are likely to have participated) this study does help explore the field. The complex situations presented, engaged participants' affective and cognitive processes. This study begins to reveal something of what being comfortable with sexuality might mean. Its weakness is that it is hypothetical. It does not ask what practitioners actually do: only what they might do. It does not ascertain what they may avoid doing.

Two other articles are worthy of mention: one an opinion piece from the US (Jackson 1994), the other a report on a small-scale study from the UK (Kingsley and Molineux 2000). They are indirectly relevant in that they explore the importance of sexual orientation to the professions' philosophy and values. Both highlight the lack of professional education and literature surrounding sexual orientation. These articles hint at a broader issue for the profession: organisational heterosexism.

**Physiotherapy**

There is little evidence in the literature of a fit between physiotherapy's professional values and skills, in supporting the sexual expression of physically disabled service users. A search conducted by the Chartered Society of Physiotherapy, in 2001, revealed only two articles, both on the 'darker side' of sexual expression. One considered AIDS and sexuality education in the physiotherapy curriculum (Amosun, Shabodien et al. 1997). The other researched the reactions of survivors of childhood sexual abuse, to receiving physiotherapy (Teram, Schachter et al. 1999). A recent research of the Allied & Complementary Medicine Database (AMED); the Cumulative Index to Nursing and
Allied Health (CINAHL), and the British Nursing Index (BNI) did not identify any specific publications on role, attitudes or comfort of physiotherapists in addressing sexual issues when working with physically disabled clients. This may reflect a lack of awareness or it could indicate the rejection of a role for physiotherapists.

Physiotherapy was considered in the 1970's as a profession with the potential to help disabled people in expressing their sexuality (Heslinga, Schellen et al. 1974; Stewart 1979). Physiotherapists could be regarded as ideally placed to address the secondary sexual dysfunctions of disability such as spasticity, fatigue and pain (Nosek, Howland et al. 2001; Stewart 1979). Their role in the rehabilitation process often demands regular client contact, facilitating a close therapeutic relationship, which might assist sexual disclosure (Summerville and Kryss 1998). However, physiotherapists work within their perceived role and this is conveyed to the service user who will tend to seek help within these expectations (Stewart 1979). Involvement of physiotherapists would therefore firstly need them to accept a role in the domain of sexual expression.

The training programme, noted earlier, was specifically developed for physiotherapists (Keall 1982). It followed research that had identified a need for service improvements around sexuality for disabled service users. The result was a curriculum to assist physiotherapists to overcome their feelings of inadequacy and to offer help. Keall (1982) outlined her pre-course assumptions. Firstly, it was felt that physiotherapists could give significant help to disabled people if they felt comfortable listening to clients and responding to their questions. Secondly, they were not trying to turn out sex therapists or marriage counsellors. Thirdly, they assumed that although the physiotherapists were well trained in physiology this would not have included much information on sexual physiology. Finally, there would be a wide range of personal sexual attitudes within the group. The aim of the programme was to enable physiotherapists to ask patients direct questions about sexual function as routinely as they do about urology or muscular function.

Although little was found in the physiotherapy literature on physical disability and sexual expression, there is an emerging role for the profession in male and female sexual dysfunction per se (Dorey 2001a; Dorey 2001b; Dorey 2003; Van Kampen, De Weerdt et al. 2003). Grace Dorey sees herself as a pioneer in the profession (2003
personal communication). This could place physiotherapy in a commanding position to address both primary and secondary sexual dysfunction in physical disability.

**Nursing**

The Royal College of Nursing published a discussion and guidance document Sexuality and Sexual Health in Nursing Practice (Royal College of Nursing 2000) stating -

>'Nurses need to recognise that sexuality and sexual health is an appropriate and legitimate area of nursing activity, and that they have a professional and clinical responsibility to address it' (Royal College of Nursing 2000 p2).

This gives a clear mandate for nursing involvement and is aimed at nurses in all settings, from hospital to home and across generic practice. It recognises that many people do not come into a health care setting because of sexual ill health but their care, illness or disability may impact upon their sexuality. It acknowledges this is a relatively new area of work with many nurses considering for the first time 'how a patient's sexuality and sexual health needs relate to their nursing practice' (Royal College of Nursing 2000 p1).

Several authors have discussed the fit with the profession's values, roles and models of practice. By the late 1960s, sexuality came to be regarded by some, as one of the basic tenets of nursing care (Clark and Hirst 1996). It was incorporated into models of practice including the Roper model (Logan, Tierney et al. 2001) which was largely accepted as the framework for the provision of all nursing care in the UK (Clark and Hirst 1996; Howlett, Swain et al. 1997). The model has 12 activities of daily living, one of which is sexuality. Nursing also has core texts outlining the professional role in promoting sexual health (Heath and White 2002; Webb 1994; Woods 1984). They included generic nursing practice in physical disability settings. Some authors suggest that, in reality, nurses are the professionals most likely to pick up on sexual concerns (Ekland 1997; Finger, Stack Hall et al. 1992). In part, this is due to the nature of the patient nurse relationship.

>'Unlike most health professionals, nurses form relationships with their patients that are both professional and intimate. As health providers, they view patients' bodies and are given the privilege of touch while carrying out nursing care. In addition, nurses tend to be the health professionals with the most frequent patient contact, and, therefore, most likely to present in the patient's moment of extreme emotion. Consequently, patients are more inclined to discuss their sexual concerns with the most familiar and accessible health provider, the nurse' (Finger, Stack Hall et al. 1992 p85).
Others assert that sexual counselling is already an established part of the role for the rehabilitation nurse and those working with the elderly (Drench and Losee 1996; Williams 1992).

Against this positive stance is ambiguity. *Sexuality* may be a heading in the nursing care plan, but how it is addressed in practice is another issue. Opinion pieces provide anecdotal evidence that nurses have largely ignored the sexuality and sexual expression of patients for example in: generic practice (Weston 1993); district nursing (Spurgeon 1994); elderly care (Brogan 1996; Clark and Hirst 1996; Drench and Losee 1996; Pangman and Seguire 2000; Smedley 1991; Spurgeon 1994); head injury (Medlar and Medlar 1990); palliative care (Clark and Hirst 1996; Howlett, Swain et al. 1997) and physical disability (Earle 2001; Ekland 1997; Finger, Stack Hall et al. 1992; Gender 1992). Various reasons are given for this neglect in nursing practice. In their review of literature Webb and Askham (1987 p79) described the nursing profession as 'ill-equipped' to initiate discussion on sexual expression with patients. Ekland (1997) described lack of organisational support, demanding workloads, personal discomfort, poorly defined roles and nurses' inability to identify the sexual health concerns of patients. Earle (2001) concluded from her review of the literature, that denial of sexual expression might be a significant feature of power relations between nurse and patient.

One early US study, using the SKAT, compared the sexual attitudes and knowledge of nursing students to those of non-health care students. The latter had more liberal attitudes (Kuczynski 1980). Kuczynski reflected that patients' psychosocial needs had been delegated to other professions and nurses therefore received a narrower educational background. Another, more fundamental interpretation, may be the nature of nursing and thus the person attracted to it. Others have noted the historical religious roots of the profession where nurses were viewed as pure and asexual (Brogan 1996; Gender 1992). 'Nursing became synonymous with the virtues of purity, modesty, self-sacrifice and humility' (Gender 1992 p73).

The SKAT was used again in a larger scale study conducted with 357 registered general ward based nurses in the UK (Lewis and Bor 1994). There was a 50% response rate and 161 data sets were analysed. The authors began on the premise that nurses should be comfortable in providing an opening to discuss sexual health issues with all patients.
The vast majority (78.5%) felt adequately educated in sexual matters and 86.9% considered sexual counselling to be within the nurses' role. Yet, 64.8% rarely or never included questions about sexuality when admitting patients to the ward. The authors noted the presence of other complex influences especially strongly held attitudes resulting from affective rather than cognitive elements. The authors suggested that even if knowledge were increased, attitudes to emotive issues would still be resistant to cognitive change. Thus, they proposed education should teach nurses how and why it is important to partition personal beliefs from professional values.

More recently, there has been an unpublished survey of 32 district nurses in England investigating their knowledge and attitudes towards sexuality of their patients (Hoddy 1999). Although 28 nurses thought sexual counselling was sometimes within the role of the community nurse, 31 said they did not have the necessary education to enable them to do this. Also, 24 nurses believed it was sometimes relevant to take a sexual history but only one person had been taught how to do this. The study lacks depth but interestingly one nurse gave negative answers to all questions and wrote 'Sexuality is not part of a community nurses role' (Hoddy 1999 p37). The researcher interprets that this is because the respondent may not have experienced a patient with a sexual problem. Yet, without skills, a nurse cannot know a patient has a problem! With a postal questionnaire, the reasons for this response cannot be explored but I suggest this response is more likely to have been motivated by the respondent's negative feelings.

Aside from disability, nurses have specialist roles in family planning, psychosexual and genito-urinary medicine. The Association of Psychosexual Nursing had its inaugural meeting in 1998, its aim was to oversee training to meet the needs of nurses to develop their psychosexual practice skills (Penman 1998). In her action research, Penman (1998) indicated nurses attended from a variety of clinical settings: specialist sexual health services, terminal care, continence and health visiting. Through case presentations, the feelings that the nurses experience in this aspect of care were explored. Penman suggested that in the clinical setting

'the solution to these problems is for nurses to defend their own vulnerability by erecting barriers. …There is less discomfort in diverting patients from the subject by offering reassurance, cracking a joke, by pretending not to have heard' (Penman 1998 p4).
Speech and language therapy

One purpose of speech and language therapy is to overcome communication barriers that impact on peoples' choices and social inclusion, even so the mandate for a role in sexual expression might seem tenuous. A search of AMED, CINAHL and the BNI research databases and the Speech and Language Therapy in Practice web site did not identify any publications on role, attitudes or comfort of speech and language therapists in addressing sexual issues when working with physically disabled clients. This lack of literature was confirmed by direct correspondence with the Royal College of Speech and Language Therapy (2005 personal communication).

The aphasia study, reviewed earlier, prompted the authors to comment on the 'obvious implications for treatment goals' by speech and language therapists (Lemieux, Cohen-Schneider et al. 2001 p261). Also, during the data generation phase of my study I was directed to a handbook used as a tool by some speech and language therapists, to assist communicating with people who are aphasic. It introduced the subject of sex after a stroke. It described how a stroke could effect sexual expression and stated that a speech and language therapist 'may be able to help you discuss the problems' (Pound, Parr et al. n.d. p33). At present these are the only references found indicating any fit with professional values or role.

Psychology and counselling

I need to clarify the profession under scrutiny. In the context of my research, it is a generalist offering psychological interventions to the service users of a physical disability team, as a member of that team. The practitioner might be chartered with the British Psychological Society as a clinical, counselling or health psychologist or they could be a counsellor or psychotherapist. This presents difficulties, with no single professional body and unprotected titles. The British Psychological Society and the British Association of Counselling and Psychotherapy are both presently negotiating statutory regulation and competence to practice with the Health Professions Council (British Psychological Society 2005; Clarke 2005).

My search included electronic databases: AMED, CINAHL, PsycheINFO, PubMed, Scopus and the Social Sciences Citation Index. I also corresponded with the Faculty of Clinical Health Psychology, the Division of Clinical Psychology and a psychologist on
the British Psychological Society's clinical research database. My inquiries did not reveal any position statement or articles specifically on the role, skills or attitudes of psychologists, psychotherapists or counsellors in addressing sexual issues when working as a generalist within a physical disability setting. There are articles on research and practice in the field, written by clinical (Glass 1995; Glass 1999; Glass and Soni 1999; Wiederman and Sansone 1999) and counselling psychologists (Linton 1990; Supple 2005) but these are not about the generalist professional role in sexual issues.

According to Wiederman and Sansone (1999 p312), 'addressing sexuality issues is an inherent part of being a professional psychologist', but is it a core skill for all? Inconsistency in professional education has already been noted (Wiederman and Sansone 1999). Research findings from a study in Israel suggested some psychologists working in traumatic brain injury did not address sexual expression (Katz and Aloni 1999). The study investigated the perceptions of team members concerning sexual dysfunction of their patients after traumatic brain injury. Thirty people participated, 19 of them were psychologists. They were asked to complete a questionnaire, to identify problems and needs related to sexual functioning and personal relationships. The study was not focused on attitudes, comfort or knowledge of staff but these became apparent when the researchers investigated the impact participation in the study had on staff. During interviews, participants identified their own uncomfortable feelings and explored how these prevented discussion with clients on sexual issues. Respondents were both dissatisfied and disappointed that they had neglected such an important issue.

One thing that did emerge from the literature which I was not aware of for other professions reviewed, is a dichotomy between psychological services and disability. Close to the context of my research was a practice report on the development of a counselling service for a multidisciplinary community physical disability team in the south east of England (Atkins, Leitner et al. 2004). The service provided general emotional support (rather than being focused on sexual expression). The report identified the reticence of counsellors who feel unskilled in working with disabled people. It highlighted the necessary changes to ensure their practice was informed by inclusive, equality principles. Feeling de-skilled was raised in a research study into the attitudes of sexual and marital therapists to disability (Parritt and O'Callaghan 2000). Depth interviews were undertaken with six female therapists who were not working in a
disability setting. They reported disabled clients evoking stronger emotional responses in them, including embarrassment and anxiety, particularly around the perception of disabled clients' sexuality as different. The authors' interpretation was that the perceived 'otherness' of the disabled client, was managed in the therapeutic encounter by splitting and distancing of the therapist (Parritt and O'Callaghan 2000 p163).

The final article to be reviewed was an opinion piece written by a sex therapist (Hall 2004). She considered whether generic counsellors should deal with clients' sexual issues or whether they should be referred on to sexual therapists. She outlined the differences between the two roles. She supported early referral on for some clients because of the expertise required by sexual therapists in biological, psychogenic, psychological and social causes of sexual difficulties.

Comparison between professions
Two postal surveys compared different professions. A US study, in spinal cord injury, noted rehabilitation nurses were significantly more involved in sexuality counselling compared to occupational therapists (Novak and Mitchell 1988). One reason cited was that occupational therapists perceived it as someone else's responsibility. In a UK study, 593 nurses, 110 doctors, 73 physiotherapists and 37 occupational therapists, all working in a general hospital, participated (Haboubi and Lincoln 2003). Therapists had less training, lower comfort levels and less willingness to discuss sexual issues compared with doctors and nurses. Participants were consistent in their low nomination of therapists to take an active role in addressing sexual issues. These studies indicate the importance of role perception not only within but also across professions. Additionally Haboubi and Lincoln (2003) demonstrated that respondents from rehabilitation wards were less likely to discuss sexuality issues compared to those in medical wards.

4.6 Physical disability teams
Some authors have stressed that all members of a multidisciplinary disability team should have awareness, knowledge and skills to ensure a positive team approach to sexual health (Glass 1995; Mona, Krause et al. 2000; Tepper 1997b). Mona et al (2000)
saw knowledge about sexuality in spinal cord injury as imperative for all rehabilitation personnel, even those not working directly with patients on sexuality issues, to ensure a positive approach to sexual health. Tepper (1997a) developed his multidisciplinary educational programme because he believed every member of the rehabilitation team should be educated 'to recognise critical points or teachable moments in the rehabilitation process' (Tepper 1997a p130). Education and counselling could be offered by nurses, physicians and psychologists but he suggested occupational therapists and physiotherapists had other valuable skills: for example in addressing tasks like positioning, managing a condom or broader issues of body image and attractiveness (Tepper 1997a). Glass (1995) a psychologist undertaking specialist psychosexual counselling in a UK regional spinal injury centre, stressed the importance of an adequately trained team. He noted that even in regional centres, where a sexual therapist is available, identification of issues is normally via other team members.

I only found one study that intentionally investigated the practice of a physical disability team (Rubin 2005). It was undertaken with a community physical disability team akin to those participating in my research. The focus was the team's communication with men with multiple sclerosis (Rubin 2005). It explored the difficulties in discussing sexual problems, from the point of view of both the team and their service users. The strategies included a one-hour focus group with the team (comprising nurses, speech and language therapists, occupational therapists and a physiotherapist) plus an interview (of no more than forty minutes) with eleven male service users diagnosed with multiple sclerosis. The analysis used the three themes of: permission giving; limited information, and specific suggestions from the PLISSIT model (Annon 1974).

The service user perspective was unanimous: they perceived a need to talk about their sexual problems and would prefer to be asked direct questions, preferably when being visited at home. They were unlikely to raise the subject. Therapists however were worried that clients would not like to be asked about their sexual problems, and may see it as intrusive. Thus patients wanted permission but the team did not provide it. The professionals described being embarrassed by their lack of information, and they spent time in the focus group discussing who would be the best person to discuss these issues. Some patients wanted immediate information whereas others would prefer to be
referred on to an expert. Team members and patients cited nursing as possibly the profession most suited to the task. From these limited findings Rubin recommends -

'The best possible solution for health professional teams and patients would seem to be a home visit from a female nurse, who is trained to give limited information to clients with a sexual dysfunction and who knows who to refer patients to for more guidance' (Rubin 2005 p37).

This study has the advantage of working with both the service users and staff of one disability team but it has limitations. It explores a narrow aspect of professional practice: communication. Difficulties are identified but are accepted at face value rather than explored in depth. Her analysis, predetermined as it was by the PLISSIT framework, cast statements into categories without a deeper look at what people were saying. This can be seen in the first extract: a therapist's comment -

'Unless a client alludes to it it's one of the first questions you shy away from because they'll see it as being intrusive and if a client doesn't identify it as a problem, why should we go exploring it?' (Rubin 2005 p35).

This statement is seen as the therapist not giving permission to the client to talk about sexual issues. This is true, but from the theoretical framework of the defended subject (Hollway and Jefferson 2000), it says much more. The reason to 'shy away' is projected to the client who will find it intrusive yet, 'Why should we go exploring it' suggest other motives. A truly qualitative approach to data analysis has not been taken. Also, the research is framed within the medical model of disability with the solution targeted to alleviate the disabled person's 'problem'. I contend this is because the study was limited to men with multiple sclerosis. Rubin cites the increased prevalence of erectile dysfunction in this group. Starting as she does from this premiss, her approach is one of managing the sexual dysfunction rather than looking at the consequences of the health professionals' attitudes. The solution disregards the practicalities of team working. Everyone in the team needs to be comfortable to raise the subject sensitively, otherwise how can referral be made for a domiciliary nursing visit?

4.7 Conclusion

Any one can experience problems in sexual expression but the empirical evidence reviewed here indicates that some disabled people may experience higher levels of
sexual dissatisfaction: from the difficulty of obtaining disability specific sexual information to the negative social environment. Quality of life, self esteem and intimate relationships can all be adversely affected. In considering professional support to redress the situation, I have presented information and research studies into the education of health and social care professionals. I have also considered roles, skills and attitudes of the five professions represented within this study.

In reviewing the literature, I have concluded that quantitative approaches are insufficient. Standardised questionnaires (or ‘home grown’ ones) like the SASAD and SKAT, do not deepen understanding. Sexual expression and professional practice is a complex topic, which demands exploration of subjective experience. The studies presented from the last three decades do indicate that sexual expression is an uneasy area of practice. To understand this, research methodology needs to allow respondents to say what it is that they find difficult and why this is so. Ultimately however it is not about individual practitioners or even individual professions but how teams provide services to disabled people. The creation of new knowledge and understanding demands in-depth and rigorous investigation of the professional practice of disability teams toward the sexual health of their service users. Disability can impact on intimate relationships and sexual expression: how do teams manage this? Do they contribute to this? Only when the field of inquiry is better understood, can realistic recommendations be made.
CHAPTER 5: METHODOLOGY

5.1 Introduction

Described here are the methodological considerations for the main study. I specified a phenomenological, qualitative approach in the protocol but this succinct statement truncates the complex process of establishing the optimal method. This chapter outlines my rationale for taking a qualitative approach, and then conveys something of the decision-making process in choosing a frame of inquiry. The main study had resonance with phenomenology, holistic ethnography and grounded theory. Eventually however, I worked within interpretative and contemporary critical theory paradigms but chose to maintain freedom within design. That is I took a pluralist rather than purist stance as this provided a better affinity with the research aims. Factors influencing the design included the sensitive topic area; studying a team; disability discourse; and the institutional power within academic and health services.

Focus groups, and depth interviews, the strategies I chose for data generation, are appraised. This research needed to explore not only the taken-for-granted world of professional practice but also the potentially defended beliefs and values of the individual team members underpinning practice (Lee 1993). The free association narrative interview was used to frame all dialogue with participants (Hollway and Jefferson 2000). Scientific rigour plus the ethical concerns inherent in this research, and how they were managed, are considered. The practical details of the study design are specified including the context of the study; the sample used; the procedure; data management and analysis. A pilot study was conducted to test procedures. This is critiqued and its contribution to the research design noted.

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1 There is disparity between authors on the terminology used to subdivide aspects of research methodology (Denzin and Lincoln 2000; Finlay 2000; Morse and Field 1996). Here approaches is given to the dualism between quantitative and qualitative research; paradigms to world views or core beliefs; frames of inquiry to the broad traditions within qualitative research that provide a guiding framework to all aspects of the study, and strategies of investigation to discrete units of activity, or techniques undertaken as steps within the research.
5.2 Approach and paradigm

In the biomedical world of health, quantitative research is the dominant orthodoxy (Dixon-Woods and Fitzpatrick 2001; French 1993; Miller and Crabtree 2000), with its logical positivism and consistent, systematic methods designed to test and verify hypotheses. The randomised controlled study is held up as the gold standard (Hyde 2004; Medical Research Council 2000; Miller and Crabtree 2000; Rolfe 2001a).

Although randomised controlled trials are indispensable to health research, this quantitative approach does tend to focus on the body as a machine, reducing the patient to an object (Miller and Crabtree 2000). It also leaves parts of the research story untold, particularly the quality of the lived experience for the recipient of health care. Unlike the patriarchal positivism dominant in the biomedical world of health research (Hyde 2004; Miller and Crabtree 2000), a qualitative approach does not depend on a universal truth to be discovered or a single reality to be apprehended. Instead, interpretive (Lowenberg 1993), post-modernist (Rolfe 2001a) constructivist (Charmaz 2000; Hyde 2004) and critical theory (Gephart 1999; Kincheloe and McLaren 2000) paradigms underpin qualitative approaches. Reality and truth are no longer considered constant and verifiable but are shaped, located, constructed and mediated. Because of these different world views 'qualitative clinical researchers can bring other powerful perspectives to the clinical encounter that can help surface the unseen and unheard and add depth to what is already present' (Miller and Crabtree 2000 p613).

Some argue that taking a qualitative rather than quantitative approach is simply a pragmatic choice with the method evolving out of the research question (French 1993; Robson 1993; Rudestam and Newton 1992). Viewing the differences between the two traditions as technical, rather than epistemological, allows a 'mix and match' approach (Robson 1993). However, that ignores the genuine paradigmatic differences that separate quantitative from qualitative methods.

'Research does not take place in a neutral environment. It is guided by assumptions about the nature of knowledge, and it has political antecedents and consequences' (Tesch 1990 p2).

Thus, some proponents argue it is not a pragmatic choice but an ethical obligation at stake (Denzin and Lincoln 2000; Tesch 1990).
This is emphasised particularly in disability studies where it has been argued research can result in the oppression of disabled people (Barnes 1997; Moore, Beazley et al. 1998; Oliver 1996; Oliver 1999b). This is because disability research has been 'located within the medical model with its built in positivistic assumptions which see disability as an individual pathology, rather than (within) the social model of disability… Consequently most of the research is considered at best irrelevant, and at worst, oppressive' (Oliver 1996 p139 italics added).

Involving disabled people and giving them more control over disability research can address oppression. A continuum of involvement has been described from consultation, through collaboration, to emancipatory or consumer controlled research (Consumers in NHS Research Support Unit 2000; Couldrick 2000; Zarb 1992). This increasing awareness was locating me in both critical and interpretivist paradigms (Denzin and Lincoln 1998; Gephart 1999; Kincheloe and McLaren 2000; Lincoln and Denzin 2000a).

Contemporary critical theory is concerned with social justice, power and oppression (Crotty 2003; Kincheloe and McLaren 2000). I cannot say I chose to work within this paradigm. Rather I recognise the ontological fit with me, finding myself engaged in the sexual politics of disability and seeking practical action (Neuman 2003). Critical theory has its critics (Hammersley 1995): the concern being that political goals can override the commitment to knowledge production. However, this research is about interrogating the values and assumption of individuals and considering how these contribute to team practice (Crotty 2003). It is also about challenging the wider organisational systems that are guided by implicit and explicit protocols, norms and expectations (Crotty 2003; Laszlo 1995; Waring 1996).

Thus, a qualitative approach that recognises the world consists of socially and culturally constructed, multiple realities, was appropriate to this study. It is consistent with discovery and exploration of professional practice. From the critical post-modernist perspective, I hoped to make visible the beliefs, values and social structures of professional practice (Gephart 1999). From the interpretivist perspective, I sought participants' meaning thereby understanding their experience of the situation (Gephart 1999). I was also profoundly convinced that in taking a qualitative approach 'what it is important to look for will emerge' (Holliday 2002 p6).
5.3 Frames of inquiry

My next step was to move from this generalist position to establishing a frame of inquiry that would nurture emergence. Writing the research protocol presented a dilemma: the need to be explicit about procedures, before the study began. Qualitative research evolves, suggesting a dynamic approach but this does not sit easily with the positivist backdrop framing, for example, NHS local research ethics committees. At an early stage, a phenomenological frame of inquiry appeared to provide the 'best fit' to this study, however, I re-evaluated this as the research developed. Denzin (2000 pxv) suggests the open-ended nature of the qualitative research project leads to a 'perpetual resistance' to impose a single frame of inquiry. I shared this resistance. Partly I had wanted to pursue the collaboration begun in the preliminary inquiry. Also, my research resonated with holistic ethnography, phenomenology and grounded theory. These are briefly outlined here, leading the way to explore freedom within the design of this research. Others have criticised what they pejoratively describe as a slurring of methods (Baker, Wuest et al. 1992; Maggs-Rapport 2001) but there is increasing support for taking this pluralist view (Johnson, Long et al. 2001; Lowenberg 1993).

Collaborative research

My original intention, following the preliminary inquiry, was to continue to collaborate with disabled people. With my dual roles of both primary researcher and university student, I was aware this could not be done in a fully emancipatory manner (Turner and Beresford 2005; Zarb 1992) as total control (and thereby power) could not be handed to disabled people. But, within that caveat, I believed collaboration could occur. However, with much discussion and personal angst it was clear there were problems in pursuing an academic award within a collaborative frame of inquiry. Firstly, there were objections on the grounds of ownership of the study and how my contribution could be evaluated. Additionally ethical concerns were raised suggesting the study would not safely navigate its way through the NHS research ethics committees. For example, would sharing data outside a physical disability team with a panel of disabled people be construed as breaching guidance on confidentiality?
Thus, here, I take ownership of another aim in the research, that of gaining an academic award (see section 1.6 - Reflective awareness: Motivation). This reveals that ultimately I am the main beneficiary of the study rather than, as I would wish to believe disabled people. In abandoning a collaborative study, critical post-modernists will say I have entered a discourse, which prioritises research as investigation over research as emancipation (Moore, Beazley et al. 1998; Oliver 1999b; Zarb 1992), and that I have joined the parasite people.

'To put it objectively (or at least non-pejoratively), disability researchers are parasitic upon disabled people, for without the host body (disabled people) there would be no disability researchers' (Oliver 1999b p184).

I discussed in supervision my sense of mourning at the loss of the involvement of disabled people in the design of the main study. In my reflexive journal I wrote

'In the interest of academic expediency, I feel the drive especially for a consumer involved study, has been bullied out of me. The richness of my plans has drifted to a half-nourished idea. We now have no consumer involvement for this stage. We also have no checking (of) practice against consumer perceptions' (Research Journal 21.10.01).

Now though I am clear that the first priority in choosing a frame of inquiry is that it must be achievable. I could not, have undertaken this research without the support of the academic institution. As a novice researcher, advice, boundaries and guidance were essential elements in moving my grand design to a tangible, doable reality. There is power, in the form of academic authority, inherent in the biomedical and academic worlds (Rolfe 2001a) and conducting this research within the NHS, and as part of a PhD, has affected the design. Others have experienced this dilemma and are challenging 'the structural, ideological and institutional barriers' (Moore, Beazley et al. 1998 p14) to critical and emancipatory approaches to disability research. In reality however this research was made possible, through the help received from my supervisory team. Their considerable support ensured the research was managed within the finite resources of time and money, and met academic and ethical procedures.

**Holistic ethnography**

This aims to analyse all or part of a culture or community. It provides rich, detailed description of the beliefs and practices of the group under scrutiny and shows how these contribute to the culture as a unified, consistent whole (Tesch 1990). I considered if disability teams could be construed as a cultural group, with a collective identity and
practices. However, the phenomenon was not culture alone. It was also about the attitudes, beliefs and feelings of the individuals. Their lived experience as practitioners. Additionally ethnography depends on a 'process of enculturation'. That is -

'the requirement for direct, prolonged, on-the-spot observation cannot be avoided or reduced. It is the guts of the ethnographic approach' (Massey 1998 p2).

Testimonies of researchers undertaking ethnography stress the importance of this observation of everyday life rather than relying on personal accounts of behaviour (Baillie 1995; Richardson 1996; Toren 1996). Ethically it was inappropriate to observe the actual work of practitioners with their clients. Also, the preliminary inquiry had indicated that the research might need to investigate an aspect of professional practice not being done. Observing a practice not being done would not necessarily provide data to enrich understanding about its omission. Pragmatically there seemed only two ways to generate data, speaking with the group or speaking with individuals within the group.

**Phenomenology**

Phenomenology as research, aims to discover the meaning of lived experience. It draws on the ontological beliefs of what it means to be a person. To understand the experience the person must be studied in context. It is not a direct description of an experience but is the search for the meaning-structure of this experience. It differs from holistic ethnography, with its emphasis on the life world and how the individual subjectively experiences this (Karlsson 1995; Schutz 1967). Different techniques of analysis have been devised (Beck 1994; Karlsson 1995; Maggs-Rapport 2001). Broadly, the data are submitted to a questioning process, in which the meaning units are identified, refined and abstracted. My need though, was to stay responsive both to the group as well as to the individual. Sometimes data suggested there were critical cultural or organisational issues. This was the dilemma of studying the practice of a disability team. Is the individual, with their personal and professional life world, to be scrutinised or is it the team, with its life world? Also, understanding meaning did not necessarily illuminate why. Phenomenology is descriptive rather than explanatory, answering what and how a phenomenon is experienced rather than explain why (Borell 1999).
Grounded theory
This 'advocates the development of theories to explain social phenomena grounded in
data, following a process of induction, deduction and verification' (Polgar and Thomas
2000 p295). Thus, it takes a more positivistic position compared with phenomenology
and holistic ethnography. It draws on the principles of theoretical sampling and
constant comparison. In theoretical sampling new cases are selected for their potential
to extend or modify emerging theory (Pidgeon 1996). Constant comparison refers to the
continual sifting and comparing of elements throughout the lifetime of the research
project (Pidgeon 1996). Grounded theory therefore provides a systematic method to
analyse unstructured data. Pidgeon (1996 p75) describes it as 'particularly suited to the
study of local interactions and meanings as related to the social context in which they
actually occur'. As such, I had considered grounded theory for this study but felt the
emphasis on theory development was not applicable. Accounts of grounded theory
appeared to build a taxonomy and thereby helped to describe, but from the outset I
wished to explain, to understand why (Bloomer 1994; Pidgeon 1996; Richardson 1996;
Strauss and Corbin 1990). Another disadvantage of grounded theory in health research
is the positivistic procedures surrounding NHS research governance (Dept. of Health
2001b). These make the flexibility of theoretical sampling highly problematic.

Freedom within design
I have not followed a single frame of inquiry nor used a 'step-by-step blueprint or
mechanical formula' (Kincheloe and McLaren 2000 p286). Instead I have experimented
and struggled to find methods of data generation and analysis that revealed practice and
communicated understanding. Kincheloe (2000) has noted the eclectic and hybrid
nature of contemporary critical theory. My research design is not a blurring of
distinctions between methods (Baker, Wuest et al. 1992). Nor is it misuse borne of
confusion (Maggs-Rapport 2001). It is both a philosophical and pragmatic decision
based on the belief that rigid adherence to a purist approach risks doing it right at the
expense of getting it right. I am with Janesick (1998) who cautioned against
methodolatry, a neologism she made from method and idolatry which she used to
indicate an over preoccupation with selecting and defending methods 'to the exclusion
of the actual substance of the story being told' (Janesick 1998 p48).
Purists argue against an eclectic approach on the grounds that rigour cannot be assessed (Baker, Wuest et al. 1992; Maggs-Rapport 2001). Yet diversity and flexibility within frames of inquiry, have been demonstrated (Johnson, Long et al. 2001; Whitemore, Chase et al. 2001). Phenomenology has evolved as new protagonists accept, and build on, or reject, and discard, key concepts in its ontology and method (Beck 1994; Holloway and Wheeler 1996). Similarly, Strauss and Glaser, the originators of grounded theory, diverged in its development, each moving towards different methodologies (Charmaz 2000; Kendell 1999; Strauss and Corbin 1994). Peoples' underpinning world-view, or paradigm, is reflected in how theory and method are used.

To assist the assessment of rigour in this study, firstly I have been transparent about my position within it. My presence constrains (or enriches) the research and I am the major tool of the study. I have endeavoured to increase my self-awareness through introspection and reflexivity. Secondly, the strategies of investigation that I used will be clearly described and critically appraised.

5.4 Strategies of investigation

The strategies chosen for generating and analysing data had to be consistent with the approach and paradigm. The first principle was to ensure the field of study occurred as close as possible to the activity under investigation. This was the practice of a team of professionals. Data generation was through focus groups constructed from practising teams. Occasionally depth interviews were conducted. These had been included in the design as a potential strategy if it was felt some experience was excluded from the focus group discussion (Michell 1999). The free-association narrative interview method (Hollway and Jefferson 2000) was used in the focus groups and interviews to elicit the respondents' own narratives, based on their own experiences. Additionally my research journal and other records added to these more formal texts. Finally, in the somewhat opportunistic nature of ethnography, some data became serendipitously available in the form of letters from electronic discussion groups.
Focus groups
The focus group has its root in market research and was developed to gauge opinions on products (Kitzinger and Barbour 1999; Madriz 2000; Morse and Field 1996). It is increasingly used in health research as it can provide a rich source of insights from participants (Polgar and Thomas 2000). Focus groups have been considered an effective technique for exploring the attitudes of health care staff and how knowledge and ideas develop and operate within a given cultural context (Kitzinger 1995). They are distinguishable from a broader category of group interviews, by the explicit use of group interaction to generate data (Kitzinger and Barbour 1999). The researcher's role is to facilitate the contributions of the group participants and to 'encourage participants to talk to one another: asking questions, exchanging anecdotes, and commenting on each others' experiences and points of view' (Kitzinger and Barbour 1999 p5).

Focus groups are fundamentally different from individual depth interviews in that the researcher is outnumbered and the participants may interact with each other (Polgar and Thomas 2000). An advantage was that this moved me away from the centre of the process, giving greater opportunity for the participants' ideas to develop and find voice. Some argue this reduces the power and influence of the researcher over data generation (Madriz 2000; Wilson 1997). Wilson (1997) advocates democratising the process further by re-conceptualising the focus group as a discussion amongst participants, suggesting this results in more naturally occurring language despite the socially contrived situation. Although I had devised a schedule for use in the focus group, I took this advice and tended not to use it, following instead the participants' discussion. The schedule helped me prepare for the group and provided a prompt if needed.

Another advantage of using focus groups in this study was the access it gave to the taken-for-granted world of individual participants. Attitudes and perceptions are not generally developed in isolation but through interaction with other people (Morse and Field 1996). Group discussion did bring tacit, even unconscious thoughts into the open initiating 'changes in participants' thinking or understanding, merely through exposure to the interactive process' (Barbour 1999 p118). The very nature of introducing sexual expression triggered, for some participants, thoughts never considered before. With sensitive topics, focus groups have also been shown to facilitate rather than inhibit discussion (Barbour 1995; Farquhar 1999). They can be emotionally more provocative.
than interviews and generate greater spontaneity and candour from participants (Barbour 1995). Group processes may assist the discussion of taboo subjects with the more confident members of the group providing a model for more inhibited members. The development of topics by one person may support others to share their views.

Disadvantages include the possibility of self-censoring and conforming influences that can lead to 'group-think' (Barbour 1995; Hollis, Openshaw et al. 2002; Powell and Single 1996). One strategy I used to discourage this was to outline at the start of every focus group that there was no need for agreement and that the study was particularly open to differing and dissenting views. Another was for me to validate different opinions during the process of the group. The facilitator also manages the group processes. Examples from this research included managing the dominant member and the not-engaged or quiet individual. Another problem identified was how to capture the richness of focus groups. Not only do focus groups allow access through discourse to the attitudes and values of the participants; simultaneously they also provide the opportunity to observe the members' interactions (Morse and Field 1996). Having a moderator present, to work alongside me as facilitator was considered, however limited funding for the project and pressures of time did not permit this.

The practicalities of convening a focus group include its size, composition, duration and frequency. Morse (1996) suggests the group size is typically 7-10 people. In one study, less useful data emerged from groups of 12 or more and the ideal size considered was 6-8 people (Wilson 1997). The compositions of the focus groups, in this study, were members of a single disability team. This was advantageous in that members already knew each other. It was not necessary to consider homogeneity or heterogeneity. There are benefits in working with pre-existing groups because the members are in the very -

'networks in which people might normally discuss (or evade) the sorts of issues under consideration. Also the "naturally-occurring group" is one of the most important contexts in which ideas are formed and decisions made' (Kitzinger and Barbour 1999 p9).

In terms of duration, 90-minute focus groups were planned. There is little direction in the literature on the optimum duration of a focus group but one author's thoughts on the duration of interviews felt applicable to focus groups. Seidman (1998 p13) suggested an interview one hour in length, carries with it 'a consciousness of a standard unit of
time' that can lead to watching the clock, whereas two hours was too long. He stressed though that the important thing was to be clear about the duration at the outset. Here, respect for practitioners included appreciating the place this research had within their busy work commitments. Clear guidance on duration, was provided at first point of contact and the time boundary was strictly adhered to.

**Depth interviews**

Individual, unstructured interviews were included in the research protocol as a potential strategy to capture data that might be missed by using focus groups alone. I saw this as important because of the taboo nature of the topic. Some people could have been reluctant to talk in a group, particularly those who felt theirs was a minority voice in the team. Michell (1999 p36) stressed the importance of combining interviews with focus groups especially when using participants who have on-going social relations outside the focus group 'which may be compromised by public disclosure'. Where requested, individual interviews were less susceptible to power relationships in the team.

Individual depth interviews, like focus groups, are not merely a method for data collection but can be a valuable strategy for the generation of data. This difference is seen in an examination of structured and unstructured approaches to interviewing. In the first, the researcher is urged to remain neutral, ask pre-determined questions consistently of each interviewee and effort is made to minimise the influence the interviewer has on the process. This is data collecting. Increasingly, a post-modernist perspective recognises that researchers 'are not the mythical, neutral tools' previously envisaged (Fontana and Frey 2000 p663). Instead, they are being seen as active agents in the process of data generation where the text is negotiated and shaped by all the players (Fontana and Frey 2000; King 1996; Masserick 1981; Seidman 1998).

Many strategies for interviewing within different frames of inquiry were explored (Fontana and Frey 2000; Hasselkus 1990; Hollway and Jefferson 2000; Kvale 1996; Lee 1993; Marshall and Rossman 1999; Seidman 1998; Wimpenny 2000). In this study, there was no positivistic sense of searching for an objective body of truth but rather recognition of the multiple realities, grounded in the context of the respondents' professional activity and themselves as human beings. Therefore removing structure and letting their voice prevail was important. With this in mind, I gave much thought to
the undertaking. Ultimately three themes influenced the interview process: pragmatic management of practicalities; the authentic use of self (that is recognising the fit with me, the researcher, as the interview tool), and the free association narrative approach.

The pragmatic management of practicalities mainly centred on accessing interviewees. This was to be a self-selected group but their reasons for electing individual interviews were not necessarily explicit. Taking part in a focus group did not preclude taking part in an individual interview. The usual reason given was unavailability for the focus group appointment. Like the focus group, the external boundary of time (up to 1½ hours) and number of interviews to be undertaken (two) were specified in the protocol as part of the application for ethical approval.

In accepting researcher neutrality as a myth, it was important to consider my position as facilitator of interviews and focus groups. In phenomenological interviewing, some authors suggest the use of bracketing (Karlsson 1995; Marshall and Rossman 1999). This describes a process where the interviewer writes a detailed account of his or her own experience thereby gaining clarity about his or her pre-conceptions. Proponents argue these pre-conceptions can then be bracketed, and thus separated, from the interview process reducing contamination and bias. It seems to me this assumes the interviewer can locate all his or her pre-conceptions and feelings. Yet, the best that can be achieved is developing awareness that can never be complete. Secondly, it assumes the interviewer can set his or her experience and pre-conceptions aside so that they do not influence the process. This seems a naïve supposition used to counter positivistic criticism. Thirdly, it is contrary to the notions of authenticity and the development of trust necessary to interview in depth (King 1996; Oakley 1981).

Like other researchers (Taylor 1995) I did not feel able to bracket my presuppositions. So I gave careful thought to how this should be managed. I gave no artificial guise of neutrality but recognised and valued multiple perspectives. Direct questions were answered rather than avoided. The interviewees became the focus, with explicit attention given to what was important or meaningful for them. I drew on my counselling skills. The interviews had no therapeutic intent but still the core conditions of empathy, congruence and non-judgemental positive regard were maintained (Rogers...
Sexual expression, physical disability & professional practice

1967). Also first stage skills of minimal encouragers\(^1\), reflection and paraphrasing were used to develop trust and encourage exploration and disclosure. Some have criticised aspects of these skills in research interviewing. Seidman (1998) for example, cautions against influencing participants' responses by using minimal encouragers. However, I consider they are integral to deepening disclosure. Thus, it seemed the important thing was not to avoid using them but to ensure they are used at all times whatever is being disclosed. The value of counselling training in the development of research interviewing skills has been highlighted (King 1996) especially the ability to attend simultaneously to both the content and the psychodynamic processes of the interview.

**Free association narrative interview**

The free-association narrative interview method (Hollway and Jefferson 2000) was used in this study in recognition that psychodynamic processes may be in action because of the taboo nature of sexual expression and its sensitivity as a topic for research (see section 2.5 - Sex as a taboo topic). This method conceives participants as human beings who not only have the capacity for meaning-making but also an ability to protect themselves against anxieties created from information arising in the research. It is a method grounded in psychodynamic understanding of both conscious and unconscious processes in the research relationship. Hollway and Jefferson (2000) use the term defended subject to describe respondents who:

- may not hear the question through the same meaning-frame of that of the interviewer or other interviewees
- are invested in particular positions in discourses to protect vulnerable aspects of self
- may not know why they experience or feel things in the way that they do
- are motivated, largely unconsciously, to disguise the meaning of at least some of their feelings and actions

(Hollway and Jefferson 2000 p26)

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\(^1\) Minimal encouragers are behaviours in the listener, for example, the nodding head or the oft repeated mm and yes, that encourage the speaker to continue their narrative because they demonstrate that the interviewer is actively listening.
The free-association narrative interview method involves conceptualising the researcher and researched as co-producers of meanings. It is the antithesis of the question and answer method which tends to elicit 'thin, rationally driven accounts which leave out more than they allow' (Hollway and Jefferson 2000 p155). There are four principles that were applied to both the focus groups and individual interviews: -

- the use of open-ended not closed questions
- to elicit stories thereby anchoring peoples' accounts to actual events
- 'why' questions were avoided as they move the account to rationality rather than meaning
- responses were followed up using the respondent's ordering and phrasing. This respects and maintains the interviewees meaning-frame

**Additional data**
Two forms of additional data also became available. Firstly, there was serendipitous data in the form of electronic mail on discussion web sites. Two different, information rich, opportunities arose during 2003. The first was the Model of Human Occupations (MoHO) web site that invited discussion on matters relevant to MoHO a conceptual model of occupational therapy. The second was from the Multiple Sclerosis Trust, when they hosted a one-day electronic 'chat room' on sexual problems in multiple sclerosis. The full proceedings were published on their web site.

Secondly, there are my records. These include my research journal, incidental letters and supervision record. My research journal combines elements of field notes and a reflexive diary. It includes records of phone calls, activity needing action and actions completed. I also used it for thinking aloud (or at least on paper). Writing often helped me to work on ideas or explore difficulties, so I came to think of it as thinking allowed. I also wrote detailed field notes before and after every interview or focus group, trying to capture what would not be on the audiotape. Detailed supervision notes began in November 1999. It was a strategy initially begun to manage the multiple tasks between each supervision session. Later, I began to realise that my journal, correspondence and supervision records provided an independent audit trail through the study.
5.5  Rigour in qualitative research

Qualitative research cannot be assessed by the same criteria of rigour as quantitative research (Marshall and Rossman 1999; Mays and Pope 2000). The positivistic conventions of validity, reliability and objectivity are replaced by measures that accommodate a post-modernist perspective such as credibility, authenticity, dependability and confirmability (Barbour 2001; Holloway and Wheeler 1996; Marshall and Rossman 1999; Mays and Pope 2000). Credibility requires demonstration that the study is properly constructed, and conducted, with a methodological grounding appropriate to the research question. It is closely allied to the concept of authenticity in that the meanings and experience of the participants, as well as the researcher, should be portrayed (Whittemore, Chase et al. 2001). Dependability here means that this research should illuminate professional practice towards the intimacy and sexual expression of service users. This does not equate with reliability or transferability where a positivist view assumes an unchanging world. Findings therefore are only dependable within the context of the study. Confirmability is with the reader: do the findings resonate with or confirm your understanding of the phenomenon? Another measure of quality, within critical theory, is the capacity of the research to enhance social justice. However, this is a longer-term objective not assessable within this dissertation. Strategies to enhance rigour were outlined in the protocol including maintaining a reflexive diary; member validation; independent audit / peer review, and the presentation of evidence.

