WOMEN WITH PHYSICAL IMPAIRMENTS
AND MENTAL DISTRESS

By

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Abstract

This thesis examines whether mental health services in the UK across the statutory and voluntary sector currently respond appropriately to the support needs of disabled women. The focus is women aged 18-65 with physical impairments who experience mental distress. In order to conduct a study in which the central focus was the experiences of twelve women with physical impairments, from their own perspectives, qualitative methods were used: one to one interviews and a focus group enabled women to share their views in relation to the small existing body of literature on physical impairment and mental health which predominantly claims that individuals will experience mental distress by virtue of living with a physical impairment. The methods devised also provided women with the opportunity to talk about their individual experiences of accessing and using mental health services. The diverse ages of the women included in the research highlights the value of considering disability and mental health in life-span perspective. The study concludes that, for the mental health needs of those women with physical impairments who experience mental distress to be met comprehensively and appropriately in the future, a wide range of changes both at an organisational and practical level are required.
Acknowledgements

I wish to express gratitude to all those who have assisted in making the completion of this work possible. In particular heartfelt thanks are due to my Supervisors Professor Ann Davis and Dr Harriet Clarke for their time, support and encouragement given in particular during 2009. I would also wish to thank fellow research Students and Departmental Staff within the Institute of Applied Social Studies for their practical help and support.

This work would have not been possible without willing participants and I am deeply grateful to each of the twelve women who gave their time to talk about their experiences and without whom this study would not have been possible.
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INTRODUCTION

Over the past two decades an increasing amount of attention has been paid to identifying and meeting the individual support needs of mental health service users and people with a physical impairment. Evidence of this can be seen in the literature that considers mental health and physical impairment from a wide range of perspectives as well as the increased range of service provision for individuals within both groups. However, the support needs of individuals who fall into both categories have largely been overlooked by service providers, practitioners and organisations for whom the main focus is either mental health or physical impairment.

The lack of attention that has been given in theory and practice to the mental health support needs of women with physical impairments has, I believe, resulted in an insufficient knowledge base of how to support women with physical impairments who may require some form of mental health support. In addition, for this group of women this has meant that their needs have arguably continued to be neglected and subsequently left unmet. This is why I believe a research study in this area is important and long overdue. Not only would such a study be innovative in covering a neglected area of experience it would also make an original contribution to knowledge in relation to both policy and practice. In addition, from the perspective of women with physical impairments who experience mental distress, it is long overdue.

As a woman who has lived with an acquired physical impairment for almost three decades and is an experienced and qualified social worker, I consider that my experience on both professional and personal levels has provided me with a foundation of knowledge and the ability to undertake such research.
THE IMPORTANCE OF THIS STUDY

My interests in this area of study originate from the issues I encountered during ten years experience of working as a Social Worker in the 1990s with women with physical impairments aged between 18 and 65 years. Many of these women either felt they needed mental health support or found themselves assessed as having mental health needs. Invariably, I found that service provision to meet those needs was either inadequate or non-existent. The efforts I and others made to provide sources of help to women service users through the provision of written material or making links with specialist physical impairment or mental health organisations were seldom successful.

This thesis examines the experiences of women with physical impairments aged between 18 and 65 years who also have (or have had) experience of mental distress in relation to accessing or using mental health services within the statutory and non-statutory sectors. This approach was taken in order to investigate whether a common set of experiences (including barriers faced) could be identified across a diverse sample of women. The thesis also seeks to achieve depth by providing a space for women’s voices to be heard. This I consider to be vital as within the academic and research literature relevant to physical impairment and mental health, attention has been drawn to the fact that there has been little focus to date on listening to the views and experiences of people with physical impairments. This is the case with regard to their experiences of services as well as their accounts of their day to day life experiences.

RESEARCH AIMS

In conducting this study my primary intention was to research the experiences of women with physical impairments, from their perspectives. I chose women because I
was unable to identify any other research study that was specifically concerned with women's experiences. My research has five aims:

1) To examine the provision of mental health services both within the statutory and voluntary sector for women with a physical impairment, aged between 18 and 65 years, living in England or Wales who also have mental health needs.

2) To examine women's experiences of accessing mental health services in addition to examining experiences of using mental health services.

3) To demonstrate the extent to which mainstream mental health services meet the needs of women with physical impairments who have mental health support needs.

4) To determine whether existing counselling service provision meets appropriately the needs of women with physical impairments who experience mental distress.

5) To explore the ways in which the concept of loss is used to understand the situation of women with physical impairments from the viewpoint of this group of women.

This thesis is informed by the findings of a piece of small scale research that I undertook in 2003 as part of a Masters Degree in Disability Studies. That study examined the experiences of eight women with physical impairments in relation to accessing and/or using mental health services (Smith 2003). In building on my 2003
research for this thesis I decided to undertake a study that was not impairment specific but encompassed a range of physical impairments. Additionally, where previous studies have in the main been concerned with the occurrence of depression among people with physical impairments, (for example: Fuhrer and Hart 1993; Sadovnik and Remick 1996) I decided that this study should encompass a range of mental health problems.

Six key themes emerged from my 2003 study which women themselves identified as being important in ensuring that their mental health needs were met. Each of these informed my thinking about the direction and design of the research for this thesis. The themes were:

- **Based on their personal experiences of accessing and using services, to varying extents women in the 2003 study did not feel that their mental health needs had been adequately met.**

The time constraints of the MA research study meant that there was insufficient scope to examine whether the reported differences in experiences were related to whether the women had acquired their impairment or whether it had been present from birth. This research therefore seeks to explore in greater depth whether women’s experiences of using mental health services are related to this factor.

- **All the women in the 2003 study reported that mental health professionals with whom they had contact overwhelmingly made an assumption that their mental distress was occurring as a direct consequence of living with their physical impairment. Mental health professionals were also often perceived as being**
reluctant to consider women’s expressed beliefs that their mental distress was not necessarily directly linked to their physical impairment.

This theme is examined further in this thesis by exploring the reasons why women may feel that mental health professionals routinely assume a link between the presence of a physical impairment and an inevitability of experiencing mental distress. It examines the extent to which women themselves are influenced by an "impairment creates depression" explanation for mental distress which may be a message received in their interactions with others, including health and social care professionals.

- Each of the women in the 2003 study reported that social and cultural factors such as accessibility issues and attitudes within society towards physical impairment had an impact on their psychological and mental well-being.

This thesis therefore pays attention to why women with physical impairments believe that social and cultural factors can impact on their mental health and in what ways this impact manifests itself.

- Women in the 2003 study made reference to recognising that with the staged implementation of the Disability Discrimination Act 1995 (DDA), they were starting to experience both improved access to the environment generally and a positive shift in attitudes towards impairment.

This theme is further explored in this thesis with particular reference to the implementation of Part Three of the DDA in 2004 and whether this has had an effect
on the perceived impact of the role played by social and cultural factors on mental well being.

- **Women in the 2003 study considered that there needed to be a variety of changes in order that women with physical impairments experiences of mental health services could be more positive.** In particular reference was made to the need for improvements in the attitudes of mental health professionals towards impairment, as well as improved access to public spaces and public transport.

This theme is developed further in this thesis by investigating the changes that women with physical impairments believe are needed. It will seek to establish both the reasons why they are needed and why women feel that those changes would lead to more positive reporting of use of mental health services.

In this thesis each of the areas outlined above are examined in more depth. And the research questions which inform the research reflect this.

**Research questions**

The topic of physical impairment and mental health has received little attention within the academic, policy and research literatures and there exists a minimal amount of research that focuses on this topic. Where the literature does examine the area it has overwhelmingly been undertaken from a medical perspective. Literature and studies that have been conducted have overwhelmingly concluded that people with physical impairments will acquire mental health support needs because of their impairment and that individuals need to go through a process of adjusting to their loss (see Stenager et al 1992, Turner and Noh 1998).
Additionally, the literature that examines the area of physical impairment and mental health is predominantly underpinned by two assumptions. Firstly, that impairment in itself is a cause of psychological distress and secondly that the solutions to it are to be found within the individual. This thesis seeks to explore the assumptions made in such traditional theories of loss with other approaches that offer a more complex account of how individuals respond to impairment.

At the same time this thesis critically addresses the literature that has focused on physical impairment and mental health using a social model approach. This is an approach in which the potential impact that social and cultural factors (such as attitudes towards impairment, barriers to service provision and disabling barriers) may have on mental well being are discussed. However, little attention is paid in this literature as well as in the research studies that have been informed by this approach, to the psychological consequence of these on individuals as well as research studies. This thesis seeks to address this issue.

The main overarching research question that this thesis addresses is:

**Do mental health services in the UK respond appropriately to the support needs of women with physical impairments who experience mental distress?**

Shaped by the main themes that emerged from my 2003 research study and those that emerged from the comprehensive literature review presented here, this thesis examines the thoughts and views of a sample group of women with physical impairments in relation to the four subsidiary questions listed below:
1. Do women with acquired and congenital impairments differ in their personal analysis of the relationship between physical impairment and mental distress?
2. To what extent do women with physical impairments perceive social disability as a source of mental distress?
3. Do women with a range of physical impairments who have experienced mental distress identify a shared set of barriers to mental health services?
4. Do women with physical impairments who also have experience of mental distress believe that mental health services within the UK could meet their needs more appropriately and if so, how?

THESIS CONTENT AND STRUCTURE

The thesis begins by considering within Chapters One, Two and Three the literature that has examined physical impairment and mental health. Chapter Four provides an account of the research design, the methods that were used to conduct the research and the reasons why those methods were chosen. This is followed in Chapters Five through to Nine by a presentation of the research findings.

Chapter Five, (which relates to the first of the subsidiary research questions) is in two parts. Part One presents the women’s thoughts and views in relation to the perceived inevitability of experiencing mental distress when living as a woman with a physical impairment. It also examines women’s experiences of the attitudes and beliefs of mental health professionals that were encountered. Part Two presents findings on the related area of loss, how women understood the concept of loss and how, or if, it had been experienced for different women.
Chapter Six (which relates to the second of the subsidiary questions) focuses on four areas:

- The potential of factors such as attitudes towards impairment and difficulties encountered in accessing the environment to impact on mental and psychological health.
- The ways in which the implementation of the DDA is perceived to have impacted on mental well being.
- The self image of women with physical impairments and the factors which women perceive as having the potential to impact on women’s self image.
- The impact of living with a physical impairment upon relationships with family, friends, or other persons relevant to the person’s life.

The findings relating to subsidiary question three are discussed within Chapters Seven and Eight.

Chapter Seven considers women’s personal experiences of mental distress before turning to look at women’s experiences of accessing mental health services and their experiences of using them.

The majority of the women in the sample group experienced counselling. Chapter Eight presents these experiences. It considers women’s positions regarding the debate that has emerged in recent years as to whether people with a physical impairment need to receive counselling from an individual who has a physical impairment themselves (or has experience of living with an impairment). The views women expressed about physical impairment and counselling including the preferred gender of counsellors are also discussed.
Chapter Nine relates to the final subsidiary question. It discusses the views of the women about how mental health services in the UK could better meet the needs of women with physical impairments who experience mental distress. Firstly, it highlights the changes or improvements which women considered were needed at an organisational or service provider level. Secondly, it discusses the practical changes which it was considered, if made, would make a significant contribution to improving the future experiences of women with physical impairments who receive mental health support.

The concluding chapter summarises the main messages which have emerged from the research findings. It then discusses the ways in which the research undertaken contributes to knowledge in this subject area. In addition, it offers a reflection on the research design and its strengths and weaknesses before exploring possible directions for future research in this field which could advance knowledge. Finally, the possible implications of the research for future mental health policy and practice of providing mental health support to women with physical impairments who experience mental distress are considered.
REVIEW OF THE LITERATURE: CONTEXT AND PROCESS

INTRODUCTION

The literature review which is contained in the first three chapters of this thesis is concerned with the topic area of women with physical impairments and mental health. The review aims to provide an analysis of literature from the mid 1970s to 2006 that has relevance to my chosen area of research. The term physical impairment is used within the review as being inclusive of impairments that individuals are born with or are acquired at some stage in their life and is therefore not impairment specific. The review examines the experiences of women aged 18-65 years with physical impairments who have (or may have) mental health needs in accessing and using mental health services. The focus here is on mental health needs that have occurred following or which may develop as a result of the experience of physical impairment or disability rather than women who had already experienced or were experiencing mental health difficulties prior to or at the time of onset of their physical impairment.

Where physical impairment and mental health is discussed within the literature or examined within a research context, overwhelmingly the focus is on depression as a response to the onset of or adjusting to physical impairment and there is little within the literature that considers any other form of mental health issue. Just as the focus of my research study is not impairment specific, it aims also to encompass a range of mental health issues for which women with physical impairments may require the support of mental health services.

Over the past decade whilst there has been an increasing amount of attention paid to the support needs of people with physical impairments and mental health
service users, the support needs of individuals who fall into both categories have been overlooked by researchers, service providers, practitioners and organisations of both service users and disabled people. A national inspection of physical disability services in 2003 found that not enough attention was paid to 'emotional and mental health needs generally' (Social Services Inspectorate 2003 para 7:16) Neither has it been recognised that people with physical impairments experience unequal access to mental health services. In a literature review commissioned by the National Institute for Mental Health in England (NIMHE 2003) which was concerned with the policy, practice and service user experience of mental health services, there was no reference to people with physical impairments who had mental health support needs. In addition, neither disability or impairment were identified as being a relevant factor when looking at experiences of discrimination and mental health services. The National Service Framework for Mental health for England makes no reference to disabled people as a specific group among users of mental health services (DoH 1999) although the Welsh National Framework for Mental Health does (Welsh Assembly 2002).

A research study by Morris, one of a small number of authors who has examined the mental health needs of people with physical impairments, concluded that the majority of respondents had experienced difficulties in accessing mental health services because of their physical impairments. Reports of positive experiences of using mental health services were found within the study to be disappointingly sparse (Morris 2004), (see pg 23 for further discussion).

**Reviewing the literature**

Where the subject area of physical impairment and mental health has been discussed within the literature, it has fallen into two broad categories; either a traditional
medical model approach to disability or a social model approach. The literature review therefore encompasses both academic work within the field of disability studies which, before the emergence of the social model of disability was informed predominantly by the medical model and that which increasingly over the past two decades has been informed by the social model. In addition it examines some of the small and growing body of material that has been written from a user led perspective. The review incorporates texts that have been based on research studies, texts that are theoretically informed and textbooks. A search of both disability related and social work journals and publications provided material that was both relevant to my study and recent in origin. A small number of journals are referred to throughout the review which were valuable in terms of the breadth of topics covered and which were of a minority that also examined the emotional and psychological aspects of physical impairment.

In covering literature from the previous three decades i.e. from mid 1970s to 2006, the review reflects the emerging contribution of the social model of disability within the disability studies literature. I decided not to extend the review over a greater time span because I thought it would have been too thinly spread to offer the basis for an in-depth analysis of the areas that I wished to explore within the research study. The literature selected is predominantly from the UK together with some non UK material that was considered to be particularly relevant to the subject matter.

A search for literature on the subject of mental health provided a wealth of material from a wide range of sources. (The searches undertaken in identifying relevant material are outlined in the next section). Theoretically informed texts published between the mid 1970s and mid 1980s predominantly assumed a presupposed causal link between physical impairment and mental health, and most adopted a 'medical' approach to the subject. Material that has been published within the previous two
decades has seen a shift in some of the literature towards a more social approach to understanding mental distress. In the journals the material located was primarily within medical based publications and where the issue of physical impairment was examined (in a minority of the published articles) it was from a medical approach.

Within the literature generally where physical impairment or mental health was the area being discussed or researched, the focus was on or related to persons within a defined age range. This enabled me to select a focus on literature that for the majority specifically related to persons aged between 18 and 65 years. This age range reflects the tri partite organisation of statutory services for physical disability and mental health services, i.e. (1) for persons aged under 18 years, (2) adult services (often 18-65 years) and (3) older persons services which usually have responsibility for persons aged over 65 years.

**Identifying material**

In identifying material of relevance to my chosen topic which had been published within my chosen time frame a comprehensive range of resources were identified and searched. These were:

- Using search terms of 'physical impairment', 'mental health', 'women', 'loss theory', 'counselling and disability', 'medical model' and 'social model of disability' (singular and in combinations) a thorough and detailed search of the University of Birmingham library catalogue was conducted. This aimed to identify material within the field of disability studies which had adopted either a medical or social approach or had been undertaken from a user led perspective. Further relevant material was located
through an examination of bibliographies listed within some books/ journal articles etc.

- A search of the British Library Catalogue
- A search of disability related and social work based journals and periodicals *i.e.* *Disability Now, Disability and Society, Community Care*. These journals were found to be valuable in terms of the breadth of topics covered relating to physical impairment.
- A search of mental health journals and publications. *i.e.* *Journal of Mental Health, Mental Health Weekly, Open mind*
- An examination of official government publications through their websites i.e. Department of Health, National Statistics Office provided valuable material and links to further sources.
- Internet based searches for conference papers or theses relevant to the topic area were conducted rigorously and repeated at intervals in order to identify up to date material. The Disability Archive at Leeds University was a valuable resource for a number of articles many of which have been written by disabled people.
- The databases of Web of Knowledge and a number of social research databases i.e. IBSS, Intute/social sciences have been searched electronically.
- Searches of the websites of major physical disability and mental health organisations and charities i.e. *Multiple Sclerosis Society, Stroke Association, Mind, Samaritans*. These individual organisations have established their own websites as a source of support and accessing information and materials relevant to the subject area were located within these.

Having identified material from these wide ranging searches, it became apparent that the searches had yielded a relatively small amount of material that looked specifically at
the subject area of my research. The material located evidenced that only a relatively small number of authors had examined the emotional and psychological impact of physical impairment on mental health with a specific focus on the experiences of women. Working with material deemed as relevant to the research study a literature review map was constructed which identified the main themes that emerged from those sources.

**Structure of the review**

The literature review is structured on the basis of the themes which emerged from my analysis of the relevant literature. Chapter One comprises two parts. Part One provides an overview of the literature examining the area of women and mental health. From the mental health literature that has examined physical impairment, a clear link between the two had been made on the premise that a level of depression will automatically be experienced by someone living with a physical impairment and the literature that discusses this link will be discussed.

Part Two examines the more recent literature that has adopted a social model perspective in considering the mental health support needs of people with physical impairments. From this literature a clear theme emerges which illustrates how factors in society such as attitudes towards impairment and disabling environments can impact on mental well being. Though such experiences for women may create feelings of anger and rejection, the literature does not tend to examine the psychological consequences of such experiences. This identified for me a gap in the current literature that I thought was important for my thesis to address. Whilst the literature that examines the mental health experiences of women with physical impairments is scarce where it does exist it suggests that a clear message emerges from women who have described their
experiences. It is the need for services to work together more closely, and improve communication with services for people with physical impairments in order to meet their needs more comprehensively. Within this literature, women often expressed a wish for mental health services and those working within them to look beyond the woman's impairment and to value them as individuals. However, given the paucity of literature on this theme area, I decided that my thesis would investigate this area further.

The literature on physical impairment and mental health tends to suggest that individuals will need to make psychological adjustments if they are to come to terms with their impairment. Chapter Two begins by examining the literature on traditional theories of loss before looking at the critiques that have been developed in more recent years. Alternative models that open up a more social perspective on how individuals react to physical impairment are then explored before the concept of loss is examined from the perspectives of women with physical impairments.

Chapter Three focuses on the growing literature that in recent years has examined the topic of counselling for people with physical impairments. This body of literature focuses on a number of areas including for example, the reasons why people with physical impairments seek counselling and the environmental and financial aspects of accessing counselling. Some of the more recent counselling literature demonstrates an overall consensus of the need for counselling training to include disability equality training, and for all counsellors to be trained to work with disability related issues. The literature relating to each of these areas will be examined. The review of this body of literature suggested to me that my thesis should include consideration of the topic of counselling for women with physical impairments and their views and experiences in relation to counselling.
CHAPTER ONE
WOMEN, PHYSICAL IMPAIRMENT AND MENTAL HEALTH

INTRODUCTION

This chapter reviews literature relevant to the topic of women, physical impairment and mental health. It has two parts. Part One begins by examining a range of the literature that has examined the topic area of women and mental health. It then proceeds to review the literature that looks at an assumed relationship between mental health and physical impairment. This literature yielded little that was specific to women and overwhelmingly focuses on depression and its association with specific impairments.

Part Two examines the more recent, smaller body of literature that has adopted a social model perspective on the mental health support needs of people with physical impairments. It looks firstly at the issue of disabling attitudes towards disabled people and how these have the potential to impact on the self image of women with physical impairments. The literature which is concerned both with access to the environment and access to service provision is then discussed. Finally, it will examine the attitudes of mental health professionals towards physical impairment and how their attitudes and beliefs have the potential to impact on the person receiving a service.

PART ONE: WOMEN AND MENTAL HEALTH

Over recent years the body of literature on women and mental health has steadily grown with the mental health support needs of different groups of women becoming increasingly recognised. The overall higher prevalence rates of mental illness for women compared to men have been well documented within the literature though some
have argued that this is not necessarily because women are more biologically inclined to mental illness. Rather, it indicates a socially constructed and gendered approach to mental illness which means that women are much more likely than men to receive a diagnosis of mental illness (Miles 1988, Busfield 1992, Kumari 1995, Perkins et al 1997, Levin 1998, Prior 1999, Kohen 2000, Davis, Barnes et al 2002, Birch et al 2005).

Holmshaw and Hollier (2000) claim that the overriding belief of Victorian psychiatrists, was that women were more likely to experience insanity as a result of the instability of their reproductive system and so women's biology was seen as a predictor of mental illness. In this way, historically, women have been positioned as 'mad' and in contemporary society women's reproductive biology is still seen as a cause of mental illness (Ward 2005). Payne suggests that psychiatry constructs certain stereotypes of women, such as the depressed housewife, the post-natal mother and the senile older woman (Payne 1999).

Ussher (1991) suggests that by identifying women's bodies as the source of their distress, this ignores other potentially traumatic or stressful circumstances (cited within Payne 1995). There is significant evidence that women who experience mental ill health have previous experience of physical, emotional and sexual abuse, the latter in particular being 'one of the major factors which lead to women's 'madness' (Ussher 1991: p266). Research by Walters suggests that women themselves identify social rather than medical causes of mental distress with three main themes being identified: heavy workload, issues of identity and social legacy (1993). Others have drawn attention to psychiatric services being patriarchal and paternalistic. The services which women receive, it is argued, further disempower them rather than giving women the skills which might enable them to tackle the causes of their situation (Millett 1991, Busfield 1996).
A consultation document published by the Department of Health on Women's mental health aimed to outline a direction to help achieve a mainstream approach to gender in mental health service organisation and delivery (DoH 2002). My analysis of responses received from a range of stakeholders to the consultation document highlighted a number of areas of concern:

- In response to being asked to identify women who should be considered to be particularly vulnerable to ill health, women with physical disabilities were one of a number of groups identified.

- Asked what aspects of service delivery should be considered in ensuring that gender and women's needs in particular are addressed, one response noted that under the Disability Discrimination Act, discrimination against people with mental health problems is prohibited. In contrast, no reference was made to discrimination against people with physical impairments also being prohibited under the Act.

- Respondents to the Consultation document were critical of its tendency, when considering the meeting of needs of particular groups of women, to revert back to a medical model. This was perceived as reinforcing an emphasis on overt symptoms and medical classification instead of encouraging thinking about a more holistic approach and/or needs led approach to identifying and meeting women's needs.

A key message from the Women's Mental Health Strategy Document (DoH 2003) was the need for services to be responsive to gender differences in mental health problems. The document however received criticism for the lack of attention paid to the
needs of women with physical impairments despite them being raised within responses to the consultation document (GLAD 2003).

In contrast to the extensive academic interest that has developed in relation to women's madness and mental health, the topic of men and mental health has for many years been an under researched area. This has begun to change in recent years in line with a growing recognition that among all social groups in the UK, suicide rates for men are higher than for women across all age groups (Mind 2000). Men aged between 25 and 44 are almost four times more likely to kill themselves while men aged 45 and over are more than twice as likely to commit suicide as women in the same age group. In the 25 years preceding 1998 young male suicides (17-34 years) increased at an alarming rate but fell by 30% between 1998 and 2005. Much of this downward trend has been attributed to the Government's National Suicide Prevention strategy (DoH 2005).

A study in the late 1990s suggested that depression occurs in men twice as often as women even though women get diagnosed and treated twice as often as men. Evidence suggests that men are less likely to see their General Practitioner about psychological problems and if they do so, are more likely to present with physical problems which may not be recognised as a manifestation of mental distress. It is argued that men tend to express their symptoms differently i.e. through the use of alcohol or drugs and are more unwilling to admit to symptoms of depression (Real 1997, Stewart 2005).

The evidence shows however, that there are clear variations in suicide rates among different ethnic backgrounds. Asian women's groups have linked the high suicide rates among young Asian women to cultural pressures. Factors such as
conservative parental values and the tradition of arranged marriages may clash with the wishes and expectations of young women themselves (Raleigh and Balarajan 1992). Of 1,979 suicides among women of all races aged 17-34 between 1988 and 1992 in England and Wales, 85 were Asian women which represented nearly double their proportion of the population (Roy 1996). The likelihood of a person committing suicide will however depend on a number of factors. Individuals who may be experiencing social problems, especially those related to family stress, divorce, social isolation, bereavement or mental or physical illness are said, when in an acute state, to be at increased risk of suicide or giving thought to suicide (Charlton et al 1994).

**Women with physical impairments and mental health**

Within the limited body of literature on physical impairment and mental health, there is little that examines the experiences of or issues specific to women. A minority of authors who have published or undertaken research in this area are themselves women with physical impairments who have an interest in, or personal experience, of accessing or being a user of mental health services (Morris 1989, 1990; Keith 1994, Begum 1995, Marris 1996). Equally there is little literature that looks at either ethnicity or age in relation to physical impairment and mental health in persons under 65 years. Work by Begum examined the experiences of Asian disabled women using community care services and receiving personal care but these studies focused on physical impairment (Begum 1990, 1995). A study by Oliver (1980) examined the experiences of men who had acquired spinal cord injury but the focus was primarily on the physical and practical perspectives of acquiring a spinal injury.

Drawing on the social model of disability, (examined within Part Two) Thomas's qualitative research on disabled women's experiences of health services, in particular
the attitudes and practices of doctors, found that women were sometimes dismissed as 'neurotic' and 'hysterical'. She argues that both disablism and sexism operate within the health service, resulting in some very distressing experiences for disabled women (Thomas 2001). Studies undertaken which have looked at specific conditions (e.g. Multiple Sclerosis, Spinal cord injury) have overwhelmingly focused on depression as opposed to a range of mental health conditions (Sadovnick 1996, Stenager 1992, Craig 1997, Kennedy 1999). Morris is one of a small minority of authors who have examined the emotional and psychological impact of physical impairment on mental health, with a particular focus on the experiences of women. Her 2004 study examined how people with physical impairments, who also have mental health support needs experienced mental health and disability services. Of eighty three questionnaires returned, a high proportion of respondents were long term users of mental health services and two thirds of respondents were women. From the postal responses twenty five persons were selected for interview, which aimed to represent a variety of individual experiences and characteristics.

The study found that individuals experienced difficulties in using mental health services because of their physical impairment. Likewise, needs relating to physical impairment were commonly unrecognised within mental health services. A number of mental health facilities were physically inaccessible to people with more significant mobility impairments with a clear failure in some instances to comply with the Disability Discrimination Act by making 'reasonable adjustments'. Experiences of both gaining access to and using community mental health services were overall described by the interviewees as being poor with only private psychotherapy or counselling being experienced in a positive light (Morris 2004).
For individuals who had experienced in-patient care, the study found that considerable problems existed in terms of the physical environment of psychiatric hospitals and the facilities within them. Difficulties in getting personal care needs met, which were often attributed to poor attitudes and a lack of understanding by ward staff were described by a number of participants. A failure to meet physical needs created considerable stress and some interviewees described how this resulted in a decline in their physical state (Morris 2004). These and other findings from Morris’ study will be explored further within this review.

**Depression and Impairment**

A small number of studies which are concerned with the mental health experiences of women with physical impairments were located within the NHS Centre for Reviews and Dissemination checklist of literature reviews (2001). Primarily these studies are about depression and its association with specific impairments with little reference to, or discussion about, women whose mental health needs may not be connected to their experience of physical impairment. Mostly, the literature is underpinned by two important assumptions; firstly, that a physical impairment in itself is a cause for psychological distress and secondly, that the extent and the likelihood of distress and the solutions to it are to be found within the individual as opposed to looking at external factors that are indicative of the barriers often faced by people with physical impairments (Morris 2002).

The studies undertaken mainly ask questions such as: is depression associated with this particular impairment?; what are the factors that make depression more likely?; and, does the experience of depression influence the way that physical impairment is experienced? The relevance of other factors (such as ethnicity, gender or economic and
social roles) are considered within only a small number of studies. Many of the studies undertaken have been quantitative rather than qualitative with experiences being measured by instruments that have been devised by psychologists, mainly for use with non-disabled populations. The definitions and measurements of impairment and disability used are those as laid down by the World Health Organisation's International Classification of Impairment, Disability and Handicap (ICIDH) and are therefore prone to the assumption that impairment in itself is the primary cause of disadvantage. There is little within the research studies that focuses on disabled people's experiences from their point of view and this is equally the case for their experiences of services (Morris 2002). In an article by Begum which recounts her experiences of the mental health system, she describes how a psychiatrist had told her 'If I was disabled I would be depressed'. She later found that the diagnosis on her medical notes was 'Understandable personality disorder because of her disability' (Begum 1999).

A longitudinal study of people with physical impairments by Turner and Noh (1988) concluded that 'the disabled are at dramatically elevated risk for depressive symptoms and a high level of depression characterises men and women of all ages' (p37). A study of students with a range of congenital and acquired physical impairments found that these students reported higher levels of psycho-social distress than their non-disabled peers (Hogan et al 2000). Studies of the experiences of particular impairments have reached similar conclusions. A study of people with Multiple Sclerosis (two thirds of whom were women) aimed to examine the incidence of depression among people with MS. The study found that almost half had experienced a major depression episode (Sadovnik 1996) and high rates of suicide were also found among this group (Stenager 1992).
Studies which have found relatively high rates of depression among people with physical impairments have made the assumption that the causal link is to be found in the experience of impairment and functional limitations rather than the social and economic factors which may accompany or be associated with impairment (such as added financial pressures and/or the likelihood of temporary or permanent job loss.) The assumption of this causal link, according to Morris, persists in spite of conflicting evidence about the co-existence of physical impairment and depression and in spite of evidence that existence and degree of depression do not appear to be related to the extent of physical impairment (Morris 2002). A study that looked at the probability of experiencing depression for people with Multiple Sclerosis found that patients with a high probability of depression tended to perceive their disability as greater than that assessed objectively by their physician. The study concluded that 'Depression is common in multiple sclerosis and adversely affects patients' perceptions of their disability' (Smith 2000: p53). Within this study there was little evidence of acknowledgement that the individual with MS was likely to have a greater knowledge of their degree of physical impairment than that which could be achieved by a physician observing them in a clinic (Morris 2002).

When accounting for individuals' experiences of types of pain which are resistant to treatment, links will often be made with psychological factors. In the case of 'phantom limb pain' clinicians will frequently use personality as a rationale to explain amputees' phantom limb pain. Research into the experience of phantom limb pain, Whyte and Niven (2001) argue is commonly designed and conducted with an implicit assumption that psychological factors play a causal role in phantom limb pain. This, they believe results from clinicians experiences of not being able to help or cure people who experience such pain persistently. In contrast, in their study of 315 people who had
undergone limb amputation it was found that 'psychological distress é did not explain any of the variance in phantom limb pain and that 'performance difficulties' were more correlated with pain than 'negative effect' i.e. depression (Whyte and Niven 2001: p944).

'Acceptance of disability' and mental health

When a causal link between impairment in itself and mental health has been called into question by the research evidence, some researchers have looked to disabled people's attitudes to impairment for an explanation. A study by Leger et al (2002) which examined the attitudes of disabled people to their impairments concluded that psychological difficulties experienced by people with a range of impairments were not correlated with degrees of impairment nor with whether the impairment was degenerative, acquired or congenital. It was argued that 'a lower level of acceptance of disability was significantly associated with more anxious and depressive symptoms' (p208). Such a view is supported by Pilgrim (2005) who claims that people differ in their psychological adaptation to losing or losing the use of limbs. While some people will develop a prolonged grief reaction to their loss or their personality is affected, other people will not react in these ways.

A study of people with rheumatoid arthritis which aimed to measure 'psychological well being' found a range of difficulties experienced with pain, activity and mobility, medication, social support, information and work. A lack of self confidence and depression were found to be common among the participants and the study concluded that these feelings were linked to the frustration at having rheumatoid arthritis (Read et al 2001). This study however appeared to pay little attention to the possibility that 'depression and lack of self-confidence' may be causally linked to the context in which someone experiences rheumatoid arthritis rather than the condition itself.
A minority of researchers who have found little correlation between the extent of impairment and depression have emphasised the social context of the experience of impairment. A study of people with spinal cord injury by Fuhrer et al (1993) found no relationship between the degree of impairment and depression and concluded that 'depression is associated with restrictions in social role performance that stem from the interactive influences of the environment' (p259). Research by Krause emphasised that in addition to the need for people with spinal cord injury to maintain their health and avoid secondary conditions, there are adjustments to be made to family and interpersonal roles, added financial pressures and a likelihood of job loss. Such changes may take an emotional toll above and beyond that resulting from the sheer magnitude of physical impairment (Krause 1998). Strained relationships between able-bodied persons and disabled persons are common (Murphy 1990, Lenney and Sercombe 1992) Non-disabled people may not comprehend a persons impairment and fail to cope with the ensuing complexities and ambiguities (French 1994). Negative interactions with others results in the socially engendered undermining of a person’s psycho-emotional well being (Thomas 1999).

PART TWO: A SOCIAL MODEL PERSPECTIVE ON THE MENTAL HEALTH SUPPORT NEEDS OF PEOPLE WITH PHYSICAL IMPAIRMENTS.

In Britain, arguably the most significant turning point for the disabled person's movement was the formation of UPIAS (Union of Physically Impaired Against Segregation). Following its formation in the mid 1970s UPIAS fought to change the definition of disability from one of individual tragedy to one of social oppression and paved the way for the development of the social model of disability (Davis 1993). Arising from the experiences of disabled people themselves, and borne out of the collective
experiences of disabled people, the social model of disability thus challenged the way
disabled people had historically been defined and controlled by the experts who
manipulate disability policy (French and Swain 1997).

The genesis, development and articulation of the social model by disabled people
demonstrated a rejection of the individual model of disability. Within the individual model
the 'problem' of disability is located within the individual and the cause of the problem is
viewed as stemming from functional limitations or psychological losses which are
assumed to arise from disability (Oliver 1996, Crow 1996). Both points are underpinned
by what has been described as the personal tragedy theory of disability which shall be
discussed further in Chapter Two.

In contrast to the medical model, the social model of disability shifts the focus
from impairment onto disability, using the term to refer to disabling social, environmental
and attitudinal barriers rather than a lack of ability. Impairment is defined as the
functional limitation(s) which affect a person's body with disability being defined as the
loss or limitations of opportunities resulting from direct and indirect discrimination.
Literature using a social model approach thus defines impairment as a permanent
feature or attribute of an individual i.e. their physical condition. Disabled people are
therefore those people with impairments who are disabled by society and attitudes
towards disability that prevail within it (Morris 2002).

Since the early 1990s, a number of disabled people, in particular disabled
women, have sought to extend the social model of disability (Swain and French 2000).
Developments have been suggested which it is argued are needed in order to make the
social model more adequate and relevant to disabled peoples lives with critiques
centring on the inclusion of impairments and personal experiences within the social model (Morris 1991, French 1993, Keith 1994, Crow 1996). In arguing for a new approach which acknowledges that people apply their own meanings to their own experiences of impairment, Crow writes of the need to recognise that disability and impairment work together and that a renewed social model needs to focus on both the external and internal constituents that they bring to the experiences of disabled people (Crow 1996). The inclusion of impairment has been rejected by Finkelstein (1996) who has claimed that the effect of considering the personal experience of impairment is to dilute the effectiveness of the social model and can only be acceptable if it assists in galvanising the broader struggle for social change. Likewise, Oliver warns of the danger in emphasising the personal at the expense of the political, claiming that most of the world still thinks of disability as an individual, personal problem (Oliver 1996).

Women with physical impairments and self image

Many disabled people have written about difficulties in their everyday encounters with non-disabled people. The literature suggests that interactions between disabled people and non-disabled people often occur in situations in which they are seen as dependent and negatively different. In addition it is argued that the attitudes of non-disabled people towards those who are can impact on self image and self worth (Morris 1989, 1991, Keith 1996). Efforts to adopt a positive sense of self may be thwarted by the devalued statues that are often ascribed to people with impairments. In failing to comply with cultural standards such as normality, their position has been likened to a pervasive, indeterminate limbo like state of being in a world that is the antithesis of everyday life (Murphy 1990). In a study that examined the experiences of women with spinal cord injury Morris (1989) argued that it was the attitudes and comments of non-disabled people towards disability that made women feel disabled in a way that the
disability itself did not. For women without impairments who experience disabling events later in life, Meekosha (2004) believes that their suddenly changed status will create major conflicts in their expectations and self image, reinforced by the public's perceptions of them as disabled.

As a woman with an acquired spinal cord injury, Keith (1994) believes that while people may be genuine in their wish to be friendly, their smiles affirm her status in their eyes as someone they are glad they are not. While people with more substantial physical impairments may use a wheelchair, which to them represents a level of mobility and independence, Keith suggests that among non-disabled people it is a minority view to perceive it as a piece of liberating equipment. For many non-disabled people Keith believes that a wheelchair symbolises a range of negative attributes which equate to dependence, need, sickness and infirmity of body and mind.

A small scale study by Tighe which examined the meaning of health and disability for a small group of women with physical impairments concluded that 'the most compelling feature of their narratives was the pressure to define their health by able-bodied standards' (Tighe 2001: p511). These women's accounts of their lives and how they made sense of them were dominated by the need to struggle against dominant social perceptions of disabled people as abnormal, sick and worthy of pity (Morris 2002). Attention is drawn by disabled people to the assumptions held commonly, both by professionals and the general public that physical impairment results in a life that is of such poor quality it is not worth living. Awareness of such attitudes can be stressful and undermining and in the long term may have an impact on an individual's mental health (Morris 2002). A study by Marris which examined the experiences of women living with chronic illnesses highlighted how they felt silenced. Many women described
the difficulties they faced in articulating their ‘physical pain and weakness’ without colluding with a sense that their lives were not worth living (Marris 1996). This view was supported by Wates (1994) who, based on her personal experience of living with Multiple Sclerosis, believes that some disabled people hide their feelings about their experiences of impairment and disabling barriers, feeling a need to reassure others and often believing that their acceptance is conditional. These findings highlight the lived experience of disability in the context of interpersonal relationships, demonstrating the significant emotional work disabled people can be engaged in when faced with disabling attitudes.

Morris argues that the attitudes and prejudices of other people can impact on the lives of disabled people and that disabled people have to establish their own values about their lives and insist that non-disabled people recognise these. Disabled people, according to Morris need to have the courage to say that there are awful things about being disabled as well as the positive things in which disabled people take pride. In order that the lives of disabled people are seen in a balanced way by non-disabled people, they must demand the right to be heard when they assert that there are wonderful things about being disabled. It is disabled people themselves who must be able to define the negative aspects of the experience of disability and not the professionals with whom people have contact (Morris 1989). While increasingly disabled people have spoken about the disabling attitudes they experience there has been little articulation of the feelings that these invoke. The experience of disabling attitudes may well cause feelings of anger and distress but there is scarce recognition within the literature of the short or long term psychological consequences of such experiences (Morris 2002).
It is not strangers alone who can affect disabled people's self image by their reactions to physical impairment. Whilst family may provide a source of support to the individual, their reactions to physical impairment may cause pain and upset to the person affected. Morris claims that while some families may feel that the individual's acquired impairment has disrupted all of the family members lives, other families will adjust and adapt to the new circumstances with the individual's impairment becoming an integral part of family life (Morris 1989, Smith 2003). The reactions of friends, in particular to the onset of impairment, can, it has been argued, be equally varying. Whilst relationships with friends may become stronger in some instances, women within Keith (1994) who described their experiences of acquiring a physical impairment spoke of how many friends were unsure how to react to their changed physical appearance and stayed away. The responses were described as being emotionally hurtful to the women concerned and often impacted on their self image (Keith 1994). Similar findings were reported in a study of women with Multiple Sclerosis who described how following diagnosis, people who they had believed to be friends ceased contact (Miles 1988).

Within a small scale study that I undertook in 2003, one of the topics discussed was the impact of physical impairment upon relationships with friends and family. The women who had acquired their impairment described how they felt friends were unsure about how to respond to their change in circumstances. In some instances it was felt that friends did not feel comfortable being either in the presence of or associated with someone who had a visible impairment (Smith 2003).

**Access to the environment**

In addition to negative attitudes towards impairment, people with physical impairments may often be confronted with inaccessible environments. Inaccessible environments and barriers to access have been problematic for people with physical
impairments for several decades and creating a barrier free environment has a firm physical dimension which is generally well understood. While improvements in environmental access have been made as a result of the staged implementation of the Disability Discrimination Act (1995), barriers to access persist for people with physical, sensory or visual impairments particularly in relation to public transport and older buildings. Since October 2004 service providers have been required by law to make 'reasonable adjustments' to physical features of premises in order to overcome barriers to access. The Act has received criticism for not providing a definitive definition of 'reasonable' and allowing service providers too much flexibility when considering the changes required i.e. the financial and other costs of making adjustments or the amount of disruption likely to be caused in undertaking necessary adjustments. This has resulted in a significant number of public places and buildings remaining inaccessible to people with more significant mobility impairments (and people with visual or sensory impairments) two years after the duties on service providers became law (DRC 2006).

Access to public transport remains one of the greatest inequalities facing people with physical impairments. While there have been regional improvements in the accessibility of public transport, provision has remained patchy and under the DDA public transport is not required by law to be fully accessible until 2017. Transport schemes such as Dial A Ride that are used predominantly by people with mobility impairments (and older persons) are with few exceptions stretched to capacity and require booking in advance, thus reducing spontaneity. Furthermore, the majority of such schemes limit the distance and number of journeys that an individual can make (Community Care 2006).
There is however a psychological dimension needed to the changes that require careful consideration and where good inclusive design will send positive messages to disabled people. With the technology and design of the 21st century that is available there is, it is argued no reason why people with mobility impairments can not have the same access to public places, buildings, transport etc as non-disabled people. While being able to use the environment is about being able to get about, at a deeper level it is about a sense of belonging. Therefore, until the environment fully supports people with impairments in full participation with their dignity and pride intact then this sense will continue to evade them (Napolitano 1996).

Like disabling attitudes the experience of disabling environments is likely in the long term to impact on an individual's mental health but there is little within the literature that examines this area (Morris 2002).