Maintaining a reflexive diary

A reflexive diary became integrated in my research journal. Operating within an interpretivist paradigm 'requires researchers, to the extent of their ability, to analyse and display publicly their history, values and assumptions, as well as the inter-relationship with their participants' (King 1996 p176). So the purpose of my reflexive diary was to develop awareness of me: my part in creating the context of the study. It was to make conscious, as far as was possible, my influence on the project. Sometimes memories would arise unbidden, triggered by the research, for example, once I wrote

'Another part of my history that I thought of today was Uncle Cedric - Secretary to the Eugenics Society. Is this partly why I am doing this research?' (Research Journal 15.05.03)
This prompted me to draw a conceptual map of the many psychodynamic factors acting as unconscious drivers of the study. Sometimes I was deliberately introspective, using different devices to aid reflection, such as self-questioning and exploration of feelings. These can be seen in the next extract, written after a participant phoned me following the second focus group. It prompted an appointment for an individual interview.

'My anxiety about returning - ? levels of anger. Yes I think she is angry with me for raising it. This was something difficult for her & her husband that she did not want attention drawn to. Also boundaries - where should any interview take place - let her choose? Insist on work setting??' (Research Journal 19.06.03)

The self-questioning allowed me to work through the issues, including the advantages and disadvantages of conducting an interview in her own home. The affective component, my anxiety, and my assumption based on this, that she was angry, allowed me to use this at the next interview. This introspection is important, for in -

'Opening up the structures and operations that underlie our research and examining how we as researchers are an integral part of the data will amplify rather than restrict the voices of the participants, even when this openness is impeded by the researchers unrecognised biases and discriminations' (King 1996 p176).

**Member validation**

Member validation has its roots in phenomenological processes and involves returning to the respondents as the analysis develops. This enables them to check the researcher's interpretation of meanings. The aim is to deepen understanding and clarify meaning. It is also a way of seeking more democratic research practices (Smith 1996) and can contribute to error reduction (Mays and Pope 2000). I returned to the participants as the analysis developed, giving them an opportunity to discuss, dispute or explore further my interpretation of the focus groups and interviews. This does not imply that my interpretation had to concur with theirs. Revealing my perceptions of the data became a stimulus, which often generated more data, which in turn deepened the interpretation.

**Independent audit / peer review**

I specified this in the protocol but abandoned it. It is a process of cross checking the coding strategies and interpretation of data by independent researchers. I had used this strategy in earlier research (Couldrick 1996). Since then my learning and understanding on qualitative approaches, and particularly on underpinning paradigms, has made me aware that I had included these strategies to meet the quantitative orthodoxy of health
research. These methods arise from positivistic notions of objectivity and inter-rater reliability and are therefore not appropriate to an interpretive, qualitative study. Barbour (2001 p1115) warns against the uncritical adoption of what she describes as 'technical fixes' as these in themselves do not confer rigour.

Presentation of evidence
I have provided a detailed account of the research design. My aim is to enable you to assess the rigour of this research by providing an adequate description of how it was conducted and transparency of my place within it. In subsequent chapters, I intend to present sufficient raw data for you to interrogate my interpretations (Smith 1996). An audit trail is also available via my research journal, supervision notes and correspondence. By these means, I trust the internal coherence of the study will be established (Smith 1996). That is, is it credible, authentic, dependable and confirmable?

5.6 Ethical considerations

A primary ethical concern in any research with people must be to 'take extreme care to avoid harm to them' (Fontana and Frey 2000 p662). Ethical principals when using human participants have been outlined (British Psychological Society 2000; British Sociological Association 2002; World Medical Association 2002). These place the onus of responsibility on the researcher to weigh the benefits of the research against any potential physical, psychological or social risk of harm. There are also clear procedures for the proper conduct of research in health and social care (Dept. of Health 2001b).

From the outset, a major concern was the feasibility of obtaining ethical approval to undertake any work with service users. Based on information gained in the preliminary inquiry, it was decided that the research could be focused on the professionals alone. It was thought that sufficient quality information would be available from team members without contact with their service users. Even so, sensitivity was necessary. Questioning and disclosure has the potential to evoke embarrassment or offence. Reflection on practice can cause dissonance in individuals or the team as a whole. The research should not undermine or diminish the team or its members so strategies integrated into the design included gaining ethical approval; voluntary participation and
informed consent; anonymity and confidentiality; attention to the role of the facilitator, and consideration of the potential influence of research funding.

**Ethical approval**

NHS ethical approval was obtained in full from East Sussex Local Research Ethics Committee (appendix B) and locality approval from Worthing Local Research Ethics Committee (as it fell within the same strategic health authority boundaries as East Sussex) (appendix C). Croydon Local Research Ethics Committee also gave full approval (appendix D) although, following a change in NHS procedures, this also required obtaining approval from the Research and Development Committee of Croydon Primary Care Trust (appendix E). Managerial consent was agreed in each site in accordance with the NHS Governance Framework (Dept. of Health 2001b).

**Voluntary participation based on informed consent**

This was established through written documentation. A Project Information Sheet (appendix F) was sent to every team member and his or her signed written consent was obtained before proceeding (appendix G). All were advised that their participation was voluntary and that they could withdraw at any time. A detailed description of what was being asked of them and the possible risks and benefits were outlined. They were also invited to contact me with any concerns, before, during or after their participation.

**Anonymity and confidentiality**

Total assurance of anonymity and confidentiality is unrealistic (British Sociological Association 2002). Instead, care was given to how information from the research could be communicated to preserve, as far as was practical, anonymity and confidentiality. In addition to Data Protection Act compliance, strategies included assurance that all data was to be securely stored. Process notes and transcripts were coded and stored separately from any identifying data. Participants were given alphabetical pseudonyms. Beside myself, only the transcriber and my supervisors had access to audiotapes and these were held separately to other data. Responsibility for information arising within the focus groups remained with the team but they were assured of my confidentiality throughout the study including in written and oral presentations. At the completion of the study, all raw data including audiotapes and transcripts will be destroyed.
Role of the facilitator
I gave considerable thought to my role both within the focus groups and the interviews (see section 5.4 - Strategies of investigation: Depth interviews). A reflective, rather than an interrogative, approach was used. Participants' choice and responsibility for disclosure was highlighted. The free association narrative interview method was chosen as a respectful strategy that might reach beyond a defensive response. There were times when I felt it ethically right to provide some reassurance, when statements of guilt or concern were expressed. The aim was exploration, not accusation.

Research funding
I thought about any potential ethical concerns following successful applications to the Hospital Savings Association Charitable Trust and the Health Foundation (formerly PPP Healthcare Medical Trust). This included help with University fees (£5000 from the Hospital Savings Association Charitable Trust) and direct expenses and replacement salary costs (£52,284 from PPP Healthcare Medical Trust). The latter, a mid-career award, was designed to develop me in my career rather than promote the research per se. Thus, I believe, funding did not compromise the research nor raise ethical concerns.

5.7 The study design specified

Context
Sufficient teams were available for the research to be undertaken within the south east of England. This geographic area is demographically diverse. It includes urban and rural communities with economic and ethnic diversity. Team structures vary. There are many different models for providing multidisciplinary rehabilitation and support in the community (Dept. of Health 2005). An inclusion criterion of receiving referrals for people with multiple sclerosis, aided comparability between teams.

Participants
In this study, purposive sampling was used to recruit three separate physical disability teams plus a team for the pilot study. The teams were chosen by their service remit and thereby their closeness to the phenomena under scrutiny. Each team provided services to adults who have a physical disability and live in the community. The teams selected
for the main study all accepted referrals of people with multiple sclerosis. Multiple sclerosis is a common condition affecting both men and women. The age of onset is normally between 20 - 50, a crucial time for the formation of relationships and family life. It is progressive in nature and known to affect sexual function. The preliminary study had indicated greater complexity around progressive conditions.

Procedure
Once a team had been identified, and ethical approval obtained, the first contact was with the team leader or co-ordinator who was approached by letter (appendix H); sent a project information sheet (appendix F) and a sample participant consent form (appendix G). This was followed two weeks later by a telephone call. Initial discussions were around: team eligibility; clarifying managerial approval; establishing contact details for all team members including people on the periphery of the team; identifying possible venues and provisional dates. Every member of the team was then approached by letter (appendix I) and informed written consent was sought.

Two focus groups, of 1½ hours duration, were conducted in each team. At the first meeting with participants they were asked to complete an attributes form (appendix J). This enabled me to search data by issues such as age and profession of the respondent. The date of the second focus group was made at the conclusion of the first. Where all team members could not attend the second group, a third 'sub' focus group was arranged to ensure all participants had the opportunity to discuss the emerging analysis. The gap between first and second focus group was between five to eight weeks. Some people elected to give individual interviews. Again, these were no more that 1½ hours duration and five to seven weeks apart. When work with the disability team was completed, a letter of thanks was sent to each participant and the team leader (appendices K & L).

Data management
All focus groups and interviews were audiotaped. The recording, or the subsequent transcript, did not represent a definitive statement of the 'truth' of the interview. However, I felt it to be the best method to provide a good data set. In a group conversation of 1½ hours duration, reliance on recollection, through field notes, would have been insufficient and would have increased bias through subjective recall. Video recording was considered but rejected. The extra attention to non-verbal
Methodology

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Communication seemed unnecessary because the text arising was a proxy for the experience being scrutinised rather than using the text as the object of analysis, as in discourse analysis (Ryan and Russell Bernard 2000). Audio taping not only allowed me to attend to the actual conversation; it also provided an aural record for comparison with the developing analysis. Unlike field notes, audio recording also allows detailed inspection of the sequence of language, 'for it is within these sequences, rather than single turns of talk, that we make sense of conversation' (Silverman 2000 p830).

Every audiotape was professionally transcribed in full with the exception of the minimal encouragers, that is the many "mms" and "yes" words. 'Crutch words' (Sandelowski 1994 p312), like "you know" were included. The transcripts identified: speakers, pauses, inaudible sections, group responses such as laughter or where group members all spoke at once. The purpose was to retain the richness and complexity. The following transcription conventions were used:

- **you** stressed syllable
- .... pause
- / onset of overlap
- { } inaudible section
- ( ) comments added to transcript

adapted from Myers and Macnaghten (1999)

Transcription critically alters the text thus 'an essential component of qualitative data preparation, become complex exercises not only in accurately representing what was said but how it was said' (Sandelowski 1994 p312). This necessary attention to detail can be seen in the following sentence where tiny changes completely alter meaning

Incorrect I think there are, you know, probably a few professionals working with the person that would see it as specifically their role.

Correct I think there are, you know, probably **few** professionals working with the person, that would see it as specifically their role.

Strategies devised to address this included thorough proof reading, followed by what I labelled disciplined listening (see below). In addition to the audio recordings and transcripts, data included electronic discussion group letters; field notes; a reflexive journal, and memos, documented in NVivo, as the analysis proceeded.
Data analysis

The first stages of analysis began as data was collected, shaping further collection as thoughts were triggered and questions formed. 'It is impossible not to start thinking about what is being heard and seen' (Pope, Ziebland et al. 2000 p114). There was no attempt to formalise this analysis but rather to monitor it through reflexive inquiry and field notes. The next shift in analysis came with immersion in the data, as a whole, prior to any reduction or coding. Some systematic strategies were developed to ensure consistent attention was given to all data including detailed and painstaking correction of every transcript. In an NVivo memo from Team A I wrote -

'It is important to listen astutely to every word, simple mistakes change the meaning dramatically…e.g. “I suppose the anxiety is that it all {serves?} a sort of sexual purpose” should have read “I suppose the anxiety is that it ought to go to a sexual therapist”

The tapes were then played repeatedly with the aim of gaining familiarity. Finally, each recording was listened to, in its entirety, a minimum of three times before transfer to NVivo for analysis. The aim was to analyse the data systematically not selectively. During this disciplined listening, notes were made in the margins of the transcripts, using different colours for the first, second and third hearing. Attention was given to immediacy and creativity rather than being constrained by plans of coding. My aim was to comprehend the whole before any subdivision and detailed analysis occurred.

To manage the volume of data a Computer Assisted Qualitative Data Analysis Software (CAQDAS) programme was used. Others have discussed the limits and strengths of CAQDAS (Baptiste 2001; Gibbs, Friese et al. 2002; Weitzman 2000; Welsh 2002). In summary, the software provides consistent, efficient and systematic data management. The analytic component however still depends on the 'skill, vision and integrity of the researcher' (Pope, Ziebland et al. 2000 p114) as no package discerns the link between theory or defines appropriate structures for the analysis. NVivo was chosen, based mainly on the personal recommendation of other qualitative researchers. NVivo provides a range of tools for handling complex, rich data and information about the data (Bazeley and Richards 2000; QSR International 2002).

To help explain the benefit of using a CAQDAS a useful analogy is the difference between writing an essay long hand or writing it on a word processor. The creative process remains with the person. As the researcher, I had to analyse the data. The
management of that analysis, that is the ability to modify, change and adjust the coding system was the value of the programme. When an essay, written long hand, is finished there is little encouragement to make changes, reorganise paragraphs, substitute words etc. This is because even quite small changes would require complete re-writing of the essay. This is like the cut and paste traditional analysis that I used in the preliminary inquiry. Once coded and cut, I was not motivated to change the coding procedure. With NVivo, codes can be constantly amended and revised.

The process of analysis developed after a long and difficult period of trial and error. I read extensively (Bloomer 1994; Charmaz 2000; Eaves 2001; Ellis and Flaherty 1992; Kendell 1999; Pidgeon 1996; Strauss and Corbin 1990; Strauss and Corbin 1994). I experimented. I reflected on the analysis in supervision. Two texts proved particularly helpful to me in moving from data generation, through the subtleties of analysing, sorting and organising, to writing about the data (Holliday 2002; Hollway and Jefferson 2000). One led me to make sense of the messy reality of talk through thematic analysis. The other provided a timely reminder of the risks of reductionism and the need to provide a holistic sense of participants and their subjective narrative.

Thematic analysis emerged through in-vivo coding, a process whereby the selected text becomes the title of the node. Through constant analysis, these nodes became codes and eventually themes. Themes were not imposed, for example from my research aims or a theoretical model. Instead, they have arisen from the participant's words. Originally, I tried to maintain the same code-set across teams. However, this did not reflect the subtle differences between teams, so a new code-set was opened in NVivo for each team plus one for the serendipity data. This avoided imposing pre-formed codes onto a team presenting similar but subtly different information. It was only in the final stages that themes were organised intuitively into a schema of professional development.

'Faced with a mass of unstructured data, the urge of any researcher is understandably to break these down using some kind of system' but this fragmentation may lead researchers to overlook the form of their data (Hollway and Jefferson 2000 p68). Here was the timely reminder. Particularly in the creative and painful process of writing up, I became increasingly concerned that in the thematic analysis, the importance of the whole was being lost. Hollway and Jefferson (2000) describe strategies that allow
subjective narratives to emerge. I was also inspired by the work of Ellis and Flaherty (1992), on innovative procedures to reveal the subjectivity of the lived experience, and I experimented with the use of poetry (appendix M). Eventually I chose to provide a narrative of each team, revealing something of the individuals and the group processes. Against this, my subsequent thematic interpretations can be assessed.

In the writing up, I have used an incremental approach, presenting the findings though increasing levels of abstraction and interpretation. The transcripts are already once removed from a social reality (Holliday 2002). They do not reveal truth. Rather they represent the individuals', and collectively the teams', thinking about this one aspect of practice, at a point in time, triggered by the research. I am not saying the transcripts are untrustworthy. They are credible but 'the written study itself takes on an agency of its own - its own story - the argument' (Holliday 2002 p100). The argument is my interpretation of the data. It depends on my ability to articulate what I have 'observed in a way that communicates understanding' (Kincheloe and McLaren 2000 p285). The presentation of findings therefore begins with a factual account of the data in chapter 6, a narrative account of the data in chapter 7 and my argument in chapters 8 to 12.

5.8 Learning from the pilot study

A pilot study was undertaken to test the procedures for the main study. The process, as well as the data generated, was analysed to establish the efficacy of the design and to highlight any intrinsic problems. In hindsight, the pilot study was included to meet the traditional positivistic approach of health research. As the study progressed, and I became more confident in qualitative enquiry, I did consider if the pilot study might have been better re-framed within a developing methodology. This would have permitted the pilot to be used within the results. Having conceived and conducted it as a pilot, however, I chose to maintain its role as rehearsal for the main study. Certainly, it provided rich learning from the most basic and practical issues to the complexities of multi-layered interpretation. The pilot study was undertaken between March and September 2002. Two focus groups and one individual interview were conducted, transcribed and analysed. The impact of the pilot on the main study is outlined.
A community stroke rehabilitation team was identified that met all the inclusion criteria but one: the team did not work with people with multiple sclerosis. Unlike teams in the main study their service users had all experienced a traumatic onset disability and were generally older. It was though, multidisciplinary and included nursing, speech and language therapy, physiotherapy, occupational therapy, counselling and dietetics.

Team membership and informed consent was a salutary lesson provided by the pilot study. Erroneously I thought that I had identified in conversations with the team leader, all the members of the team. On arrival to undertake the first focus group, others were present and expecting to participate. These people had not been sent project information sheets or informed consent forms. Thus in the main study, I meticulously established the names of all team members. This was essential to ensure the team leader was not selecting participants. It also resolved the practical difficulties, although I did take spare forms to each focus group just in case.

The pilot study highlighted the need to address the most basic, practical issues such as venue, equipment and transcription. The room, recommended by the team leader, was wholly unsuitable. It was cited next to a noisy kitchen. Worse still the secretary did not participate in the focus group, but remained in the room, at her desk, typing and taking phone calls! I therefore visited every venue, before the event, to ensure it's aural and visual privacy. Trials of recording equipment established the advantages of using two sets: to provide a back up in case of equipment failure and to allow access to one tape whilst the second was with the transcriber. I experimented with transcription and transcribed one tape myself. I found using a professional transcriber released my time to attend to the analysis. These practical issues may seem trivial but addressing them in the main study ensured my full attention to the task of facilitation.

The focus group schedule, developed for the protocol, was revised to aid clarity and readability (appendix N). I used it in the first focus group but not the individual interview. Instead, I moved toward an open dialogue with me reflecting what was said, using the interviewee's ordering and phrasing. This experimentation confirmed the suitability of the free association narrative interview. I also tried some different strategies in the second focus group. One related to member validation and sharing the emerging analysis, so that it could be contested or affirmed, and refined. In the pilot, I
used a formal typewritten document but this had an air of completeness and rigidity that limited discussion. So, I changed to taking rough, handwritten notes of the preliminary analysis, to the teams in the main study.

Language and talking in code was identified. My preamble and introduction to the first focus group included the following statement:

"One of the things I have found in researching sexual expression is that there is no common language to discuss the issues. I want to reassure you that you may use any language that feels comfortable to you and any language that your service users may use".

Language however was still an issue. Sometimes the communication was non-verbal. In some instances, I could intervene to bring this into a verbal domain by reporting what I was seeing for example by saying, "I can see by your face that …". Subtler, but equally as difficult to record, were times when people lowered their voice or just mouthed the words. One result was a loss of audio quality. This highlighted the need for extra vigilance within the session, in field notes and transcription. Similarly 'talking in code' was another issue, for example, the double bed being used as a code for sexual activity. Reflection on these problems of language heightened my awareness.

The act of initiating the research affected the results. For example, in the second focus group, a physiotherapist reported an incident that had occurred after the first focus group. She described the patient's wife following her out to the doorstep.

"Nice lady. Followed me to the car. She just said what about sex? I said sorry. She said what about sex; we haven't got a sex life at the moment. … Right on the doorstep, a busy street - so I said it is a physical problem or a libido problem. She said we used to have a very active sex life before hand, and its not even mentioned now, or there's no indication that he wants to be involved in that side of things. He had only been out of hospital 2 days. So I suggested they waited a while to see what happened. Poor chap had literally only been home, so that was quite interesting. I did feel I (big sigh) but we had discussed it so recently beforehand (in the first focus group). Which was quite handy"

The physiotherapist had never been approached directly before. This could be regarded as a coincidence however it alerted me to what I labelled first case scenarios. This awareness went with me into the main study allowing me to explore, in the sessions, what triggered these first case scenarios.

Similarly, I became conscious of inconsistent or changing stories. A participant would outline their view only to contradict it later. For example, one participant began by
asserting the team did address issues of intimacy and sexual expression. In one breath, he said that he provided openings to discuss sexuality but then gave several examples of how he discouraged disclosure. This required sensitive analysis. Somehow, the movement in opinion or the difference between espoused and actual practice has to be revealed. One strategy instigated for the main study therefore was disciplined listening. Member validation was also useful to explore contradictions further with participants.

The team in this pilot study demonstrated little actual experience of dealing with sexual issues affecting their patients so I experimented with the use of examples and vignettes. Often the discussion focused on a positive wish to help, for example one person said

"I would want to do all that I could do, if there was a problem"

This creates its own dilemma in that a somewhat naive and unrealistic situation may be fantasised. At one point in the pilot, I interceded with a brief, context specific vignette. I found the use of an example moved the conversation from the general to the tangible and specific. It triggered a more realistic discussion on knowledge, skills and attitudes. It was a helpful strategy, which I incorporated into the main study.

Managing truths and prejudices was an issue. Sometimes statements were made that, from my reading and the preliminary inquiry, were not wholly accurate. For instance,

"The thing is a lot of our patients are very elderly aren’t they so, it probably wouldn’t be one of their first worries."

This may be true for some service users but it may also be an example of ageism and the denial of the sexuality of older people. Statements like this, that sit somewhere between truth and prejudice, are not easy in terms of facilitation. It links to the personal use of self in the facilitator role (King 1996; Measor and Sikes 1992) and how external knowledge can be brought into the discussion. Experimenting in the pilot, I presented the executive summary of the preliminary inquiry during the second focus group. Although participants said this was helpful, on reflection, I felt it to be oppressive and did not repeat it in the main study. However, I did give myself permission in the main study to the occasional moment of immediacy: letting the voice of disabled people into the sessions by sharing a little of their experience, for example, on the priority of sexual expression. Immediacy demands a deftness, or lightness, of touch and always with a conscious return to the participant, hearing and exploring what they are saying.
The pilot study also raised my awareness of levels of interpretation. Using focus groups and interviews, rather than direct observation, means respondents interpret and present their patient's conversations and behaviour. Imposed on this is my interpretation, as the researcher, of what the respondent is saying. I tried to remain alert to these complex levels of interpretation in the main study.

5.9 Conclusion

In this chapter, I have discussed why interpretive and contemporary critical theory paradigms are both compatible with the aims of this study and with me. Although different frames of inquiry were considered, a pluralist design has been utilised avoiding a rigid, mechanical approach to data generation and analysis. Others have noted

'We find unhelpful the preservation of tight symbolic membranes between different approaches to qualitative research. We do not believe that qualitative research … should be constrained within the straightjackets of so-called paradigms or traditions' (Atkinson, Coffey et al. 2001 p11).

With this in mind, the factors influencing the study design have been presented and the strategies of investigation described in considerable detail. This will enable the credibility, authenticity, dependability and confirmability of the study to be judged. An aspiration for the future is that the quality of this study may also be measured by its contribution to social justice for disabled people.
CHAPTER 6: OUTLINE OF DATA

6.1 Introduction

The Concise Oxford Dictionary defines data as 'known facts or things used as a basis for inference or reckoning'. In qualitative research the natural setting is used both as the place of inquiry and as a source of data. Thus, the data in my study does not consist solely of the words spoken or written, from focus groups, interviews and emails. This chapter provides an outline of all the data drawn on, in the main study. My aim is to present factually, without interpretation, the totality of the material so that my later analyses are contextually sensitive and meaningful (Henwood 1996). This includes demographic information and a profile of the three disability teams. Briefly, the organisational structure of the settings is described and those factors that distinguish one team from another (Holliday 2002). For two teams an artefact is presented: the teams' initial assessment tool. A chronology of all the focus groups, and interviews, is included as it gives a sense of the volume of data underpinning my findings in this research. The period of data generation spanned October 2002 until February 2004. The nature of the serendipitous data is also described. The serendipitous data can feel disconnected from the primary field of inquiry: disability teams, but it is connected. Both the Model of Occupation (MoHO) and the Multiple Sclerosis Trust electronic discussions provided directly relevant information about expectations, understandings and beliefs concerning disability professionals' roles in supporting the sexual health of service users.

So here is an outline of the data, not an analysis. This is because the findings are presented incrementally with increasing levels of abstraction and interpretation. The next chapter begins the analysis. It is a narrative account of each team set against the research objectives. The thematic analysis with my deeper interpretation occurs after that. The aim of this chapter, and the next, is to provide a foundation that will allow you to judge the authenticity and dependability of my interpretation and thereby its integrity and rigour.
6.2  A collective profile of the three teams

Demographic profile
The teams were all located in the south east of England and provided services to large areas of the counties of East and West Sussex and the London Borough of Croydon. These areas together include both urban and rural communities plus areas of significant poverty and affluence (Commission for Health Improvement 2001; East Sussex Brighton & Hove Health Authority 2000; East Sussex County Council 2001; Rodriguez, Szanto et al. 2003). The age structure of the population of East and West Sussex is characterised by a high proportion over pensionable age with a correspondingly low proportion of young adults (East Sussex County Council 2001; Rodriguez, Szanto et al. 2003). On the other hand, Croydon has a slightly lower proportion of older people compared to the national average and more residents in the 25 - 44 year old age group (Commission for Health Improvement 2001). Statistics for ethnicity, indicate that 98.7% and 96.6% of the populations of East Sussex (East Sussex County Council 2001) and West Sussex (Rodriguez, Szanto et al. 2003) respectively, is white. This is higher than the national average. In contrast, ethnic minority groups comprise 22% of the population of Croydon, which is considerably higher than the 6.2% average for England. Its ethnic population is diverse with no single group predominating.

Professional profile

<table>
<thead>
<tr>
<th>Professional groups</th>
<th>Approached</th>
<th>Participated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational therapists</td>
<td>15</td>
<td>10</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Nurses</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Speech &amp; language therapists</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Psychologists</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Social workers &amp; resource officers</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Support staff (working under direct supervision)</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Nutrition &amp; Dietetics</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>46</strong></td>
<td><strong>30</strong></td>
</tr>
</tbody>
</table>

*Table 6.1: Numbers, by professional group, of those approached & those who participated*
The combined figures for the three teams are presented in table 6.1. This provides details of the numbers of people approached, by professional groups, and the total number of those who agreed to participate. In total 46 people were identified as members of the teams and all were approached. Of these, 30 people participated.

The largest profession represented in the study was occupational therapy closely followed by physiotherapy. As will be seen, these two professions and speech and language therapy were represented in all three teams. There was no nursing establishment in one team. Another had no psychology input and two teams no social workers. Although grouped by profession, the roles each person took could be quite varied and this is developed further under each team's profile. Of the 46 people approached there were five men. Three agreed to participate: a psychologist, an occupational therapist and a support worker (working under the direction of a physiotherapist and an occupational therapist).

Service profile
Disability Team A consisted of a network of professionals from different health trusts and a local authority. The other two teams were designated services, funded and managed by a single primary care trust, with all staff employed by that trust. All three teams provided services to physically disabled adults living in the community. I established with the team leaders, that all three teams took referrals for people with multiple sclerosis. Each team also took referrals for people with other diagnoses. All teams considered themselves a specialist multidisciplinary service offering expertise in physical disability. Table 6.2 shows the numbers of people approached, and those who participated, by their employing organisation.

<table>
<thead>
<tr>
<th>Employer</th>
<th>Approached</th>
<th>Participated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Care Trusts</td>
<td>31</td>
<td>25</td>
</tr>
<tr>
<td>Local Authorities</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>Acute Hospital Trusts</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Specialist Services Trust</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>46</strong></td>
<td><strong>30</strong></td>
</tr>
</tbody>
</table>

*Table 6.2: Numbers, by employer, of those approached & those who participated*
6.3 Disability Team A

This was the team, working across agencies, in a collaborative network, informally convened. Its purpose was to address the complex problems experienced by people with progressive neurological conditions, where presenting needs required the involvement of more than one discipline. The types of conditions encountered included motor neurone disease, multiple sclerosis, Huntingdon's disease, multiple systems atrophy, progressive supra-nuclear palsy, and Parkinson's disease. The professional make up of the network, and those willing to participate, is presented in table 6.3

<table>
<thead>
<tr>
<th>Professional groups</th>
<th>Approached</th>
<th>Participated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational therapists</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Nurses</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Speech &amp; language therapists</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Psychologists</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Social workers &amp; resource officers</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Support staff (working under direct supervision)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Nutrition &amp; Dietetics</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>20</strong></td>
<td><strong>9</strong></td>
</tr>
</tbody>
</table>

*Table 6.3: Numbers, by professional group, of those approached & those who participated in Disability Team A*

Leadership for the team was jointly undertaken by a specialist Parkinson's disease nurse and a specialist motor neurone disease / multiple sclerosis nurse. There was no psychologist within this network. The local Multiple Sclerosis Society Group had purchased three hours of counselling per week, which was available only for patients with multiple sclerosis. The counsellor was not identified as a member of the network.

Just under half those approached agreed to participate. One local authority occupational therapist discussed her involvement because she was a friend. We agreed she should not volunteer. For the others, the low participation may have been attributable to the more dispersed nature of this team. For example, at the time of the focus group, two different health trusts employed the physiotherapists. The local authority employed the
social workers. The primary care trust employed five occupational therapists and the local authority the other four. The network does not receive referrals. Each agency receives and manages its own referrals according to their own eligibility criteria and assessment protocols. Service users with progressive neurological conditions and complex needs form only part of each member's caseload. For some, like the social workers, it is quite a small part of their professional duties, the majority of which would be for the frail elderly. That said, I received no information from the social workers and resource officers indicating why none volunteered to participate. The dietician was unable to participate due to staff shortages in her service.

Another possibility for not participating was not seeing the topic as relevant to practice. Early on, as part of recruitment, I attended a team meeting to discuss the project. Aidan was the joint team leader and Parkinson's disease nurse specialist. Afterwards I wrote -

"There were few questions. Aidan did ask the group, "But how many of us deal with sexual issues". I felt caught on the hop. How do I deal with this here and now? This is the issue. But if he dismisses it now, how do I encourage his attendance? I stopped him and suggested this was exactly the conversation I would wish to have within a focus group' (Research journal 14.11.03).

But perhaps this did not resonate with his own practice enough for him to attend. That is, if he was not alert to the sexual expression of service users, it is de facto low priority and difficult to allocate time to, within the pressures of work.

The responsibilities, roles and gender of participants can be seen in table 6.4.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Position</th>
<th>Role</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anita</td>
<td>Manager / Pract.</td>
<td>Occupational therapist</td>
<td>female</td>
</tr>
<tr>
<td>Beryl</td>
<td>Practitioner</td>
<td>Physiotherapist (Neurology)</td>
<td>female</td>
</tr>
<tr>
<td>Carol</td>
<td>Practitioner</td>
<td>Physiotherapist (Hospice)</td>
<td>female</td>
</tr>
<tr>
<td>Della</td>
<td>Practitioner</td>
<td>Occupational therapist (Wheelchair service)</td>
<td>female</td>
</tr>
<tr>
<td>Eliza</td>
<td>Practitioner</td>
<td>Occupational therapist (Hospital outreach)</td>
<td>female</td>
</tr>
<tr>
<td>Fiona</td>
<td>Pract. / Manager</td>
<td>Nurse (Team leader and specialist MS/MND nurse)</td>
<td>female</td>
</tr>
<tr>
<td>Ginny</td>
<td>Practitioner</td>
<td>Speech and language therapist</td>
<td>female</td>
</tr>
<tr>
<td>Henry</td>
<td>Pract. / Manager</td>
<td>Occupational therapist (Hospital outreach)</td>
<td>male</td>
</tr>
<tr>
<td>Irene</td>
<td>Practitioner</td>
<td>Occupational therapist (Local authority)</td>
<td>female</td>
</tr>
</tbody>
</table>

*Table 6.4: List of participants from Disability Team A*
The team members who agreed to take part were more diverse than in the other two teams. This is because the services provided by each agency are not uniform. For example, of the five participating occupational therapists: one was a manager in charge of occupational therapy services for the primary care trust; two provided outreach rehabilitation from the hospital; one was from the wheelchair service, and one from the local authority. Of the two physiotherapists, one worked mainly in the hospital and particularly in the gymnasium and hydrotherapy pool. The other provided palliative physiotherapy at the hospice. In this inter-agency network, it was not appropriate to have a key worker system. Rather, members of Disability Team A met regularly to liaise with the other professionals likely to be involved in complex cases. It provided a forum to seek advice, to give and receive support, and to make referrals.

One last point to note with this team is that I knew five participants. I spent time reflecting on this and wrote:

\[\text{Participants. Several members of the focus group were already known to me. Two were University X students Diana and Henry (Henry even a personal tutee) and one a University Y student Eliza, (where I was a visiting lecturer). With these 3, I had conducted a half-day workshop on sexual issues in OT practice. I also know Anita through management links with work and Lorraine through work links in my training role. How much does knowing participants effect the study?} \text{ (Team A, NVivo memo)}\]

Unlike the friend who did not participate, I considered these acquaintanceships were professional. The students had all been qualified for more than a year. Therefore, I felt the relationships would be robust enough not to grossly distort the power relationship. Having thought through these issues, I judged that any consequence on the research might not necessarily be detrimental, it could equally be positive.

### 6.4 Disability Team B

This team had been established by the primary care trust to provide services for people with a physical disability. This included a wide range of disabling conditions with almost half the referrals being for people with multiple sclerosis. Other conditions included Parkinson's disease, cerebral palsy, orthopaedic conditions and various dystrophies. The administrative base of the team was a health centre. Rooms were available at this base where patients could be seen but all the team members undertook the majority of their work in service users' own homes. The team, via one of the nurses,
also had access to two respite care beds. The professional formulation of those approached and those who participated is given in table 6.5.

<table>
<thead>
<tr>
<th>Professional groups</th>
<th>Approached</th>
<th>Participated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational therapists</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Nurses</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Speech &amp; language therapists</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Psychologists</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Social workers &amp; resource officers</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Support staff (working under direct supervision of physiotherapist)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Nutrition &amp; Dietetics</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Totals</td>
<td>11</td>
<td>11</td>
</tr>
</tbody>
</table>

*Table 6.5: Numbers, by professional group, of those approached & those who participated in Disability Team B*

A list of participants, their responsibilities, roles and gender is given in table 6.6. All are employed by the primary care trust and all agreed to participate in the study. Unlike Team A, these participants acted both within their professional roles and as generic key workers. The team leader was a nurse. There was only one occupational therapist in

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Position</th>
<th>Role</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Janet</td>
<td>Practitioner</td>
<td>Physiotherapist</td>
<td>female</td>
</tr>
<tr>
<td>Kitty</td>
<td>Manager / Pract.</td>
<td>Nurse (also team leader)</td>
<td>female</td>
</tr>
<tr>
<td>Lesha</td>
<td>Practitioner</td>
<td>Physiotherapist</td>
<td>female</td>
</tr>
<tr>
<td>Maeve</td>
<td>Practitioner</td>
<td>Occupational therapist</td>
<td>female</td>
</tr>
<tr>
<td>Nancy</td>
<td>Practitioner</td>
<td>Nurse (and incontinence advisor)</td>
<td>female</td>
</tr>
<tr>
<td>Odele</td>
<td>Practitioner</td>
<td>Psychologist</td>
<td>female</td>
</tr>
<tr>
<td>Peggy</td>
<td>Practitioner</td>
<td>Physiotherapist</td>
<td>female</td>
</tr>
<tr>
<td>Quita</td>
<td>Practitioner</td>
<td>Support worker (supervised by physiotherapist)</td>
<td>female</td>
</tr>
<tr>
<td>Rhoda</td>
<td>Practitioner</td>
<td>Nurse (with some responsibility for respite care)</td>
<td>female</td>
</tr>
<tr>
<td>Sarah</td>
<td>Practitioner</td>
<td>Speech &amp; language therapist</td>
<td>female</td>
</tr>
<tr>
<td>Shena</td>
<td>Manager / Pract.</td>
<td>Speech &amp; language therapist</td>
<td>female</td>
</tr>
</tbody>
</table>

*Table 6.6: List of participants from Disability Team B*
this team and she had been appointed six weeks before the first focus group. It was implied that this was due to recruitment difficulties. The psychologist and speech and language therapy manager were the only staff to have duties with other services and were the only members of the team not based at the health centre.

Referrals for Disability Team B were received centrally. Any member of the team might undertake the initial assessment although, where staff availability permitted, the assessor was allocated in response to the presenting problem. Initial screening included completion of an 'in-house' multidisciplinary assessment tool, summarised in table 6.7. After recording basic information and contact details this form covers sixteen areas.

1. Medical - past medical history and current condition
2. Other professionals involved
3. Type of accommodation
4. Physical condition - including pain, skin care, sensory loss, sleeping, respiration, eating & swallowing, diet, urinary incontinence and faecal incontinence
5. Self care - including: feeding, washing, bathing / showering, dressing and toileting
6. Domestic tasks - including: housework, laundry, cooking, shopping and use of money
7. Communication - which included: hearing, comprehension, speech, sight, reading and writing
8. Mobility - including bed & chair transfers, indoor and outdoor gait, steps & stairs and transport
9. Psychological factors such as memory, mood, behaviour, and concentration
10. Relationships / Sexuality
11. Employment - including present and previous employment and the clients perspective on their wish to be employed or not and the help they need to be employed
12. Benefits and Allowance - this asks if correct allowances have been claimed
13. Leisure Activities - with a note 'specify information required'
14. Respite Care - checking if it is being received or is required
15. Other relevant information - includes manual handling requirements, equipment in situ and whether carers have been shown how to use equipment
16. Main Carer - which gathers details of the main carer and their occupational / health status and provides a place to record other members of the household

Table 6.7: Summary of Team B's initial assessment form
Item ten, Relationships / Sexuality, is a bold heading with three blank lines below. It is the only section to have no prompts, cues or guidance notes. After the screening visit the case would be discussed and, if accepted, allocated to a key worker based on identified need. Cases are rarely closed although they may become inactive. The key worker may hold case responsibility for many years.

6.5 Disability Team C

This team is funded by the primary care trust to provide an intensive community neuro-rehabilitation service. This includes people with stroke, head injury, multiple sclerosis, Parkinson's disease, motor neurone disease and other neurological disorders. All the team members are employed by the primary care trust. The professional formulation of the team, and those willing to participate, is indicated in table 6.8.

<table>
<thead>
<tr>
<th>Professional groups</th>
<th>Approached</th>
<th>Participated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational therapists (includes one locum)</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Nurses</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Speech &amp; language therapists</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Psychologists (includes one trainee)</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Social workers &amp; resource officers</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Support staff (supervised by occupational therapist and physiotherapist)</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Nutrition &amp; Dietetics</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Totals</td>
<td>15</td>
<td>10</td>
</tr>
</tbody>
</table>

*Table 6.8: Numbers, by professional group, of those approached & those who participated in Disability Team C*

The team co-ordinator was the speech and language therapist. Unique to this team was the absence of nurses. This is because the service remit was intensive rehabilitation. Patients requiring on-going nursing support were deemed inappropriate and would be referred on for a slower, less intensive programme. Two psychologists agreed to participate in my study. One, a trainee at the time of the first focus group, was a month from completion of his training. A list of participants, their responsibilities, roles and gender is given in table 6.9.
Referrals for Disability Team C were received centrally. Eligibility criteria were based on the ability of the client to cope with, and benefit from, intensive therapy from at least two different disciplines. The intervention was limited to 14 weeks and was only available to those who could manage ambulance transport, or who could provide their own transport. Any member of the team undertook the initial assessment, with allocation usually linked to staff availability. After the screening visit, usually completed within two weeks of referral, the case would be discussed and allocated to a key worker based on identified need. The screening tool used was developed 'in-house' and is summarised in table 6.10. At the time of my fieldwork with the team, there was no specific reference to sexual expression or relationships on the assessment form.

From the initial assessment, a summary of recommendations would be made and, if appropriate, the case was prioritised for intensive neuro-rehabilitation. If the referral was accepted, the patient was seen for three to eight appointments per week. All appropriate professionals assessed the client during the first three weeks. They compiled a multidisciplinary assessment with a staged intervention programme. Cases were reviewed every three weeks and this involved the service user and their family. To assist service evaluation the Brain Injury Community Rehabilitation Outcome Scale

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Position</th>
<th>Role</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tanya</td>
<td>Manager / Pract.</td>
<td>Speech and language therapist and team co-ordinator</td>
<td>female</td>
</tr>
<tr>
<td>Tatum</td>
<td>Practitioner</td>
<td>Occupational therapist</td>
<td>female</td>
</tr>
<tr>
<td>Tracy</td>
<td>Practitioner</td>
<td>Occupational therapist</td>
<td>female</td>
</tr>
<tr>
<td>Unwin</td>
<td>Practitioner</td>
<td>Psychologist</td>
<td>male</td>
</tr>
<tr>
<td>Vicky</td>
<td>Practitioner</td>
<td>Physiotherapist</td>
<td>female</td>
</tr>
<tr>
<td>Wendy</td>
<td>Practitioner</td>
<td>Occupational therapist</td>
<td>female</td>
</tr>
<tr>
<td>Xavie</td>
<td>Practitioner</td>
<td>Occupational therapist (locum)</td>
<td>female</td>
</tr>
<tr>
<td>Yvonne</td>
<td>Practitioner</td>
<td>Physiotherapist</td>
<td>female</td>
</tr>
<tr>
<td>Zanna</td>
<td>Practitioner</td>
<td>Psychologist</td>
<td>female</td>
</tr>
<tr>
<td>Vince</td>
<td>Practitioner</td>
<td>Support worker</td>
<td>male</td>
</tr>
</tbody>
</table>

Table 6.9: List of participants from Disability Team C
1. Medical history - present neurological condition, other conditions and previous medical history
2. Social environment - including any involvement by Social Services
3. Physical & Sensory - includes any weakness, problems with balance, falls, swallowing, continence, menstruation, any loss of sensation
4. Communication - first language, comprehension, speech and written communication
5. Functional Mobility - includes bed, chair & toilet transfers, mobility indoors & outdoors, stairs, public transport
6. Personal & Domestic Activities of Daily Living - includes washing, dressing, essential meal/drinks preparation, housework, shopping, and managing finances
7. Cognitive abilities - includes concentration, initiation and organisation, perception / neglect, orientation and memory
8. Daytime and Leisure Activities / Interests - both past and present
9. Psychological Factors - such as mood, insight / awareness, reduction in self-confidence, impact on family relationships.
10. Other Relevant Information - this is a large space for any other comments

**Table 6.10: Summary of Team C's initial assessment form**

(BICRO-39), a patient questionnaire, was used to obtain subjective feedback. In this the service user rates: how much assistance they need with personal care, mobility and self-organisation; how much time they spend with their partner & children, parents & siblings and how much time is spent in socialising and in productive employment. The final question is on their psychological well being. There are no direct questions relating to intimacy and sexual relationships, only tangential ones like, "How often do you spend some time with your partner or spouse?" Or, "How often do you feel lonely?" Cases are closed when intervention is completed. If a patient was re-referred to the team, another key worker might be allocated.

### 6.6 Chronology of focus groups and interviews

Table 6.11 gives focus groups and interview dates and who was present.
### Table 6.11: Chronology of focus groups and interviews with the three disability teams

<table>
<thead>
<tr>
<th>Date</th>
<th>Activity</th>
<th>Code</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disability Team A</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.01.03</td>
<td>1&lt;sup&gt;st&lt;/sup&gt; focus group</td>
<td>A fg1</td>
<td>Anita, Beryl, Carol, Della, Eliza, Fiona &amp; Ginny</td>
</tr>
<tr>
<td>20.01.03</td>
<td>1&lt;sup&gt;st&lt;/sup&gt; interview</td>
<td>A iiA1</td>
<td>Irene</td>
</tr>
<tr>
<td>27.01.03</td>
<td>1&lt;sup&gt;st&lt;/sup&gt; interview</td>
<td>A iiB1</td>
<td>Henry</td>
</tr>
<tr>
<td>28.02.03</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; focus group (main)</td>
<td>A fg2a</td>
<td>Anita, Beryl, Carol, Fiona &amp; Ginny</td>
</tr>
<tr>
<td>03.03.03</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; interview</td>
<td>A iiA2</td>
<td>Irene</td>
</tr>
<tr>
<td>05.03.03</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; focus group (sub)</td>
<td>A fg2b</td>
<td>Della &amp; Eliza</td>
</tr>
<tr>
<td>10.03.03</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; interview</td>
<td>A iiB2</td>
<td>Henry</td>
</tr>
<tr>
<td><strong>Disability Team B</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.05.03</td>
<td>1&lt;sup&gt;st&lt;/sup&gt; focus group</td>
<td>B fg1</td>
<td>Janet, Kitty, Lesha, Maeve, Nancy, Odele, Peggy, Quita, Rhoda, Shena,</td>
</tr>
<tr>
<td>16.06.03</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; focus group (main)</td>
<td>B fg2a</td>
<td>Kitty, Nancy, Janet, Sarah, Peggy, Lesha, Quita, &amp; Rhoda</td>
</tr>
<tr>
<td>17.06.03</td>
<td>1&lt;sup&gt;st&lt;/sup&gt; interview (phone)</td>
<td>B iiA1</td>
<td>Nancy</td>
</tr>
<tr>
<td>23.06.03</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; focus group (sub)</td>
<td>B fg2b</td>
<td>Odele, Shena &amp; Maeve</td>
</tr>
<tr>
<td>28.07.03</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; interview</td>
<td>B iiA2</td>
<td>Nancy</td>
</tr>
<tr>
<td><strong>Disability Team C</strong></td>
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<tr>
<td>10.09.03</td>
<td>1&lt;sup&gt;st&lt;/sup&gt; focus group</td>
<td>C fg1</td>
<td>Tanya, Tatum, Tracy, Unwin, Vicky, Wendy, Xavie, Yvonne &amp; Zanna</td>
</tr>
<tr>
<td>01.10.03</td>
<td>1&lt;sup&gt;st&lt;/sup&gt; interview</td>
<td>C iiA1</td>
<td>Vince</td>
</tr>
<tr>
<td>12.11.03</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; focus group</td>
<td>C fg2</td>
<td>Tanya, Tatum, Vicky, Wendy, Xavie &amp; Yvonne</td>
</tr>
<tr>
<td>19.11.03</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; interview</td>
<td>C iiA2</td>
<td>Vince</td>
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<tr>
<td>19.11.03</td>
<td>Post f/g interview</td>
<td>C iiB1</td>
<td>Tracey</td>
</tr>
<tr>
<td>10.12.03</td>
<td>Post f/g interview (phone)</td>
<td>C iiC1</td>
<td>Zanna</td>
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</tbody>
</table>

It also provides the codes I use to reference supporting evidence in the analysis. In total, there were eight focus groups of 1½ hours duration; eight face-to-face interviews ranging from ¾ to 1½ hours duration, and two shorter telephone interviews.

### 6.7 Serendipitous data

Holliday (2002 p7) notes the importance to research of 'serendipity and opportunism'. During the phase of my research when I was gathering data from the teams, two separate electronic discussions occurred. The first was a series of emails posted on the
Model of Human Occupation (MoHO) discussion group web site, on the subject of sexual expression, at MOHO@LISTSERV.UIC.EDU. The second opportunity was provided by the Multiple Sclerosis Trust. They published a 'chat room' discussion hosted on their web site www.mstrust.org.uk. I downloaded these texts and coded them using NVivo. I have used the information in them to provide further supporting material for the emergent themes in my research. They are summarised below.

**The Model of Human Occupation (MoHO) e-discussion**

The MoHO is a model of practice that helps to conceptualise the domain of occupational therapy. The MoHO web site invites electronic discussion from occupational therapists on matters relevant to MoHO. The model's originator is Professor Gary Kielhofner. In a book on the model, he stated that

> 'Occupation refers to human activity; however, not all activity is occupation. Humans engage in survival, sexual, spiritual and social activities in addition to those activities that are specifically occupational in nature' (Kielhofner 1993 p138).

The email discussion confirmed this was still his position. Twenty-one emails were posted in the ten-week period from 11th February to the 27th April 2003. Seven of these were from Professor Kielhofner. This e-correspondence provides the only available explanation to date of his position.

In his emails, Kielhofner set out why he saw the sexual drive as fundamentally different to the drive for action that underpins occupation. He suggested sexual activity is based, like hunger and pain aversion, on tissue needs whereas occupation is based on the drive to be effective (Kielhofner 2003a). He was sharply critical of making 'anything into occupation' and rushing 'in like fools to address whatever we feel like' (Kielhofner 2003b). Instead, he recommended developing a depth of understanding about a delimited area of human life (occupation) arguing that sexuality was beyond the phenomena that MoHO seeks to explain (Kielhofner 2003d). He 'vehemently' disagreed with a proposal that occupational therapists should advocate for clients or signpost them to resources (Kielhofner 2003c). This he aligned to becoming 'a second rate service' in an endeavour to compensate for a society that does not provide adequate services (Kielhofner 2003c).
In his concluding email, he focused on the intersection of occupation with non-occupational activities such as sexuality and spirituality (Kielhofner 2003e). He sought to define where an occupational therapist's expertise ends. He provided an example of the intersection of occupational therapy with spirituality.

"If a client of mine made it clear that spirituality was a part of how he/she made meaning of life and coped with the illness, I would certainly want to know how this person's beliefs influenced the choices he/she made for occupational engagement and what occupations held meaning for this person. I would, as a person with expertise in occupation query whether the person can participate in the spiritual-related activities she/he desires and whether occupational factors (performance limitations, environmental barriers, role overload, time management, etc) are interfering. I would certainly also acknowledge and unjudgementally validate the client's viewpoint that may include spiritual content. If the client sought advice that was 'spiritual' in nature I would listen respectfully, acknowledge that the client's beliefs appear to be very important to him and that he/she seemed to be struggling with them, inform the client I have no expertise in the area, and to offer to find an appropriate spiritual counselor" (Kielhofner 2003e).

In this example, there is validation of the client's spirituality. The therapist listens non-judgementally to the client's spiritual concerns. Kielhofner proposes that the therapist address any issues that fall within their own professional competency (e.g. performance limitations, environmental barriers, role overload, time management etc). The occupational therapist acknowledges the limitations of their expertise but provides information about, or refers the client on to, a spiritual counsellor.

I will return to this example later because his response to a person's spiritual needs is similar to my proposals in terms of facilitation of sexual expression (see section 13.2 - A sexual health practice model for disability practitioners). However, there is a crucial difference. Culturally service users will not make clear the importance of sexuality in their lives unless they are given permission to do so (Annon 1974). I have used this electronic discussion as additional data in this study because it sets out Kielhofner's position. His emails are explicit: he intends no 'open invitation' for occupational therapists to deal with sexual expression in therapy (Kielhofner 2003e).

**Multiple Sclerosis Trust web site**

The Multiple Sclerosis Trust hosted an electronic 'chat room' on sexual problems and pregnancy in multiple sclerosis. It was advertised to their membership and was available all day and into the evening of the 23rd June 2003. It was open to both people with multiple sclerosis and health or social care professionals. The experts available to field questions during the day included: 2 specialist multiple sclerosis nurses, an erectile
dysfunction specialist nurse, and a retired psychiatrist with personal experience of multiple sclerosis. The transcript was published in full, on their web site\(^1\). During the day 25 people contacted the site. The majority of inquiries were from people with multiple sclerosis or their partners. The published discussion was scrutinised especially for the information it gave to people about professional practice.

The discussion demonstrated a need for a forum to ask questions. Both men and women, were seeking information, for example,

**Jim:** *(Talking about problems with both erection and orgasm)* It's not a question I've found easy to talk about with people. Are there specialists I can be referred to?

**Steve:** I have a problem with spasms if I lie in some positions - this can be very awkward. Are there any ideas that could help with this?

**Gail:** … but where do I get a vibrator from? I don't want to go to a sex shop I would be too embarrassed.

**Sam:** Can you tell me what an erectile dysfunction nurse does? I'd not heard of them before this chat room.

Advice was requested on a range of sexual issues including loss of libido; decreased sensation in the genital area (both male and female); erectile dysfunction; management of fatigue; drug regimes and management of continence.

Sometimes the inquiry was managed within the chat room. More often, the chat room specialists recommended the inquirer talk with a professional.

**MS Nurse:** It is important to discuss your problems with a professional (i.e. a nurse or doctor or incontinence advisor) who will be able to offer individual advice to you according to your circumstances.

The same multiple sclerosis nurse identified key professions.

**MS Nurse:** The most informed professionals to discuss sexual problems with are either your MS Nurse, your GP, your continence nurse or your urologist.

Some of these professionals are experienced in disability issues. Of these it was the multiple sclerosis nurse in particular who was seen as having specialist skills in 'assessing sexual problems' and being 'specially trained' to help with sexual expression. One inquirer who sought information on sexual expression related to 'bladder and

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\(^1\) Downloaded from www.mstrust.org.uk/cgi-bin/pages.pl?cgiaction=displaychild&key=386 on 26.06.03 at 7.38 p.m.
bowel' problems was advised to seek a 'thorough assessment from the incontinence nurse'. He was assured the incontinence nurse 'will advise you on this'.

This electronic discussion has been included because it demonstrates that disabled people are being told that at least two professionals with expertise in disability: the multiple sclerosis nurse and the incontinence advisor have knowledge and skills around sexual expression and are able to facilitate exploration of the issues.

6.8 Conclusion

This chapter has outlined the extent and nature of the data. It includes a profile of the professional groups that participated in the study and a brief description of the composition and purpose of each of the three Disability Teams. The number and chronology of the focus groups and interviews has been presented as well as a summary of the serendipitous data used in support of the thematic analysis. This outline of the data underpins Chapter 7 where my interpretation of the data begins.
CHAPTER 7: DATA ANALYSIS IN A TEAM CONTEXT

7.1 Introduction

In the opening pages of this dissertation, I said that sexual expression was either not addressed or is difficult to address in practice. This statement is based on my research with the disability teams of this study. I accept this finding is contextually specific and not generalisable to all physical disability teams, however I suspect that many disability practitioners will find it resonates with their experience. In this chapter, I intend to demonstrate the integrity of this statement, embedded in the data, within the contexts of the three teams. To do this a narrative of each team is provided and, using the participants' language, I shall present key discussion points that arose in the focus groups and interviews. My intention is to convey the uniqueness of each team as well as the interplay of issues. Against these descriptions, for each team separately, I shall review the objectives of the study outlined in chapter 1 (see section 1.5 - Aims of the research). Factors that inhibit practitioners from addressing sexual expression are introduced here. They are critically analysed in subsequent chapters to enable a deep understanding of the powerful deterrents to practice.

This chapter begins the task of analysing the data. It should be seen as an intermediary step between the facts presented in chapter 6 and the interpretive stance of the next five chapters. In these later chapters, themes are disengaged from the context and reconstructed to present my understanding of what underpins professional practice. However, my aim at this stage is to provide a tangible sense of the teams, and the group processes, against which the thematic analysis has been developed.

7.2 Team A's narrative

A multi-agency network
Disability Team A is the inter-agency network. Perhaps as a consequence, individuals spoke more from a personal rather than team perspective. I have tried to represent this individuality despite grouping the information by profession. It should be remembered
that, although not employed in the same agencies, the team provides services to a shared
client group. When Irene talks of referring to the community rehabilitation service this
is managed by Anita, led by Henry and staffed by Eliza.

**Nursing**

I began the first focus group by asking if sexual expression of service users was a
professional concern (A fg1 p1). Fiona was first to respond.

> **Fiona**: Yes I would say that it is. I mean as part of my ‘assessment’ sheet as… the MS
and MND nurse, erm part of that – it’s actually termed ‘relationships’… erm but I take that
to cover any relationship… relationships whether they’re within a family but also what sort of
relationship there is between the partner and husband or wife (A fg1 p1).

She had only been in post four months but in that time she said sexual issues 'have
openly been brought up within a patient consultation' on 'three or four' occasions (A fg1
p3) implying it *was* part of her practice. She was aware of the profound effect disability
could have on a patient's whole life including sexual expression which could effect the
'fibre of the relationship' (A fg2a p3). She was clear it *should* be part of her practice.

As the discussion progressed however, it emerged that although she was committed in
theory, it was not a routine part of her practice.

> **Fiona**: I said it’s on my assessment (group laughter)… honestly, I put my hand up… I do
tentatively ask, but it’s not something that I automatically go into (A fg1 p26).

The times when sexual expression had been raised, the patient had raised it. Reflecting
on her practice, she said -

> **Fiona**: I must admit that having known that I was coming to this group, it has raised my awareness at
how little input I have given to sexual problems (A fg1 p30).

Fiona spoke of her lack of confidence, especially not knowing what help was available
and having little knowledge or skills (A fg1 p25). Because of this research, she had
applied to attend a three-day conference on sexuality and disability (A fg2 p29).

When discussing team roles there was a round of laughter as everyone suggested sexual
expression should fall more to Fiona than any other team member (A fg1 p22). It is
difficult to ascertain if this was about Fiona as an individual rather than her role because
the group did not infer a role for the other clinical nurse specialist, her co-team leader,
Aidan. Two people implied it was the role. Henry saw the clinical nurse specialist as
more able to discuss sexual issues 'because they can bring it up very much as a medical
thing' (A iiB2 p9). Likewise, Irene suggested the clinical nurse specialist might be the first person she would consult (A iiA2 p6).

**Occupational therapy**

Of the occupational therapists, none provided permission for service users to discuss sexual concerns and there were very few examples from practice. Sexual expression or intimacy was not on any occupational therapy assessment forms, nor had it been considered in the development of the single assessment tool (A fg1 p10). There was agreement that theoretically, sexual expression could be included within occupational therapy but, as will be seen, views were mixed about the boundaries of involvement.

**Specialist occupational therapy roles**

Della felt sexual expression should be part of a generalist occupational therapist's role but not within her present position in wheelchair services (A fg1 p1) because of the limited time available (A fg1 p1; A fg2b p2 & 6) and the specialist nature of the work (A fg1 p1). She saw her involvement constrained by the service users' perception of her role (A fg1 p3 & 4). Most of her patients were also being seen by other physiotherapists or occupational therapists (A fg2b p2) implying that there was an alternative, possibly more appropriate person to raise sexual concerns with. Della felt patients might approach anyone in the team so all should have some skills (A fg1 p22). It was an area of practice she had no direct experience of (A fg2b p14).

Irene, like Della, has a specialist occupational therapy role, working for the local authority with a specific remit for environmental management. She opened her interview by saying that none of her service users had ever raised sexual issues (A iiA1 p1) which I found interesting as sexual expression had previously been part of her role when working in cardiac rehabilitation and stroke services (A iiA1 p1). When reflecting on her present practice she recognised situations where it might have been a concern for the service user (A iiA1 p1 & 2) but it was an area she did not cover.

She attributed this mainly to the focused nature of the work and that it was not a 'rehab type of environment' (A iiA1 p1). She was conscious of the pressure of waiting lists 'for things that we specifically need to do', the statutory requirements (A iiA1 p5). The limitation of her time (A iiA2 p3) was a strong deterrent. She described many things,
which might improve people's independence for example dressing, that she did not have the capacity to do herself (A iiA1 p5). She would refer these people to the community rehab team or elsewhere but,

Irene: … after a while you tend to be quite focused – sadly in a way – on those needs you can directly meet. Erm, and so I think probably there’s quite a lot of peripheral areas that are less… explored … I think probably I’ve got out of the habit of looking at some of those areas in as much detail really (A iiA1 p2).

She described the lack of time as 'a shame' although I noted in the margins of the transcript my sense that relief (A iiA1 p5) may accompany this. She suggested her supervisor too would not be 'overly keen' on her attending to anything outside the local authority's statutory obligations (A iiA1 p5). She saw a conflict between the priorities of the service and the potentially high priority a sexual problem could have for the service user. It could 'overshadow everything else' (A iiA1 p6).

Additionally she feared being intrusive or offending service users (A iiA1 p2 & 3; A iiA2 p4). In her previous roles, sexual expression was introduced as part of group work inviting people to approach therapists individually if they wished. In her current position, she was working one-to-one in service user's homes. She identified that she would be more comfortable if the client raised it (A iiA1 p3). She was aware she did not enable disclosure on sexual issues (A iiA1 p3). Even when considering replacing someone's bed, there would be no discussion of intimacy needs (A iiA1 p13).

In imagined scenarios, she indicated a level of confidence about what she could manage within her role and where she might refer on (A iiA1 p4). Within Disability Team A, she suggested the most relevant practitioners to address sexual expression were the specialist neurology nurses. Many of her service users though are not seen by other health or social care professionals (A iiA1 p4). She acknowledged a potential gap -

Irene: I think there are, you know, probably few professionals working with the (disabled) person, that would see it as specifically their role (A iiA2 p5).

Generalist occupational therapy roles

Anita, a manager, spoke about the place of sexual expression within the occupational therapy role (A fg1 p25; A fg2a p25). For her it was important to have 'boundaries' rather than a 'potential openness' (A fg2a p25). She described a line between discussing
sexual expression 'for a clear reason,' (A fg1 p25) as part of the wider functional assessment, rather than discussing sex 'per se' (A fg2a p25). Her example was in reviewing sleeping arrangements and considering specialist beds (A fg1 p15; A fg2a p25). Here she said it was important for occupational therapists to consider the intimacy needs of the patient and carer in making their professional recommendation (A fg2a p25). It was a task she said she felt comfortable with (A fg1 p25) but as a manager she worried that it was not always fully explored before 'beds were brought downstairs' (A fg1 p15). She had no formal strategies to explore sexual expression.

Anita: You just have to… you take it down as far down a path as you can possibly go and hope that they’ll pick up on sort of erm on the issues that you’re erm laying open, rather than… you can’t ask direct questions…/ (A fg1 p2).

Eliza commented that a number of occupational therapists she knew would be unable to explore intimacy needs when changing sleeping arrangements (A fg1 p16). This led Anita to think about training needs.

Anita: So I think there’s work to do, there’s ongoing work to do in making sure that people are looking at that, but then there’s also giving them the skills to feel comfortable with the issues that might come up once they’re sort of, you know, opening them up to be more open with those things (A fg1 p16).

She also acknowledged a personal component because what one person might be comfortable with another one wouldn’t (A fg2a p6). She said,

Anita: You couldn’t insist on people doing this in a certain way, I mean if the College of OT suddenly said ‘Right, you know, we want everybody to have a standard thing and everybody, you know, a protocol for discussing sex’, you know, I mean people just would be horrified, they’d just ‘I just can’t do that’ (A fg2a p16).

Despite suggesting sexual expression was a purposeful activity (A iiB2 p5) it was not part of Henry's practice. He did not raise it with service users and apart from one patient, no one has raised it with him. He disclosed,

Henry: … I know I have terrible limitations with this… … I’ve seen many people in the community, many people with many conditions, yet I struggle to recount specific issues around sexuality… which says a lot really (A iiB1 p12).

He used the research interviews introspectively exploring why he saw sexual expression as a 'taboo' and 'difficult' area (A iiB1 p1). This ranged from the organisational context (A ii B1 p3) to him as a person (A iiB1 p7). He suggested, with its problem solving, client centred approach, sexual expression could be part of occupational therapy (A iiB2
p14) but for him, it was not the 'norm' of practice (A iiB1 p7). He believed, as an occupational therapist, he had the potential capability to address sexual issues but unintentionally 'we keep away from it' (A iiA1 p2). He said sexual expression always,

**Henry:** … sort of remains separate. I think maybe a lot of times as services, we have kept that separate… that’s about, somewhere else or for someone else. … I don’t intentionally do that, but I’m wondering if that’s the message we’re giving people (A iiB1 p3).

It was more than lack of knowledge or experience because he was certain training needs would be met if sexual expression were routine practice (A iiB1 p10). He noted in other areas, how he was able to work comfortably 'with what I don't know' (A iiB1 p6). He indicated that the absence of sexual expression from any policies and procedures was 'almost giving you permission to avoid it' (A iiB1 p4). He felt no sense of authority to explore this area with service users (A iiB2 p3). At a personal level, he feared accusations of malpractice and, as a man, felt particularly vulnerable (A iiB1 p14-15). He talked of anxiety and risk (A iiB2 p2). These were about failing the client (A iiB1 p3); the responsibility in addressing such a sensitive subject (A iiB1 p6-7), and lack of support (A iiB2 p6). To undertake this work he cited the need for clear boundaries (A iiB1 p16) and protocols. As an occupational therapy team leader he also noted he 'couldn't ask staff' to incorporate sexual expression into their practice (A iiB2 p19).

Eliza said sexual expression was a legitimate part of occupational therapy and referred to the holistic nature of the profession 'looking at every aspect of a person’s life' (A fg1 p2). However, the discussion had highlighted for her how little it had been part of her practice (A fg1 p30). She never explicitly asked service users (A fg2b p7) in case it was not relevant or appropriate (A fg1 p2; A fg1 p30). My sense was that despite being the most vocal person in the first focus group she was defended and ambivalent (Team A NVivo memo). In the second focus group, I reflected on the implicit assumption of the research study: that professionals should be able to deal with sexual issues. I asked,

**Researcher:** How do I give you permission to kind of come down from that and say well maybe as a therapist I can do my work without taking sexual issues on board? (A fg2b p1)

**Eliza:** I think most of us, quite genuinely, when the thought is put in our head about whether it’s erm sexual issues or spiritual issues or erm, I don’t know… any… anything that involves human relationships, we do feel it’s part of our role, because of as OT’s we feel that we should be looking holistically… … I think most of us would, would like to think that we would explore all those issues. I mean, exploring them doesn’t mean that we think we’re the one that has got the answer or the person to tackle it (A fg2b p1-2).
I believe she is saying that sexual expression theoretical fits with occupational therapy but it is not currently in professional thinking; it is not 'put into our heads'!

She cited only two occasions when sexual expression had been discussed. Once when she was a basic grade at an orthopaedic ward round a patient had anxiously tried to raise the subject with the consultant but was dismissed in an 'horrendous' way (A fg1 p22). Eliza said to the patient -

**Eliza:** ‘That’s not what you wanted to hear was it?’ ‘No’. So I took her… to a nurse, a staff nurse from the ward because I was only a very new basic grade, and I had no understanding (A fg1 p22).

The second occasion was a man, a 'neuro patient' (A fg2b p7).

**Eliza:** … it was a very direct question, ‘I’m losing function in my legs’, you know, ‘all of this is happening to me – am I going to be able to continue to have sex?’ (A fg2b p7)

Because he asked a direct question, she felt she had permission to respond in a direct way and they talked about positioning (A fg2b p7). 'It wasn’t a lengthy conversation' but she felt it gave him 'enough' to manage what she saw as a practical problem (A fg1 p22). She noted how much harder she would have found it if he had included emotional concerns (A fg2b p7). She saw her role as talking about the practical side, beyond that, she would consider referral (A fg2b p7). She saw a boundary between occupational therapy, where she used 'pre-counselling skills', and counselling (A fg2b p9).

**Physiotherapy**

At the start of the focus group, Carol disclosed that 'quite often' in the gym, patients introduced sexual concerns (A fg1 p2). So there were examples from practice for the physiotherapists to consider. One incident occurred only the day before with a patient who had had a spinal cord tumour partially excised. During his physiotherapy, he said he had had an erection that morning, 'out loud in the middle of the gym with other patients near' (A fg1 p19). He was wondering if this was a sign of progress. Another example occurred during an assessment of a man with multiple sclerosis.

**Carol:** … obviously we look at physical aspects of how people are moving and all that sort of rolling on the bed and standing up and all that sort of… erm and it was sort of as he was moving around, he just came out with this… that he wasn’t able to perform … and obviously had some erectile dysfunction… (A fg1 p13).

However, there was some ambiguity about whether sexual issues *should* be part of physiotherapy practice. In the first focus group Carol said,
Carol: I think that physios should accept that role really, but we’re not prepared for it… I don’t feel confident in dealing with it in physical or psychological terms (A fg1 p28).

Thus suggesting a theoretical role but owning her lack of confidence. Likewise, Beryl implied an openness to consider sexual expression but it not being part of her practice.

Beryl: … I like to feel that I am open and that people could discuss these things with with me, it’s it’s not something that… er has ever really come up… so I have no, very little experience of of speaking to people about… such problems (A fg1 p2-3).

She felt it was not necessary to know the answers 'to these problems' but if a problem is identified they 'can direct them to someone who can help' (A fg1 p30). In the second focus group, I reflected what I saw as a theory practice divide and highlighted how this could be caused by the inherent bias of the research.

Researcher: One of the things that was really intriguing to me is that you were all saying yes in theory this ought… and I was thinking how, just by the very fact of me asking the question kind of puts that in the equation, and I think how do I enable people to say ‘Actually, no’. ‘I don’t want, this isn’t part of my role, I don’t want to do this’ ….

Carol: Yeah I mean last time in the summary I think you said ‘Well maybe it was physios rather’, or it sort of came on to us that there was more of a physical sort of physio role to deal with and I went away thinking ‘Gosh, is it?’ (Laughter) … You know, do we want to take that on – is it really our responsibility? (A fg2a p4-5)

She went on to consider if perhaps the physical aspects of sexual expression might be within the role but felt clear that the 'emotional sort of psychological issues' were not (A fg2a p5). Beryl agreed adding that given the lack of privacy in a gym 'you shouldn’t be asking … about these sort of things' (A fg2a p5). I understand this to mean that the physiotherapists were not certain that it should be part of their professional role.

However, they were faced with the dilemma of patients raising the subject with them.

Carol: But when they do want to talk about it anyway, that’s when it’s difficult to know where to take that you know (A fg2a p5).

She described what happened after her patient with multiple sclerosis had disclosed his problems in sexual functioning.

Carol: … and I thought well ‘I can’t deal with that’. … He said it in passing, not face to face… he was with his back to me, walking across the room on his crutches, demonstrating how he walked at that point, and he just came out with that… and erm I didn’t prolong the conversation, I didn’t really know how to deal with it (A fg1 p13).

Likewise with her spinal cord patient the day before, she thought to herself, not only was there an inappropriateness in talking in the public space of the gymnasium but she also felt that 'I just, didn’t want to go further with it' (A fg1 p3).
Speech and language therapy
The speech and language therapist Ginny indicated a theoretical role, which was followed through in her practice but she outlined boundaries and limits to the role. This included being responsive to inquiries but not initiating them.

Ginny: … from a role point of view, I mean most people wouldn’t associate speech and language therapists with having sort of sexual… any sort of role in sexuality. … I actually get approached quite a lot… erm within a hospital context and within the home (A fg1 p5).

She considered sexual expression to be part of communication and once patients saw beyond speech therapy as 'elocution' (A fg1 p5; A fg2a p9) -

Ginny: … it doesn’t take long before they’re asking me about their physical needs, their wheelchair problems, their… you know, and all the other things, and so I think my role gets bigger and bigger and bigger and I have to keep sort of saying ‘well have you spoken to?’ and ‘do you want to?’ and ‘do you want me to put you in touch with?’ and so I find I have a much more… I don’t even know the word…
Fiona: Sign posting effect (group laughter)
Ginny: Yes (A fg1 p5).

She was open to sexual inquiries and provided examples from her practice. This included one couple where the man had motor neurone disease. Ginny had a good relationship with them and he had approached her about the difficulties of oral dribbling during sex. So they talked about positions 'and things' (A fg2a p10). In another example, she was doing a lifestyle book for a woman moving into care (A fg2a p28). It outlined her daily routines and included private time for physical intimacy with her partner. Another example was the wife of a stroke patient who needed information on sex now her partner had been catheterised (A fg1 p18).

Initially she attributed this to working one-to-one in a private area (A fg1 p5) but later, on reflection, she felt it might be more to do with her, rather than her professional role (A fg2a p9). She described her profession as middle class (A fg1 p8), prissy (A fg1 p8; A fg2a p9) and po-faced (A fg2a p9).

Ginny: … so yeah maybe it is, maybe it is a ‘me’ thing rather than a speech and language therapy thing (A fg2a p9).

Ginny did not provide permission for service users to discuss sexual issues. The patients had initiated all approaches to her.
Ginny: … that’s been initiated by them… and if they’ve got communication problems that might be quite difficult for them to initiate, but it’s how, how comfortable I would feel about actually initiating that discussion. … I don’t think I’ve ever been aware of specifically asking any questions about, you know…(A fg2a p9).

Ginny appeared to be the only person in Disability Team A with good knowledge about referral resources and the role of sexual dysfunction services (A fg2a p7). In part, this may be due to her previous specialist experience of working with transgender clients.

Taking part in the focus groups made Ginny reconsider her professional role and the importance of communication to intimacy and sexual expression. She was left with questions about the depth and limits to the role including providing permission to discuss sexual expression (A fg2a p26).

Ginny: I suppose we, we ought to do it, we ought to do more… about it but then… should it be that we just acknowledge that yes there is a problem and here are the specialists I’ll pass you on to, or should we be specifically asking, you know, how’s your sex life and, you know, do you have difficulty communicating these things (A fg2a p8-9).

7.3 Evaluation of research objectives for Team A

Disability Team A members indicated that intimacy and sexual expression should, in theory, be part of service provision. The clinical nurse specialist was seen as the most appropriate person to address sexual expression although participants also considered it appropriate to occupational therapy and speech and language therapy. The physiotherapists were not sure about a theoretical professional role. However, patients did disclose to them, highlighting their lack of skills to manage disclosures positively. No members of Disability Team A were routinely addressing sexual issues in practice. The specialist MS / MND nurse and speech and language therapist had addressed issues when raised by service users. The occupational therapists had made some very limited interventions. No members of Disability Team A demonstrated confidence or competence in providing permission to patients to discuss their sexual concerns. There was little confidence and competence demonstrated to provide limited counselling and support. Apart from the speech and language therapist, the knowledge of support, guidance and referral resources for both the emotional and physical aspects of sexual expression were limited. The speech and language therapist had specialist skills around transgender clients but otherwise there were no unique or shared specialist skills within

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the team. As work was not being done in this area, support networks were not developed. The MS / MND nurse did identify her need for further learning.

7.4 Team B's narrative

The whole team
All eleven members of Disability Team B attended the first focus group. This was unexpected, as only nine consent forms had been posted back to me. I wrote afterwards,

   Post Group - 11 people!! Two turned up unexpectedly - did consider turning them away but it felt like I may alienate the team (Research Journal 12.05.03).

In terms of group process, this size of focus group was difficult to manage but it did mean that, unlike the other two teams, there were no absent voices.

In theory but
The first focus group began with three positive statements from Rhoda, Maeve and Lesha who all agreed that the sexual expression of their service users was within the team's remit. However, each statement carried a caveat: a but!

   Rhoda: I think it is (within the team's remit) and I think it causes people a great deal of distress, I don’t feel particularly well qualified to deal with perhaps issues that come up (B fg1 p2).

   Maeve: I think it is something that comes under our remit, just because of the way we look at the whole whole way of life of our clients really, and that that comes into it, erm, … it’s a bit of a sort of new… new thing to me to actually include that as part of my practice, to look at people’s sexual function and discuss it with them, but I think it is part of what we’re about (B fg1 p2).

   Lesha: Definitely, I think er I think clients would erm… ask us for advice if they felt that that’s what they wanted (B fg1 p3).

Rhoda said it was part of the remit of the team but she did not feel confident. Maeve agreed but had never included it in her practice before. Lesha considered it was part of the responsibility of the team but assumed service users would raise the subject. These statements epitomise the position of the team. The majority believed that, in theory, sexual expression should be part of the team's practice. In reality, very little work was done around this area.

   Kitty: I think that’s why we were all quite pleased to hear from you because we felt it was an opportunity to to highlight the fact really that we do feel it’s an important part of of working with people but that we’re not really fulfilling it and we’re not able to (B fg1 p5).
This theory practice divide provided the substance of the focus groups, with much of the discussion on the deterrents to practice.

There were two significant exceptions to this position. Firstly, Nancy was adamant that sexual expression should not be raised. Secondly, Odele did include sexual expression routinely within her work. These alternative stances are developed later.

**Enabling disclosure**

Sarah challenged Lesha's view, that patients would raise sexual expression.

Sarah: I do agree that it is something we should look at but I don’t… imagine that a lot of people would feel comfortable asking for advice on it… I think if you bring it up and say it to them – ’Is that a problem?’ – then perhaps some people would (B fg1 p3).

Sarah was describing the need to give permission and yet she went on to say that she personally would not be able to give permission, to ask 'those sort of questions' (B fg1 p4). Kitty noted that there was a question on relationships and sexuality on the initial assessment form so the practitioner 'has the opportunity to ask ' (B fg1 p4). However, the key worker usually completed the assessment at the first visit, which was not seen as the right time to ask about sexual issues (B fg2a p19).

Sarah: I think we would probably all would agree we skim over that a little bit, you know, and then you’ve got to remember … I’ve got to pick it up later but you may not be the professional next going in and it can easily get lost (B fg2a p19).

Kitty spoke for the team when she said no one generally provided permission routinely to discuss sexual issues (B fg1 p4).

Despite no explicit permission, some service users had raised sexual issues with team members. Rhoda particularly, but also Lesha and Quita, all had examples from practice. However, Rhoda noted how disclosure could be avoided.

Rhoda: I think it might be the hints that people drop that maybe we choose not to pick up, because like people will say to me 'Oh, you know, we just don’t have any time to be together’ or 'It’s difficult to be close’ or, you know, and I I know I have thought oh I’m not going there today, so you just say ‘Oh yes it’s very difficult’ or you know ‘I can understand’ instead of actually they’re, what they’re actually I think is trying to hint that there is actually more… to it, and perhaps that’s where you don’t pick up.

Researcher: So you’re saying Rhoda that we choose perhaps not to pursue the hints that are dropped?

Rhoda: Sometimes yes (B fg1 p16).
A dissenting voice

Nancy did not agree that sexual expression should be raised (B fg1 p4). She reasoned that it was a service user's right to choose whom to talk to (B fg2a p17). She said sex was not important for everyone and that the patient would raise it if they wanted to (B fg2a p17). Others challenged her. Quita suggested their service users probably had an increased incidence of sexual concerns, and disability professionals, by providing permission, gave a choice to service users to talk if they wished (B fg1 p19). Nancy was adamant that patients, if they had a problem, would manage this within their own social networks (B fg1 p19). Rhoda highlighted the isolation of many disabled people.

Rhoda: But if people are very isolated they can’t/
Nancy: You’ll seek somebody out to unburden yourself and I think clients do exact(ly, the same) they’re not different.
Rhoda: They do that (disclose) to us because they can’t get out.
Nancy: No, they’re not different to other people.
Quita: That’s why they choose people like Rhoda I think purely because… you the cha, a chance is there and then they need to unburden.
Nancy: But you don’t routinely discuss those things at work, well why do you expect clients to do it? And if they do have a need then they will probably seek somebody out.
Quita: They’re more likely to have a need aren’t they because of their disabilities.
Nancy: Are they?
Quita: Well yes, because fatigue aspect and all the other disabilities/
Nancy: Yeah, again it’s what’s important isn’t it (B fg1 p19-20).

I experienced Nancy's contribution as hostile (Research Journal 12.05.03). Repeatedly she expressed the belief that patients would raise sexual issues if it was a big problem but otherwise it was something 'they have to deal with themselves' (B fg1 p6). For her, the clinician raising the subject was not equated to giving the service user permission. Rather it was intrusive and did not respect their privacy (B iiA2 p8).

Nancy was quieter in the second focus group. At the start she said that, in the intervening weeks between groups, 'several times' she had been approached by services users wishing to talk about sexual expression (B fg2a p2). It was 'uncanny' (B fg2a p2) and she felt 'spooked' (B fg2a p2) as it had not happened before. She attributed this to being aware: more 'more tuned in' (B fg2a p2). She did recount one of these episodes (B fg2a p25-26) but, later in the focus group, became quiet with a 'closed posture' (Research Journal 16.06.03).
She telephoned me after the second focus group as it had distressed her (B iiA1 p1). She spoke of her experience not just as a health care worker but also as a carer. Nancy had been widowed only fourteen months earlier. Her husband, in his mid fifties, was diagnosed with cancer and died, at home, ten months later (B iiA2 p2). She had felt inhibited in the focus group with her colleagues, who, she said, 'tip-toe around her' (B iiA1 p2). We agreed an individual interview.

In this, she described what for her had been the 'undignified' process of dying (B iiA2 p4) and the constant intrusion of professional care that accompanied it (B iiA2 p3 & 4). She undertook the nursing care for her husband. In the second focus group, she had found the team discussion about roles of lover versus carer particularly difficult (B fg2a p28). Amongst everything else, 'the dying', she did not experience the loss of sex as a big issue for them (B iiA2 p9). Yet she described the intimacy they were able to maintain (B iiA2 p5 & 9). To the end, it was important for them to share the same bed and she had managed to get a double pressure care mattress (B iiA2 p16). As a carer, Nancy would have resented sexual expression being raised with her (B fg1 p4) seeing it as intrusive (B iiA2 p8). The importance of personal experience is developed later (see section 11.5 - Personal experience guides practice).

**The other nurses**

Kitty, the team leader, took a supportive role in the focus groups encouraging others to talk but saying little about her own practice. I formed the impression that she was keen for the team to do more in this area (Team B NVivo memo). When Quita was describing a client, where sexual issues had become part of the physiotherapy intervention, Kitty commented that this may be just one case out of the 850 cases presently on the team's case load (B fg1 p5). She mentioned training, arranged for the team some two years before, on the PLISSIT model (B fg1 p13). She was concerned about supervision and how any learning could be made part of practice (B fg2a p24).

*Kitty:* It’s not just a matter of having a study day on it either, it’s the ongoing support if you do actually get… you know, start to make it, you know, much more a part of what you do (B fg2a p24).

I suspected that she was personally more comfortable with the subject possibly because she had previously worked in an HIV and AIDS setting.
Rhoda spoke substantially more in the focus groups than other team members did. There may be several reasons for this but two factors are pertinent. Firstly, she appeared to be the team member receiving most indicators from service users that they had sexual concerns (B fg2a p29). Also, she presented deep levels of personal conflict about sexual expression within her role. She said sexual expression should be part of the team's remit (B fg1 p26) but prevaricated. Having positively explored how the team could provide permission (B fg1 p31), in the second focus group she said -

*Rhoda:* … and er part of me doesn’t feel comfortable with making it more overt because I really I’ve got a thing about that well if you make it more overt you making it sound like we can do more about it and in actual fact we’re having a big struggle to actually do anything about the issues that we find now (B fg2a p19).

I sensed a little hostility or resignation, which I attributed to possible feelings of powerlessness. This is more explicit in re-writing her last line as 'I'm having a big struggle to actually do anything about the issues that I find now'.

So despite feeling sexual expression was important, in practice, it was difficult and sometimes she chose not to respond (B fg1 p16). For her there were many deterrents to practice. These included not feeling qualified or trained (B fg1 p2) especially around relationship issues (B fg1 p12). She had no confidence that it was part of her role (B fg1 p8-9). She indicated that she could listen, give general advice, help service users identify the problem but then there was 'knowing what to do from then on' (B fg1 p2). She described her increasing insecurity when the work moved toward relationship issues and working with couples (B fg1 p12). For example, she described working with one young woman whose sexual expression was affected by fatigue, numbness in her pubic area and vaginal dryness.

*Rhoda:* So that’s to me, that is a real legitimate role but then that did then open up into other areas. It started with purely physical things and what could she do to manage that and then went, it sort of because once you start talking about that sort of thing you can’t say ‘Right, I’ve dealt with that, stop now, I don’t want to talk to you anymore’ (B fg1 p12).

I wondered if she merged problems of intimacy and sexual expression secondary to disability with the overall quality of the service user's relationship with their partner.

She also spoke about not feeling supported by the Trust, suggesting that the Trust would not approve her taking on a facilitative role around sexual expression (B fg1 9 & 22; B fg2a p29). Additionally she said referral resources were limited. She had referred
service users to psychology but was deterred by the long waiting lists (B fg1 p12, 13, 14) and the limited nature of their intervention.

Rhoda: I think that on average they usually get like six sessions, so they start working, and quite often it’s enough to raise a few issues or bring their awareness up but it doesn’t actually solve the problem and then they’re left with… with what they’ve they’re left with and then it’s just left to the key worker to deal with the other issues (B fg2a p9).

Limiting psychology to six sessions, she did not see as helpful (B fg2a p9). She had also referred patients to the erectile dysfunction clinic and counselling services but again there were long waiting lists and she said these services had no expertise in disability (B fg1 p12 & 14).

Psychology
Odele was the only team member to confidently own sexual expression as part of her role (B fg1 p7). For her sexual expression was integral to psychological and physical well being (B fg1 p7) and, although uncommon (B fg2b p8), it had been part of her interventions with service users (B fg1 p7; B fg2b p8). She did not routinely raise the subject but used her professional judgement, 'almost a hunch' (B fg2b p8), in deciding when to invite discussion. She saw her remit as working with issues arising from the disability (B fg1 p28). Where sexual problems arose from some earlier trauma, she was expected to refer on to other services (B fg1 p28). Where appropriate she would see the service user and partner together and separately (B fg1 p7). Often the work was around loss (B fg1 p8). Her expertise was in the emotional aspects and she said -

Odele: I wouldn’t feel that I’d er be in a position to assist somebody with making suggestions about, you know, physically about sex, if if they were having a specific problem, I wouldn’t have the faintest clue about what to suggest (B fg2b p7).

On reflection, she did not identify any one in the team she would refer to but said she might refer back to the consultant (B fg2b p7).

Odele did not act as a key worker and therefore referrals to her were dependent first on identification of a problem and second, agreement of the service user to be referred. Getting agreement from the service user, was seen by other team members as problematic (B fg1 p13; B fg2a p7).
Occupational therapy

Maeve had only been in the team six weeks. Prior to this, her work had been in an acute hospital setting where 'sexuality didn’t really get a look in' (B fg1 p23). She described herself as being comfortable in asking open-ended questions about how couples were coping but would never ask direct questions about sexual expression (B fg1 p5). She compared it to continence, another area that she would not have raised before joining the team (B fg1 p30). However, she had learnt how to phrase questions within the assessment and now felt confident raising continence issues. She asked -

Maeve: I know maybe perhaps sexuality is more personal but they’re both still sensitive subjects, so why one and not the other? (B fg1 p30)

Speech and language therapy

Both Sarah and Shena did not raise sexual expression with service users nor had it been raised with them. Sarah echoed the theory practice dilemma feeling that sexual expression 'is something we should look at but I don't' (B fg1 p3). She did not feel qualified and even doubted her confidence 'to just listen' (B fg1 p3). She lacked knowledge and experience and wondered about appropriate boundaries and vocabulary (B fg1 p3). She too compared it to asking about continence, which she had learnt to do as part of her responsibilities as a key worker (B fg2a p18). Initially she had found this uncomfortable (B fg2a p18) but was helped by knowing about referral resources and having observed how others managed the task (B fg2b p6). Likewise, Shena noted the fit of sexual expression with both speech and language therapy (B fg2b p6) and the key worker role. She said that, like others in the team, she would be willing to discuss sexual issues (B fg2b p9). However, she shared some of Nancy's concerns about raising such a private issue (B fg2b p3). She said she would find it difficult to raise on an initial visit or when she did not know the service user well (B fg2b p4) yet recognised that people may not know they can discuss it, if it is not raised.

Physiotherapy

Amongst the physiotherapists, Janet, Peggy, Lesha and their support worker, Quita, there were differing views. Lesha and Quita did not directly raise sexual expression but would consider it, if raised by the service user (B fg1 p3). 'One or two ' of their service users had confided in them (B fg1 p3). In one example, they were jointly working with
a woman whose physiotherapy intervention plan was couched in terms of getting back to the marital bed (B fg1 p11). They attributed patient disclosure to the intensity of the work, which allowed a good rapport to develop (B fg1 p3). In the example, it was also about the personality of the service user and her openness (B fg1 p5). Another example that Quita gave was of a woman who sought reassurance that if she needed personal care in the future her husband would not be expected to provide it; 'because she wanted him as a husband and a lover' (B fg2a p28).

For Janet and Peggy, sexual expression was not part of their practice (B fg1 p4). Janet said they were good at identifying problems in a relationship but there was a boundary, which stopped them asking questions about sexual aspects.

**Janet:** … and certainly as a physio I don’t ask directly and in all my time I’ve not really ever got involved with that, so I don’t think they, you know, if you think of the percentage of people we’re addressing those issues with it’s very very small from our client group, but in fact it must be quite a big problem with, with a large number of them (B fg1 p4).

They felt they had no referral resources, no formal training and no expertise (B fg1 p4-5). Without formal training Peggy noted,

**Peggy:** … as a physio we shouldn’t be doing something actually we haven’t been trained for (B fg1 p9).

But it was not just the absence of training acting as a deterrent. It was also about limited time and treatment priorities (B fg1 p10).

**Effect of doing research**

A marked feature in this team was the change that occurred between focus groups. Kitty opened the second group with -

**Kitty:** We don’t know whether you’ve got some sort of magic vibe but a couple of people in the week after you came had several instances of people wanting to talk about sexual issues (B fg2a p1).

Those affected by *first case scenarios* included Nancy, Rhoda, Maeve and Shena. Mostly this appeared to be about increased awareness. For example Maeve described seeing two service users where she was more alert to their concerns.

**Maeve:** … there has now gone, flags up in my brain. … but I suppose it’s like erm for any part of my OT erm assessment, if if things don’t get flagged up in some way that there’s a problem then I’m not going to pursue them with huge sort of tenacity (B fg2b p5).
The example Nancy gave was a man who spoke to her about the loss of physical intimacy in his marriage. His wife's role had changed from lover to carer (B fg2a p13). This disclosure was a new experience for Nancy which she attributed to the fact that 'he felt he could talk to me' (B fg2a p26).

Nancy: I think he felt totally emasculated... erm and he he stopped being even a person never mind a husband... (B fg2b p26)

No action was necessary other than to allow him to mourn the loss, which he found helpful. I did wonder if she was telling us (the team and me) that she too could hear sexual concerns. On balance however, I felt her raised awareness had created a facilitative environment that had allowed her to hear and respond in an affirming way.

**The professions seen as appropriate**

Odele owned sexual expression as part of her role although she noted personal limitations around the more physical aspects of disability and sexual expression (B fg1 p15; B fg2b p7). Lesha echoed this suggesting that when she had referred to Odele it had been about relationship issues whereas as a physiotherapist she might be 'going in with a different angle' (B fg2a p4). At one point in the group Odele suggested that different professionals on the team potentially could work together to address sexual issues. She cited the physiotherapist's knowledge of 'physical mechanical things' that as a psychologist she knew very little about (B fg1 p15). Janet responded,

Janet: But it’s not something that really as physios we’ve actually looked at very much... so it’s ignorance on my part (B fg1 p15).