**Accessing service provision**

One of the primary aims of this research is to examine the experience of using mental health services for women with physical impairments, but to do so requires firstly an examination of accessing service provision. This section examines issues around accessing service provision, looking at community care services, access to healthcare support (in particular that provided by a General Practitioner) before looking at access to mental health services. An examination of issues concerned with accessing services such as personal care and healthcare support I believe to be of relevance because difficulties with, or an inability to gain access to such provision may have the potential to impact on mental well being.
The unequal relationship that exists between professionals and disabled people where the former have the power to define the needs of the individual and how they will be met has been written about by disabled people (Davis 1993). The processes of assessment to ensure that basic needs are met are frequently difficult and slow and disabled people are often left feeling powerless. From the disabled person's point of view, the process is frequently characterised by all-powerful professions and their organisations determining the nature of an individual's impairment, the needs associated with it and the level of assistance for which the person qualifies (Morris 2002). A participant within Morris’ study (2004) described how, having acquired her spinal injury, all decisions relating to her care needs were made without any consultation with herself and that she felt everything was taken out of her control.

Olkin writes of how disabled people, while wanting to deny the extent of physical dependency, find that in order to obtain assistance with their daily lives, (i.e. personal care needs or daily living activities) weakness and a lack of ability to cope have to be stressed. People with physical impairments will often have to spend large amounts of time and energy seeking information about how best to meet their needs and advocating to get them met. The bureaucratic and attitudinal barriers that are likely to be encountered in the process can be stressful for the person concerned and create feelings of anger and helplessness (Olkin 1999). Individuals with communication difficulties may find it harder to get their needs met which subsequently may have consequences for their mental health. A study of social exclusion among young disabled people found that many who did not use speech to communicate reached the end of their formal schooling without proper assessment of, or provision to meet their communication needs as they entered into adulthood (Morris 2001). Developments in communications technology over recent years have had a significant impact on the lives
of some disabled people, through the possibilities that have been created. People who are able to hear and understand but unable to produce speech are now able to express themselves verbally by means of an artificially produced voice, thus enabling them to be heard and understood by others (Wilson 2003).

From the literature, evidence suggests that the medical and associated professions sometimes treat people with physical impairments in ways that are potentially damaging to their mental health and this for some individuals is particularly the case when physical conditions are not recognised. Participants within Morris' study stated that they did not want professionals to assume that their mental health experiences were necessarily caused by their physical impairment. However, they did want recognition of the fact that both impairment and disabling barriers may have an impact on mental health (Morris 2004). Burne's study of people's experiences of living with ME found that many had experienced a failure by health professionals to recognise the physical nature of their symptoms. For some, the way they had been treated was said to have created emotional distress and mental health problems (Burne 2002).

Research by Begum aimed to explore disabled women's experiences of healthcare with a particular emphasis on GP contact. Her study found that GPs reaction to impairment often got in the way of responding to healthcare needs and whatever symptoms the disabled woman presented with these were often automatically attributed to the impairment per se. Incidences of positive experiences were low and GPs often refused to believe that the women had physical symptoms, choosing instead to interpret such symptoms as psychological in nature. The study found that this was particularly evident among women with MS or ME, conditions that can prove difficult to diagnose and GPs therefore assumed the women's symptoms to be rooted in psychological
difficulties. Within Begum’s study one woman described how her GP had on two occasions tried to admit her to an acute psychiatric ward on the grounds that she was hysterically suicidal when in fact she was experiencing an arthritis flare up and was in acute pain (Begum 1995).

In Lonsdale’s study the experiences of twenty women of living with a physical impairment were examined. In the study women reported that health professionals with whom they came into contact, overwhelmingly regarded 'the disability' as the main problem. By contrast, the women themselves did not believe this to be the case (Lonsdale 1990). Within the small scale study that I undertook (Smith 2003) the eight women interviewed described how their GPs automatically attributed the feeling of being depressed to their physical impairment. One woman who was born with her impairment described her difficulty in getting her doctor to accept that the depression she was experiencing was not directly linked to her impairment but that the GP immediately pointed to that as the cause. Another woman conveyed her frustration at her GP's apparent refusal to accept that she was suffering from an eating disorder until an acute hospital admission resulted from a very low body weight. By this time both her physical and mental health had suffered and the interviewee described the anger she felt at having to experience such attitudes from both the GP and other medical professionals. Better communication, improved access to information and a recognition by GPs of disabled women's expertise in their own health needs were all identified as key factors in ensuring that contact between disabled women and their GPs was constructive and beneficial (Begum 1995).

Research undertaken by Pelletier (1985), that examined mental health service provision for people with significant physical impairments, concluded that there were
several major barriers to accessing adequate mental health services such as access difficulties, financial costs and attitudes to disability. Morris suggests there has been little recognition of the issue since then (Morris 2002) and a comprehensive search of the literature for material on this topic area would appear to support this conclusion. A fragmentation of needs across services (physical disability and mental health) was reported frequently in Morris (2004) study, as at its worst a stark physical division of services and described by one participant as 'having to go to one town for my mind, another for my body'. A key theme to emerge from Morris' study (2004) was that people did not want to be excluded either from mental health services because of needs relating to their physical condition, or from physical disability services because of mental health needs. Participants expressed a wish for services that saw them as a 'whole person', addressing both mental health needs and those relating to physical impairment. The need for services and professionals to communicate and work together was seen as paramount as was the need for easy access to flexible services that addressed individual needs (Morris 2004).

The division between physical disability and mental health services has been highlighted by Begum which she considers to have resulted in a failure to meet the needs of people with physical impairments who have mental health support needs. Outlining her experiences as a disabled woman with mental health support needs, Begum describes how statutory services pushed her from pillar to post. Provision of accommodation in mental health supported housing was refused because of her physical impairment and services for disabled people were unable to provide help as she self harmed. Her experiences of the voluntary sector were no more positive: a self harm survivors' conference was held in a location that had no access for a wheelchair user and a Mind counselling service did not feel they had the experience to work with a
disabled person (Begum 1999). Other women service users, in contrast have spoken of a positive experience of the voluntary sector, (Davis 1993, Morris 2004) welcoming the flexible, innovative approaches and sensitivity offered which is often lacking in services provided by the statutory agencies (Kohen 2000, Smith 2003).

A Mind publication provides examples of a wide range of services and initiatives including self help groups or drop in centres many of which have developed outside of statutory service providing agencies in response to a perceived failure by women of traditional health and social service provision (Mind, 2001). Ease of access to services, the ability to share experiences and enabling women to take control over their lives were characteristic of this type of provision. Such services acknowledge that the solution to women's mental health difficulties must be found through addressing practical needs (such as housing and finance) as well as providing the opportunities for counselling and other psychological supports.

In recent decades a growing number of voluntary organisations have offered a valuable service through the provision of counselling and befriending schemes. The growing demands placed upon them however, frequently with little financial support often results in their continued existence being threatened and service users being uncertain as to whether the valued support will continue (Mind 2001).

A number of interviewees within Morris' study (2004) had turned to self help or complementary therapies when statutory disability and mental health services were felt to have been inadequate in meeting their needs. Among the interviewees mixed experiences of both self help groups and complementary therapies were reported but the key characteristic that people appreciated within these settings was that they felt
both accepted and listened to (Morris 2004). A review of self help interventions which looked at the efficiency of self help approaches found that whilst popular with many people with mental health support needs there was insufficient evidence to draw firm conclusions about their efficacy (Lewis 2003).

Recent years have seen a growing recognition of the value of self help groups and peer support. A recognition that people living with chronic conditions, whether associated with physical or mental illness, benefit from improved information, peer support and training in self management was documented by the Department of Health in *The Expert Patient: A New Approach to Chronic Disease Management* (DoH 2001). Within two years, 144 Primary Care Trusts had joined the Expert Patients Programme which aims to provide training in self management programmes for people living with a range of physical or mental health conditions.

**Attitudes towards impairment**

The literature suggests that negative attitudes of mental health professionals towards people with a physical impairment can be attributed to a lack of contact with people with a physical impairment and little awareness or understanding of physical impairment itself. An unfamiliarity with physical impairment can, it is suggested, result in disempowering attitudes and create distress for the person concerned. This is particularly so when mental health professionals make decisions about service users but do not involve them in the decision making process. A lack of involvement in treatment decisions has been a source of dissatisfaction among non-disabled users of mental health services for many years (Begum 1995, 1999). Morris suggests that for disabled mental health service users, not being involved in decision making about their care may have additional consequences i.e. if the effects of prescribed medication on
the person's physical impairment are not considered. Also there may potentially be
difficulties in accessing and using mental health services if needs relating to the
individual's impairment are not recognised and addressed (Morris 2004).

Women participants within my 2003 study believed that mental health
professionals overwhelmingly subscribed to the medical model approach to disability
and perceived the women's impairment as a tragedy. Participants felt strongly that the
practice of being passed around services and different workers within mental health
services should not be permitted. Based on the women's experiences, my study
highlighted the need for mental health professionals to have both an increased
awareness and understanding of physical impairment. Additionally, it concluded that
until they began to consider alternative non-medical based models then women with
physical impairments would be unlikely to receive a service that truly addressed their
mental health difficulties, (Smith 2003). Research by the Samaritans which was
concerned with looking at the impact of physical impairment upon mental well being
concluded that the effect a physical disability has on an individual's mental health is
being neglected (Samaritans and McNamara 2000). In research undertaken by some of
the larger physical disability organisations, it was found that people who had
experienced the onset of impairment felt they were handled insensitively by statutory
agencies. In addition they were given little guidance regarding sources of help for
emotional problems (Stroke Association 2003).

Morris' study of spinal cord injury among women found many to be critical of the
way in which medical staff ignored the situation in which they suddenly found
themselves and the emotional aspects of their change in circumstances were given
scant attention. Emotional experiences were overwhelmingly ignored and the emotional
needs of the women were inadequately addressed (Morris 1989). A study of women’s experiences of acquired physical impairments found ample evidence that women experienced major psycho-social problems including depression, stress or lowered self esteem but that these were largely neglected (Nosek and Hughes 2003). Within Morris' study, people with physical impairments who had experienced in-patient psychiatric care found it was often characterised by a lack of personal assistance being available from nursing staff, a lack of disability awareness and inaccessible ward environments. Medication prescribed for the physical condition, often for pain relief was withdrawn on admission and was not available when needed (Morris 2004).

CONCLUSIONS

This chapter has provided an overview of literature relevant to the topic area of women, physical impairment and mental health. It has shown that over the past two decades the mental health support needs of different groups of women have increasingly been recognised. However, a significant gap in the literature was identified in the lack of attention that has been given to recognising the mental health support needs of women with physical impairments. Where research had been undertaken or where authors had published in this area, this was by women with physical impairments who either had an interest in and/or experience of accessing mental health services. Therefore, I consider it important that the thesis addresses this existing gap.

Part One has shown that the small number of studies which have examined the mental health experiences of women with physical impairments have focused overwhelmingly on depression and its association with specific impairments. Within these studies there has been little consideration of mental health needs that may not be linked to the woman’s impairment and attention has seldom been given to the social
and economic factors which may be associated with impairment. The lack of attention given within the studies to the views of the individuals with physical impairments, either in relation to their mental distress or their experiences of using mental health services has been highlighted. Again, these are all areas that the thesis wishes to explore.

Part Two has examined literature from the early 1980s onwards which has adopted a social model perspective in considering the mental health support needs of people with physical impairments. It has demonstrated the wide range of factors which people with physical impairments identify as either having impacted on or having the potential to impact on mental well being.

It has shown for example how the attitudes of able-bodied people towards people with a physical impairment can affect self worth. Similarly, efforts to adopt a positive self image may be impeded by the devalued status commonly ascribed to people with physical impairments. Linked to this the chapter has highlighted how assumptions among the general public and professionals within health and social care organisations, that living a life with a physical impairment equates to a life of poor quality have the potential to impact on mental well being. Where women have spoken in the literature of their experiences of working with mental health professionals, their belief in the need for mental health professionals to have a much greater awareness and understanding of physical impairment has been consistently asserted.

Whilst in recent years people with impairments have begun to talk about their experiences of disabling attitudes there has been little recognition within the literature of the feelings that such attitudes may invoke. Similarly, more recent literature provides evidence of attention being paid to the impact of living with a physical impairment upon relationships but the short or long term psychological consequences that may result
have largely been ignored. Part Two has further highlighted the difficulties that people with physical impairments have encountered in accessing the environment over several decades. However, to date there is little literature which examines from the perspectives of people with impairments any ways in which the implementation of the DDA is considered to have impacted on their lives. Within my thesis I aim to examine each of these areas and in so doing endeavour to make a small contribution to filling in significant gaps in the literature and research studies that currently exist.
CHAPTER TWO

PHYSICAL IMPAIRMENT AND THE CONCEPT OF ‘LOSS’

INTRODUCTION

I considered it important to explore the literature relating to the concept of loss because in more recent literature, a number of disabled people have described the experience of disability as being enriching. Further, disabled people have talked about how becoming disabled has opened up new and satisfying opportunities that might otherwise not have happened (Morris 1989, Vasey 1992) Individuals with sufficient resources may have more time for interests and hobbies. Also they may gain a more interesting perspective on life and in finding society’s expectations difficult to satisfy they may legitimately avoid them (Swain et al 2003). This contrasts markedly with established theories of loss which claim that the experience of impairment is a tragedy and that disabled people need to grieve and mourn their impairments.

Where theories of loss have been examined within the literature on physical impairment and mental health, they have commonly suggested that individuals will need to make psychological adjustments if they are to come to terms with their impairment (French 1994, Oliver and Sapey 1999, Hurst 2000, Morris 2002). This has been augmented by grief and stage theories which predict that disabled people are expected to grieve and express feelings of anger and denial before they can become psychologically whole again (Lenny 1993, Reeve 2000). This chapter reviews literature relating to physical impairment and the concept of loss.

It firstly reviews some of the literature which has examined the concept of loss from an established perspective before discussing the literature which is critical of loss theories. Within this body of literature a number of alternative approaches are examined
which have been presented as providing an explanation of how individuals respond psychologically to physical impairment.

Predominantly within the literature on 'loss', disabled people are viewed as a homogenous group and my literature search was unable to locate any material that considered specifically the notion of loss in relation to women with physical impairments. Equally within the literature there is little distinction made between people with less severe impairments and those with impairments defined as life limiting or progressive in nature. Neither is there any differential made between the experience of 'loss' for individuals born with a physical impairment and those who acquire their impairment at some stage in their life.

**THEORIES OF LOSS**

Established theories of loss have been based on the assumption that people with physical impairments will need to adjust to their life changes because becoming disabled is psychologically devastating. Grief and stage theories state that the tragedy of impairment can only be resolved by grieving the loss and going through a period of mourning akin to that of bereavement. By adopting this approach the individual is expected to go through stages of denial, anger, fear and bargaining before finally reaching the recovered stage of acceptance of impairment (Sapey 2004). In a study by Weller and Miller (1977) that examined the process of rehabilitation in people with a significant spinal cord injury, it was suggested that the acquisition of a spinal cord injury was likely to give rise to psychological reactions similar to those of the mourning process and that an adjustment to the onset of disability requires a process of mourning. The study concluded that the initial reaction of 'shock' is followed by 'denial' or despair that any recovery is possible, leading to anger at others and finally to
'depression' as a necessary preliminary to coming to terms with diminished circumstances. This 'acceptance' or adjustment may not be reached until one to two years later (Weller and Miller 1977, Segal 1989).

In his paper which looked at ways in which a variety of health and welfare professionals worked with disabled people, traumatic loss was defined by Berger (1998) as among other things 'being disabled'. The phrase 'traumatic loss and disability' was used in a way that combined the two and which made the assumption that to be disabled equated to having suffered a loss. An initial denial that loss has occurred was suggested by Berger to be common as people's ability to perceive the reality of their situation was likely to be impaired (Berger 1998). This view was supported by Webb who stated that:

'é grief follows inevitably from disabilityé ..all disability involves loss and if grieving is not experienced then it will be hard for other, more obvious gains to be made'

Webb (1993: p202)

Disabled people can, in such circumstances Lenny (1993) believes, find themselves in a 'catch 22' situation. Expressions of contentment and happiness following disablement are often perceived as representing a form of denial (Lenny 1993). People who have acquired their impairment in particular, run the risk of being regarded as abnormal and in need of psychological guidance (Oliver 1995).

**Criticism of theories of loss**

The central role of theories of loss in informing the individual model of disability, in which the problem of disability is located firmly within the individual has resulted in few writers within the disability studies field considering them to have any merit, and a
number of general criticisms have been levelled at them (Sapey 2002). Theories of loss, according to Oliver and Sapey (1999) implicitly picture the individual as determined by the things that happen to him or her and suggest that adjustment to disability can only be achieved by working through a number of fixed stages. Further, the way in which adjustment is portrayed predominantly as an individual phenomenon and a problem only for the disabled person, results in the family context and the wider social situation being neglected (Oliver and Sapey 1999). In reviewing the literature on a stage model of adaptation after the experience of a traumatic event, Silver and Wortman (1980) found little evidence to support it. Further, individual psychological adjustment studies have been criticised for their failure to acknowledge the repercussions of living within a society which contains a whole set of beliefs and practices about disability (Abberley 2001).

Theories of loss have, over the past decade attracted significant criticism from opponents who have rejected the assumption that disabled people (with acquired impairments) will inevitably need to adjust to their life changes. A dismissal of the possibility that a disabled person might not experience loss and an assertion that they need to adjust in this way indicates, Sapey believes, an ideology of superiority on the part of non-disabled people (Sapey 2004). Such assumptions, critics argue, are a product of the psychological imagination and constructed upon a bedrock of non-disabled people’s beliefs about what it is like to experience impairment (Oliver 1996, Reeve 2000). That a disabled person is assumed to have suffered a loss is described by Finkelstein as ‘a value judgement based on an unspoken acceptance of the standard being able bodied normalcy’ (1980: p12). Critics believe it to be the fear of non-disabled people, and their perception of impairment as a form of death that accounts for the dominance of the theories of loss within the psychology of disablement. The depth of
this fear, it is argued runs so deep that it becomes almost impossible for disabled people to convince non-disabled people that this is not the case (Abberley 1991). In developing a critical approach to practice within human services there is a need, Sapey believes, for non-disabled people to reflect on their fears of disablement and to listen to and learn from what disabled people are saying, i.e. that the onset of impairment will be experienced in as many different ways as there are people experiencing it. By viewing impairment as necessarily resulting in a loss which requires individuals first to grieve and then to adjust, professionals, it is argued, are unlikely to be able to provide help that is of value to disabled people (Sapey 2002, 2004).

A failure to give consideration to the social dimension of disability and an assumption that the sole response to impairment will be one of a person in loss, have attracted further criticism of theories of loss. Opponents acknowledge that when a person becomes chronically ill or acquires an impairment their lives will be changed in some way (e.g. around future life choices) and that to an extent a theory of loss may be appropriate. However, it is argued that the real problems for most disabled people such as losses within work, social life etc stem from living within a disabling environment as opposed to the experience of impairment itself. Therefore, theories of loss which claim to offer an explanation for personal responses to impairment, fail to offer an explanation for the emotional distress experienced by disabled people living within a disabled environment (Reeve 2000). A more appropriate means of understanding the reactions of people to their change of circumstance is according to Oliver, through viewing the onset of impairments as ‘significant life events’ (Oliver et al 1987). Whilst not denying the impact of impairments, or that people’s experience of life changing injuries might include loss, such an approach it is argued calls into question the implications that established loss theories have for those who do not conform to the stages approach. To
assume that everyone who experiences the onset of impairment will necessarily go through the same stages, or that such stages would lead to recovery without attention being paid to the material and social environment, is also felt to be inappropriate (Oliver and Hasler et al 1987). In viewing the onset of impairment in terms of significant life events, it is suggested that it then becomes possible to include the impact of impairment, social responses towards people with physical impairments and the meanings that individuals attach to what is happening to them (Sapey 2002).

THEORIES OF LOSS: ALTERNATIVE THEORIES

In response to the criticisms that have been directed at established theories of loss, a number of alternative theories have been proposed within the literature which have been presented as providing an explanation of how individuals respond to physical impairment. Each of the theories have in different ways impacted on the ongoing debate surrounding loss and disability.

Within the dual process approach, it is suggested that rather than going through specified stages of grief, people with a physical impairment will shift between a loss and a restoration orientation with either one being dominant at any one point in time. By acknowledging restoration orientation, Sapey believes this helps to explain and include the experiences of disabled people who have rejected the stages approach. Instead of seeking conformity to a particular model, restoration is viewed as an individual activity that is likely to draw on personal strengths and material resources (Sapey 2004). Rather than acceptance being a stage of a process, the dual process theory recognises that fluctuations may occur over a period of time, typically illustrated by anniversaries of events which may trigger an episode of grief. Thompson (2002) claims the approach to be advantageous in that it represents a move away from the narrow psychologistic
approach which presents grieving as a natural process. Furthermore, the dual process approach acknowledges the complexity of the lives that people may lead both before and after the onset of impairment. In addition, the dual process approach Sapey claims, alerts us to a complex web of socio and political factors which interact to make loss experiences far more complex than established theories of loss would have us believe (Sapey 2004).

A study by Oliver (1987) which examined the social implications of Spinal Cord Injury, sought to measure the levels of dissatisfaction that people had with their spinal injury. The study found that levels of dissatisfaction diminished after a period of 6-8 years but that this could not be explained by a stages of recovery process as this did not tally with people's experience. The dual process theory allows us to rethink this as periods of different orientations with restoration becoming more dominant over time, though seldom absent and certainly influenced by other social and environmental factors (Sapey 2004).

A further proposed theory, meaning reconstruction, has been premised on the fundamental argument that when individuals experience a profound loss, they also experience a loss of meaning and disruption of their own life story. The process of grieving within a meaning reconstruction approach is therefore perceived as one of making sense of the loss and reconstructing whatever life means, particularly those areas that are directly affected by loss (Thompson 2002). Neimeyer and Anderson (2002) describe three important aspects to reconstructing meaning after a loss, namely sense making, benefit finding and identity reconstruction. According to Sapey in terms of sense making, whilst most people will ask the question why?, the ways in which the
question is answered will vary according to the individuals psychological disposition, spiritual beliefs and social support systems.

In considering the two latter aspects attention is drawn to Swain and French's discussion of an affirmation model of disability. A range of literature was reviewed in which it was claimed disabled people pointed to benefits that they had derived from being disabled and contrasted this to the dominant view that conceptualises disability as a personal tragedy (Sapey 2004). The way in which some disabled people had not only incorporated disability and impairment within their lives, but in addition had overtly asserted the value of its inclusion within a positive identity is drawn attention to (Swain and French 2000). Within the meaning reconstruction approach the need that people have to establish a positive identity when aspects of their being which contributed to that identity have been lost is acknowledged. Where established individual models to disablement suggest that individuals will need to come to terms with change, in particular with a diminished social role and hence to accept an inferior identity, within the social model the need for attitudes of others towards impairment to change is emphasised. Meaning reconstruction, according to Sapey, appears compatible with this approach in that it does not impose any specific mode of change. Also it recognises that the new meanings that people construct to make sense of their loss are varied (Sapey 2004).

In helping to make sense of the experiential ways in which disabled people have been challenging the notion of disability and impairment as a loss, Sapey believes that the dual process approach offers the most clear challenge to the 'psychological stages' theory of loss. Whilst such experiences Sapey accepts do not deny the consequences or experiences of impairment having tragic circumstances, they seldom match the expectations of a stages approach. Whilst adjusting to a sick role, people do not totally
put their lives on hold but take control as they are able to and incorporate their new self into an existing life (Sapey 2004).

**Experiences of loss: disabled people’s perspectives**

In a rejection of established psychological theories of loss, Oliver (1983) has argued that many disabled people neither grieve nor mourn their impairment and may indeed find the experience of disability enriching. Within literature where disabled people have talked about their experiences of living with a disability, women and men described how becoming disabled had opened up new and satisfying opportunities that may not otherwise have happened or have been achieved (Morris 1989, British Psychological Society 1989, Lonsdale 1990, Keith 1996, Swain et al 2003). Bosnich's (1985) study of women's experiences of Spinal Cord Injury found women to have increased self esteem, having mastered new roles and overcome obstacles to do so. The study found that the injury had provided many of the women with the stimulus to free themselves from constraints imposed by stereotypes, therefore, despite the disability, and sometimes because of it, many women spoke of having achieved a strong sense of self. Sometimes the challenge of the disability itself had allowed the women to gain insights and develop capacities that they might not otherwise have done (Bosnich 1985).

For those individuals who do mourn, Oliver argues that it is likely that they are mourning the loss of their independence rather than the loss of bodily function or appearance, a situation which could be diminished to a large extent by social and environmental change (Oliver 1983). However, based on the literature drawing on women’s views of their experiences of impairment, Campling (1981) argues that many women who acquired an impairment suddenly described their experience as being
profundely disruptive and disturbing. One woman recalled how after the onset of impairment she felt 'she had little left to offer anyone and so avoided people' while another woman described 'a sense of numbed shock, anxiety and loss of direction when I realised that this was it, I was now permanently paralysed' (Campling 1981).

French suggests that people who acquire a physical impairment in circumstances where the onset is rapid are more likely than people with congenital impairments, or those who develop their impairments more slowly, to feel an acute sense of loss. Having lived previously as a non-disabled person, those who acquire an impairment in adulthood are likely to comprehend their disadvantaged status in society more clearly than people who were born with their impairment (French 1994). A study by Sapey (1996) which looked at the issue of loss, explored the social impact of 100% increase in wheelchair use for a group of people in the North East between 1986 and 1995 in which in-depth interviews were conducted with wheelchair users about their experiences. While some participants with acquired impairments believed that people with congenital impairments were likely to have a different experience of loss, having not experienced a sudden realisation of impairment, this was not universally agreed. One woman described how as a young child at special school her impairment did not present a problem as each pupil had a disability and therefore she was not 'different'. On moving to secondary school her differences became more recognised as she was exposed to an able-bodied environment in which she was the sole person with a physical impairment (Sapey 1996). Similar experiences were described by women in Campling (1981).

Marris's study examined women's experiences of living with chronic physical conditions and impairments. The study found that the precise nature of an individual's loss was likely to vary depending on factors such as an individual's particular condition,
favoured areas of work or leisure or personal desires and ambitions. Whilst for Marris it did not matter that she was not able to fly a plane or to become a deep sea diver, it was recognised that for someone else these things may represent a significant area of loss in their life (Marris 1996).

Sapey's study identified other aspects of being disabled other than impairment in which loss may be experienced (such as loss of friends, loss of job). Losing control of what happened after the onset of impairment and being excluded from fundamental decisions, for example, about how their homes would be adapted were described by many participants. Having decision making taken away by professionals was recollected by many of the participants as being a source of frustration and constituted an important area of loss of control for individuals. A further area of loss identified which Sapey believes is seldom recognised by professionals is the price that people with a physical impairment often have to pay with regard to a general loss of privacy and an increased vulnerability in order to receive care services (Sapey 1996).

CONCLUSIONS

This chapter has reviewed a range of the literature relating to physical impairment and the concept of loss. It began by reviewing literature that has focused on established theories of loss before then examining alternative models which have claimed to offer a more accurate portrayal of how individuals respond to living with a physical impairment. The chapter concluded by examining literature on loss from the perspectives of individuals living with a physical impairment.

The chapter firstly highlighted how established theories of loss have been founded on an assumption that people with physical impairments will need to adjust to their life changes because becoming disabled is psychologically devastating. Grief and
stage theories were shown to claim that the δραγέδυο of impairment can only be resolved by individuals both grieving for their loss and going through set stages before arriving at the recovered stage of δεκαντεstå of acceptance of impairment

On a number of levels critics have been seen to argue that established theories of loss do not provide a true representation of how individuals respond to living with a physical impairment. For example, their failure to acknowledge the repercussions of living within a society that contains a whole set of beliefs and practices about disability, and by locating the problem of disability firmly within the individual have led to them being awarded little merit from writers within the disability studies field.

In stating that individuals with a physical impairment will experience loss, theories of loss, critics believe, have been constructed upon a bedrock of non-disabled personâ€™s beliefs about what it is like to experience impairment. In reviewing the literature on established theories of loss it became apparent that little, if any, distinction had been made between the experience of loss for those with less severe impairments and those with impairments of a progressive or a life limiting nature. This topic will be examined within the thesis.

The chapter has highlighted the view that by viewing the acquisition of an impairment as a σημαντικός σεντο as opposed to a δοσός this enables consideration of the impact of impairment and social responses towards people with physical impairments in addition to the meanings that individuals attach to what is happening to them. It has further shown how over recent years, opponents of loss theories have proposed alternative approaches which they claim represent a more realistic explanation of how individuals respond to physical impairment. Whilst the dual process
and meaning reconstruction approaches do not deny there can be negative experiences or consequences of living with an impairment, proponents argue that an individual's response to impairment seldom matches the expectations of a stages approach.

In focusing on the experience of loss from the perspective of people with physical impairments, the chapter has shown that over the past two decades, people have begun to describe how acquiring an impairment has enriched their lives and provided them with opportunities that may not otherwise have arisen. This has been in marked contrast to the established theories of loss which have expected individuals to grieve for the tragedy that is their impairment.

Attention was also paid to an expressed view that people who acquire an impairment are more likely than people with congenital impairments to feel an acute sense of loss. Within the literature there is little that compares the experience of loss for people born with their impairments with those whose impairments are acquired at some stage in their life. The thesis therefore aims to examine whether the experience of loss, if and where it occurs, is experienced differently for women in each category.

Finally, the chapter highlighted how the nature of an individual's loss may depend on a range of factors including the severity and nature of the impairment itself and areas of life that may have been affected by the individual's physical impairment. These areas will also be examined within the thesis.
CHAPTER THREE
COUNSELLING AND PHYSICAL IMPAIRMENT

INTRODUCTION

This chapter focuses on a review of the literature that examines counselling and physical impairment. A review of the material within this area was considered to be of relevance to my research study for a number of reasons.

Counselling as a form of treatment or psychological support has expanded significantly within recent decades and a growing body of literature has emerged which has examined the processes of counselling when working with a wide range of different client groups or circumstances (such as counselling work with children, relationship or bereavement counselling). As a result there has been an increase in the number of people who have turned to counselling to help resolve personal difficulties in their lives. This increase includes people with physical impairments who want access to counselling which meets their perceived needs and which may be related among other factors to stress, relationship problems or issues associated with impairment or disability.

A review commissioned by the Joseph Rowntree Foundation in the early 1990s examined the need for and availability of counselling for disabled people. The review found a strong belief among many disabled people that mainstream counsellors had little experience of working with people with a physical impairment and therefore had little understanding of the issues raised by an acquired impairment. All of the research participants involved felt they would have benefited greatly from access to counselling and emotional support and aftercare at an early stage following onset of their
impairment. Disabled people, it concluded, need access to a counselling service which meets their needs as they perceive them (Social Policy Unit, York University 1992).

In Lonsdale's (1990) study of women's experiences of physical impairment, the majority of women expressed a need for counselling at various stages in their lives. In particular, the onset of impairment was identified as a time when it was felt that counselling would have been welcomed but was seldom offered. Similar views were expressed by women in Morris' (1989) study where she described how the emotional and psychological aspect of acquiring a Spinal Cord Injury was often totally ignored within the rehabilitation process. In my 2003 study which examined the experiences of using mental health services for women with physical impairments, counselling emerged as one of the main areas in which poor experiences were reported, both in gaining access to and utilising the service provided (Smith 2003).

For these reasons a review of the literature that focuses on counselling and physical impairment and research studies was considered to be relevant to my research study.

**Reviewing the literature**

There is a strong link between the literature reviewed in this chapter and the literature reviewed in the previous two review chapters. The counselling literature has drawn heavily on established psychological loss theories. But in recent years counselling responses to disability based on the use of these theories has begun to be criticised for their disempowering nature. Critics have argued that loss theories reinforce the notion that disability is an individual problem caused by impairment rather than recognising the role that society plays in creating and maintaining disability.
COUNSELLING: THE CONTEXT FOR DEVELOPING
A FOCUS ON WOMEN AND DISABILITY

These contributions to the literature have led to demands that approaches to counselling should recognise the potential for oppression within the counsellor-client relationship and should utilise the social model of disability as one of its foundations. In addition, during the past decade a number of changes have been suggested to improve the counselling experience of disabled clients which have highlighted the absence of Disability Equality Training (DET) from counselling training courses. This literature argues for DET to become a mandatory part of all counselling education and training in order that qualified counsellors have a full understanding of the social model of disability and how disability is socially constructed.

The process of securing counselling for people with physical impairments can, the literature suggests, often be problematic and that physical or communication barriers may emerge even before a counselling relationship can be established. An area of debate in recent years both among counsellors and people with physical impairments has centred around whether or not people with impairments should be counselled by counsellors who themselves have a physical impairment. While the evidence suggests that in reality there is usually no choice for the person seeking counselling, the arguments put forward both for and against counsellors with an impairment providing counselling to people with an impairment are considered in this review.

This review considers how counselling is defined within the literature with attention given to the topic of women and counselling. It notes that in comparison with other client groups the body of literature that focuses on working with people with physical impairments is very small. This absence is interesting given that a number of
Defining counselling and its aims

The literature reveals that the outstanding feature of the development of counselling in recent decades has been its expansion. Within the UK the number of counsellors and the general availability of counselling has shown a significant increase since the 1970s (McLeod 1998). A range of factors have been identified as playing a part in this growth. McLeod suggests has argued that caring and 'people' professions such as nursing, teaching and social work provided quasi-counselling until their roles began to be financially and managerially squeezed in the 1980s. As a result members of these professions sought training as counsellors and have created specialist counselling roles within their organisations as a way of preserving their contact with clients. There has also been significant growth in the diversity of counselling practice with counselling being delivered through one to one contacts, in groups, with couples and families, over the telephone or through written materials such as self help manuals (McLeod 1998).

The literature contains a range of definitions of counselling, the variety of which demonstrate the different meanings that it has for different people. Whilst for McLeod counselling is:
'an activity that has emerged within Western industrial society in the twentieth century as a means of promoting and maintaining individualism and the sense of a person as a bounded, autonomous self'  
McLeod (1998: p 3)

For Burke and Streffire (1979) it is:

'denoted by a professional relationship between a trained counsellor and client'  
Burks and Steffire (1979: p14)

An emphasis on exploration and understanding rather than action is provided by the British Association of Counselling who define counselling as:

'an opportunity for the client to work towards living in a way that he/she experiences as being more satisfying and resourceful'  
BACP (1998)

The areas of overlap between counselling and other forms of helping such as nursing, social work and even everyday friendship are highlighted by Feltham and Dryden (1993). The existence of such contrasting definitions and interpretations arise from the process by which counselling has developed. Counselling has evolved and changed rapidly during the twentieth century and contains within it a variety of different themes, emphases, practices and schools of thought (McLeod 1998).

More than four hundred distinct models of counselling and psychotherapy were identified by Karasu but he proposes that there are three 'core' approaches that are
widely recognised: *psycho-dynamic, behavioural and humanistic approach*, each of which represents fundamentally different ways of viewing human beings and their emotional and behavioural problems (Karasu 1986). Psycho-dynamic counsellors have focused primarily on insight, those adopting a humanistic approach aim to promote self acceptance and personal freedom while cognitive behavioural therapists are mainly concerned with the management and control of behaviour (McLeod 1998).

The literature reflects McLeod’s view that the expansion of counselling within the later decades of the twentieth century has been characterised by the provision, under a variety of labels, as a range of competing products which offer the client/consumer more or less the same choice (McLeod 1998). Psychotherapy for example, is sold as an upmarket version of counselling which is provided by practitioners who are highly trained and specialist professionals often with a background in medicine. Within the counselling literature there exists considerable debate over the difference between counselling and psychotherapy. Some writers claim that a clear distinction can be made between the two, with psychotherapy representing a deeper, more fundamental or involved process of change with more ‘disturbed’ clients (Lawrence and Maguire 1997, Miller 2006). Others have argued that counsellors and psychotherapists basically do the same kind of work, using identical approaches and techniques but are required to use different titles in response to the demands of the agencies who employ them (Brearley and Birchley 1994, Dryden and Mytton 1999).

Underlying the diversity of theoretical models, there are a variety of ideas expressed about the aims of counselling and therapy. McLeod, amongst others suggests that these aims relate, implicitly or explicitly to insight, self awareness and empowerment (McLeod 1998).
**Women and Counselling**

A number of contributors to the literature claim that organisations which provide counselling services for women have had a significant impact on the current understanding of women’s psychology and the issues women explore in counselling (Walker 1990, Perry 1995). The development of counselling within women's organisations has been influenced by many factors. In particular, a wish to respond to the 'whole woman' and to move away from relating to the woman as someone defined only in relation to others, so valuing her essentially in her own right and for her own self has been a primary concern (Walker 1990, Chaplin 1999, Kohen 2000).

A second significant strand in the development of counselling over the past two decades has been the establishment of women's self help groups. Self help groups such as Anorexic Aid and organisations such as Women's Aid were started in response to the lack of provision by the statutory services. Community based counselling services within Family Service Units also arose in response to a perceived lack of community based mental health provision. In order for women to make maximum use of mental health services, it is argued that they need to be situated within travelling distances. Women's role as carers for family members and others and the complications inherent in that role and its combination for some with paid work means that geography can be vital in determining whether or not services are accessible (Perry 1995).

A central and essential strand in the development of self help groups has been identified as the belief that the most effective support is given by women who have shared similar experiences, sometimes called survivors (Perry 1995). As such groups have engaged with very complex areas of women's lives, there has been a growing recognition of the need for counselling training for group facilitators (Seden 2003). This,
it is argued is important to ensure that survivors who support other survivors need to ensure that clear boundaries are maintained between their own experiences and those of group members. The necessity for survivor facilitators to be in therapy themselves has also been highlighted demonstrating the important belief in counselling as appropriate for all women as opposed to an esoteric service for the few (Boswell and Poland 2003). The women’s self help movement together with Women’s Therapy Centres have responded to criticisms that counselling is overwhelmingly a white, middle class activity for the well educated and have sought to provide a widely accessible service that is more readily available and widespread (Ernst and Maguire 1987). The significance of Women's Therapy Centres, Perry argues, has been far reaching in that their projects are examples of women working with women, in ways which appreciate, value and validate the characteristics and strengths of women. Within such settings, women are taken seriously and the possibility exists for women's needs and circumstances to be effectively acknowledged and addressed in counselling (Perry 1995). The importance of the environment in which counselling takes place is well documented within the literature (Chaplin 1989, McLeod 1994) and workers within women's organisations consciously make the environment as welcoming and pro-women as possible. Putting women at ease is viewed as being of importance in creating a supportive environment for women who may spend much of their time looking after other people. An emphasis on welcoming women in their initial encounter with an organisation, it is argued, has not been evident in white, male, euro-centric models of counselling where the emphasis is on getting down to business straight away (Walker 1990, Perry 1995).

A major drawback to the provision of long term counselling or psychotherapy is, the literature suggests, the attitudes of funding bodies as through the 1990s onwards,
local authorities, as the main funders of women's organisations, have expected miraculously short term solutions to the difficult situations that women face. In so doing, funders have failed to acknowledge the depth and extent that difficult circumstances have on women and so they can be accused of contributing to minimalising and trivialising women's experience. Moreover, there is an expectation from funders that counselling will only be offered when there is 'a problem' (Perry 1995) and that 'no problem, no counselling' is essentially a fact of life within the public sector (Dryden et al 1981: p21).

Counselling models

In examining the development of feminist counselling and therapy, Walker argues that feminist therapy is concerned with both making the counselling process accessible and comprehensible and committed to an egalitarian relationship rather than one embedded in a hierarchical mode. Encouraging women to trust themselves, to become more assertive and to be able to acknowledge and express anger are also identified as central themes in feminist work. Within feminist counselling and therapy the experiences of women are heard and are neither invalidated or repressed (Walker 1990). Feminism within counselling has resulted, according to Walker, in a far greater awareness of the impact of gender within the therapeutic process. It marks a radical movement away from psychological and mental health services that have had great difficulty in understanding issues basic to women, their organisations and to society (Walker 1992).

McLeod identifies the cornerstone of the development of feminist therapy and counselling as the location of the origins of widespread emotional suffering among women in the gendered nature of social relations. Her study across a population of women who had attended a centre where feminist therapy and counselling was
practised aimed to provide views of its significance so that conclusions about its positive and negative effects could be drawn (McLeod 1994). Feminist therapy informed by a psychotherapeutic approach, Mcleod suggests, has located the primary influences on emotional development as lying in the nature of maternal-infant relations in infancy, with formative effects on the impact of women's unconscious state which have in turn inhibited conscious thoughts and actions. By contrast, feminist therapy informed by humanistic or person centred counselling has focused on how the individual woman has within herself the resources for meeting her emotional needs but that their expression is inhibited by the hostile nature of current interpersonal and social relations. Such therapy has been characterised by a variety of modes of practice ranging from one to one work, to groups led by therapists or self help groups (Ernst and Maguire 1991).

Despite the egalitarian intent of feminist therapy's analysis and practice, within the literature a number of criticisms have suggested that its shortcomings mean that feminist counselling and therapy is unlikely to resolve the inequalities implicated in women's emotional distress. Firstly, the process of feminist counselling arguably has the pathologising effect of defining emotional suffering as rooted in problems in the individual woman's personality (Dobash and Dobash 1992). In addition, despite the self help ethos of feminist counselling, the counsellor-client relationship is viewed as intrinsically hierarchical. This subsequently gives rise to the danger that women in therapy may defer to the counsellors view of the nature of their problems as opposed to being able, possibly for the first time, to express what these are in an uninhibited way and thereby gaining some true resolution of them (McLeod 1994).

Women participants in McLeod's seminal study described how they felt their emotional needs were treated as important and that their experience of therapy had
created a greater sense of self worth and that they felt happier. In contrast with their previous experiences, the women described how they felt that the counsellor genuinely cared about their welfare. A change in the women's emotional state represented a massive achievement, set against the scale of their previous distress and the input of prior relationships and treatment. Though criticisms of feminist therapy were few in this study, some women's experiences suggested that their emotional needs were subordinated by their differential experiences as women from ethnic minorities, lesbian women and so on which suggested that 'feminist' therapy cannot be assumed to take account of the diversity of women's experiences (McLeod 1994).

In addressing the controversial issue of why counsellors should have direct experience of inequality, Burstow argues that it is possible for counsellors to respond in a way that is useful through awareness and sensitivity towards conditions which they may lack first hand experience of (Burstow 1991). However, some of the contributions from lesbian women (Perkins 1991) and black women, (Shah 1989, Birmingham City Council, Women's Unit 1995) suggest that it is only when women organise on the basis of shared experiences of social divisions other than gender that their significance for shaping the emotional well being of the women themselves starts to become apparent.

In concluding her study, McLeod suggests that the practice of feminist therapy should be seen as providing only a partial solution to the problem of securing women's emotional well being. Promoting well being, she argues, should not be walled off as designating a separate emotional state that is only amenable to therapeutic intervention. Realising women's emotional well being, she argues, requires a different, more complex and extensive range of initiatives in addition to feminist therapy that tackle the unequal nature of social relations beyond gender subordination alone (McLeod 1994).
PEOPLE WITH PHYSICAL IMPAIRMENTS AS A CLIENT GROUP:

APPROACHES TO COUNSELLING

As an increasing number of people have turned to counselling in recent years to help resolve personal difficulties in their lives, evidence from literature and research studies has indicated that people with physical impairments also want access to counselling (Lonsdale 1990, Lenny 1993, Etherington 2002.) They may wish to look at childhood traumas, stress, relationship problems or issues associated with impairment or disability and, like able-bodied people, are seeking counselling which meets their perceived needs (Withers 1996, Reeve 2004). Whilst impairment may on occasions be accompanied by chronic or intermittent episodes of illness or pain leading to periods of emotional distress this is not always the case and people with impairments can be emotionally stressed in ways that are not associated with their impairments (French 1994, Morris 2002).