However, the consensus suggested that it was a nursing responsibility and therapists expressed concern about the level of support the nurses received to manage this (B fg2a p27). Kitty also acknowledge that possibly one of the difficulties was that,

Kitty: … it probably does fall more heavily on certain members of the team and maybe more support is needed but we don’t know where that’s coming from either...(B fg2a p29).

**7.5 Evaluation of research objectives for Team B**

Apart from the one dissenting voice of the incontinence nurse, Disability Team B members indicated that intimacy and sexual expression should, in theory, be part of service provision. The team leader expressed concern that it was an aspect of care not
being managed well at the present time. The psychologist was the only professional to clearly encompass sexual expression within her professional role but this required referral, as the psychologist did not act as a key worker within the team. Otherwise nursing was seen as the most appropriate profession. The occupational therapist and some physiotherapy personnel considered aspects could theoretically fall within their professional role. Apart from the psychologist, no team members demonstrated non-intrusive permission giving skills, enabling service users to discuss their sexual concerns. No members of Disability Team B were routinely raising sexual expression. Some referral resources were identified but they were seen as limited either because of waiting times, limited intervention or lack of expertise in disability. The psychologist identified her proficiency around the emotional and relationship aspects of sexual expression. One nurse felt more confident in addressing physical aspects of sexual expression but revealed anxiety around the relationship and emotional issues. No professional development and support systems were identified.

7.6 Team C’s narrative

Sexual expression is a concern for disabled people
Disability Team C had previously identified that sexual expression was a concern for their service users: ‘that it was a gap we weren't filling’ (C fg1 p20). Based on this awareness, some three years earlier they had invited a representative from SPOD to speak at a team meeting. Consequently, they had altered their multidisciplinary initial assessment tool to include a question on relationships and sexual expression.

The initial assessment
The first focus group opened to a discussion about this screening tool. The SPOD event had highlighted -

    Tracy: that it was a question that we should be asking and so we put it on to that very first assessment (C fg1 p3).

This was a clear and open approach that indicated that sexual expression was of equal importance compared to other aspects of function. However, it was a section -
Yvonne: … hardly ever completed or filled in and people found it quite difficult to ask.
Tanya: I think we decided that was too confrontational on the first visit.
Yvonne: Which is why we stopped (C fg1 p2).

The difficulty was discussed. The timing of the question felt inappropriate if the patient was still in hospital (C fg1 p3). Also, at the initial assessment, rapport had not been developed. Part of screening was to assess suitability, so the question was being asked before it was established if this referral would be accepted (C fg1 p3). Sometimes it was about lack of privacy as other relatives may be present at the assessment (C fg1 p3).

Tracy: So we found that more and more it was getting left off, so when we revamped the form we were… up front enough I suppose to leave it off this time but it hasn’t been replaced anywhere else formally (C fg1 p3).

It has been omitted from the form for approximately a year now.

**A responsibility felt by the team**

Seeing sexual expression and intimacy as important to service users placed responsibility on the team to include it in their practice. I wrote that I sensed Disability Team C was proceeding with more authority to address sexual expression (Team C NVivo memo). Yet, this apparent consensus is deceptive. Tanya, Yvonne and Wendy appeared as the 'flag bearers': the team members supporting this viewpoint. From their perspective professionals should create the opportunity for service users to discuss their concerns if they wish. Whereas Vicky, Tracy, Xavier and Tatum agreed in theory but expressed less certainty and confidence. For example, Tracy said she only considered sexual issues if the service user brought it up (C fg1 p2). Zanna believed other members of the team were managing this aspect of care making it unnecessary for the psychologists to be involved (C iiC1 p1). Also, some team members who did not participate in the research, would not raise sexual issues (C fg2 p2; C iiB1 p11).

**The flag bearers**

Tanya presented with authority and confidence in addressing sexual expression and appeared to provide a role model for the team (C fg2 p7). She seemed adept at picking up subtle hints around relationships and had developed strategies to invite exploration without intrusive questioning (C fg1 p4-5). She attributed this to the privacy and one-to-one nature of her work (C fg1 p5). She had heterosexual and lesbian examples from practice. Tanya only saw patients with speech and communication difficulties.
Yvonne neither asked service users about intimacy nor explicitly gave permission to discuss sexual expression. Yet, I sensed that an awareness of sexuality was embedded in her practice (C fg1 p19-20; C fg2 p5). In her assessments she asked patients what they felt their physical problems were and, 'a surprising number will say sex' (C fg1 p19). In her view, including the question on the initial assessment was a positive step although she understood why it was taken off (C fg1 p10). She noted a change since qualifying in 1975, when sexual expression was never raised, to open discussion now.

**Yvonne:** And I have to say more since I've worked here and I don't know whether that's just because time has moved on and people are more prepared to discuss it now, but I... the number of cases before, I can probably count on the fingers of one hand and now... it's it's nowhere near the majority of people but it is a substantial... number of people (C fg1 p19).

Yvonne went on to quantify this, suggesting that perhaps almost a quarter of Disability Team C's patient group expressed sexual concerns (C fg1 p19).

Wendy had supervisory responsibility for the other occupational therapists and had introduced an Activities of Daily Living assessment form that included sexual expression. She assumed a position of authority regarding sexual expression, within the focus group. She was the only person who had attended a post-graduate course on sexual issues in physical disability (C fg1 p26). Sexual expression had become a routine part of her practice both in Disability Team C and in previous occupational therapy roles (C fg2 p4). She had heterosexual, gay and lesbian examples from practice. Wendy described herself as one of the few people that think sexual expression is something that health professionals 'should just routinely address' (C fg1 p9). Wendy had recently been widowed and drew on this experience in the focus group (C fg1 p9). In my field notes, I ascribed Wendy the title of the voice of boldness (Research Journal 12.11.03) because, in her examples and contribution, she was bold and confrontational.

**Some team members are less certain**

I gave the title the voice of caution to Vicky, Xavie, Tatum and Tracy (Research Journal 12.11.03). Tracy had been in the team eight years and Vicky nearly a year. Xavie and Tatum had only been with the team for four and six months respectively. Vicky frequently sought solutions to the inherent tension between the stated importance of enabling service users to discuss sexual or relationship worries and the difficulties of doing this in practice (C fg1 p30). She made several suggestions to alter procedures, so
that sexual expression could be routinely raised (C fg1 p29 & 31). These four practitioners disclosed their discomfort and spoke of the many deterrents in practice. These are developed in future chapters. In summary, they had no sense of expertise.

Wendy directly confronted these concerns, but was interrupted by Tracy.

Wendy:  … that is a big issue that I think we get ourselves screwed up around saying we are not expert in that … you know. Well we should be beginning to be expert and I have worked in so many different jobs where people have said thank God somebody has brought it up I mean to the extent now where I actually say that we should er, you know /

Tracy:  / So where have we got in the team a file that says 'Advice on sexual dysfunction' we've got a /

Wendy:/We've got leaflets … does it… is it actually so difficult to say to somebody "Are you having problems… in your sexual relationships?"

Xavie:  Its going to be difficult because it is not standard practice

Wendy:  But I do it… with my patients (C fg1 p9-10).

Differences between members can be seen. Wendy was saying professionals should be gaining expertise. Tracy refuted the routine nature of practice in the team, evidenced by having no resource file on the subject. Xavie believed that addressing sexual expression is 'not standard practice'.

An example from practice

Tatum introduced an example from her practice in the team. This provided a useful vehicle for discussion in both focus groups. It was the only time someone had tried to raise sexual concerns with her. It involved a man who had had a stroke.

Tatum:  Erm well the only experience I've had on the team here is... it's just I think people do find it quite difficult to bring the subject up and it was... something I don't routinely erm bring up, but it's just I went to to somebody's home and (his wife) just suddenly got terribly upset and and said that erm... the patient er, her partner, had become less cuddly and how it was just awful, just terrible and then she ran out the room crying... and he just stood there just thinking oh dear, you know, and and he went out into the garden … She ran into the kitchen and what she was saying was that they've got no sex life. … When I came back here I knew I had to do something about that and... I spoke to some team members here and and obviously dug out the leaflets which erm I sent... to her erm... and for him to have a look at as well and... I think he was just afraid of having another stroke... and I think having read the leaflet, I think they probably both did, I didn't ever check that they had to be honest... er but he did come in very very cheerful (group laughter)...(C fg1 p16).

This example highlighted many issues. Firstly, it demonstrated the priority of sexual concerns to some service users. Despite the involvement of four team members, no one had formally provided an opportunity for the service user or his partner to discuss their sexual concerns. On her last visit, when Tatum was concluding, his partner made a
disclosure. There was a sense of urgency: the partner's last opportunity to raise a major worry. The example also demonstrates the problems of discussing sexual concerns both in terms of language and feelings. Tatum assumed "being less cuddly" was a euphemism for the cessation of sexual activity. It was not only difficult to tell the therapist, it appeared the couple had not been able to discuss these concerns with each other, either. They and the therapist were embarrassed.

The example also revealed Tatum's lack of confidence and skills. She acknowledged in discussion that she didn't know what to do. Exploring it with the couple was difficult.

Tatum: … I spoke to her in very broad terms on the hoof, because, thinking well what am I gonna do here to think on my feet, so I just sort of saying, you know, oh you er… do you think he's afraid that he might… have another stroke? Do you, would you, think there are other issues around that? And she thought that maybe he did and she was worried and whatever and she calmed down, I went out to speak to him, he was in the garden, so … called him in as well and I just said that we'd got some leaflets back at base for them both to read (C fg2 p16).

Anxious and unable to explore further Tatum made an assumption about what the issues were. She did provide information, a leaflet, but did not check if this was the necessary and appropriate action.

Wendy's examples from outside the team

Wendy's examples were very different. She drew mainly from previous roles and, in repeated listening to the tape, I found myself reflecting on her process in presenting them. In one example, from her work at a low back pain clinic, I felt she was modelling how to confidently raise the subject and provide information in a light hearted manner (C fg1 p14). Another bizarre example was not about disability, rehabilitation or occupational therapy. It arose from a time when she was involved in making hand splints. She was approached to make a phallus shaped splint to assist surgeons in undertaking reconstructive vaginal surgery. It involved a member of staff finding a suitable object, a large syringe case, on which the splint could be moulded.

Wendy:… I said "Can you get... can you get us a big syringe case and tube?'", and well she came back with something that was about the size of a pencil, you know, and I (overlapping group comments here)... and I said erm... she was er she was about 21 and I said... "I don't mean to be rude" I said "but are you a virgin?" and she said yeah, I said right... you what you've given me is about the size of a tampax, that isn't gonna be a lot of good for this woman who's got... a partner or/...(C fg1 p23).

The member of staff was very embarrassed and Wendy spoke of the difficulty people
who are sexually inexperienced may have in talking about sex (C fg1 p24). This example created noticeable discomfort amongst others team members particularly Vicky and Tatum. On reflection, I suggest Wendy may have been informing the team that she was both widely experienced and unshockable. It provided an example of sex as taboo, that is some participants had a negative emotional response to this disclosure.

Tracy confirmed this in her individual interview saying,

**Tracy**: I was feeling angry because I just thought that’s Wendy all over, just not to understand… not to be sensitive to… the fact that… it wasn’t required of that girl, as an occupational therapist, to be sexually experienced, and it wasn’t part of her training and… if you, like, she (Wendy) is the more mature experienced therapist it was her duty to help her (the junior staff member) grow and understand and not to humiliate, because what what… what was that girl learning from that experience, probably she’d never want to talk about sex again with a patient… … to be celibate or not to have sex or not to have a partner… is just as much a right to be respected as being sexually experienced and feel free with your body and and that you can talk about it… and I felt I felt quite cross actually… that it was er seen as a erm a weakness of that girl, because I thought well that could have been me… to be like quite honest, it could have been me that she did that to… whereas Wendy sees it as… see aren’t I great, I can talk about sex I’m… I’ve got no problem talking about penises and vaginas and… erections and… so forth, why can’t you (C iiB1 p9).

Tracy was angry that the junior member of staff's innocence was interpreted as a lack of clinical skills and a point of professional criticism. It is a good example of the affective response that can be engendered in discussing sexual expression.

**The psychologists**

Although Zanna and Unwin took part in the first focus group, their contribution was significantly less. They described being focused on cognitive issues, therefore they said, sexual expression fell outside their remit (C fg1 p6). They introduced their role to service users as being around cognition and mood. Zanna noted this may close the doors to disclosure and outlined her reasoning (C iiC1 p1). Firstly, it was linked to the lack of psychology hours within the team (C iiC1 p1). Zanna had two half days allocated to the team. Whereas other disciplines could offer 3 or 4 sessions per week to a service user, she could never offer more than one (C fg1 p15). She felt that she had to be very specific, prioritising work that could not be dealt with by other members of the team (C iiC1 p1). A consequence of having less contact with service users meant their rapport was less developed too (C fg1 p15). From her perspective sexual expression fell better to occupational therapy (C iiC1 p1).
The support worker

Vince's voice sat outside the team, partly because he attended interviews not focus groups and also because he was a support worker. He did not have autonomy, saying he must ‘follow the instructions of the therapist because they are responsible for what you do’ (C iiA1 p3). Vince regarded sexual expression as an important concern for service users, which should definitely be part of the team's remit (C iiA1 p5), but it was not for him to raise the subject. Nor had he been asked by a therapist to address it in his practice (C iiA1 p3). He had heard the team discussing service users' sexual concerns including, on one occasion, a client who had discussed his sexual surrogacy arrangements with the previous psychologist (C iiA1 p7). Beyond that, I felt, Vince was making assumptions about the expertise of the qualified staff. In essence, he was saying he did not know how much it was included in the work of the team.

Vince: . . . But as I said I’ve heard from referrals that people have sexual problems but I don’t know how they’re dealt, the therapist, in the end I don’t know…(C iiA1 p14).

He did have rare examples of male service users implying to him they were experiencing sexual difficulties (C iiA1 p4; C iiA2 p3). His action each time was to advise them to tell their therapist.

What Vince did explore and develop were the issues of being a man working in a disability team. There were three main aspects to this. Firstly, there was the anxiety of accusations of professional misconduct. Because men are considered sexually predatory, he believed they needed to safeguard themselves from any accusation of improper conduct (C iiA1 p16; C iiA2 p2&10). Secondly, he was used as a chaperone to accompany therapists if they were feeling at risk (C iiA2 p5). Finally, the catchment area of Disability Team C is ethnically diverse. Vince described how work was delegated on a gender basis between the two support workers in the team, one male and one female. He suggested 80% of the Asian population, particularly amongst the Muslim community, preferred a worker of the same sex (C iiA1 p3).

Not all workers will include sexual expression

Overall, the sense from the team was that sexual expression should and ought to be included in the treatment remit. The disparity, between this position and the difficulties in practice, led some of the team, to explore procedural changes - to seek solutions (C
One option identified was to place responsibility on the key worker. All professional staff, with the exception of psychology, undertook the initial screening assessment and acted as key workers but responsibility for raising sexual issues could not be left with key workers alone because,

Tanya: Yeah but not everybody on the team's happy … no not everybody's happy to do that (C fg1 p29).

The participants in the study noted that they might have a more positive perspective on sexual expression as part of practice than others in the team 'who perhaps voted themselves out' of the research (C fg2 p2). Some of those not present, would be unwilling to enter discussion regarding sexual expression with service users. Tanya refuted a suggestion I made that those who had not been at the SPOD team event may be less comfortable to raise sexual issues. She went on the say,

Tanya: a lot of the people that haven’t come to this (research) were at the SPOD… and they are people that erm wouldn’t bring it up (C fg1 p4).

Personal issues were seen as stopping these people addressing sexual expression. Tracy developed this further in her individual interview. She challenged the implication that the team routinely addressed sexual expression.

Tracy: And we all weren’t doing it either so we weren’t doing it consistently (laughter)... like Kaamilah wouldn’t dare ask it. … And I respect her, I mean Kaamilah, you know, brought up as a Muslim and she’s a practising Muslim and she… she’s a very… lovely person and, you know, she’s not been, in her culture, been brought up to talk about sex in such an open way and she would she wouldn’t feel natural doing it and that’s fine… and why should she be put under pressure… to do that, you know (C iiB1 p11).

My impression was that those participating in the research accepted, and respected, this individual position of other team members. Vicky pointed out it was not due to these workers' lack of awareness but personal issues.

Vicky: Yeah I think, I think even they wouldn’t deny that… people need the opportunity to do to to discuss these things (sexual expression) or erm that that is to raise them and be be directed in terms of seeking help so it’s not that they don’t see a need, it’s more they don’t personally perhaps feel they could address it… you know oh may be embarrassed about or whatever I can’t speak for them but… it’s not a denial of need I don’t think on their part, more a more of their sense of er “I I don’t think that I could do this” (C fg2 p2).

Support to practice
A recurring theme was the importance of sexual expression to service users against the difficulties of facilitating disclosure.
Vicky: I think we’re all aware that from the patient’s point of view it’s an important part of their lives and therefore … it’s about opportunities to ask the question and erm certainly where we work in physio it’s quite a public area and even when situations arise where something’s said there’s a tendency to not follow through … simply because, you know, there are too many people around basically … erm and because it’s not formally any one person’s job to do it. If it’s not raised incidentally then it’s quite often not addressed … I think (C fg1 p4).

Unlike Disability Teams A & B therefore, much of the data is not about whether sexual expression should be raised but about the factors that support or deter team members in addressing this aspect of care. Deterrents are explored in future chapters. What are presented here are the factors that instil greater confidence and competence in this team compared to Disability Team A or B.

I believe the greatest weight must be given to awareness. It is difficult to identify what triggered this. With the exception of Wendy, it does not appear to arise from professional education. It was enhanced by the team's SPOD training. Awareness may allow service users to own the importance of sexual expression for them - even 'on the first visit they may want to talk about it' (C fg1 p4). Thus, there is a self-perpetuating cycle: some therapists in the team did include sexual expression within their practice; that triggered team discussion; that begets awareness.

Providing permission is the next step from awareness. Yvonne used the expression opening the gate.

Yvonne: But having asked the question right at the beginning then … eight weeks into the episode … because the question has been raised that they've given that you've opened the gate and then they, and then they can say "You know you asked me" or "By the way….", you know (C fg2 p22).

Some members of the team had developed permission giving strategies. Tanya and Wendy worked within the PLISSIT model, explicitly raising the subject routinely. Some in the team introduced the subject when they thought it was an issue.

Tracy: I'm more up front about asking the question.. with with… very little of a hint from a patient (C fg1 p3).

And all in the focus group would try to work with the information if the patient brought up sexual concerns. Timing and sensitivity were both considered important. Although the initial interview was seen as too soon (C fg1 p3), several people felt the topic should be raised early in treatment (C fg1 p11) thereby providing permission for patients to discuss their concerns, as and when, they needed to.
Another supporting factor was that, having provided permission, sometimes the task, seemed relatively simple. Yvonne suggested that some patients were able to deal with the issue themselves. The intervention then is one of affirmation: 'allowing them to express the thought' (C fg2 p22) and legitimising their concerns (C fg2 p19). The patient might need referral on to user groups (C fg2 p22) or active support to see their GP (C fg2 p23). Intervention might include accessing information that patients could follow up, either independently or with the therapist (C fg1 p6; C fg2 p16 C fg2 p22). Sometimes it was about helping a couple communicate.

Vicky: … it's giving people permission to talk about it, not necessarily just with you, but with each other because he doesn't want to bring it up in case it's a pressure that she doesn't want, she doesn't want to say it because she's afraid for herself (C fg1 p31).

Often it was about addressing a service user's fear, for example of having another stroke (C fg2 p16; C fg1 p10; C fg1 p22), being undesirable (C fg1 p10), or of hurting the disabled partner (C fg1 p17). Occasionally it required specific treatment. Wendy described a treatment programme to address a sexual problem caused by the woman's tight hip adductor spasm. Wendy recounted the gratitude of the couple adding, 'it was such a simple thing to do' (C fg1 p27). Unwin suggested that raising sexual expression could also help to 'highlight there is a service gap in the area' (C fg1 p16).

Another important supporting factor was the holistic nature of the work of Disability Team C and the feeling of involvement 'with the whole of an individual's life' (C fg1 p20). Working in the community was seen as particularly helpful, as the role of the team was not just working toward discharge but 'being involved in what they are going to be doing when they've finished with us' (C fg1 p20). It was also enhanced by the intense nature of the contact with sessions 'three or four times per week' (C fg1 p4).

Additionally the team was used to working with the families of service users. I had raised this in the second focus group because Disability Teams A & B were anxious about having two clients, the couple, instead of one service user.

Tanya: But that’s important in this team, the family are just as much the clients really because we deal with the family… as a whole. … I mean, you know, they’re not actually our clients but our clients are… enormously affected by their family and the people that are close to them, so we involve them as much as possible in all or everything we do (C fg2 p24).
Two elements in the context of Disability Team C's practice assisted in working with the families. Firstly, a pre-requisite for referral was the involvement of at least two team members. Additionally people could be seen at home and in the health centre.

Xavie: And I suppose not all our visits are domiciliary or in the home… patients actually come here as well, so they come out of their family environment … you don’t get any privacy with the patient because the family… you you then have two people that you see all the time because patients do… , you know, are being brought in here as well and… I I think that that is a that is a… /
Yvonne: /And it means that we have a facility which we’ve used occasionally that, you know, one therapist is seeing… the patient while the other is seeing the wife… separately and then we’re getting them together and then and maybe er, we’ve had the situation, I mean not not just with husbands and wives but with… mothers and daughters and that kind of thing where… you know, the the relation of the… the the whole relationship is is part of the, in some cases, part of the problem but certainly part of the issue (C fg2 p24).

Finally, I sensed that Disability team C had a strong sense of autonomy and did not feel constrained by organisational factors. This was not raised in their discussion so I brought it up at the end of the second focus group and asked if their primary care trust would agree with them. This produced some mirth and light-hearted banter -

Wendy: Extraordinary idea/
Yvonne: I might have to ask permission (group laughter).
Vicky: Are they younger? (The other teams in the study)
Researcher: No, no, no.
Tanya: Well maybe it’s just an opt out… maybe it’s…/
Researcher: But there is that sense, you know, people are saying well you know I do feel it’s part of my role but I’m not sure that it’s sanctioned by the Trust… ?:/ I think that’s a cop out.
Tanya: / I think so too.
Vicky: Anyone working in that level of fear… I’d be looking at the Trust, can you identify them I wouldn’t want to work with them (group laughter)… that’s worrying (C fg2 p30).

7.7 Evaluation of research objectives for Team C

In Disability Team C intimacy and sexual expression was a legitimate area for service provision. It was seen as important and there was a sense of responsibility in the team to enable service users to discuss their concerns and to provide limited intervention and simple suggestions. It fitted with all the professional roles especially occupational therapy, where it was included on their assessment form, plus speech and language therapy and physiotherapy. However, sexual expression was not located fully, nor could it be encompassed within any one of these roles and not every team member could be expected to address it. The psychologists did not address sexual expression
due to the limited hours available. The speech and language therapist, an occupational therapist and a physiotherapist were including it within their practice routinely but there was no mechanism to ensure every service user had permission to discuss sexual concerns. Some team members had addressed issues when raised by service users but they lacked confidence and competence. The team believed sexual expression was more difficult to address than other aspects of care. There was knowledge of referral resources although the majority of interventions were managed within the team. There was support available for practitioners within the team.

7.8 Conclusion

Drawing on the data this chapter reveals a theory practice divide and an ambiguity about professional roles. Sexual expression was seen as a complex and difficult area of practice, which the majority of participants lacked confidence and competence to address. One nurse initially indicated sexual expression should not be part of professional practice (although her opinion changed slightly in the course of the study). Otherwise, in summary, all participants said sexual expression is an important aspect of care that should be part of the remit of their disability team. In reality both Disability Teams A & B, apart from occasional events, did not address the sexual expression of their service users. Three members of Team C did routinely provide opportunities for their service users to discuss sexual concerns but the majority did not. Even without explicit permission, all teams had examples of service users introducing the topic. Some staff had no skills to manage these disclosures in a sexually affirming way and avoided the subject. Others managed as best they could. Of the five professions represented, not one consistently addressed or excluded sexual expression from its remit. Two teams highlighted nursing as possibly the most appropriate profession yet no nurses expressed any expertise. The psychologist in Team B did encompass sexual expression within her remit but limited her area of proficiency to the emotional and relationship aspects.

My aim here has been to provide a credible account of the working practices of the teams, underpinning my assertion that sexual expression is either not addressed or is difficult to address in practice. The factors contributing to this ambiguous picture, the
deterrents to practice, are developed in the subsequent five chapters. There I develop my understanding of the difficulties in including sexual expression in the teams' practice. Not all factors deter - some encourage. This was seen in the practice of Team C. Encouragers included: awareness; skilled permission giving; simple solutions; holistic practice; the intense nature of the team's intervention, and the ability to work with families.
CHAPTER 8: THE INDIVIDUAL

8.1 Introduction

Overwhelmingly the participants in this research indicated that they believed the sexual expression of service users should be considered within the service provided by their three teams. However, in practice only the psychologist in Disability Team B and the three 'flag bearers' of Disability Team C had the skills to raise the subject with service users. My aim now is to move from portrayal of this theory practice divide to its exploration, to understand the conscious and unconscious processes, which inhibit practitioners from addressing sexual expression. In this, and the next four chapters, I consider the deeper issues revealed in this study. My analysis is organised around five building blocks of team practice: the individual; professional socialisation; the affective component; professional practice, and finally teamwork and the wider context. At this juncture, I shift from first level analysis, reporting what the teams said, to critical appraisal of what I consider is embedded in the data. Toward the end of each chapter, the impact of these findings is discussed.

Disability teams in this study represent the combined working practice of individuals who have been educated and socialised into a professional role. Each individual however begins their journey to professional qualification already imbued with values and beliefs about sexual expression. In this chapter, I shall consider the individual as he or she arrives at the point of embarking on professional training. Chapter 9 explores the development of the individual, during professional socialisation. It would seem to me that an individual's opinions and beliefs do not remain static. They are subject to reappraisal through exposure to a changing social and cultural environment. This includes personal experience of sexual and intimate relationships. In this study, participants were not expressly asked to reveal anything of their own sexual identity or the attitudes they brought to practice before training. However, echoes of this important facet are present in the transcripts. Four themes, grounded in the individual's personal experience, have been identified. These are talking about sex; the use of language; learnt moral values, and asexualising attitudes.
8.2 Individuals are socialised not to talk about sex

Many participants indicated that they were brought up to believe that sexual expression is a private aspect of self: something they are socialised not to openly talk about.

Nancy: I don’t know, how much how much do any of us talk about those things outside, I mean OK professionally we’ve got to talk like you said… but generally people do not talk about it, you might with a girlfriend, a mate…

Sarah: Over two bottles of wine (laughs).

Nancy: Two blokes might, but in fact I think probably men do it less than women… talk about it that is (group laughter)... I mean you don’t go and discuss it with your mother, you don’t go and discuss it with… anybody do you? (B fg1 p19)

Despite the highly sexualised society in which we live, practitioners indicated that 'sex isn't really talked through in society' (C fg1 p12), not by nice people.

Beryl: Well, ‘nice’ people didn’t talk about things like, did they (A fg1 p9).

Nice may equate with class. It is also linked with politeness or correctness.

Fiona: … going back to beliefs and groundings, it’s not something you do in polite conversation is it? You don’t go to a cocktail party and… they’d think you were a bit of a tart if you went round asking everybody, you know, talking about your sex life (A fg2a p4).

Fiona suggested talking about sex was more than impolite. It has negative connotations. It risks disapprobation (in this instance, to be thought of as a tart). This may account for one strategy, noted in the pilot study, of some participants mouthing words silently rather than saying them aloud. To say them aloud may invite disapproval. Fiona highlighted the importance of personal beliefs and upbringing and made a comparison with talking about other intimate things.

Fiona: It’s down to your own beliefs, that’s it, and your own upbringing … The way you’re brought up and your beliefs and the way society is. … It it all makes you the person you are, so therefore if you’re not encouraged to be open as you’re growing up or whatever, then you’ve got this natural sort of inhibition, if you like, about going that, that further step if you like and talking about sexual issues when you are quite happy talking about the bladder and bowels and all the rest of… all the rest of the ‘below area’ (A fg2a p16).

So talking about sex is impolite. It does not respect privacy, and risks censure.

Participants indicated that ease in discussing sexual issues varies, for example it is culturally easier now than it was thirty years ago (C fg1 p20). Some highlighted differences with the age of the therapist (A iiA1 p10; C fg1 p11-12; C fg1 p20). Irene felt it may be difficult for older people to talk to her about sex when 'I probably look
like their granddaughter' (A iiA1 p10). Yvonne said it was easier for patients to talk to someone 'comfortably middle-aged' (C fg1 p20). Gender too made a difference (A fg2a p13; C iiC1 p15). For example, Anita noted that she would be much more uncomfortable talking with a man than a woman.

Anita: I think mainly because I wouldn’t probably discuss sexual issues with a man anyway… outside, less likely to, … You’re more likely, you know, going right back to when you were a teenager, you’re more likely to discuss things with girlfriends than you do with…(agreement from the group) erm, and that’s for me, from a personal point of view, I’ve just, have never experienced really discussing sex with men (A fg2a p13).

It was also affected by culture with ethnic diversity increasing the practitioners' sense of ignorance of what might, or might not be offensive (A fg2b p18; C fg1 12).

I suggest that this diffidence in talking is a primary deterrent to practice. Individuals learn a social boundary of privacy that should not be crossed. Much of Annon's (1974) PLISSIT model is based on a notion that service users need permission to discuss sex. What this study reveals is that practitioners need permission too. Otherwise, this diffidence is carried into practice undermining confidence and competence.

Irene: … if it’s not seen as something you usually talk about it makes it more difficult to have it as part of the normal, you know… the normal assessment process if you like or you know the normal process of working with people (A iiA1 p11).

Or as Henry put it,

Henry: … but a lot of other people think well, it’s taboo, you don’t talk about it and… well, I think my influences, my parents, a lot of influences I had in my life is about well, never been spoken about… so that’s already in my mind… that’s the norm, is you don’t talk about these things… so to, in a professional capacity, start teasing that out it’s almost like it’s not the norm for me… (A iiB1 p7).

8.3 No common language

A consequence of sexual expression not being discussed is the lack of common language. This as a recurring theme in the transcripts, which affects both the service user and the professional. Clients can be heard, in the examples given, hinting they may have sexual concerns (A fg1 p15; C fg1 p16). Euphemism, like being 'less cuddly' (C fg1 p18), rather than explicit language, is used. Several participants noted 'not having the vocabulary' (B fg2a p21). This deficit is taken with them to their professional role.
Fiona: … and the use of language as well, I think that’s…. I think I find that a very difficult area actually erm and yet, as a nurse, you would think that, you know that they… I would hope that we would be more open than that but yes I do find it difficult… even within my role now (A fg2a p1).

She described her own use of euphemistic language in speaking with one young couple.

Fiona: …I asked them how their relationship was and I thought ‘That’s very trite Fiona’… I really did sit back and think ‘That’s not really what you’re aiming for is it?’ (A fg2a p2)

Even within the interviews and focus groups, hints and innuendo were used. Explicit language appears uncomfortable. Additionally if the language is uncomfortable for the service user, it carries a perceived risk of jeopardising the therapeutic relationship (A fg2a p1) (see section 10.4 - Discussing sexual expression may cause damage).

8.4 Personal moral values

Closely allied to learning about the privacy afforded to sexual behaviour are other learnt beliefs about what is appropriate: personal moral values. Although this was not formally raised in the focus groups, the transcripts indicate their importance to practice. For example, Yvonne noted her team shared a similar culture and class and, reflecting on a patient, said that what they saw as his sexually inappropriate behaviour was -

Yvonne: … his lifestyle it was what he did … were all kind of geared up to deal with this sexual inappropriateness … in another context it wouldn't need dealing with (C fg2 p10).

Rhoda gave another example of internalised values. She described a husband looking after his severely physically and cognitively impaired wife. He had begun an extra marital relationship and some of the district nurses thought 'that’s terrible or it’s wrong' (B fg2a p14). Rhoda suggested he was discreet and the wife did not know of the relationship, and in her opinion it 'was a good thing for him' (B fg2a p14).

Rhoda: Trouble is then you get all our personalities and judgements and everything involved in it and you, could it become, is that a moral thing to do or somebody saying, you know, some people say it was good, some people say it was… it’s ever so I mean it’s ever so complicated (C fg2a p14-15)

The concern is the conflict of differing values. Vicky suggested devising a leaflet to be given to every new referral but it met with all the anxiety of how it might be received.
Yvonne: But what information are you putting in there because you're assuming there that people have got partners... and you're assuming that they've got the same partner and you're assuming that... they're not going to be offended by any information that you've packed in there/ (C fg1 p29).

Diversity in lifestyles means nothing can be assumed. Others feared being asked to do something immoral, like facilitate sexual abuse (A fg1 p29; A iiB1 p10); or illegal, like procuring a prostitute (B fg1 p26; C fg1 p28); or unethical, like masturbating a client (A fg1 p12; C fg1 p28). Although these examples were all hypothetical, I felt they highlighted their anxiety about how they might manage moral values distinctly different from their own. The difficulty of separating the individual from the professional can be seen here too. It can be argued that it would be outside most health professional codes of ethics to masturbate a service user. This would be the sanitised position, rather than to own feelings like disgust or abhorrence borne of personal values.

Others considered the importance of setting their values on one side (A iiB2 p21; A fg1 p10; B fg1 p24) otherwise these moral judgements might be conveyed into practice (A fg1 p10; B fg1 p26). But how do we recognise what are our learnt moral values and how do we put them to one side? Henry, separate from this study, had recently re-evaluated his Catholic upbringing. He reflected with candour about the sexual messages in his childhood and the behaviours he was brought up to believe were wrong (A iiB2 p20). This included divorce, adultery, homosexuality and masturbation (A iiB2 p20). His re-appraisal had changed his thinking. I contend that professional competence depends on self-awareness, if intimacy and personal relationships, in all their diversity, are to be supported.

8.5 Asexualisation

Some participants demonstrated asexualising attitudes toward their service users. For the most part, these attitudes seem embedded in the individual, although I will return to corporate denial of sexuality later (see section 12.7 - Institutional asexualisation). Some examples are about age and some directly about disability.

Lesha revealed her ageist attitudes.
Lesha: I’ve got one client who must be in her late fifties/early sixties. She’s got MS. She’s in a wheelchair and she has a fantastic relationship with her husband but not sexually. They go out for lunch and they go to the sea and, you know, they meet up with friends and they share a drink together and he is her main carer but they’re obviously the best of friends as well, and… it would never be something that I would talk to them about because I’d think that well they have a fantastic life without sex and/ (C fg1 p13).

Shena confronted Lesha.

Shena: /Well how do you know / they’re not having sex then if you’ve not talked to them about it, are you just making an assumption? Lesha: Oh maybe they are, maybe I’m just making that assumption. I just think ‘Oh they’re old!’ (Group laughter and inaudible comments) (B fg1 p23-24).

Similarly, there were embedded stereotypical views of sex being the preserve of the young, conversely implying the asexualisation of older people. For example -

Fiona: erm, so yes they are obviously still sexually active… as you would expect from that age group erm (A fg2a p2).

There was evidence of asexualising attitudes toward disabled people. This has an historical context with some participants recalling the 70s and 80's when it was assumed that 'disabled people did not have sex' (A fg1 p12) and 'didn’t think about things like that’ (A fg1 p8). Echoes of this can still be heard in the personal values of some participants particularly toward people with severe impairments. One example, given by Fiona, reverberated through both focus groups.

Fiona: There’s one particular case that I found quite sad… erm, a patient with MND. His wife had been to the doctor for her own reasons… erm, it was her yearly check up or something like that, I think she’d gone for a smear or something, and the doctor, who is also her (husband's) GP, she turned round and asked her (the wife) what contraceptive methods she was using… Now I found that quite insensitive in that situation … and I just said, oh I’m sorry I can’t believe what you’re telling… (A fg1 p10).

The patient's wife was angry with the GP and retorted 'the MND method' (A fg1 p11). Fiona responded empathetically but deeper exploration in the second focus group revealed some asexualising attitudes.

Fiona: I think there is an underlying contention here as well in that the GP, since the patient was actually diagnosed with MND, has not actually seen the patient … I think that was the issue as well, that, she (the GP) should know better than ask me this, if she’d have come and seen him she would know that, you know/ that it was pretty/ Beryl: /Oh right yeah / that it was pretty unlikely / that they would be able to have that sort of relationship anymore. Fiona: Yeah exactly. Researchers: Although I want to… why, because with motor neurone disease it’s not usual that sexual function is affected? I mean, you know, everything else is affected and that can damage a sexual relationship, but… Beryl: Well I mean he’s almost quadriplegic really, isn’t he.
Carol: There’s no head control.  
Beryl: In terms of limb function, I mean there’s not a lot of function anyway, so…  
Fiona: No, no.  
Ginny: But yet that’s the presumption that… that because of his disabilities it would not be possible (A fg2a p21).

For this couple, we do not know if sexual expression was desired. Perhaps coitus was not possible, but demonstrated here is an assumption that severe physical incapacity is synonymous with sexual incapacity. In the ensuing discussion, it was also noted that the GP might have sought to offer contraception in case it was required for extramarital relationships. Ginny indicated that assumptions were being made 'because we are not able to discuss it freely' (A fg2 p23). Later, after the conversation had moved on, Carol returned to the case and said -

Carol: But I’m amazed, that case you told me about just a few minutes ago about, people with such severe disability who’d want to still cope with being in a double bed  
Fiona: Yeah but again, it's, it's whose needs is it meeting?” (A fg2a p26).

It seemed neither Carol nor Fiona considered that someone so physically impaired would even desire physical intimacy.

Individual attitudes are not static and may be refined in the light of experience. This had happened to Henry whilst working with an elderly man who lived alone. He was on peritoneal dialysis (A iiB1 p5). Henry described making asexualising assumptions.

Henry: You think with all the paraphernalia, you think well is he gonna, he wouldn’t be a sexual being because of it, so again it’s like …thinking you’d have to be a an attractive being to partake in sexual activity and what’s attractive to you as an individual, you know, you know, you’re making judgements, you’re bringing a lot of your own… stuff to it and I think that’s I think that’s one of the key issues really, you bring a lot of your own… I think to this sort of subject matter you bring a lot of your own issues to it, more so than some problem solving processes you go through (A iiB2 p2).

Henry's attitude had altered because the service user had introduced the subject, challenging Henry's personal beliefs (A iiB1 p5). Here Henry highlights how these personal attitudes 'your own issues' are taken into professional practice. This is developed later (see section 11.5 - Personal experience guides practice). If individuals, including disabled people, are socialised not to discuss sex it may be rare for professionals to have their prejudices challenged in this way.
8.6 The impact of individuals' beliefs and values

From the transcripts it can be seen that the practitioners in this research are firstly individuals whose behaviours, values and attitudes to sexuality have been moulded by the social and cultural climate in which they live. Four themes have been presented. Firstly, individuals in society are generally not socialised to talk about sex because of a taboo discouraging discussion of what is considered private behaviour. Next, there is a lack of a common, neutral and agreed language to discuss sexual issues. Also, individuals come to professional education with personal moral values and some do hold asexualising attitudes toward older and disabled people. This last confirms what disabled people were saying in the preliminary inquiry: that health professionals can perpetuate the asexualising attitudes that pervade society.

I am not proposing that these themes provide a comprehensive account or are shared by all participants. Also, I do not present them as absolute truths. I hold that they were true for some of the participants in this research, at the time of the focus groups. Their importance to this research is in providing tangible evidence, which begins to deconstruct why sexual expression is either not addressed or is difficult to address in practice. Opinions have been expressed, about the influence of beliefs and values (Crouch 1998; Ekland 1997; Gender 1992; Herson, Hart et al. 1999) but there has been little data that actually demonstrates how they hinder practice.

The attitude surveys reviewed earlier indicated a theory practice divide, for example in occupational therapy (Conine, Christie et al. 1979; Conine and Quastel 1983; Evans 1985; Guest and Kopp Miller 1997; Novak and Mitchell 1988) and in nursing (Hoddy 1999; Lewis and Bor 1994). These studies found that despite practitioners' espoused positive attitudes toward the inclusion of sexual expression in professional practice, they did not correlate with actual practice. Partly the problem with these studies was about the methods used in establishing attitudes. As discussed earlier, (see section 4.5 - Professionals' roles, skills and attitudes: Occupational therapy) inventories such as SASAD and SKAT may obtain a sanitised, and thereby a distorted, view of professional attitudes. It may be difficult for an individual to identify or own their prejudices on a simple questionnaire. Indeed participants in this research did not identify themselves as
having asexualising attitudes. Instead, where these attitudes have been exposed, it has been through the opportunity of peer discussion in focus groups and the free-association narrative techniques that allowed participants to explore their thoughts and feelings.

The earlier studies do not deepen understanding of the relationship between attitudes and practice (Guest and Kopp Miller 1997; Lewis and Bor 1994). This research reveals the nature of beliefs and values that can actively deter the involvement of practitioners. If a nurse or therapist has no common, agreed acceptable language it would be difficult to initiate a discussion. It has been identified that severe physical incapacity in motor neurone disease is not synonymous with sexual incapacity (Vincent and Rodríguez-Ithurralde 1997). Yet, an assumption was made by several practitioners in Disability Team A that a service user, severely incapacitated by motor neurone disease, would not desire physical intimacy. This attitude would almost certainly preclude a positive enabling approach to sexual health. Perhaps this is what occurred for Gail in the preliminary inquiry. Despite her wish, no one raised the subject with her or her husband who had motor neurone disease.

Only two other studies begin to reveal the importance of beliefs and values to actual practice. A primary finding in Rubin's study (2005) was that practitioners resisted raising sexuality with patients because they were worried that such questions would be intrusive. Like participants in my study, they were reluctant to cross the social barrier that prohibits talking about what is deemed private behaviour. Using scenarios, Yallop and Fitzgerald (1997), revealed that therapists' clinical reasoning could be influenced by attitudes that were not consciously known to the respondents. In some instances attitudes, which could be quite emotional and value laden, hindered the respondents' ability to see deeper issues. This is seen in the asexualising attitudes presented here.

Plummer (1996) suggested that one way people manage their anxiety about differing moral values was to create a pact of silence. That is, if no discussion on sexual expression is initiated, then one individual is not confronted with the diverse moral values of another. Although not conclusively shown here, this does resonate with the expressed fears of respondents. That is, in raising the subject they might be asked to condone or participate in actions that are illegal, immoral or unethical. So now we
have: a social barrier to protect privacy, compounded by difficulties of language, being further exacerbated by a possibly unconscious intent not to open up the subject.

That individuals come to the threshold of professional practice with personal beliefs and values about sexual expression is self-evident but thereby lies the problem. That is because it is self-evident it is also taken-for-granted with no direct consideration of the impact of these beliefs and values on practice. For example, many might agree that

'Sexuality pervades the air we breathe, but we still lack a common language for speaking about it.' (Weeks 2000 p163)

Practitioners in this research confirmed it. Yet, as I will show in the next chapter little appeared to have been done to address problems of sexual language in professional education. Limitations of language, or impact of personal values, may cause concern in other curriculum areas dealing with taboo subjects such as culture, dying or excretion. I suggest however, that in matters sexual, they are more sensitive and more influential. Deconstructing taken-for-granted values provides a foundation for understanding the discomfort (Medlar and Medlar 1990; Ross and Channon-Little 1991; Yallop and Fitzgerald 1997), resistance (Milligan and Neufeldt 2001), or embarrassment (Katz and Aloni 1999) described by other authors.

Deconstruction also reinforces the importance of professional education if sexual expression is to be addressed within professional practice. It highlights that individuals undertaking professional training need opportunities to reflect on their personal values. They need exposure to modelling and practice that develops sexual language and communication skills. They require knowledge that challenges asexualising attitudes. Some will need to know that, in their professional capacity, they have permission to break social norms of privacy and invite discussion on sexual expression. There are other precedents in professional practice. Occupational therapists cross normal social boundaries of space and on home visits will view bedrooms and bathrooms as a routine of practice (A fg2a p15-16). Likewise, physiotherapists (A fg1 p14; A fg2a p14) and nurses (Finger, Stack Hall et al. 1992) cross the normal social boundaries of touch.
8.7 Conclusion

Like Henry, I see the personal 'stuff' that the practitioner brings, as a key issue. Individuals, before they enter training to become a health or social care practitioner, are not a neutral 'blank sheet'. They have absorbed values and attitudes about sexual expression. These bring internalised rules or norms. Sometimes these may be explicit and conscious. Frequently they are implicit and often unconscious. I have presented here some of the personal beliefs and values that practitioners in this study held. They include barriers to talking openly and easily about sexual expression because there is a social norm of privacy. Also, there is no common, acceptable language to discuss sex. Participants in the study held personal moral values and feared this may conflict with those of the service user: this may encourage a silent pact of avoidance. Some practitioners also held asexualising attitudes toward disabled or older people. I have discussed how each of these themes may inhibit practitioners from taking a positive approach to service users’ sexual health.

I have suggested that internalised beliefs and values may be of more significance in addressing sexual expression than they are to other areas of professional practice. Without adequate exploration of these attitudes as part of professional education, practitioners will only have this personal experience to guide practice. In the next chapter, I will explore the process of professional socialisation.

These research findings corroborate information gained from the perspective of disabled people that some health professionals do perpetuate society's asexualising attitudes both toward older and disabled people. The information reviewed here indicates that the problems some disabled people experience, related to acceptance of, and support for, their sexual health, are located within the diffidence of health and social care practitioners due in part to the social norms and taboos affecting any individual.
CHAPTER 9: PROFESSIONAL SOCIALISATION

9.1 Introduction

In this chapter, the thematic analysis continues but here it is set against the development of the individual, during professional socialisation. To enter a health or social care profession, the individual undergoes a combination of formal academic education and supervised clinical practice (Health Professions Council 2004; Nursing & Midwifery Council 2002). This process of professional socialisation, undertaken over several years, confers a basic competency. College based theory includes the knowledge and skills needed for practice. During this time, individuals are supported to develop the attitudes necessary for the role. They also learn to apply their growing knowledge through supervised, graded practice. This period helps to define the professional role. Professional learning is neither finite nor time limited. Increasingly practitioners are expected to develop specialist skills through post-graduate training. Also professional regulation requires them to demonstrate continuing fitness to practice (Parliament 2002; Parliament 2003c). This includes engaging in a constant learning cycle to remain responsive to service needs (Dept. of Health 1998a; Dept. of Health 2001c).

My interpretation of the data suggests that professional socialisation for the participants in this research, did not lead to role acquisition in the domain of sexual expression. Contributing factors included deficiency in educational programmes and absence of role modelling. Post-registration training, although helpful, was minimal. Two teams had instigated some training for the team. A few participants dismissed the training they had received, because it did not overcome the anxieties of practice. Despite participants espousing a theoretical role, the data provides little indication that they engaged in a learning cycle to improve their knowledge and skills around sexual expression. Although this could be attributed to lack of opportunity, there are also signs of resistance, avoidance or not seeing further learning as necessary. Older participants felt the situation may have improved for practitioners that are more recently qualified, but this was not substantiated by the data.
9.2 Role acquisition

A positive sense of role acquisition from pre-registration education can only be ascribed to two out of the thirty participants: the psychologist, Odele and the occupational therapist, Wendy. Odele said,

Odele: I see it as definitely part of my work and very important really erm and I don’t feel awkward talking about it because I guess it’s being, it it comes up in in the training as one of the areas of things that the psychologists do …(B fg1 p7).

For her there had been relevant training on relationship issues including family therapy and couple counselling (B fg1 p7). This learning was focused on psychosocial rather than physical issues of intimacy and sexual expression (B fg2b p7). Wendy had received a lecture from SPOD during pre-registration training. Possibly of more importance, she had observed practitioners during two separate placements addressing sexual expression: once in a back clinic and once at a psychiatric unit for deaf people (C fg2 p11-12). Talking of this second placement she said of the educator -

Wendy: I was full of admiration for her because I thought this is an area of paramount importance to this community (C fg2 p12).

For the others, there was no sense of role acquisition. Apart form Odele and Wendy, participants had neither observed nor held discussions with practitioners on clinical placement about the management of sexual expression. Likewise, none of the other participants appears to have entered their profession with a clear vision that sexual expression would be part of their practice. Sarah indicated the importance of pre-registration education -

Sarah: I guess there are some professions who will have had the topic of sexuality alluded to at the very least during their training and maybe covered in in more detail than others, erm… I mean, in my training it never came up at all, erm… but I guess that that perhaps means that that, you know, some speech therapists will feel that it definitely isn’t something they’re interested in and that it definitely isn’t part of their role (B fg2a p3-4).

9.3 Deficiency of educational programmes

With the exception of Odele, participants, regardless of profession, felt their professional education had not prepared them to address sexual expression in their
Many either had no training at all, or at most a single lecture or a half-day workshop. Pressure on curricula may dictate that many topics are dealt with briefly. What emerges here is a sense that what training is available is not just brief: it feels tangential or encapsulated, separated from the rest of the course. The majority of participants in this research appear to have entered their profession with no exploration of their personal beliefs and values. Most did not obtain the vestiges of competence that could be built on later with the acquisition of professional experience. This was epitomised by Eliza, who said,

**Eliza:** … how many erm therapists of any description are actually trained and given any body of knowledge or any real skills (*about sexual expression*)? (A fg1 p5)

Of the occupational therapists Anita, Tatum, Tracy and Wendy had received a single lecture given by SPOD (A fg1 p4; C fg2 p12; C fg1 p26; C fg1 p26). However, there appeared to be no integration of this to the rest of the programme.

**Anita:** SPOD it just always reminds me of this one lecture we had in the three years (*knowing group laughter*) when SPOD came, when we were training… it just always reminds me… came in and did a half hour talk and that was the… out of three years, that was our…? (A fg1 p4)

She described it as someone 'telling us about the work they did' (A fg1 p6) rather than any discussion or debate on the implication for the work the students would do as occupational therapists. Or the SPOD talk was dismissed as inadequate: 'they just brought a box of fake vaginas, pumps, vibrators' (C fg1 p26).

Della, Henry and Eliza, during their training, attended a half-day workshop, given by me, explicitly on sexual expression and occupational therapy, this too was limited.

**Eliza:** … I mean (*the workshop*) really just *highlighted* the *importance* of not ignoring it… and… if you *could*, and if you felt *comfortable*, to *explore* that area, if patients *wanted* to. But, I don’t know… it was *very* interesting but – (*laughs*) sorry – it was very very interesting, but I don’t know that it actually provided me with any *skills*. It didn’t give me, it didn’t give me any *more* confidence to think of… what *questions* I might ask, what sort of open ended questions I might ask, … But I don’t, I don’t know that your session *per se* gave me any *skills*… it gave me *knowledge* but it didn’t necessarily give me any *skills* (A fg1 p7).

There had been no mention of sexual expression elsewhere in the problem-based programme (A fg1 p7). This suggests no integration with other professional knowledge. Henry was on a different programme and knew me as his personal tutor. Again, sexual expression was encapsulated into a single workshop. He wondered,
Henry: … if it wasn’t a er a study area of yours, would we have had any discussion on it, I don’t know (A iiB1 p10).

He spoke about the workshop, parts of which were particularly challenging, concluding,

Henry: … the beauty, the benefit of it all was how thought-provoking it was… and about how selective are we as therapists, you know, do we say one thing from a philosophy point of view and do another? (A iiB1 p11)

Despite this, it did not leave him with any sense of competence or authority to practice. From his perspective, I suspect I was a lone 'renegade' voice. Of the three, Della was more positive about her training, but unlike Henry and Eliza, for her my workshop followed awareness raised on placement (which included a session by SPOD) at a residential home for people with severe disability (A fg1 p6-7). This placement highlighted the importance of sexual expression to the residents: it 'was the biggest issue that was coming across' (A fg1 p12).

Irene suggested there 'was hardly anything' (A iiA1 p9) on sexual expression in her college programme, apart from 'SPOD being a good organisation' (A iiA1 p9). She went on to say,

Irene: … we did address issues, starting to recognise that sexuality, you know, was as much an issue for someone with disability as any other person, so I mean, you know, it wasn’t just ignored but there was sort of fairly little in terms of, you know, how you could actually help practically, or in advice (A iiA1 p9).

For Maeve there had been nothing on sexual expression in her pre-registration course (B fg2b p18). For Xavie, although the most recently qualified occupational therapist, she could not remember.

Xavie: I think I think we had like, you know, we we touched on that but... I can't remember it... I know we touched on it in specific things but I was er, I can't remember it (C fg1 p26).

Of the physiotherapists, Beryl, Carol, Janet and Peggy did not recall any learning around sexual expression in their training (B fg2a p4). Some had received information on pregnancy and physiotherapy (A fg1 p6; C fg2 p12) but, for the others, there had been minimal exposure. For Vicky this was about reproduction not sexual function, for example, in a lecture on spinal injury,

Vicky: … what I can recall learning is that the sperm are viable at the very beginning and then they're not very soon after, if you don't save the sperm very quickly then... but the idea that they'd actually be participants in anything we never reached/ (C fg1 p24).
For Lesha there was information on sexual expression but she described this as being 'small sections of it, it was never, you know, big things' (B fg2a p5). Yvonne did recall just one lecture, linked to spinal cord injury.

Yvonne: There, there was something about... no there was something about pumps... (laughter from some group members)... to to get an erection and that a sex life was possible and that these are young/.../men and they need it (C fg1 p24).

The information is old and possibly poorly remembered. That said, it is interesting to note the potential teaching about the sexual needs of women and older men! None of the physiotherapists were supported to look at their own attitudes or given any indication of what a physiotherapy role in sexual expression could be.

The four nurses, in this research did appear to have more information provided in their courses. However there is still no sense of grounding or confidence. Fiona recalled some information on sexual development and sexual health in her pre-registration adult nursing training but added,

Fiona: I trained in the late sixties, early seventies, so it wasn’t something that I could say ‘yes, it was there, it was part of my training’.... (A fg1 p9).

Similarly, for Rhoda, despite explicit knowledge on some aspects of sexual health, she indicated this was insufficient.

Rhoda: … (sexual expression is) included in nurse training by saying well you should ask people about their sexuality and that’s quite (laughs) that’s about it isn’t it, but you know, and and, you know like, so you might know about family planning and contraception and erectile dysfunction but / that’s about the… it’s a very / Kitty: / It’s a very physical…. it’s nitty gritty isn’t it, yeah.

Rhoda: It’s not dealt with any depth at all (B fg1 p7-8).

For Nancy it was very briefly touched on in her general training but the focus was,

Nancy: … the medical, surgical, practical side of things, we don't get into the emotional relationships, I'd say that’s never really explored (B fg2a p5).

She said she had received virtually no explicit training on sexual expression as an incontinence nurse. She did explain to service users the benefit of a supra-pubic catheter over a urethral catheter in being able to 'carry on in a normal fashion' (B fg1 p18) but Rhoda said to Nancy,

Rhoda: You’re not actually trained are you to er…
Nancy: No no.
Rhoda: You just pick it up as you go along.
Nancy: I think, you know, that’s (as) much of the training as I got… er with sexuality and catheters whereas yes a man can tape it down and put a condom over the top of the catheter… actually you know that’s not terribly practical (group laughter)… or comfortable (more laughter) (B fg1 p18).

There was nothing at pre-registration level for any of the speech and language therapists (A fg1 p8; B fg2a p3; C fg2 p12). Ginny attributed this to the culture of the profession.

Ginny: I mean I see speech therapy as quite a prissy sort of profession really, we were terribly middle class and terribly… that sort of thing wasn’t discussed (A fg1 p8)

She continued,

Ginny: … and the only thing I remember at all from my training was when we were talking about working in a head injury unit and that, you know, young men might get ‘excited’ because we were women (group laughter), so we had to put on a white coat and put on this professional … and that’s the only thing I remember (A fg1 p8).

Ginny felt the college was supporting an asexual approach to practice, as a way to manage the perceived sexual risk. This cautionary note has a parallel in social messages about the dangers of sex.

Unlike Odele, the two psychologists in Disability Team C did not present a sense of confidence gained from their training. In fact Zanna could remember very little and checked with Unwin about current psychology training.

Unwin: I don't... I'm thinking I don't think we've had anything outside learning disabilities... I don't think (C fg1 p25).

Thus, within the multidisciplinary teams there was no indication of sufficiency or efficacy of education on sexual expression. The little education available had been delivered usually, not by core staff, but specialists such as SPOD. During a focus group in Disability Team B, I summarised what had been said about pre-registration education, concluding

Researcher: … it’s not on the agenda?
Kitty: A bit like death.
Sarah: Well I don’t know, at least you do talk about bereavement a bit more (B fg1 p18).

Although not explored in depth, they were saying that more was available in training around loss and bereavement and how this might be managed sensitively. I believe this research reveals that pre-registration education on human sexuality is deficient. It does
not appear to provide the rudiments of skill, knowledge, nor an opportunity to reflect on
the social norms and attitudes the individuals brought to training. Eliza could have been
talking for many when she said the training that was available ‘wasn't given to me as a
piece of knowledge that I could use’ (A fg1 p7).

9.4 Post-registration education

Some participants had undertaken relevant post-graduate training. This appeared to me
to make a demonstrable difference to their awareness and practice. However, this is
balanced against Irene's contribution, which indicated that post-graduate experience and
training, of itself, is not sufficient to change practice.

Wendy was the only individual to undertake specific post-registration training related to
sexual expression and physical disability. The two-day course was a significant event in
her professional career.

\textbf{Wendy}: I went on a two day SPOD course … that was run by people with physical
disabilities… that actually changed my whole perception about why I now bring up sex
more routinely, I don't do it with absolutely everybody but... by much much more routinely
because they were so... sure that they wanted to be able to talk about it and that nobody else
would, and that they couldn't talk to... their GP, their their GP had to be very good for them
to be able to talk to them about it and the consultant never had time to talk to them about it
and the only people they ever got to see were therapists and... if it if you made it a no no for
people then they then they were left with thinking this is an insolvable problem (C fg1 p26-
27).

The power of hearing the service user voice is evident. Wendy had heard the
importance of sexual expression to disabled people. Sexual expression has been part of
her practice since then 'and it's something I have grown and developed' (C fg2 p4).

Others had done some allied training that appeared to broaden attitudes and support
their confidence. Most noticeable was Ginny who had done some specialised work
around transgender clients (A fg1 p5). She was the one in her team challenging
assumptions and appeared more aware of diversity in relationships. Likewise, Kitty in
Team B presented with more confidence. She had been working in an HIV and AIDS
setting. So although sexual expression was not in her general training,

\textbf{Kitty}: When I was working in HIV and there was stuff around HIV counselling which was
mostly about talking about sexual issues as well as the sort of practical advice (B fg2a p5).
My sense of Kitty was that she welcomed this research because it was a difficult subject for the team. Lesha and Yvonne had done some sexuality training when they worked in a neurology rehabilitation centre with head injured people (B fg2a p 5) and in learning disabilities (C fg1 p25) respectively,

**Yvonne:** … where interestingly you can talk about sex till the cows come home and nobody raises a … there'd be no embarrassment talking about sex at all (C fg1 p25).

Perhaps because of this training, both Lesha and Yvonne were sufficiently open to have had examples of sexual expression arising in their professional practice, and Yvonne particularly demonstrated an ability to discuss it with the service user.

On the other hand, Irene had learnt about sexual issues in stroke and cardiac care by observing her manager. She had been expected to conduct educational programmes that included giving information on sexual function to service users. This included being available for individual inquiries at the end of group sessions. Yet, in her current setting she had completely excluded sexual expression from her practice. It would appear this was about service expectations (see section 12.6 - Permission from the organisation).

As with pre-registration education, sometimes post-registration learning was disregarded. For example, Rhoda had undertaken some short courses and two years of a Masters degree in counselling (C fg2 p29) but this was dismissed.

**Rhoda:** I mean I have done some counselling training but I never qualified so I haven’t had any official training (B fg1 p7).

Her reasoning appeared linked to an unresolved conflict between being a counsellor versus using counselling skills within another professional role. In talking about relationship difficulties that a service user may have, she said,

**Rhoda:** / that’s one area where I don’t feel that I work particularly effectively because I’m not sure that I’m meant to be (doing it) … I do it sort of unofficially, telling people that I’m not a counsellor and that I’ll help and I’ll listen but I can’t, I can’t counsel them, but every one of us, because we’re key workers, is actually doing that work with no support or no official training…/ and no debriefing/ (B fg1 p5).

'Official training', I understood to mean training that is approved by the employing organisation and acquired through the completion of recognised programmes of study.
9.5 Training for the team

Both Disability Teams B and C had identified learning needs for the team and arranged specific team training on sexual expression. For Disability Team B, it had been some two years before and was on the PLISSIT model (B fg2 p24). Although Kitty still had the handouts, there was a sense that the training had not been applied by the team because there was no follow up or 'ongoing support' to make it 'much more a part of what you do' (B fg2a p24). The training did not appear to arise from an identified need established in the service user group.

There was a tangible difference for the training organised for Team C. They had identified that sexual expression was a concern for their service users (C fg1 p20). Based on this awareness, they had invited a representative from SPOD to speak at a team meeting. Consequently, they had altered their multidisciplinary initial assessment tool to include a question on relationships and sexual expression. Although later removed, there was a more pervasive sense in this team that 'you should be able to cope with it' (B iiB1 p10) and Wendy (C fg1 p8), Yvonne (C fg1 p19) and Tanya (C fg1 p5) were routinely including sexual expression within their practice.

9.6 The learning cycle

Professional fitness to practice, nowadays includes engaging in a constant learning cycle to remain responsive to service needs. Simplistically this might imply that, as several participants had indicated sexual expression should be part of their practice but they lacked skills and knowledge, they would be actively seeking learning opportunities.

Diana: … I think we should all be able to deal with it to a certain extent. … Perhaps we need a little more knowledge of SPOD and things like that (A fg1 p23).

Some participants, directly because of undertaking this research, did change their practice. Fiona sought to acquire knowledge and skills in this domain. Wendy was the only participant, prior to the research, to identify her learning needs. Partly this can be attributed to the paucity of opportunities to extend professional skills in this area. The data offers other explanations for example avoidance of courses. There was also an indication that some participants accepted, unchallenged, their lack of knowledge.
There were several examples of practice change wrought by participation in the research. Perhaps the most dramatic was Xavie.

Xavie: … after our first meeting I sort of definitely came away feeling professionally guilty I think… because I thought… despite my own personal “I’m not very comfortable with this” I don’t want to be the pers person that sort of stops the pathway where there might be problems because the patient might not get another opportunity after me, erm, so professionally I I felt… you know, I have to deal with this (C fg2 p7).

She had reflected on Tanya’s contribution, using her as a role model, to include a question on sexual expression as part of her initial occupational therapy assessment.

Xavie: … I sort of almost forced myself and decided beforehand “Ok I’m going to do the initial interview and I am going to bring it up” and really sort of psychologically, you know, preparing for that… and I remember you said you sort of go over it, and I sort of went through it with the patient so that they could see it as well on the checklist “Well what about this” and then you’d sort of come to the toilet issues “What about your… have you got any problems?” and then it’s it’s right there – “Have you got any sexual difficulties?” – and it’s almost just like reading and the first time I could feel a bit of vibration in my own voice but I I have started doing it after that and I do think… I maybe sort of accepted in myself that… despite personal issues maybe that is a kind of skill that can be developed as well … in this context in this kind of environment in this team, you know, it’s something that you can’t skip, it needs to be … I felt that in my role… I had to do it (C fg2 p7).

Participation in the focus group had raised Xavie’s awareness and she had directly initiated change. Tanya asked whether it got any better after that first time (C fg2 p7). Xavie confirmed it had and that she was now raising sexual expression routinely with every patient because ‘you can’t make an assumption’ about who it is appropriate to raise it with (C fg2 p7). It had gone well and one woman ‘spoke about it a little’ (C fg2 p7). Xavie had also identified support strategies for herself if someone revealed problems beyond her sense of competence (C fg2 p7).

Partly because of participating in the research, Fiona had applied to attend a three-day conference on sexuality and disability (A fg2a p29) organised for the multiple sclerosis nurse specialist group. She indicated that sexual expression, for her, was now -

Fiona: It it’s very much on the agenda, … … that’s why I say I don’t think I have the option to opt out of it, you know, because I think it is very much part of the the national agenda as well with MS people (Team A fg2a p29-30).

This is a reference to the new national guidelines for the management of long term conditions and multiple sclerosis (Dept. of Health 2005; National Institute for Clinical Excellence 2003).
Other participants had not identified further learning options. In part, this is because there is little educational material to promote practice in this area. No courses had been seen advertised in the professional literature (either profession specific or inter-professional) for many years (C fg2 p30; C iiB1 p7). Some participants noted there were no practice or research articles in the professional literature, for example in speech and language therapy or physiotherapy (C fg2 p11). A psychologist at a conference recently attended by some members of Team C noted how little information there was on stroke and sexual expression (C fg2 p17). The little knowledge that had been gleaned was from articles (A f1 p6) and leaflets, written for service users, by disability organisations (A fg1 p5; A fg1 p26; C fg2 p21; C iiB1 p4).

If practitioners feel uncomfortable in this area of practice, even when available, training courses might be avoided. For example, in my interview with Tracy I asked if she had seen any course advertised.

**Tracy:** No I don’t think I have but it’s not something I would look at really… not really… upper limb’s far more my style *(laughs)* (C iiB1 p7).

With little knowledge or skills, practitioners may feel unable to address sexual expression. Yet, if they are not addressing sexual expression in practice it is difficult to see a need for further training. This was epitomised by Irene, who when asked whether she had sufficient training, replied -

**Irene:** Erm, well I have for the amount the issue is addressed at the moment *(laughs)*, but I mean I guess obviously if it’s something in which, you know we were gonna be a bit more proactive in … I feel I would need more training (A iiA1 p13).

I suggest this becomes a self-perpetuating cycle.

Additionally practitioners may accept unchallenged their limited knowledge. Nancy provides an example. Following the initial focus group, for the first time in her career, several clients had approached her, wanting to talk about sexual concerns. She said,

**Nancy:** … I was probably more comfortable with it knowing that nobody else… felt any happier either, that I wasn’t sort of out of my depth because somebody else wouldn’t have, would have had *(done)* it better, so I just thought well, we’re all in the same boat really and so you just do the best you can with er what you’ve got at the time (B fg2a p3).

She described the reassurance that she gained from the first focus group, that no one else in the team would feel any 'happier' or would have 'managed it any better'. That is
no one appeared any more confident or competent. Despite the increase in people raising the subject with her, she did not identify any wish or need to increase her knowledge base, to search out information or seek advice. I suggest some people may believe that sexual expression is considered so fundamental, so intuitive, that learning about it is unnecessary 'you just do the best you can with what you've got'.

9.7 The impact of professional socialisation

The impact of professional socialisation on practice in the domain of sexual expression cannot be underestimated. These findings indicate that, unlike some other western countries, sexuality education is not universally 'accepted as part of all health professional training' (Weerakoon 1994 p41). This is discussed in relation to pre and post-registration education however I shall also consider why professional socialisation is not the whole story, and therefore, on its own, not the solution. The importance of education to address attitudes, skills and knowledge in sexual health has been cited by many (Finger, Stack Hall et al. 1992; Gender 1992; Glass 1995; Medlar and Medlar 1990; Weston 1993; White and Heath 2002; Wiederman and Sansone 1999). In my research, practitioners said that the professional education they had received had not prepared them to address sexual expression in their practice. This is consistent with the findings of other researchers, where therapists and nurses felt inadequately prepared (Conine, Christie et al. 1979; Conine and Quaste 1983; Evans 1985; Haboubi and Lincoln 2003; Kuczynski 1980; Lewis and Bor 1994). Some have implied this is due to the variability in professional curricula (Payne, Greer et al. 1988; Wiederman and Sansone 1999). My findings indicate that other issues, not just lack of curriculum time, may be operating. These include encapsulated teaching; lack of professional role models; possible asexualisation within training programmes, and lack of awareness or resistance to the espoused theoretical role.

The role, and thereby the educational requirement, in addressing sexual health, for each of the five professions represented in this research, is different. Although I refer to disability practitioners: I do not imply a single profession. The level of skills and knowledge required around sexual health varies for each profession. Therefore, it is useful to identify a minimum level of pre-registration education with additional
expertise gained in post-registration education. I suggest all health and social care professionals should recognise service users, including disabled people, as fully human inclusive of sexual identity and sexual needs and their work should support sexual health. This seems to me to be consistent with longstanding NHS policy (Dept. of Health 1992; Jacobsen 1988). Each profession needs to consider if routine provision of permission to discuss sexual expression, is a necessary competency for all registrants. Specific knowledge and skills could be gained, after qualifying, for those working in disability services. Good quality community rehabilitation and social care includes prevention of secondary complications like a negative impact on sexual roles (Dept. of Health 2005). Each profession has different learning needs. For example, the psychosocial and biomechanical aspects of sexual expression can be seen as more relevant to psychology and physiotherapy respectively.

Pre-registration education provides the foundations of role identity. Only two out of thirty participants in this research identified themselves as having a positive professional role around sexual expression, acquired during their pre-registration education. Lack of, or poorly defined, role identity has been cited by others as deterring professionals from addressing sexual expression in practice (Conine and Quastel 1983; Crouch 1998; Earle 2001; Ekland 1997). Positive role perception has been correlated to increased comfort in addressing sexual issues (Yallop and Fitzgerald 1997). I shall consider why practitioners believe that, in theory, they should address sexual expression but qualify with no sense that it is part of their role.

Unique to this research is the identification of encapsulated teaching, experienced by several participants. By that, I mean where teaching did occur on sexual expression, it was managed as a discrete entity outside the main programme, delivered by a specialist in a single workshop. This reinforced the separateness of sexual expression from the routine of practice. It also indicated the necessity of having a specialist, rather than programme tutors. Anita was taught SPOD's role, not the practitioner's, role. Encapsulated learning provides no opportunity for role modelling, whereby the pupil can observe the practitioner using sexual language and demonstrating how the social norms of privacy may be crossed. It also meant that the teaching was within one tiny part of the programme and did not pervade the curriculum. For several, it was a one-hour lecture or a half-day workshop in a three-year programme. Additionally whatever
learning occurred in college, it was not seen to be applied in practice. The importance of observing application was seen in Wendy's experience of clinical practice.

Other authors have implicated the faculty (Gender 1992; Wiederman and Sansone 1999) and tutors (Brogan 1996; Lewis and Bor 1994; Webb and Askham 1986) for inadequate delivery of appropriate learning opportunities. Here Ginny described her tutors as fostering an asexual approach to practice. I contend a reasonable assumption is that the faculty is subject to all the tacit social norms identified in the previous chapter. If so, one interpretation is that asexualising attitudes may be embedded in the curriculum. The preliminary inquiry highlighted the integral nature of sexual identity to personhood, self-esteem, confidence and quality of life. Yet, sexuality and sexual function do not appear in the curriculum. The disability specific curriculum modules reviewed earlier have all been from overseas (Goldstein and Runyon 1993; Johnson and Walczak 1984; Katzman 1990; Keall 1982; Neistadt 1986; Tepper 1997b; Weerakoon 1994) (see section 4.4 - Professional education: Developing training for disability professionals). With little to raise the awareness of UK based tutors, their beliefs and values may be unchallenged. They too may partake in the 'silent pact' (Plummer 1996). This interpretation requires further investigation.

Tutors will protest and cite an overcrowded curriculum but change may be more about awareness and approach, rather than extensive modules. Kuczynski (1980 p342) proposed a course on human sexuality was insufficient, instead -

'The total faculty must believe that problems in sexuality are as important as physical and psychological problems and continually point these up to their students and help students deal with them'.

The International Classification of Functioning places relationships, including intimate and sexual relationships, on par with mobility, communication and self-care (World Health Organization 2001). Faculties may wish to evaluate if their health and social care programmes reflect this. A parallel is the work that has occurred in the last decade to develop culturally sensitive curricula. The sexual citizenship of disabled people needs to reverberate throughout all health and social care programmes. This may raise questions in class, but that allows course tutors to model how unsought inquiries might be managed. That said, some disciplines might wish to consider more substantive programmes to explore attitudes as well as extending skills and knowledge.
In this research both pre and post registration education was presented as deficient however that, in itself, does not explain the theory practice divide. Learning opportunities that were available were dismissed. Despite a three-hour workshop, Eliza said she had not been given any 'real skills'. Disability Team B had received training on the PLISSIT model, but learning had not been applied to practice. Rhoda had undertaken two years of a counselling course, but it did not constitute 'official training'. I suggest that these opportunities did not overcome the emotional deterrents to practice.

Also apart from Fiona, no one appeared to have engaged in a learning cycle. A practitioner, who had identified that they lacked knowledge or skills in a necessary area of practice, would be expected to address this. At post-registration level, the literature consistently proposes inter-professional education for disability practitioners (Cohen, Byrne et al. 1994; Ducharme 1987; Glass 1995; Tepper 1997b). However, no participant in this research had seen such a module being advertised. This confirms my experience. I have not seen an inter-professional, disability specific programme, available for many years. The new course Fiona had identified was for specialist MS nurses only. Henry was certain training needs would be met if sexual expression were part of the role. I think he is right. This implies either a self-perpetuating cycle whereby lack of awareness and skills means the subject is never raised. If sexual expression is never raised the practitioner does not need skills to deal with it. There is no identification of learning needs so post-registration training is not developed. Alternatively, as seen with Tracy, it might indicate a resistance to learning. This may be potentially stronger than the espoused role identified. If you do not learn about sexual expression, you cannot be expected to address it.

9.8 Conclusion

Most practitioners had no sense from their professional socialisation, that sexual expression could be part of their role. So, although they espoused a theoretical role, they had not acquired the role in practice. For many, there was no pre or post-registration education on sexual expression. Where training occurred, it was often encapsulated and separated from the core business of professional education. SPOD or
specialist practitioners had delivered much of the training identified in this research. Tutors on the educational programmes did not appear to be personally involved and therefore did not provide a role model. This reinforces the message about the separateness of sexual expression from the routine of practice. It may also suggest to students that sexual expression is so difficult it should be left to specialists. I have posited that asexualising attitudes may be embedded in the curricula but this requires further investigation. Where education was available, participants were not always able to build on it, either through observation of the applied practice of others, or through their own supervised practice. In the few examples given, where greater confidence was acquired, it was associated with observation of positive role modelling or increased awareness of the issues from the perspective of disabled people.

No post-registration inter-professional education modules around physical disability and sexual expression are currently available, indicating that practitioners are not identifying this as a learning need. This may be due to lack of awareness but it could indicate a resistance to learning. In the next chapter, I shall look at the affective component within the data. Managing negative emotions may provide a more powerful deterrent, outweighing the espoused role identified.
CHAPTER 10: THE AFFECTIVE COMPONENT

10.1 Introduction

The literature reviewed in chapter 4 highlighted the importance of practitioners feeling comfortable if they are to address sexual expression. The data from this research reveals considerable discomfort. This affective response became a major theme. Some participants spoke of discomfort. Others described feelings of anxiety, fear and danger. Embedded in the data are also examples of hostility and anger. I did consider locating the affective response in the chapter dealing with professional practice. However there are also examples from the fear of what might happen (thereby stopping practice) which is more properly located with the individual. I propose that the emotional element is pertinent to the four separate sections: the individual, professional socialisation, professional practice and team working. The affective response of practitioners is therefore discussed here in a chapter of its own.

Recognising this affective component is crucial to understanding the clinical picture. I believe the consequence of strong negative feelings is defensive practice including avoidance. Originally, using in-vivo coding, separate emotions, like anxiety and fear, were differentiated. In writing up, these nodes have been refined, not according to the feeling identified, but by the causative factor. I have identified from the data what creates discomfort. This is subdivided into four themes: discomfort leading to avoidance; 'would I be able to deal with it'; concern that discussing sexual expression may cause damage, and the perceived dangers of sex. I have tried to discriminate between an emotional response triggered by actual practice, from that arising from the individual's imagination of what might occur. Some participants spoke directly of their feelings but sometimes I felt their emotions were more subtly embedded in the text, therefore I have included not just overt but covert examples. That is, those recognised and owned by the participant and those they may be less aware of. These are my interpretations.
10.2 Discomfort leading to avoidance

Some participants saw avoidance as a positive approach to managing the negative feelings, which caused discomfort.

Anita: … and I think that we all should accept that there are some things that, you know, are maybe something we’re not comfortable with … then to actually do it is probably more/ It’s probably more destructive than than overlooking it in the first place (A fg2a p5).

Anita suggested that to address sexual expression in the face of strong negative emotions had the potential to be 'destructive'. I suspect that here 'overlook' meant not responding to or not introducing the subject: thereby the therapist and service user would not have to endure the therapist's discomfort. Shena expressed a similar concern. She said that she would find it uncomfortable raising sexual expression with service users and worried that her discomfort 'would show' (B fg2b p4). Her anxiety was that experiencing the practitioner's discomfort would be damaging for the service user. I cannot say if these concerns are true, as this research did not investigate the consequence of therapists' negative emotions for the client. However, the preliminary inquiry indicated that the service user might alternatively experience 'overlook' as the practitioner not seeing them as a sexual person. This too is damaging. This is explored further in the discussion (see section 10.6 - The impact of the affective component).

Some people acknowledged their avoidance due to negative emotions. For example, Xavie had 'stopped using' the prompt about intimacy and sexual problems on Team C's initial occupational therapy assessment form (C fg1 p7). She had worked with patients with whom it would have been appropriate to include the question, but she avoided it -

Xavie: … because, you know, I didn’t feel comfortable… I, you know, it’s something that I personally feel really uncomfortable, unless someone, er unless a patient approaches it with me, then it’s fine but it’s not something I would I would… initiate (C fg1 p7).

However sometimes avoidance was covert. I asked Nancy about the parallels in her role as an incontinence nurse -

Researcher: … where you must be asking very intimate things?
Nancy: Mmm, and I think that, you know, is an opportunity where people do… have have that chance to sort of… go into to to more detail about their sex life if they feel… that’s an issue for them. I mean maybe it’s because we can’t all discuss so intimately and or be very happy about it then it will get brushed aside, but perhaps people actually aren't that worried about it, they do adapt as you say, you learn to live with less (B fg1 p17)
It is not clear who is 'not happy', the service user or nurse, and who then brushes it aside. Many service users may not wish to explore sexual issues but I suggest Nancy's discomfort leads to her brushing sexual concerns aside. She then justified her avoidance by arguing that it is not a concern for the service user who learns to adapt.

Some may dispute my next covert example, derived from a joke made by Disability Team A. Fiona was reflecting on a direct sexual inquiry made to her in a busy thoroughfare, by a female service user. It had made Fiona feel uncomfortable and in the focus group she was appraising whether she could have managed the situation better. She attributed her feelings to the public context rather than the subject matter and wondered if she should have taken the service user back to her room in the unit.

Fiona: She’s actually in a room on her own, so I could have taken her back to the room but the physiotherapist came to take her to the gym, so…
Carol: Well, that was lucky then wasn’t it?
Anita: Good old physios, always there when you need them (A fg2a p14).

Humour can be a way of expressing feelings. I have interpreted this as a tacitly understood notion of being rescued (thereby avoiding) discomfort. Earlier Carol had explicitly talked of needing 'an escape route' (A fg2a p11). She had compared her situation to Ginny's. Ginny works one to one in a private room, whereas the physiotherapists work alongside others in open plan areas like the gym.

Carol: If I was shut in like Ginny in a room with somebody and then he talked about it (sex), I’d think ‘Oh my goodness… there’s no getting away from this, I’ve got to deal with it now, face it’ (A fg2a p11).

10.3 Would I be able to deal with it?

Asked how she would feel having to face it Carol said -

Carol: Erm… not that comfortable, no, I wouldn’t be sure what was going to come up next and would I be able to deal with it? You know… whether I’d be professionally able to… (A fg2a p11).

This doubt: 'Would I be able to deal with it?' was a pervasive theme in all three teams. The uncertainty of what may be disclosed and whether practitioners could cope with the disclosure caused considerable anxiety and fear.
Henry: … it’s just knowing what’s behind that door, you know, you can open it but you don’t know what to expect (A iiB2 p8).

Sarah: Well it’s a fear of what you’re going to be confronted with as well if you ever open that can of worms isn’t it (B fg2a p21).

Even participants, who individually felt more comfortable addressing sexual expression, identified it as an issue within their team (B fg2b p11; C fg2 p22). For example -

Tanya: One of the reasons that people don't raise it is that it could open a can of worms and what do you do with it when people say they have got a problem (C fg2 p22).

The following extract epitomises the sense of fear of opening up the subject of sex. Vicky likened it to Pandora's box where, once the lid is opened, the practitioner may be confronted with issues that he or she then cannot ignore.

Vicky: I think professionals don’t for… for all sorts of reasons, it’s that sort of Pandora’s box I'm not going to ask this question because I don’t want to hear the answer, I may not be able to cope with what comes next… and we’re all we’re all guilty of that and not just about sex (laughs), about lots of things, I think I won’t ask that question because I haven’t… erm I know there’s going to be… issues (C fg2 p17).

As Vicky indicated, professionals may use this strategy for many reasons. It is especially pertinent though when considered as a way of managing the discomfort of addressing sexual expression. It is closely allied to the anxiety of managing conflicting moral values (see section 8.4 - Personal moral values) and feelings of inadequacy because of a lack of skills (see section 9.3 - Deficiency of educational programmes). Fearful imagery was used. Henry compared it to playing 'Russian Roulette' and 'whose going to get copped with it' (A iiB1 p9). That is, disclosure might raise moral or ethical issues, for example concerns of abuse for a carer, or other complexity, that could potentially make the intervention difficult or lengthy (A iiB1 p9-10). Maeve too acknowledged the negative feelings of being faced with moral issues such as infidelity.

Maeve: But I agree with what you’re all saying about not… it’s not really our business to approve or disapprove, but I think you’ve also got to recognise that if it does put you in a difficult position and it can make you feel uncomfortable and you are gonna put your own moral judgement on it in some way (B fg1 p26).

Once disclosed, it cannot be unsaid. Pandora could not put the lid back on the box.

The sensitivity of sex heightened the emotional response. It was not just lack of skills and knowledge but wanting expert skills to address something perceived to be so sensitive.
Janet: I think we’re a bit frightened because… you want, that sort of topic you want to deal with well don’t you (group agreement), but you’re not trained… (B fg1 p5).

In listening to the provisional analysis from the first focus group, Zanna confirmed that sexual expression was far more anxiety provoking than other areas of practice for staff (C iiC1 p1). Or, as Henry said 'the stakes are higher' and the reactions maybe more acute (A iiB1 p7). The sense of lacking skills becomes more problematic -

Tracy: … because if you open up something as delicate as that with someone er you've opened up a major need and then you're going to say well actually I’m not trained to go any further with you and then close the door again so, you know, I think you have to be careful how you you broach it with someone (C iiB1 p6).

Henry also indicated a 'massive responsibility' (A iiB1 p6). That is, a practitioner may raise a disabled person's expectation when the problem is insoluble. The 'fear factor' (A iiB1 p3) then is of 'letting them down' (A iiB1 p3). This too could lead to avoidance 'because if you don’t go down it you're not burdened with it' (A iiB2 p6). In taking responsibility you could also 'feel very alone with it' (A iiB1 p18) because there may be no support from colleagues. Kitty also feared that some people may not wish to be referred on and 'then you're left with it' (B fg1 p12). Nancy described being uncomfortable because sexual expression is outside her expertise and the service user's problems may be entrenched and insoluble.

Nancy: … I don’t really want to go there because I don’t feel comfortable with it, because it’s counselling and you think you’re taking on far more than you can deal with because you may not be able to resolve those things, and there's a whole long long history of problems erm...(B iiA2 p14).

10.4 Discussing sexual expression may cause damage

Some participants feared that discussing sexual expression had the potential to damage the therapeutic relationship with the service user. Anita noted raising the subject might 'jeopardise the relationship at the outset' (A fg2a p1). Irene too described her anxiety.

Irene: I feel a bit worried in case it’s very much the wrong thing to say to them … if erm they find any talk about sexuality erm… difficult to cope with or if it’s something which has been a big problem in their relationship and therefore they feel quite embarrassed about it or something like that, erm … I feel a bit concerned, you know, about whether it could be like totally the wrong thing and therefore a bit of a problem in your relationship with the client (A iiA1 p3).
Intrusive, insensitive questioning could embarrass a service user and damage the therapeutic relationship. This statement can also be interpreted within a psychoanalytic model as projective identification: Irene may be the one who finds it difficult and embarrassing. What is clear is that Irene's affective response (overt fear of damage) deters her from discussing sexual expression. Irene agreed with this interpretation at our second interview (A iiA2 p1).

Nancy provided an example from actual practice of perceived damage to the relationship with a service user's partner. It arose from one of the approaches received by Disability Team B after the first focus group. The patient raised the issue of sex with Rhoda, when his wife was present.

Nancy: … and his wife was absolutely horrified, she was so embarrassed. Rhoda was embarrassed because she felt for the woman she felt for the chap… and so they agreed to meet again and the next time I went with them because Rhoda said ‘You know I think we should do this together because there are continence issues’ and she said ‘I feel really uncomfortable’. And the wife didn’t come to the next meeting, so we spoke to him about it and ok he raised the sexual issue again erm… I think it’s unlikely we will get to talk to his wife again about it, and I think she will now resent our contact with him because it’s actually made her very vulnerable and she feels very threatened now…

Researcher: So in some ways it’s damaged the/

Nancy: It’s actually made things very difficult that she knows… er that we know that he’s not happy about his sex life, and I I think it’s probably made it very difficult for her to trust us (B iiB2 p12-13).

It must be noted the wife was not present at the second meeting and it is Nancy's perception that she is feeling threatened, vulnerable and unable to trust Disability Team B. On both occasions, the service user raised sexual issues with them. Rhoda chose to hear his concerns. I find the number and intensity of negative feelings attributed to his wife quite remarkable, yet, if Nancy is correct, the damage is considerable.

Henry too presented a recurring fear that including sexual expression within practice would somehow make things worse (A iiB1 p17). He cited a hypothetical risk to the service user's self-concept. That is the therapist could raise sexual expression, and after leaving the home the service user might feel ashamed or experience a sense of failure.

Henry: … and you may be oblivious, that's the danger, completely oblivious of what you have done (A iiB1 p23).

Other anxieties for him were risks to professional relationships within the team. He suggested some members of the team might not want to engage in the issues, causing
divisions. Team working in his service has 'got a long way to go, and would that set it back?' he asked (A iiB1 p17). Also, because there is no tradition in Disability Team A of addressing sexual expression, he feared he 'would be judged' (A iiB1 p18) by the other practitioners if he took such cases to the network meetings for support or advice.

**Henry**: … especially if I was to go on all the time, I… you know,… I think someone would be saying 'What, has he got it on the brain or something?' (A iiB1 p18)

Being a man in a predominately female profession may exacerbate these feelings. Interestingly he compared it to taking cases to network meetings around toileting issues. Then there would be no sense of being judged because 'that’s the norm, in our profession' (A iiB1 p18).

Some practitioners feared that the relationships of service users could be damaged. This was an issue particularly concerning Rhoda. In the focus groups, she was ambivalent as to whether sexual expression should be addressed, as seen in the following extract.

**Rhoda**: One of the things that er worries me again is… if if, you might not be able to do anything about it, but if if you can get people talking and communicating then that usually helps, but it’s like with bereavement if people get people talking and that will help their self esteem and they can share, but the only difficulty with that is when it’s about sexual matters or sexuality if you get them talking and they are totally honest with each other you could end up with the relationship breaking down … if they really were to look at how they felt and what they really want to do, they may choose not to stay in that situation, so I’m always like thinking ooh I don’t know, should I be doing all of this or should I just sweep it under the carpet (B fg1 p21).

Odele intervened supportively, in the focus group, to suggest that it is the clients then who are making a choice.

**Rhoda**: They are, but I, I sometimes feel that it’s me that’s sort of like I’m the one who’s got them talking and I’ve almost been instrumental in it or, that’s my fear that I’ll be instrumental (B fg1 p21).

Not only was she anxious that she may be instrumental in the breakdown of the clients' relationship, she also feared that she might be held professionally responsible for something bad happening (B fg2b p11).

### 10.5 The dangers of sex

Henry was the only person to use the word danger (A iiB1 p19; A iiB2 p4) but it was implied by others in descriptions of: feeling vulnerable (A fg1 p15; B fg1 p26), putting...
oneself at risk (A fg1 p17; A fg2a p12), or needing to protect oneself (A fg1 p16; C iiA2 p5; C iiB1 p8). Dangers included: the risk of litigation; risks to personal safety, and mistrust of the service user's motives.

In terms of litigation, Henry feared being seen as voyeuristic or perverted (A iiB1 p7). He later gave a detailed hypothetical example to demonstrate his concerns. In the example, sexual expression is explored with a service user. A problem then arises, for example, a Disabled Facilities Grant is refused. Henry developed this imagined scenario to the point that the therapist is in a court of law, defending their practice.

Henry: … and prosecuting lawyers saying ‘Did you go in and talk about this (sex) sir? Did you or did you not… answer the question.’ ‘Yes I did.’ ‘No further…’ you know, it it’s… dangerous, you know (A iiB1 p19).

This may seem irrelevant in that it is a fantasy of what could happen, yet for me it indicates the level of fear that can be associated with including sexual expression in professional practice.

A risk to personal safety that was identified was the practitioner becoming the sexual object. Ginny highlighted this from a hypothetical perspective. As a female therapist talking to a male service user -

Ginny: … he may well think that’s a come-on and you’re putting yourself at risk aren’t you? (A fg2a p 12-13)

Tracy gave two examples from practice where this had occurred. One patient had had a brain-stem stroke causing severe disfigurement.

Tracy: ... he had a young attractive wife and I I he said “But I just can’t get an erection”, so we sat, we did talk I did talk about it there with him, but I didn’t feel comfortable I must admit because I felt he was a bit… on the eye for me, so I preferred to talk about it at the clinic, but then he would talk about it in the middle of… an upper limb session, “Well why is it I can’t get an erection?” You know, with all these other patients around (C iiB1 p7).

Tracy arranged a meeting with the patient and his wife following which, the couple went to their GP.

Tracy: The GP said it was too early at the moment and just to leave it, but in the end I had to avoid talking about it … I felt that this man was really frustrated, you know, I felt he was really sexually frustrated and I’m a young female going into his home and I didn’t feel comfortable…(C iiB1 p7-8).
Tracy experienced the patient's disclosures as inappropriate. Factors perceived as heightening risk included: Tracy being a young woman; the service user being a young, sexually frustrated man; working alone with him and working in his home. The next couple of visits she went in with Vince to 'protect' herself and after two or three visits 'he calmed down' (C iiB1 p8) and Tracy returned to visiting him on her own.

Another risk, bringing a sense of danger, stems from mistrust of the service user's motives. Sarah described an experience where she felt very uncomfortable because the service user spoke several times of his sexual difficulties. He was married. This 'legitimised' the inquiry reducing the perceived risk (B fg1 p16). Nevertheless he was -

Sarah: quite graphic in the details and I’m in his house on my own with him and he’s quite a lot older than me and, you know, I don’t want to pursue it, I mean, as it turns out it’s quite a medical discussion so it isn’t actually… that threatening to me but it, you know, it could potentially be, so erm…(B fg1 p16).