Within the literature on counselling and physical impairment there is an overall consensus that as a client group disabled people have generally not been well served by counsellors and psychotherapists. In addition, a legacy of prejudicial attitudes exists with a dire need to undertake more consciousness raising, training and research. Thus, while some disabled people do manage to find counselling services that are helpful, many others are faced with inaccessible counselling agencies and counsellors who have little understanding of the lived experience of disability (Reeve 2004).

In her book on disability and counselling Wilson cites an example of a woman with a physical impairment who entered into counselling and the counsellors initial desire was to take care of the woman and make her physical condition better. The counsellors' inability to bring about a physical change caused for her a sense of
helplessness and frustration. However, by becoming aware of and acknowledging this, the counsellor prevented not only a mismanagement of the relationship that had been built but was also provided with a glimpse into the woman's ongoing experiences. As a result she could participate in creating common ground for building a fuller understanding of her predicament (Wilson 2003). According to Wilson, counsellors, like other care workers, will often experience an internal struggle between the omnipotent wish to make a difference by appearing strong and able, against the awareness that acknowledging one's own limitations and frustrations are a prerequisite for empathy and understanding. Wilson suggests it is only when therapists are able to let go of their fantasy of being a saviour, that they arrive at a more realistic perception of their role. In addition, they become aware that their task is not to change or improve their client's physical condition, but to participate in a mutual process in which clients will be helped to develop their autonomy. In letting go of the fantasy of control counsellors may, in Wilson’s view, find themselves confronted not only by their clients' helplessness and vulnerability but also by their own. It is the discomfort caused by close proximity to the fragility of human existence that is probably, Wilson believes, the main reason why many counsellors refrain from or are hesitant about working with disabled people (Wilson 2003).

A study conducted by Parkinson (2006) explored the conceptions and attitudes of trainee and practising counsellors towards people with disabilities. It examined how they perceived disability in general and how the counsellor felt they might approach a client with a disability. The study found that of the twenty five counsellors interviewed, 75% viewed disability in terms of tragedy or irrevocable loss. When this finding was fed back to the counsellors they expressed surprise at it as each believed that they were not conscious of this attitude until it was raised within the discussion group. Among the
group there was a general consensus that counsellors attitudes to, and beliefs about, disability should be explored in depth as part of Disability Equality Training (DET) sessions. They thought as well that every counsellor needs to understand the potential strength of influence that disability might bring to bear on the counselling relationship (Parkinson 2006).

According to French, counselling is an area where it is believed professional workers, with appropriate training may be well placed to assist disabled people. However, French is surprised that whereas many disabled people reject the notion that disability is an internal state of body or mind, research studies have shown that many express a need for counselling (French 1994). A comprehensive strategy developed by the Derbyshire Coalition of Disabled People to enhance community based provision was based on seven key needs and priorities formulated by disabled people, one of which was counselling (Davis and Mullender 1993). In Lonsdale’s study of women’s experiences of physical disability, a number of women expressed a need for someone to talk to or for counselling at various times in their life. The onset of a disabling condition was identified as a time when it was felt that counselling would be welcome and this view was particularly expressed by women who had acquired an impairment during adolescence (Lonsdale 1990).

Within the wide variety of approaches that are used within counselling Lenny (1993), has rejected behavioural approaches for use with disabled people because of their assumption such approaches make that any problems encountered by the individual arise from within themselves rather than from society (Lenny 1993). Recent literature provides evidence that many disabled people have increasingly come to confront and reject both general views and professional assumptions that disability is a
problem for impaired individuals. (Morris 1989, Ayrault 2001, Brown and Brown 2003) Instead, they have argued that disability is a problem of a disabling society and that impaired individuals are disabled by a society which is not organised for and takes little account of their needs (Morris 1991, Keith 1994, Marris 1996, Begum 1999). This view has informed notions that while disabled people may need self help groups, social programmes etc, they unequivocally do not need counselling. Yet, as disabled people have begun the collective process of empowerment they have articulated a need for counselling rather than for Occupational Therapists, Social Workers or other individual based professional interventions (Lenny 1993). A psycho-dynamic approach to counselling, Lenny argues, can never provide a basis for understanding the experiences of disability in general and that attempts to use its skills and techniques uncritically may result in more harm being done than good.

Lenny claims that counselling has become an important mechanism in recent years for addressing, if not resolving the paradox between the individual and society. For some disabled people counselling is seen as a way of dealing with the relationship between their individual impairments and a disabling society. For those individuals interested in counselling, Lenny advocates person centred counselling because of its lack of assumptions about how people respond to disability. Person centred counselling, Lenny claims encourages people to explore and express their own thoughts and feelings without intervention or evaluation by the counsellor (Lenny 1993).

In contrast French (1994) believes that cognitive counselling may be a useful approach in working with disabled people. By adopting this approach, damaging thinking patterns (such as a disabled person telling themselves they are unintelligent or unattractive) are confronted, and assistance given in replacing them with more positive
thoughts. Utilising this approach may, French believes, help disabled people who through their life experiences might have developed low self esteem and self confidence. A cognitive approach to counselling may also encourage disabled people to act on their own behalf by expressing their feelings, needs and desires in a self assured and confident way (French 1994).

Disability: a missing element in counselling training

Whilst the expansion of counselling in recent decades has resulted in a steady increase in the number of counsellors in training the number of disabled counsellors or student counsellors has remained consistently low (Withers 1996, Reeve, 2004). Corker’s view is that disabled people generally wish to become counsellors for the same reasons as non-disabled people. Additionally, for some disabled people the desire to become a counsellor may be directly related to personal knowledge, gleaned from stories that disabled people have told of their negative experiences of counselling (Corker 2004). Reeve highlights the high cost of training courses combined with inaccessible teaching rooms and course materials as resulting in the exclusion of many disabled people who have the potential and interest to train as counsellors (Reeve 2000). An increasing need for counselling courses to become accredited and recognised academically has led to more courses being offered within university settings which also potentially excludes disabled students if entry requirements stipulate a first degree. Training courses will often require students to undertake skills practice within counselling agencies and in addition may expect students to have received counselling themselves. The inaccessibility of many training venues together with the high cost of receiving counselling it is claimed further compounds the barriers which may well be encountered by disabled people who would like to become counsellors (Reeve 2004).
The scarcity of disabled students on counselling courses results in disability 'not being present in the room' in the same way that gender, sexuality and ethnicity are (Reeve 2000). Disabled people who have trained as counsellors have reported having to deal with reactions of pity and embarrassment both from prejudiced tutors and fellow students (Withers 1996).

Research shows how little teaching is devoted to issues around Equal Opportunities and Disability Equality Training on counselling courses. (Morris 2002, Corker 2004, Lago and Smith 2004). The training which is part of these programmes has traditionally focused on individual impairment. According to Parkinson this content reflects a remit to 'alleviate' or 'treat' the disabled persons impairment and to make that person as 'normal as possible' (Parkinson 2006). This position it is argued, does little to remove the barriers to physical and psychological exclusion of disabled people and could be seen as perpetuating the negative barriers that such services aim to remove (Beckett and Wrighton 2000).

The assumption that the experience of loss is central to disabled people's experience is, according to Corker, commonly linked to the widespread belief that to be disabled is to have a negative self identity and that counselling then becomes a process of helping disabled people towards a more 'positive' world view (Corker 2004). Using the counselling process to build an affirmative identity it is claimed may pressure clients with hidden impairments to 'come out' before they are ready or willing to do so. Also, it can persuade clients to engage in a narcissistic pursuit of a utopia that does not exist in order to avoid the distressing aspect of their lives (Craib 1994: p198). This, Corker believes can result in the acquisition of a false consciousness that does not stand up to scrutiny in the disabled person's everyday life and is inconsistent with their experience
of oppression. A focus on either a ‘positive’ or ‘negative’ identity within the counselling process can have two effects. Firstly, it is argued that it can complicate the relationship between the counselling process and the balance of power in the counselling relationship in a way that prevents the counselling practice from meeting goals that are truly client centred. Secondly, such a focus will frequently reinforce the medical model assumption that people are their impairments or their experience of disability (Corker 2004). Though a struggle over identity is often on the agenda when disabled people seek counselling, this struggle is not always concerned with impairment or disability (Withers 1996, Corker 1996).

A general lack of approaches in the counselling literature that are informed by the social model together with little or no teaching of disability as an equal opportunities issue in counselling training has resulted Reeve argues in the prejudices and stereotypes which abound in society about disability neither being exposed or challenged by counsellors. This in turn creates the potential for adverse effects on future counselling relationships if counsellors are unaware of their own prejudicial attitudes towards disabled people (Reeve 2000). While the provision of DET would, according to Reeve make counsellors more aware of disability as a social construction rather than an individual tragedy, such provision does create counselling that is empowering for disabled people. To address this Reeve proposes two possible solutions that recognise the potentially oppressive nature of counselling and seek to redress the power imbalance. These are examined below.

**Future directions: naming the oppression**

McLeod (1998) believes that since the late 1970s there has been an increased awareness of the importance of cultural differences between the counsellor and the
client and of the effect this has on counselling practice. For example, within *trans-cultural counselling*, (TCC) counsellors work across cultural boundaries and accept that there is another worldview than their own (D'Ardenne 1999). In recognising the potentially oppressive aspects of counselling TCC actively addresses, according to Reeve, the issues of cultural difference between counsellor and client. In particular it is felt to address any cultural and racial prejudices of the counsellor and how they affect the counsellor-client relationship. Many of the issues covered by TCC such as the reality of prejudice and discrimination in the life of the client are also, some authors argue, appropriate issues to consider when working with disabled clients (Lago and Thompson 1996, D'Ardenne 1999). In its present form TCC does not, Reeve feels, provide a complete solution for working with disabled clients as generally disabled people are not a homogenous group and are likely to be living alone, within families or within communities of non-disabled people (Reeve 2000).

To address this Reeve (2000) advocates the creation of a new approach called *disability counselling* that recognises oppression within the counselling room and incorporates the social model of disability as its cornerstone. With the social model of disability at the centre, *disability counselling* (like TCC) would be 'profoundly social and political as well as personal and individual' (Reeve 2000: p4). Such an approach would challenge disablist attitudes and prejudices in the same way that TCC challenges institutionalised racism within the counsellor. *Disability counselling*, it is claimed will also be aware of the connection between social context and a disability counsellor would be expected to look at disability from a social model perspective. In addition, they would be expected to help disabled clients move away from blaming themselves for being socially excluded. While it is true that not all people with a physical impairment consider themselves disabled (Shakespeare 1996), Reeve strongly believes that counselling
from a social model position is preferable to ignoring the reality of oppression both within and outside the counselling room. Training for this approach would place a strong emphasis on self awareness work on the part of the counsellor to help address the attitudes and beliefs about disabled people which may have been instilled since childhood.

A second proposed solution draws attention to counselling approaches which within the past decade have adopted a social and political rather than a psychological stance. Such approaches have aspired to achieve comprehensive, anti-oppressive practice that offers empowering counselling for all people, irrespective of race, gender, class or disability. These counselling approaches have potentially much to offer disabled people as well as other oppressed and disadvantaged groups within society (Swain and Griffiths 2003, Wilson 2003). Significant emphasis within such approaches is placed on counsellors being trained in areas which recognise the totality of human experiences: political, social and historical contexts in addition to the psychological aspects. Whilst social approaches to counselling are evolving, Reeve believes it is vitally important for disability as a socially created oppression rather than individual tragedy to be represented and included from the outset. In so doing such approaches are more likely to meet the needs of disabled people instead of leaving it to other professionals to make assumptions on their behalf (Reeve 2000).

In advocating alternative counselling approaches for disabled people, Reeve reflects on their potential to be divisive and asks whether another way of differentiating between disabled and non-disabled people is either wanted or needed. Disabled people are not a homogenous group, like others they are multifaceted through ethnicity, gender, class and sexuality (Shakespeare 1996). Therefore Reeve questions whether it
makes sense to offer counselling which emphasises the disabled dimension of a person. Reeve concludes that it is far from clear whether disabled people are best served by a monolithic approach to counselling which addresses specifically the concerns of disabled people or by one of the emerging social approaches to counselling with their holistic view of clients as human beings (Reeve 2000).

Research undertaken by Oliver (1995) aimed to examine whether a specific model of counselling was needed to help disabled people cope with the emotional effects of their disability. The study interviewed counsellors (both able-bodied and disabled) who had worked with disabled people for a minimum of three years. In general terms Oliver found that the counsellors did not believe that disabled people needed to be counselled in ways that were significantly different from any other group.

On balance what emerges from this literature is that there is a need for disability as social oppression to be incorporated into the counselling theories that inform counselling practice. Without this oppression within the counselling room will be sustained, preventing disabled people from the possibility of gaining benefit from their contacts with counsellors (Reeve 2000).

**Access to counselling services for people with physical impairments**

A small number of research studies have examined mental health provision for people with physical impairments (Pelletier et al 1985, Smith 2003, Morris 2004). These studies have agreed that the experience of securing accessible counselling services can frequently be problematic for disabled people. Physical barriers to access are likely to emerge before a counselling relationship can be established as a result of inaccessible buildings, communication barriers or a lack of information for people from
different cultures or ethnic backgrounds (Begum 1999, Morris 2004). Counselling services within the voluntary sector are often located in old buildings where access may be problematic for people with significant mobility impairments. In addition they frequently operate on a shoestring budget and have long waiting lists which it is acknowledged is problematic for all those involved (Reeve 2004). Pressures on voluntary sector organisations have become more acute in recent decades as the government has cut resources for statutory services such as social work and mental health and has come to expect more from the voluntary sector (McLeod 1998, Thomas 2001, Morris 2002). While larger organisations such as the Multiple Sclerosis Society and The Stroke Association offer counselling to individuals diagnosed with those conditions, such provision is not routinely available for people with less common or less recognised impairments (Smith 2003).

For many people with a physical impairment, the literature claims that counselling in the private sector, whilst generally more diverse in its provision, is unlikely to be a viable option due to the high costs involved. Counselling may often take place within the counsellors’ home where access may be problematic for people with a significant mobility impairment (Morris 1994, Lago and Smith 2004). According to Corker there is also a need to think of disability in terms of the indirect consequences of these barriers and those manifested as barriers to training, which can result in disabled people not having access to disabled counsellors even though this would be their preferred choice. For some disabled people this may result in having to work with a counsellor who they may not feel comfortable with but continue with in the belief that having a counsellor is better than no counsellor at all. Equally, disabled people may have little choice except to approach familiar free sources of help, commonly NHS primary care services, which are
associated with limitations on the approaches offered as well as the settings in which they take place (Corker 2004).

Morris’s study (2004) which examined mental health provision for people with physical impairments found that although talking treatments received the highest rating of any services among respondents, it was often hard to find an accessible therapist or counsellor. The study concluded that there was a failure in many instances to comply with the Disability Discrimination Act (DDA) by making reasonable adjustments (Morris 2004). Where physical access to counselling is either difficult or impossible, telephone counselling may be offered as an alternative. However, based on experiences described within the limited research studies that have been undertaken most respondents did not feel this to be an approach that they felt comfortable with or felt helped them to build a relationship (Smith 2003, Morris 2004). However, in my 2003 study I found that a significant number of the women in my small sample spoke positively about the availability of telephone counselling such as that provided by the Samaritans at times of crisis in their lives or when their mental distress was acute.

In addition, for one interviewee in this study the provision of a telephone based crisis service meant that transport issues were not a concern and the availability of someone at the end of the phone twenty four hours a day provided her with a source of reassurance. Telephone counselling also gave the choice to the individual as to whether to disclose the existence of a physical impairment. For another interviewee it prevented, in her opinion, a counsellor making an assumption that her impairment was predominantly the reason why counselling was being sought (Smith 2003: p37).
For people who have communication difficulties the provision of telephone
counselling is unlikely to be appropriate. For the counsellor, the art of listening when
working with individuals who have either communication difficulties or language
impairment is particularly important (Dalton 1994). Developments in communications
technology in recent years have, it is claimed, had a significant impact on the lives of
some disabled people. According to Wilson, the psychological effects of such advances
have yet to be investigated but that for psychotherapy, where communication is the
main tool, technology is of particular interest as it has opened up and continues to offer
new possibilities in working with speech impaired clients (Wilson 2003).

In their chapter on working with people with communication difficulties, Brearley
and Bochley (1994) argue that it is essential for the counsellor to be honest about
whether they have understood what has been said. Equally, it is important that they are
able to concentrate fully on what the client is saying. For people who use non-verbal
communication, anxiety may block a counsellor’s ability to begin to work easily in an
unfamiliar mode. Such anxiety may be recognised by the client and thus block their
ability to use his/her system effectively (Brearley and Bochley 1994). Olkin highlights the
need for counsellors to display sensitivity and be flexible about the parameters of
counselling sessions when working with disabled clients as the effects of impairment
may have the potential to impact on the frequency, timing and length of counselling
sessions. Factors such as the availability of community transport or care assistance
may also influence when a disabled client is able to attend in addition to their punctuality
(Olkin 1999).

A further aspect of the counselling relationship examined briefly within the
literature is that of home visits. Wilson believes this is a sensitive area which requires
the exercise of judgement by the counsellor. For people with severe physical impairments who seek professional help, leaving their home to meet in a neutral place may be very difficult or even impossible in which case home visits are the only viable option (Wilson 2003). The literature suggests that the lack of neutrality brought about by counselling taking place within the clients private space needs to be recognised alongside additional factors such as others sharing the space, unexpected callers and telephone calls. Wilson believes that therapeutic support which takes place within a client's home is a compromise as the home is likely to contain a range of memories and experiences that need to be addressed from a distance. Wherever possible it is argued that clients should be offered uncompromised therapeutic support, but in instances where clients are not able to leave their home this equally needs to be recognised. Simultaneously, the counsellor needs to be aware that home visits have the potential to create confusion and undermine the therapeutic relationship (Wilson 2003).

**Disabled counsellors for disabled people**

Within more recent counselling literature, there has been an emerging debate among both counsellors and disabled people as to whether or not disabled people should only be counselled by disabled counsellors (Reeve 2004). Within Oliver's study, which looked at counsellor's perspectives of counselling disabled people, a range of views were expressed. While some counsellors suggested that a disabled counsellor may be too subjective or too close having had their own experience of disability, others felt that a non-disabled counsellor may be too objective or too distant, having had no personal experience of disability. The able-bodied counsellor, it was suggested, could be accused of not being able to understand what it is like to be disabled and therefore be unable to understand the needs of this client group. In contrast, some counsellors felt that no two impairments or experiences of those impairments would be the same
and that by the very nature of the profession, a good counsellor should be able to empathise with another person whatever the issues raised or differences in life experiences (Oliver 1995).

In my 2003 study, each of the women who had sought counselling had expressed a preference for a disabled counsellor based on a belief that they would have a greater understanding of disability issues. One interviewee had been particularly keen to locate a woman counsellor with a physical impairment, believing that this would provide her with a counsellor who understood and could empathise with the mental distress she was experiencing. A frequently expressed view was that the mental health professionals who were providing counselling were unfamiliar with physical impairment and had little previous contact with people with physical impairments (Smith 2003). Such views were also identified in Morris’s study (2004) which examined the mental health support needs of people with physical impairments. Voicing her frustration one woman interviewee stated:

‘I don’t think the counsellor had any understanding of the chronic pain that I experience and how it can get you down so much’

Participant cited by Morris (2004: p26)

According to Morris, disabled people may express a wish for a disabled counsellor because of the shared experience of impairment and disability. Alternatively they may prefer a non-disabled counsellor, their preference resulting from an internalised oppression which has created a belief that a disabled counsellor will not be as good as one who is not disabled (Morris 2002). Whilst Reeve takes the position that it is not necessary for disabled people to be counselled by disabled people she
recognises that if more disabled counsellors were available within the counselling professions this would improve client choice. For most disabled people who are seeking a disabled counsellor, the existing scarcity means that choice rarely exists (Reeve 2004). There are few counselling agencies that specialise in working with disabled clients. Skylark, (based in North London) and Mosaic, (based in Leicester) are voluntary organisations which provide counselling services to disabled people and are managed and staffed by disabled people. Geographically however, these are localised services and are available only to people with impairments living within the area in which they are based.

Experiences of exclusion from services can have an emotional effect on clients as it serves to remind them that they are 'different' (Reeve 2004). Thomas claims that the psycho-emotional dimension of disability can be further compounded by counsellors who fail to treat their disabled clients with forethought and respect i.e. forethought in moving furniture that would present an obstacle for a person with a mobility impairment. The failure of counsellors and agencies to consider the access needs of potential disabled clients is in part a result of the low number of disabled counsellors within counselling practice (Thomas 1999). In addition some counselling agencies do not consider that disabled people want counselling. When agencies have never come into contact with disabled clients and they fail to recognise the potential barriers posed by inaccessible buildings or information about services being neither culturally sensitive nor available in accessible formats. Reeve suggests there is also a myth that disabled people are counselled 'somewhere else' by experts who have specialist counselling skills to work with this client group (Reeve 2004). As anyone can become disabled at any time through accident or illness such a myth, Reeve argues, defends a counsellor
against having to look at their own fears and vulnerabilities around illness, disability or death.

CONCLUSIONS

This chapter began by firstly discussing a range of literature that has focused on the topic area of women and counselling before then examining literature which is concerned with counselling and physical impairment. Whilst the body of literature that has discussed the process of counselling for women within a wide range of groups or circumstances has steadily grown over the past two decades I was unable to locate any material that focused specifically on counselling for women with physical impairments.

The chapter has shown how over the past decade counselling responses to disability based on loss theories have received criticism both for their disempowering nature and their failure to recognise the potential for oppression within the counsellor-client relationship. Equally, the lack of approaches used within counselling that are informed by the social model have resulted in stereotypes about disability that exist in society not being exposed or challenged by counsellors.

In providing counselling that is likely to be of value to people with impairments the chapter has discussed literature that has argued a need for counselling approaches which utilise the social model of disability as one of its foundations. By moving away from the viewpoint of disability as a personal tragedy and the associated assumption that it has a negative impact on the life of the disabled person this it has been suggested will benefit all disabled clients. It has also shown that in addition to Disability Equality Training becoming a mandatory part of all counselling education and training, attitudes and beliefs about disability should be explored in depth as part of DET
sessions. Attention was drawn to the responsibilities that counselling agencies now have for making their services accessible to people with impairments and the need for counsellors to consider individual needs when working with people with a physical impairment.

Approaches to counselling which during the past decade have recognised the potentially oppressive nature of counselling, for example, trans-cultural counselling or have adopted a social rather than psychological stance have been advocated for their aspiration to achieve anti-oppressive practice and offer counselling that is empowering for all. The chapter has however reflected on whether specific counselling approaches have the potential to be divisive and to emphasise the disabled dimension of clients.

Literature which has debated whether people with impairments should be counselled by people with impairments has also been examined. Whilst studies undertaken have looked at counsellors views of people with impairments only being counselled by counsellors with an impairment there is little evidence of people with impairments having contributed to this debate. Attention has been drawn to the lack of availability of trained counsellors with a physical impairment often as a result of the barriers to counselling training that exist. Preferences to work with a counsellor with an impairment it has been shown are therefore unlikely to be met and individuals are faced with the reality of a choice not existing. Within my thesis each of these topic areas will be examined.

The chapter has further shown that over recent decades people with physical impairments have began to express their wish to receive counselling and like able-bodied people have sought counselling which meets their perceived needs. The importance of recognising that people with physical impairments may also be parents,
friends or siblings and as such are likely to be subject to the same range of emotions and difficulties as able-bodied people has been asserted. In two studies that examined experiences of using counselling services for a group of individuals with physical impairments poor experiences were reported. Physical barriers to access were frequently reported whilst for others the counsellors’ lack of understanding of the lived experience of disability resulted in counselling relationships which were felt to have had little benefit. That such studies were conducted close to two decades apart arguably suggests that a lack of progress has been made in the area over this time period.

Within Chapters One to Three a review of the literature from the mid 1970s to 2006 which has discussed the topic area of physical impairment and mental health has been presented. Each of the chapters has highlighted areas that will be explored further within the research study. The areas that the study seeks to examine have been central to considering the research design and the methods that will be used in conducting the fieldwork stage of the study. This will now be the focus of the next chapter.
CHAPTER FOUR
RESEARCH DESIGN AND METHODS

INTRODUCTION

This chapter is concerned with my research design and research methods. Having restated the study’s main aims and the research questions that it seeks to address, the chapter begins by outlining why I chose to use a qualitative approach to conduct the study. It also outlines the methods that were used to undertake the fieldwork stage of the study and how a decision to use the chosen methods was arrived at. The chapter then discusses the ways in which study participants were located and the strategies that were used to select a sample group. Within this section ethical issues that were central to consent to participation such as protection from harm, informed consent and confidentiality and anonymity are discussed.

The pilot study that was undertaken is then discussed. Firstly, I explain the pilot study process before outlining the amendments that were made to the interview schedule having reflected on the interviews undertaken. The chapter then provides detail relating to the remaining interviews undertaken and the subsequent focus group that was held. The chapter concludes with a discussion of the approaches that were used to undertake my analysis of the data and describes my data analysis processes.

THE RESEARCH AIMS.

As stated in the introduction to the thesis, the primary intention of the study is to research the experiences of women with physical impairments from their perspectives. It has five aims.
1) To examine the provision of mental health services both within the statutory and voluntary sector for women with a physical impairment, aged between 18 and 65 years, living in England or Wales, who also have mental health needs.

2) To examine women's experiences of accessing mental health services in addition to examining experiences of using mental health services.

3) To demonstrate the extent to which mainstream mental health services meet the needs of women with physical impairments who have mental health support needs.

4) To determine whether existing counselling service provision meets appropriately the needs of women with physical impairments who experience mental distress.

5) To explore the ways in which the concept of loss is used to understand the situation of women with physical impairments from the viewpoint of this group of women.

THE RESEARCH QUESTIONS

The main research question that this thesis seeks to address is:

**Do mental health services in the UK respond appropriately to the support needs of women with physical impairments who experience mental distress?**

In addition it seeks to examine the thoughts and views of a sample group of women with physical impairments in relation to four subsidiary questions:
1) Do women with acquired and congenital impairments differ in their personal analysis of the relationship between physical impairment and mental distress?

2) To what extent do women with physical impairments perceive social disability as a source of mental distress?

3) Do women with a range of physical impairments who have experienced mental distress identify a shared set of barriers to mental health services?

4) Do women with physical impairments who also have experience of mental distress believe that mental health services within the UK could meet their needs more appropriately and if so, how?

**RESEARCH DESIGN: A QUALITATIVE APPROACH**

In designing the research my aim was to design a study that had a clearly defined purpose and demonstrated a coherence between the research questions and the research methods proposed. The design aimed to facilitate the generation of valid and reliable data and to have due regard both for the practical constraints of time and finances, and for the realities of the research context and setting. In choosing to focus specifically on women’s experiences this was not to disregard the experiences of men with physical impairments who may have mental health needs. However, evidence from the limited body of literature suggests that their needs are likely to be different from those of women and as previously stated I wished to focus on women’s experiences in depth.

Within the realms of research, qualitative research is often undertaken using a naturalistic and interpretive approach and where there is a wish to understand
meanings or look at, describe and understand the experiences, beliefs or values of a group of individuals (Wisker 2001). According to Bryman:

> The way in which people being studied understand and interpret their social reality is one of the central motifs of qualitative research

Bryman (1988: 8)

Key elements which are commonly agreed give a qualitative research its distinctive character include:

- Aims which are directed at providing an in-depth and interpreted understanding of the social world of research participants by learning about their social and material circumstances, their experiences, perspectives and histories.
- Samples that are small in scale and purposively selected on the basis of salient criteria.
- Data which are very detailed and information rich.

In addition qualitative methods are commonly used to address research questions that require explanation or understanding of social phenomena and their contexts. Further, qualitative methods are chosen for them being well suited to exploring issues that hold some complexity and to studying processes that occur over time (Hammersley and Atkinson 1995, Holloway and Wheeler 1996).

The introduction to the thesis stated that one of the study’s main objectives was to examine the experiences of women with physical impairments from their perspective. I therefore believed that a qualitative approach would offer me the greatest potential for women to talk about their experiences from their viewpoint.
RESEARCH METHODS: A MIXED METHOD APPROACH

In conducting the fieldwork, a mixed methods approach was used. Firstly, face to face semi-structured interviews and secondly, a focus group. In using this approach I hoped that each method would bring a specific insight to the study.

Within the small number of studies undertaken that have focused on physical impairment I only identified one that had used a mixed method approach. In Morrisô study (2004) from questionnaires that were completed, a sample were then selected for interview. This study differs in that both methods involved face to face contact and focuses solely on women and therefore my study arguably makes an original contribution to this body of literature.

The questions in the interview schedule were constructed to focus on subsidiary research questions 1 and 2. My decision to use semi-structured interviews was based on the experience I had gained whilst undertaking my 2003 research. I had found that this approach to interviewing produced data that was highly relevant to the research questions being addressed and was rich in detail. The purpose of using semi-structured interviews was to present an opportunity for participants to provide responses based on thoughtful consideration of their individual experiences, whilst also providing a structure that allowed for comparisons to be made between individuals (Mason 1996). I also believed that semi-structured interviews would provide a balance that enabled participants to answer more in their own words than is perhaps possible within a standardised question and answer format.

In addition to using interviews I held a focus group. This was held after the interviews had been completed, with the purpose of exploring issues generated through the interviews at a more strategic level. In particular the focus group schedule was
designed to focus on subsidiary questions 3 and 4. Ritchie (2003) believes that the group process and interaction between participants that are characteristic of focus groups illuminate the research process. In addition, because focus groups involve discussion and hearing from others they give participants a further opportunity to refine what they may have talked about within their interviews (Ritchie 2003).

I felt that a focus group would be of value to the research as a means of bringing together women with physical impairments who may have had similar experiences of mental distress, but which they may not have wished to share within the confines of a one to one interview. Furthermore, given that traditionally within society there has arguably been some reluctance among people to talk about experiences of mental distress, participants may feel able to be more open within a group setting.

Within qualitative studies a focus group might be used as an initial stage to raise and begin exploration of issues relevant to the subject area which are then taken forward through in-depth interviews. However, given that within the focus group women were being asked to talk about topic areas of a sensitive nature, and based on previous experience of setting up focus groups, I considered it more likely that women would talk more openly within a setting where the researcher was now known to them. It was for this reason that the focus group was held after the interviews had been completed.

In using this method consideration needed to be given to a range of practical issues including individual needs, the geographical location of the women and accessibility of the focus group venue. This was essential both for the participants and for myself as a researcher with a physical impairment.
RECRUITMENT OF PARTICIPANTS

Following ethical approval for the study (discussed later in chapter) I then began the process of recruiting participants. To enable the fieldwork stage of the study to be conducted, a sample group of 10-12 women, aged between 18 and 65 were sought, who had a physical impairment and had either previously experienced or were currently experiencing mental distress. My attention therefore turned to the establishments or organisations that I could contact and where there would be a likelihood of identifying women who met the study criteria.

Important to this research was the exploration of whether the experiences of accessing and/or using mental health services differed between women born with their impairments and those who acquired them so I endeavoured to identify 5-6 women within each of these categories. I also hoped to identify a group of women whose composition reflected a spectrum of the specified age range and from different ethnic backgrounds. Further, I aimed to include mothers or women who had other care responsibilities and women who did not have dependants. The age range chosen was to a large extent determined by service provision categorisation. As stated in the introduction to the thesis, the nature of the mental distress or physical impairment was not specified because my aim was to recruit a sample of women who reflected a range of physical impairments and mental health difficulties.

In deciding on the size of the sample group it was important to acknowledge that the type of information that qualitative studies yield is rich in detail. Based on previous experience of undertaking qualitative research and the volume of rich data that was generated I was keen to ensure that the sample group was not of a size that by virtue of time limitations would prevent the research questions from being fully explored. Also I
took the view that a larger sample might potentially generate data that was insufficiently in-depth to enable analysis to be carried out at a level required of a doctoral thesis. Therefore, in enabling justice to be done to this detail it was necessary for the sample size to be kept to a reasonably small scale. Equally it was important to ensure that the sample group was not too small to present a risk of key constituencies within the sample population being missed or being insufficiently diverse to allow exploration of the varying influences of different factors (Ritchie et al 2003).

I therefore decided that a sample group size of around 10-12 women would be both justifiable and realistic. A group of this size would also allow me to research key issues in depth whilst also being sufficiently large enough to allow comparisons to be made between individuals. Also, as the study was seeking to provide an opportunity for women’s voices to be heard, I wanted participants to be given scope to talk about their experiences in detail from their own perspectives. My chosen sample group size I thought would allow this.

An A4 poster which provided a basic outline of the study been undertaken and details of where further details could be obtained (see Appendix 1) was circulated among female students of a residential college of Further Education for students with a range of impairments in Warwickshire and to female members of the college’s recently established Alumni Association. The flyer was also sent to students with physical impairments who were registered with the University of Birmingham Student Support Services and to the Heads of Supported Learning at two West Midlands colleges located close to my home location. Preliminary enquiries to each of these organisations was made whilst waiting for ethical approval to be granted in order to ascertain informally whether my research would be of interest to the women registered with them.
This was done with the purpose of, subject to ethical approval being granted, I would then be able to progress the study without losing valuable time and each of the organisations contacted registered a keen interest in the study. Also, given that ethical approval looked likely to be granted at a time when colleges were closing for the summer vacation it was helpful for me to know in advance whether my study was likely to be of interest to their female students.

Branches of the Multiple Sclerosis Society, The Stroke Association, and Spinal Injury Support Groups located within the West Midlands area were also approached with my overall aim being to identify a sample group that comprised of women across an age range and with a range of impairments, both congenital and acquired.

**ETHICAL RESEARCH PRACTICE**

Following circulation of the research study details, there was a good response from individuals associated with a range of organisations who expressed an interest in participating in the study. From the outset of the research it was imperative that prior to agreeing to participation, the informed consent of each participant needed to be obtained. In providing prospective participants with an Information Sheet which provided detailed information about the study and what involvement in the study would entail, care was taken to ensure that the format was accessible. Furthermore, producing an Information Sheet that was written in terms that were meaningful to participants my intention was to provide a foundation for a research process that reflected openness and honesty from the outset (*see Appendix 2*). In giving consent to participation in the study, there were a number of ethical issues that were discussed within my ethical review process (*see Appendix 3*), and which prospective participants needed to be fully aware of so that informed choices could be made.
Protection from harm

Firstly, in undertaking the study there was no intention to induce harm to participants. However, given that within both the interviews and focus group women would be asked to share their experiences of mental distress, consideration needed to be given to any potential to cause harm. Where sensitive areas are being addressed there was a need for awareness that painful experiences may be uncovered which could lead to individuals disclosing information which they may have never previously shared (Lewis 2003). Similarly, the potential of interviews to have a seductive quality and lead to an apparent willingness by participants to disclose information which they may later regret also needed to be acknowledged (Ritchie and Lewis 2003). Ethical guidelines of the Economic and Social Research Council draw attention to how risk may be difficult to either quantify or anticipate fully prior to the start of the research (ESRC 2005). It was my responsibility as the researcher to ensure that in accordance with ethical guidelines risk identification and management were an ongoing concern.

Confidentiality and Anonymity

An ethical issue central to the study was maintaining the confidentiality of participants. Confidentiality and anonymity was guaranteed to all participants unless there were clear and overriding circumstances to do otherwise (BSA 2004). Prior to consenting to involvement in the study all participants were fully informed of the circumstances in which confidentiality could not be guaranteed.

In accordance with the ethical guidelines of the BSA (2004) care was taken to prevent data from being presented in a form that would permit actual or potential identification of participants. Whilst it was recognised that individuals may wish for their ID to be disclosed in order to maintain ‘ownership’ of the data (Lewis 2003) as the
researcher I was responsible for presenting to participants the potential disadvantages of removing anonymity. Each participant was asked if they wished to choose a different name for the purpose of the study but only one chose to do so. The choices made were reconfirmed throughout the fieldwork process.

Within the focus group setting there was inevitably a sharing of information. Therefore, within the group, in order to allay any concerns for confidentiality participants were asked to treat what others said as confidential and to not be repeated outside of the group setting.

**The right to withdraw**

The ethical guidelines of the ESRC (2005) and SRA (2003) clearly highlight the researcher’s responsibility to inform participants (actual and prospective) from the outset that participation is wholly voluntary, and that they have the right to refuse to participate or withdraw from the study at any stage and for whatever reason.

From my perspective as the researcher, an individual’s expressed wish to withdraw from the study at an advanced stage of the research process i.e. during writing up could have potentially led to a significant re-working of large sections of text. Therefore, in order to minimise the potential of this scenario occurring, the informed consent of all participants was reconfirmed throughout the data collection process.

**Payment for participation**

Within research studies where individuals consent to participate a prominent ethical concern is that:
Money may induce people to participate in research by compromising the voluntary nature of their decisions or willingness to explore the risks and benefits of the study.

Dickert et al (2002: 368)

Whilst needing to be aware of the potential that offering payment can have on informed consent there are a variety of reasons why people may choose to participate in research. Faulkner (2004) claims that research studies may provide an opportunity for individuals to share their experiences with others or to provide a sense of belonging to a group. Within my 2003 study women stated that their primary reason for participating was due to the opportunity they had been given to talk about an area of their lives which was important to them but which was seldom acknowledged. Similar views which were expressed within this study are discussed within the final chapter.

Participants in my 2003 study were not paid for their involvement, but, given the longer time span that the fieldwork in this study was conducted over (approximately eight months), I felt that a form of payment was justified in recognition of the time and energy given.

Ritchie and Lewis (2003) outline the usefulness, when considering research design, of giving thought as to how participants can be given something in return for their time and assistance given. Within my study and in accordance with the Principles of Good Practice of reimbursing study participants (DoH 2006), out of pocket expenses i.e. travel and subsistence were met in full so as to ensure that no individual was left at risk of being financially worse off as a result of their involvement in the study. If the assistance of a PA/carer was required to enable an individual to participate then their expenses were also met. As a token of appreciation for their time and involvement,
each participant was given a small payment which was either in the form of gift tokens or cash payment or a donation to their chosen organisation.

In making token payments I was equally endeavouring to work with the principles of a participative approach which was central to the study’s aims. Payment for participation can also help to emphasise a distinct change in the relations of power between the researcher and participant, whereby it signifies a shift in their role from client or service user to research participant (Ungar and Teram 2000) whilst also acknowledging the real contribution being made by the participant to the project (SURGE 2003).

IDENTIFYING THE SAMPLE FOR PARTICIPATION

In selecting a sample group a criterion based approach was used whereby members of the sample were chosen with a purpose of meeting the sample group criteria (Patton 2002). The composition of the sample group I was seeking had been decided at an early stage of the research, having been informed by the principal aims of the study, existing knowledge about the area being studied and gaps in knowledge about the study population.

From the 43 initial responses received, over a period of two weeks Information Sheets were sent out to the 29 women who remained interested in becoming participants. Women were asked to make contact if any of the information provided was unclear to them or if they had any other questions relating to the research. Contact was made by two women who initially were keen to participate but subsequent declines in their mental health led both women to feel that they were not sufficiently well to talk
about areas of their lives in which they were currently experiencing difficulties. Their decisions were fully respected and each were thanked for their expression of interest.

Within the next stage telephone contact (where possible) was made with each of the remaining twenty seven women, the purpose of which was twofold. Firstly, to introduce myself personally as the researcher and secondly to ensure that participants felt fully informed about the study. At this stage potential participants were asked to provide some basic details about their background and circumstances so as to verify their eligibility for taking part. Prior to this contact each woman was asked via email to indicate their preferred mode of contact and any preference for days and times of day, in order to minimise inconvenience. Two women with speech impairments stated their preferred mode of contact was a face to face meeting so introductory visits were made to these two women at their choice of location. Having ascertained with certainty their wish to participate in the study, consent forms were completed and signed by both parties (see Appendix 4).

From the telephone contacts made the varied geographical locations across the UK in which the women were living became clear. This diversity would have been beneficial in that it would have enabled me to make comparisons between mental health service provision in different areas. However, time constraints and consideration for practical arrangements meant that realistically a travelling time limit of two hours needed to be put in place, particularly as it was considered that a minimum of two visits would be required to conduct the interview. That said, two women living beyond this travel remit were extremely keen to be involved in the study and having spoken to each at length their experiences appeared to be highly relevant to the research questions that
the study was seeking to address. After careful consideration, a decision was therefore taken to include these two women in the sample group.

From the twenty seven women, a sample group of twelve were selected and consent forms duly completed. Six women had congenital impairments and six had acquired impairments. All women stated their ethnic origin to be British White. In terms of geographical diversity one woman was living in Dorset and one woman in Avon. Two women were living in the Birmingham area and the remaining eight lived within two hours travelling time of Birmingham. During August and September 2007 a pilot study was carried out which entailed interviewing two of the twelve women in the sample group, one of whom had a congenital impairment and one an acquired impairment. This is discussed below.

THE PILOT STUDY

In her discussion on the role of pilot studies, Wisker (2001) states that pilot studies are a critical part of research in the opportunity they provide to gauge whether the interview schedule flows smoothly and whether the questions asked were accessible and clearly understood by the interviewee (Wisker 2001). In addition they allow for the scope and depth of the data sought to be tested.

For the pilot study and working with my draft interview schedule, (see Appendix 8) two complete interviews were undertaken. My draft schedule consisted of questions which it was hoped would generate data that was in line with the research questions that the study was seeking to address. For both women the interviews were conducted over two stages. Having completed introductions and checked that interviewees were happy with the location and recording arrangements the interviews began by confirming
in Section One personal details i.e. name, age, chosen name for study etc before proceeding to ask in Section Two a range of questions relating to the woman’s life history. The purpose of this was to gather background information but also to establish a relationship with the participant. Legard and Keegan highlight the importance of the researcher’s ability to establish as good rapport with their participant and that good working relationships are achieved where the researcher puts the participant at ease and a climate of trust is created (Legard, Keegan et al 2003).

Both women were found to talk quite openly, in particular about their experiences of special school education and how this was felt to have impacted on their lives. The latter part of Section One focused on the women’s daily lives which led to them talking about hobbies/leisure pursuits etc.

The interviews then focused in Section Three on physical impairment and both women talked about the impact of their impairment on everyday life and activities. A series of questions which were concerned with the women’s contact with services relating to their physical impairment were then asked which generated interesting discussion.

The interviews then proceeded within Section Four to focus on mental health. They began by talking with participants about the small amounts of research that have looked at physical impairment and mental health. Two quotes from the literature of which the content related to the assumption of a causal link between physical impairment and mental distress were shared with the women who were then asked to share their thoughts on each. The subject of women’s experiences of mental distress was then broached, and as had been anticipated, this proved to be the most emotional
part of the interview process. Each of the women became upset when talking about their experiences of mental distress. I responded by asking them if they wished to take a break, stop recording of the interview temporarily or cease altogether. Both women chose to take a short break after which they were happy to resume recording.

Having shared their experiences of mental distress, the interviews proceeded to examine in Section Five the women’s experiences of accessing and/or using mental health services. Here, I found that the order of questions in the interview schedule were not rigidly adhered to as when sharing their experiences of mental distress the women’s descriptions contained references to accessing and using services. Both women spoke at length about their experiences of receiving counselling and in particular about their preference to work with a counsellor with an impairment. Their thoughts around female or male counsellors were also shared. At the close of the first (and subsequent) interviews, both women were given opportunity to ask any questions they had in relation to what had been discussed and thanked for their time given.