She found it strange that 'someone would just bring that up' (B fg1 p16). On further exploration, what concerned her were his motives in speaking with her. From her perspective, the issues were being addressed medically. Odele empathised.

Odele: … I think occasionally there is, you do get an uncomfortable feeling that that’s potentially could be just getting-off on it when they’re talking to you about it and that’s horrible (B fg1 p17).

Others had noted times when service users were perhaps trying to shock them (A fg1 p15; B fg1 p26) or they did not trust their motives (A fg1 p16; B iiA2 p12).

10.6 The impact of the affective component

Core texts refer to the importance of the professional being comfortable to discuss sexuality in healthcare (Crouch 1998; Davies 1988; Neistadt and Freda 1987; Ross and Channon-Little 1991; Webb 1994; Wells 2000; White 2002). With one notable exception (Wells 2000), most provide little explanation of comfort or how this affective component impacts on practice. Different aspects are cited: comfort with one's own sexuality (Crouch 1998; Gender 1992; Neistadt 1993); comfort in discussing sexual expression generally (Davies 2000; Finger, Stack Hall et al. 1992; Neistadt 1993) or specifically in physical disability (Davies 1988; Williams 1992). Proposals have been made to improve practitioner comfort through the identification of, and setting aside,
personal values (Ekland 1997; Gender 1992; Weston 1993) or through educational programmes (Hay, Byrne et al. 1996; Medlar and Medlar 1990; Tepper 1997b; Wiederman and Sansone 1999).

Quantitative research, into the views or attitudes of health professionals towards discussing sexual expression, provides the merest (and sometimes confused) glimpse of discomfort. In one study, of the 813 participants, 60% said they felt comfortable to discuss sexuality with patients but 50% reporting feeling embarrassed (Haboubi and Lincoln 2003). Some people who reported being comfortable must also have reported feeling embarrassed. Embarrassment was identified by over half (54%) of the 161 nurses in Lewis and Bor's (1994) UK study. Nursing practice was not found to be correlated significantly with the attitudes measured. The attitude scale used was developed from SKAT. It investigated attitudes toward subjects like masturbation, heterosexual relations and abortion, not how practitioners' felt in discussing sexual issues. Although the authors' concede the important influence of emotions to practice, the research did not develop understanding about the practitioners' affective response.

Qualitative research has potential to explore the affective domain but some authors have not developed this. For example in Rubin's (2005) study, deep emotions are revealed in the excerpts published from the transcripts, yet there is minimal representation of these feelings. Rubin indicated only that practitioners were wary of giving permission to patients to discuss sexual issues, as they were worried it might seem intrusive. They were also embarrassed that they did not have enough information to give patients. I believe she understated the powerful effect that negative emotions have on practice.

Only one study directly investigated comfort (Yallop and Fitzgerald 1997). Negative emotional responses hindered the respondents' ability to tap into 'what is unspoken or embedded in the communication' (Yallop and Fitzgerald 1997 p58). Additionally respondents were less sure of the role of occupational therapists in the scenarios that increased their discomfort. Where participants had a sense of power and control they felt more comfortable. This is closely aligned with the theme, identified here, of danger seen for example in fear of litigation or risk to personal safety.
In my research, I have interpreted the affective component as such a powerful deterrent to practice that it warranted its own chapter. The data has revealed an intensity of negative feelings like fear and danger, involving fantasies of Russian roulette, courts of law and accusations of professional malpractice. The sensitivity and taboo of sexual expression heightened the affective response, making it more difficult than other practice areas like micturition and incontinence. The data demonstrated how negative feelings could lead to avoidance of sexual issues in practice. Anita suggested that avoidance was less destructive than proceeding to ask about sexual issues when a practitioner felt uncomfortable. Similarly, Neistadt (1986 p543) proposed that -

'Only therapists who are comfortable discussing sexuality with their clients should attempt to counsel. Others can refer their clients to another qualified staff member for counselling.'

I have three concerns with this. Firstly, if the practitioner feels, because of their discomfort, that they should avoid sexual issues, this is conveyed to the service user and the subject will not be raised. So there can be no identification of need and thereby no referral on. Neistadt's approach does not separate problem identification from problem exploration. Some nurses and therapists may not feel sufficiently comfortable to explore sexual issues in depth. However, unless a second (comfortable) practitioner screens all service users to identify sexual concerns, disabled people may miss opportunities to access appropriate help.

Secondly, the preliminary inquiry indicated that no one raising the subject was, of itself, damaging. Individuals who responded interpreted omission of sexual expression from health and social care as asexualisation: sex is not important and no longer matters. Other researchers have identified such damage (McAlonan 1995) and it may contribute to the internalised oppression of disabled people (Shakespeare, Gillespie-Sells et al. 1996). That is, disabled people may begin to believe the message and this can create barriers to them developing or retaining a healthy sexual identity and pursuing fulfilment through sexual expression (Shakespeare, Gillespie-Sells et al. 1996).

My final concern with the practitioner 'overlooking' the subject is the power and control that it gives to the professional. It negates a client-centred, needs-led approach. An aspect of care is undertaken, or denied, on the basis of the practitioner's feelings. This
has led me to propose minimum levels of knowledge and skills for disability practitioners (see section 9.7 - The impact of professional socialisation) and disability teams (see section 12.2 - Team working to support sexual expression).

Avoidance may not be the only way practitioners manage powerful negative feelings. Festinger's (1957) theory of cognitive dissonance provides an explanation of how feelings may alter thinking. He suggested individuals seek to eliminate dissonance by altering their cognition (beliefs and opinions). Thus, rather than experience fear or danger, practitioners may alter their beliefs, for example seeing sexual expression as a low priority concern (see section 11.6 - Treatment priorities). This research provides an alternative view of the theory practice divide: although practitioners said sexual expression ought to be addressed, other more consonant beliefs may dictate their behaviour, thus eliminating dissonance. Freud articulated ego defence mechanisms, which may manage negative feelings, for example projection or denial (Freud 1946). Examples of participants' feelings projected to the service user have already been seen. In chapter 12, projection of participants' feelings to the wider organisation is considered.

Whatever the theoretical framework, I believe people do have a homeostatic tendency to return to a stable equilibrium of comfort and safety, for example through avoidance, altering beliefs, or projecting feelings onto others. Understanding this underlines the significance of the affective component identified here. It has been said that

>'For a change in practice to occur it is likely that one would need to impact on the practitioner's affective domain' (White 2002 p246).

The affective domain however is seen as resistant to change (Lewis and Bor 1994) leading others to suggest that practitioners learn to separate personal feelings from professional roles (Ekland 1997; Gender 1992; Lewis and Bor 1994). An alternative approach is to recognise practitioners' feelings as a major learning tool to develop practice. This approach is described in detail by Clifford, Rutter and Selby (Wells 2000 p5). They explore through case studies and reflection on practice, how psychosexual awareness can be developed in health care practitioners. They recommend Balint seminars both for programme tutors learning to integrate sexuality into the curriculum, and for practitioners addressing sexual expression within their practice.
10.7 Conclusion

Discomfort is a bland term used in the literature when discussing professional practice and sexual expression. This chapter indicates what discomfort actually means. Participants experienced it, not only from actual practice, but when imagining what could happen. They described considerable anxiety and fear to broach the subject of sexual expression with service users. For some this was directly linked to concerns about managing conflicting moral values. Sexual expression was seen as more anxiety provoking than other areas of practice. Participants feared raising service users' expectations, then failing them, if the problem were insoluble. They feared damaging the situation. Damage could be to their therapeutic relationship with the service user, or between the client and their partner, or to the relationships within the team. Some participants conceived addressing sexual expression as dangerous. Identified risks included litigation, personal safety and potentially perverse motives of service users.

No other research has placed such emphasis on practitioners' emotions. Recognising the powerful effect of strong negative feelings is important to understanding the total omission of, or difficulty experienced with, including sexual expression in practice. People have a homeostatic tendency to return to a stable equilibrium of comfort and safety. One way to achieve this is to project negative feelings onto others. Or consonant beliefs (supporting non-involvement) might over ride dissonant beliefs; for example that sexual expression should be addressed. Another way, demonstrated in the data, was to avoid sexual expression, either consciously or unconsciously. I have challenged a view that, where a practitioner feels uncomfortable, it is legitimate to negate responsibility for sexual health. Either through individual development or team organisation I suggest that every service user should have the opportunity to access appropriate help. Omitting sexuality disregards client-centred and needs led care. It may also be damaging to service users who interpret this avoidance as asexualisation. Although the affective component is distressing to practitioners, these feelings have the potential to provide a valuable learning tool.
CHAPTER 11: PROFESSIONAL PRACTICE

11.1 Introduction

The thematic analysis continues but here the deterrents that team members experienced, in addressing sexual expression in their professional practice, are critically analysed. This builds on the earlier chapters. We have seen how the individual enters training already imbued with beliefs and values. The majority of participants suggested that their pre and post-registration education gave them little knowledge or skills to address sexual expression. In the previous chapter, I explored how strong negative emotions inherent in the topic may be managed. There is an inevitable overlap with some material in this chapter. The difference is that here I am not presenting what participants learnt, or how they felt, but how they acted.

All participants, bar the incontinence nurse, said that in theory sexual expression should be part of service provision. In this chapter, my aim is to enrich understanding of the barriers. These included the hidden or unseen nature of sexual expression. It was also about role uncertainty: that is, professional identity in practice. One result of this uncertainty was that generally practitioners had no sense of authority, bestowed by their role, to address sexual expression. Additionally, a specialness was afforded to sexual expression: it was not regarded like any other activity. Another important deterrent noted was that for the most part, practitioners only had personal experience to guide practice. Finally, the treatment priorities of the therapist are discussed. These challenge the rhetoric of client-centred practice and, in the context of pressured workloads and limited time, discouraged practitioners from addressing sexual issues.

11.2 An unseen issue

The transcripts revealed that some service users were seeking to discuss sex but their concern was unseen or ignored. Carol gave an example of not seeing. In the first focus group, she had described the approach made by a patient with a spinal cord tumour (A fg1 p19). In the second focus group, she was concerned to stress such disclosures were
a 'minor issue' for the physiotherapists (A fg2a p7). Ostensibly minor was about frequency and Carol was revising her earlier assertion that unsought disclosures happened 'quite often' (A fg1 p2) implying instead that they were occasional (A fg2a p7). My impression however was that minor was also about importance. That is, the importance of this service user's concern (did his erection denote progress), was not recognised. It was not perceived as a serious health concern worthy of intervention. She did not address it. She also did not reflect to him the importance or legitimacy of his concern. Nor was he directed to a nurse, the consultant or anyone else.

Not seeing service users' concerns is different to ignoring them. Some explanation of avoidance was explored earlier (see section 10.2 - Discomfort leading to avoidance) but now I wish to demonstrate how some participants managed unsought disclosures. There were examples of unsought disclosures to nurses (A fg1 p18; B fg2a p2); occupational therapists (A fg2b p7; A iiB1 p5; C iiB1 p7); physiotherapists (A fg1 p13 & 19; B fg1 p5); speech and language therapists (A fg1 p5 & 18; B fg1 p16), and support staff (B fg1 p5; C iiA2 p3). Unsought disclosures could be made to anyone in the team.

**Shena:** it depends on the situation and the client and the relationship, not necessarily about what you’re doing, it could easily be with a speech and language therapist psychologist or OT or whatever, I think, depending on that relationship (B fg2b p6).

Often the participant was aware, they did see the service user’s concern, but they chose not to respond. Maeve, for example, spoke of not acting on the clues given (B fg2b p5). Sarah didn't 'want to pursue it' (B fg1 p16). Rhoda reported choosing 'not to pick up' on hints (B fg1 p16). Fiona described changing the subject (A fg1 p4).

Where sexual expression is barely addressed there was no way of identifying the need. Quita and Lesha, who believed service users would raise sexual expression if it were an issue for them, said approaches were 'rare' (B fg1 p5). Some participants implied it may be relevant for a significant number of their service users (A iiB2 p14; B fg1 p4) but there was no way to ascertain the scale of the problem (B fg1 p21 & 28). In Disability Team C where more was being done, Yvonne proposed it was one quarter of the team's client group (C fg1 p19).

Its almost total omission from main stream professional literature (C fg2 p26) exacerbated the unseen or hidden nature of sexual expression in disability. This finding
resonates with my experience. Most research articles that I found on sexual expression were in specialist journals such as Sexuality and Disability. These were difficult to locate. Not only does this mean information is not easily accessible to disability practitioners, it may also perpetuate a notion that a specialist, not the disability team member, should undertake this area of practice.

11.3 Role uncertainty

Both electronic and team data revealed that no single profession included sexual expression as part of its core role. The three 'flag bearers' of Disability Team C, affirmed a fit with occupational therapy, physiotherapy and speech and language therapy. Yet, as this excerpt indicates it did not fit comfortably in anyone's defined role.

**Unwin:** … it’s not in anyone’s defined role and so I suppose it just falls to one side unless you make a real effort and actually directly address it as part of routine.

**Researcher:** Can I, can I just check that out – it’s not in anyone’s actual defined role, is that right here?

**Unwin:** I don’t believe so.

**Wendy:** Yes… it doesn’t belong to anybody exactly… I, as a person, as an OT, I see sexual relationships, or the actual sex act if you like, as part of an activity of daily living… Now whether you do it every day, whether you er you know… whatever you do I see it as it come under the broadest sense of the OT’s remit in activities of daily living.

**Yvonne:** And I see it as a physical activity. So it comes under physical… erm activity as well and I will I will often ask the question… before I assess people I will ask them their physical difficulty that they’re having and after I’ve finished assessing them I will ask them if there’s any questions I haven’t asked them that I should have asked them… but that categories sex as a physical activity and of course there’s, there will be other huge… /

**Tanya:** Even I can see it as communication as well, so… you know, I don’t, you know, I think it is spread between us all (C fg1 p12-13).

With no clear ownership ‘it's not formally any one person's job' (C fg1 p4), there is a potential to assume someone else is addressing it (C iiB1 p12). I suggest a positive role identity, encompassing the domain of sexual expression, is essential to facilitative practice. Conversely, role uncertainty is a deterrent to practice. This research reveals the uncertain role of each profession.

Psychology, for example, was divided. Odele saw her expertise around interpersonal and intrapersonal skills (B fg2b p7) and was clear that sexual expression fell within her remit (B fg1 p7). Zanna and Unwin however attended to cognitive skills only (C iiC1 p1) and assumed other members of the team were addressing sexual expression adequately (C iiC1 p1). Both Odele and Zanna lacked expertise in biomechanical issues.
The seven physiotherapists in this study presented a range of views. Two or three were not at all certain that sexual expression should be part of their role (A fg2a p5; B fg1 p9 &10). Others were more positive about the skills they had to offer and saw, either in theory, or undertook in practice, a role in addressing sexual expression (B fg1 p3; B fg2a p4; C fg1 p13). Yvonne confidently and consistently accepted the role within her professional boundaries (C fg1 p12). It was suggested that some service users might introduce the subject to physiotherapists because physiotherapy often crossed the normal social boundaries of touch (A fg1 p14; A fg2a p14; C fg2 p5). For Yvonne the close physical contact encouraged patients to raise intimate questions.

Yvonne: I think if you’re sat right up close and er… you know you could almost er… you can almost feel something kind of bubbling up and then a question comes or er … that closeness… n n non-sexual intimacy allows them to ask the question (C fg2 p5).

The physiotherapists' expertise was seen to be in the biomechanical domain (A fg2a p5) but some aspects, particularly relationship issues, were seen as outside their remit.

Vicky: and erm while I'm happy and have in the past addressed problems of spasticity and those physical complications erm… they give rise to problems with the relationship that I actually don't feel able to to properly address … I don't want to get into this (C fg1 p14).

Other team members in Disability Teams A & B saw nursing as the profession with potentially the greatest expertise (A fg1 p22; A iiA2 p6; B fg2a p27). Implied in the data is an assumption by the other professions that nurses can facilitate discussion on sexual issues and that they consider broad aspects of the topic, from relationships and feelings, to medication and biomechanical problems. Yet, none of the four nurses expressed confidence or competence to encompass sexual expression within their professional remit. Fiona and Kitty were more comfortable. Rhoda said 'it’s not a recognised part of the nurse role or the nurse specialist role' (B fg2a p29) and Nancy, the incontinence nurse, was adamant sexual expression should not be raised. This contrasts markedly with the data from the Multiple Sclerosis Trust e-discussion. Here the specialist multiple sclerosis nurse and the incontinence advisor were cited as the most informed professionals for people with multiple sclerosis to discuss sexual problems with. There were no nurses attached to Disability Team C.
For me, an interesting group was speech and language therapy. I was not sure how they would view their role and had not anticipated such active involvement. The speech and language therapists in Disability Teams A & C, both demonstrated competence and confidence. They attributed this to working one-to-one, on communication, in a private context (A fg1 p5: C fg1 p5). Ginny limited her involvement to discussing sexual expression with those who raised it with her. Tanya was routinely raising it with most of her patients including those who were aphasic (C fg1 p4).

Tanya: … but as a speech and language therapist some of my patients can’t talk at all… and… erm, even if if they’ve got a fairly severe expressive language problem I do I have a book that I go through which erm… looks at all the problems related to stroke or head injury or or whatever… and it’s mostly talking about aphasia and how difficult it is in lots of different situations and prevention of further stroke, and on one of the pages it it does say about sex, so I’m turning over the pages and we’re talking about pain and fatigue and then we get to sex and I say “Is this an issue for you – do you want to discuss it further?” if they can understand that, erm… and if they say yes then, you know, I try just to facilitate them talking it further, if they say no then I turn the page… before I turn the page I say “Well, if you ever want to come back to that then point to this book and show me” (C fg1 p4).

Yet Disability Team B speech and language therapists were not involved.

For the ten occupational therapists, there was greater consistency with all suggesting that sexual expression could theoretically be part of their role. It was seen as consistent with an holistic approach however only Wendy was regularly including sexual expression within her practice. The wheelchair service and local authority practitioner both expressed doubts about the fit with their specialist roles. Supporting the role was the parallel with other personal activities of daily living including intimate areas such as defecation (C iiB1 p8) and menstruation (C fg2 p9). Occupational therapists also transgressed normal social boundaries, not of physical contact but of space, spending time in people's bedrooms, bathrooms and toilets (A fg2a p15-16). This provided better opportunities for disclosure. The participants' views contrast sharply with Kielhofner's unequivocal position that sexual expression should not be part of practice.

The other professionals in Disability Team C indicated that greater responsibility for sexual expression fell to the occupational therapists (C fg2 p3; C iiC1 p1) partly because Sexual Activities is on Disability Team C's Activities of Daily Living Checklist. This is an in-house, non-standardised, occupational therapy assessment. It includes the question: Does your disability effect your sexual relationship? This is an intrusive question requiring respondents to expose something of their private sexual relationships.
That criticism aside, it does suggest a mandate for the occupational therapists to facilitate exploration of sexual expression. On the other hand, sexual expression was not addressed by the occupational therapists in Disability Team A or B.

Role uncertainty meant that participants lacked a sense of authority to address sexual expression. Apart from Odele and Wendy, no one was confident that sexual expression was squarely within their professions' remit. On the other hand, no one was adamant that it was outside either, as all could see a fit with some aspects of their professional role. Having no sense of authority, bestowed by professional values or education, was an important deterrent. It undermined confidence and influenced treatment priorities.

Importantly this role uncertainty is conveyed to the service user.

Vicky: The problem is that once we start treating them we erm… we very quickly within our first sort of three appointments, all of us I’m sure, give them an impression of what our role is in their recovery and… on the whole that won’t include discussing sexual function or intimacy or those things, it’ll be about functional activities in the kitchen or doing the stairs or getting the bus… and we we because we’ve identified our territory they may feel less inclined then to bring it up with us (C fg1 p11).

Henry spoke of client-centred practice and letting the service user set the agenda.

Henry: I suppose a lot of it is about what people are telling you, and whatever they’re telling you depends on what you’re introducing yourself as being. I think if you’re not clear about what you, how encompassing you can be… you haven’t given that person permission to explore (A iiB1 p1-2).

This theme also highlights the breadth of sexual expression and how it spans professional expertise. In the preliminary inquiry, disabled people stressed the importance of understanding the effect of disability on sexual expression, not only from a biomechanical but also from an emotional perspective. Some aspects of sexual expression are seen as more appropriate to one profession than to another. Sharing skills is developed later (see section 12.2 - Team working to support sexual expression).

11.4 Specialness of sexual expression

Vicky: But this isn't 'anything else'. I ju you see I I this is where I disagree, to some extent... it isn't just anything else, if it was we wouldn't be here talking about it... you know.

Tanya: Mmm, it is different (C fg1 p31).
Like Vicky, I felt some participants attributed a specialness to sexual expression not accorded to other activities, making it infinitely more complex than other aspects of healthcare. This, no doubt, is closely linked to its taboo nature and the heightened emotional response identified earlier (see section 10.3 - Would I be able to deal with it?). In essence, I felt some were describing a transpersonal, spiritual element.

**Tracy:** … because it’s personal and it’s intimate and… er it’s the most intimate act you can be involved in with another human being (C iiB1 p2).

It is also allied to the individual's personal experience (see section 8.4 - Personal moral values) but the point I make here is the corresponding pressure put on practice. Some expressed fear that if sexual expression was not managed well, this specialness could be damaged. This was exemplified in Tracy's criticism of Wendy's blunt approach. Tracy suggested sexual expression required a much greater level of skill and sensitivity (C iiB1 p10). Some people were concerned about the risk of reductionism on this specialness. Xavie described using the occupational therapy assessment form, where sexual expression was included with other activities such as transfers, work and using public transport. The implication was that sexual expression was being 'addressed as if it was just a function' (C fg1 p13) and not afforded the respect it deserved.

Sexual expression was seen to be so much more complex than other tasks or situations professionals had to manage for example bereavement (B fg1 p18) or depression (B fg1 p3). Henry (A iiB1 p21), Maeve (B fg1 p30) and Sarah (B fg2a p18) all suggested addressing continence was simpler and easier. There was openness about incontinence as well as a network of support (A iiB1 p7-8; A iiB2 p12). Xavie related complexity to task analysis. She said, when it came to sexual expression 'you could analyse that for years because there's so many different categories' (C fg1 p26).

### 11.5 Personal experience guides practice

In this study for the most part, practitioners only had their personal experience, 'our own values and background, beliefs as well' (A fg1 p10) to draw on. For example, Vicky described the influence of her experience.
The effect of this on practice can be seen in the task of providing permission to service users to discuss sexual expression.

Several participants spoke of their greater confidence to explore sexual expression if the service user raised the subject (A iiA2 p4; A fg2b p7; B fg1 p3). I contend that what they are seeking is permission from the service user to cross the social boundary of privacy (see section 8.2 - Individuals are socialised not to talk about sex). Openness and directness from service users removed the fear of offending them. For Henry, he saw the service user raising the issue, 'almost like a green light' (A iiB1 p5) which removed the quandary of how to introduce the subject. It also shifted the onus of responsibility from him, that it would not be his fault if it brought up a distressing revelation by the service user that was insoluble (A iiB1 p5-6). In one example, a particular client was discussed where the team felt his sexual anxiety was contributing to the presenting problems but it was not explored.

Eliza: … I mean alarm bells are ringing in our heads, but he hasn’t actually said ‘This is something I, I feel is a concern and I want to discuss it with /someone’ or ‘I want to explore this problem’, he hasn’t/
Fiona: /He hasn’t said ‘I need help with it’ (A fg1 p23-24).

In not asking for help, he had not given any team member permission to raise the subject with him. With only personal experience to guide practice, practitioners are left with a social boundary of privacy that risks censure if they cross it.

It is possible to raise sexual expression in a way that is not intrusive; respects privacy yet invites disclosure for those who wish to do so. Few participants had developed these skills. That left people with only one strategy: asking direct questions.

Nancy: … I don’t, personally I don’t think it’s quite right to actually approach sexuality in line assessment, you know “how’s your sex life”, no, I would resent it if somebody was asking me those questions (B fg1 p4).

Shena echoed this.

Shena: I wouldn’t feel very comfortable in going in and asking a direct question about how is your sex life, oh yeah erm, because I, personally, I wouldn’t want someone to do that to me, …(B fg1 p15).
Without skill development, it was understandable that practitioners feared being offensive or impolite with service users.

Working from personal experience alone meant practitioners had to draw on their 'own life skills' (A fg1 p7). Ginny, for example, suggested her approach was more about herself as a person than any acquired professional skills (A fg2a p9). For each person these skills will have limits. In Tatum's example, she indicated that she could not have done more than provide the stroke leaflet.

**Tatum:** I said oh I'm going to send you erm... the the leaflet about sort of relationships after stroke... "Yes please"... so... that's er, but I don't think I've gone... I'm I'm rather like you, I think that... what happens behind the bedroom door is your... it belongs to you, and there are some people who are not like that but I am like that (C fg1 p30-31).

Using ones own experience requires a level of personal confidence which some linked to maturity and adulthood.

**Anita:** It’s that you need experience of life or … cos as a 21, 22 year-old coming out of college there’s just no way I would have wanted to erm…/ … it’s only when you become more confident within your own role and confident, not necessarily about sex, but confident… as a person and as an adult, that you feel that you can deal with those sorts of situations (A fg1 p8).

Similarly, Rhoda said,

**Rhoda:** I think it depends on how confident you feel yourself really… with sexuality and sex and all the rest of it, I mean that, you know, if you’re not feeling confident yourself or if you’re having problems yourself then you’re not gonna be particularly effective in trying to help somebody else I wouldn’t think (B fg1 p5).

I suggest this is true of many other things. For example, the practitioner dealing with his or her own recent bereavement may not be best placed to support a bereaved client. However, I contend that, in areas like bereavement, it is easier to get professional support. Partly this is because of the privacy afforded to sex. That is some practitioners would not wish to disclose their own personal anxieties around their sexuality yet they may be comfortable to reveal they have been bereaved.

I believe Nancy's personal experience of her husband's terminal illness was an important factor in her position, that sexual expression should not be addressed. Nancy deals with personal issues around continence however when it came to sexual expression she said

**Nancy:** You don’t have a right simply because you have a profession around you to go and ask somebody very personal questions, do you? (B fg1 p30)
This is true, but it misses the point that for some service users sexual expression may be a high priority concern. For Nancy and her husband, amongst all the other losses -

Nancy: … that *(sexual expression)* wasn’t a big issue, you know, … whatever you had it’s not going to be there much longer *(B iiA2 p9)*.

However, her personal experience was of terminal cancer care and not disability. They cannot be regarded as the same experience.

### 11.6 Treatment priorities

The data indicates that treatment priorities can be established around what the therapist sees as important thereby ignoring sexual expression. This may be due to lack of awareness however, many participants did acknowledge that sexual expression might be important to service users *(A fg2a p3; A iiA1 p6; A iiB1 p17; B fg1 p6; B fg2a p8; C fg1 p4; C iiA1 p5)*. Possibly even being 'the most important thing to them' *(C fg2 p17)*. Yet, this awareness rarely translated into treatment planning.

There was evidence of assumptions being made.

Nancy: *(It's)* a question of priorities isn’t it, what’s *important* to people, you know, if if your most pressing concern is that you can’t actually *walk* … or that you can’t *control* your your bladder and bowels, you know, how… how high up the list is sex? *(B fg1 p6)*

This was a rhetorical question. Nancy was clear that sexual expression would be a low priority to service users. This may be true for some service users but, without any strategies to discuss sexual expression, their priorities cannot be established. The preliminary inquiry revealed that for some disabled people sexual expression was one of the earliest and highest priority concerns. With only personal experience to guide practice, the practitioner may project what their concerns would be, upon the service user. An alternative explanation is that, if the practitioner is experiencing strong negative feelings around addressing sexual expression, making it low priority reduces dissonance.

Another way to make it low priority is to conceive sexual expression as a non-essential activity. Wendy drew a parallel between sexual expression and menstruation, noting that both require privacy during assessment to explore potential problems.
Vicky: But that’s not optional... whether or not you bleed once a month isn’t an optional extra, whether you go to the toilet and how you wipe yourself isn’t an optional extra/ … / Wendy: It’s also still something which you have to deal with, you can as you, say like bringing it up because mother in law might be there, you know, people may still be around. Vicky: But you can bring, you can bring things up because it they are a fact of life that’s unavoidable (C fg2 p9-10).

That is defecation, micturition and menstruation can be raised because they are unavoidable, they are not optional but essential activities.

The medical model perspective also relegates sexual expression to a non-essential activity as seen here. Vicky was reporting an experience from an acute setting where a doctor had not considered that a young head injured man might be sexually active.

Vicky: … it’s about our… view of of what people are allowed to do and once you’re sick you’re sick aren’t you, you’re far too busy being sick to be doing anything like that.

Tanya: Are you saying that’s true or are you saying that’s the perception?

Vicky: I I think it’s the perception and an awful lot of people have it, erm… more or less erm and we don’t always admit it and I have to say I sort of harbour it myself. … and I think, you know, if you’ve got far more more things to worry about/

Tatum: I think we do Vicky, I think I do have more/

Tanya: But then it may not be, that might be the most important thing to them.

Wendy: Might be the only thing they can do (laughs).

Vicky: Absolutely… I’m not denying that erm and what I’m saying is when I rationally think about it I wouldn’t disagree with you one bit… but... back in my, back in my psyche the thing that is what… is the way… I function when I’m not thinking, my sort of reflex behaviour is… it’s more important that you can stand up and sit down and transfer and that you’re not breaking your carer’s back and that you can get in and out of the bath safely erm and those other things… or I’ll say optional extras again and I don’t really mean that, but Yvonne: It’s quality of life isn’t it... which to some extent is an optional extra because the medical model is very much about saving life (C fg2 p17-18).

Vicky was one of the participants most open to look behind her declared view to the less conscious aspects of her practice. Here she acknowledged harbouring some asexualising attitudes: when people are sick they are deemed not to be thinking about sexual expression. There are more important things to worry about. I suggest, although her sentence remains unfinished, Tatum agreed. Vicky appreciated that sexual expression was important to some service users and accepted it should be addressed within the team's practice. She candidly went on to explore, almost subsumed in her unconscious, her priorities for treatment. From her professional perspective, other issues were more important. These are the activities necessary to live safely in the community. From this standpoint, sexual expression is low priority and becomes 'an optional extra'. Yvonne compared this to other activities like employment and leisure which she felt 'in terms of the medical model of saving life are optional extras' (C fg2
p18) and added that sexual expression 'is the same sort of area only with taboos on top' (C fg2 p18).

Treatment priorities must be set in the context of workload and limited time. Both the specialist occupational therapists, Della (A fg2b p2) and Irene (A iiA2 p3), felt there was no time to do anything other than the tasks required of their specific roles. Several others expressed a similar view

**Peggy**: … I mean from, you know, a physio point of view I think we’ve got so many other things that we’re dealing with in our time, you know we’re stretched for time, we’ve got to get on with looking at people’s exercises and walking and, you know, so we’re not looking for extra work in that scenario (B fg1 p10).

If the task is low priority and time is limited, it will not be addressed -

**Vicky**: … because we only have 14 weeks... and to do all the things we want to do that we see as part of our role, directly as part of our role (C fg1 p6).

### 11.7 The impact of professional issues on practice

Findings from this study suggest that some participants were either unaware, or chose to ignore, service users' tentative inquiries related to sexual expression. There are many reports of the general lack of awareness amongst professionals (Earle 2001; Ekland 1997; Friedman 1997; Katz and Aloni 1999 p49; Medlar and Medlar 1990). This, I believe, is the first research to identify, from practitioners, how unsought inquiries were managed. This is a step prior to Annon's (1974) conceptual model PLISSIT, which assumes practitioners accept responsibility to identify sexual concerns. Some may not believe that it is within their role, or for personal reasons feel unable to provide permission. However I agree with Wilton (2000 p3), where service users are seeking 'support in dealing with issues of sexuality there is a clear professional responsibility to respond'. Unsought inquiries can be managed in an affirming way that supports sexual health. Commitment to this requires awareness of the important link between positive sexual health, self-esteem and general wellbeing.

The hidden nature of sexual expression adds to the very problem of raising awareness. Lack of awareness stems not just from the absence of formal training. It includes for example the lack of: consistent inclusion in models of practice; observation of others;
professional discussion and literature. Many researchers have explored the link with quality of life, esteem and wellbeing and made recommendations for improved care within disability services (Chandler and Brown 1998; Disability Now 2005; Mona, Krause et al. 2000; Nortvedt, Riise et al. 2001; Taleporos and McCabe 2003; Walters 1998). The vast majority is published in specialist journals rather than in the main stream ones read by disability practitioners. Similarly disabled people have undertaken some profound research but this does not appear to have suffused the professional literature (Gillespie-Sells, Hill et al. 1998; Shakespeare, Gillespie-Sells et al. 1996).

Contrasted to the preliminary inquiry, sexual expression as an unseen or ignored issue is a damaging health care practice. Disabled people described 'being blanked' when they had tried to raise sexual concerns. Even if practitioners decide that sexual expression is an area not within their role, they can still use simple strategies to normalise and validate a service user's concern and suggest who may be able to help. These strategies affirm a positive sexual identity. I propose therefore that, at an absolute minimum, all disability health and social care practitioners should be able to manage direct questions, hints, jokes and euphemisms in a sexually affirming way. Not hearing an unsought disclosure as an important request for help, may give an unintended message to the disabled person, that this aspect of their life is over, it is no longer important. Not seeing, or ignoring, the unsought disclosure also fails to promote access to more specialised sexual health services (Dept. of Health 2005; Medical Foundation for AIDS & Sexual Health 2005; National Institute for Clinical Excellence 2003).

In terms of role identity, this study indicated that none of the five professions represented here, embraced or refuted a role in sexual expression in disability. The research reviewed earlier portrayed a similarly mixed picture (see section 4.5 - Professionals' roles, skills and attitudes). This finding is also congruent with the perspective of disabled people, explored in the preliminary inquiry. They were concerned that there was no clarity about who they could approach, or indeed if it was the responsibility of any profession.

The themes analysed here suggested a greater consistency regarding the theoretical role for nursing and occupational therapy. This possibly reflects an on-going dialogue represented in the greater number of studies available, into the roles, skills and attitudes
of these two professions. Also, both professions aspire to holistic practice. Nursing was the only profession to have a clear policy on professional role in sexual health, provided by their professional body (Royal College of Nursing 2000). Yet this guidance was not apparent within the practice of the four nurses in this research. Other participants in Disability Teams A & B though, saw nursing as the appropriate profession. This is consistent with the comparative studies reviewed (Haboubi and Lincoln 2003; Novak and Mitchell 1988; Rubin 2005). From the contribution of the occupational therapists in this research, one might assume that the profession is ready, at least in theory, to embrace the role. This accords with findings in my MSc study (Couldrick 1996) but is contradicted by Kielhofner's position. MoHO is a model used widely across the UK. Despite his several emails, I could find nothing in his reasoning that satisfactorily justified his position (Couldrick 2005). The role of the specialist local authority occupational therapist was mentioned in one study that investigated seven disabled people's experiences of sexual health support (Northcott and Chard 2000). Only three had received any inpatient or community rehabilitation whereas all had had adaptations in their home. The local authority occupational therapy role, as Irene said, is specialised. However including sexual expression within it could provide support to a greater number of disabled people as it would access many who do not receive rehabilitation or other health care support.

Physiotherapy, psychology and speech and language therapy appeared as professions offering differing but valuable and complementary skills to address aspects of intimacy and sexual expression. As far as I am aware, this is the first research that has investigated the role of these three professions in sexual expression and physical disability. The role of physiotherapists in attending to secondary sexual dysfunctions, like spasticity and hip-pain, was supported in the discussion of one study (Nosek, Howland et al. 2001). Likewise a role for speech and language therapists was identified to assist the communication of sexual concerns for people who are aphasic (Lemieux, Cohen-Schneider et al. 2001). These opinions are congruent with the views expressed by some participants here.

Understanding the specialness afforded to sexual expression helps to illuminate the complexity of the subject and why it cannot be considered like any other activity of daily living. Postal surveys and attitude scales do not allow practitioners to describe
what the issues are for them (Conine, Christie et al. 1979; Conine and Quastel 1983; Evans 1985; Guest and Kopp Miller 1997; Hoddy 1999; Kuczynski 1980; Lewis and Bor 1994). Other research has hinted at these deeper issues (Couldrick 1996; Lewis and Bor 1994). Here they begin to emerge.

The paucity of practitioners' skills is also revealed. Without awareness training and skills development, most only had their personal experience to guide them. It is understandable that some wanted permission of the service user because the only approach they had considered was direct and insensitive questions. Rubin (2005) found service users wished to be asked direct questions but her sample, of men only, was small (11). Other studies have indicated some disabled people do not want to be asked about their sexual activity (Northcott and Chard 2000; Oliver and Gallagher 2000). Therefore I disagree with Rubin and suggest that a routine inquiry should be an invitation to discuss sexual concerns, only if the service user wishes. It is important to protect the privacy of patients, but this is not the same as ignoring people's needs.

The mismatch of treatment priorities between professionals and service users indicated in the preliminary inquiry is corroborated by this research. For Clare her sex life was more important than using the toilet independently (Couldrick 2001). Here some practitioners discussed sexual expression as an 'optional extra': a non-essential activity. Whereas for some disabled people sexual expression was a higher priority to them than other activities of daily living, including being able to walk, transfer, feed themselves or write (Couldrick 2001). One woman in Northcott and Chard's (2000 p417) study said

'I think I would probably not have been divorced now, if there had been some kind of counselling regarding that (sex): things would have been different'

Given the significant increase in sex and relationship dysfunction identified in one study (Chandler and Brown 1998), the authors noted that, although these are not life threatening consequences of neurological disease, their occurrence may be associated with considerable unhappiness and poor quality of life. Like participants here, many health and social care professionals will cite the undoubted workload. If this is really the constraint, problem identification and immediate sign posting to other helping agencies would be sexually affirming without increasing substantially the time required.
11.8 Conclusion

This chapter has considered the practice of the individuals, working within disability teams, ascribed by their professional and personal identity. Until asked to participate in this study, for some practitioners sexual expression had been an unseen or hidden area of practice. In part, this is due to the privacy afforded to sexual expression but it is also about the absence more generally of sexual expression from professional practice. Due to its hidden nature, there is no way of ascertaining the number of service users who may want support or advice around sexual problems caused by their disability.

In this study, no professional group consistently included sexual expression within its remit. Nor did any group consistently exclude it. This role uncertainty is conveyed to service users, setting parameters on what is appropriate to raise with the professional. The breadth of sexual expression means that it spans different professionals' expertise. Additionally, practitioners have attributed specialness to sexual expression making it more complex or sensitive than other aspects of healthcare. Despite this breadth and complexity most participants only had their personal experience to guide their practice. This makes tasks such as providing permission difficult with several participants seeing direct and intrusive questions as the only option. Some suggested they would be comfortable if the service user raised sexual expression with them. I contend that this provides the professional with permission to cross the social boundary of privacy afforded to sexual expression.

Because sexual expression is not easily discussed with patients, the professional prioritises treatment goals and they may assume these are in accord with the service users' priorities. The priority given to sexual expression is influenced by a medical model approach, which reduces it to a non-essential activity: an optional extra. Given the reality of high caseloads and pressure on staff time, low priority activities are unlikely to be addressed. If it is not addressed in practice, it may not be seen, and so the cycle continues!
CHAPTER 12: TEAM WORK & THE WIDER CONTEXT

12.1 Introduction

'The values and perspectives of the group help determine what is deemed important and what is not, what is granted attention and what is ignored' (Kincheloe and McLaren 2000 p287).

In this chapter, the thematic analysis is related not to attributes of individual participants, but to the combined practice of the disability team. Previous chapters dealt with deterrents arising before, during and after becoming a practitioner. Here I seek explanation of the theory practice divide (that sexual expression should be addressed by the team but is either not addressed or very difficult to address in practice) arising from the construction and values of the team based within the wider context of practice.

The chapter is constructed in two parts. Firstly I consider how the teams collectively supported (or could support) this aspect of care. This is done through analysis of the different tasks involved and it leads to my discussion of the role and responsibility of the team. Then four themes that acted as deterrents for the team to address sexual expression are highlighted. Some could be considered as deterring the individual, however I believe the themes presented are located mainly in the ethos of the team. The first includes the characteristics of the service user group, like age and gender; the additional difficulty of working with people with progressive disorders and working in the community rather than a hospital setting. Another theme identified was the necessity, when focusing on sex, to consider the couple rather than working solely with an individual service user. Two teams also lacked any sense of permission or authority to address sexual expression from their primary care trust or, more globally, from the NHS: the wider organisation. This can be seen both in the attitudes attributed to the organisation as well as in the description of resource management. Finally, the fourth theme returns to asexualisation but from an organisational or institutional perspective. These themes are then discussed and related to earlier research and the preliminary inquiry.
12.2 Team working to support sexual expression

Providing permission
The teams mused on how permission could be given to all service users who wished to discuss sexual concerns. It was the process described in team C as *opening the gate* (C fg2 p22), allowing discussion if necessary, and was undertaken by the 'flag bearers' of that team. It was not done routinely by any one in Disability Teams A or B. Participating in the research prompted some to consider how this could be resolved without members having to ask personal questions. For example, they suggested it could be included in a service pack (B fg2a p19), leaflet (C fg1 p29) or through a poster in a clinical area (B fg2a p19).

In Disability Team A, there was increasing agreement, as the discussion developed, that the nurse should take a specialist lead to provide permission (A fg1 p22). Similarly, in Disability Team B, sexual issues did 'fall more heavily' on Rhoda, one of the nurses (B fg2a p29). The idea of a specialist nurse accords with Rubin's (2005) research undertaken with a comparable community physical disability team. It led her to recommend appropriate training for nurses to enable them to provide permission. This research however highlights the need to separate permission giving from exploration of service users' sexual concerns and providing limited information or undertaking any intervention. A specialist worker within a team may be a practical solution for these next stages (see below) but the team must be able to identify patients who need support or advice thereby ensuring access to the identified specialist. Thus, I contend that permission giving cannot fall to one person.

It also cannot fall to one profession. Not all service users of Disability Teams A & B were seen by a nurse and Disability Team C was purposefully constructed with no nursing input. A nurse to provide permission routinely to all service users would be impossible for the teams as currently constructed. More consistency regarding a fit between sexual expression and the roles of nursing and occupational therapy might lead some teams to delegate the task of permission giving to these two professions (see section 11.7 - The impact of professional issues on practice). For this to work, that is to ensure permission was routinely given to all, a nurse or occupational therapist would
have to assess every service user on the team's caseload. This would have management implications for staffing ratios.

Another solution considered was placing the task of permission giving within the key worker role (C fg1 p29). Disability Team A did not have a key worker system. Disability Teams B & C did and a parallel sensitive task (identifying incontinence issues) had been successfully allocated to the key worker role (B fg2a p18). Yet, participants, particularly in Disability Team C, acknowledged other team members who would be unable or unwilling to provide permission (C fg1 p29-30).

**Yvonne:** How would we manage with staff who have chosen… not to talk about sex with patients (C fg1 p30).

Also, a range of difficulties was experienced when a direct inquiry about sexual expression had been included on the initial key worker assessment (B fg1 p4; C fg1 p2-3). As seen earlier, the screening visit may not be the right time to provide permission (see section 7.6 - Team C's narrative: The initial assessment). There was also a risk identified: of a rote, checklist approach.

**Eliza:** If it was on somebody’s checklist, it could be asked once and the client say ‘Oh no no no, everything’s fine’, tick - done that bit, phew, right, I don’t have to ask again, nobody else has to ask/ (A fg2b p6).

**Exploration**

There was some limited discussion in the focus groups about how the teams would manage the next step of exploring the nature of the problem, ascertaining what help and advice was required. Exploration requires an ability to analyse the tasks associated with intimacy and sexual expression identifying where the problem is located. It may be about loss of social opportunity, role change, physical or emotional issues.

**Sarah:** But as I say some of the, some of the issues might be to do with relationships which at least we can point people in the right direction, it might be to do with more physical mechanical issues where there are places so/

**Kitty:** So we have to find out their, what their problem is really (B fg2a p18).

Without knowing the nature of the concern proper action cannot be taken, for example, provision of written information, referral to a team colleague or to an external agency.

It may be practical for a specialist worker to undertake the task of exploration. In the
data, there were examples of nursing, psychology, occupational therapy, physiotherapy and speech and language therapy assuming this role. In each case, it appeared to be via self-selection, based as much on personal as professional skills.

**Shena**: … it depends a lot on the person and the skills they’ve got, you know, that that’s I think where the problem is, it’s kind of like, you know not having a policy or whatever, but it’s kind of like it does come down to individuals and personalities and how they how they do it… (B fg2b p4).

However, as Shena indicates, without a team policy this leads to an ad hoc approach.
Assumptions might be made that someone else is addressing the issue (C iiB1 p12) with the whole team avoiding involvement.

**Eliza**: … if everybody is … sort of shying away from the same thing erm … refrain(ing) from taking responsibility and and it might be that you’re thinking ‘Oh that’s more physio’ or physio’s thinking ‘Well, that’s more OT’ or we’re all thinking ‘That’s more MS specialist nurse’, but unless that’s actually clearly stated it it’s not really very fair to the client because we could all just be sort of batting this ah, this problem around (A fg2b p3).

**Addressing issues that are within the team's expertise**

From Disability Team C's experience often the task was relatively simple to address either individually or working together within the team (see section 7.6 - Team C's narrative: Support to practice). The example given in the Royal College of Nursing (2000) discussion document utilised inter-professional practice. Odele (B fg1 p15), Wendy (C fg2 p15) and Yvonne (C fg2 p13) all cited the advantages of close inter-professional working to provide better solutions for the service user. Close working supported different styles and skill levels.

**Yvonne**: I think that’s where in a team like this… it’s it’s it’s true of all of our skills, we all have areas and expertise and and… personality traits that lend towards certain aspects of treatment and in a team… where more than one of us sees a patient and where we kind of mix and mingle quite a lot there’s room for one person to say “I don’t feel I can do this”. … and I think that that’s where the professional development happens really nicely in a team like this that you get a bit of mix and match and… (C fg2 p13).

For her complimentary skills, flexibly used, were the way to address sexual expression.

Deciding what fits appropriately within a team's expertise was not highly developed.
Participants were uncertain about their own personal boundaries and even less certain about team boundaries. It was a novel area for all teams.
Tracy: I’m saying that perhaps we need to decide how far we can go (as a team) with giving them advice and we, you know, I mean you give them a leaflet or there’s leaflets available – is there a video available? Erm I’m not saying we shouldn’t give them any advice, what I’m trying to say is/ (C fg1 p8-9).

Participants appeared to accept differing positions from each team member but there was also a sense of a limit for the team, as seen here. Wendy was highlighting where her personal comfort ended and it triggered this forthright response.

Wendy: … there are some things that I know I will be unhappy about like the issues around whether it’s ethically how do you, you know, finding a prostitute for somebody... or erm being, you know, being able to (?), being actually being manually... mu, you know, assisting somebody, physically... to be able to have sex.
Vicky: I think at that point it's far beyond the remit of this team.
Tanya: Oh definitely.
Wendy: It is, it is... but it's/
Tatum: But your remits (limits) are, I think you need to know where your remits are.
Wendy: It is... but they're also, that's also a personal thing within... /
Vicky: /No... no I don't think that's personal for members of the team, I think I would want to be on a team where it was clear that we weren't participating in the act in any way and weren't seen as participants (C fg1 p28).

Thus, what was, or was not, within a team's remit might require consensus.

Referral and advocacy

Because so little exploration of sexual expression occurred within the teams, there were few actual examples of referral. Those presented were based mainly on individual knowledge (A fg2a p7; B fg1 p12; C fg2 p19 & 23) rather than team links with other services. The GP was cited especially around erectile dysfunction (C fg1 p27; A iiA1 p12) and for diagnostic review (A iiA1 p12). The Disability Teams noted that they probably had considerably more expertise around the management of physical disability than the GP (C fg2 p21) or the staff at the psychosexual dysfunction clinic (B fg1 p14). But, the transcripts did not reveal any team advocating to improve accessibility where other service providers were seen to lack skills around disability (B fg1 p14).

12.3 Reflections on the role and responsibility of the team

Others have stressed the importance and value of a multidisciplinary approach to sexual expression (Ducharme 1987; Glass 1995; Mona, Krause et al. 2000; Tepper 1997b). Yet, there has been virtually no investigation into the role of the team in this aspect of
care. In analysing the tasks\(^1\), the findings here indicate that community disability teams need to explicitly plan how the sexual health of service users might be supported. No ready made formula can be stipulated because the construction of each team varies. The responsibility, I suggest lies with the team because there is no clarity at this time about professional roles and, given the problems identified here for individual practitioners, there is a potential to avoid the task. Procedures may vary but they need to be systematic, overt and encompass all the tasks.

The team, needs to consider how all service users are given permission to disclose (if they choose) any sexual concerns. Routine permission giving was problematic in all three teams, a finding consistent with Rubin's (2005) study. Potential solutions include giving permission via a leaflet that outlines the services provided by the team and advises service users how to proceed if they wish to discuss sexual expression. Another solution is training and support for all key workers, making them proficient in identifying service users and supporting their referral to a nominated staff member. If all service users were assessed by one discipline, for example nursing or occupational therapy, the task of permission giving could be delegated to that profession. These are team decisions and depend on the construction and membership of the teams. However, my personal view is that all health and social care professionals, working in physical disability teams, should be able to sensitively and routinely provide permission. Tepper (1997a & 1997b) indicated that comprehensive sexual health care depended on each member of the rehab team 'providing, at minimum, permission to patients to bring up their sexual questions' (Tepper 1997a p130). Unless all team members can provide permission, there is a potential for sexual concerns to remain hidden (National Institute for Clinical Excellence 2003).

Departing from the PLISSIT model (Annon 1974), I am also suggesting separating the task of providing permission from exploration. Given the current low level of expertise and available training, it may be impractical to assume that all staff would be able to explore sexual concerns. Some teams might consider that the task of exploration should fall to a single profession. There is research support for a nursing lead (Rubin 2005) and a practice example of an occupational therapy lead (Ritchie and Daines 1992).

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\(^1\) These were: providing permission; exploration; addressing issues within the teams' expertise; referral and advocacy.
Disability Team B had the option of using the psychologist. Without a coherent, articulated strategy however, the risk is an ad hoc approach where sexual expression is assumed to be someone else's responsibility (Herson, Hart et al. 1999; Katzman 1990; Novak and Mitchell 1988). Exploration and functional analysis (Glass 1995) are necessary to identify what can be addressed within the team's remit. I suggest therefore that it is a team responsibility to ensure that service users, who wish to discuss intimacy and sexual expression, have opportunities to explore the nature of the issues. Fostering an appropriate skill mix within the team would be necessary. For example, is a speech and language therapist's involvement necessary for aphasic service users to discuss their concerns? A team approach to the identification of staff able to explore sexual concerns could enhance referrals and might improve support and supervision.

Rubin's (2005) study was structured around the initial stages of the PLISSIT model consequently there was little discussion about addressing issues within the team's remit. Arising from my research, I have proposed a new injunction: the need to discuss and negotiate agreed limits and boundaries to the involvement of the team. Earle (2001) indicated that addressing barriers to services was a laudable nursing role. Examples of these barriers were identified in the preliminary inquiry, however achieving consensus within the team might be advantageous. To exemplify, over 4% of the general population are paying for sex (Johnson, Mercer et al. 2001), I suggest that the team might need to consider its remit to procure a sex worker (Earle 2001). A team approach, with clear protocols, would help to protect its members.

My research indicates that there was little collective knowledge within the teams of available resources. This echoes a concern noted in the preliminary inquiry. Respondents requested research to identify what help, advice and services were available in the statutory and non-statutory sector. Knowledge amongst disabled people was poor. I propose that knowledge of referral resources should also be conceived as a team responsibility. Increased awareness of the range of available services is a key factor in improving 'access to, and uptake of, services' (Medical Foundation for AIDS & Sexual Health 2005 p49). An affirming approach toward sexual health of service users would necessitate better service links and referral strategies to counselling and psychology services, Relate, the GP, family planning or psychosexual services.
It has been the investigation of team working (rather than professional roles, skills and attitudes) that has led me to propose that it is a team responsibility to encompass sexual expression within care planning. Analysing the tasks, it is apparent that team members may take on different aspects appropriate to their personal and professional skills. These tasks will be developed further in a proposed new model of practice (see section 13.2 - A sexual health model for disability practitioners). The construction of the team and the development of clear service strategies would ensure positive sexual health care.

12.4 Nature of the service user group

Lesha had worked in a head injuries unit (B fg1 p23); Irene and Wendy in cardiac care (A iiA1 p1; C fg1 p17); Peggy, Yvonne and Zanna in learning disabilities (B fg2a p6; C fg1 p25; C iiC1 p1), and Shena in a spinal injuries unit (B fg2b p13). They contrasted addressing sexual expression in these settings and indicated it was easier compared with their present setting. Analysing what made it easier, revealed deterrents linked with their current service user group. These included the service users' age and gender; progressive disorders; the community context; the private rather than public nature of their concerns, and the medical model approach taken by the team.

The ability to sexually express oneself was seen as high priority for people with spinal cord injury and head injury, for example, Lesha said -

Lesha: … when I worked with young head injuries it was definitely something we discussed and it was there and it was important to the clients and and discussed quite a lot and, you know, it was very prevalent and… we talked about it in the team meetings and it was right top of their priority list and what have you (B fg1 p23).

Participants said this was because these injuries predominately affected young men (B fg2b p12-13; C fg1 p24). Young men were ‘very verbal’ (B fg2b p13) and permitted to be overtly sexual (B fg2b p12; C fg1 p24). Whereas service users in the community disability teams were mostly middle or older-aged and half were women. From her work in the hospice Beryl noted that younger people were seen to have greater needs for intimacy and were usually cared for in single rooms unlike older people who were placed in four or six bedded bays (A fg2a p24).
Secondly, addressing sexual expression was seen as easier when working with people whose disability was due to a single, non-progressive event.

Peggy: … it’s so much more complicated in our client group, … there are so many more issues aren’t there and the fact that you can’t change that they’ve got this disability and it’s probably gonna get worse / (B fg2a p15).

There was concern that routinely raising sexual expression might be detrimental, for example to someone just coming to terms with the diagnosis of multiple sclerosis.

Janet: … you go in and they think yes I’ve got a bit of a problem with a slight limp and a problem with my eyesight, and they’re already worried that they’re facing a very big action. You don’t want to raise yet another area where they might, can give them an idea of having problems where they might not have problems, I think it’s so difficult (B fg1 p31).

This is difficult and requires sensitivity but there is a fine line between that and avoidance. Nancy demonstrated avoidance. She assumed progressive disability would lead to sexual dysfunction and the loss should not be talked about.

Nancy: … in progressive illness they’re adapting slowly anyway aren’t they… you don’t get… the same life back, you’re whole life changes, it happens it’s true, but for some of these other conditions they’re so slowly progressive that people are adapting little by little they don’t realise that that’s (sexual function is) changing. They’ve actually accepted that these things, that they can’t do the things they did. … It’s not appropriate to talk about those things anymore because it doesn’t happen (B fg2a p17).

Traumatic onset disability often entailed hospital admission. There were mixed views about home versus hospital as a context for sexual health practice. Advantages cited for hospital were structured and routine rehabilitation programmes (A iiA1 p1; B fg2a p7; C fg1 p17). Also, more support mechanisms were available both for the patients, who could share their experiences with each other (B fg2b p13), and for the staff (B fg2b p14). However some saw working in the service user's home as a safer more comfortable environment to discuss sexual expression (A fg1 p2 & 4). Others suggested it could be intrusive (A iiA1 p2) or that the practitioner would be more vulnerable (A iiB1 p15; C iiB1 p7-8) in the client's 'territory' (A fg1 p2). Interestingly, for the few who were more confident to address sexual expression, there seemed to be no apparent difference between home and hospital (A fg1 p5).

In the client groups of the community disability teams, sexual concerns were private, not public. Whereas, in learning disability and head injury services sexual expression could not be 'left out of clinical practice' (C iiC1 p1). This was because service users
would present publicly with disinhibited, problematic, sexual behaviour (B fg2a p6; B fg2b p12; C fg1 p24). Consequently, learning disability services were seen as 'further ahead' (B fg2a p6) with 'a lot more work' done by psychologists and nurses (B fg2a p7). Also in learning disabilities there was 'more of a social approach' (B fg2a p6) with attention given to normalisation and clients' human rights (C fg1 p25). This contrasts to the medical model approach highlighted earlier (see section 11.6 - Treatment priorities) and again indicates how the ethos of the team can support or deter practice.

12.5 Two clients not one

Another deterrent was having more than one person to consider. This was a particular anxiety (albeit mostly hypothetical) in Disability Teams A & B. For example -

Henry: … I think this is what makes it complex because you can go in and you can see the situation, but but you’ve got two people… and they’ve got their own… you know, so who becomes your patient? (A iiB2 p9)

Or as Maeve put it -

Maeve: … how far do we go with our actual client, the person who’s been referred to us as a client and how far do we take on the carer’s erm side of things as well, and… I think that was quite… quite an interesting sort of blurring… blurring line (B fg2b p2).

Nancy saw difficulties where one partner 'feels the relationship to be satisfactory and the other doesn't' (B fg1 p18) and said 'both people’s consent' was needed before you could enter discussion about 'their sex lives' (B fg1 p11). For Rhoda, it was in working with couples that she felt her 'boundaries start to get stretched' and she lacked confidence (B fg1 p12). This could be seen to be about the individual for example, uniquely in her team, Odele confidently accepted sexual expression within her role, and said she would want 'to involve both people' (B fg2b p7). My experience within the focus groups however, was that the culture of the team, its sense of purpose, was implicated. Thus working with the partner was not an issue for Disability Team C: it was an essential part of their practice (C fg2 p24) whereas it was not part of the ethos for the other two teams.
12.6 Permission from the organisation

A deterrent reverberating through the research was that Disability Team A & B had no sense of permission, no authority, to address sexual expression. Whereas in Disability Team C there was no doubt that addressing sexual expression as part of the role of the team, was supported by the primary care trust and the wider organisational context (C fg2 p30). Whether lack of permission arose from the individual's beliefs and feelings, or from the employing organisation, is difficult to unravel but here the perceived lack of employer support is reviewed. It was not part of this study to test the veracity of these perceptions. It may be true that the organisations did not consider sexual expression to be within the service remit. On the other hand, it is possible that people experiencing negative emotions project their discomfort onto the organisation.

Whatever the interpretation, the data revealed considerable anxiety that engaging service users in discussions about sex may not be sanctioned, or even disapproved, by the organisation. Henry located it in the wider context saying sexual expression was 'not the standard fare by the NHS or Social Services' (A iiB1 p3). He suggested 'someone' could say it was not part of the role and, if things went wrong, the organisation might leave the worker unsupported, 'high and dry' (A iiB2 p6). For Rhoda disapproval was located with the primary care trust.

Rhoda: I suppose I don't know how far, from the Trust point of view, I've got backing to do that sort of work (B fg1 p9).

She was uncertain the health trust would see sexual expression as part of her role (B fg1 p9, p22; B fg2a p29) and, if it reached litigation, they might not support her (B fg1 p9).

Rhoda: I think it’s the whole way the team (is) working, the relationship is very woolly because we’ve got no official ‘This is what you should be doing’ or ‘Yes we’ll give you training or debriefing’ or anything, and yet it’s an integral part of our role (B fg1 p9).

This was interesting set against Disability Team B's initial assessment tool, which explicitly included Relationships / Sexuality. The team also had a training day on the PLISSIT model. Yet, Rhoda doubted that addressing sexual expression was sanctioned.

Irene highlighted how resource management could remove any sense of permission to explore sexual expression. In local authority practice, the issue was
Irene: … trying to juggle the needs of the service and the needs of the client … at the end of the day you've got limited resources and, you know, a lot of demand (A iiA2 p5).

Her role in the local authority was to fulfil its statutory duties. She noted it would not be 'overly keen on anything which is outside our statutory obligations' (A iiA1 p5). The pressure of long waiting lists and performance targets (A iiA1 p5) meant time should not be spent on things 'outside the core remit' of the service (A 11A2 p6). Henry spoke about 'the pace' of service delivery leading people to 'think I haven't got time to go down that path' (A iIB2 p3). Rhoda suggested the health trust would disapprove as it might 'open up the flood gates for all the emotion that has to be dealt with' (B fg2a p29). Shena too noted the trust may fear being 'overwhelmed by referrals' (B fg2b p10) which could impact on other parts of the service. For example, increased referrals to Odele would affect her role in addressing memory problems (B fg2b p10).

Resource management was not just workload but it was also about equipment too. Where sexual needs had been identified, for example, requiring a double profiling bed, or pressure care mattress, funding processes meant this was difficult or even impossible to meet (A fg2a p26; A iiA1 p14; B fg2a p11; B iiA2 p16). In talking about her experience with her husband Nancy said,

Nancy: … we did manage to get a double mattress in the end, but you know what does that say? The NHS does not provide double mattresses (B iiA2 p16).

Anita had recently considered a request for a £5000 bed for somebody with a long term condition, where it was the only equipment that -

Anita: … will facilitate what this patient needs, and meet their intimacy needs at the same time … you have to actually then put intimacy needs into the the cold light of day and money as well and you sort of think oh gosh, you know, where does this, you know, how far can you do that? (A fg2a p26)

Charitable sources were being considered but including sexual needs in equipment requests exacerbated the difficulties of managing finite resources.

Supervision was another point at which the lack of support from the organisation was seen. As sexual expression was rarely being addressed, it was also not discussed in supervision. That said, Della was concerned that supervisors may not feel 'comfortable and equipped' to address sexual issues (A fg2b p10). Irene was certain that her supervisor would be advising her to pass this work on, bearing in mind the pressure of
other service users waiting to be seen (A iiA2 p5). Similarly, Henry suggested supervision would be used to focus away from sexual expression (A iiB1 p17). He also said the supervisor might not ‘thank you for erm exposing that issue’, because of the complex ethical issues it might raise (A iiB1 p4).

Having no policies or protocols left participants with uncertainty about the support from the organisation. Henry noted sexual issues were not on the business plan for the NHS, the primary care trust or even the service (A iiB1 p17). "It's not on the organisations’ -

*Henry:* … agenda, it's not on a continuing professional development agenda, it's not part of your standards, erm, it's not overtly stated is it? … it's almost giving you permission to avoid it (A iiB1 p4).

He said service specifications or operational guidelines protected the worker. His parallel were the guidelines on accepting gifts or on professional conduct (A iiB1 p4). Without these, he felt it was not clear what you should and shouldn't do, and that left him feeling vulnerable. Similarly whilst on placement at a residential unit, Della had heard that staff were being employed 'completely off the record' to masturbate residents who were too disabled to masturbate themselves (A fg1 p12). It provoked this response

*Anita:* But you can’t have it off the record… you’ve either… it’s either an open with protocol and policies and it’s a clear…

*Ginny:* To protect everybody.

*Anita:* That’s right, so it’s either a thing that’s done and accepted, or else it isn’t done. You can’t really have it in the middle (A fg1 p13).

This reiterates the need for clear policy guidance to protect practitioners.

In contrast however, an agreed policy may demonstrate the overt commitment of the organisation, but alone, it would not overcome the many personal anxieties expressed in this study. Some people said a standard protocol or procedure, whereby everyone was expected to address sexual expression, could not be enforced (A fg2a p16; C iiB1 p1).

## 12.7 Institutional asexualisation

One final aspect to consider about the wider context of practice is institutional asexualisation within the health service. Although this was not openly discussed, it is latent within the transcripts of all three teams. There is reference to the subtle asexualisation of patients, not just disabled people, in health care especially in acute, in-
patient settings. Ginny commented on the asexual approach on the wards (A fg1 p9). Although the current nursing model included sexual expression, she was clear that patients were not permitted to express their sexuality

  **Ginny:** … and if anybody dares to sort of pull the curtains and have any sort of relationship on the ward, everybody’s up in arms… even in side rooms and things. It’s quite interesting, it’s there as a model that they’ve got to think about…(A fg1 p9).

Likewise, in discussing the asexualisation of disabled people, Rhoda said -

  **Rhoda:** Don’t you think that maybe (it’s) because it makes it easier for us to work with them, you know… (B fg2a p15).

She went on though to add that it was not just disabled people but other patients she had nursed, many of whom might also have sexual concerns arising from their health status.

  **Rhoda:** … what I’m saying is I don’t know whether erm the way the care is delivered actually ignores the sexuality of the disabled people any more than we’re treating any other patient with any other illness, I don’t think it’s any different… I just think it’s just the way that, it’s a medical model of health provision… (B fg2a p15).

My point here is to understand the attitudinal context of health care provision. This analysis has considered how professionals breach normal social boundaries of touch (A fg1 p14; A fg2a p14; C fg2 p5) and space (A fg2a p15-16). The data suggests that, to manage this, participants acquired an asexual approach: a way to be professional.

  **Vicky:** … it’s not a conscious thing at all, I just I just wonder if somewhere there in the background there’s that sense that I can get very physically er involved… without emotionally without any interference of any emotion or any sexual element …(C fg2 p5)

### 12.8 Impact of teamwork & the wider context on practice

These four themes, that discourage inclusion of sexual expression within the teams' remit, are unique to this study. They build on the germinal findings from my MSc study into occupational therapy practice (Couldrick 1998). There the impact of the team context was seen in perception of roles, acceptance of sexuality for some client groups (young men and those with HIV & AIDS) and available support and supervision. Research deficits may offer further support for the findings (see section 4.3 - The impact of disability on sexual expression). For example, practitioners here highlighted that greater attention was given to sexual expression in spinal cord injury. Graves (1993 p244) noted the 'woefully limited' research for disabled people other than those with spinal injury. From my experience, there is less research evidence to guide or support
community disability teams. The themes also overlap. Many of these deterrents can be associated with asexualising attitudes of society. Middle-aged, older people and women may not raise their sexual concerns if permission is not provided. Thus, the user group does not challenge the assumptions of the team. Likewise, because inappropriate sexual behaviour, for the most part, was not a problem within this client group the team is not confronted to act.

Hospital versus community provision and the timing of help was considered in the preliminary inquiry and was raised by the practitioners in the teams. Although participants felt including sexual expression was more difficult in the home setting increasingly rehabilitation, care and support is being moved to the community (Dept. of Health 2006). So despite the perceived difficulties, it seems to me important that community teams include sexual expression within their practice. Also, unlike learning disability settings, the work of the physical disability teams in this study does appear more aligned to the medical model of care (see section 11.6 - Treatment priorities), which may discourage holistic practice that attends to people's rights to family life and quality of life.

The reticence of practitioners revealed here, to work with the couple, is at odds with the respondents in the preliminary inquiry. In my consultation with disabled people they stressed support was required for the couple as well as the disabled person, especially in accommodating the changes within their relationship. Research has indicated the huge impact disability can have on the couple (Korpelainen, Nieminen et al. 1999; Lemieux, Cohen-Schneider et al. 2001; Wermuth and Stenager 1995). These authors and others (Chandler and Brown 1998; Esmail, Esmail et al. 2001; Glass 1995) have recommended inclusion of partners. Esmail et al (2002) highlighted the importance of early intervention with couples to avert crises. I suggest the couple needs broad interpretation to include people who are married or cohabiting, and heterosexual plus same sex partnerships (Esmail, Esmail et al. 2001). It may also need to include others who are not living together and concurrent sexual partners (Johnson, Mercer et al. 2001).

Including the couple accords with a social model approach. It is about considering the social environment rather than the individual impairment.
Recent Department of Health guidelines have indicated the need to include sexual expression within holistic rehabilitation (Dept. of Health 2005; National Institute for Clinical Excellence 2003) yet two teams did not feel supported by the NHS or their primary care trust. Ducharme (1987) described encompassing systems, agencies and institutions within training. White (2002) touched briefly upon systems of care delivery. The lack of perceived support from the organisation however has not been identified within other research. There may be a problem with the national guidelines because they do not specify whose role it is. The taboo of sexual expression may mean the task is yet again seen to be someone else's responsibility and not the team's. Resources too, as far as I am aware, have not been cited in the research reviewed. Delivering health and social care cost effectively, is a reality but I believe fiscal limitation does not justify ignoring the sexual and intimacy needs of disabled people. Even where a double profiling bed cannot be supplied, a sexually affirming approach can still be taken, by acknowledging the difficulty and the subsequent loss it may entail.

I posit that all these issues contribute to, or are compounded by, institutional asexualisation in health and social care. Transcripts from this research hint at the way professionalism may be managed 'without interference of any emotion or any sexual element' (C fg2 p5). This resonates with 'the enormously asexual way that health care is delivered', reported in the preliminary inquiry. It requires further investigation but others have discussed the paradox of involvement and detachment in the sensitive management of professional boundaries (Wells 2000). Homophobia and heterosexism in health and social care (Wilton 2000) may additionally exacerbate asexualisation. I have been challenged that asexualised health care is delivered to all patients, not just those with a physical impairment. This may be true but it is beyond the scope of this research. My concern here is with disabled people. There is clear evidence that both their sexual identity and citizenship may be compromised as a consequence of their disability. Thus health and social care, I believe should directly support their sexual health and not add to the damage through a normative approach of asexualisation. Additionally these attitudes historically may be more about managing behaviour within institutions. Health care however is increasingly being returned to a community setting suggesting another reason to reappraise this approach.
12.9 Conclusion

In this chapter I have focused on the professional ways of working of the physical disability teams as a whole and set their work within a wider organisational context. The different way the teams are constructed influences how sexual expression can be addressed. It has highlighted some advantages and disadvantages of developing specialist practitioners to address sexual expression within the team whilst also demonstrating all team members need to increase their skills. My personal view is that routine sensitive permission giving strategies should be within the basic competence of all disability professionals. Based on the findings of this research I have proposed that community disability teams take responsibility thereby ensuring holistic practice, encompassing sexual needs, is offered to all service users.

The organisational culture, that acts to deter disability specialists supporting the sexual health of their service users, has also been exposed. There are many deterrents. The age and gender of the client group, plus the fact that many have progressive disorders all make addressing sexual issues more difficult when compared to other settings. Additionally the community nature of practice, and a medical model approach, means less support is available for both staff and patients to discuss sexual concerns. Sexual expression usually involves more than one person. Some practitioners lacked skills and were anxious about working with the couple. There was also a perceived lack of support from the wider organisation. For practitioners with high workloads it is unlikely they would attend to grey areas, which they believe may not be approved or authorised. Finally, there is evidence of an institutional culture of asexualisation within the health service. I have indicated that all these factors must be addressed if services are to avoid offering health and social care that damages the sexual identity of disabled people or supports their disenfranchisement.
CHAPTER 13: RECOMMENDATIONS

13.1 Introduction

'Inquiry that aspires to the name critical must be connected to an attempt to confront the injustice of a particular society or public sphere within the society. Research thus becomes a transformative endeavour, unembarrassed by the label political' (Kincheloe and McLaren 2000 p291).

Like previous studies, this research has confirmed a theory practice divide: the teams espoused a theoretical role in sexual expression that was not borne out in their practice. New knowledge arising from this research is the depth and breadth given to understanding this phenomenon. Detailed analysis revealed the profound, complex, multi-layered, often unconscious, processes that influenced practice. These explain the powerful resistance to change. They also indicate how change might successfully be achieved. Here I shall draw together ideas arising from the research and make recommendations. These are far reaching and consider diverse elements in health and social care provision. They implicate many people. Ultimately I propose that the responsibility to support the sexual health of service users, to place them at the centre of service planning as fully human inclusive of sexual needs, lies with the disability team.

This research has led me to propose a new model of sexual health practice for disability professionals and to press for changes to their pre and post-registration education. Over thirty years ago Annon (1974) highlighted the importance of giving clients permission to discuss their sexual concerns. This research has revealed the necessity of giving practitioners permission too. My recommendations therefore include the development of organisational policies, professional guidelines and raising awareness. These strategies would provide teams with authority (permission) to ensure sexual expression of the service user becomes routine practice. They would also begin to redress the asexualisation of disabled people within health and social care. Sexual expression is not a remote or specialist aspect of the self: it pervades our very being (Woods 1984). Similarly I suggest dissemination of sexual information and allied research should pervade mainstream professional literature and not be relegated to specialist journals, books and training programmes.
13.2 **A sexual health practice model for disability practitioners**

This research reveals the inadequacy of the models of practice described earlier (see section 2.7 - What can be done by experts in disability). Here I consider their deficits and use the different tasks and skills identified in this study to develop a new five-stage model of practice. This is summarised in table 13.1 (p258). Annon's (1974) model PLISSIT began with giving the service user *Permission* to discuss sexual concerns followed by the provision of *Limited Information*. The first skill for practitioners, cited by World Health Organization (1974) and in Earle's (2001) Continuum of Facilitated Sex, is the provision of sexual information. Thus, at the outset, we meet a major limitation of these three models. They are only applicable to disability practitioners who consider they have a remit in the sexual health of their service user. Yet this research has demonstrated that, of the five professions represented, not one consistently saw sexual expression as part of their role yet all received unsought inquiries.

**Stage 1: The recognition of the service user as a sexual being**

I argue that there is a crucial step in the promotion of sexual health of disabled people, not identified in these earlier models of practice: the recognition of the service user as a sexual being, with sexual needs and desires. I contend that no health or social care professional, claiming expertise in disability, can absolve themselves from this awareness. It is about social justice and equality. As the transcripts analysed in this study suggest, there may be practitioners who, for whatever reason, will be too uncomfortable to develop their role in sexual expression. Yet, a positive approach to sexual health is possible even before Annon's strategy of permission giving.

Recognition, as the first step, supports sensitive skills of acknowledgement, normalisation, affirmation and validation. These can be used even where a disability professional does not wish to facilitate exploration of sexual expression. As an example, the following could be used in a key worker assessment.

> 'You may have some sexual concerns (acknowledgement), many service users do (normalisation). It is not my area of expertise (acknowledging limitations) but I appreciate it is important (affirmation). If you wish, I can ask my colleague to speak with you.'

Recognition also helps to facilitate a positive response to the unsought sexual disclosure. Practitioners who dismiss or ignore unsought inquiries are contributing,
albeit unwittingly, to the asexualisation of the disabled person. The following response indicates how a sexually affirming approach can be taken to an unsought inquiry.

'This is an important question (affirmation). It is a concern several of my patients with (describe impairment) have raised in the past (normalisation). However I don't think I am the best person on the team to talk to (acknowledging limitations). The nurse in our team has much greater expertise than I do. Can I ask the nurse to contact you?'

Or for the practitioner who is confident to move to the stage of exploration -

'This is an important question (affirmation). Perhaps we could book some time and a quiet room where it would be easier to talk.'

Acknowledging the importance and priority that sexual expression may have for the service user, affirms their sexual identity.

What I propose here for Stage 1 is very similar to Kielhofner's example of dealing with a spiritual issue (see section 6.7 - Serendipitous data: The Model of Human Occupation (MoHO) e-discussion). I disagree with his vehement rejection of sexual health from occupational therapy and I fear that his protestations will exacerbate occupational therapists' anxieties in taking a positive approach. His example however so closely aligns to my suggestions of affirmation, validation and acknowledging limitations, I have suggested there is a place for compromise in his position (Couldrick 2005).

**Stage 2: Permission to discuss their sexual concerns**

Recognition of every service user as fully human, inclusive of sexual needs, provides the rationale for inviting them to discuss their sexual concerns, if they want to. For a community disability team, it is about identifying those people wishing to explore their concerns and supporting them to talk to the appropriate member of the team. Because of the social taboo deterring talk of sexual behaviours, clear and direct permission is required. One study indicated the service users' preference for being asked direct questions (Rubin 2005), others do not want this (Oliver and Gallagher 2000). Until further empirical evidence is available, I advocate sensitive strategies such as indirect questions or statements that invite service users to respond if they wish without seeking any personal information. Permission giving needs to invite disclosure about establishing and maintaining intimate relationships as well as sexual function. It can be done quite simply during any professional's initial assessment, for example
'I find some people also want to talk with me about their relationships or have questions about sex. I am happy to discuss these if you do have any concerns.'

This approach is compatible with Disability Team Cs analogy of 'opening the gate'. It respects individuals' privacy yet invites people to proceed if they wish.

Dialogue is not the only option. Patient information leaflets on the services provided by the team, posters in clinical areas and user group leaflets could all be used. Generic, nursing and occupational therapy assessment tools are all suited to include a permission giving statement. The important issue is that every service user has the opportunity. Therefore, some teams could require all those undertaking screening assessments to provide a statement that invites disclosure later in the process.

'If you do have any questions you wish to explore about your personal relationships or sexual expression, do let your key worker know. We have quite a lot of resources within the team and if we can't help we probably know someone who can.'

The skills of the speech and language therapist, in this study, have been shown as especially valuable in routine permission giving when dysarthria or aphasia is present.

**Stage 3: Exploration**

Having provided permission, my next proposed step is exploration. This is not explicit in the three models under scrutiny although it does form part of Annon's Specific Suggestions. Providing permission to discuss sex, of itself, is insufficient because sexual expression is multi-faceted. Skill is required to identify the issues. In Disability Team C, the man with a stroke who was 'not cuddly any more' is a good example. Disclosure occurred but the therapist, without skills to explore, could only assume he was frightened of having another stroke. I believe every disability practitioner could help service users explore their sexual concerns. However where, for whatever reason, this was not possible, exploration could be assumed by specified team members.

I conjecture that it is in the exploratory stage where the approach of the disability professional may differ vastly from that of the sexual health professional. The expert in sexual health might seek a sexual history and explore performance related to the human sexual response cycle. Whereas the expert in disability needs to understand where, in the development of intimacy and sexual relationships, does the disability impact. It may be about social opportunity, self-identity, or moving a relationship toward intimacy.
The service user may seek to explore how the consequences of impairment can be managed during intimacy, for example using a hoist, having a stoma or not being able to undress. It could be about role changes between sexual partners because of the care needed. Or it might concern the management of fatigue, spasticity or pain.

**Stage 4: Addressing issues within the team's expertise and boundaries**
The next stage would be addressing issues that fall comfortably within the professional roles of the team. The World Health Organisation (1974) proposed the provision of elementary sex counselling. This is a limited description of what can be done and, with the increased professionalisation of counselling, it may confuse disability practitioners about what rightly falls within their role. This was seen with Rhoda (B fg1 p7). Addressing the problem is included within Annon's (1974) Specific Suggestions. He recommended formulating ideas about causes and developing appropriate goals and treatment plans. Greengross (1998 personal communication) believed setting clear boundaries around the task might enable disability practitioners to engage in addressing sexual issues. She felt practitioners were deterred because sexual expression was so broad that it was easy to become overwhelmed. This resonates with 'Pandora's box', or the 'can of worms' reported. Disability professionals are familiar with needs identification, treatment planning and goal setting thus they have potential to analyse sexual problems, devising specific, targeted goals that are properly within the team's expertise.

It may require a clear understanding of the different professional roles and might require inter-professional working. Earle's (2001) continuum provides examples of potential goals for nurses. Although some are appropriate to a residential setting, they could be helpful when establishing a care package or helping the service user to consider their options. Goal setting might include enabling access to any assistance available to the general population. Examples include social opportunity, privacy, erotica and prostitution. Physiotherapists might address biomechanical issues that cause discomfort during intercourse. The occupational therapist might provide the Family Planning Association's catalogue (FP Sales 2005) on simple electronic equipment like a vibrator or masturbator, for those with impaired hand function. Goals could include providing disability specific sexual information or reframing sexual intimacy as strategies for fulfilment rather than penis / vagina penetration. The speech and language therapist...
might be able to assist the aphasic patient to communicate with their partner. The psychologist could address interpersonal skills and emotional adjustment, including issues related to body image and self-perception.

**Stage 5: Referral and advocacy**

Always some issues will fall outside the disability team's role; hence, the next step of my model is referral. That is providing information on, or referring service users to, appropriate agencies. This is equivalent to Annon's (1974) *Intensive Therapy*. Referral is the final skill of the World Health Organisation (1974). I dislike the term intensive therapy, as quite simple issues require referral, for example to the GP for a medical review, or to a family planning clinic for contraceptive advice. Where the problem is linked to the relationship, Relate might be the option. Where it is an issue of impotence then there is the psychosexual health services. For some conditions, referral may be to a telephone help-line, like that provided by the Spinal Injuries Association.

Where intervention falls outside the team's expertise advocacy may be necessary. This could be highlighting unavailable or inaccessible resources. It may include offering disability expertise to the main stream service. With the service user's permission, information on their functional ability may be particularly useful. Advocacy at the simplest level may be advice on the best methods of communication for the service user. Advocacy may improve access, for example the family planning clinic doctor may agree a home consultation when she understands that a hoist, available in the home, would be necessary to enable a pelvic examination.

Thus arising from this research is my recommendation for a new model of intervention, for use by experts in disability, which promotes the sexual health of disabled people. I believe the model I have outlined clarifies the responsibilities of individual practitioners as well as the combined professional practice of the team. I have presented a summary of the model to promote sexual health in table 13.1 on the next page.
13.3 Implications for pre and post-registration education

This study reveals a need to improve pre and post-registration education for health and social care personnel, addressing their attitudes, knowledge and skills in this aspect of care. Others have developed educational modules around sexuality and disability for occupational therapy (Hay, Byrne et al. 1996; Neistadt 1986); physiotherapy (Hay, Byrne et al. 1996; Keall 1982); nursing (Katzman 1990; Morrissey and Crouch 1998) and across health professions (Tepper 1997b; Weerakoon 1994). Although I support their proposals the findings presented here, indicate a more fundamental review of professional education is required, rather than the inclusion of an encapsulated module.
I suggest the primary focus of a review must be to consider the reality, or otherwise, of institutional asexualisation of disabled people within educational programmes (see section 9.7 - The impact of professional socialisation). Is there a demonstrable acceptance of disabled people as sexual beings both within the curriculum and in the attitudes of staff delivering it? A useful parallel has been the progress made over the last decade on recognising western ethnocentrism in health provision (Herdman 2001; Hocking and Whiteford 1995; Paul 1995). Much work has been done on developing the cultural competence of health and social care practitioners (Hyde 1998; National Center for Cultural Healing 1999; O'Hagan 2001; Qureshi 2004). I recommend a similar examination of the approach taken to sexuality and disability education.

This study has also exposed the potential problems associated with delegating teaching to specialist external staff (see section 9.7 - The impact of professional socialisation). Course tutors need to consider their own confidence and competence to teach in a way that affirms the sexual citizenship of disabled people. I suggest they investigate how the stages of the proposed model could be embedded in the curriculum. This should include enabling students to explore their personal beliefs and values and to build their knowledge and skills. Pre-registration education needs to introduce sexual concepts encouraging practitioners to consider the fit of sexual expression with their professional role. Lack of role acquisition has been shown here to be a major deterrent to practice. I contend all health and social care practitioners, at minimum, should achieve stage 1 of my proposed model: recognition and validation of disabled peoples' sexuality.

I believe it is realistic for pre-registration programmes to consider all five stages of the proposed model. Failing this, educational opportunities post-registration, when practitioners are beginning to specialise in service areas, may be the appropriate time to build enhanced skills and knowledge. Training could be team based or consist of short focused programmes or extensive, validated continuing professional education modules. The emphasis however needs to be on inter-professional learning, developing understanding of other professional roles in addressing sexual expression, and the importance of joint working to manage the breadth of issues that can arise. Participants in this study have acknowledged the importance of direct contact with disabled people, especially in challenging their preconceptions, therefore I would advocate wherever
possible the involvement of people, with direct experience of disability, in programme design and delivery.

### 13.4 Organisational policies

This research indicates a need to develop organisational policies, both at national and local level, that ensure health and social care services protect and support the sexual health of disabled people. Inclusion of sexual expression within policies demands awareness of, and the ability to challenge, the existing unquestioned norms in health and social care around sexuality (see section 12.8 - The impact of team work & the wider context on practice). This study indicates how professional practice is underpinned by pervasive contextual mechanisms contributing to the social construction of disabled people as asexual, whereby their sexual concerns can be unseen or avoided. National policy development would promote professional practice both for experts in disability as well as experts in sexual health.

At a national level, it is possible that the story of the sexual enfranchisement of disabled people is beginning to be heard. Sexual expression has been included in recent NHS guidelines on multiple sclerosis and long term conditions (Dept. of Health 2005; National Institute for Clinical Excellence 2003). Sexuality and sexual expression also forms part of the underpinning competency framework for the National Service Framework for Long Term Conditions (Skills for Health 2005). These may be the forerunners of other disability specific, sexual health recommendations. Identifying the necessity for routine evaluation of sexual function and wanted sexual and personal relationships is to be applauded. However, these documents are not explicit about where responsibility lies. If a disability practitioner or team is uncomfortable with matters sexual, they could make assumptions that these guidelines and skills are for neurologists or specialist sexual health workers. Thus, they can absolve themselves from responsibility. Hence the importance, not just of national policy but also local policy, turning national rhetoric into practice guidelines.

Development of local policies and guidelines would provide organisational support, instilling authority in practitioners, reducing their fears and vulnerability. A policy
allows practitioners, managers and service users to know what can (and what cannot) be expected from the service. A positive policy, which identifies the role of the team in the sexual health of service users, also acts as a permission giving strategy both for staff and clients. Likewise, it would be advantageous for a policy to identify where a team is unable, for whatever reason, to include sexual expression within the team's remit. The advantage for the disabled person is that this locates the 'problem' squarely within service provision rather than implying they should not have sexual needs.

Additionally the task of policy development can, of itself, help to develop service provision. Rather than imposing a policy, a disability team could use the process of policy development to explore staff attitudes and to consider training needs (Ducharme 1987; Glass 1995). Although time consuming, the discussions would help to identify the stance of management and practitioners. As seen in this study, every team is constructed differently. A standard approach cannot be applied. Each team needs to struggle with how they can support the sexual health of service users. Do they develop one specialist within the team? Does one profession take the lead? How will every team member identify need? Can sexual expression be appropriately included within the team's tools of practice? Policy development which involves all interested parties, is more likely to be implemented (Fegan, Rauch et al. 1993). Throughout this research, the involvement of disabled people has been seen as an important factor in gaining awareness and understanding. I therefore reason that effective policy development should involve service users. Although based in learning disability not physical disability, Fegan and colleagues (1993) provide some guidance on policy development.

Another advantage of policy development is that potential problems are identified and addressed before the need arises. This attends to the damaging practice identified in the preliminary inquiry whereby a service user's sexual concern ceases to be discretely managed but becomes the subject of a grand consultation exercise. That is, the service user discloses sexual issues. The uncertain practitioner raises it in their supervision: the supervisor raises it at the team meeting: the team leader raises it with the management team, and so on. Instead, the uncertain practitioner and his or her supervisor would have an explicit policy document to guide practice.
13.5 Guidelines from professional bodies

A recommendation unique to this study is for the provision of position statements or guidelines by the professional bodies. The intention would be to clarify roles and boundaries in work related to sexual expression. This study has demonstrated that uncertainty about what fits appropriately within domains of practice, acts as a strong deterrent. As can be seen with the nurses in this study, the provision of a policy document (Royal College of Nursing 2000), of itself, does not redress the problem. Although not explicit, it seemed unlikely that the nurses who participated had read, or knew of, their professions position statement. Their lack of awareness however, does not diminish my recommendation for having position statements.

A statement or discussion document provides a starting place for defining practice. It would also indicate where curriculum development both pre and post-registration may be required, thereby influencing professional socialisation and practice. Confidence in one's own professional role contributes to positive inter-professional practice. This would be particularly pertinent in sexual expression, which, as demonstrated, spans professional roles from intra and inter personal issues to biomechanical and neuro-physiological functions. I am not suggesting a position statement is a task lightly or easily undertaken. Professional bodies exist for, and of, their membership. The membership is subject to the socially and culturally constructed notions of sexuality and is influenced by the affective component of a taboo subject. A policy document from a professional body would require consensus of its members. Yet without such policies, ambiguity and uncertainty remains, and damaging health and social care practices continue. I believe documentation from professional bodies could be a powerful tool in assisting disability teams to develop sexual health policies. Four professional groups in this study had no professional guidance or position document.

This research confirms the dichotomy of occupational therapy. Kielhofner, a leading theoretist in the profession 'vehemently' rejected a professional role (Kielhofner 2003b). Whereas all the occupational therapists in this study identified a theoretical role, seeing it as congruent with their professional values. Yet, only one routinely included it in her practice. UK specific studies are rare (Edmans 1998; Ritchie and Daines 1992).
however a debate in the profession has begun. Based on my experience of this research I have contested Kielhofner's position (Couldrick 2005). I believe it is now time for the College of Occupational Therapists to clarify the situation for UK therapists and encourage them to use their skills to fulfil every stage of my proposed model.

Novel findings of this study concern physiotherapy and speech and language therapy. One physiotherapist and one speech and language therapist were routinely enabling disclosure and addressing issues within their professional role. Although there was not agreement on the fit with their professional values, this research indicates the positive contribution that can be made. For physiotherapy, this is especially around the secondary sexual dysfunctions. For speech and language therapy, it is about facilitating communication of sexual concern for people with speech impairments. Presently there is no discussion occurring within the Chartered Society of Physiotherapy or the Royal College of Speech and Language Therapy. There may be future debate about the extent of the role, but I contend that a position statement on the validation of service user sexuality and managing unsought inquiries (stage 1 of the model) should be an absolute minimum. I believe professional guidance could go much further and include permission giving, exploration and intervention within professional boundaries. Others may argue that involvement in all stages of the model, for these two professions, may be more appropriately taught within post-registration education, after the practitioner specialises in physical disability.

The findings for psychology in this study are inconclusive. There may be greater professional conformity than indicated by Disability Teams B & C. However, the data shows that the other team members were uncertain about the role of psychology in sexual expression. Clarity from the British Psychology Society, or from one or more of its divisions (for clinical, counselling or health psychology), and other counselling and psychotherapy professional bodies, would help to clarify professional roles.

13.6 Raised awareness within specialist disability services

Urgent attention should be given to appreciating that health and social care practice should enhance, not damage the sexual identity of disabled people. Occasional but clear
examples of individual practitioners' asexualising attitudes were evident. More
important was the wider institutional context whereby sexual expression is not part of
professional education, socialisation or practice. The denial of sexual expression is
subtle and pervasive. This research included many practitioners who had rarely
considered sexuality and disability. Just the awareness generated by participating in the
study triggered first case scenarios (see section 7.4 - Team B's narrative: Effect of doing
research). In addition to education programmes, sexual expression needs to be included
within core texts, models of practice and the professional literature.

Two useful generic models may be the International Classification of Function (ICF)
(World Health Organization 2001) and the social model of disability (Oliver 1996). The
ICF identifies sexual and intimate relationships as a health related contributor to quality
of life of equal importance with communication, mobility and self-care. I believe this
health domain is within practitioners and teams responsibility. The issue however is the
ownership of this. As this research has shown, to manage negative feelings
professionals may assume sexual health is the responsibility of others. Promotion of the
social model of disability within health care, does not directly address sexuality but it
confronts assumptions about treatment priorities (see section 11.6 - Treatment priorities)
and the need to include the partner as part of the social environment (see section 12.5 -
Two clients not one). It highlights how social attitudes contribute to a disabling society.
The ICF establishes the importance of health professionals' attitudes separate from, and
additional to, those pervading society (World Health Organization 2001).