The second interviews began by looking in Section Six at the role of external factors and their potential to impact on mental well being. Findings from my 2003 study were used to indicate the areas that women’s views were being sought on i.e. attitudes towards impairment or barriers to accessing the environment. An issue to emerge from both interviews was that women considered that relationships with family and friends could be affected by living with an impairment. Friendships, in particular, women spoke of as being affected by a limited ability to access the environment. Women’s thoughts around whether implementation of the Disability Discrimination Act was felt to have impacted on these areas were also discussed. In the final section the interviews
focused on women’s thoughts around future mental health service provision and any changes or improvements which they considered were needed.

**Reflection on the Pilot Study**

Having undertaken the pilot study a period of reflection followed which considered two specific areas. Firstly, a reflection on how the interview process itself was felt to have worked, and secondly to look at areas of the schedule which were felt to require amendment.

The interview process itself was felt to have gone smoothly which was a view shared by both participants. A combination of previous experience of undertaking interviews and careful and detailed planning of the pilot interviews I felt were significant to the interview process having worked well.

Having reflected on the interviews, a small number of amendments were made to the draft schedule. Firstly, in gathering background information both women talked about areas central to their lives, i.e. hobbies, leisure and employment so a question relating to these areas was incorporated into the revised schedule. It was however found that in later interviews women talked about these areas within the context of their ability or otherwise to access the environment.

Recalling the emotion that was shown when sharing their experiences of mental distress, this served as a valuable reminder of the sensitive nature of some of the issues being addressed by the study. As the researcher, the women’s upset reinforced the need for me to be guided throughout the fieldwork process by women’s wishes.
when talking about times of their life in which they had experienced mental distress and to be ever alert to the risk of inducing harm.

In sharing their experiences both women spoke of how they would have welcomed an opportunity to work with a counsellor with an impairment and to have had a choice about the counsellor’s gender. The draft schedule was not felt to have given sufficient scope to these two areas so the revised schedule introduced questions which enabled discussion of these areas. Questions relating to several of the topic areas were felt to have worked well and therefore remained unchanged. These included the areas that focused on physical impairment and its impact on everyday life, and the effect of living with a physical impairment upon relationships.

**MAINSTAGE INTERVIEWS**

During the main data collection stage, interviews were conducted with women individually and with women in a group.

**Individual Interviews**

Working with a revised schedule, *(see Appendix 9)* the process of undertaking interviews with the other ten women in the sample group began. In total (including pilot study) 28 interviews were undertaken between August 2007 and March 2008. For eight women, two interviews were required to complete the schedule and each interview lasted approximately two hours. Two women, each of whom had a speech impairment requested that the interviews be carried out in three stages. For the remaining two women, the interview schedule was completed over four stages at their request because of reduced energy levels. Transcription of the interviews, which I personally transcribed were completed in mid-April 2008. In keeping with the study’s participative
approach completed transcriptions were sent to each participant with a Stamped Addressed Envelope provided for the signed transcription to be returned subject to participants being in agreement with its content.

Undertaking the transcribing myself enabled me to revisit the interview process and to see in written form the emergence of different themes and topics. It also allowed me to see the range and depth of issues around physical impairment and mental health that women considered to be of relevance and importance in terms of their personal experiences.

Focus Group

The focus group, of which I was the sole facilitator was held in March 2008 and was attended by eight women. During the recruitment process participants were advised that involvement in the focus group was optional as it was important to recognise that for some women, for whatever reason, attending the focus group may be too difficult. The group was conducted over a two hour period (with a ten minute interlude) and was recorded using an enhanced voice recorder. Working with a schedule (see Appendix 11), the focus group was conducted using a semi-structured approach. Within the group care was taken to ensure that each woman had an equal opportunity to contribute. This was particularly important for two women with speech impairments who were unable to speak up easily and who could have felt, without proper management of the group process, excluded from sharing their views.

UNDEARTAKING DATA ANALYSIS

Having received approval of the transcriptions I then proceeded to undertake my analysis of the data. At an early stage I gave consideration to using CAQDAS to assist
with the data analysis process. Whilst Spencer et al (2003) acknowledge the benefits of speed that computer assisted software can offer to a researcher handling large amounts of data, Weitzman claims that the speed and power of the software carry the risk of encouraging the researcher to take short cuts (2003: 807).

In carrying out analysis of qualitative data Coffey and Atkinson (1996) suggest there is no single or most appropriate way of undertaking analysis. According to Tesch the analytic process should be comprehensive and systematic but not rigid. However, he maintains that analysis is not a structureless process that can be undertaken inattentively and that data analysis requires methodological knowledge and intellectual competence (Tesch 1990).

In undertaking my analysis I decided not to work with CAQDAS methods based on a concern that by doing so this may remove some of the closeness to the data that I felt having undertaken the transcription process myself. In analysing data generated from the fieldwork using the Analytic Method Framework my intention was to facilitate rigorous and transparent data management which enabled all the stages of the analytic hierarchy to be constructed.

As the number of interviews undertaken grew it became apparent that within many of the topic areas a number of similar themes or concerns were expressed. Therefore, where patterns emerged these were documented for future reference and in particular the context in which those issues were talked about within the interview setting. Early data analysis is recommended by Miles and Huberman, believing that this assists the researcher in moving back and forth between existing data and generating strategies for collecting new, and often better, data (Miles and Huberman 1994).
The initial stages of analysis required the data to be sorted and reduced so as to make it more manageable. The interviews and focus group combined produced in excess of 200,000 words of rich data so it was essential that organised steps to manage the data effectively were applied from the outset. Ritchie and Lewis (2003) describe becoming familiar with the data as a crucial activity for the researcher at the start of the analytic process and that the process should continue until the diversity of circumstances and characteristics within the data set has been understood. I endeavoured to become familiar with the research data through re-listening periodically to the interview recordings and reading comprehensively the transcriptions. These processes combined enabled me to make a careful selection of the data to be used that was of particular relevance to the research questions that the study was seeking to address and to the stated aims of the research.

Having considered the volume of data to be analysed I decided to initially work with data collected from six of the interviews so as make the process more manageable. Six interviews were chosen at random so providing a cross sample of women and an array of experiences. For each woman, a pen picture was compiled (see Appendix 6 al). Pen pictures were shared with participants who were also given the option of contributing to them.

For each participant, a table was devised which outlined in Column One the ten main topic areas that were covered within the interviews and as outlined in the revised schedule (see Appendix 12). Using the women’s own language, the themes that emerged from the interviews relating to the topic areas were outlined in Column Two though inevitably there was some overlap between areas. This process further increased my familiarity with the data as it was a task that required careful and thorough reading of the transcriptions. Having completed this process for six women, each of the ten topic areas were then individually mapped on large scale paper (see Appendix 13).
Whilst this was a time intensive task, it was an approach that in undertaking the literature review had been worthwhile in terms of being able to see visually in one place the different themes, ideas and concepts that were emerging around any one subject area which then allowed further in-depth exploration. Where it was not immediately clear under which topic area some material should be included, this was not disregarded and was reviewed at a later stage of the analysis process.

Having completed the process of engaging in cross-interview thematic analysis, using whole transcriptions an initial colour coded framework was then developed to support my analysis of the material and drawing upon the recurrent themes that had emerged from the six interviews. This approach offered me both a systematic overview of the scope of the data and was helpful in making comparisons or connections across the data set. Also, by working within and across case studies the aim was to avoid fragmenting the data to a point that the individual narrative became lost and that linkages between different aspects of a woman’s story became difficult or impossible to create.

The mapping process was then repeated for interviews 7-12. My intention had initially been to merge a colour coded framework from the latter interviews into the initial coding framework developed for interviews 1-6. However, given the volume and complexity of data being worked with I decided to compile a separate coding framework for interviews 7-12. This ensured that each piece of data was afforded the same level of attention and that the analysis process was identical to that undertaken for interviews 1-6. Having constructed a coding framework for interviews 7-12 this was then used alongside that devised for interviews 1-6 identifying thoughts, views and experiences of the women that were either very similar or very different. Also built into the coding
framework were any original thoughts or experiences that had not become apparent from my analysis of interviews 1-6. From this stage the framework was categorised further using sub headings for each of the main subject areas covered within the interviews.

Upon completion of analysis of the interview data, analysis of the focus group data was undertaken. Given that focus group data differs from that gathered in interviews, there were additional features that needed to be considered in terms of their significance for analysis i.e. interaction between participants. In undertaking my analysis the individual merits of whole group and participant based analysis were considered. Whilst participant based analysis would have permitted individuals contributions to be analysed within the context of the group discussion, I decided to use whole group analysis. This was because, in using an approach that treats the data produced by the group as a whole unit this was felt to be in keeping with one of the group’s main aims which was to discuss shared experiences. In addition, this approach still enabled additional information such as that relating to group interactions to be taken into account as part of the overall evidence.

Having completed my analysis of the data, I progressed to writing up of the findings which were derived from the analysis. Chapter Five firstly presents the women’s thoughts and views in relation to the perceived inevitability of experiencing mental distress when living as a woman with a physical impairment. Secondly, it examines the study’s findings in relation to the concept of loss.

Chapter Six focuses on four areas. It discusses the potential of factors such as attitudes towards impairment to impact on mental and psychological health before
examining the ways in which women considered the DDA to have impacted on mental well being. The self image of women with physical impairments and the impact of living with an impairment upon relationships with people relevant to women’s lives are then discussed.

In Chapter Seven the women’s personal experiences of mental distress are discussed before their experiences of accessing and using mental health services are focused on. Chapter Eight presents women’s experiences of counselling. It also considers the women’s views in relation to preferences that were expressed for a counsellor who was able-bodied or a counsellor who had an impairment and for a male or female counsellor.

Chapter Nine presents women’s views with regard to how mental health services in the UK could better meet the needs of women with physical impairments who experience mental distress.
CHAPTER FIVE

LIVING WITH A PHYSICAL IMPAIRMENT- AN INEVITABILITY OF MENTAL DISTRESS?

This chapter will focus on two key areas. Part One discusses the study’s findings relating to women’s perceived inevitability or not of experiencing depression when living as a woman with a physical impairment and Part Two discusses the concept of loss. Part One examines whether findings from the study identified any differences in analysis of the relationship between physical impairment and mental health between women born with their impairments and women whose impairments had been acquired. It also examines additional factors which the women considered had the potential to contribute to an onset of mental distress. This is followed by a discussion of the attitudes and beliefs that were encountered in women’s contact with mental health professionals in respect of mental health or psychological difficulties that were experienced by women living with a physical impairment. Finally, Part One examines whether visibility or invisibility of impairment was viewed as having been significant to mental health professional’s perception of the woman’s impairment.

The focus in Part Two is the concept of loss. Firstly, it will examine women’s thoughts around the concept of loss and stage theories which suggest that the tragedy of impairment can only be resolved by an individual grieving for their loss. It will then discuss the experiences of loss of women within each category of impairment. The final section examines findings from the focus group as to whether loss is experienced differently for women with acquired impairments to those with congenital impairments.
PART ONE: THOUGHTS OF MENTAL DISTRESS

As was shown within Chapter One, studies which sought to examine a link between living with a physical impairment and experiencing mental distress found relatively high rates of depression among people with a physical impairment. Subsequently, these studies made the assumption that the causal link was to be found in the experience of impairment and functional limitation. (Oliver & Zarb 1987, Craig & Hancock 1997) In-depth analysis, both of the individual interviews and focus group data, showed a wide range of views expressed concerning the perceived inevitability of experiencing mental distress when living as a woman with a physical impairment.

For almost half of the women there was a shared view that some form of mental distress was likely to be experienced during the course of living with their impairment. Carly believed that living with a physical impairment brought with it a certain inevitability of experiencing a form of mental distress, most likely to be depression.

"Personally I think that if you are living with a physical impairment then you will experience some form of depression throughout your life. I'm not saying that it will be an ongoing thing but something that affects you at different times as you go through life.. I'd say it probably is inevitable that you will experience not necessarily a severe depression but yes, some level of depression."
Carly (age 18, congenital stable impairment)

Whether or not mental distress was experienced (and the extent of that distress), was considered by the majority of women likely to depend on whether the woman had been born with her impairment, whether the impairment was acquired suddenly or if the impairment was of a progressive and/or unpredictable nature. The probability of experiencing mental distress was, the findings showed, felt likely to be higher among women whose physical mobility was significantly affected by their impairment and where their impairments had a substantial impact on day to day living. Further, analysis
of the data indicated a widely held belief that mental distress was more likely to be experienced by women who had acquired their impairments; additionally, mental distress for this group of women was considered likely to be both more acute and prolonged if the impairment had been acquired suddenly i.e. as a result of a stroke or a spinal cord injury. However, being born with a physical impairment was not felt to exclude such women from experiencing depression or a different form of mental distress.

In contrast, findings from the study demonstrated that seven women disagreed with the link made within the limited research studies that have been undertaken, of a relationship between physical impairment and mental distress. For this group of women, the suggestion made within these studies (examples of which were shared with sample group), that the presence of a physical impairment will inevitably equate at some stage of living with the impairment to an experience of mental distress was rejected.

Amongst the women there was a widely held view that where depression or another form of mental distress was experienced, that it would be experienced differently for each individual. In their interviews, women with acquired impairments spoke of their experiences of mental distress in the months after acquiring their impairments, some of whom had experienced acute distress: these women believed that their experiences of mental distress had resulted from acquiring their impairment or having received diagnosis of their condition and facing up to significant life changes.

However, Jackie and Louise, both of whom acquired their impairments, did not believe that mental distress would automatically be experienced in the immediate months following onset of impairment. Jackie, who acquired her impairment suddenly at
the age of thirteen, recalled how she had not felt a particular need for professional mental health support until twenty five years after her impairment was acquired. This, Jackie stated, coincided with her need to come to terms with finishing work and the emotional trauma that she consequently suffered. Louise, who also acquired her impairment at the age of thirteen, described how her first experience of acute clinical depression occurred four years after her onset of impairment.

"It wasn't until then that it hit me that the impairment was to be a permanent fixture in my life and that it wasn't something that was going to go away. All the time I spent in hospital there was maybe a naïve belief that I was going to get better and would walk again but then when arrangements were made for me to go and live in a residential home with other disabled people, that was when the reality hit home and the experience of depression was horrendous."
Louise (age 39, acquired progressive neurological impairment)

Episodes of 'if only' days, were perceived across the sample group as more likely to affect women who had acquired their impairments through trauma or those diagnosed with a progressive impairment. For the latter, these women were perceived as living with a constant knowledge that their physical abilities would diminish, and with an additional uncertainty over the rate at which this would occur and within an unspecified time span. For those women with acquired impairments who experienced subsequent episodes of mental distress, these were considered to have been less acute than the first episode. Having adjusted to varying extents to the changed circumstances of their lives, subsequent episodes were described as periods of 'just feeling a bit down' or 'if only days'. During these episodes, each of the women explained how they yearned to be able once again to perform the everyday tasks which they had previously taken for granted. These women spoke of having had to adjust both to a change in their life circumstances and a significant reduction in their physical abilities.
In contrast, women living with congenital impairments that are generally classed as non-progressive i.e. spina bifida or cerebral palsy, spoke of having only ever known one level of physical capability. However, this group of women did not consider themselves to be exempt from experiencing ‘if only’ or ‘off days’. Whilst the women with congenital impairments did not feel they had had to make adjustments in the same way as women who had acquired their impairments had, (with the exception of physical changes in mobility which the women considered to be an inevitable part of the natural ageing process) each had personal experience of going through episodes of ‘if only’ days.

Katy, who was born with her impairment described a typical ‘if only’ day;

"I was born with my impairment and have always used a wheelchair. As I’ve grown up I’ve been through several of what I call my ‘if only’ episodes when I find myself wishing that I could do a, b or c. They may only be the smallest thing and the sort of things that an able bodied person takes for granted but they are things which I’ve never experienced."

Katy (age 43, congenital stable impairment)

Katy explained how she did not view these episodes as equating to experiencing acute mental distress but more as a feeling of general sadness. Findings from the study highlighted a belief that where mental distress occurred it would be experienced differently for each woman. Many women spoke of the need to differentiate between a feeling of ‘being a bit down’ and a diagnosis of clinical depression, which was perceived as being more likely to require some form of mental health support.

"I think it can be a fine line between what is real depression and what is more a general feeling of being down or feeling a bit blue. But you do have to differentiate as clinical depression left untreated can lead to you becoming quite mentally unwell as I know from my own experiences and I should have sought medical intervention earlier than I did."

Frankie (age 27, congenital fluctuating impairment)
Personal experiences of mental distress

Within the individual interviews, women aired their personal views in relation to the inevitability of experiencing mental distress when living with a physical impairment.

Judith, whose acquired impairment resulted from a stroke, attributed the onset of her depression in equal measure to having suffered a stroke and the ensuing prolonged hospital stay which she had found difficult to cope with. Frankie described how her unpredictable impairment was frequently characterised by episodes of acute pain and she believed the experience of pain to be one of a matrix of factors that can lead to mental distress. In addition to their experiences of pain, a number of women highlighted the difficulties which at times they endured in coping with extreme fatigue and the ways in which their impairment could impact upon energy levels. The data clearly showed that the combination of reduced energy levels and extreme fatigue were felt over time to have the potential to impact in a negative way on mental well being. For some women the view was expressed that, at their most acute, such factors could be more difficult to cope with than the impairment itself.

Maria partly attributed her experience of depression, following her diagnosis of Multiple Sclerosis, to a lack of available support and information from health professionals relating to her condition. In addition, feelings of isolation and vulnerability that were experienced in the traumatic months following her diagnosis were talked about in some depth.

"In the first few months after I was told I had Multiple Sclerosis all the health people were kind and offered endless cups of tea but what I really needed was facts about the condition and what I should expect to happen or to look out for. I knew I would have to give up work so I needed to know if there were any disability benefits I could claim for but I just recall it mainly been left up to you to find things out for yourself."

Maria (age 51, acquired progressive neurological impairment)
Each of the women’s experiences of mental distress will be discussed in greater detail in Chapters Seven and Eight. In talking about their experiences of mental distress, women highlighted a number of factors which they felt had had an influence on those experiences.

Experiences of Mental Distress: Additional factors of influence

Studies undertaken which have made a causal link between living with a physical impairment and the experience of mental distress have in recent years attracted criticism for the lack of attention paid to the social or economic factors which may accompany impairment, such as added financial pressures and/or the likelihood of loss of employment for those of working age. The importance of giving consideration to a wide range of factors that may contribute to the experience of mental distress was expressed throughout the group.

Firstly, whilst some women identified their impairment as having been a contributory factor to their experiences of mental distress, equally they held a firm belief that their impairment had neither been the primary or sole cause. Drawing on her personal experiences, Alison believed that her physical impairment had played a role in her experiences of mental distress. However, her upbringing and relationship difficulties were also identified as factors that were relevant to her experiences of mental distress, for which she had sought mental health support over a number of years.

I often felt as I was growing up that I was treated differently to my brother and my relationship with my dad has often been difficult as I feel he has always compared me to others in the extended family who have either gone to university or got good jobs but my achievements aren't talked about... it's as if they don't count and that has impacted on me psychologically over time definitely. Dad thinks I'm only in employment because I use a wheelchair and he doesn't think I've got anything under my own merit. I also got caught up in the idea of a big wedding but I married too young and my marriage broke down when I was only twenty three which was really traumatic.”

Alison (age 39, congenital stable impairment)
Several women in the sample group shared Alison’s view that any experience of (or likelihood of) mental distress for women with a congenital or acquired impairment, was likely in part to be determined by the level of support and encouragement provided by spouses, family or friends. The importance of having a good support network and ready access to people who were both positive and provided ongoing, informal psychological and emotional support was also emphasised. The availability of support networks were viewed by the majority of the women as being crucial to the process of adjustment to living with a physical impairment. In particular this was felt to be the case for women who had acquired their impairments and subsequently were likely to be confronted with significant upheaval and changes to their life.

Analysis of the data showed a consensus that any reaction to, or response to, the onset of living with a physical impairment was also likely to depend on the character and personality of the individual concerned. In addition, some women expressed the view that incidences of mental distress for women with acquired impairments may be linked to what the woman did prior to onset of impairment i.e. employment/career and/or lifestyle.

**Attitudes towards impairment**

Data from the interviews and focus group consistently showed an expressed view of the need for mental health professionals to fully recognise that an experience of mental distress is unlikely to be solely a result of physical difference. Analysis of the data demonstrated the women’s strong assertion that factors such as barriers to access and/or services, and attitudes within society towards impairment, have the potential to impact on mental well being over an extended period of time.
Lisa, who was born with a hereditary impairment, described how attitudes within society towards impairment had been a contributory factor to her experience of depression.

"For me, the depression seemed to come about in part from the realisation that as a woman with a physical impairment the world seemed to view me differently than it did an able-bodied woman."

Lisa (age 45, congenital progressive impairment)

Similar views were described by Pippa:

"My depression was partly about how other people, able bodied people in society perceived me as a young woman with a physical impairment. The impairment was a contributory factor but I wouldn't say it has been the primary cause of the mental distress I've experienced since I was a teenager."

Pippa (age 35, congenital stable impairment)

The ways in which external factors were perceived as having the potential to impact on the psychological and mental well being of women with physical impairments will be examined in greater depth in Chapter Six.

**Mental Health professionals: Women’s experiences of attitudes and beliefs**

In Chapter Three it was shown how mental health professionals overwhelmingly assumed that where mental distress is experienced by an individual living with a physical impairment, the distress was linked directly to the presence of the individual's impairment. My small scale research study in 2003 examined the experiences of a small group of women with physical impairments in accessing mental health services. In the study, women described how mental health (and other health) professionals with whom they had contact, had for the majority assumed a direct relationship between the presence of a physical impairment and the lived experience of mental distress.

Analysis of both the interview and focus group data highlighted the importance that women in this study attached to mental health professionals recognising that no two
women will experience or live with their impairment in an identical way. Equally, there was a shared consensus of the need for mental health professionals to both recognise and appreciate the individuality of each woman, in addition to understanding that the circumstances of their life and physical impairment are unique to them.

Findings from both data sets of this study displayed a consistent theme in relation to women’s experiences of the attitudes and beliefs of the mental health professionals with whom they had worked/were working. This was an assumption made or perceived belief they held that any mental distress that had been or was currently being experienced was a direct result of the woman living with a physical impairment. Whilst there was a group wide agreement that the woman’s impairment needed to be taken into account as part of her identity it was equally agreed that mental health professionals needed to shift away from the assumption that a woman’s experience of mental distress is likely to be inextricably linked to her physical impairment. This was believed to apply, irrespective of whether the woman’s impairment had been present from birth or had been acquired at some stage during her lifetime.

Many women talked about their experiences of working with mental health professionals who had explained their depression as a natural or to be expected reaction to living with a physical impairment. Based on the women’s experiences of contacts with mental health professionals, the study found that the attitude and belief overwhelmingly encountered was of mental health professionals who viewed their impairment (regardless of the nature and circumstances around it) as a tragedy per se. Frankie described her first experience of working with a mental health professional when she entered into counselling:
"When I first went into counselling it was after I had got my diagnosis of hypermobility syndrome and I was just trying to get my head around things. The counsellor kept going on about how tragic it must be to be given such a diagnosis and that it wasn't surprising that I was feeling depressed and it wasn't what I wanted to hear. After a few weeks I gave up going as her approach was no use to me at all and I asked for someone else instead."
Frankie (age 27, congenital fluctuating impairment)

Working with Mental Health professionals

For the majority of the women there was a perception that the mental health professionals with whom they had contact utilised a medical model approach to disability in their work. Similarly, most women believed that the mental health professionals with whom they had worked, perceived the women as 'tragic' people who were living with terrible conditions. This perception was felt to be particularly prevalent in situations where the physical impairment had been acquired, and reinforced further where the impairment had been acquired at a young age and/or suddenly. For all the women in the study such beliefs and perceptions were considered to be unhelpful. In addition, they were seen as creating the potential to influence how experiences of using mental health services were rated in terms of their effectiveness in addressing the mental health issues that the women were experiencing.

Of the twelve women interviewed, only two described their experiences of working with mental health professionals as mostly positive. These professionals were described as people who were prepared to listen to the women's thoughts around a range of contributory factors which were believed to have contributed to their personal experiences of mental distress. In addition, the professionals were open to exploring these issues within their working relationship. Interestingly, for both of these women, there was agreement that their positive experiences were to a large extent determined by the professionals having a social work background. Therefore, these workers were felt to be both aware of, and prepared to work with, a social model approach to disability
within their work with the women. The women's experiences of both accessing and using mental health services are the central focus of Chapter Seven and Eight.

Helen, shared her belief that she had educated her therapist around the issue of disability and physical impairment, and that her therapist had openly acknowledged that this was the case.

"My therapist said that I have educated him around impairment and disability and that it wasn't an area that was given a lot of attention during his counselling training so he tells me he has learnt a lot from me if that helps in any future work he does with anyone with an impairment then that can only be a good thing."

Helen (age 43, congenital stable impairment)

Visibility or Invisibility: Perceptions of Impairment

Findings from the interview data highlighted how the visibility or invisibility of a impairment appeared to impact on mental health professionals overall perception of impairment. Where the physical impairment had been immediately visible to others i.e. the person was a wheelchair user or had a significant mobility impairment, women's experiences were of mental health professionals latching onto this as an obvious reason or explanation for their experience of mental distress. Women whose impairments were visible spoke of how they had felt pitied and/or patronised by the mental health professional with whom they were working. Pippa recalled how the Community Psychiatric Nurse with whom she had regular contact, assumed how difficult her life must be.

"She would say oh how awful to be spending every day of your life in a wheelchair and you are so young and I'm there trying to say to her look, it isn't that bad this is just how my life is."

Pippa (age 35, congenital stable impairment)

Pippa felt strongly that this Community Psychiatric Nurse had little understanding or awareness of disability or physical impairment. Likewise, the data showed how for
most of the women, their contacts with mental health professionals had been characterised by individuals who were perceived as having little understanding or awareness of disability and physical impairment. The women felt that mental health professionals lacking experience of, or prior exposure to impairment, resulted in mental health professionals holding a belief that living with a physical impairment must be one of the worst circumstances in which a woman can live. In particular, this was perceived as being the case for women whose impairment had a significant impact on both her physical ability and day to day living.

In contrast, Frankie explained how, during periods when her impairment was stable, it was largely invisible to people she did not know and that this in turn had been experienced as impacting on people’s perception of her impairment. Whilst Frankie spoke of not wishing to have an impairment that was immediately visible to others, she did feel that within society there was a greater understanding and awareness of visible impairments. In addition, experiences that Frankie had gone through had led her to conclude that society has greater compassion and sympathy towards women (and men) whose physical impairments are visible:

“...I might be standing on a bus on a day when I’m in considerable pain and many times I’ve asked someone if I could have their seat, explaining to them that I’m experiencing pain but often the request will be refused because to look at you are normal. Yet if I’m standing on a bus on a day when I need to walk with my stick, as a general rule someone will get up and offer you their seat. And absolutely I think it’s because the stick represents to them a disability and they want to be seen to be understanding by offering help so yes I do think visibility or otherwise of impairment is significant to how people respond towards you” Frankie (age 27, congenital fluctuating impairment)

As discussed above, the study highlighted the frustration women felt towards professionals who were perceived as being unable to recognise or acknowledge other factors which the women believed could contribute to an experience of mental distress,
for example, loss of employment or relationship difficulties. The need for mental health workers to give meaningful consideration to the role of such factors in the overall picture of the lives that they were living was viewed as being of great importance. In addition, the need for mental health professionals to view the woman in a holistic way, and to look beyond their impairment was considered by each of the women to be vital. Without this consideration, the women believed it unlikely that women with physical impairments would view mental health service provision as a positive and effective form of treatment for their mental distress. These are themes which are developed further in later chapters.

PART TWO: THE CONCEPT OF LOSS

Chapter Two discussed how the earlier literature on loss made the suggestion that individuals will need to make psychological adjustments if they are to come to terms with their impairment (Oliver & Sapey 1999, Hurst 2000, Morris 2002). This has been added to by stage theories which predict that people with physical impairments need to grieve and express feelings of anger and denial before they can become psychologically whole again (Reeve 2000). According to stage theories the ‘tragedy’ of impairment can only be resolved through an individual grieving their loss and going through a period of mourning akin to that of bereavement. By adopting this approach, the individual is expected to go through stages of denial, anger, fear and bargaining before finally reaching the recovered stage of acceptance of impairment. Within this section the women’s thoughts around the concept of loss will firstly be presented. The findings with regard to whether loss, if experienced, is experienced differently for women who acquire their impairments to those who are born with their impairments is then explored.
Experiences of Loss

Analysis of the data from both the interviews and the focus group showed a widely held belief among the women that at some stage of living with their physical impairment, they would experience loss. However, it also indicated considerable variation both in how the concept of loss was understood and how loss was experienced for different women.

Across the group there was a consensus that the experience of loss was likely to be a very personal one. Whilst there were likely to be similarities within their overall experiences, ultimately it was considered that each woman would experience loss in a different way. The extent to which loss was experienced was, as in the case of experiencing mental distress, felt to be linked both to the severity of the woman's impairment and the manner in which it impacted on her day to day life. Jackie described how, after acquiring her spinal cord injury, she recognised that she would not be able to pursue a career looking after animals.

As a child I always loved animals and thought that when I grew up I would like to be a vet. But when the injury affected the use of my hands I knew it probably wasn’t going to be an option. And as I hadn’t started on training for that given I was only thirteen, I didn’t take it so badly than I might have done if I’d been in the middle of training to be a vet and I was young enough to think about other careers that I could do even though I was in a wheelchair.

Jackie (age 43, acquired spinal cord injury)

Equally the data showed how women considered that both the experience of loss, and the depth of feeling surrounding it, were likely to depend on the woman’s character and personality, and that two women diagnosed with the same impairment may cope in very different ways.
Acquired Impairments and Loss

As discussed in Part One, some women with acquired impairments described how in the initial months following onset of impairment, they had experienced mental distress. For these women mental distress had occurred when the reality of their impairment, and what it might mean in the context of their lives, had hit them. Women with acquired impairments described how, following the onset of their impairments, they had experienced emotions ranging from shock and anger to confusion and disbelief. Maria, who was in her early thirties and a mother of three young children when diagnosed with Multiple Sclerosis, recalled her sense of disbelief:

"When I was diagnosed with my MS I honestly just couldn't believe it...it felt like the martians had landed and that I was in some surreal place. I don't mind saying that it took me a long time to come to terms with the diagnosis and after lots of searching for information about it, what the implications would be on my life overall and for all of us a family."
Maria (age 51, acquired progressive neurological impairment)

Jackie recalled how, having acquired her spinal cord injury the doctors told her that she would not walk again and would need to use a wheelchair permanently. Jackie described how, upon learning this she experienced over many months a sense of disbelief but did not feel she had been depressed or mentally distressed. Though Jackie went on to work in full time employment for twenty five years, (stopping about thirty years after acquiring her impairment), there remained for Jackie a feeling of not having totally accepted her impairment and that it was more a case of having to get on with life.

"In the long term you have a choice as I see it...you try and accept things and rebuild your life or you go into yourself and vegetate. If you do that then the chances of becoming very depressed will be that much higher."
Jackie (age 43, acquired spinal cord injury)

Jackie experienced a massive sense of loss when faced with being unable to return to work following an episode of acute illness, and the absence of work created a large void
within her life. She had not begun work until her early twenties as a result of acquiring her spinal cord injury, but had succeeded in working for over twenty years.

"Work gave me a structure to my day but more than that, it made me feel normal ..it was something that I could do in spite of my impairment and it kept me active mentally. Work allowed me to mix with other people and gave me a sense of being integrated into society. When that went it created this massive void in my life and I wasn't prepared for the effect it would have on me."
Jackie (age 43, acquired spinal cord injury)

Another area in which Jackie spoke of experiencing a sense of loss was after the birth of her daughter. At this time she became acutely aware of her mobility limitations and felt a strong sense of loss for the activities and tasks that she was not able to be actively involved with as her daughter grew up.

Louise spoke of how in the initial years after acquiring her impairment she did not experience a sense of loss (highlighted within Part One of this chapter). Rather, her initial onset of depression occurred some four years after acquiring her impairment. For Louise, loss was felt at a point of realisation that she would not make a miracle recovery and that her impairment was to be a permanent feature of her life.

"My sense of loss was at it its most acute when I realised that there was to be no recovery and I would be spending the rest of my life in a wheelchair. I felt that I would be excluded from the outside world and that there would be so many things that I hadn't had the opportunity to do as a teenager and now wouldn't have the opportunity to do all sorts of other things."
Louise (age 39, acquired progressive neurological impairment)

For Judith, the sense of loss that she experienced following her stroke was felt to have been caused by her inability to do the smaller tasks that she had always taken for granted as opposed to the bigger things.

"Learning how to pick up a cup with my right hand when I had always been a left handed person I found it really tough and frustrating and I would just end up in tears."
Judith (age 61, acquired impairment following stroke)
Whilst some of the women with acquired impairments talked of having 'accepted' their impairments, they did not identify with having gone through different stages before reaching that point. Typically, the data showed how women’s experience was of going through a slow but continual process of adjustment. Equally, acceptance of their impairment was not viewed as 'a recovered stage'. Rather, analysis of the data showed that the processes of adjustment that women stated they had gone through were on a par with those outlined in the dual stages approach. This approach is one of a number of alternative theories, that, in more recent years have been presented within the literature as providing a more accurate explanation of how individuals respond to physical impairment. Within the dual stages approach, it is suggested that people with a physical impairment will shift between a loss and a restoration orientation rather than going through specified stages, (see Chapter Two p 51).

Within the focus group, women who had acquired their impairments described their 'acceptance' of their impairment as typically fluctuating over a period of time. Such fluctuations were perceived to often have been a result of external influences or factors, e.g. anniversaries of onset of impairment. For example, Jackie described how, after a lengthy hospital stay during which she regained a limited level of independence, she believed that she had accepted her impairment. However on returning home to an environment that was not at that time fully wheelchair accessible, that sense of acceptance diminished having found her levels of dependency on others for help with everyday tasks had increased. Women in the group who had acquired their impairments described in some detail how, particularly in the initial years following onset, anniversaries of onset of impairment had reinforced thoughts around their lives prior to onset: what their lives 'had been' and what they felt had been 'lost'. This had led some women to question how well they had truly 'accepted' their impairment but that such
self-questioning tended to diminish both in its intensity and frequency with the passage of time.

**Congenital Impairments and Loss**

As had been identified from women with acquired impairments, findings from the study highlighted how the women with congenital impairments (for whom their level of physical ability had remained relatively stable through their lives) did not identify with the stage theories approach to adjusting to impairment.

Lisa developed symptoms of her genetic condition as a young child. Now in her mid forties, Lisa felt that she had ‘about ninety per cent’ accepted her condition, though periodically found herself wishing to be able to live a different life.

‘Although I was born with my condition and have never how it feels known to walk through sand and feel the sand between my toes, I do find myself wondering sometimes just how it feels. But I don’t really see it as a loss... to me it is more a sense of curiosity and wondering how certain things feel.’

Lisa (age 45, congenital progressive impairment)

Frankie described experiencing loss during her teenage years when she was unable to take part in school physical activities because of her impairment. However, for her this was an experience of feeling different rather than a grieving process. Her later feelings of anger and confusion arose when, at the age of twenty one she was given a changed diagnosis from arthritis, with which she had lived with for ten years, to hypermobility syndrome. These feelings were exacerbated after she suffered an injury and Frankie described having to come to terms with the reality that her impairment was to be a permanent feature in her life. In addition she spoke of going through a period of adjustment to recognising her own limitations but did not experience this process as having distinct stages.
The feelings of uncertainty that Frankie experienced around registering as a disabled person were believed to be inextricably linked both to the self acceptance of her impairment, and identifying herself as a disabled person. Having reached a point at which she felt that she had accepted her new life circumstances, Frankie believed that this then enabled her to move forward.

Pippa described how her impairment formed part of her identity:

"This is me and this is my impairment... it is part of me and I do things as I have always done them so for me I don't feel there has been any real process of accepting or adjusting to things.

Pippa (age 35, congenital stable impairment)

However, Pippa described how periodically as she grew up, she had felt a sense of loss for not having had the same life opportunities as her able-bodied friends were seen to have had. Carly, who was born with her impairment, recalled experiencing a sense of loss at approximately aged twelve, having at that time realised that her impairment was to be a permanent feature of her life. Until that time Carly described how she had lived with a hope that one day she would walk.

However, she spoke of feeling glad that she had been born with her impairment as it was Carly's belief that to acquire an impairment must be soul destroying. In addition to the differences in her physical mobility compared to that of her able-bodied peers, Carly described experiencing loss in another dimension;

" When friends were going places that I couldn't access in those days or when friends were having their first boyfriends I could feel quite left out .. but overall I see my life as just being different and not particularly better or worse than anyone else's. At the end of the day I can't change how things are so you just have to get on with it, you just accept it."

Carly (age 18, congenital stable impairment)
A sense of feeling excluded from society was also highlighted by Helen, who believed that her speech impairment had increased her feelings of isolation through the difficulties it created in communicating with others in public arenas. Helen believed that the sense of loss she experienced as a young adult had been a result of the physical condition with which she was born. Secondly, it was attributed to having had an unhappy upbringing from which she felt a sense of having missed out. Helen and other women in the study explained how a sense of loss had been felt in relation to different stages of their lives such as forming relationships, getting married and having children, all of which were perceived as being the 'normal' things to do. For women who had grown up with siblings and friends within their own age group, a feeling of loss was described as having arisen from witnessing the things that they were doing yet feeling that the same sort of opportunities were not open to them because of their impairments.

**Progressive Impairments and Loss**

Elisabeth talked of experiencing loss at different times in her life as her congenital condition progressively declined. While some of those experiences were felt to have resulted from changes in her physical ability, others were viewed as having stemmed from personal losses she had experienced, in particular the death of her husband from cancer at a young age. However, it was Elisabeth’s view, that as each physical change occurred, she had endeavoured to adapt to the circumstances in which she found herself, but that overall this had been an unconscious process. In her interview she said she was unable to identify with going through stages of adjusting to her impairment, at the end of which she would consider herself to be ‘recovered’.

Similar views were expressed by other women who were living with progressive impairments. These women spoke of going through a continual process of adjustment
as their conditions progressed and their level of dependency on others for day to day living increased. Interestingly, for two women contrasting views were expressed in relation to their transition to wheelchair use. For Lisa, progressing from using a manual wheelchair to a powered wheelchair was an indication of a decline in her physical ability but was not experienced as loss. The transition was viewed as allowing Lisa greater independence and removing feelings of exhaustion and was therefore viewed in a positive stance.

By contrast, Maria described the experience of losing the ability to walk and becoming a wheelchair user as devastating and she spoke of having great difficulty in accepting that she was to be a wheelchair user for the rest of her life. Losing the ability to drive and subsequently progressing from using a manual wheelchair to a powered wheelchair were both factors which for Maria caused an acute sense of loss.

**Congenital or Acquired Impairments: A different experience of loss?**

Over recent years the literature that has examined the concept of loss has attracted criticism for the lack of attention given to a consideration of whether loss, if experienced, is experienced differently for individuals born with their impairments to whose who acquire theirs. This final section of the chapter discusses the findings from the focus group on the topic.

Amongst women with congenital and acquired impairments, there was a consensus that for individuals who experience loss, that this occurs at different times in people’s lives and that women come to terms with their impairment in different ways. Women in the group shared the view that a more acute sense of loss was likely to be felt by women who acquired their impairments, and particularly where the onset had been sudden and/or the woman’s mobility had been affected significantly by the
impairment. Within the group there was a shared view that women with acquired impairments will have acquired more expectations from life than women who were born with their impairments. In addition, it was widely felt that women who acquire their impairments will also have to learn how to operate as a disabled person.

For all the women in the focus group there was a considered belief that women who acquire their impairments will experience loss differently to those who are born with their impairments. In addition, a range of opinions were expressed as to whether women born with their impairments experience loss or not. Some women with congenital impairments described having grown up not knowing what it was to be able to walk or run. Therefore, for these women there was to varying extents, a sense of 'not being able to miss something that you never had'. However for other women born with their impairments, they explained how, as highlighted earlier in the chapter, although from a mobility perspective there may be a sense of not missing something that you have never had, loss might be felt in other ways.

Women who had acquired their impairments talked about their personal belief that they had accepted and come to terms with their impairments. However, all of these women stated that given the opportunity, they would welcome having their able-bodied lives back. This for Judith was despite, since acquiring her impairment having been presented with opportunities in her life that she believed she may not otherwise have had.

CONCLUSIONS

This chapter set out to examine whether women with congenital impairments and acquired impairments viewed an experience/s of mental distress as being inevitable by
virtue of their living with a physical impairment. It has shown that whilst almost half the women (both with congenital and acquired impairments) believed that mental distress would be experienced, seven women rejected the causal link suggested within the literature that an experience of mental distress was likely to be inevitable. Whilst some women identified their physical impairment as having contributed to their experiences of mental distress, the chapter examined a range of other factors that needed to be considered by mental health professionals when examining any assumed link between physical impairment and mental distress. In addition, the chapter has shown the importance that all the women attached to the need for mental health professionals to recognise that no two women will experience or live with their impairment in an identical way. Women also wanted mental health professionals to acknowledge and appreciate the individuality of each woman and to understand that the circumstances of their life will be unique to them. Each of these themes will be explored further in later chapters.

In relation to loss, this chapter has shown a widely held belief existed between the women, that at some stage of living with their physical impairment they would experience loss. However, it also demonstrated the variety of ways both in how the concept of loss was understood and how it was experienced. Whilst women were seen to consider that experiences of loss were likely to be more acute amongst women who acquired their impairments, similarities and differences were seen in how loss was experienced, irrespective of whether the impairment was of a congenital nature or had been acquired.

Additionally, the chapter demonstrated how women’s experiences of loss were attributed to factors other than their impairment. Although the physical impairment was felt to have contributed to experiences of loss, broader life changes which had resulted
for women with acquired impairments from the onset of impairment were identified as having played a significant part in experiences of mental distress. For women with congenital impairments in particular, experiences of loss were attributed to not having had at different stages of their lives the same opportunities as able-bodied people within their age group.

In relation to loss, evidence from the data has provided a clear indication that women were neither in agreement nor identified with the stages theory approach to adjusting to impairment. Whilst women with acquired impairments spoke of having gone through a process of adjustment to their physical impairment this was perceived as being a slow process; neither was adjustment to impairment felt to equate to a total acceptance of impairment nor did women view themselves as having ‘recovered’. Where a process of adjustment had taken place this was experienced not as solely a process of adjusting to the impairment per se but as making adjustments to areas of their lives that had been significantly affected by their acquired impairments.
CHAPTER SIX

PHYSICAL IMPAIRMENT AND SOCIAL DISABILITY

Within this chapter the focus will be on four key areas. Firstly, it discusses the research findings in relation to the potential of factors such as attitudes towards impairment and difficulties encountered in accessing the environment to impact on mental and psychological health. The chapter then considers the recent introduction of disability legislation within the UK and examines the ways in which the implementation of the Disability Discrimination Act is perceived by the women to have impacted on their psychological well being. Thirdly, it examines the topic of self image and the factors which the women believed impacted or had the potential to impact on their self image. Finally the chapter discusses the research findings with regard to the impact of the women’s physical impairment upon their relationships with family members, spouses and friends.

PART ONE.

THE ROLE OF EXTERNAL FACTORS: ATTITUDES TOWARDS IMPAIRMENT AND MENTAL WELL BEING

Within Chapter One some of the more recent literature that has adopted a social model perspective on the mental health support needs of people with a physical impairment was examined. In contrast to the medical model of disability, the social model of disability shifts the focus from impairment onto disability, using the term to refer to disabling social, environmental and attitudinal barriers rather than a lack of ability. Impairment is defined as the functional limitation(s) which affect a person’s body with disability being defined as the loss or limitations of opportunities arising from direct
and indirect discrimination. From the literature a clear theme emerged which illustrated how factors in society such as attitudes towards impairment and disabling environments have the potential to impact on mental well being. Though such experiences were shown as creating feelings of anger and rejection for people, the literature did not examine the psychological consequences of such experiences.

For all the women, analysis of the data demonstrated a strong belief that factors such as being unable to access the environment over a prolonged period of time have the potential to impact on mental well being. It was also agreed that the attitudes of other people in society towards women (and men) with physical impairments, had the potential in the long term to impact on psychological health. However, all the women felt that the potential for an inability to access the environment impacting on psychological health was considerably less in the early twenty first century than it had been fifteen to twenty years ago. This was attributed to the fact that the environment during the 1980s was much less accessible to people with a physical impairment. Attitudes towards people with a physical impairment were also felt to have been very different at that time. All the women agreed that significant improvements in people’s awareness around disability in general had been witnessed during the past ten to fifteen years and that attitudes in society towards disability had shifted quite significantly. However, the data illustrated that whilst women were encouraged by the greater insight into disability and impairment that people appeared to now have, they believed that there remained scope for further improvement. Women who grew up during the 1970s and 1980s described how today’s environment was much more accessible than when they were teenagers and young adults. However, these women also spoke of continuing to encounter a mix of attitudes and reactions towards them when going out in public as a woman with a physical impairment.
For all the women in the study, the data showed the changes they had witnessed over the past two decades both in the attitudes of other people towards people with physical impairments and a greater awareness of impairment overall. Such changes were attributed to two factors: firstly, the environment becoming more physically accessible to people with mobility impairments and secondly people with impairments becoming more visible within society, with most women having a belief that one (improved accessibility) has had a knock on effect on the other (improved visibility). In addition, as people with impairments have become more visible in society, the women felt this had led to able-bodied people having more contact with people with impairments than had been the case in previous decades.

Amongst the women there was a shared view that historically there had been within society both an ignorance and a lack of knowledge around disability. This, in the main, was seen as resulting from the lack of contact able-bodied people had with anyone with a physical impairment. Both attitudes towards, and misconceptions about, impairment were perceived by many women to have often been a response to hearsay or what people read about disability and people who were not able-bodied. Such common misconceptions that were talked about included a belief that people with physical impairments needed to live and/or be cared for within some form of residential institution or, that people with impairments did not go out to work or live as part of a family unit. Elisabeth, who due to the nature of her impairment always required the assistance of a companion to access public places, described such attitudes as ranging from irritating to anger making.
I can always remember as I was growing up in the fifties and sixties having this battle in my head whenever the opportunity came up to go out for a while. A part of me wanted to stay indoors as I knew the reaction I would get when outdoors people staring at you and wondering why you were in a wheelchair and it wouldn’t be uncommon for a total stranger to come up to whoever I was with and say ‘What happened to her?’ and that used to really upset me. But I also felt that I had a right to be out and about just like everyone else and I wanted to be out. My dad used to say just to ignore people who stared at you but it did hurt. Of course things are quite different now and you don’t get the staring and the personal questions as people generally don’t look twice if they see someone out in a wheelchair now but I can remember encountering all sorts of unwelcoming attitudes and responses towards me which were really hurtful.

Elisabeth (age 62, congenital progressive impairment)

Helen expressed her sense of frustration when people talked to her personal assistant rather than her. This she believed was due partly to her being a wheelchair user and partly due to her speech impairment which affected her ability to communicate with people easily.

Helen really gets me down when people talk to the person who’s pushing my wheelchair and not me because I thought we had left the days of does she take sugar syndrome behind. I think to a certain extent we probably have and the average person will accept now that just because you are sitting in a wheelchair it doesn’t mean that you haven’t got a brain in your head. For me personally it’s more about my speech impairment and people not wanting to be embarrassed by not understanding what I’m trying to say. My PA is very good though and she will say to people ‘It’s OK you can talk to Helen or she will just walk away so then people have to talk to you directly. But it can get you down when people respond to you like that and I can feel quite hurt but you don’t always have the energy to challenge people.

Helen (age 43, congenital stable impairment)

Carly, the youngest woman in the study, talked of feeling fortunate that she had attended school in the early twenty first century, at a time when positive and significant shifts in attitudes towards impairment were occurring across society. During her primary schooling within a mainstream school, Carly recalled few instances of experiencing problems with attitudes towards her impairment. She described how she became a novelty to her classmates who would take it in turns to push her around the playground.
in her wheelchair. However, difficulties with attitudes towards her impairment were for Carly experienced when she progressed to secondary school at the age of twelve. Such attitudes were considered to have resulted in part from her peers being at a self conscious age during which a level of status was attached to the people with whom you were seen to associate with in school. Carly believed it to be the visibility of her impairment that had significantly contributed to the difficulties she faced in forming friendships at that time. Carly’s experience differed widely from that of Jackie, who described how two decades previously her teenage friends had routinely included her in any activities that they did. Jackie explained how these friends were people she had known from secondary school before she acquired her spinal injury at the age of thirteen and believed that in the early 1980s teenagers were not as self conscious as they are today. These different experiences will be examined later in the chapter when discussing the study’s findings in relation to the impact of living with a physical impairment upon relationships with others.

Judith, who acquired her impairment in 2001, believed that environmental access in the early twenty first century was much improved in comparison to what it had been in previous decades. Physical access to the environment and public buildings had not been experienced by her as overly problematic or a major source of frustration. It was Judith’s view that her transition to becoming a disabled person had been less difficult than if she had acquired her impairment twenty years previously. In addition, Judith did not feel that she had encountered any significant problems with the attitudes and/or behaviour of people towards herself or her impairment. However, Judith expressed her view that if her speech had been impaired as a result of her stroke, then she believed that her experiences may have been different. From her experience of a prolonged hospital stay following her stroke, Judith recalled witnessing people looking
uncomfortable around patients whose speech had been markedly affected by their stroke and were seen to avoid one-to-one contact with them.

Frankie’s first experience of barriers to accessing the environment occurred when she progressed from walking unaided to using a walking aid. At this time she recalled experiencing a marked change in the attitudes and behaviour of able-bodied people towards her. Prior to using a walking aid Frankie’s impairment had not been immediately visible to others but it was her view that people associate a walking aid with a physical impairment and that subsequently people responded towards her in a more sympathetic way. Amongst the women there was a consensus that, although as has been stated, attitudes in society towards impairment have improved over recent years, there continues to be a credibility gap that exists between visible and non-visible impairments. The previous chapter indicated how women perceived able-bodied people to be more believing of impairments that are noticeably visible. Further, the data illustrated how people’s awareness around impairment overall was considered to be much greater for a physical impairment that is visible in comparison with one that is not. Likewise, for all the women there was a shared view that better awareness of physical impairment is yet to be matched by people’s awareness of mental health issues.

In addition to the marked shift in people’s attitudes towards impairment that had been witnessed, each of the women made reference to the positive impact this had had on their mental well being: throughout the group there was a widespread recognition of greatly improved disability awareness within society, especially during the past decade or so. Simultaneously, the data showed unanimous agreement of an ongoing need for further improvements in disability awareness and educating people, including young people and children, around disability and impairment.
PART TWO. THE DISABILITY DISCRIMINATION ACT: THE IMPACT ON MENTAL WELL BEING.

Improved environmental access

For all twelve women there was a consensus that overall the Disability Discrimination Act had been a positive development in terms of the improved access to the environment and services that had been brought about through its implementation. Access to public arenas for people with physical impairments was described by all the women as much improved to what it had been in the early 1990s and significantly better when compared with previous decades. Whilst the improved physical access was collectively welcomed, such changes were perceived as been long overdue. Feelings ranging from anger to disappointment and frustration were expressed among women who were concerned that it had taken until the early twenty first century to attain the level of access to the environment that people now have. In addition, the slow pace at which improvements were felt to have taken place, had, for all the women led, to a feeling of being less important than able-bodied persons and a perceived sense of being second class citizens. Many women felt that smaller shop owners and businesses have been slow and/or unwilling to make the changes required of them. Loopholes within the DDA continue to be used by shops and businesses to avoid making their premises accessible to people with impairments because of the financial costs involved. In situations and locations where access difficulties persisted, some women questioned how beneficial the DDA had been.

There was a group wide agreement that an inability to access the outside world over a prolonged period of time had the potential to impact on a woman’s mental well
being. Women who had grown up in an era when access to the environment and public places was either generally poor or non-existent, felt well qualified to describe how this had impacted upon their mental well being. Jackie, a wheelchair user for almost thirty years described how:

"For such a long time there were so many places that you just weren't able to get to or get into and there was often for me this real sense of isolation and being cut off from the outside world. It was just like you didn't belong. But we didn't question the lack of access as it just seemed that was how things were."

Jackie (age 43, acquired spinal cord injury)

Jackie described how throughout the 1980s it had felt to her that everything was a battle in relation to either physically accessing places or accessing services relating to her impairment. Jackie talked of how, having completed her further education she would have liked to have studied at university but that a lack of access within UK universities for a wheelchair user with a high level of support needs prevented her from doing so.

"At college they were quite supportive of me wanting to pursue a university education but when I approached the universities themselves, there was a sense of them been taken aback that someone in a wheelchair wanted to study for a university degree. I think it comes back to how attitudes were then and an assumption that people with physical impairments didn't go to university when they finished school well people were expected to either spend their days at day centres or adult training centres or just at home."

Jackie (age 43, acquired spinal cord injury)

Elisabeth described the feelings of frustration that she recalled experiencing both during her childhood and young adult years in the 1950s and 1960s.
“I used to get so frustrated when my brother and sister would go out to play or just hang around with their friends and you would be left watching from the window as mum would say that I wasn’t safe to be out with them. Then when I left school I spent all these years at home and would fill my time by reading because I couldn’t access any of the local places like shops or cinemas. Over the years it really got me down as my brain was crying out for stimulation and contact with the outside world but the physical world was sending a strong message that people like me weren’t really a part of it. When I finally got the opportunity to go to a night class after eleven years at home it was like I had entered a whole new world and one where I had been excluded from for far too long. I often say to people that I feel I didn’t begin to live my life until I was twenty eight up until then it had been more of an existence.”

Elisabeth (age 62, congenital progressive impairment)

Helen who was born with her impairment and had been a wheelchair user from a very young age expressed similar thoughts. Although Helen was twenty years younger than Elisabeth, her experience was also one of growing up in a hostile environment that afforded poor wheelchair access.

“I can remember coming home from school on the adapted bus and my brothers and sisters would be allowed out to play with friends when they got home from school but I couldn’t go with them as the fields were at the top of a hill with lots of steps so we rarely got to play together outside the home. And I couldn’t spend time with friends from school either as the bus would then take them home which could be miles away as the special school took in kids from miles around.”

Helen (age 43, congenital stable impairment)

Helen described such experiences as leading to a sense of feeling excluded from a society in which she was unwelcome. However, Helen talked about the positive benefits that had come about in recent years since the implementation of the Disability Discrimination Act and of the welcome effects the legislation had had on her mental well being. The study’s findings in relation to this area will now be examined.

The DDA and Mental well being.

Findings from the study clearly illustrated how, in addition to the improved access to public spaces that implementation of the DDA brought about, benefits were felt in other ways. Each of the women described how for them the DDA was considered to have
impacted on their mental well being.

Carly spoke of having felt fortunate to have grown up at a time when access, in addition to attitudes to impairment and disability were all moving forward in a positive direction.

"I think that if I had been born twenty years earlier then my life experiences would have been very different as access to public places for anyone with a disability twenty years ago was so restricted. I feel lucky that I’ve been able to go to mainstream school and now I’m in mainstream college studying for A levels and hoping to go to university to study for a social work degree and I don’t think those opportunities would have been there for me back then. At the very least my choices I know would have been much more limited."

Carly (age 18, congenital stable impairment)

Several women within the group spoke of additional benefits that the disability legislation had brought beyond improved physical access. These women described how they became able to access support, aids and equipment to assist with studying or employment. Frankie described the positive ways in which the Disability Discrimination Act had benefited her.

"The DDA has been great for me in terms of the improved access on and around the university campus. Where as before I would struggle on many days with heavy doors and climbing flights of stairs, the automatic doors and installation of lifts have made things a lot better and had a real impact on being able to maintain my energy levels. And for me the assistance I have had with equipment etc has been invaluable and that help wouldn’t have been there not so long ago."

Frankie (age 27, congenital fluctuating impairment)

In addition to the benefits that the DDA brought to Jackie’s life, she described how the Access to Work scheme had enabled her to do her job effectively on a daily basis through the personal and practical assistance she was afforded.
When the building I had been working in for years finally got a lift installed it made such a difference to my working day. For years I had to trudge around the outside of the building in all weathers to access it at another level. Yet when it got put in it seemed madness that it hadn’t been done years earlier but then of course there was no obligation to do so before then. And better access for my wheelchair meant that I could do my job pretty much like everyone else and that was good for me mentally. Jackie (age 43, acquired spinal cord injury)

Elisabeth talked about how, since the DDA was implemented, the opportunities for her to access public spaces and to engage in diverse activities had steadily grown. In addition, it was felt that her current life opportunities and the structure of her daily life were unrecognizable compared to what they were twenty to thirty years ago. Improvements in physical access had for Elisabeth in turn helped to provide the mental stimulation which she had longed for over many years. For example, Elisabeth described how she was now able to access theatres, museums and social meeting places which in turn enabled her to have social contact with other people. This she stated had reduced her long held feelings of being socially isolated which in turn had a positive effect on her mental well being.

The progress that had been made over recent years in making public transport accessible to people with physical impairments was welcomed unanimously. Improved access to public transport was described by all the women as having been key to them accessing places or participating in activities which previously they had been excluded from. Improvements in access to both public areas and public transport were felt by each of the women to have led to a greater sense of inclusion for them personally. In turn that was viewed as having had a positive impact on mental well being in terms of feeling more integrated in society as opposed to historically a feeling of being excluded from it.
However, the need for further progress to be made in making all forms of public transport comprehensively accessible to people with physical impairments was expressed by all the women. Access to public transport within their home areas was for the majority of women described as patchy and variable. Accessing suitable transport was identified as being a greater problem for women who lived in rural or semi rural locations where transport links were more limited than in urban areas. Maria described the barriers that she faced in accessing transport in her home town that could accommodate her powered wheelchair.

Maria described the barriers that she faced in accessing transport in her home town that could accommodate her powered wheelchair.

Maria (age 51, acquired progressive neurological impairment) Similar sentiments were expressed by other women in the group who were wheelchair users.

In terms of progress over recent years, the data illustrated a shared agreement across the group that there now exists within society a much greater realization that people with impairments want the same level of access to transport, the environment and goods and services as able-bodied people. There was also a collective belief that access to public transport needs to be equal for everybody, regardless of their level of physical ability, if people with a physical impairment are to live in a society that is fully inclusive.
PART THREE: PHYSICAL IMPAIRMENT AND SELF IMAGE.

In addition to examining the impact of attitudes towards impairment on mental well being, the study also discussed whether the attitudes of able-bodied people towards impairment impacted on the women’s self image. Further, it examined the way in which disability and impairment is portrayed within different realms of society (such as the media, including on television) and whether such portrayals were believed to contribute to the women’s perception of their self image.

For Helen having a positive self image was felt to be important to her. Both Helen and Lisa talked of how they liked to look presentable as this provided them with a sense of feeling normal and of being like other women. In addition, Lisa stated that by dressing smartly this gave a boost to her confidence when out in public and to her sense of self worth overall. Helen described how, in spite of her continual efforts to feel normal she considered her self image to be poor and that for many years she had considered herself a burden to her family. In particular, Helen felt that her self image had been affected by her speech impairment as this was something, that, in addition to her physical limitations, increased her sense of feeling different from a normal woman.

Elisabeth’s experience of living with a physical impairment which had significantly affected her mobility and physical appearance from birth, was also felt to have impacted on her self image. For many years Elisabeth believed, that as a female with a physical impairment, she was inferior to able-bodied people.

“Well you never saw people like me out and about in the streets or in public places or people like me in magazines or on the television so it just felt that to be like me must be a really negative thing.”
Elisabeth (age 62, congenital progressive impairment)
Similar thoughts were expressed by Alison. In addition, she attributed her poor self image to the fact that being the first born to a farming family, she was a disappointment to her father.

It’s well known in farming circles that sons are valued more than daughters because traditionally sons will continue the farms work down the generations. My dad I know was disappointed when as the first born I was a girl and even more of a disappointment that I was born with a disability. Growing up he showed me little love or affection which was in total contrast to the affection he showed my brother when he was born some years later and that has impacted on my self image for a long time.

Alison (age 39, congenital stable impairment)

A turning point in Elisabeth’s self image becoming more positive she attributed to reading a book in which a group of women talked about their experiences of living with a physical impairment. Prior to this, Elisabeth described how she had grown up with a belief that she always had to compete on other people’s terms and fulfill their expectations. Also she grew up with an expectation of her that she would conform to other people’s normal behaviour of which she gave an example;

In many ways my upbringing was quite a strict one and my parents were very particular about good manners. I can remember my mother always trying to get me to hold a knife and fork properly and it was a long time before she truly accepted that because of my malformed joints I couldn’t hold cutlery in the so called normal or proper way. So because of that we never went out as a family for a meal as mother thought that if we went out I would look out of place and that people would be looking at me.

Elisabeth (age 62, congenital progressive impairment)

Elisabeth spoke of the strong belief she now holds of it being what you do that matters and not how you do it and that if people are unable to accept that then she believed the problem to lie with them. Further, she spoke of striving to maintain a positive self image and to not be affected by pressures to do things in a so called normal way.
Throughout the group there was agreement of the significant role played by the
media in shaping the self image of women with physical impairments. Within
mainstream television, in magazine publications or in film and theatre women felt there
to be minimal real or accurate representation of women with physical impairments.
Whilst there was recognition that over the past decade disabled people or characters
have been seen on television, they were felt to have overwhelmingly been cast in
programmes of which either the subject is disabled people or the content disability
related. Feelings of dissatisfaction were expressed concerning the portrayal of women
with impairments in the media either as heroes or of having achieved some amazing
feat, as charitable cases or victims that are worthy of pity and sympathy. Such
representations the data showed were felt to offer an inaccurate and unrealistic
reflection of how the majority of women with physical impairments live their lives. In
addition, portraying the lived experiences of women with physical impairments in such a
way was felt to contribute little of benefit in improving attitudes towards or awareness of
impairment and disability.

The younger women in the study (aged under 45) talked about how the content of
women’s magazines, in particular those which focused on fashion or beauty could affect
their sense of self worth. The absence of women with physical impairments in these
publications and the constant presence of slim women with so called perfect body
figures, were described as reinforcing a feeling that as women with physical
impairments their bodies were far from perfect and added to their sense of not being
normal. However, these women also recognized that the use of such models in
women’s magazines has been widely reported as having an impact on the self image of
able-bodied women and that it was not an issue solely for women with physical
impairments.
PART FOUR: THE IMPACT OF PHYSICAL IMPAIRMENT UPON RELATIONSHIPS.

The impact of living with a physical impairment upon relationships with family members and other significant people in their lives was a further area that this study examined. In the one to one interviews, a range of individual experiences were talked about in relation to whether, and in what ways the women felt that their physical impairment had impacted upon relationships with spouses, relatives, family members or friends.

Katy, who was born with her impairment did not encounter any difficulties within her immediate family as her younger siblings had always known her as someone with a disability. After the initial curiosity of her siblings in establishing why she was ‘different’ her physical condition was not an issue for them. However, Katy felt that if her impairment had been acquired then her experiences may have been different as she believed there would have been adjustments to make as her impairment was integrated into the family unit. Throughout her childhood, Katy recalled having few friends having initially been educated at home and later attending a special school which drew children from a large geographical area and therefore provided little opportunity for friendships beyond the school environment. Opportunities to form friendships were further hindered during Katy’s childhood years in the 1970s by a lack of access to public transport and a non-availability of wheelchair accessible vehicles. Katy recalled how she did not make lasting friendships until her mid teens when she attended a further education residential college where an accessible environment allowed her the opportunity to spend time regularly socializing with her peers.
Alison described above how a difficult relationship with her father as she was growing up had impacted on her self image, and that difficulties with their relationship continued to exist. In terms of friendships, Alison described herself as having a sociable, outgoing personality and it was this that had helped her to make friends both with people with and without impairments. She talked of the frustration she felt when encountering able-bodied people who assume that all her friendships are with people who themselves have a physical impairment and express surprise when told this is not the case. Whilst Alison recognised that this may have been likely during decades when opportunities to socialise with able-bodied persons were very limited, she believed that improved environmental access meant that those opportunities were now much greater and that the attitudes of some people in society needed to change to reflect this.

I have lots of friends as I’m quite a sociable person...some are able bodied and others aren’t but whether or not they have an impairment isn’t of consequence to me at all as it’s about the person themselves and the friendship that we have. I work in an environment where the work force is predominantly able bodied so I’ve made friends there but I’ve also got friends from my days at residential college for students with disabilities and I value all those friendships equally.

Alison (age 39, congenital stable impairment)

For Alison the main area in which relationship difficulties had been experienced was following her marriage at the age of nineteen. Although her husband also had a physical impairment, he was not a wheelchair user and Alison talked of how her in-laws would have preferred that he married an able-bodied woman as opposed to herself, a wheelchair user. Whilst Alison believed that the love for her husband had been real, she felt strongly that the tensions created by her in-laws attitude towards her led to considerable upset and subsequently the breakdown of her marriage four years later.
Maria talked emotionally of the difficulty that her husband had in coming to terms with and accepting her diagnosis of Multiple Sclerosis. Whilst he found her progressive decline traumatic to witness, Maria described how as a family unit they coped as best as they knew how. Maria stressed how it was important to her that she remained strong for her children who periodically became upset at the downward changes they were witnessing in Maria’s physical ability. In terms of friendships, as her condition progressed and her ability to do things declined, Maria spoke of many of her friends drifting away, due she felt to them feeling uncomfortable or unsure how to be around her. Individuals, who prior to the onset of her impairment Maria termed as friends were felt to not cope well with ill health and that the decline in Maria’s condition was upsetting for them to observe. In addition, Maria felt that for some of her friends there was a fear of confronting that what had happened to her could equally happen to themselves. There were however a small number of people who she considered to be her true friends. These were people who Maria stated had stuck by her and who continued to provide practical and emotional support during both the good and the bad stages of her progressive condition.

Having acquired her spinal cord injury, Jackie talked about how her family had provided support and encouragement in the process of rebuilding her life. In addition they were positive in integrating her impairment into the family environment and circumstances. Jackie explained how for many years her grandparents had difficulty in coming to terms with her acquired impairment for which she believed the cause was two fold. Firstly, she recognised that during her grandparents generation people with impairments lived in institutions and were not felt to have a place within society. Secondly, having acquired her impairment at just thirteen years of age, Jackie believed that her grandparents considered it be a tragedy that their grand-daughter would be
spending the rest of her life unable to walk and they viewed her life as having little quality.

For Jackie, making and sustaining friendships in the initial years after acquiring her injury were not experienced as being problematic. This she attributed to her young age and that her peers enjoyed the novelty of going out with someone who used a wheelchair and it was not something that they were embarrassed by or felt uncomfortable with. These friendships were considered by Jackie to have played a major role in helping her to overcome the physical barriers to the environment and public places that were commonplace throughout the 1980s. However, the age at which her impairment was acquired was felt by Jackie to have been relevant to her experiences. Jackie believed that if her impairment had been acquired ten years later i.e. in her early twenties, then her experiences of friendships may have been very different and that the dynamics of those friendships and relationships were likely to have been altered. Jackie believed that people in their early twenties for example, would have grown in maturity and would not lift her out of her wheelchair so they could take it to turns to have a go at driving her powered wheelchair. Jackie also spoke of how many people, having reached their early twenties, would have settled into couple relationships and no longer went out on group adventures as they had done as friends some ten years previously.

Helen described having a difficult relationship with her parents from a young age and that she had grown up feeling hated by her mother and unloved by her father. Growing up, Helen said that emotional support was provided by an older sibling with whom she continues to have a close bond. Helen believed her upbringing had led to significant emotional and psychological difficulties throughout her life and that she had
lasting memories of feeling unloved as a person. However, despite the negative memories of her childhood and young adult years, Helen stated that she neither blamed nor felt anger towards her parents. Over many years, Helen talked of how she had come to recognise that during the years she was growing up there was little support given to parents raising a disabled child and little information for them to access relating to her particular impairment.

Elisabeth, born with her congenital impairment, described how her parents had always sought to provide the best available care and quality of life for her as she was growing up. However, she recalled how at times their approach left her with a sense of being controlled. Elisabeth recalled that as she grew up she was neither allowed to take responsibility for, or be involved in, decisions that were being made about her. Over a number of years this led at times to feelings of resentment towards both her parents and others involved in her medical care. As an adult in her forties, Elisabeth recalled how family members had continued to provide any practical support that was required. However, during these years there were times when Elisabeth considered that her need for emotional support was greater than that for practical support but that this was absent.

“I can remember vividly when I was undergoing breast surgery and was really anxious to know whether the breast cancer had come back and I felt a real need for some emotional support at that time but it wasn’t there for me. Over a long time I had feelings of resentment towards my sister as I had always tried to be there for her through any difficult times and it has tarnished my relationship with her in the long term.”

Elisabeth (age 62, congenital progressive impairment)

Frankie spoke of her partner, family and close friends having provided her over many years with practical and emotional support. A close relationship with her parents was described by Frankie as being of great importance of her. Whilst at times she felt a
sense of them been over protective, the encouragement and support given to Frankie which enabled her to pursue as normal a life as possible within the limitations of her condition was valued highly. The importance of the qualities in other people of being considerate and understanding towards someone living with an impairment characterised by unpredictability and fluctuation were emphasised by Frankie, who believed that her partners ability to be both of these was key to her strong, long-term relationship with him.

The onset of Louise’s physical impairment at the age of thirteen led to varied reactions from family members, in particular upon their realisation that the significant impairment was to be a permanent feature of Louise’s life. Whilst some family members were described as having been hugely supportive, there were others who, whilst happy to have a telephone conversation with her, seldom had face to face contact. It was these family members who, over many years were felt by Louise to have provided minimal practical assistance or emotional support. For the siblings who had provided her with support over almost three decades, Louise explained how their own children had grown up knowing her as a wheelchair user and that no relationship difficulties with her nieces and nephews were experienced once they understood why Louise used a wheelchair and that they accepted her as she was.

Where friendships were concerned, Louise experienced a number of difficulties. In the initial months after acquiring her impairment Louise described how her able-bodied friends had visited her in hospital but that contact with them lessened with the passage of time.
During the first few months in hospital friends would visit and talk about how long it would be before you were better and able to go home. But of course as time went on and it became clear that you wouldn’t be going home and there would be no recovery I think they weren’t quite sure how to deal with that. They didn’t know what to say but looking back I’m sure if I had been one of them I would have felt the same. One day they have a friend who is able to walk, run and do all the normal stuff and then weeks later she is lying in a hospital bed paralysed from the neck downwards and not able to do anything for herself. 

Louise (age 39, acquired progressive neurological impairment)

Opportunities to make friendships during her teenage years were for Louise restricted by the extended periods of time that she spent as a patient on a childrens ward with patients who were often much younger than herself. She found patients who were of a similar age either too unwell to form friendships or on recovery they would return home and not maintain contact despite their well intended promises. In terms of forming friendships at special school, Louise expressed views similar to those of other women who had attended special school. Whilst for Louise there was some contact with friends during school hours, equally she recalled how break times or lunchtimes would often be allocated to physiotherapy or hydrotherapy sessions. In addition, as talked about by other women, the opportunity to socialise outside of school was curtailed by the distances at which people lived from each other and a lack of access to suitable transport.

Following her discharge from a four year stay in hospital, at the age of eighteen Louise moved to live within a residential care home for young adults with physical impairments. Louise described the difficulties faced whilst living there of having a relationship with a fellow resident, due to the lack of privacy that was afforded to them.
There was a chap at school I had been friends with and we became quite close but only got to see each other at school with me spending my weekends and evenings at the hospital. It just so happened that he lived in this residential home and so whilst we got to spend more time together within the home it was really difficult to have any sort of girlfriend-boyfriend relationship as there was very little privacy and relationships between residents were not allowed in the so called rules of the home.

Louise (age 39, acquired progressive neurological impairment)

Having now lived with her acquired impairment for almost thirty years, Louise stated that she had a small circle of friends who had stuck by her over a long period of time since acquiring her impairment. These friends, Louise stated, saw her as a person first and not foremost as a woman with an impairment. For a long time Louise described how she had difficulty in accepting this to be the case but now believed it to be true.

In contrast to the difficulties experienced by the women who had attended special schools in making friendships, women who attended residential colleges of further education for students with a physical impairment experienced few barriers in forming friendships. However, these women were keen to emphasise that the common thread of having an impairment did not constitute making automatic friendships. The data illustrated how friendships had been made based on having things in common or similar hobbies or interests. Friendships that were made were described as being forged in much the same way as able-bodied people form friendships.

More so than her physical limitations, it was Helen’s view that her communication difficulties had been significant in her efforts to form friendships with people. Whilst advances over recent years in information technology were perceived by the women as having contributed to breaking down some of the traditional barriers in making friendships, this for Helen had been mainly within the home setting for example through internet forums or social networking sites. While such advances were welcomed,
contact with friends through use of the internet was not felt by Helen to equate to face to face physical contact with people within routine social settings such as for example, coffee shops or pubs.

Elisabeth talked about the lack of opportunity to make friends at boarding school due to all the pupils having complex needs and thus affording little opportunity for interaction with one another. Upon leaving school in the mid 1960s Elisabeth spent eleven years at home due to a large degree to poor environmental access. Elisabeth recalled how her friends during those years were people who were much older than herself, and who in reality were friends of her parents.

Based on her personal experiences of relationships Elisabeth believed that disabled women have more difficulty than disabled men in forming couple relationships. In addition, like Alison, she believed that relationships could be affected by attitudes in society towards people with impairments. During the years of her marriage to an able-bodied man, Elisabeth recalled how people would often express surprise that Charles was her husband, assuming that he was the person who looked after her. However, Elisabeth believed that attitudes towards impairment had shifted significantly since she entered into adulthood in the late 1960s. Following the death of her husband, Elisabeth talked of how some years later she sought a relationship through a number of mainstream dating agencies. Such attempts were all described as negative experiences.

“I had contact with two agencies, we’re talking early 1980s so not that long ago and when I made initial enquiries about joining the agencies and mentioned my disability the response was appalling basically saying that they couldn’t see how an able bodied male would want to have a relationship with someone with my level of disability and they suggested that an agency just for disabled people would probably be my best bet.”

Elisabeth (age 62, congenital progressive impairment)
These experiences were felt by Elisabeth to have had a long term impact on her self image and had resulted in Elisabeth abandoning her attempts to seek a relationship.

Judith talked about the difficulties that her grown up children initially had in coping with the affect of her stroke and her reduced physical abilities. In addition, Judith recalled how her grandchildren had been fearful of visiting her in hospital as they were confused by what had happened to her and required comforting and reassurance about what was taking place. Following her stroke, Judith recalled how friendships were not maintained and that though work colleagues and friends had visited regularly during her long hospital stay, their contact drifted off when she returned home. This was felt by Judith felt to be due to people being unsure how to be around her, what to say, or how to help.

“It was as if within the hospital environment people felt safe visiting. Visiting you in hospital was almost the expected thing to do and people would know it was only for an hour or so and then they would go home. But once you were back at home it was as if things were different and people didn’t know what to say. People who you were used to seeing in your home before and at ease suddenly seemed uncomfortable being there or at least that was how it seemed.”

Judith (age 61, acquired impairment following stroke)

Prior to her stroke, Judith believed that her mainly female friendships had been forged through working in the same workplace and that they had work in common. However, when work was no longer a part of Judith’s life the foundation of their friendship was felt to have disappeared. While Judith described feeling hurt by the reactions of people whom she had thought were true friends, there was also a realisation that prior to her stroke, she had no experience of knowing or having regular contact with anyone with a severe physical impairment. Therefore, Judith acknowledged that her response was likely to have been no different than that of her friends towards
her. Since acquiring her impairment Judith talked about how she had made more friends than she had during all her years lived as an-able bodied person. In addition, Judith had been presented with opportunities which as an able-bodied person she believed that she may not have had.

CONCLUSIONS

Within this chapter the significance for the women in the study of the role played by external factors and their potential to impact on mental and psychological well being has been examined. The chapter has shown the existence of a group wide belief that a marked positive shift has taken place over the past two decades in the attitudes of able-bodied people and society in general towards physical impairment. The improved environmental access that has occurred in particular over the last decade has also been viewed as being instrumental in bringing about a positive shift in attitudes. However, the chapter also highlighted a collectively expressed belief that there remained substantial scope for improvement both in attitudes towards and awareness of disability and impairment.

The environmental and psychological benefits that women believed had resulted from the implementation of the Disability Discrimination Act were examined in Part Two. The chapter demonstrated within Part Three how the media was considered to be highly influential in impacting or having the potential to impact on the self image of women with physical impairments. Within Part Four the wide variety of ways in which women felt that their impairments had affected relationships with family members and other people significant to their lives was examined.

Across each of the areas examined within the chapter, there has been a clear illustration of how women's different life experiences and the ways in those experiences
were seen to have impacted on mental well being, had been determined by a number of factors. The era during which women grew up and their age were shown to have been significant to how women talked about their experiences both within different areas of their lives and within the context of their life overall. Historical shifts in areas such as attitudes towards impairment and increased awareness and understanding around disability were shown to be reflected for example, within how women talked about their experiences of friendships and how, or if, their impairment had affected family relationship or dynamics within the family unit. Women who had grown up during an era when poor environmental access meant that there was little integration of people with impairments and able-bodied people, recalled having had few opportunities to form friendships. In contrast, the chapter has shown that far fewer instances of barriers to forming friendships were reported among the younger women in the study who had grown up at a time when there was opportunity to access mainstream schooling, access to the environment was improving steadily, and people’s awareness around disability was becoming more widespread.

Improvements in access, in particular within the past decade were seen to be welcomed for the removal of physical barriers which for much of the twentieth century had prevented access to a large degree to public spaces. However, the changes were also seen to have had a positive effect on the mental well being of all the women through the sense of inclusion within society that was considered to have resulted from improved environmental access. In particular, better access to the environment was welcomed by women who had grown up during decades when their access needs had not been considered and opportunities to access public buildings, spaces etc and to interact with other people with or without an impairment were severely limited. Improved access was also seen to have increased opportunities for the younger women to enter...
into higher education or to work in an environment alongside able-bodied colleagues, both of which led to a sense of feeling included in a society that acknowledged their specific needs or requirements. This contrasted markedly to the experiences of women who had grown up during the mid-twentieth century when there was minimal opportunity to access higher education or meaningful employment, and women had felt excluded from a society which only catered for the needs of people who were able-bodied. Findings from this chapter will be considered further in later discussion.
CHAPTER SEVEN

PHYSICAL IMPAIRMENT AND MENTAL DISTRESS

Within this and the subsequent chapter the research findings relating to the women’s personal experiences of mental distress are discussed. The chapters examine whether women with a range of physical impairments who have experienced mental and/or psychological distress identified a shared set of barriers to accessing mental health services.

Part One of the chapter focuses on the women’s individual accounts of their experiences of mental distress and examines the factors which they believed were significant in contributing to those experiences. It shows how, for many of the women, both the nature of their experiences and the factors which were identified as having contributed to those experiences were significant to the terms they used to describe their experiences. The data indicated that women who were referred to Psychology or Counselling services referred to their difficulties in the main as ‘psychological problems’. Other women, who had received treatment and/or support from specialist Mental Health services in contrast were seen to describe their experiences as ‘mental distress’ or ‘clinical depression’. For these women, such terms or diagnoses had commonly been used by the mental health professional with whom they had worked. For women aged over fifty, they considered themselves to have grown up during an era when there was within society a marked stigma associated with ‘mental illness’. Consequently, the data highlighted their endeavours to avoid terms such as ‘mental health problems’ preferring instead to described their experiences as ‘times of feeling sad’ or ‘feeling down’
Part Two and Part Three discuss two related areas. Firstly, Part Two examines the study’s findings relating to both individual and collective experiences of accessing mental health services. Part Three then discusses the findings relating to women’s experiences of using the services which had been accessed. Chapter Eight will then examine the topic area of counselling for women with physical impairments.

**PART ONE: EXPERIENCES OF MENTAL DISTRESS.**

Findings from both the individual interviews and the focus group demonstrated that amongst the women many different forms of mental and psychological distress had either previously been or were currently being experienced. Equally, the data identified a range of factors which the women believed were either of relevance to or played a significant role in contributing to their experiences of mental distress. In addition, the data showed that for both the women born with their impairments and those whose impairments were acquired, their experiences of distress varied widely in their duration, frequency and perceived severity.

**Bereavement and Mental Distress.**

Within the group, a number of women had suffered a family bereavement or the loss of someone who was significant to their lives. They spoke of the mental distress which they experienced following their loss and how access to a counsellor during that time would have been welcomed. The wider availability of bereavement counselling that was seen by these women as now existing in society was felt to be indicative of how bereavement can lead to an experience of mental distress both for women (and men) with or without an impairment.
Born with her physical impairment, Katy spoke of her belief that the periods of depression and episodes of feeling down that she had experienced for more than twenty years, were not solely related to her impairment. The death of her father (with whom Katy had had a close relationship) and a subsequent admission to residential care some months later were both identified as factors which had significantly contributed to two of her acute episodes of depression.

"From a very young age I can remember my dad helping a lot with my care and doing all the lifting and carrying me. He was always trying to devise ways so that I could do things for myself and be independent and he took me everywhere with him so we had a very close relationship and I was devastated when he died and became very depressed. Because mum couldn’t manage on her own I ended up going into residential care which was full of people much older than me and it was awful you were basically a number and I had no control over any part of my life. It felt like you were losing your identity so I was very depressed there and it wasn’t until I returned home some months later that my mental health improved."
Katy (age 43, congenital stable impairment)

Family bereavement was also identified by Elisabeth as the trigger for one of her acute episodes of mental distress. The loss of her husband when Elisabeth was in her early thirties was described as initially causing a deep sense of grief. Over time this had developed into a state of depression that left her feeling unable to cope with everyday life. Elisabeth’s depression was exacerbated by the deep sense of anger she felt towards medics who for many months had dismissed her concerns about her husband’s health.

"Only a few months after we married I could see that Charles wasn’t well and we were backwards and forwards to the GP who insisted it was nothing and because they were doctors he thought they were right but I could see he was going downhill but nobody would listen to me and I was told that I was neurotic. By the time the cancer was found it was too widespread to treat and he died within a few weeks. The anger just built up inside me over time and that combined with the grief, well I became very low and depressed."
Elisabeth (age 62, congenital progressive impairment)
In her interview Elisabeth talked about other factors which she felt had played a role in the episodes of mental distress which she had experienced during her adulthood. These shall be examined within the chapter.

**Physical Impairment and Mental Distress.**

Pippa recalled her first experience of depression occurring during her mid-teens when she was subjected to bullying and abuse by care workers employed at her boarding school. Pippa spoke emotionally of how senior school staff were unwilling to listen to the distress that she was trying to express, and that this was compounded further by her communication difficulties. In addition, her sense of isolation was heightened by the long distance that she was living from home and her inability to have regular contact with family. Pippa recalled how, for many months her mental distress was untreated and subsequently escalated into episodes of self harm and ultimately resulting in Pippa making an attempt on her life. Whilst Pippa considered her actions to have been a desperate cry for help, it was the continued unwillingness of other people to listen to her distress which led Pippa to attempt suicide. She believed this to have been the only option available to her that was likely to result in someone listening to her distress.

This was in contrast to a second suicide attempt almost twenty years later in 2006 which Pippa stated was indirectly linked to her physical impairment. Having undergone surgery related to her impairment, she recalled how the unsuccessful operation had left her in considerable pain for many months and also resulted in her mobility being further reduced. This left Pippa feeling that her future life would be one of poor quality, and that she had felt unable to face up to that likelihood.
The surgery was meant to make things so much better and I felt really positive about it so when it was unsuccessful that was a real blow. The surgery caused real disruption to my everyday life and meant I was off work for months. Yet work was key for me in providing both the mental stimulation and social contact I needed to keep me well mentally. Pippa (age 35, congenital stable impairment)

An enforced prolonged absence from work, combined with her post-surgery pain, led to Pippa becoming acutely mentally unwell and subsequently led to a suicide attempt. Pippa spoke about how her friends had played a vital role in assisting in her recovery process while she was suffering from acute clinical depression. This, she stated was in total contrast to her unsatisfactory experiences of receiving support from mental health professionals working within the statutory sector. Women’s experiences of using mental health services will be discussed in Part Three.

Pippa’s experience was similar to that of Carly who also believed that her first experience of mental distress had been linked to her physical condition. Carly recalled in her early teens becoming depressed following major surgery related to her impairment. The experience of undergoing surgery was, for Carly, traumatic and the prolonged pain and slow recovery process had led over time to a downward spiral in her mental well being. As a result of being confined to bed, Carly found herself unable to attend school and she found that the absence of regular contact with her friends and other people affected her psychologically.

Frankie spoke of the psychological difficulties she had experienced as a result of her physical impairment not always being immediately visible to others:
Frankie (age 27, congenital fluctuating impairment)

Whilst Helen had experienced mental distress since her mid-teens, a diagnosis of clinical depression was not made until her late twenties at which time she suffered a nervous breakdown. Helen recalled how other people made an assumption that she was sad because of the physical limitations that resulted from her impairment. Further, her episodes of crying and screaming were viewed by others as a means of seeking attention even though Helen argued that this was not so. Whilst Helen considered her mental distress to be partly linked to her physical impairment and the impact it had on her everyday life, other factors were also felt to be relevant in contributing to that distress.

Helen (age 43, congenital stable impairment)

The unwillingness of people over a number of years to listen to the mental distress that Helen was experiencing, was, she stated, compounded by her speech impairment. Difficulties in communicating verbally with others were identified as having created a barrier for her in being able to express how she was truly feeling. Technological advances in recent years were viewed by Helen as having enabled her to communicate with people more easily using a range of equipment. However, access to communication aids during the 1980s when she initially experienced acute mental
distress had been very limited, and she had struggled to access appropriate support for her distress.

Having lived almost continually with varying levels of mental health difficulties for thirty years, Helen spoke of living constantly with a desire to be totally free of those difficulties. Conversely, Helen considered her mental health difficulties to be as much a part of her life as her physical impairment was and that she was unable to recall a time when she was not experiencing some form of mental health difficulty. Whilst her depression was not always at the front of her mind, it was described by Helen as a presence that never went away.