In terms of sexual health models I have identified limitations of existing models,
including PLISSIT, and proposed an alternative. Foley's model (primary, secondary
and tertiary sexual dysfunction) also helps to identify what disability professionals can
do (Foley and Sanders 1997a; Foley and Sanders 1997b). More important than sexual
health models may be profession specific models that encompass sexual health.
Awareness also includes deconstructing sexual dysfunction to avoid a penis / vagina
fixation (see section 2.7 - What can be done by experts in disability: Limitations of
sexual dysfunction diagnoses). Sexual expression is so much more than sexual
function. The focus must be on sexual health, which includes pleasure (Tepper 2000)
and sharing joy through emotional and physical intimacy (Zilbergeld 2004).
13.7 Raised awareness within sexual health and other services

This research has not been about relationship or sexual health services. Nevertheless, the findings suggest that greater awareness around physical disability would benefit these services. All services, statutory and non-statutory, are required to make reasonable adjustment, thereby making them accessible to disabled people (NHS Executive 1999; Parliament 1995; Parliament 2005). Services are improving but testimonies in the preliminary inquiry and in the main study indicate there is still someway to go. Enabling access is not just about the built environment. Primary care trusts have been urged to improve the uptake of sexual health services for marginalised groups like disabled people (Medical Foundation for AIDS & Sexual Health 2005). A proactive agenda of disability awareness within relationship and sexual health services, plus targeted health promotion for disabled people, might improve uptake.

13.8 Dissemination into mainstream professional discourse

Another recommendation is wider dissemination of relevant information and research into the mainstream of professional discourse. A unique finding of this study is that sexual expression is encapsulated and segregated as a specialist activity separate from holistic practice. Some participants had noted the omission of sexual expression from their professional journals. They did not think about sexual issues in practice in part because it was not appearing in their journals. This resonated with my experience of searching for, and reviewing, the literature for this study. While scholarly papers on the role or educational needs of disability professionals in sexual expression are only published in specialist journals (Esmail, Esmail et al. 2001; Kendall, Booth et al. 2003; Tepper 1997b), the unaware practitioner (or team) will never see them. Finding relevant papers for this study required a committed endeavour, instigating requisitions via the British Library. I submit that the specialist journals, for example Sexuality and Disability, may in fact exacerbate the situation, removing as they do the debate from main stream professional discourse. To exemplify, when research into aphasia and sexuality (Lemieux, Cohen-Schneider et al. 2001) appears in Sexuality and Disability it is not readily available to the majority of speech and language therapists in the UK.
Similarly, the little teaching and learning reported in this study, both at pre and post-registration levels, had been delivered almost exclusively, not by core teaching staff, but by specialists such as SPOD. Often this was a single lecture or half-day workshop, which was not integrated into the core curriculum. This separateness reinforces the notion that sexuality is too specialised a subject for course tutors (who are often former practitioners). It again removes the debate from main stream professional discourse. Some tutors may be unable to teach levels 3 and 4 of my proposed model but I can find little justification for not being able to teach within stages 1 and 2. Encapsulated teaching, delegated to a specialist, reinforces the specialness afforded to sexual expression (see section 11.7 - The impact of professional issues on practice). Yet, the preliminary inquiry demonstrated that some disabled people saw sexual identity at the ontological core of their being, not as a discrete, appended entity.

This is the point to return to the closure of SPOD. I have proposed that disability specific sexual education, information and support should move from specialised, segregated services into the main stream. The problems with encapsulation and segregation are, for me, the only laudable argument for the closure of SPOD. Whilst SPOD existed, health and social care services, as well as service user groups, were able to project all responsibility for disability and sexuality to SPOD. A potential benefit from the closure of SPOD could be that both statutory and non-statutory disability services take ownership of their responsibility to support the sexual health of disabled people. Presently there is no evidence that this is happening. Indeed a finding of a recent study showed that 70% of the 1,115 disabled respondents thought the government should fund a specialist, disability specific, psychosexual counselling service (Disability Now 2005). If this were to materialise, I would be anxious that disability services could continue to abdicate their responsibility around sexual health.

13.9 Conclusion

A community disability team can help preserve sexual identity and foster a positive approach to sexual expression, thereby contributing to health and quality of life of their service users. In the teams investigated, this is not a routine, established part of their remit. In the spirit of contemporary critical theory, I have outlined far-reaching
recommendations with the aspiration to transform practice. Although these recommendations can each stand alone they are also in a dynamic tension with every other recommendation. For example, a position statement by a professional body would raise awareness. National policy development has the potential to influence the curricula delivered by higher education institutes. Changes in curricula could lead to local policy development. Throughout my recommendations is a continuing theme: the involvement of people with the direct, lived experience, of disability. Collaboration with them in policy development, delivering learning modules and undertaking research, I believe would enhance outcomes.

These recommendations reach beyond the disability teams and relate to the work of all organisations involved in health and social policy for disabled people. It includes the Department of Health; the National Institute of Health and Clinical Excellence; the chartered societies and colleges representing the professions, and the locality organisations in which services are provided. They also concern higher educational institutions delivering professional education. Each of these systems consists of a body of people who, like practitioners, are influenced by the social construction of sexuality and thereby it's affective component, the taboo of sex. Hence my belief, that seeking the inclusion of additional education modules on sex and disability, is insufficient. For change to occur a comprehensive approach is required.
CHAPTER 14: FINAL THOUGHTS

14.1 Introduction

Some will say that the previous chapter, where I stated my position and outlined detailed recommendations to achieve change, was premature. For me it was important that such wide-ranging recommendations were contained in a dedicated section. Here though, in the final pages, I return to a more traditional approach of summarising findings to justify change. I do not intend to reiterate the detailed discussion but to highlight the significant new knowledge - particularly the deterrents to practice. In doing this, I aim to clarify what I perceive as the problem. I remain open to the fact that others may not share my view, and may believe change is unnecessary. I will therefore address the consequence of doing nothing and this will lead to a restatement of my primary recommendation. The chapter concludes with the limitations of this study and my suggestions for future research.

14.2 The research recapitulated

This research centred on whether health and social care professionals, with expertise in disability, protect and support the sexual health of their service users. A preliminary inquiry was undertaken with disability organisations and a small number of disabled people. This enhanced my understanding and aided the development of the study. Constructed within a contemporary critical theory paradigm (Kincheloe and McLaren 2000), data was generated through focus groups and depth interviews, framed on the free association narrative method (Hollway and Jefferson 2000). These strategies were chosen to explore both the taken-for-granted world of professional practice as well as the potentially defended beliefs and values of individuals underpinning practice.

The field of inquiry was three multi-disciplinary teams, working with disabled people who lived in the community. All the teams accepted referral for people with the diagnosis of multiple sclerosis, a progressive disorder that affects both men and women. My aim was the investigation of the teams' professional practice, toward the sexual
health of service users, where disability impacts on intimacy and sexual expression. Serendipitous data was also included. Electronic discussions occurred on the Model of Human Occupation (MoHO) and the Multiple Sclerosis Trust web sites. These provided directly relevant information about expectations, understandings and beliefs concerning disability professionals' roles in supporting the sexual health of service users.

The findings were presented both through a narrative account of each team's practice and thematic coding. Themes were developed from in-vivo coding. That is they arose from the data rather than being imposed upon the data. They were organised into five domains: the enculturation of the individual; professional socialisation; the affective component; professional practice, team working & the wider context.

14.3 Core findings

The findings indicated that:

- Sexual expression was a very uncertain area
- It was not consistently addressed by any team investigated
- There was a theory practice divide
- Professional roles were unclear and ambiguous
- There were multiple deterrents to addressing sexual expression in practice

With one exception, participants all said the service their team provided should support, and assist the restoration of, the sexual health for their service users. In reality, there were multiple deterrents to practice. An opportunity (permission) was not provided for every service user in any team to discuss their sexual concerns. Even without explicit permission, all teams had examples of clients introducing the topic. Some staff had no skills to manage these disclosures in a sexually affirming way and avoided the subject. Others managed by drawing on personal experience.

Of the five professions represented (occupational therapy, physiotherapy, nursing, speech & language therapy and psychology), not one consistently included, or excluded,
sexual expression from its remit. Nursing was considered in two teams to have most affinity with this aspect of practice, although no nurses expressed any expertise. In the third team, which had no nurses, occupational therapy was indicated. Because of the multifarious nature of sexual expression, each of the professions had positive skills to contribute. That is sexual expression was seen to span all professional roles. However the reality was that a majority of participants were either unaware or avoided involvement in sexual aspects of intervention.

The theory practice divide and ambiguity of roles has been cited in profession specific studies but this is the first research to investigate the practice of community disability teams. In single profession studies, it could be assumed the task is being undertaken elsewhere in the service. Here the research reveals *service provision*. In two teams, virtually nothing was being done in this aspect of care. Although more was offered in the third team, it was not consistent for all service users. Importantly, unlike any other study, this research has provided in depth explanation of these findings. It is in revealing the multiple deterrents to practice that the lack of awareness; oversight and diffidence of practitioners can be understood.

### 14.4 Why it is such a difficult area of practice

**The individual**

Significant findings were the individual's beliefs, attitudes and values around sexual expression, obtained through a process of enculturation, prior to any professional education. Social rules and norms had been acquired, for example of not directly talking to other people about personal sexual behaviour. This respects privacy. Talking about sex also carried a risk of censure, or the risk of exposing other people's different, and possibly conflicting, moral values. A further barrier to talking openly and easily was the lack of a common acceptable language. Additionally, some participants held asexualising attitudes toward older and disabled people. These internalised values appear to be of more significance in sexual expression than in other health care areas because of the diverse and taboo nature of sex. These findings are obvious and universal but here is the first evidence of their impact.
Professional socialisation
For many participants there was no pre or post-registration education on sexual expression, therefore these values and norms were neither explored nor challenged. Only one person, a psychologist, described what she felt was adequate education in this area. She and an occupational therapist were the only participants to qualify with a sense that sexual expression was within their role. So, despite the espoused role for the team, no profession in this research had acquired a role in sexual expression from their professional socialisation. For most, there was either no mention of sexual expression within their course: or they received a single encapsulated tutorial, separated from the core curriculum, and delivered by specialists. Practitioners and tutors never modelled how discussing sexual issues could be done in a way that respected privacy. One participant described tutors imparting an asexual approach to practice. I have posited that asexualising attitudes may be embedded in the curricula but this requires further investigation. Other studies have noted that nurses, physiotherapists, psychologists and occupational therapists have felt ill equipped to address clients' sexual concerns but this research is the first that has provided some description of the actual education received by disability professionals.

However, the findings indicated that it was not just deficiency of training that deterred practice. Albeit brief, two teams had initiated a learning opportunity, however this did not overcome the anxieties of practice. Participants were unable to build on learning through observing applied practice or through supervision. One person dismissed a course as not being officially recognised. Another participant described her resistance to training. No relevant post-registration multidisciplinary education modules were available. However, it was noted that training courses would be developed if sexual expression were an established part of the service. In the few examples given, where greater confidence was acquired, it was associated with the observation of a practitioner or increased awareness of the issues from the perspective of disabled people.

The affective component
The emotional response triggered both by actual practice or from imagining what might occur, was possibly the strongest deterrent to practice. Other studies have highlighted discomfort but this is the first, to hear in the words of practitioners speaking about their actual practice, what discomfort means. It included strong negative feelings like
embarrassment, fear, hostility, anger and danger. The thought of raising the subject provoked anxiety and fear. Participants also feared raising clients' expectations, then failing them. They feared damaging the situation. Damage could be to their therapeutic relationship with the service user, or between the client and their partner, or to the relationships within the team. Some participants conceived addressing sexual expression as dangerous. Identified risks included litigation, personal safety and potentially perversely motivated service users. Sexual expression was seen as more anxiety provoking than other areas of practice.

None of the previously reviewed research placed such emphasis on practitioners' emotions. I have proposed that people have a homeostatic tendency to return to a stable equilibrium of comfort and safety. This research has revealed how these strong negative feelings were sometimes managed. One strategy was to project negative feelings onto others. Another way, demonstrated in the data, was to avoid sexual expression, either consciously or unconsciously. Or consonant beliefs (supporting non-involvement) overrode dissonant beliefs; for example, that sexual expression is a low priority for service users.

**Professional practice**

This research has revealed that, for several practitioners, sexual expression had been an unseen, hidden area of practice. In part, this was attributed to the social norm of privacy, but it was also about the absence more generally of sexual expression from professional practice. There were examples of unsought inquiries being avoided or ignored. Mostly practitioners only had personal experience to guide them and did not have skills to raise the subject sensitively, in a way that respected privacy. Some wanted the client's permission to cross the social boundary of privacy. No single profession included sexual expression as part of its core role. In practice, it spanned different professionals' expertise. Some saw occupational therapy as the most appropriate profession, yet a leading theorist has rejected such a role. In the Multiple Sclerosis Trust e-discussion it was stated that the specialist multiple sclerosis nurse and the incontinence nurse had specific expertise around sexual issues but this does not accord with the findings here. Indeed the incontinence nurse refuted the team should raise the subject with service users. Additionally, participants attributed *specialness* to sexual expression making it more complex or sensitive than other aspects of healthcare.
Exploration of participants' clinical reasoning indicated that for some sexual expression was a low priority for intervention. This was influenced by a medical model approach, which reduced sexual expression to a non-essential activity: an optional extra.

**Team work and the wider context**

Researching community disability teams has provided insights not previously available. The first is the importance of team construction to the task of addressing sexual expression. Although some participants indicated that nurses should take the lead, in no team were nurses seeing all the service users. Similarly, the task was not seen to fit well with the initial assessment and the key worker role. Secondly, aspects of the service user group made intervention around sexual expression more difficult when compared to other groups. For example they were not young men (who are seen as more overtly sexual) but of all ages and of both genders. Progressive disorders also were seen to make raising the subject much more sensitive. Some cited working in the community as potentially more difficult. Because service users did not present with challenging sexual behaviour, team members were not compelled to address sexual expression. Also some practitioners lacked skills and were anxious about working with the couple. Thirdly, this research is the first to identify the impact of the organisation. Some participants especially in Disability Teams A & B felt the NHS or primary care trust would not sanction a role in sexual expression, this was seen in the lack of policies, resources or supervision to support this aspect of care. Finally, the findings provided some evidence of an institutional culture of asexualisation within the health service. This requires further investigation.

**14.5 Is there a problem requiring change?**

To consider if these findings constitute a problem requires returning to the private domain of individual impairment and the public domain of disability and the political context of practice.

At the level of impairment, sexual expression has been identified as an important contributor to health and quality of life (World Health Organization 2001). This includes the wellbeing derived from a positive sexual identity as well as the capacity to
express sexuality and to build intimate and sexual relationships, in all their diversity. If this is so, how can health care then exclude sexual expression? This seems in marked contrast to the aims of holistic rehabilitation, which includes improving function, enabling participation and enhancing quality of life. With few notable exceptions, most participants in this research lacked awareness or proficiency, to support the sexual expression of service users. This finding is reflected in the preliminary inquiry where sexual expression was seen as a neglected area of health and social care.

Sexual health provision is available elsewhere in the health service and thus may not be necessary within community disability services. However, disabled people appear to have less information or support available to them when disability impacts on sexual expression. Findings here indicated that sexual health services had less expertise in disability than the community disability teams. Also, Greengross (1976 p9) noted 'as long as we deny the sex feelings of the disabled, we inhibit them from being able to ask for help'. That is disabled people may need positive recognition of their sexuality to enable them to access these services.

Within the public domain, sexual health requires a positive and respectful approach.

'For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled' (Medical Foundation for AIDS & Sexual Health 2005 p27).

However, disabled people, rather than respect, can sometimes feel disenfranchised by a society which regards them as asexual (Milligan and Neufeldt 2001). I am certain no participant in this study consciously regarded disabled people as asexual. Yet, there were examples of practitioners disregarding the sexual needs of older or severely physically impaired people. Denial of the importance of sexual expression and avoidance of matters sexual, were also seen. Additionally there were indications of asexualisation within health care provision and education. It is possible this is how all health care is delivered: that is, it is no different for all health care users. That is beyond the scope of this research. What is important is that the very structure of health and social care provision should not contribute to the more global oppression of disabled people by denying them a sexual identity and thereby full citizenship.
14.6  Recommendations to achieve change

Essentially, for change to occur, the disabled person must be regarded as fully human, with sexual needs like all others. A sexually affirming approach is necessary at every level of health and social care planning and delivery. This includes when service users are receiving treatment or intervention through a community physical disability team.

Within a community physical disability team, this entails enabling service users to disclose and explore their sexual and intimacy concerns. Issues that fall properly within the professional domain of the teams can then be addressed. Otherwise sign-posting and referral is required. This research has revealed the present uncertainty and the lack of clarity about professional roles as well as the many deterrents to practice. Thus, I have proposed that community disability teams (rather than a single profession or individual) take responsibility for ensuring holistic practice, encompassing sexual needs, is offered to all service users. To do this it is necessary to consider the skill mix and construction of the team. Also, because of the social norms around privacy, systems need to be in place to provide every service user with the opportunity, should they wish to discuss these concerns. Procedures may vary but they need to be systematic, overt and encompass all the tasks. I believe such an approach would reduce the damaging stigmatisation of asexualisation, enhance social inclusion and promote quality of life for physically disabled people.

To support disability professionals and assist the team to develop this aspect of care I have made further detailed recommendations for change. These are outlined in Chapter 13. They include a new model for the promotion of sexual health in physical disability teams. I have also suggested improvements in pre and post-registration education as well as the development of organisational policy from national to local level. Position statements or guidelines from professional bodies would support practitioners, as would better awareness both in disability services and sexual health services. Finally, I have suggested that relevant research and practice reports need dissemination into mainstream professional literature.
14.7 Limitations of this study

It is for you to assess the rigour of this research: are the findings credible, dependable and confirmable. 'Showing my workings' (Holliday 2002) I hope allows you to judge whether the methodology was appropriate and the study properly conducted. I have endeavoured to present participants' voices authentically with sufficient data for others to interrogate my interpretations. Disclosing my reflexive awareness has made explicit what are my interpretations and opinions. Despite my bias I believe the research is valid. In terms of dependability, it does portray the professional practice of the three teams under scrutiny. The skill mix and construction of disability teams will differ and although demographically varied, all were based in the south-east of England. Therefore, the findings cannot be generalised to all community disability teams. Instead, this study provides a starting point. It will be for other researchers to test universality. As for confirmability, the findings resonate with my experiences of professional practice. Do they resonate with yours?

There are limitations. My first concern is the abandonment of collaboration with disabled people in the main phase. I concede the academic problems of consumer involvement (see section 5.3 - Frames of inquiry: Collaborative research). Reflecting on the analysis however I wonder if I have given too much credence to the participants' declarations of recognising and valuing the sexuality of disabled people. Disabled people may have interpreted more forcefully the practitioners' lack of awareness and, sometimes, active avoidance, as institutional asexualisation. Collaborative research might also have helped to redress the processes of power imbalance between professional and service user. Others have noted the neglect of sexuality within the disability movement (Finger 1992; Shakespeare 2000; Shakespeare, Gillespie-Sells et al. 1996). The importance of collaborative research would be in engaging disabled people and practitioners jointly in the discourse of sexual citizenship.

Also, I was unable to compare what practitioners say they do with their actual practice, as I did not speak directly with the service users of Disability Teams A, B and C. What people say about their practice may vary quite considerably from reality. Here most participants did not sensitively or routinely attend to the sexual expression of service
users. This is consistent with Rubin's (2005) findings that were compared with the service users' wishes: they unanimously wanted sexual expression raised in a direct manner. Instead in my research, I have used the preliminary inquiry to provide the perspective of some disabled people (see section 3.1 - Introduction). Their potential bias has been discussed (see section 3.9 - A limitation of the preliminary inquiry). However, they were not the service users of the teams under scrutiny. They cannot indicate the proportion of service users who might seek sexual health support.

As indicated in the results the more diffident or dissenting team members may have avoided participation. It is probable that practitioners, who are too uncomfortable to explore sexual issues with service users, would not volunteer to participate in focus groups or interviews. Covert research strategies might be necessary to explore their views. If this has distorted the study, the projected impact on findings is that probably greater proportions of team members are uncomfortable to address sexual expression.

### 14.8 Avenues for future research

A unique feature of this study has been the identification of multiple systems impacting on the professional practice of disability professionals in the domain of sexual expression. These systems are wide reaching: from the social and cultural impact on individuals' attitudes to sexuality; to their emotional world; their professional education and socialisation, to the organisational context of health and social care. Little change has occurred since the first pioneers exposed the sexual disenfranchisement of disabled people, over thirty years ago (Greengross 1976; Heslinga, Schellen et al. 1974; Stewart 1979; World Health Organization 1974). More research is needed. Here I reflect on methodologies that may help to optimise future studies including systems theory and the involvement of disabled people. I have also highlighted my priorities for further investigation. These include: institutional asexualisation; disability teams and their practice; individual professions and professional education.

I recommend that future researchers should investigate the suitability of systems theory as a potential research approach. I came to systems theory (Skyttner 1996) and soft systems thinking (Waring 1996) late in my research. Earlier studies that looked at
practitioner attitudes, skills and comfort, related to the sexual expression of disabled people, provided incomplete understanding. Investigating practitioners with little attention to the context of their practice, may be one reason why so little change has occurred over the last thirty years. This research has begun to define and explore the multiple interconnected systems of health and social care for disabled people, which unwittingly contribute to their sexual disenfranchisement. Systems science is seen as a way 'of handling real world, large-scale, intertwined problems of complex systems' including 'the soft variables such as values, motivation and sentiments' (Skyttner 1996 p397 & 398). These are all integral elements of my research findings. The study of the 'synergy' of the whole system (Waring 1996 p26) might allow modelling to analyse where applied action on the system could deliver effective change.

In the early stages of this study, I collaborated with disabled people to establish the research agenda. I found their help immensely valuable. It increased the breadth and depth of my understanding and helped me to focus my endeavours. The importance of their involvement also emerged in the findings, demonstrating that it was often through hearing the direct experience of disabled people that practitioners' perceptions changed. Any future research, I believe, should involve the very consumers of that research: disabled people. At the very least, they should be consulted. Better still, collaborative and emancipatory approaches should be considered wherever possible. Involving disabled people in the research helps to ensure relevance, aid access to service users and promotes dissemination (Couldrick 2000; Hanley 2005). It also redresses issues of power and oppressive practice (Kincheloe and McLaren 2000).

As I reach the end of my investigation, increasingly I see a need to look more deeply into the institutional asexualisation of disabled people. In this study, I asked practitioners about their practice. By the very nature of stereotyping and prejudice, these issues may be unconscious. To some extent, the free association narrative interview allowed me some access to unconscious material but I suggest exploring the asexualisation of disabled people may require different strategies. I do not recommend a return to the ubiquitous use of attitude scales like SASAD (Guest and Kopp Miller 1997) and SKAT (McCabe, Cummins et al. 1999) but methodologies that get to the clinical reasoning underpinning practice. Scenario instruments may be useful (Yallop
and Fitzgerald 1997). It may also be profitable to examine successful research strategies used in the investigation, for example, of institutional racism and sexism.

So little research has been undertaken into the work of disability teams, that team practice I believe should remain in the forefront of future studies. 'Community rehabilitation, centred on a person's home and employing the full range of disciplines', has been identified as a quality requirement to enable and support people with long-term neurological conditions (Dept. of Health 2005 p35). This study has demonstrated that sexual expression crosses professional competencies and does not sit well within any single professional domain of practice. Additionally disability teams are each constructed differently. This study has introduced some of the group processes embedded within team practice, which require further investigation.

Allied to my recommendation for further research into disability teams, is the need to explore their actual practice. Hence I suggest future researchers endeavour to include the teams' service users. Rubin's (2005) is the only study that has investigated practitioners and service users from the same team. Despite the limitations of Rubin's study, the ability to investigate both practitioners and service users, does add credibility to the findings. Direct involvement of service users would also help to clarify the type of help and support required, and how, where and when this is best delivered.

This study has identified a gap in research into the professions of speech and language therapy, physiotherapy and psychology. Although I have advocated for research into team practice, some empirical work is required into these professions. This would build on the findings of this study by developing knowledge around professional role identity and values as well as the attitudes and skills of these practitioners. Uni-professional studies would also stimulate debate and raise awareness within these professions.

Finally, I believe further research is needed into the educational systems and educators that support disability practitioners. Findings from this study revealed a deficiency of educational programmes both at pre and post-registration levels. It is too easy to assume that the overcrowded curriculum prevents better acknowledgement of, and teaching about, sexual expression. Higher educational institutions may not be placing disabled people, as fully human beings with sexual needs like all others, at the centre of
professional learning. Educational practice is set within the same multiple and complex systems seen in this study. It is equally open to institutional asexualisation of disabled people. It therefore warrants further investigation.

14.9 Conclusion

In this final chapter, I have summarised the study and its findings. The qualitative approach taken has allowed a breadth and depth of understanding, previously unavailable, into why this is such a sensitive and difficult area of practice. This includes the complex systems and multiple deterrents that contributed to participants' lack of confidence and their feelings of discomfort. The findings demonstrated that strong negative feelings can lead to defensive practice. Disability practitioners are firstly individuals subject to the cultural and social shaping of attitudes and beliefs. This study has mapped their professional journey from becoming health or social care practitioners to their membership in a physical disability team. This mapping has highlighted how professional education, professional bodies, and the organisational structures of health and social care all influence professional practice.

A personal aspiration is that this research may contribute to social justice for disabled people. Based on the findings I have made comprehensive recommendations for change. Essentially disabled people must be recognised as fully human, inclusive of sexual needs and desires, and the services provided by community disability teams need to encompass this. I have also reviewed the limitations of this research and indicated new directions for future study.

Unwittingly, practitioners' lack of competence may contribute to the oppression of disabled people by inferring sexuality no longer matters to them. The sexual disenfranchisement of disabled people is a story first told over thirty years ago. Others are placing it on the 'agenda of the disability movement' (Shakespeare 2000 p165). This study has placed it on the professional practice agenda. Health and social care should support the sexual health of people living with disability and not add to any cumulative damage caused through negative social attitudes.
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University of Brighton

School of Healthcare Professions

School Ethics Panel (SEP)

Ethics Comment Form

Protocol Title: A Qualitative Exploration of Physical Disability Teams’ Professional Practice

Investigators’ Name: Lorna Couldrick

Supervisors’ Names: Gaynor Sadlo and Kevin Lucas

Date Received: 11/1/02

Comments:

The School Ethics Panel considers:

i) that the application be submitted to the relevant external Ethics Committee, with the supervisor’s prior agreement

ii) that the application should be submitted to the University of Brighton Research Ethics Committee, with the supervisor’s prior agreement

iii) the study has been approved by the SEP subject to the inclusion of the points noted below

iv) this application for ethics approval is required to be resubmitted to the SEP addressing the points noted below

v) the study has been approved by the SEP X

Signed on behalf of the Panel ......[Signature]: KS, GW, MM

Date .........16/1/02..........
Dear Lorna

Study title: Sexual Expression, Physical Disability and Professional Practice - Phase 2 - A Qualitative Exploration of Physical Disability Teams' Professional Practice

The above study was reviewed by the East Sussex Local Research Ethics Committee, under their Vice-Chairman Dr Howlett, at the meeting on 30 January 2002.

The study was approved.

It would be appreciated if, on its conclusion, you could supply a brief report to the Committee of your findings and conclusions.

Yours sincerely

Kerry Longhurst (Mrs)
Research Ethics Committee Administrator
05 March 2003

Mrs Lorna Couldrick
66 Martyn’s Way
Bexhill on sea
TN20 2SH

Dear Mrs Couldrick


Worthing Local Research Ethics Committee considered in full the locality issues relating to the above application on 3 March 2003.

The issues reviewed were as follows:

- The suitability of the local researcher
- The appropriateness of the local research environment and facilities

The LREC members consider that the locality issues have been adequately addressed and the proposed research can be conducted within the boundary of this LREC on the understanding that you will follow the conditions set out below.

Conditions

- You have a favourable opinion from a Lead LREC for the ethics of the proposed research.
- You do not undertake this research in an NHS organisation until the relevant NHS management approval has been gained as set out in the Framework for Research Governance in Health and Social Care.

Worthing LREC

- You do not deviate from, or make changes to the protocol without prior written approval of the lead LREC and notifying this LREC of the approval, except where this is necessary to eliminate immediate hazards to research participants or when the change involves only logistical or administrative aspects of the research.
- Please notify this LREC when you have completed your research, or if you decide to terminate it prematurely.

Yours sincerely

Dr Andrew Nayagam, FRCP
Chair – Worthing LREC

Copy to: Mrs Kerry Longhurst (Brighton LREC Administrator)
CERTIFICATE OF LREC APPROVAL

This is to certify that the research proposal entitled

Re: Sexual expression, physical disability and professional practice – Phase 2 – A qualitative exploration of physical disability teams professional practice. L17/03

Has passed a process of ethical review by Croydon Local Research Ethics Committee (LREC)

[Signature]

Dr John Chang
Chairman, Croydon LREC

7th July 2003

Please note: Ethical approval does not give you permission to carry out the work within your Trust. This must be confirmed with the Research and Development Department.

What are LREC’s?

- LREC’s are committees appointed by the Department of Health. The Department of Health requires all research of the kind you have submitted to be approved by an appropriate LREC.
- LRECs are responsible for assessing whether or not it is ethical for a medical research study to go ahead according to guidelines issued by the Department of Health.

What does it mean if research has been approved by an LREC?

If research has been approved by an LREC, this means, among other things, that the LREC is satisfied that

- The researchers are properly qualified;
- A number of legal requirements have been complied with;
- Adequate procedures are in place to protect the confidentiality of information;
- The information sheet gives adequate information about what participation in the research involves; about the possible risks and benefits of participation; and about whether or not compensation is automatically available to you if you are harmed as a result of participating;
- Adequate procedures are in place for obtaining the free and informed consent of all potential participants;
- Research protocols adhere to NHS guidelines.
APPENDIX E

Croydon NHS
Primary Care Trust

Headquarters
Knollys House
17 Addiscombe Road
Croydon
Surrey
CR0 6SR

Department of Public Health
Tel: 020 8274 6114
Fax: 020 8274 6008
Catherine.Scott@croydonpct.nhs.uk

Our reference: 5K9/07/03/05
29 July, 2003

Mrs Lorna Couldrick
66 Martyn's Way
Bexhill on Sea
East Sussex
TN40 2SH

Dear Mrs Couldrick

Sexual expression, physical disability and professional practice – Phase 2 – A qualitative exploration of physical disability teams professional practice

The above proposal has now been reviewed, and I can confirm that the R&D Committee is happy for your research to proceed subject to the following conditions:

1. No research is undertaken until all requirements of the appropriate research ethics committee(s) are met.
2. The protocol approved by the ethics committee(s) and this committee is followed and any changes to the protocol are undertaken only after further ethics and R&D approval.
3. You must notify us promptly of any adverse incidents involving PCT patients, staff or anyone else that occur during or as a result of this research using PCT procedures for Incident Reporting.
4. You must ensure that NHS staff and independent contractors are provided with information about this research if it may have an impact on the care they provide.
5. You must complete and return the PCT research report forms that will be sent to you annually and when your research is completed.

It remains your responsibility to ensure that you comply with any legal or regulatory framework that applies to this project.

Yours sincerely,

Catherine Scott
Public Health Specialist
PROJECT INFORMATION

Sexual expression, physical disability and professional practice

You are being invited to take part in a research study. Before you decide if you would like to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please do not hesitate to ask if there is anything that is not clear or if you would like any more information.

What is the purpose of the study?

The aim of this study is to investigate the professional practice of disability teams, in supporting service users whose disability impacts on intimate relationships and sexual expression. This impact may arise from neuro-physiological damage, psychosocial processes or from environmental barriers, both physical and social.

It is the second phase of an ongoing project. Disabled people have contributed in the identification of the research question.

Why have I been chosen?

Your team is one of several teams that have been chosen. This is because your team involves a number of professionals, all with expertise in the area of disability, working to support and enable disabled people living in their own homes. I am hoping a wide range of different professions will take part.

Do I have to take part?

No you do not have to take part. If other members of the team wish to participate, it may be possible for them to take part without you being involved. It is up to you whether to take part in this study. You may withdraw from this study at any point in the future, no reason need be given.

What will happen to me if I do take part?

The first step is to organise a mutually convenient time for all the team who are able to take part, to meet for a focus group for no more than 1½ hours. This may feel a bit like a team meeting, with all members being consulted on issues surrounding sexual expression,
physical disability and professional practice. A month or two later I will return to the team, for a second focus group, to share with you with my understanding and initial thoughts on that first group. Everyone will be able to contribute to and develop this analysis. Following the first focus group, I would be willing to undertake some individual interviews with any team members if they would value this.

What do I have to do?

Firstly please read and sign the two Participant Consent Forms. Return one to me in the s.a.e. provided. The second copy is for you to keep. Then I would like you to attend and participate in both focus group sessions. If after the first group you feel you would be able to contribute more in an individual interview please let me know. There is nothing more you need to do.

Are there any risks or benefits?

Although risks are minimal, as you can imagine, there could be some embarrassment. Sex is a sensitive topic. However I would welcome people taking part even those who may not feel totally comfortable. No one will be asked to reveal anything of their own private lives and each person will be able to choose how much they wish to disclose in the group. Reflecting on practice can be disturbing although my experience has been that people find it stimulating too. As for benefits, I am afraid there is no financial reward. You will though have the gratification of being able to contribute to an area of practice not studied before.

Will my taking part in this study be kept confidential?

All information given by you will be kept strictly confidential and securely stored. Any information, which is given to anyone other than me, will have yours, and your teams, names removed so that you cannot be recognised from it. At the completion of the study, all raw data including audiotapes and transcripts will be destroyed.

What will happen to the results of the study?

The results of the study will help to identify ways to improve the quality of life for disabled people. The results will provide a basis for discussion and practice development.

Contact for further information

Please do not hesitate to contact me if you would like any further information. I may be contacted either at work or at the address at the top of this Project Information Sheet.

Thank you for taking the time to read this. I do hope you will consider taking part.

Lorna Couldrick, MSc, SROT, BACP AccC, CertEd.

14.11.02. Version 1
PARTICIPANT CONSENT FORM

Sexual expression, physical disability and professional practice - phase 2 -
A qualitative exploration of physical disability teams’ professional practice

Researcher: Lorna Couldrick, MSc, SROT, BACP, CertEd

Work base: University:
Social Services Training Department, Clinical Research Centre,
East Sussex County Council, School of Health Professions,
10 Pembury Road, Eastbourne. Aldro Building, Darley Road,
BN23 7HQ BN20 7UR
Tel: 01323 767929 ext. 211 Tel: 01273 643647

Name of participant: SAMPLE

Work Base:

Telephone number: Please alter these details if incorrect

I have read the project information sheet that was sent to me. I understand that the aim of this study is to explore and illuminate the professional ways of working of disability teams toward the sexual expression of their service users. The investigator has explained to my satisfaction the purpose of the study and the possible risks involved. I agree to participate in this research project on the understanding that:

- my participation is entirely voluntary
- I may withdraw from the study at any time
- no reason is required should I wish to withdraw
- participation involves me in no more than two focus groups
- focus groups will not exceed 1½ hours duration
- I may volunteer to participate in an interview of no more than 1 hours duration
- all information I may give will be treated in a confidential manner
- all material recorded on audio tape will be securely stored and destroyed at the end of the project
- if I have any questions about the research, before or after my participation, I may contact the researcher

Signature of volunteer: Date:

Please return one form to the researcher in the s.a.e. and retain one copy for yourself.

The study is being done as part of an MPhil/PhD in the School of Health Professions at the University of Brighton. The appropriate NHS ethics committee has approved the research protocol.
Dear «First name>,

I am writing to you in your capacity as Co-ordinator of the «Base». My purpose is to ask if the service would be willing to participate in a research study this summer. The research would be with staff, not your client group. I am a MPhil/PhD student at the University of Brighton and am investigating sexual expression, physical disability and professional practice. This letter outlines the purpose of the study; how the «Base» was selected; the procedure; an indication of the time commitment and an assurance, as far as is reasonably possible, of confidentiality. I have also enclosed a copy of the Project Information Sheet and Participant Consent Form. What I would like to do is to telephone you during the week beginning 12th May, when you have had time to consider all this information, in order to discuss any questions you may have. Then, if the team is willing to proceed, I will send copies of the Project Information Sheet and Participant Consent Form to every member of the team.

Purpose of the study. The first phase of the study, done in collaboration with disabled people, identified what they felt needed to be researched. In this second phase I hope to investigate the professional practice of disability teams, in supporting service users whose disability impacts on intimate relationships and sexual expression. This impact may arise from neuro-physiological damage, psychosocial processes or from environmental barriers, both physical and social.

How the «Base» was selected. The plan, for the main study, is to work with three disability teams. Each team must include several professionals who have expertise in the area of physical disability and who work to support and enable disabled people who live in their own homes. This includes, for example, people with multiple sclerosis.
The procedure. The proposal is to conduct no more than two focus groups of approximately 1½ hours duration. The first is an opportunity for free ranging discussion. At the second, hopefully held within two months of the first, I will return to the team with my emerging analysis. This will give the team the opportunity to add afterthoughts, tell me of any omissions, and advise me if I have misunderstood anything. After the first focus group, if some team members wish to speak to me on their own, I can conduct individual interviews with up to three different professionals. Again I would return to these individuals with the developing analysis.

Time commitment. The major commitment is trying to meet together with as many team members as possible on two occasions for up to 1½ hours each time. Any team members who would like to be interviewed would need to allow for two, 1 hour, sessions.

Confidentiality. All information given by the team will be kept strictly confidential and securely stored. Any information given to anyone other than me will have all individual and team names removed. Every endeavour will be made to ensure, as far as is reasonably possible, that neither the team nor its members can be recognised. At the completion of the study all raw data, including audiotapes and transcripts will be destroyed.

This study has been approved by the East Sussex, Brighton & Hove Ethics Committee and I will obtain locality approval from Croyden Local Research Ethics Committee. I do hope I have given you sufficient detail. As I said I will be telephoning in two weeks time. If you wish to speak to me earlier do not hesitate to contact me on any of the above telephone numbers.

Thank you for considering this request.

With my good wishes,

Lorna Couldrick

MSc, SROT, CertEd, BACPaccC
Dear «First name»,

I understand from <name of team leader> that you may be prepared to help me with my research project. Enclosed is the Project Information Sheet and two Consent Forms. If you are willing to participate after you have read all the information, please return one signed consent form to me in the envelope provided, the second copy is for you to retain.

I was thinking <date> might be a suitable day for the first focus group but I will telephone all volunteers to discuss this further. So, even if you cannot make the <date>, do return the form. Please can you ensure the contact details I have for you are correct.

With my good wishes,

Lorna Couldrick

MSc, SROT, CertEd, BACPAccC
APPENDIX J

Attributes

1. Name: «First name» «Last name»

2. Please amend this to the full & correct title of the post you currently hold?
   «Post held»

3. Please give a very brief description of your current role within the <team>

4. Are you required to be state registered or hold a professional qualification
   
   Please circle which ever applies
   Yes
   No

   If yes please go to question 5, if no please go to question 6

5. Which year did you qualify / become state registered?

6. Approximately which year did you begin working in health or social care? (Not to be answered by those who have responded to Q5 above)

7. Have you worked in any other health or social care capacity?
   E.g. was a nurse before training to be a psychologist - please describe briefly

8. Please indicate your age by ticking the appropriate category

   21 - 25
   26 - 30
   31 - 35
   36 - 40
   41 - 45
   46 - 50
   51 - 55
   56 - 60
   61 - 65
   I do not wish to answer

9. Approximately how long have you been working in or with the <team>?

10. Please write in the title of the group that you consider best describes your ethnic origin. E.g. White Irish, Black British, Mixed Caribbean, Indian, Chinese.
Dear «First name»,

I just wanted to say thank you for helping me with my research. I have found the commitment from the <name of team> team enormously valuable. I appreciate the time you personally so generously gave and your openness to the research process.

Even though this phase is complete, if you have unanswered questions or further thoughts on the process, now or in the future, do not hesitate to contact me.

With my good wishes,

Lorna Couldrick

MSc, SROT, CertEd, BACPAccC
Dear «First name»,

I just wanted to say thank you to you for helping to facilitate my entry into the team to undertake the research as well as your considerable personal contribution to the study. I have found the work with the «name of team» team enormously valuable. I appreciate the time you personally so generously gave and your openness to the research process.

Even though this phase is complete, if you have unanswered questions or further thoughts on the process, now or in the future, do not hesitate to contact me.

Please would you also pass on my thanks to the whole team.

With my good wishes,

Lorna Couldrick

MSc, SROT, CertEd, BACPAccC
Poem - Nancy's tale

I was one of those that suffered from the effects of the last meeting.
It could be my awareness being more tuned in,
But it was people coming out and saying,
"I don’t know what we’re gonna do about sex".

I thought I do not believe this.
And it’s happened several times.
I don’t know whether I’ve got something
Stamped upon my head.

Previously I'd said that it was quite rare
For clients to actually bring it up.
I mean you might get there in a roundabout way
In talking about the effects of continence and so on.

But these were like totally unconnected.
People started telling me all about their sex life
And I thought this is unreal.
It does seem rather uncanny.

I felt really spooked.
I thought it was strange.
But I didn’t have a problem
And I talked on what was appropriate I felt at the time.

There was a man, one recent female and another man as well,
So just three that I can think of,
But actually, I think it’s probably been more.
I didn’t feel badly about it.

I was probably more comfortable with it
Knowing that nobody else felt any happier.
That I wasn’t out of my depth
Because somebody else wouldn’t have managed it any better.
So I just thought well, we’re all in the same boat really
And so you just do the best you can with what you’ve got at the time.

My first attempt at expressing qualitative data through poetry. The words I have added are in italics, otherwise this is just an edited version of what Nancy said in her individual interview.
FOCUS GROUP / INTERVIEW SCHEDULE

Opening statements

• Thank participants. "Thank you all for agreeing to participate in this research project"

• Introduction to focus group. "As you know my name is Lorna, this is the second phase of a project investigating sexual expression, disability and professional practice".

• Reassure participants. "I want to reiterate that there is no hypothesis to be tested. There are no right or wrong answers. What I am interested in is the professional practice of disability teams and the opinions, values and beliefs of team members that underpins that practice".

• Outline the procedure. "In a moment, I will ask each of you to introduce yourself, saying your name and a few words about yourself. I know you all know each other but this is particularly important for transcription purposes".

"I do have some prompts but I would like you to feel free to discuss aspects of this subject as they occur to you. This is a focus group and the aim is to develop a team discussion that explores practice. This discussion today, with your colleagues, may help develop some understanding of what underlies that practice".

"The plan is that I will take this audiotape away to transcribe. I will return to the team with my first attempts at analysis. This will give you some opportunity to add afterthoughts, tell me if you think I am missing anything, and advise me if I have misunderstood anything".

"If today’s meeting triggers more thoughts that you wish to discuss further, I would be happy to conduct individual interviews with up to three members of the team".

• Language. "One of the things I have found in researching sexual expression is that there is no common language to discuss the issues. I want to reassure you that you may use any language that feels comfortable to you and any language that your service users may use. Crude, clinical behind the bike sheds or biblical, it is all acceptable".

• Confidentiality. "Again I wish to reassure you that I will make every effort to keep information confidential. In speaking or writing about the project I will not reveal the location of the team nor identify individuals within it. All information will be securely stored and destroyed at the end of the study".

• Voice location. "Can we begin by going round and each person saying their name and a few words about themselves?"
Introduction

1. It can be difficult to begin but I thought perhaps that we could start by discussing whether the sexual expression of service users is seen as a legitimate area of service provision for the team.

Check levels of agreement / disagreement. Strength of opinion. Listen for barriers/enablers. Has everyone contributed? Is it something that would be relevant to all members of the team or certain members? Check professions indicated / excluded. Check individuals indicated / excluded. Seek exploration of statements.

Develop narratives

2. Have any of you experienced addressing sexual issues in practice? Can you tell me about an incident / time / client?

Elicit narratives. Try to develop examples from all those who have had experience. Gather detail on how this experience arose, the context, the practitioner's feelings, and the outcome. There may be no examples.

Confidence and competence where narratives have been offered

3. In reflecting on these experiences, I wonder what other members of the team think and feel.

Check thoughts of storyteller plus other members of the team. Who leads and does this help / hinder others? Check particularly for statements that outline degrees of competence and confidence in giving permission, providing limited counselling and referring on. What enables, what discourages?

4. Is there a sense that this kind of problem falls to one team member or might it arise for any team member?

Is it the person or profession? Where are skills invested / recognised / acknowledged?

Confidence and competence where NO narratives have been offered

3. I am wondering what your thoughts / feelings are that no one has had this kind of experience?

Is this omission invested in the client group or staff group? Check for statements indicating lack of competence and or confidence.

4. Now that you have reflected on the idea, tell me how you would feel if the next client you saw asked to speak about the effect of disability on their intimate relationships.
What barriers or discouragers do they encounter?

Support, guidance and referral resources

5. It would be useful to have an idea of the education or training any of you have had in this aspect of health care.

Check whether this encompasses emotional and mechanical impact of disability. Pre post registration, profession specific? Enabling or disabling?

6. What about support and guidance in practice?

Within team? External to team? Professional supervision networks? Team training / development. Referral resources for emotional aspects? Referral resources for mechanical aspects?

A team approach

7. Now that you have had a chance to listen to each other, I wonder if you could tell me about the team's approach to this aspect of care.

Unique / shared or specialist skills? Ability to identify issues and refer to other team members? Agreements / disagreement of opinion about roles?

Revised: 26.02.06. Filename: interview schedule