The experiences of these four women served to reinforce one of the main themes to emerge from Chapter Five. Here, women stressed the importance of mental health professionals recognising that whilst some women may view their impairment as being relevant to an experience of mental distress, the impairment per se was seldom considered to be the primary or sole cause.

**Work and Mental Distress.**

Extended absences from work, a need to give up employment as a consequence of their physical impairment, and the reduced social contact that resulted from that, were identified by other women in the study as factors that had been significant to their experiences of mental distress. Judith explained that prior to her stroke, work had played a major part in her life, providing her with both paid employment and regular social contact with work colleagues. Having found herself unable to return to work following her stroke, Judith recalled how this left a void within her life. In addition, she spoke of the struggle she had over many months adjusting to that void, and described
how the lack of contact with other people over a period of months had led to her becoming socially isolated. These two factors combined were viewed by Judith as having led over a period of months to an onset of depression. Judith stressed the importance she now placed on having regular social contact with others in order to maintain her positive mental health. On a daily basis, Judith spoke of making efforts to visit locations that provided an opportunity for social interaction with others, for example, a luncheon club or the stroke support group. A similar view was expressed by Jackie, who experienced anxiety and turmoil when confronted with being unable to return to the job in which she had worked for twenty years, following a decline in her physical health.

“When I was faced with finishing work I was really anxious and in turmoil. Work didn’t just bring structure to my daily life, it gave me a sense of living a normal life and gave me something I valued highly which was financial independence.”

Jackie (age 43, acquired spinal cord injury)

Jackie described how the process of counselling had provided her with the opportunity to work through the anxiety that she was experiencing and to turn her life in a new direction.

Whilst for these women the absence of paid work was identified as being linked to their experiences of mental distress, the data showed that for other women, the severity of their mental distress left them feeling unable to cope with their work environment. Helen expressed the view that over many years her mental distress had been more disabling than her physical impairment by virtue of her mental distress affecting both her body and soul. She described how, at the height of her distress she had been unable to fulfil her commitments to both paid and voluntary work, having felt unable to function within those capacities. Similar thoughts were talked about by Alison who outlined the ways in which at times her mental distress had impacted on her.
Living with my physical impairment I’m still able to brush my teeth and comb my hair but when my depression is at its worst it makes me feel like I can’t even get out of bed in the morning and I can’t face going to work and having to be around other people. In that way I would say that my mental distress when at its worst makes me feel more paralysed than my impairment does.

Alison (age 39, congenital stable impairment)

Elisabeth also identified work as having played a major role in one of her acute episodes of clinical depression. The mental distress she endured in the late 1980s was described by Elisabeth as having resulted from acute stress that she was suffering within her workplace and feeling unsupported by her managers during this time. In addition, her depression was attributed to the deep sense of loneliness that she was experiencing, having relocated from the Midlands area where she had lived for many years and where family and friends remained.

Acquired Impairments and Mental Distress.

In her interview, Maria spoke of two factors which she considered to have been significant to the onset of her mental distress. Firstly, a feeling of sadness was described for the individual difficulties and challenges that two of her adult children had previously faced, and were continuing to face in their lives. Due to the nature of her impairment, Maria had often found herself unable to provide the help or support that they needed at a time of crisis or difficulty. During these times, Maria talked about how she felt she had not fulfilled her role as a mother. In addition, she recalled her most acute experience of what she described as a deep sadness as occurring in the months after her impairment was diagnosed, as she attempted to adjust to the massive change in life circumstances with which she was faced.

Judith, who acquired her impairment in her early fifties, stated that her most severe episode of mental distress was experienced in the months following her stroke. Her
distress was felt to be directly linked to the sudden onset of impairment and the long
term impact it was to have on many areas of her life.

\[\text{I think my distress was caused by a combination of things... one thing that really got me down was my long stay in hospital... I found the ward environment hard to cope with and there was no space where I could just be quiet with my thoughts as I was adjusting to a massive change in my life circumstances.} \]

Judith (age 61, acquired impairment following stroke)

The experiences of Maria and Judith were however in contrast to those of Louise and Jackie who also acquired their impairments. Jackie spoke of how initially she retreated into herself, having learnt that as a result of her spinal cord injury she would be unable to walk again. She talked about how it had been the support provided by fellow patients that pulled her through, and that her first experience of feeling depressed did not occur until many years after her injury was acquired. Louise, as was discussed within Chapter Five, also spoke of how the onset of her depression did not occur until four years after onset of impairment, and at a time when the reality that it would be a permanent feature of her life had set in.

Data from the focus group showed that Jackie and Louise shared the view that the young age at which their impairments had been acquired had been significant in their first experiences of mental distress, occurring long after their impairments were acquired. Louise and Jackie similarly described how they had naively believed that their young age would protect them from becoming permanently disabled. Whilst this was found to have been a false belief, it was not realised until three to four years after their impairments had been acquired.

In addition, both women stated that, having just become teenagers, neither were in long term relationships, parents, nor in a chosen career, all of which were factors identified by the women who had acquired their impairments as adults as being relevant.
to their experiences of mental distress. Therefore, both Jackie and Louise spoke of how they had been young enough to restart their lives, but within the parameters of a new set of circumstances.

Over the thirty years that she had lived with her acquired impairment, Louise spoke of experiencing several prolonged episodes of acute clinical depression and other forms of mental distress, many of which required mental health treatment. Louise talked of having seriously self-harmed during episodes of acute distress, and that over a longer period she had self-harmed more superficially. Through her actions of cutting herself, Louise described how for many years, self-harming became part of her coping mechanism as it provided her with a means of releasing some of the angst she was experiencing during these times of distress.

In addition, Louise described episodes during which she had experienced suicidal ideations. During the 1990s she had twice made attempts on her life, both of which were deemed by mental health professionals to be serious enough to warrant admission to acute psychiatric care. Louise’s experiences of mental distress, were, she stated, further compounded by a diagnosis of anorexia nervosa that was given in her late teens, some four years after her impairment was acquired. Prolonged episodes of clinical depression and eating distress were felt, over an extended period, to have led to her being identified by those conditions even when she was mentally well, and Louise expressed unhappiness at the way in which she believed labels had become attached to her.

Louise firmly believed that the onset of her eating distress was linked to a sense of loss, both for what she had gone through and for the opportunities she had missed out
on since acquiring her impairment. In addition, the eating distress was felt to have been associated with a realisation that there was to be no return to the life she had led before the onset of her impairment and that she would never regain her able-bodied status.

“I can remember things getting to a point where I had felt I had lost everything from my mobility to my teenage years and looking back now I think that my weight loss and continually reducing my food intake was a means of expressing that loss and it let me retain some control over one area of my life which had just changed so much.”

Louise (age 39, acquired progressive neurological impairment)

The onset of her eating distress at the age of eighteen was identified by Louise as the starting point of a long history of problems with food. However, she believed that she had now learnt to live with her issues with food, and that with the support of others she was able to be sensible and rational around her food intake. Having now lived with varying levels of eating distress for twenty-five years, Louise was of the opinion that a full recovery and a return to normal eating patterns was unlikely, but that she refused to give up hope.

Approximately fifteen years after acquiring her impairment, Louise spoke of twice attempting to end her own life. Both suicide attempts were, Louise stated, the result of feeling that she had had enough of living and her feeling unable to cope with life any longer. She spoke of how, in the preceding weeks and months, she had endeavoured unsuccessfully to get mental health professionals to listen to the distress she was experiencing around her suicidal thoughts. Subsequently, Louise’s distress escalated to the point at which she acted on those thoughts and ultimately resulted in an emergency admission to psychiatric care.
**Congenital Impairments and Mental Distress.**

Frankie recalled within her interview, how her first experience of mental distress in her late teens was related to stress that developed into a social phobia. She described how, before seeking therapy she had become unable to socialise with friends outside of environments where she felt safe and comfortable. In addition, Frankie explained how she had found herself unable to eat in the company of other people either within her home environment or a larger social setting. More recently, her experiences of stress and anxiety were felt to have been linked to the fluctuating effects of her impairment which had impinged on her academic progress and completion of her doctoral degree. However, Frankie felt that the successful therapy that she had undergone over five years meant that she now felt well able to recognise at an early stage the symptoms of a downward turn in her mental well being. At this time Frankie would take the actions which she deemed were necessary to halt any further decline.

For Elisabeth, the data showed that a number of factors had singularly, or combined, contributed to the episodes of mental distress which she had experienced over four decades. Firstly, a sense of feeling down and low over many years was attributed to seeing herself from an early age as being different and the odd one out. A realisation by Elisabeth during her mid teens, that her congenital impairment was to be a permanent fixture in her life, led to a prolonged and acute episode of depression. Subsequent episodes of mental distress were experienced by Elisabeth as her physical condition progressed and her mobility and ability to perform everyday tasks declined.
Stigma and Mental Distress.

Elisabeth talked emotionally of how, during her most acute experiences of mental distress she had felt ‘on the edge of going mad’. The difficulty she had in expressing to anybody the distress that she was experiencing was described:

‘On top of what I was going through I felt ashamed and embarrassed that I hadn’t been able to cope alone and I didn’t want to admit that I was suffering from mental distress as it felt like a sign of my own weakness. The thought of losing my job and colleagues knowing that I was getting treatment for mental health issues really bothered me and I tried hard to keep it from anybody.’ Elisabeth (age 62, congenital progressive impairment)

Elisabeth’s attempts to conceal her mental distress were felt to be linked to a historical stigma that was associated with suffering from a mental illness and which she perceived as still existing within society in the late twentieth century. A sense of reluctance to share with family, friends or other people relevant to their lives, that they were suffering mental distress and/or receiving mental health support for their difficulties was also voiced by other women. For example, Maria explained why she preferred to speak of her distress as ‘sadness’ rather than ‘depression’. This was because she believed that, for many years people had associated depression with mental illness and Maria was reluctant to become labelled as being mentally ill. However, she believed that the stigma that has historically been linked to mental illness was now significantly less than what it had been twenty to thirty years ago. Maria’s view was supported by some other women who believed that people now talk more openly in general about suffering from mental distress, and that it is now more ‘acceptable’ to be receiving mental health support.

Louise recalled how, during her in-patient stays on psychiatric wards she was reluctant to be visited by either family or friends due to the feelings of stigma she felt concerning the environment within which she was receiving treatment. Louise explained
how this had created internal conflict for her, as through her actions of banning visitors, believed herself to be reinforcing the myth that to be suffering from a mental illness was shameful, and that people with mental health problems were to be avoided.

PART TWO: ACCESSING MENTAL HEALTH SERVICES.

One of the main aims of this study has been to determine whether women with a range of physical impairments who had experienced mental distress identified a shared set of barriers in accessing mental health services. Part One has shown a spectrum of factors that were identified by the women as being significant in their experiences of mental distress. Likewise, the data showed the women to have had a range of experiences in relation to accessing mental health services. Having access to information, structural barriers to access and waiting for services were frequently identified across the group as having been significant to experiences of accessing services. These and other factors which were highlighted in the data will each now be examined.

Access to Information.

Throughout the data women highlighted how having access to current and appropriate information about mental health services was key to enabling them to access the services they required. Having access to information about services that could provide the mental health support they required was seen by each woman as being vital. Additionally, women spoke of the importance of information being jargon free and for it to state clearly what the service’s eligibility criteria were and what it provided. Women who had waited up to a year to be seen by a counsellor shared the view that at the point of referral their GP should have informed them that they were likely to endure a long wait to be seen. This will be examined further when discussing
waiting times for services. Finally, there existed a group wide agreement, that without readily available access to information and knowledge women were unable to begin the process of accessing the services they required.

**Structural barriers to access.**

Analysis of the data showed that for many women accessing a range of mental health services, in particular statutory sector services, had been experienced as a process that was fraught with difficulties. Women whose mobility was severely affected by their impairment had found that physical barriers (such as steps to buildings within which services were located or a lack of accessible transport to reach the location) had frequently prevented them at an early stage from accessing the mental health support they required. Structural barriers to access buildings were shown by the data to have been especially problematic for women who had attempted to access services prior to the introduction of disability legislation when service providers were not obliged to provide accommodation that was accessible to people with impairments. Katy’s experience of trying to access mental health support was typical of that of a number of the women.

> “When I became depressed after losing my dad and having to spend time living in a residential home, the GP said he would sort out someone that I could talk to as I was told staff at the home didn’t have the time. But it was hopeless—the two buildings they offered me to go to had a flight of steps to the door and there was no way you could access the building in an electric wheelchair. Someone suggested I could be carried into the building but they said that might be a health and safety risk. Eventually they found a place which involved a fifty mile round trip which was exhausting— in the end I gave up as the whole thing was just bringing me down further.”

Katy (age 43, congenital stable impairment)

Jackie and Carly both spoke of how the locations in which they had received mental health support had been adequate for their mobility requirements. However, as the required services were located within health centres that had been built post
implementation of the Disability Discrimination Act, the providers were obliged to ensure that the access requirements of people with a range of impairments were met.

**Waiting for services.**

Having been referred to mental health agencies, many of the women endured a lengthy wait before reaching a point at which an initial assessment for treatment was offered to them. Waiting times in excess of twelve months, whilst felt to be unacceptable were shown by the data to be common, and lengthy waits to be assessed were described as being a source of frustration for many women. Whilst waiting times were overall shorter for women who had been referred to their local Community Mental Health Team for an initial assessment, some women spoke of waiting in excess of a year for an initial assessment by Psychologists or Counsellors working within their local Primary Care Trust. These women spoke of feeling let down by the person who had been initiated the referral, (overwhelmingly the GP) who gave no indication at the point of referral of the likely waiting involved. Louise described her feelings of frustration:

> When my GP suggested it might be helpful to talk to a psychologist I was OK with that. .. having spoken to the GP a few times it was clear that he wasn’t really listening and to be fair I know their time is limited. But when I got a letter telling me the wait was minimum twelve months for assessment I could hardly believe it as I needed help now. my distress was happening now. Then I found out it was likely to be up to another six months before the therapy process actually began, it was crazy. I knew that my distress needed help now and in the end a couple of months later I ended up in hospital but I felt annoyed with my GP for not telling me the waiting times involved as I were no doubt that he knew

Louise (age 39, acquired progressive neurological impairment)

Two women had received their psychological support from a counsellor within a multi-disciplinary hospital based team. Having waited approximately six months to be offered an initial assessment, this was considered by both Pippa and Louise to have been too long, given the severity of the distress they were experiencing. Maria and
Judith described how they had attempted to seek counselling through the Multiple Sclerosis Society and The Stroke Association respectively, each of whom promoted the specialist counselling and emotional support that they were able to offer. Both women spoke of their hope and anticipation that through these organisations they would be offered the specialist support they were seeking within a reasonable waiting time. However, the reality was waiting times that were on a par with those of women who were awaiting treatment through their local health trust, due to each organisation employing only a small number of workers who covered large geographical areas.

For two women in the group, waiting times to access services had not been experienced as problematic. Both Carly and Frankie recalled the process of gaining access to psychological support within their academic environments as having been relatively easy. They described how their counselling support was currently been provided within their respective academic institutions, and that as they had been able to self refer, accessing their student support services had not been problematic. In addition, as those services could only be accessed by staff and students of their institutions, waiting times had been minimal and both women were offered an assessment of their needs within two to three weeks of their referral. This was welcomed in that it was seen to minimise the risk of their mental distress becoming more acute while waiting to be assessed. Both women considered themselves to have been fortunate in being able to access the mental health support they required with relative ease and without enduring a long wait. However, both Carly and Frankie expressed concern that upon leaving their academic institutions, attempts to access support of an equivalent nature in society at large were likely to prove considerably more difficult.
The role of the General Practitioner.

One of the most frequent topics raised in relation to accessing mental health services, was, the data indicated, the important role played by General Practitioners (GPs) in determining whether or not services were accessed. For a quarter of the sample group the support of their GP was rated as being good, both initially and subsequently in making referrals to services that were appropriate to the mental distress they were experiencing. However, three quarters of the group rated the response of their GP as either poor or mediocre. These women felt that the actions taken by their GPs had often been inadequate and not in line with the support that the women themselves were seeking. Pippa explained the difficulties that both she and her mother had experienced in getting the GP to acknowledge the mental distress that she was experiencing:

"Although I was quite depressed I put off going to my GP for quite a while as from past experiences I always felt that he didn’t take your distress seriously. But as things got worse I desperately needed help so my mum requested a home visit which was refused so she spoke to the practice manager and told him I was hysterical and self harming within half an hour the GP was on the doorstep and three hours later a psychiatrist turned up but to this day I know the GP only came as he was made to by his boss and he should never have questioned my mum’s request for a visit."

Pippa (age 35, congenital stable impairment)

For a GP to respond to a woman who spoke of feeling depressed or feeling low in mood by prescribing anti-depressant medication was a shared experience of many women. These women typically described a scenario in which their GP would listen for a few minutes before reaching for their prescription pad and suggesting they return a month later if there had been no improvement in their symptoms. Whilst all the women were fully aware of the time pressures that GPs often worked under, many believed that GPs prescribed anti-depressant medication too readily. Three women who had been prescribed anti-depressants, spoke of how their GP had failed to enter into dialogue with them about their willingness or otherwise to take the prescribed medication. In
addition, some women considered their GP to have been slow to refer on to mental health services and expressed a sense of exasperation around this. The data showed that for many of the women there was a belief that GPs delayed making referrals to mental health services due to the pressures on them that already existed, and GPs were often perceived as acting as gatekeepers to services. Judith spoke of her GP having been reluctant to refer her on to mental health services and advised Judith that she needed to move on from her stroke and to rebuild her life.

Jackie was one of the minority of women who spoke of having an excellent response from her GP. Having approached him to discuss accessing counselling, she stated that he had listened to what she said and acknowledged her reasons for not wishing to be prescribed medication. Jackie believed that the strong relationship she had had with her GP for close to twenty years, combined with the fact that he knew her well, were key to him responding speedily to her request. Within four weeks of referral Jackie was offered her first of six sessions with a counsellor based within her local health centre, but considered herself lucky to have been offered counselling within such a short space of time. Jackie’s recent positive experience of accessing mental health support contrasted markedly with the difficulties she had faced in accessing psychological support after acquiring her impairment. During her prolonged hospital stay, the focus was overwhelmingly on rehabilitation and regaining the optimum level of mobility that was deemed possible for her. Jackie spoke of how the emotional and psychological needs of patients on the spinal injuries unit were overwhelmingly ignored by medical and nursing staff during her ten month stay in hospital, and that emotional support was provided by other spinally injured patients;
The emotional support that other patients gave each other was something that I valued highly as these were people who were going through to varying degrees the same sorts of things that you were and having the same sorts of feelings. I don’t mean disrespect to people who have gone through training and got qualifications but in situations like mine I think there can be absolutely no substitute for personal experience and unless you have been through something like this yourself you can’t begin to understand what it’s really like. Jackie (age 43, acquired spinal cord injury)

In Chapter Eight the study’s findings in relation to whether positive experiences of receiving mental health support were more likely to result from working with individuals who themselves had a physical impairment will be examined. Having now examined women’s experiences of accessing mental health services, Part Three will discuss women’s experiences of using the services they accessed.

PART THREE: USING MENTAL HEALTH SERVICES.

Data that was provided within the women’s interviews highlighted a number of barriers which were considered to have been relevant to their experiences of using mental health services. The length of contact that some women had with services, awareness and understanding of impairment among mental health professionals and use of non-statutory services were among a wider spectrum of factors that women talked about. Each of these shall now be examined.

Length of contact with services.

The data consistently showed amongst the women a strong feeling that having accessed a service, the length of contact offered by the mental health professional was felt to have been insufficient for their needs. For some women, the number of therapy sessions allocated to them and the time span over which they took place were felt to have been inadequate.
Across the group it was acknowledged that the high demands placed upon mental health services prevented workers from being able to offer open-ended contact. In addition, women who had waited approximately a year to be seen by a therapist believed this to have been a consequence of resources continually being stretched and subsequently people waiting longer to be seen. However, most women believed there to be a need for more flexibility in the number of sessions offered by the Counsellor or Psychologist, which should be determined both by the nature of the mental health issues that needed to be addressed and the extent of the distress that an individual was experiencing.

Some women expressed satisfaction with support being offered over a specific time frame and with the purpose of addressing specific issues. These women were happy to end their involvement with services or their counsellor when the set goals that had been agreed between the two parties had been achieved. However, other women spoke of a need for longer term involvement with services which would then provide them with a form of safety net. Alison explained how she and her counsellor agreed that Alison would have extended breaks between her sessions thus enabling her to have access to the counsellor over a longer time frame, and providing her with a point of contact:

ñBy having breaks between my sessions it enabled me to have the contact I felt I needed for that bit longeré so if I was having a bad day I could pick up the phone and generally could get to speak to the counsellor. The first time I had mental health support, before I knew it my case had been closed and there were days when I had nowhere to turn. Then any re referral meant another wait to be seen again and next time around you would see a different worker.ô
Alison (age 39, congenital stable impairment)

Many of the women emphasised the importance they attached to seeing the same worker during the time that they were receiving mental health support. Consistency of worker was seen by each of the women as being key to providing the best possible opportunity to build a relationship with the worker involved. The disruption and sense of
frustration that was created by a change of worker, due to sickness absence or change of job was highlighted in particular by those women who had had experience of long term contact with mental health services.

**Using privately funded services.**

When their involvement with a mental health service had come to an end, some women still felt they had mental health issues which had not been addressed. As a result, most of these women had reluctantly sought counselling for which they would have to pay privately. With the exception of one woman, these women explained how the high cost of private counselling had prevented them from being able to sustain contact beyond two or three visits. In addition they spoke of finding a change in therapist as disrupting and not beneficial to them. Among the women there was also consensus that where a need for mental health support had been identified, and in particular a need for counselling support, adequate provision should be available without having to consider accessing a service which they had to fund themselves.

Helen described her experience of working with a private counsellor as positive, due to there being no limit placed on the length of contact with her counsellor. Helen believed that continued support from her therapist had assisted in the maintenance of her mental well being. This contrasted with anxieties that she had previously experienced as her involvement with mental health professionals in the statutory sector was nearing completion. However, Helen felt fortunate that she had been able to part-fund the private therapy sessions through her direct payments. Without this, she would have been unable to afford the substantial costs involved and the counselling support provided by her counsellor would have come to an end.
Awareness and understanding of impairment.

One of the strongest messages to emerge from the data was a feeling held by most of the women, that the mental health professionals with whom they had contact had a limited awareness or understanding of disability or impairment. For the majority of women, the professionals with whom they had contact were seen overwhelmingly to be working within a medical model approach to disability. The woman’s impairment was invariably perceived by the mental health professional as being a tragedy, and their mental distress a natural and to-be-expected response to the life that they were living.

This was experienced by Louise during her stays on psychiatric wards. She spoke of how the majority of ward staff displayed little understanding or awareness around impairment and that the overwhelming assumption made by both her nursing and medical team was that Louise’s depression was inevitable given what she had been through in her life and at such a young age;

“The ward staff saw me as this tragic young woman who had this awful life and who had to spend every day sitting in a wheelchair. You would try and tell them that it wasn’t all about my impairment and that there were other things causing my distress but with the exception of a couple of staff who would at least try to listen and understand, well it was like talking to a brick wall.”
Louise (age 39, acquired progressive neurological impairment)

Mixed experiences of receiving mental health support were attributed by some women to mental health professionals, i.e. CPNs or counsellors asking the individual to talk about areas of their lives which women felt were not relevant to the distress they were experiencing. Frankie described how her counsellor had appeared unable or unwilling to listen to what she had to say;
When I initially met the counsellor, she asked me what I saw as the main issues that I wanted to look at within our sessions and what I hoped to achieve which I outlined to her. She would talk about a whole range of things connected to my life and I could see that she was trying to put the pieces of a jigsaw together but other stuff she talked about I just couldn't see it was relevant to or had any connection with the difficulties I was having. I got really fed up eventually so I asked to change to another counsellor—her approach was very different and she was excellent in many ways.

Frankie (age 27, congenital fluctuating impairment)

Judith stated that during her counselling sessions, the counsellor would continually refer to the subject of her childhood. As Judith strongly believed her happy childhood to have had no relevance to the mental distress she was experiencing, she had great difficulty in forming a relationship with her counsellor. The approach used by the counsellor led to Judith feeling that the counselling had not been an effective form of treatment in addressing her mental distress.

Positive experiences of using services.

Analysis of the data showed that for a small number of women using mental health services had been a positive experience. In particular, more positive experiences were reported by women who perceived the professional with whom they had contact as having a reasonable understanding of impairment. In addition, that professional had been prepared to listen to the woman’s view of how they perceived their distress, and the factors that were felt to be relevant in contributing to it.

A number of women affirmed their belief in counselling as an effective form of treatment when experiencing mental distress. This was coupled with a need to be prepared to put the work into the therapy process even though this may be difficult and/or painful. Elisabeth spoke of finding the process of counselling difficult to go through due to some of the complex issues she needed to talk about. However, upon completion of her allocated sessions she had felt glad that she had persevered and felt that undergoing counselling had been a worthwhile process. Elisabeth explained that
having received counselling, she had come to understand that there was no shame in admitting to having a problem. The process was believed by Elisabeth to have helped both her self esteem and confidence in addition to helping her recognise her personal strengths.

Frankie and Carly both believed that working with their respective counsellors had been a positive experience, and that the work undertaken with the counsellors had enabled them to develop coping mechanisms. As a result of the work done in counselling, Frankie explained how she now felt able to work through any reoccurring difficulties independently. The support received from the counsellor was also identified by Frankie as having played a major role in maintaining her mental well being.

**Experience of in-patient care.**

Louise was the only woman in the study who had experience of receiving in-patient care within three different psychiatric units. Louise described the experience of in-patient care as being very poor in a number of ways. During her first admission, which was a result of her substantial weight loss, Louise explained how the sole focus during her eight month stay was on weight gain and reaching a set target weight. Louise described how during her admission there was minimal opportunity to talk with staff on the ward about the reasons behind her eating distress. After an eight month stay, and upon reaching her target weight, Louise spoke of how she was discharged only to be readmitted on two further occasions as a result of losing weight she had gained during her admissions.

Two further admissions during the 1990s were recalled by Louise as being characterised by environments that were not suitable for a wheelchair user.
Every day on the ward was hard going in terms of access as the bathroom doors were barely wide enough to get your wheelchair through. There were no adapted bathroom facilities or buzzers to call for help so you were dependent on staff to help you with personal care but it was clear they didn’t have a clue around the mobility needs of someone in a wheelchair. And the cold and bare ward in which I felt really isolated all just added to making the overall experience a really negative one.

Louise (age 39, acquired progressive neurological impairment)

Louise explained that it took two months for the medical team to accept her view that the ward environment was neither suitable nor appropriate for her physical and mental needs. This resulted in her returning home from hospital after two months with little marked improvement in her mental state. Overall, Louise’s experiences of inpatient care were described as having been traumatic and had left her with a negative view of the appropriateness of psychiatric care for women with physical impairments.

Using non-statutory services.

While the data provided evidence of very mixed experiences of using statutory mental health services, experiences of using non-statutory services were described by many of the women as having been both positive and beneficial. Helen spoke of her positive experience of using a local support group for people with depression. She recalled how within the group people were able to talk openly and that she had felt relaxed in their company. Whilst her ability to contribute verbally to group discussions had been hindered by her speech impairment, Helen had found listening to others helpful. Through listening to others, this had helped Helen to recognise that other people were experiencing feelings similar to her own which in turn helped to erase some of her feelings of being abnormal. During her long wait to access to one to one counselling, Judith spoke of valuing the support that was provided by fellow members of the stroke support group which she attended. Here she came into contact with people who she perceived to have a mutual understanding, having gone through difficulties of a
similar nature to her own. Lisa also spoke of gaining valuable emotional and practical support from members of an online forum which had been set up by individuals living with the same rare condition as her own.

For those women who had experienced acute mental distress, the data highlighted the important role that the Samaritans had played during these times. This was primarily because the Samaritans were contactable at times when the statutory services were overall not. In addition, the data showed the value that was placed on telephone help lines such as that offered by the Samaritans, in that they eliminated any worries around physical accessibility. The absence of time constraints being placed on telephone calls was widely welcomed by women who used these services as was the confidentiality that Samaritans workers guaranteed to callers. Whilst women recognised that the provision of telephone based help lines could be of limited benefit to women with communication difficulties, and that contact could now be made by email, the data showed how the majority of women would have a preference during times of acute distress for a listening ear on the other end of the phone. Louise described her experiences over a number of years of using the Samaritans:

“I would say in many respects my experiences of using Samaritans was much better than any of the statutory services I used especially when my distress was really acute. Often during the nights things could seem so much worse and the Samaritans were always there at the end of the phone day or night. They never put you under any pressure, would listen to you for as long as you felt you needed and just knowing the service was there was a real source of reassurance for me.”

Louise (age 39, acquired progressive neurological impairment)

**Contact with General Practitioner.**

The women reported mixed experiences of contact with and support received from their GP, prior to a referral to mental health services being made. All the women agreed that it was beneficial to have a good relationship with the GP, because they were key to
accessing the services that the women required to address their mental health issues. Negative experiences of contact with their GP had led some women to become reluctant to have contact with them, due to the inappropriate response which they believed that they would be met with. Women who were registered with multi-GP practices described how they would sometimes ask to see an alternative GP or make a request to change GP. However this option was not available to women who lived in more rural locations where the surgery was run by a single GP.

CONCLUSIONS.

This chapter began by discussing findings from the research relating to the women’s experiences of mental distress. By analysing data from both the individual interviews and focus group, it has examined a range of factors which were believed to have played a role in contributing to the women’s experience of distress. Across the group there was acknowledgement that individual physical impairments had to varying degrees been significant to experiences of mental distress. However, the chapter has illustrated how women did not consider their impairment per se to have been the major influence. This was at odds with women’s experiences of contact with mental health professionals who, as discussed in Chapter Five, overwhelmingly saw the woman’s mental distress as having resulted from living with a physical impairment.

The second part of the chapter considered the variety of experiences that were encountered by the women in their efforts to access mental health services/support. For many of the women physical or structural barriers were shown to have impinged on their access to services, though the recent introduction of disability legislation was considered to have reduced the incidence of this occurring. Both the long waiting times for assessment for mental health support, and the role played by the GP were identified
as significant factors in the collective experiences of accessing services. Throughout, the importance of accessing up to date information was stressed by women. In the absence of access to correct information, the process of accessing appropriate services was felt to be unable to commence in earnest.

In discussing the women’s views about using mental health services, the data again provided evidence of a wide spectrum of experiences. For the most part, the data highlighted how the majority of women had felt the services with which they had involvement had not met their specific needs as a woman with a physical impairment. More positive experiences were reported by women who had consistent contact with their allocated worker, which had permitted a greater likelihood of being able to form a good working relationship.

In addition, positive experiences of using services were seen to occur in instances where the mental health professional was perceived as having a reasonable level of understanding and/or awareness of impairment, and was prepared to listen to the woman’s perception of her mental distress. Each of these areas will be revisited in Chapter Nine which will examine the recommendations made by the women in relation to future provision of appropriate mental health support for women with physical impairments.
CHAPTER EIGHT
COUNSELLING AND WOMEN WITH PHYSICAL IMPAIRMENTS

In Chapter Seven, the personal experiences of mental distress of each of the women were discussed. For the majority of the women, counselling was shown to have often been provided alongside other forms of treatment in seeking to address the difficulties that they had previously experienced or were currently experiencing.

Within the sample group of twelve, ten women had undergone counselling on one or more occasions. Of the ten women, six had only experienced working with a female counsellor whilst three had worked both with female and male counsellors. One woman had worked with a male counsellor only. Of the ten women, the data showed how five had held a strong preference for working with a counsellor with an impairment or with previous experience of living with an impairment. For each of the five woman the reality had been that a choice between an able-bodied counsellor and one with an impairment did not exist, and none had worked with a counsellor with an impairment. The two women who had not received counselling each spoke of how their preferred choice would be to work with someone with an impairment if they at any time required counselling. This for both women was felt to be particularly so if the distress they were experiencing was impairment-related.

In recent years an area of debate, both among counsellors and people with physical impairments, has centred around whether or not people with impairments should be counselled either by counsellors who themselves have a physical impairment or have previously experienced living with a physical impairment. Focusing on three related areas, this chapter begins by discussing the data relating to the preferences the women had for working with a counsellor with or without an impairment, and the reasons given for their preferred choice. Part One also examines the difficulties that were presently seen to exist for women (and men) with a physical impairment who wish to train as counsellors.
Within my small scale study (Smith, 2003) which examined the provision of Mental Health services for women with physical impairments, it was found that all but one of the women had a strong preference to work with a female counsellor. This study has explored this area in greater depth and Part Two examines the study’s findings in relation to preferences that were expressed for a female or male counsellor. It also discusses whether, women who had undergone counselling had considered the counsellor’s gender to have affected the counselling relationship. Part Three is concerned with the remaining data related to counselling.

PART ONE: IMPAIRMENT AND COUNSELLING.

Analysis of the interview and focus group data provided evidence of a range of views expressed concerning both the perceived advantages and disadvantages of receiving counselling from a counsellor who themselves had a physical impairment or had previously experienced living with an impairment, compared with a counsellor who was able-bodied. These views shall now be explored.

Counsellors with physical impairments: A shared understanding

Of the ten women who had undergone counselling, five felt strongly that they would have liked an opportunity to work with a counsellor who themselves had a physical impairment or alternatively at some stage of their life had experienced living with an impairment, i.e. a temporary impairment. The women stated that this preference was held because of the shared experience of impairment and disability. Also it was based on a considered belief that a counsellor currently living with an impairment or one with previous personal experience of impairment would have a good level of understanding of issues around disability and impairment.
In contrast, these women felt that an able-bodied counsellor with no personal experience of physical impairment would have little or no understanding of what it is like to live with a physical impairment. In addition, it was felt unlikely that an able-bodied counsellor would be able to empathise with the difficulties that the woman was experiencing, especially if those difficulties were directly associated with the woman’s physical impairment.

The majority of the sample group shared the view that a counsellor with an impairment was likely to be advantageous if the issues that were being addressed within counselling were either linked directly to the woman’s impairment, or were in coming to terms with an impairment that had been acquired. Jackie described how patients on the spinal injuries unit had provided emotional support for each other (see Chapter Seven p187). She spoke of the benefits that she had derived from talking with individuals who were going through difficulties similar to her own. It was Jackie’s stated view that for women with acquired impairments, who had either expressed a need for, or were identified as requiring professional counselling, that a counsellor with an acquired impairment was likely to be the person best well suited for a woman to work with. Whilst Jackie spoke of recognising the importance of trained counsellors working with a professional qualification, she believed that without some personal experience of living with a physical impairment it was not possible to have a true or full understanding of what it is to live with an acquired impairment. However, several women drew attention to the need for any counsellor with an impairment to acknowledge, as was highlighted within Chapter Five, that although their may be similarities in the ways in which individuals live with their impairment, ultimately their experience will be unique.

For four of the women who had received counselling, the issues addressed within their counselling sessions were said to be related to other areas of the woman’s life and not
related to their impairment, such as financial worries or relationship difficulties. The data showed how, in those circumstances, it was felt that the need for a counsellor with an impairment was arguably less important and that an able-bodied counsellor may be equally well suited to work with them in addressing their difficulties. However, Alison was cautious of this view and believed that consideration needed to be given as to whether the difficulties that had led to a need for counselling had their origins in, or were linked indirectly to, the woman’s impairment.

“My first experience of counselling was after the break up of my marriage and I was struggling to cope. The counsellor was an able bodied woman and at the time I didn’t really think it mattered that she didn’t have an impairment... but as time went on because she had no past experience of impairment I came to realise that she couldn’t see how or the ways in which my impairment had a knock on effect on my relationship with my husband and eventually led to us breaking up.”

Alison (age 39, congenital stable impairment)

Alison’s experience had led her to believe that able-bodied counsellors needed to have a level of awareness around impairment, even where the difficulties being experienced by the woman were not directly impairment-related. This is explored further below.

**Counsellors with impairments: Alternative views**

Analysis of the data showed, however, that the other seven women did not believe it was necessary for a counsellor to have an impairment in order to be able to offer counselling to a woman with a physical impairment. This group of women felt there should be no automatic assumption made that a counsellor with an impairment is likely to be the person best suited to provide counselling to a woman with a physical impairment who requires counselling. These seven women expressed the view that, as no two impairments or experience of those impairments were identical, a good counsellor should be able to empathise with another person whatever their concerns, cultural differences, or diverse life experiences.
However, these women did consider it important for a counsellor to have a good understanding of disability and impairment. In addition it was considered vital for the counsellor to have insight into how the woman’s impairment may potentially impact on different areas of their life. Above, Alison spoke of how her experience of working with an able-bodied female counsellor did not have a positive outcome. This was in contrast to her more recent positive experience of working with a female able-bodied counsellor, which Alison attributed to her coming from a similar background to her own. Because the female counsellor had also grown up in a farming community, Alison perceived her as having a good understanding of the issues that Alison wanted to address and was able to empathise with the difficulties that she was experiencing. She explained how, prior to entering into counselling, her preference would have been to work with a counsellor with a physical impairment, but her experience of working with a counsellor from a similar socio-economic background had proved to be invaluable. Alison’s experience, she said, alerted her to a realisation that a counsellor may have attributes other than an impairment which may be equally or more important in providing the optimum opportunity for the counselling relationship to have a positive and worthwhile outcome. For Alison, working with a woman whose background had similarities with her own, had resulted in a positive counselling relationship in which the goals which had been set were achieved, and the mental distress which she had been experiencing, substantially alleviated.

Jackie described her recent experience of emotional distress as having been linked to coming to terms with finishing work. As her distress was indirectly related to her impairment, Jackie did not therefore feel a need to work with a counsellor with an impairment. The experience of working with a female able-bodied counsellor was described by Jackie as having been very positive, and, upon completion of her sessions she felt that the difficulties which had been causing her emotional distress had been worked through. Through talking
with her counsellor, Jackie spoke of arriving at a recognition that although finishing paid employment represented a downturn in her physical strength, it also created the opportunity for her to pursue other areas of work in which she had an interest and that allowed her to work flexibly and within her limitations.

Counsellors with physical impairments: The issue of choice.

Though the data showed the majority of women to have a preference to work within counselling with an individual with a physical impairment, or with lived experience of impairment, the reality was that such a choice did not exist. Of the ten women who had received counselling support, the data showed that none had experience of working with a counsellor with a physical impairment. Elisabeth described her attempts to seek counselling with a counsellor with an impairment.

"The first time I was referred for counselling it was through my GP and so was going to be provided through the local health services. I remember phoning up some weeks later and asking if I could be allocated to a counsellor who had an impairment themselves as I thought that might be better for me. Well the line just went quiet for what seemed like ages and then she said that they didn’t have any counsellors with any form of disability and that she had never heard of a disabled person being able to work as a counsellor."

Elisabeth (age 62, congenital progressive impairment)

The response that Elisabeth had met with was believed to have reaffirmed her long held belief of the lack of people with a physical impairment working as counsellors.

The difficulties that were experienced by some women in their efforts to find a counsellor with an impairment or experience of living with impairment, led, the data showed, to a collective belief in the need for a much greater availability of counsellors with impairments. Whilst in Chapter Three (p 84) it was argued that it was not necessary for people with impairments to be counselled by someone with an impairment, there was acknowledgement that an increased availability of counsellors with an impairment would
improve client choice for people who would prefer to work with a counsellor with experience of impairment.

Of the ten women who had experience of counselling, four had sought private counselling. This had occurred either when allocated therapy sessions had been completed, or in instances where undergoing counselling with an able-bodied counsellor had been a negative experience. Each of the women spoke of unsuccessful endeavours to locate a counsellor with a physical impairment. Helen had searched within a forty mile radius of her home for either a counsellor with personal experience of physical impairment or an individual for whom working with people with a physical impairment was their specialism.

„After my poor experiences of time limited counselling on the NHS I set about finding someone who could really help and I thought that help might best come from someone with an impairment themselves. I found lots of people who specialised in working with alcohol or drug problems and all sorts of other areas but nobody who specialised in working with issues around disability and impairment.ł

Helen (age 43, congenital stable impairment)

Helen believed the lack of counsellors working with people with impairments to have come about as a consequence of counselling training courses devoting little time to the areas of disability and impairment. This in turn had resulted in trainee counsellors being unable to gain an understanding of these areas and subsequently work specifically with people with impairments.

Across both the interview and focus group data an agreed need for more teaching around disability and impairment to be included within the syllabus of professional training courses was clearly stated. By providing training courses with an increased focus on disability and impairment, this it was felt would enable able-bodied counsellors to have a greater awareness of issues around disability and impairment. Furthermore, through disability equality training becoming a mandatory part of all training courses, women
believed that counsellors would come to have a full understanding of the social model of
disability and how disability is socially constructed rather than being caused by a person's
impairment.

Within their interviews six women spoke to varying extents about how they had felt
patronised by and/or pitied by their counsellor. For a counsellor to speak to or act towards
the woman in a patronising manner was felt by the women to introduce an element of
sympathy towards them from the outset. For all six women this was perceived as being
unhelpful and created the potential for an unbalanced working relationship. Pippa recalled
how she had felt patronised by her Community Psychiatric Nurse and that this had
contributed to a negative counselling experience.

“When I was allocated to a CPN who was going to offer me counselling I was
relieved to find it was a woman and thought it would be oké but almost from day one
I felt pitied and patronised by her and she would say how she understood how difficult
it must be living the life I had and how tough life must be. It seemed like I was
spending a lot of time trying to get her to understand that it wasn’t how I saw things at
all but she didn’t seem able to listen or accept what I was saying and it was a pretty
negative experience.Ø
Pippa (age 35, congenital stable impairment)

Women who had felt pitied or patronised by their counsellor shared the view that
counsellors needed to move away from the viewpoint of seeing physical impairment as a
personal tragedy and making the assumption that an impairment has a negative impact on
the person’s life. By shifting away from such viewpoints, it was believed this would benefit all
clients with a physical impairment in that it was considered likely to improve the counselling
experience.
Counselling Training: Barriers to access.

Alison and Helen both spoke of how they had wished to train to as professional counsellors, each believing that their personal experiences of mental distress would have made them suitable candidates. Helen explained how her desire to become a counsellor was in part a result of listening to people with physical impairments recall their negative experiences of counselling with an able-bodied counsellor. Secondly, she believed in her ability to offer clients a positive and worthwhile experience of counselling, having personally lived with both physical impairment and mental distress. Whilst Helen was conscious of the difficulties that she may have encountered in working with people in the usual way due to her speech impairment, recent advances in technology would, she believed, have enabled her to work effectively as a counsellor.

Both Alison and Helen explained how their access to professional training courses had been hampered by a lack of academic qualifications, having been educated within a special school setting where the opportunities to study for academic qualifications had been very limited. Alison described how her lived experiences of both physical impairment and mental distress had been totally disregarded throughout the application process.

“When I looked into training to become a counsellor I hit a brick wall at every turn as they all wanted qualifications in English, Maths etc with good grades and because I received my education in a special school there wasn’t the opportunity to study for O levels because you weren’t expected to go on and achieve anything. At a couple of places I got an interview and I drew attention to what I could offer given my real life experiences but what they really wanted was a piece of paper and personal experience it seemed counted for nothing.”

Alison (age 39, congenital stable impairment)

An increasing need in recent years for counselling courses to become accredited and recognised academically has led to more courses being based within university settings with entry requirements stipulating a first degree. As a result, some women felt this to reduce
further the likelihood of women (and men) with a physical impairment being accepted onto training courses, particularly for those who had been educated within a special school environment and had left school with few recognised formal qualifications.

**Shared understandings, not segregated services.**

Whilst within the study women individually voiced a preference for working with a counsellor with an impairment, the data showed that collectively women were not in favour of people with physical impairments being counselled only by counsellors with physical impairments themselves. Many women felt that to adopt such an approach would potentially lead to a situation in which people with physical impairments became segregated and could also lead to a sense of feeling socially excluded. All of the women within the focus group shared the view that only making counsellors with an impairment available to women with a physical impairment who required counselling, would represent a backward step at a point in time when people with physical impairments are gradually becoming more integrated within society overall. To implement a regime in which women with physical impairments only had access to counsellors with physical impairments, was also felt to offer little in the way of progress in educating able-bodied people around disability and impairment.

Chapter Three drew attention to the importance of all counsellors being trained to work with disability issues as and when the need arose. Like able-bodied persons, people with physical impairments may wish within counselling to look at childhood traumas, relationship difficulties or issues associated with impairment or disability and are ultimately seeking counselling which meets their perceived needs. Five women described how on occasions their impairment could be accompanied by chronic or intermittent episodes of illness or pain which could lead to episodes of emotional distress. However, they were emphatic that counsellors needed to recognise that this was not always the case, and that women with
impairments could be emotionally stressed in ways that were not directly associated with their impairments.

In addition, attention was drawn by all but three of the women to the fact that as individuals they were not just a woman with an impairment but also parents, friends or siblings who were subject to the same range of emotions and difficulties as able-bodied people. Therefore, these women felt that their physical impairments should to some extent be disregarded and that they should have access to the same range of counselling services as able-bodied people, should those services be required.

In-depth analysis of the data has clearly shown there to be no definitive right or wrong answer to the question posed of whether a counsellor with a physical impairment was felt likely to be the person best qualified to counsel a woman with a physical impairment. Data from both the interviews and the focus group showed that some women had a preference to work in counselling with a counsellor with direct experience of impairment. However, there were a range of other attributes identified which across the sample group were perceived as being important that the counsellor was able to display. In addition there was group wide agreement that where individual choices for working with a counsellor with or without an impairment were expressed, that those choices should, wherever possible, be respected. However, the stark reality for the ten women who had received counselling was that a choice did not exist and that their expressed preferences counted for little.

**PART TWO: GENDER AND COUNSELLING**

In addition to discussing any preferences that were held for working with a counsellor with or without a physical impairment, the study invited the women to share any preferences they had with regard to the counsellor’s gender and the reasons for their preference. As with
the impairment versus able-bodied debate, a range of views were talked about which shall now be examined.

**Female or Male counsellor: Personal thoughts**

Analysis of the data showed that for the majority of the women, (ten of twelve) their preferred choice would be to receive counselling from a female counsellor. This preference was primarily explained by the women’s perception that they would feel more comfortable talking to a woman, particularly if the areas being addressed within counselling were gender related. Women in the study who had received counselling from a female, recalled how they had felt at ease in the presence of a woman. However, for those women who to date had only worked in counselling with a female counsellor, they recognised that they were therefore unable to make a comparison with working with a male counsellor.

In contrast, Frankie and Helen spoke of currently working with male counsellors and rated their counselling experience as positive. Both women spoke of how they would prefer to work with a male counsellor in the future should the need arise, regardless of the issues that counselling was being sought for. Frankie and Helen individually explained their preference as resulting from a general feeling that they got on better with men than with women. Both women spoke of having formed a good working relationship with their respective counsellors with relative ease, and had felt able to talk with them openly. Helen spoke of having previously received counselling within the statutory sector from female counsellors, at the end of which she considered there to have been little improvement in her mental state. In addition she felt that the set goals which had been agreed by both parties at the outset of their counselling sessions had not been achieved to any significant degree. Whilst Helen was aware of the requirement for all counsellors to be non-judgmental in undertaking their work, she perceived the female counsellors with whom she had worked to
have been both judgmental and critical of the way in which Helen viewed different areas of her life.

Helen believed that her preferred choice to work with a male counsellor was in part a response to the poor relationships that she had endured with her sisters as she grew up. In contrast it was Helen’s elder brother who she recalled as having been on hand to provide the emotional support that at various times she felt in need of.

Even as a young child I can remember not getting on with my sisters and it was my older brother who I would go to if I got upset. He was the one as I grew up that was always there with a listening ear and when I was diagnosed with cancer for a long time he was the only person I felt able to confide in. My relationships with my sisters I definitely think have impacted on the preference I have for working with a male counsellor as I am doing now.

Helen (age 43, congenital stable impairment)

Frankie stated that when she first entered into counselling, she had no marked preference for working with a female or male counsellor. However, following a three month period of working with a female counsellor she felt that little progress had been made in addressing her emotional distress, and that the suggestions made by the counsellor as a way of coping with that distress were not of benefit to her.

The counsellor made suggestions as to changes I could make to my daily routine which might help in addressing some of the difficulties I was having but those changes were unrealistic because of the nature of my impairment and the counsellor appeared to have little insight into impairment. I tried to explain to her how my impairment impacted on everyday life but the counsellor didn’t seem able to grasp it, and it may seem harsh but often it felt like she wasn’t truly listening.

Frankie (age 27, congenital fluctuating impairment)

As a result of Frankie’s request to work with a male counsellor, she described how this had been beneficial to her and had resulted in a positive experience of counselling from which she had learned a great deal. In addition, upon completion of her allocated sessions Frankie spoke of having achieved her primary aim of addressing the emotional distress she
had been experiencing. Recalling her negative experience of working with a female counsellor, Frankie spoke of recognising that their different personalities may have been a factor, and that working with a different female may have altered her views of working with a same gender counsellor. However, Frankie felt that if she needed counselling in the future, that her likely preference would be to work with a male counsellor. Frankie considered herself fortunate to have had her request for a change of counsellor granted and felt it unlikely that outside of her university environment such a request would have been met due to the high demands placed upon counselling services.

Experiences of counselling: The effect of gender

For four of the women who had previously undergone counselling, the mixed feelings they held about any preferences for a counsellor of a specific gender were described. These women explained how, prior to being referred for counselling, they believed their preference would have been to work with a female counsellor for the reasons that were outlined above. In instances where women found themselves allocated to a male counsellor, each explained why their initial expectations of them had been low. Each woman assumed that a male counsellor would not listen as well as a female counsellor, nor would they understand the difficulties a woman was going through in the way that it was felt a woman would. Lisa described the underlying feelings that she experienced during the initial weeks of working with a male counsellor.

“I’ve been with my husband now for many years and have lost count of the times I’ve said to him ‘you don’t listen, you don’t understand and I just assumed that I’d feel the same way about a male counsellor but as time went on I gradually relaxed and felt able to talk to him though ultimately I think I still would have felt more comfortable talking to a woman.”

Lisa (age 45, congenital progressive impairment)
For Louise, the reality of working with a male counsellor had proved to be pleasantly
different from what she had anticipated. On a number of occasions over a fifteen year period
Louise had received counselling for her clinical depression, but described her most positive
experience as having occurred when she worked with a male counsellor.

“When in the mid 90s I was going through a bad episode with my eating disorder
I was referred to a therapist who I was told specialised in counselling people with
eating disorders. I went along assuming that it would be a woman probably because
eating distress is something you associate more with women so when I came face to
face with a man I was a bit taken aback. For the first few sessions I remember having
very low expectations of him as I couldn’t see how as a man he could have any
proper understanding of what I was experiencing. However over time I came to
realise that although he didn’t have personal experience of suffering from an eating
disorder his understanding of issues that are often all part and parcel of having an
eating disorder were really good and he was a good listener too.”
Louise (age 39, acquired progressive neurological impairment)

Louise’s positive experience of working with a male counsellor led her to a realisation
that a woman may not necessarily be the person best suited to work with. Furthermore, she
stated that other skills or attributes that a counsellor may have need to be taken into account
and the worth of each considered. This theme shall be developed further within Part Three.

Female or Male counsellors: The issue of choice

Whilst the majority of women voiced a preference for working with a female counsellor,
the data showed a collective awareness of the reality that, unless counselling was being
privately funded, a choice was unlikely to be offered. Two women recalled having made
contact with the counselling services to which they had been referred to make their
individual preferences for a female counsellor known, but were advised that specific
requests could not be met. In contrast, Louise, who had been referred to the psychology
department of her local Mental Health trust for counselling, spoke of having been given an
opportunity to choose with whom she wished to work, but believed her circumstances to
have been exceptional.
I got referred to a psychologist who was working as part of a neuro-rehabilitation multi disciplinary team when I was having difficulties coping with a downturn in my physical condition but the referral got lost and it was almost a year before they acknowledged this. Because of a whole series of errors I made a complaint to the local trust and almost by way of amends I think I was asked along for an initial assessment with two psychologists—one male and one female and was asked to let them know the following day who I thought I would prefer to work with but I don’t think I would have been given that choice had it not been for the errors they made and openly acknowledged.

Louise (age 39, acquired progressive neurological impairment).

Just as analysis of the data was shown to indicate that there was no right or wrong answer to the question posed of whether a counsellor with an impairment was likely to be the person best well qualified to counsel a women with a physical impairment, this was equally shown to be so in relation to the counsellor’s gender. The data showed that for the majority of the women, their preference was to work with a female counsellor, based on a belief that a woman would be more likely to have a better understanding of the difficulties they were experiencing. In addition, women overall were perceived as being better listeners than their male counterparts. However, some women spoke of the need to recognise that same gender counselling was not an automatic guarantee of being able to form a good working relationship with the counsellor. Attributes such as the counsellor’s personality was one of a range of factors that were felt could be significant in contributing to a counselling relationship that was perceived both as having been effective in treating the woman’s mental distress, and in which the outcome was viewed positively.

PART THREE. WOMEN WITH PHYSICAL IMPAIRMENTS AND COUNSELLING: PERSONAL THOUGHTS

Part One and Part Two have examined the areas of impairment and gender within the context of the women’s experiences of or thoughts around counselling. Within the interviews and focus group women were asked to identify other areas, beyond impairment and gender
which they considered to be of importance within the context of a counselling relationship. Analysis of the data demonstrated a range of factors which women felt had either impacted on or had the potential to impact on the counselling relationship, for example, the availability of long term support and the counselling approach adopted by the counsellor. In addition, a range of qualities and attributes which women perceived as being important that the counsellor was able to exhibit were highlighted. Each of these areas will now be discussed.

A need for long term counselling support.

In Chapter Six, women with long term progressive conditions spoke of the need for mental health professionals to appreciate that due to the nature of their impairments, they may potentially need counselling support to be provided over a longer time span. This group of women, whose long-term conditions were often also unpredictable in nature, voiced their belief that short term, time-limited counselling support was not the most effective way of meeting their needs. Across the sample group it was acknowledged that to offer counselling support over an extended time period did not tally with how the system worked. However, the need for a system that offered scope for greater flexibility, and one in which individual need was paramount as opposed to the client fitting into the confines of what the service offered, was collectively agreed. Elisabeth described how minimal consideration had been given to her individual requirements.

As well as the physical access issues that had to be overcome before you even got to the point of meeting the counsellor, I felt that the counsellor worked within a set approach that was rigid and didn’t feel that I was an individual whose life circumstances were unique to me. Though the counselling in some respects helped me to work through some of the emotional stuff I was going through, it was too quick, too short. Given that my condition is progressive and that physical changes are happening at random intervals I felt that I needed something longer term to help me cope with that but it just wasn’t something that the service offered or took account of. Elisabeth (age 62, congenital progressive impairment)
Other women had who considered their experiences of counselling to have been poor spoke of feeling that the counselling they had received had not been well suited to their needs or did not consider their individual requirements. Where poor experiences of counselling were recalled, the data showed this to have affected women’s rating of the effectiveness of their counselling.

The use of counselling approaches.

In reviewing the literature that has focused on counselling with people with physical impairments, the wide range of approaches that may be used were discussed. Three women considered that the approach used by the counsellor within counselling sessions had been significant to their rating of the effectiveness of the counselling they had received. Helen explained how within her counselling sessions, the counsellor worked with what he described to her was a cognitive approach.

“My counsellor explained that in using this approach the aim basically was to try and confront negative thoughts that I was experiencing and to work to replace those with more positive ones. And that the approach might be helpful in improving my low self esteem and lack of self confidence. As my counselling sessions have gone on, over time I’ve come to realise that it’s an approach that works well for me and I see the counselling that I’m still having as being a positive experience.”

Helen (age 43, cognitive stable impairment)

Helen’s view of there existing a link between the counselling approach utilised by the counsellor, and effectiveness of the counselling received, was supported by Judith who described her counselling sessions as not having had a positive outcome (Chapter Seven p191). This was attributed mainly to the counsellor wishing to focus intently on her childhood years, but having experienced a happy childhood, Judith firmly believed that the emotional difficulties she was experiencing were associated with acquiring her impairment and bore no significance to her childhood.
A negative experience of counselling in the 1980s, Elisabeth believed had been created by the approach used by her counsellor within their counselling sessions.

"When I went into counselling I was at a low ebb and all the bad things going on in my life I was blaming myself for. The counsellor told me we would be using a behavioural approach and although I didn't really know what it meant I was happy to go along with it as I thought he knew best. But after a while I felt I was getting nowhere and wondered whether it was because of the way we were working and the counselling approach he was using."

Elisabeth (age 62, congenital progressive impairment)

Having learnt that behavioural approaches saw the problems being experienced as arising from within the individual as opposed to society, Elisabeth stated that use of this approach served only to reinforce her negative thoughts of self blame. Having suggested a change of counselling approach within her privately funded sessions, Elisabeth talked of how the use of a cognitive approach had brought greater benefit. This approach she found provided her with the opportunity to explore her negative thoughts and to assist her in replacing them with more positive ones.

**Impairment related factors: a need for consideration.**

The data showed that across the sample group women emphasised the need for all counsellors to display sensitivity and flexibility around the parameters of counselling sessions when working with clients with impairments. Women spoke of the need for counsellors to consider not only the physical location of the counselling service but also any individual access needs that a client may have. In addition, many women called for counsellors to be more creative and flexible in the methods that they used to communicate with clients, in particular for any individual with a communication difficulty. The need for counsellors to be fully aware of the effects that an individual's impairment may have on the frequency, timing and length of counselling sessions was a view widely expressed among the twelve women. Women whose mobility was significantly impaired highlighted how
counsellors also needed to consider issues such as the availability of accessible transport or care assistance which may affect when or if a client with a physical impairment can attend scheduled counselling sessions. Alison described how factors over which she had little control, had on occasions impacted on her time limited counselling sessions.

“Because my counsellor wasn’t hospital based I wasn’t entitled to ambulance transport and had to use ring and ride and although you can say a time you need they can never guarantee it so quite a few times I would be late and you ended up with a shorter session because the next person would be waiting for their slot. The energy that it took for me to go through what at times could turn out to be only half an hour session made me wonder at times whether all the effort was worthwhile.” Alison (age 39, congenital stable impairment)

Women in the study whose mobility was significantly reduced said that counselling within their home setting would be more convenient than travelling to a location which took considerable effort and entailed using precious energy. Women with significant physical impairments described how leaving home to meet in a neutral place could be very difficult or close to impossible and would therefore prefer to receive counselling within their home environment. These women recognised that counselling in the home did not provide a place of neutrality, and that factors such as the counsellor sharing the woman’s personal space, unexpected visitors or phone calls needed to be acknowledged. However, it was still felt that individual needs had to be given equal consideration. This was particularly important for women for whom the nature of their impairment made it very difficult if not almost impossible for them to leave their home setting. Attention was drawn by some women to the responsibilities of counselling agencies, since the implementation of the Disability Discrimination Act, for ensuring that their services are accessible to people with impairments.
Alternative sources of Mental Health support.

The need for greater recognition of the variety of ways in which women could be provided with emotional support was talked about by six women. For example, Judith recalled that when experiencing mental distress as she adjusted to her acquired impairment, she felt a need to talk to a professional counsellor about how she was feeling. Faced with a long wait to access one to one counselling, Judith began to attend a support group for individuals who like herself had suffered a stroke. Having attended regularly for six months, Judith explained how she came to recognise that the informal support which was provided by people who had gone through experiences that were akin to her own was what she actually needed. Judith said that she continued to attend the group which she viewed as a valuable source of support both for the social contact and emotional support that it provided her with.

 Jesús The support that I got from attending a group where there were people who were going through the same sorts of things as I was I found a big help. It made me realise that there may be times when you need to distinguish between a need for professional counselling and a need for emotional support that for some women may be best provided by another means or within a different forum and that counselling with a professional may not be the only way of getting the support you need. Jesús Judith (age 61, acquired stable impairment)

Whilst Pippa had been provided with details of a local support group for people suffering with depression, she had felt that she would not be comfortable talking about her mental distress with people that she did not know well. She talked about how emotional support had been provided by close friends whom she had felt able to confide in and feel at ease with. However, Pippa spoke of recognising that when her mental distress was acute she required professional help. Lisa also, in Chapter Seven (p 194) spoke of being supported by members of an online forum who were individuals living with the same impairment as her own.

There was a consensus across the group that the high costs of private counselling placed it beyond the means of the majority of people living with a physical impairment.
Helen spoke of feeling fortunate that she was able to part fund her long term counselling support through the Direct Payments scheme* as she recognised that most other women were unlikely to be given that opportunity. Where a health professional had identified a need for professional counselling as a means of treating the woman’s mental distress, it was unanimously felt that this should be provided by the statutory sector within a reasonable time scale. Faced with the prospect of a long wait before counselling began, three women spoke of having been advised to approach local voluntary sector organisations which offered counselling. However the reality of doing so for these women, prior to implementation of the Disability Discrimination Act, was that such services were frequently located within old buildings that were inaccessible to people with significant mobility impairments. Waiting times for counselling were also found to be in line with those within the statutory sector and each woman similarly described how they had felt passed around services. Katy described the sense of frustration she experienced in trying to access counselling:

“When my GP referred me for counselling he didn’t say there would be a long wait. Months later I found out I was still way down the list and faced further waiting due to what I was told were budget cuts, they suggested I try a local voluntary organisation who might be able to see me sooner. But of course they told me the same thing, that they were operating with little funding and that as statutory funding was cut so the pressure on them increased and waiting lists went up. It felt you were being passed from pillar to post and in the end I gave up as I was so fed up.”
Katy (age 43, congenital stable impairment)

Findings from the focus group showed that all the women considered it to be vital that the counsellor had respect for the woman and treated her as an individual. Women also spoke of the importance they attached to the counsellor presenting as being a good listener and that they gave attention to the words being spoken. All of the factors highlighted were believed to be key to providing the optimum opportunity for a good working relationship with
the counsellor to be formed, regardless of their gender and whether or not they had an impairment.

Part Three has examined the areas which beyond impairment and gender, women considered were important in providing optimum opportunity for the counselling experience to be a positive one. It has shown how women with long-term progressive conditions wished to have access to long term counselling support which would be available during episodes of physical decline. Whilst there was group wide agreement that high demands on services meant that long term support was rarely available, women held a firm belief that counselling services needed to be more considerate of individual circumstances when working with clients with a physical impairment. It has also shown how for some women the counselling approach used by the counsellor had affected the rating of their counselling experiences. With regard to working with the counsellor, it has indicated the importance that women placed on wishing to be treated with respect and to be valued as an individual. Good listening skills were similarly highlighted as providing the opportunity for the formation of a strong working relationship.

CONCLUSIONS

This chapter began by highlighting the ongoing debate that has taken place in recent years among both people with impairments and counsellors, as to whether people with impairments should be counselled by counsellors who have personal experience of impairment. Analysis of the data has indicated within the chapter how that debate is likely to continue. From the data it is has been shown, that when a woman with a physical impairment enters into counselling there is no definitive answer as to whether the counselling is likely to have a more positive outcome if the counsellor has a physical impairment or not. From the range of views expressed around preferences for a male or female counsellor, it was shown that the majority of the women held a preference to work
with a female counsellor. However, it was recognised that being counselled by a female did not provide a guarantee of being able to form a good working relationship with the counsellor. A range of other attributes which were also perceived by the women as being important the counsellor was able to display were discussed.

In addition the chapter has highlighted how currently all the women felt that as a client group they were not being well served by counsellors. Whilst some women recalled certain aspects of their counselling as having been positive, many others encountered counsellors who had little understanding of the lived experience of disability and/or impairment. Many women considered that the counselling they had received had not been appropriate to their needs. Poor experiences of counselling, the data showed, served to reinforce a belief in the need for Disability Equality Training to become a mandatory part of all counselling training courses.

While an expansion of counselling over recent decades has been matched by a steady increase in the number of counsellors being trained, by comparison the number of disabled counsellors remains very low. Throughout the group there was agreement of the need for increased opportunities for people with impairments to be able to train as counsellors. By allowing more flexibility in admission criteria to professional training courses, this would enable greater consideration of individuals’ life experiences and circumstances and what they could bring to a counselling relationship. Until this occurred, women with a physical impairment who voiced a preference for receiving counselling from a counsellor with an impairment, would be unlikely to have their wishes fulfilled.
Footnote.

Direct Payments is a scheme through which individuals who wish to have greater control over the care they are provided with, who it is provided by, and at what times of day or night. Following assessment by a Social Worker to ascertain the level of personal care and support with day to day living required and the number of hours required to meet those needs, the total cost is calculated. Using Direct Payments the Local Authority in which the individual lives pays the required monies into the person’s bank account and these are then used to purchase the care they require.
CHAPTER NINE
MENTAL HEALTH SERVICES FOR WOMEN WITH
PHYSICAL IMPAIRMENTS: LOOKING TO THE FUTURE.

INTRODUCTION

This chapter focuses on the future of mental health services for women with physical impairments. It does this drawing on the perspectives and ideas of the women who took part in the study. It draws on findings from the final part of the interviews in which the women were asked to talk about the ways in which they believed that mental health services in the UK could better meet the needs of women with physical impairments who experience mental distress. The chapter also focuses on the findings from one of the discussion topics of the focus group in which eight women shared their views in relation to whether mental health services in the UK could meet the needs of women with physical impairments who experience mental distress in a more appropriate way. Where suggestions for improvements were made, women were asked to share their vision of how those changes could be achieved.

In both the interviews and the focus group discussion, women were asked to share their thoughts on two distinct areas. Firstly, the women were asked their views on any changes or improvements which they considered were needed at a service provider level. Part One of the chapter focuses on findings from this area. Secondly, women were asked their views about any practical changes which they believed would make a significant contribution to improving the future experiences of receiving mental health support for women with physical impairments. The findings from this area are examined in Part Two of this chapter.
The suggestions made in relation to future service provision were made in the context of women’s own experiences of contact with mental health services. This section therefore briefly summarises the range of services that the sample group had direct experience of attempting to access and/or using. Whilst two women had been able to access mental health support through a self referral process that operated within their respective higher education establishments, for the majority of women experiencing mental distress, their General Practitioner had been the first point of contact. Louise was the only woman in the study whose first contact with mental health services was an admission to a specialist psychiatric ward (for Louise, this was a ward for adolescents with eating disorders.)

For four women, their GP was the sole professional involved in treating their mental distress. However, each of these women explained that this had not been their choice. This was attributed to a lack of appropriate mental health services in the geographical area in which they lived, and for two women, Katy and Lisa, to a reluctance of the GP to refer to out of borough services which they were eligible to access. Katy and Lisa spoke of how they had sought additional support from online support groups which could be accessed easily in their home environment.

Of the six women referred on to specialist mental health services by their GP, only two were referred when experiencing mental distress for the first time. For these two women the severity of their distress was assessed by the GP as being sufficiently acute to necessitate a priority referral to mental health specialist services i.e. Community Mental Health Teams. The remaining four women recalled how their referrals to specialist mental health services were made after contact with their GP and/or drug treatment over a period of time were not felt to have been sufficient in treating the
woman’s mental distress. In addition to women’s contact with services located predominantly within the statutory sector, a small number of women had used support groups located within the voluntary sector.

**PART ONE: TRAINING OF MENTAL HEALTH PROFESSIONALS**

From the data gathered from the interviews five strong themes emerged in relation to the future training of Mental Health professionals. Firstly, the data clearly highlighted that in order for women with physical impairments to receive improved mental health support that met their needs, one of the major changes required was the need for all mental health professionals to have a much greater awareness and understanding of disability and impairment. There was a group wide view, that if mental health professionals had a clear understanding of the social model of disability this would improve their understanding of disability and impairment. Secondly, women shared the view that if Disability Equality Training became part of the education of mental health and health professionals, then there would be improvements in the responses made to women with physical impairments who experienced mental distress. Thirdly, the potential benefits which many women considered that service user input could bring to those undertaking professional training courses was identified. Fourthly, the issue of choices within counselling relationships was identified as a critical issue for the training of mental health professionals. Finally, the need for mental health professionals to give consideration to factors central to the women’s everyday lives when working with women with physical impairments was identified.

**The social model of disability.**

A commonly expressed view was that a greater understanding of disability and impairment could be achieved by those working within mental health both becoming
familiar with, and adopting a social model approach to disability within their work. Across the group it was felt strongly that by mental health professionals adopting a social model approach within their work, in contrast to a medical model approach, that the experiences of receiving mental health support for women with physical impairments would be improved. There was a consensus in the interviews that women did not wish to receive counselling or other forms of mental health support from mental health professionals who treated the woman in a pityingly sympathetic way. What they did want was to have the opportunity to work with a mental health professional who would listen to and support them in addressing the mental distress they were experiencing. Elisabeth recalled how her progressive impairment and physical appearance had attracted sympathy from her counsellor.

"By the time I went along to counselling I was at a really low point and just really felt a need to talk to someone to offload everything and get it out of my system. But the counsellor kept asking what I felt were quite intrusive questions about my condition and she had this look of real pity in her eyes which wasn't what I needed. It took a long time to move on from that and for me to feel that I was actually getting something out of my counselling sessions with her." Elisabeth (age 62, congenital progressive impairment)

Until those working within mental health had a good knowledge base of the social model of disability, women felt that they would not receive a mental health service that was either of a consistently good quality or that matched their needs. Across the group, women reinforced their view that whilst mental health professionals continued to work within a medical model approach to disability, in which women were characterised by what they were unable to do by referring to their medical diagnoses, then women with impairments would continue to receive inappropriate mental health support that did not meet their needs.
Disability Equality Training.

One of the clearest messages to emerge from analysis of both data sets was the women’s shared expression of the urgent need for mental health professionals to have a much greater understanding and awareness of disability and impairment. From past experiences of receiving mental health support from professionals working within a range of health and social care organisations, the majority of the women recalled their lack of a good understanding of disability and impairment. A better understanding amongst mental health professionals, of both disability and impairment, was considered to be vital if mental health services in the years ahead were to meet in an appropriate way the mental health needs of women with physical impairments.

There was widespread belief that improvements in mental health service provision in the United Kingdom for women with physical impairments could be achieved through changes to the training courses of all mental health and other health professionals, who, in their line of work had regular contact with women who were experiencing mental distress. Within Chapter Eight (page 203) many of the women’s shared belief in the need for Disability Equality Training (DET) to be incorporated into the syllabus of professional training courses was discussed. Developed by disabled people in the 1980s to address the need for information about disability, DET courses aim to help people understand the meaning of disability, to identify changes in their work practice and plan strategies to implement change. There was consensus that the introduction of DET would assist in providing mental health professionals both with a greater understanding of disability and impairment and the ability to identify and address discriminatory forms of practice within their work with people with impairments. The data highlighted women’s hope that through DET, mental health professionals would find ways to challenge the organisational behaviour which reinforces negative myths and
values, and prevents disabled people from gaining equality and achieving full participation in society. Until DET was routinely included in the syllabus of professional training courses, the majority of women felt that mental health professionals with no experience of physical impairment would continue to work with a minimal understanding of disability or impairment. This was deemed as unhelpful to women like themselves seeking mental health or psychological support.

Whilst the need for DET within counselling training courses has in recent years been documented within the literature, (Brearley & Bochley 1996, Lago & Smith 2004) analysis of the data demonstrated the strength of feeling expressed for DET to be included within the training courses of other mental health professionals to whom a woman may be referred for mental health support, such as Community Psychiatric Nurses. A number of women considered counselling support to be part of the CPN’s role and said it was equally important for them to have a good understanding of disability and impairment. Pippa explained how the lack of understanding around disability and impairment that she encountered when working with her Community Psychiatric Nurse, had contributed significantly to her poor experience of receiving mental health support.

“When I was allocated a female CPN I thought things would be ok but from quite early on I realised that any awareness or understanding that she had around disability stuff was minimal. at first she would talk to my mum rather than me and then when I talked to her the one day about issues at work she started to look through her notes as if to say & says nothing in here about you going out to work, are you sure that’s right? Pippa (age 35, congenital stable impairment)

As their working relationship developed, Pippa’s psychiatric nurse shared with her that she had no previous experience of working with anyone with a physical impairment, and acknowledged that she had initially felt out of her comfort zone when
she first met Pippa. Her poor experience, Pippa stated, served to reinforce the belief she held of the urgent need for mental health professionals to have some input around disability within their professional training courses.

In addition to mental health professionals, General Practitioners were a group of professionals who the majority of women identified as needing to develop a greater understanding of disability and impairment. For the majority of the women, their GP had been the initial point of contact when seeking mental health support, and these women stressed the important role that GPs played in ensuring that the referrals they made for mental health support were appropriate ones. The importance of GPs providing relevant and accurate information in their referrals to mental health services which indicated clearly the nature of the distress being experienced was highlighted by the data. A quicker response by GPs to refer to appropriate services that could provide the necessary support required, was one way that women felt mental health services could meet their needs more efficiently and effectively. Several women highlighted the need for GPs to recognise that when mental distress was experienced, this may not solely be as a result of the woman’s impairment, and that GPs needed to listen to what the woman was saying. Service User involvement in the training of mental health and other health professionals was indicated by half of the women as being one way in which their understanding and awareness of disability and impairment could potentially be significantly improved.

**Service User involvement.**

Through listening to the personal experiences of those who had lived both with physical impairment and mental distress, women believed that mental health and health professionals whose role may be instrumental in accessing the mental health support
that women required, could improve their understanding and awareness of disability and impairment. Four women in the group had previous experience of giving presentations around disability to local statutory and non-statutory groups and organisations. These women believed that mental health/health professionals would develop a greater understanding and awareness of disability through listening seriously to the personal stories of women with physical impairments who had experienced mental distress, in addition to lecture based teaching and books. Alison suggested that many mental health professionals were cautious about learning from service users and were reluctant to consider new approaches to their training. However, she believed that all health professionals needed to give consideration to what they could learn from listening to service user experiences.

“\nI think these so called professionals need to listen to us and to what we are saying rather than just assuming that they know what is best which is how things seemed to have worked for so long. I think for quite a few people there is a feeling of well we have the qualifications so we must be the experts. but I really feel that the professionals need to learn from real people as well as books and from the so called experts.”
Alison (age 39, congenital stable impairment)

The majority of women believed that General Practitioners were one group of professionals who were unlikely to show support for service user input initiatives. This was considered to be disappointing given that usually, when seeking mental health support, their GP was the first point of contact. Helen spoke of how, on numerous occasions she had endeavoured to involve GPs within her local and wider community to presentations that she delivered around a range of disability issues, including one that focused on physical impairment and mental distress. She explained how, through her presentations, one of the primary aims had been to get GPs to both listen to and learn about the experience of mental distress from the personal viewpoint of a woman with a physical impairment.
Each time I would give a talk all of the local GPs would be invited alongside other health and social care professionals but it was more often than not the GPs who didn’t show up, generally saying they were too busy but I think personally it was more down to a lack of interest as I don’t think many doctors see disability or mental health as particularly exciting areas of medicine—maybe I’m wrong but that’s what my experiences have led me to believe.

Helen (age 43, congenital stable impairment)

Whilst women recognised that GPs were not mental health specialists, they were however perceived across the group as having a position of power, given that ultimately they acted as gatekeepers to services and made the decision as to whether a referral to mental health services would be actioned.

**Choices in counselling.**

Findings from the data provided evidence of a widely held belief, that a greater availability of counsellors with impairments would improve the experiences of using mental health services for those women who held a preference to work with a counsellor who had personal experience of living with a physical impairment. Likewise, the data indicated the women’s collective belief in the need for a greater element of choice as to whether they wished to receive counselling from a counsellor who was able-bodied or one who had a physical impairment. However, there was widespread recognition across the group that choice as a concept only had value if in reality that choice existed. Whilst the previous chapter (page 206) highlighted that none of the women were in favour of all people with physical impairments only receiving counselling from individuals who were themselves physically impaired, equally the opinion was voiced that a system that allows for individual choice and preferences to be met is required.

The majority of the women expressed the view that being offered a choice between working with an able-bodied counsellor or one with experience of living with a physical
impairment, would only become a reality if greater opportunities were provided for
women (& men) with physical impairments to train as counsellors. As was highlighted
within Chapter Eight (page 205), there was collective agreement that the barriers to
counselling training for people with physical impairments should be removed (such as a
lack of academic qualifications). In addition, the data showed that when selecting
potential candidates for counselling training, there was a need for course selectors to
acknowledge other life experiences that the individual with a physical impairment may
have encountered, in addition to an appreciation of what the individual could bring to a
counselling relationship.

In her interview Elisabeth spoke of how, when been assessed for needs relating to
her physical impairment, she had valued the fact that the social worker had a significant
mobility impairment. This, she stated was because her impairment led Elisabeth to feel
the social worker had a good understanding of Elisabeth’s needs and that she could
empathise with the difficulties Elisabeth experienced with daily living activities. It was
this shared understanding which Elisabeth felt strongly would have been beneficial in
providing her with appropriate mental health support that met her needs.

An understanding of the lived experience of impairment.

The data demonstrated how women felt that in order for future mental health service
provision to be experienced in a more positive way, the relationship between the mental
health professional and the woman needed to be effective and purposeful. From the
outset, women spoke of the need for a clear understanding between the two parties as
to why mental health support was being sought, and secondly, what mental health
issues the woman was seeking to resolve or address.
Those women in the group, who due to the nature of their impairments had a high level of care support needs, spoke of how their experiences of mental distress were felt to have been linked in particular to other factors, for example, the provision of care from private agencies. In instances where care support was provided through the statutory sector, women described how care providers could often be inflexible and that the structure of their daily life at times became dictated by the care that they needed to receive. Women recalled having to explain to the mental health professionals with whom they were working, the ways in which such factors could affect their daily life and the potential that they had to impact on their psychological and mental well being. In addition, as was stated in Chapter Eight (page 207), women emphasised how people working within mental health professions needed to recognise that women with physical impairments are also likely to be parents, siblings, friends, involved in or seeking work and so on, and that as such are likely to be subject to the same range of life experiences as able-bodied women such as loss of work, bereavement, or providing support in the context of personal relationships.

Finally, many women expressed the view that mental health professionals needed to have both a greater understanding and appreciation of some of the issues that women with impairments may be confronted with on a daily basis in society, particularly attitudes towards impairment. Whilst within Chapter Six women spoke of a belief that attitudes towards impairment within society were improving overall, many women cited examples of how they continued to encounter difficulties with attitudes within a range of environments and/or from individuals working within them.
PART TWO: THE NEED FOR PRACTICAL CHANGES

In this second part of the chapter, the practical changes which women believed were needed in order to achieve improved future mental health provision for women with physical impairments are discussed. Within both data sources, a significant number of practical changes and considerations were highlighted, which individually or collectively, women believed would enhance the experiences of receiving mental health support for women with physical impairments.

For all the women, reduced waiting times were identified as an area of concern, and it was widely agreed that improvements were needed to ensure that appropriate support was required, in particular at times of acute mental distress. In addition there was a shared belief in the need for mental health professionals to show greater consideration for the impact of the woman’s impairment on factors such as times of appointments offered, their duration and location and that professionals should endeavour to offer greater flexibility in the support being provided. Without such consideration, women believed that they would continue to receive a service that did not meet their specific needs.

For those women whose impairments were of a progressive nature, the data highlighted their expressed wish for access to long term mental health support and consistency of worker. Through combined provision of both, these women believed an opportunity would be provided for a good working relationship to be formed. Through being able to access long term support, it was believed that this would contribute significantly to providing the potential for positive experiences of receiving mental health support.
Provision of locally based support groups were, the data indicated, a further way in which women felt that future progress in mental health service provision for women with physical impairments could be developed. However, having access to information about availability of support groups and other mental health services that women were eligible to access, was considered across the group to be vital in ensuring that the required services could be accessed without encountering difficulties.

Whilst only one woman had experience of in-patient psychiatric care, Louise's varied experiences within a range of hospital environments enabled her to detail comprehensively the changes which she believed were essential in order to improve the experience of psychiatric in-patient admissions for women with physical impairments in the years ahead.

Each of these areas shall now be discussed.

**Reduced waiting for appropriate support.**

Firstly, there was a group wide agreement that mental health services for women with physical impairments could be improved through service providers making greater efforts to reduce the length of time waited before an assessment of need was offered. In particular, several women stated they would have a greater degree of confidence in mental health services if assurances could be given that at times of acute mental distress, waiting times would be kept to a minimum. Four women recalled how both the difficulties they had encountered in accessing services, and long waits to be seen had exacerbated their mental distress. However, these women spoke of recognising that waiting times were not an issue that was unique to women with impairments who were attempting to access mental health support. Half of the sample group similarly talked
about how the prospect of a long wait to access a service had impacted both on their
expectations of and confidence in mental health services.

"I waited about nine months before I got offered an initial assessment so by
that time I felt really fed up. The problems I was having were big to me and yet it
felt like they were not important to them at all—how could you think any different
when you were waiting that long? By the time I got a date to be seen I already
had low expectations of the psychology service and for quite a while I admit it did
impact on my commitment to really working through the problems I was having."
Carly (age 18, congenital stable impairment)

Additionally, several women recalled how they had visited their GP on numerous
occasions before their request for a referral for mental health support was agreed,
which had led ultimately to delays in getting their mental health difficulties addressed.
Lisa described how she had become frustrated by the length of time it took before she
was referred for counselling.

"By the time I went to my GP I was already feeling quite down but past
experiences of going to the GP had put me off going again unless I got to a point
where I felt I wasn’t coping. Within about five minutes he was talking about anti-
derpressants which he knew I wasn’t a big fan of but decided that as that was all
he was offering I would have to give them a go. It took another three visits each
about a month apart before he agreed to my request to be referred for
counselling and I feel those months I spent on medication alone were really
wasted time."
Lisa (age 45, congenital fluctuating impairment)

Women who had encountered long waits to be seen by a mental health
professional, spoke of how in future they would welcome increased opportunities to self-
refer to counsellors or other mental health services for which a need had been
identified. Many women considered that the ability to self-refer would assist in reducing
overall waiting times. However, throughout the group there was an awareness that in
reality self-referral to mental health professionals was unlikely to be granted, based on
the concerns of service providers that they would be overwhelmed with a demand for
their services which they could not meet.
The impact of impairment.

As discussed within Chapter Eight, (page 215) the data highlighted the importance that women attached to mental health professionals giving consideration to the impact of the woman’s impairment on practical issues including the times and length of appointment times. Women spoke of the need for more flexibility in the number of contact sessions offered by the worker, and the frequency and times at which those sessions were arranged. For those women in the group whose mobility was significantly impaired, they explained how their limited mobility made it difficult for them to leave their home environment and that accessing transport that met their mobility requirements could be problematic. Whilst these women acknowledged that counselling in the woman’s home environment was not considered to be the norm, experiences of using mental health services, it was felt, could be improved by a greater appreciation of individual circumstances.

A number of women drew attention to the ambiguity which appeared to exist with regard to which services could be provided to an individual in their home surroundings. Pippa recalled how part of her CPN’s role had been to offer counselling, which was conducted within her home, but when she was offered counselling from a psychologist, this was conditional on their sessions being conducted at the counsellor’s place of work. Helen recalled that when receiving counselling her speech impairment was not given due consideration.

“When I was having my counselling sessions through the local mental health trust I was told that the sessions would be approximately fifty minutes but not over an hour. Well because of my speech I could hardly talk about anything in that length of time yet there was no flexibility and after fifty minutes was up the counsellor would say ..OK well finish there for today and I’m thinking we’re hardly touched on anything. I just found it so frustrating and all the effort of getting there seemed hardly worthwhile."  
Helen (age 43, congenital stable impairment)
Until mental health professionals gave greater consideration to the individual needs of women with a range of impairments, and offered greater scope for flexibility in the mental health support they offered, it was felt by each of the women that they would not receive a service that was tailored to their individual needs. Additionally, women spoke of the responsibility that mental health service providers had, following implementation of the Disability Discrimination Act, in ensuring that people with a range of impairments were not discriminated against.

**Long-term and consistent support.**

Women in the study whose impairments were of a progressive nature, expressed the view that future mental health services could be made more appropriate to their needs by consideration being given to their own perceived need for long-term support. This group of women stated that they did not consider themselves to have an ongoing need for mental health support. However, they believed that by being able to easily access mental health services at times when they felt in need of support, for example, when experiencing a decline in their physical abilities, that this would provide them with a mental health service that was based on individual needs.

The majority of the sample group spoke of how they would have rated past experiences of using mental health services more positively if they had been provided with a continuity of worker. Whilst those women who had received counselling from a psychologist reported working with the same individual for their allocated counselling sessions, women who had received mental health support from Community Mental Health Teams or mental health social workers recalled how they had frequently had to adjust to a change of worker. Having access to a named professional, with whom the woman could endeavour to form a working relationship with, was, the data showed,
valued highly as was having a worker who could be contacted directly as and when the need arose. Many women spoke of experiencing frustration when repeat episodes of mental distress necessitated a new referral being made. This subsequently resulted in further waiting to be seen in addition to frequently being allocated to a new worker who knew little of the woman’s life circumstances. Louise, who had experience of contact with her local Community Mental Health Team on several occasions, spoke of the frustration she felt when, on repeated occasions, she found herself allocated to a different team member.

“The days seem to have long gone when you had a social worker or another professional for ever and a day and you could just ring up and talk to them when you needed to. The emphasis now is absolutely on short term work with a focus on crisis involvement. The worker deals with the immediate problems and then once the crisis is over they move on when in reality you still need the help but mental health services have just become a sticking plaster culture.” Louise (age 39, acquired progressive neurological impairment)

Across the group, women spoke of their recognition that as a client group they were not unique in expressing a wish to have a named mental health professional to support them during times of mental distress. However, the data showed how women considered the circumstances of their lives to be different to those of able-bodied women who may experience one episode of receiving mental health support for a specific mental health issue, in contrast to their own perceived need for longer term mental health support. Amongst the women there was consensus that a consistency of worker would improve the overall experience of receiving appropriate mental health support. However, there was widespread acknowledgement that an increasing demand over recent years on mental health services would mean that continuity of worker would not become a reality unless the circumstances of the individual were deemed to be exceptional. The ideal of continuity of worker was also felt by each of the women to be affected by a range of other factors including staff shortages, employee sickness or
individuals leaving their jobs. Three women who had received support from their local CMHT similarly recalled how staff sickness had appeared to be an ongoing problem and that cancelled appointments, often at short notice had been a source of frustration. Pippa described also how it became difficult to form a good working relationship with her CPN as a consequence of her regular absence from work which had resulted in there being long gaps in between their appointments.

Whilst a wish for a named caseworker over an extended period of time was acknowledged as being highly unlikely in the near future to become a reality, the data clearly demonstrated this to be one of the strongest views expressed in relation to how mental health services in the UK could improve service provision for women with physical impairments. Drawing on personal experiences, a small number of women recalled how, until recent years, the mental health support they had received through the voluntary sector, had offered a level of flexibility which took account of individual needs. However, as demands on their services in recent years had increased significantly, so their ability and willingness to offer flexibility had reduced substantially.

**Improvements in joint working.**

Within previous chapters, the need for mental health and other health professionals to consider a range of factors central to women’s lives that may contribute to the experience of mental distress has been emphasised. In addition, the data indicated a shared belief in the need for mental health professionals to both communicate with, and work alongside other professionals who may be working with the woman, as was deemed necessary or appropriate. In so doing, it was felt by each of the women that this would assist the mental health professional to work within a holistic approach, and would ensure that the woman’s physical impairment and mental distress were not
compartmentalised. Katy spoke of feeling frustrated by the lack of communication and joint working between different professionals who were working with her.

‘I had a social worker who was dealing mainly with the care side of things, there was an Occupational Therapist who was dealing with various aids etc, district nurses who were there for the nursing part of your care and then there was the Community Psychiatric Nurse. Well they all came in and filled in their own forms which meant you repeating the same stuff over and again yet none of them spoke to one another. there was absolutely no communication and you just felt like a person who was split up into all these little boxes and no one saw you as a whole individual
Katy (age 43, congenital progressive impairment)

In Chapter Seven, (page 186) Judith and Jackie were critical of the way in which the focus of their rehabilitation had been wholly on mobility and regaining the maximum level of independence as was deemed possible by their medical team. In contrast, the psychological impact of acquiring an impairment suddenly was for both women largely ignored and they were left to seek support for their emotional distress after their discharge from hospital. Both Judith and Jackie shared the view that the mental health needs of women with acquired impairments would be better met in future by integrating a level of psychological support into the overall rehabilitation programme. Through joint working between ward based health professionals and hospital based mental health professionals, both women believed that this would result in the woman being seen in a holistic way and that the physical and psychological effects of acquiring a sudden onset physical impairment would cease to be treated in isolation. Whilst it may be argued that joint working can be hindered by structural and organisational factors, professional perspectives and skills which enable a holistic approach to disability awareness, should be core to the training and education of the health professionals working with the individual.
Provision of support groups.

In meeting their future mental health needs in a more appropriate way, many women shared the view that a greater availability of support groups for women with physical impairments who had experienced, or were currently experiencing mental distress, would be beneficial to them. These women believed that support groups could provide a forum in which the opportunity was provided for women with physical impairments to talk with other women who were experiencing difficulties of a similar nature to their own. Alison was one woman who felt that if a support group had been available within a reasonable travelling distance of her home, then this would have been benefited her in a number of ways. Firstly, Alison felt that having access to a support group would have reduced the feelings of frustration that she experienced whilst waiting to see a professional counsellor. Secondly, Alison believed that the availability of a support group that accommodated her access needs would have helped to reduce the feelings of being alone with her thoughts.

Many women also felt that mental health support groups for women with physical impairments could potentially benefit women who, neither felt a wish for, or a need to receive professional mental health support. Alternatively, for women faced with the prospect of a long wait to access counselling, it was considered that support groups could provide a level of support through the opportunity they provided to meet informally with other women who were experiencing mental distress similar to their own. Additionally, the data showed how women felt that mental health support groups would provide an arena in which mutual support was provided and with an additional potential of reducing the feelings of social isolation, which many women recalled experiencing when living with their mental distress as expressed by Alison, noted above.
Frankie described her one experience of attending a support group for women who were experiencing stress and anxiety.

“At first when I was told about the group I wasn’t sure that it was for me but I went along and for a few weeks had to make a real effort to go but after that I felt for a while that I was getting something out of going. However over time I realised that my experiences were quite different from the other women there partly because most of the women were much older than me and secondly I was the only woman with an impairment so I felt a bit out of place and after a while stopped going. I definitely feel that we need more support groups not just for women with a range of physical impairments but for women in the younger age bracket as I think their experiences can be different." Frankie (age 27, congenital fluctuating impairment)

Whilst within Chapter Eight (page 207) some women expressed a wish to have access to the same range of counselling services as able-bodied women, just over half of the women believed that specific support groups for women with physical impairments who experience mental distress have a unique role to play in providing support to them. However, it was widely agreed that the provision of support groups in meeting the mental health needs of women with physical impairments would only be beneficial if their long term financial security could be guaranteed. Ongoing concerns and uncertainty over financial security were viewed by many of the women as having the potential to impact detrimentally on the mental distress of those women for whom a support group may form an integral part of their support network. Within Chapter Eight (page 217), Judith described how the stroke support group which she attended, provided her with the level of social contact that she required in order to maintain her mental well being. In addition it provided her with emotional support from individuals who had previously experienced or were living through experiences similar to her own.
The support group I go to, although it doesn’t focus totally on providing emotional support it does so almost without trying and we all feel the same. The thing that bothers me is the constant rumours about the group closing down because of a lack of funding or because the rents on the building are too high. It’s always there hanging over you and if this group were to fold I would feel the loss massively. The powers that be should be providing more groups like this and not closing them down. At the end of the days it’s people’s lives and it shouldn’t always come down to money but of course often it does.

Judith (age 61, acquired impairment following stroke)

Whilst the majority of women were in favour of increased provision in future years of nation wide based mental health support groups for women with physical impairments, three women explained why attending a support group had not been beneficial for them. Both Pippa and Helen shared the view that they had not felt comfortable talking to individuals who they did not know well, and that they had preferred instead to talk to friends in whom they felt more able to confide.

I went along to a support group for people with depression a few times but each time there were different people there so I didn’t feel I could talk about the personal stuff I was going through to people who I might not see again. I would much rather pick up the phone or switch the computer on and have an online chat with one or more of my closest friends. I know they perhaps don’t have the level of understanding that some of those in the group did but the one thing my closest friends do for me is just sit and listen and I think I value that more than anything.

Pippa (age 35, congenital stable impairment)

Louise attributed her mixed experiences of attending a support group for people with eating disorders to her perception of the reasons for her eating distress as being different from those of the other women attending the group, all of whom were able-bodied. Whilst Louise felt that certain aspects of her eating distress were similar to those of other women attending the support group, due to the nature of her impairment she considered there to be aspects of the other women’s eating distress that she felt unable to identify or reason with.
Therefore, whilst the majority of the women considered that future provision of support groups for women with physical impairments who experience mental distress would represent a positive development in service provision, the experiences of three women indicated the possibility that they were not what every woman felt a need for in supporting them when experiencing mental distress.

**Improved access to information.**

Chapter Seven (page 181) highlighted how a good knowledge of mental health services that were available, was considered by all women key to ensuring optimum opportunity for accessing mental health support that met the woman's individual needs.

In their interviews several women who had accessed services spoke of how they had received appointments from a range of services but had been provided with little, or no information either about what the service provided or what could be expected from it.

Pippa recalled the response of her CPN when she asked her for some information about the Community Mental Health Team.

> Ñil got a letter giving me an appointment to see a CPN from the local mental health team but I knew nothing about them, what they did or offered or who the people were who worked within the team. When she arrived my mum asked her for some information about the service but she had nothing and seemed really surprised my mum had asked. I think services just assume that you know what they are about but how can you if you haven't had any dealings with them before?

Pippa (age 35, congenital stable impairment)

Pippa's experience was shared by other women who viewed the availability of information about a service, what it provided and what a service user could expect from a service as being a basic but vital starting point for accessing the help and support required.

Data from both the interviews and focus group provided evidence of the women's belief that future provision of mental health services for women with physical
impairments could be significantly improved through greater availability of relevant, up-to-date information about services that were available for them to access. Having access to information which laid out clearly in jargon free language what the service criteria were, women felt, would encourage them to request a referral be made to it. Helen’s recollection of how her knowledge of services which would potentially be of benefit to her had been gleaned from other service users, was typical of the experiences of four other women.

For a while I attended a day care centre for adults with long term mental health problems and it was through people that I got to know there that I learnt about all these services I could possibly access. The information didn’t come from any of the mental health professionals I was working with and yet I saw it as part of their job to let you know about things that were out there in the community which might be of some benefit to you. If you don’t know these places or services exist, how can you make a start to access them?

Helen (age 43, congenital stable impairment)

Women in the group whose ability to access public places was affected by the severity of their impairment spoke of how in turn this impacted on accessing information which is routinely placed within public buildings (for example, GP surgeries or public libraries). Several women felt strongly that in addition to providing service information in traditional leaflet based format, mental health service providers should be urged in future to harness and make use of recent advances in technology. By providing information about their services on their websites, this would assist in ensuring easier access to information for those with significant mobility difficulties. Carly recalled how she had gained her knowledge of the services which she was eligible to access in meeting needs relating to her physical impairment through her local authority’s website, and she believed that similar information should be available in relation to mental health needs. However, a small number of women felt that a perceived reluctance on the part of GPs and mental health professionals to advise women about service provision, may
in part be an attempt to protect services which had existing high demands placed on them from becoming overloaded.

Without exception, women considered themselves entitled to be fully informed about availability of mental health services that may be appropriate in treating their mental distress. Additionally, by mental health service organisations providing services that met the needs of women with physical impairments, this it was collectively believed would lead to an increased incidence of women with physical impairments reporting positive experiences of receiving mental health support.

**In-patient care.**

As the only woman in the study who had experience of receiving in-patient psychiatric care, Louise believed that substantial changes at both an environmental and attitudinal level were required in order to improve the experiences of psychiatric in-patient care for women with physical impairments in the years ahead. Foremost, as discussed within Part One, Louise reaffirmed the need for both medical and nursing staff on in-patient wards to have a much greater understanding of disability and impairment and overall better disability awareness.

Louise felt passionately that mental health in-patient admissions could better meet the needs of women with physical impairments by virtue of a shift in attitude from both medical and nursing staff. Louise recalled how she had repeatedly encountered from members of the medical and nursing teams, a belief that her mental distress was causally linked to the physical impairment with which she was living. Mental health in-patient support for women with physical impairments who were experiencing mental distress, Louise believed, would be unlikely to improve until both medical and nursing
staff became better educated and had a greater understanding of disability and impairment.

Drawing on her personal experiences, Louise outlined how on a practical level the physical environments of psychiatric hospital wards needed to be improved so as to provide full wheelchair access. Through offering a fully accessible environment to patients whose mobility was significantly impaired, Louise spoke of how they would then not be dependent on others for everyday tasks.

“My last hospital admission, well I was in quite a bad way and yet I knew I didn’t want to end up back in hospital because of my previous experiences. In the end it was either go informally or face the prospect of sectioning which I couldn’t put myself through but the whole admission just felt undignified and then with having to ask for help all the while because the ward wasn’t accessible for me it was horrible and undignified and just made me more miserable and depressed.” Louise (age 39, acquired progressive neurological impairment)

During three of her four in-patient admissions, Louise recalled how the majority of ward nursing staff had openly acknowledged to her their lack of any previous contact with a patient with a significant mobility impairment. In addition, as other patients on the ward were self caring they were unfamiliar with assisting patients who had personal care requirements. Louise described how nursing staff had been unable to recognise that the layout of social spaces on the ward was not suitable for a wheelchair user, and that a resulting inability to use such spaces had increased her level of dependency on others for help with daily living activities. For example, Louise recalled how she had been unable to use the patients’ kitchen to make a drink and became dependent on others to provide her with a drink, though fellow patients were found to be more willing than ward staff to assist her. In addition, a lack of call buttons in bathrooms and bedrooms had created for Louise a sense of vulnerability due to her inability to summons assistance. Once again, the inability of ward staff to recognise that such
factors were likely to be problematic, reinforced to Louise their overall lack of disability awareness.

In contrast to her negative experiences of in-patient psychiatric care, Louise recalled her one positive experience of in-patient psychiatric care. An admission to a specialist ward environment, represented to Louise, a positive example of the way in mental health service provision could meet in a comprehensive and beneficial way the mental health needs of women (and men) with physical impairments. Louise explained that the neuro-psychiatric ward which was located within a specialist hospital for patients with neurological impairments, catered for individuals who were experiencing long term psychological difficulties or acute mental distress. Here, Louise was heartened to encounter ward staff who, whilst being mental health trained, also had a wide knowledge base of neurological impairments and the potential ways in which individuals' impairments might impact on their mental well being. Unlike her previous admissions, which had been characterised by days which had little or no structure to them, Louise described her days on the ten patient ward as being well structured with a typical day consisting of at least one counselling session. In addition, her daily programme included obligatory attendance at one of the wards support groups and spending one to one time with a named member of the ward nursing team. Whilst the ward environment and admission represented to Louise a positive example of how future mental health provision could meet appropriately the needs of women (and men) with a wide range of physical impairments who required in-patient care, she recalled how fellow patients had been frustrated by an average admission waiting time of six months. In addition, each patient was offered a maximum two week admission with little scope for flexibility unless the individuals circumstances were considered by the ward multi disciplinary team to be exceptional. Louise felt strongly that nationwide provision of
such specialist wards would be a welcome future development in providing appropriate mental health provision for women (and men) with physical impairments who experience mental distress.

CONCLUSIONS

The central focus of this chapter has been to discuss the study’s findings in relation to the ways in which women believed that mental health services in the UK could in the future, meet more appropriately the needs of women with physical impairments who experience mental distress. Part One has examined the changes or improvements which were considered to be needed at a service provider level. Part Two has discussed the practical changes which, if implemented, women believed would contribute significantly to improving the future experiences of receiving mental health support for women with physical impairments who experience mental distress. Chapter Seven clearly showed how the majority of women had not felt the mental health support with which they had been provided had been appropriate to their specific needs. The suggestions made in relation to future provision were made in the context of women’s personal experiences of contact with mental health services and any barriers that had been experienced either when accessing and/or using mental health services.

Part One reinforced the view expressed by all the women across the study’s findings, that a greater understanding and awareness of disability and impairment among mental health professionals was considered vital if mental health services in the UK in the years ahead are to meet comprehensively and appropriately the mental health needs of women with physical impairments who experience mental distress. Through becoming familiar with and learning about the social model of disability, women believed this to be an important way in which understanding and awareness of disability and
impairment among mental health and other health professionals could be improved. By adopting a social model approach within their work, there was a shared belief that experiences of receiving mental health support for women with physical impairments could be significantly improved.

A greater awareness and understanding of disability and impairment it was felt by some women could further be improved through mental health professionals (and other health professionals who were involved in providing support to individuals experiencing mental distress) listening seriously to the experiences of those who had experience of both physical impairment and mental distress. The need for inclusion of Disability Equality Training within the training courses of mental health and other health professionals i.e GPs, in the future, was indicated by many women with Chapter Eight. Through its inclusion women believed this would represent a positive development in improving future mental health service provision through the opportunities it would provide to improve professionals understanding and awareness of disability and impairment.

A greater element of choice as to whether counselling was provided by a counsellor with an impairment or one who was able-bodied was identified as an area that needed to be addressed. Whilst Chapter Eight showed no woman to be in favour of all people with physical impairments only receiving counsellors from individuals who themselves had a physical impairment, it was equally believed that a choice should exist for women had had a preference to receive mental health support from someone with a lived experience of impairment. By removing barriers to professional training courses, this was seen as one way in which an increased number of counsellors with physical impairments could be achieved.
Part Two was seen to highlight a range of practical changes and considerations which, singularly or combined, women considered would enhance future experiences of receiving mental health support for women with physical impairments. Within Chapter Seven, a variety of factors, including long waiting times to be seen, and a need for access to information about the availability of services were talked about in the context of the women’s mostly negative experiences of both using and accessing mental health services. In particular, negative experiences were seen to have been recalled by women whose mental health support had been provided by the statutory sector. Through making greater efforts to joint work with other professionals who may be involved in providing support/care to a woman, women believed this would assist mental health professionals in building a wider picture of the woman’s life. In turn this would lead to a greater understanding of her impairment and the ways it which may impact on different areas of her life. Increased incidences of joint working many women hoped would also encourage mental health professionals to shift away from compartmentalising their physical impairment and experience(s) of mental distress, and in turn to adopt a more holistic approach in which they were seen as a whole person.
CHAPTER TEN
WOMEN WITH PHYSICAL IMPAIRMENTS AND MENTAL DISTRESS:
CONCLUSIONS AND FUTURE DIRECTIONS

INTRODUCTION

In conducting this research, the overarching aim has been to produce a study in which the central focus has been the experiences of women with physical impairments, from their own perspectives. In introducing the study, the five aims that it set out to achieve were outlined. Firstly, it aimed to examine the provision of mental health services both within the statutory and voluntary sector, for women with a physical impairment, aged between 18 and 65, living in England or Wales, who also have mental health needs. Secondly, the study aimed to examine the experiences of a group of women with physical impairments who had or were currently experiencing mental distress, of both accessing and using mental health services. Thirdly, it sought to determine the extent to which mainstream health services within England and Wales currently meet the needs of women with physical impairments with mental health support needs. Further, the study wished to determine whether existing counselling service provision meets appropriately the needs of women with physical impairments who experience mental distress. Finally, the study aimed to explore the concept of loss, with an emphasis on the views and experiences of women with physical impairments being examined.

The main research question that this study sought to answer was: Do mental health services in the UK currently respond appropriately to the support needs of women with physical impairments who experience mental distress?
Founded on the predominant themes to emerge from the review of the literature, it also set out to address four subsidiary research questions, each of which were addressed within the findings chapters. Chapter Five examined two key areas. Firstly, it focused on the topic area of a perceived inevitability of experiencing mental distress when living with a physical impairment and examined whether women with acquired and congenital impairments differed in their personal analysis of the relationship between physical impairment and mental distress. Within Part Two, the related area of loss was explored.

Chapter Six paid attention to the area of physical impairment and mental distress and sought to identify whether the sample group perceived social disability to be a source of mental distress. The women's perception of how factors such as attitudes towards impairment and difficulties encountered in accessing the environment could have an affect on mental well being was also examined. In addition it discussed any ways in which the implementation of the DDA was perceived to have impacted on their mental well being.

Chapters Seven and Eight examined whether women identified a shared set of barriers to accessing mental health services. Chapter Seven focused on women's personal experiences of mental distress and their experiences of both accessing and using mental health services. This was followed in Chapter Eight by a discussion of the topic area of counselling for women with physical impairments.

Based on their experiences of contact with mental health services, Chapter Nine discussed the women's thoughts and views women in relation to whether mental health
services within the UK could, in the future, meet their needs more appropriately, and if so, how?

This concluding chapter considers three areas. Part One provides a summary of the main messages to have emerged from the study. It also discusses what the study has contributed to the small body of literature that to date has examined the topic area of physical impairment and mental health, and has focused specifically on women. Part Two offers a reflection on the research study's design and outlines what were considered to have been its strengths and weaknesses.

Part Three proceeds to firstly discuss what this may suggest about the conduct of future research within this largely neglected area. One of the key aims of disability research carried out in the disability studies tradition is to improve the lives of people with impairments. Therefore, Part Three will explicitly consider the key messages emerging from this study for future mental health practice and service provision within the UK for women with physical impairments who experience mental distress.

PART ONE: SUMMARY OF THE MAIN FINDINGS

PHYSICAL IMPAIRMENT: THE INEVITABILITY OF MENTAL DISTRESS?

Chapter One highlighted how within the literature that examines physical impairment and mental health, a clear link between the two has been made on the premise that a level of depression will automatically be experienced by someone living with a physical impairment. Chapter Five showed that whilst some women were in agreement with this view, others rejected the premise of a causal link between living with a physical impairment and experiencing mental distress. For those women who felt that an experience of mental distress could be inevitable, it was shown how this was
likely to depend on a range of factors such as the nature of the woman’s impairment, and specifically, the impact of the impairment on her ability to perform everyday tasks independently.

A clear message to emerge from Chapter Five was that whilst some women considered their impairment to have been a contributory factor to their experience(s) of mental distress, there was a group wide belief that the physical impairment was not always the primary or sole cause. The importance of mental health, and other health, professionals involved in the treatment of women experiencing mental distress giving consideration to a range of factors that may contribute to the experience of mental distress was stressed. Within this chapter women also emphasised the importance they attached to mental health professionals recognising that no two women’s experience of their impairment will be identical. Likewise, the need for those working within mental health to appreciate the individuality of each woman and to recognise that the circumstances of their life and physical impairment are unique to them was strongly asserted.

Based on women’s experiences of contact with mental health professionals, Chapter Five further highlighted how the attitudes and beliefs that were overwhelmingly encountered were of professionals who viewed their impairment as a ‘tragedy’. Feelings of being pitied or patronised by the mental health professional were felt to have resulted from individual workers lack of understanding and/or awareness of disability or impairment.

**THE CONCEPT OF LOSS**

Part Two of Chapter Five highlighted the belief of many of the women that at some stage of living with their physical impairment they would experience loss. However,
women's differing experiences clearly demonstrated considerable variation both in how the concept of loss was understood and how it was experienced. The way in which loss was experienced was felt by the majority of women to be linked to the severity of the impairment and the extent to which the impairment impacted on her everyday life. Depth of feeling around loss was also seen to be associated, by most of the women, to the age at which the impairment was acquired.

Within Chapter Two the grief and stage theories which suggest that individuals living with a physical impairment need to go through specified stages before arriving at the 'recovered' stage of acceptance were discussed. Findings from the study however have shown that women's experiences of loss did not match with the expectations of established theories of loss. Whilst the six women with acquired impairments each believed that they had accepted their impairments, they were firm in their assertion that they had not gone through specified stages in order to arrive at that point. For those women who had acquired sudden onset impairments, their experiences were described as being a slow process of adjustment. However, acceptance of their impairment was not viewed as a 'recovered' stage, with acceptance of their changed circumstances typically fluctuating over a period of time.

For those women with progressive impairments, the chapter demonstrated how their experiences were typically described as going through periodic stages of adjustment as changes in their physical condition occurred. The chapter also highlighted how similarly, women born with congenital impairments did not identify with the stages theory of loss and spoke of their impairment forming part of their identity. For those women with congenital impairments, there was a shared view expressed, that, having grown up not knowing walking or running, there was a sense of being unable to miss something that had never been experienced. However, women with congenital
impairments firmly believed that although from a mobility perspective they did not consider themselves to have experienced loss, it had been experienced in other ways.

Within the literature on loss, predominantly the focus is on loss in relation to the impairment per se with minimal consideration of other factors that may contribute to an experience of loss (such as an unhappy childhood or a family bereavement). Also, whilst the literature routinely portrays loss as being a one off event, this study has shown how for many of the women loss had not been experienced as a singular event. Several women spoke of experiencing a form of loss at different stages of their lives and that it had occurred, for example, in relation to barriers to forming friendships or marriage, which were perceived as being the 'normal' things to do.

In describing their experiences of loss the study has shown that women’s responses to their impairment were resonant of how alternative theories of loss (as discussed within Chapter Two) propose that individuals respond to living with their impairment. Through many women’s descriptions of fluctuations occurring over a period of time, typically illustrated by anniversaries of events which may trigger an episode of grief, their experiences in particular were seen to speak clearly to how proponents of the dual stages approach believe that individuals respond to their impairments. This is, that people living with a physical impairment, rather than going through specified stages of grief, will typically shift between a loss and restoration orientation with either one being dominant at any one point in time.

Within the existing literature that discusses the concept of loss little consideration is given as to whether experiences of loss differ for individuals with congenital impairments and those who acquire their impairments. This study has however
highlighted a group wide belief that loss will be experienced differently for women born with their impairments to those who acquire them. Several women believed that loss was more likely to be experienced by women with acquired impairments than women with congenital impairments and that loss would be felt more acutely in instances where onset of impairment had been rapid and where the woman’s mobility and level of independence had been substantially affected.

**PHYSICAL IMPAIRMENT AND SOCIAL DISABILITY**

Chapter Six sought to determine the extent to which women perceived social disability to be a source of mental distress. It clearly demonstrated the women’s firm belief in the potential of an inability to access the environment over a long period of time to impact on mental well being. This was shown to have been particularly pertinent for those women over forty years of age who had grown up during an era when environmental access had been poor and the outside world had been experienced as being unwelcoming of people who were not able-bodied. However, the study showed an agreement across the group that the potential for inaccessible environments to impact on mental well being was now significantly less than fifteen to twenty years ago as a result of a steady improvement in access to the environment and public places.

Within the literature that has examined changing attitudes over recent years within society towards people with impairments, from the personal perspective of people with impairments, positive shifts in attitudes have been reported. Such views were mirrored within Chapter Six where a collective belief that attitudes towards impairment had changed quite significantly for the better during the past two decades was voiced. The changes that women had witnessed in attitudes towards impairment, and improved
disability awareness overall, were attributed predominantly to both the environment having become more accessible to people with physical impairments and people with physical impairments having become more visible within society.

**Disability Discrimination Act and mental well being.**

A clear message to emerge from Chapter Six was the positive benefits which women considered they had derived as a result of improved access to the environment and services following implementation of the Disability Discrimination Act. The introduction of disability legislation at the end of the twentieth century was highlighted across the sample group as having provided opportunities to both access places and engage in activities which in previous decades had not been possible due to the structural barriers to access that then existed.

Within material that has been published since implementation of the DDA attention has been drawn to the resulting improved environmental access for people with a range of impairments. The opportunities that those with impairments now have to access public spaces (and engage in the activities taking place within them) which historically had not catered for their access requirements has similarly been stated. In contrast, this as yet small body of literature has seemingly yet to focus on the impact of the DDA on mental well being which is an area that this study has examined. Across the sample group women described how for them personally the DDA had had a positive effect on their mental well being. For example, schemes such as Access to Work which provided human support and/or aids or adaptations had enabled a number of women to work alongside able-bodied colleagues. Such provision had provided these women with a feeling of being normal or included and subsequently had a positive impact on their mental well being. Additionally, improvements in making public transport accessible to
people with physical impairments were described by the women as having led to a
greater sense of inclusion within society.

Women who had entered into adulthood and experienced disability in the decades
before the DDA was introduced, in contrast spoke of not having had such opportunities
during that time. Elisabeth was typical of women who upon leaving school either
remained at home, went on to attend day care or work within workshops where menial
tasks were carried out in return for a small wage. Additionally, the chapter provided
evidence of how women who had been educated within a special school setting
routinely left school with few, if any, recognised qualifications. This was in contrast to
the younger women in the study who, as a result of a shift in the late twentieth century
towards integrating pupils with physical impairments into mainstream schools, had left
school with qualifications on a par with those of their able-bodied peers. In highlighting
such differences in experiences, the study has clearly indicated how age, and the era
during which women grew up, had been significant factors both in terms of women’s
experiences of education and subsequent life opportunities such as employment and
career openings.

The existing body of literature on women and physical impairment includes several
eamples of women’s accounts of living with their impairments within the context of
different areas of their lives, for example, education or employment. However, these
texts or studies have predominantly focused on a set point in time and have not made
comparisons between the experiences of women living through different eras. In
working with a group of women whose ages spanned five decades this study has
enabled comparisons in experiences to be made and has therefore possibly made a
small but valuable contribution to this body of literature: the study particularly indicates the importance of a generational, or life-span in context, focus in disability research.

**Physical Impairment and Self Image**

In examining women’s thoughts in relation to their self image Chapter Six showed that the majority of women believed their self image to have been affected by virtue of living with a physical impairment. The range of factors which women identified as having the potential to have a negative impact on self image matched those which, over recent years, have been described in the literature by individuals living with a physical impairment as having affected their self image. For example, across the group the media was believed to have been highly influential in impacting on women’s self image, in particular through its inaccurate representation of women with physical impairments within the press or on television. Through portraying women as either heroes or victims, women believed that the media painted a false picture of how the majority of women with a physical impairment live their everyday lives. By continuing to present the lived experiences of women with physical impairments in such a way, there was a shared feeling that further improvements in societal attitudes towards, or greater awareness of, impairment would be hampered.

**The impact of physical impairment upon relationships.**

Within Chapter Six, a range of factors which, singularly or collectively, women believed had impacted on their relationships with other people who were significant to their lives were discussed. Differences in relationships with family members were seen to exist between women born with their impairments and those who acquired them. Of the six women born with their impairments, four had experienced no major relationship difficulties with family members. For two women their difficult relationships within the
family unit were attributed to their fathers’ disappointment that they had been born with a lifelong impairment. For women with acquired impairments, the chapter demonstrated how individual family members had reacted in different ways to the onset of their impairment. Reactions of family members were also experienced as being variable within different generations of the same family. In addition, the age at which impairment had been acquired was felt to have been instrumental in how family members had responded to the woman’s impairment onset.

**Congenital Impairment and Friendships.**

Chapter Six showed the range of experiences that women had in relation to the ways in which their impairment had impacted upon friendships at different stages of their lives. In addition it highlighted differences in experiences of how friendships were experienced for women born with their impairments and those with acquired impairments. For those women with congenital impairments who had attended special school, similarities were apparent in terms of friendships existing solely within the school environment. The wide geographical locations that special schools drew from frequently meant that friendships could only be conducted within the school setting. Women who attended special school between the 1950s and 1980s spoke of how the availability of technology which today enables people to have contact with friends without the necessity for physical presence was not available during their school years. Whilst social networking sites or internet forums were shown to be welcomed by the women for the opportunities they provided to form friendships, such contact was not felt to equate to physical face to face contact.

**Acquired Impairments and Friendships**

Two women who acquired their impairments as teenagers in the late 1970s recalled how friends had initially rallied around and visiting regularly during their hospital stays.
However, in the longer term Louise’s experience was of friends struggling to come to terms with the sudden onset of her paralysis and drifting away which she attributed to the low level of understanding and awareness of impairment that existed at that time. For women whose impairments were acquired whilst in employment, similar experiences of friends initially visiting and providing support but subsequently drifting away over a longer time period were described. These women were seen to share the view that able-bodied friends had felt uncomfortable around them and women had felt hurt by the reactions of people who they had considered to be good friends. Women with progressive impairments typically spoke of friends being unable to deal with the unpredictable changes which could occur in women’s abilities. The experiences of these women were shown to have contrasted with women whose acquired impairments were relatively stable or for one woman whose impairment was not visibly apparent and who had not experienced friends drifting away. The chapter also showed how women with acquired impairments valued highly the friendships of typically a small circle of close friends who were there to provide support and friendship at all times.

The chapter further provided evidence of how age and environment could be significant to experiences of friendships. Whilst Carly experienced no difficulties in forming friendships at a mainstream primary school where she was the only pupil with a physical impairment, on transferring to secondary education in the early twenty-first century, she encountered difficulties in making able-bodied friends. This, Carly attributed to pupils who were entering adolescence being image conscious and self conscious of the people they were seen to form friendships with. The chapter highlighted how Carly’s experience was in marked contrast to that of Jackie who twenty years previously in the early 1980s, and at a similar stage of her education, recalled how fellow able-bodied pupils had actively involved her in their activities and were not
self conscious of being in her company. These different experiences indicated the reality of currently living in an age where people (and arguably in particular women) are highly image conscious and give credence to who they are seen to have friendships with.

Whilst the impact of physical impairment upon relationships with others is an issue that has began to be discussed in the literature over recent years, and women have written about their friendships and relationships within the context of living their lives as a woman with a physical impairment, little attention has been given to how the responses of family members, friends etc may impact negatively on mental well being. Likewise, the literature to date has provided few examples of comparisons being made between the experiences of women with congenital impairments and those with acquired impairments, both of which are areas that this study has examined.

**EXPERIENCES OF MENTAL DISTRESS**

In examining women’s personal experiences of mental distress Chapter Seven highlighted how women with physical impairments could experience the same mental health problems, and were likely to be subject to the same range of life experiences as able-bodied women. Within this chapter, one of the key messages from Chapter Five was re-affirmed, which was women’s strong belief that their experiences of mental distress were not solely attributed to living with a physical impairment and that other factors needed to be considered.

**Acquired Impairments and Mental Distress**

Women with acquired impairments were seen within Chapter Seven to be more likely to view their impairment as a significant factor in the overall experience of mental distress having previously known able-bodiedness. However, women stressed that
their impairment per se was not necessarily the primary cause of their distress and that it was associated more with what the impairment represented within the context of their lives i.e. possible loss of employment, breakdown of relationships. The chapter also demonstrated how for many women mental distress had not been a one off episode. In particular, women with progressive impairments whose conditions were typically characterised by fluctuating levels of pain and/or fatigue were seen to have experienced recurrent incidences of distress.

**Congenital Impairments and Mental Distress**

Women with congenital impairments, and in particular those with impairments which were of a non-progressive nature, spoke of having only ever known one level of physical capability, they did not however consider themselves to be exempt from experiencing depression or another form of mental distress. This group of women spoke of a belief that the onset of their mental distress had been linked to a realisation that their impairments were to be a permanent fixture in their lives. Also, women with congenital impairments were shown to have attributed their experiences of mental distress to factors such as bereavement or relationship difficulties and they highlighted how, just like able-bodied women they were likely to be subject to a range of life experiences that may contribute to an onset of mental distress.

Noteworthy from this chapter was the difference in terminology used by women to describe their mental distress and the avoidance among women in the higher age range groups (50+) of use of terms such as *being mentally ill* or *suffering from mental health problems* preferring instead to talk about *feeling fed up* or *down in the dumps* Such avoidance was far less noticeable amongst younger women in the sample group who spoke openly about *being badly depressed* or *being mentally ill* This was felt to have
been a reflection of a shift that has taken place over the past ten to fifteen years of people talking more openly about experiencing mental distress. However, despite this shift women still felt there to be a level of stigma attached to people who received treatment for mental health difficulties and that there remained significant scope for improving understanding and awareness of mental illness among society.

**Accessing Mental Health Services**

Chapter Seven further highlighted how for the majority of women accessing mental health services had been experienced as a process fraught with difficulties and a shared set of barriers to accessing services were identified. Physical barriers to access were shown to have been particularly problematic for women who had attempted to access services prior to the introduction of disability legislation. Long waiting lists to be seen and the role played by the GP were equally identified as having been influential in whether or not services were accessed when required.

**Use of Mental Health Services**

A key message to emerge from Chapter Seven was that many women considered the length of contact offered by mental health services to have been insufficient for their needs. Also, an urgent need for more flexibility within service provision that should be determined by the nature of the woman’s mental health issues, and the severity of mental distress being experienced, was called for. Whilst a small number of women had been satisfied with the mental health support they had received the majority had felt a need for longer term contact with services. Equally, it was shown how greater opportunities for building relationships with a mental health professional were considered more likely to occur where there was a consistency of worker.
The study clearly highlighted how experiences of contact with mental health professionals, had for the majority of women been characterised by individuals who were perceived to have a limited awareness and/or understanding of disability and impairment. Through shifting away from working within a medical model approach to disability women felt strongly that this would lead to increased positive reporting of using mental health services. Where positive experiences of working with mental health professionals were reported, this was seen as having occurred where the worker was felt to have a reasonable understanding of impairment and had been prepared to listen to the woman’s own perception of her mental distress.

**Use of non-statutory services**

In contrast to the mixed reporting of receiving support from mental health services within the statutory sector, Chapter Seven highlighted how women’s use of non-statutory services had overwhelmingly been positive and beneficial. The importance of organisations such as the Samaritans was highlighted in particular by women who had experienced acute mental distress. The ability to access their telephone based service which eliminated any worries about buildings access, and the absence of time constraints placed on telephone calls was welcomed.

In Chapter One attention was drawn to the fact that whilst over recent decades the mental health support needs of different groups of women have been increasingly recognised, this has not been the case for women with physical impairments. In examining the experiences of mental distress of a group of women with physical impairments and their experiences and accessing and using mental health services this study has endeavoured to draw attention to the support needs of women with physical impairments who experience mental distress.
COUNSELLING AND WOMEN WITH PHYSICAL IMPAIRMENTS

In considering the ongoing debate within the literature that has centred in recent years on whether people with physical impairments should be counselled by someone with an impairment themselves, Chapter Eight outlined what women believed to be both the advantages and disadvantages of receiving counselling from someone with an impairment. Where preferences to work with a counsellor with an impairment were expressed, this had been on a perception that such an individual would have a good understanding of disability and impairment in contrast to an able-bodied counsellor who it was felt would have little understanding. However, other women did not believe it necessary for a counsellor to have an impairment in order to be able to offer effective counselling. This group of women believed that as no two impairments, or experiences of those impairments is likely to ever be identical, that a good counsellor should be able to empathise with another person whatever their concerns or life experiences.

The issue of choice

Whilst preferences for a counsellor with an impairment were voiced by some women, the study showed how in reality a choice did not exist and women called for an increased availability of counsellors with impairments. Chapter Eight highlighted how for many years access to counselling courses for women (& men) with impairments had been hampered, typically by a lack of academic qualifications, and/or inaccessible course venues, and calls were made for barriers to training to be removed. In particular, the need for course selectors to recognise what an individual with an impairment could bring to a counselling relationship by virtue of their life experiences was emphasised.

A lack of counsellors specialising in working with people with impairments was viewed by the women as having resulted from professional training courses having little
focus on disability and impairment and a greater element of teaching around disability and impairment within syllabuses was called for. By Disability Equality Training becoming a mandatory part of counselling training courses, women firmly believed that counsellors would come to learn about the social model of disability and how disability is socially constructed.

Whilst some women voiced a preference to work with a counsellor with an impairment, the study indicated that collectively women were not in favour of people with physical impairments only receiving counselling from individuals who themselves had an impairment. To adopt such an approach, women believed, would represent a backward step at a point in time when people with impairments are steadily becoming more integrated in society and would offer little in terms of progressing people’s awareness of disability and impairment.

Gender and Counselling

The expressed preference of the majority of the women to work with a female counsellor was a key theme to emerge from Chapter Eight. Here, women expressed their belief that they would feel more at ease working with a woman, especially if the issues being addressed within counselling were gender-related. However, women also considered that other attributes such as the counsellor’s personality or socio-economic background could also contribute to the formation of a strong working relationship. Once again the study showed that whilst women expressed preferences for gender of counsellor choice was only likely to be available to those who received privately funded counselling.
Considering Counselling in Context

Whilst the chapters’s main focus was on counselling as a means of addressing women’s mental distress, it also indicated a need for recognition of the alternative ways in which women could be provided with mental health support, such as the use of voluntary sector services or support groups. A wish for counsellors to recognise that women with long-term impairments may require long term support, and that greater consideration needed to be given to individual needs, was expressed by several women. In addition, women wished to see evidence of counsellors displaying sensitivity and flexibility when working with women with a physical impairment and to be creative and flexible in the methods they used to work with people.

The topic of counselling for people with physical impairments has attracted considerable discussion within disability studies literature in recent years. Within this study many of the areas focused on within this body of literature have been examined. However, within the existing literature there is little that focuses on counselling for people with physical impairments from their perspectives, which this study has sought to do from the viewpoint of a group of women. In addition this study has examined the topic area of the counsellor’s gender and women’s views in relation to this.

LOOKING TO THE FUTURE

Within Chapter Nine many of the main themes to have emerged from the discussion of the findings were reaffirmed. Firstly, at a service provider level, the need for a greater understanding of disability and impairment among mental health professionals was considered to be vital if mental health services in the years ahead were to meet appropriately and comprehensively the needs of women with physical impairments who experience mental distress. The introduction of DET to the training
courses of mental health and other health professionals, women believed, would provide them both with a greater understanding of disability and impairment and with the ability to identify and address discriminatory forms of practice within their work with people with physical impairments. Similarly, until those working within mental health professions gained a good knowledge of the social model of disability, women considered they were unlikely to receive a quality service that matched their needs.

The study showed a group wide consensus that mental health professionals’ understanding of disability and impairment could be further improved by them listening to the lived experiences of those with physical impairments who had experienced mental distress. Through listening to the personal stories of those who had lived through mental distress, women believed that this would enable an understanding of disability and impairment that could not be derived from attending lectures or reading books.

The need for practical changes

A number of practical changes which women considered were needed in order to improve future mental health provision were highlighted by the study. Efforts to reduce waiting times were identified as one area in which changes would be welcomed. For many women the prospect of a long wait to access services was shown to have impacted on both their confidence in, and expectations of, services. Further, a wish to be able to self-refer to statutory sector services was commonly expressed based on a belief that this would assist in reducing waiting times. Some women considered that an increased availability of support groups would be beneficial through the opportunity they could provide to talk with others who were experiencing mental distress of a similar nature and also help to reduce feelings of social isolation.
In striving to improve future mental health provision, women urged mental health professionals both to communicate with and work alongside other health and social care professionals working with the individual, as was deemed appropriate. By working in conjunction with other professionals women believed this would encourage mental health professionals to work within a holistic approach and would go some way to ensuring that the woman’s physical impairment and mental distress were not compartmentalised.

A good knowledge of mental health services that were available was considered throughout the group to be key to ensuring optimum potential to access services that met individual needs. Women believed that service provision could in future be greatly improved through greater availability of relevant, up-to-date information that was written in jargon-free language and laid out clearly what the service provided and who was eligible to use it.

In identifying a range of ways in which women believed that future mental health service provision could be improved for women with physical impairments who experience distress, this research has made an original contribution to the body of literature that focuses on physical impairment. The thesis began by stating that over the past two decades an increasing amount of attention had been paid to identifying and meeting the support needs of mental health service users and people with physical impairments. In contrast, the support needs of individuals who fell into both categories has been overlooked by service providers, practitioners and organisations for whom either mental health or physical impairment is their main focus. This study has begun to fill this existing gap, with a specific focus on women’s needs.
PART TWO: REFLECTIONS ON THE RESEARCH DESIGN

The success or otherwise of a research study is dependent on the research design and the research methods utilised in undertaking the study. Within this section I shall reflect on what I consider to have been the strengths and weaknesses of the research design and suggest how this may influence any future research in this area. Given the nature of the subject area being examined, it was likely that whilst there would be similarities across the women’s experiences, equally their experiences of mental distress would be highly personal to them. It was therefore essential that the research methods used allowed for individual experiences to be talked about whilst simultaneously having a structure that enabled the research questions to be comprehensively addressed.

The use of semi-structured interviews

The semi-structured interviews were conducted over a minimum of two sessions (for two women with speech impairments this was three sessions and for two women interviews were conducted over four sessions at their request due to reduced energy levels). Given the number of topic areas to be covered within the interviews, realistically, one interview would have been insufficient in gathering the richness of data that would be required for analysis within a doctoral study. Further, the individual requirements of the majority of the women meant that a two stage interview was more appropriate. The two-stage interviews were typically two weeks apart which allowed me as the interviewer to have sufficient time to listen to the initial interview and make notes on any queries that arose which could then be checked out in the second interview. However, if a shorter or longer time span in between interviews was requested then those wishes were respected.
The semi-structured interviews as a data collection method worked well in that their structure presented women with an opportunity to talk more openly than would have probably been possible within a standardised question and answer interview format. The two-stage interviews were also felt to have been advantageous in the opportunity they provided at the second stage for women to correct or add to details talked about within their first interview. Also, by the second stage there was a sense of women feeling that they now knew myself as the interviewer and therefore felt able to talk more openly and/or with greater ease about their experiences of mental distress. Some women had talked about their mental distress within the first interview and had found this to be emotive and/or upsetting. Therefore, the subsequent interviews provided a further opportunity to meet with the individual and ensure that they had not been adversely affected by the interview process, having checked at the outset that they indeed wished to continue their involvement in the study.

At times, the time and energy invested in conducting the two-stage interview was felt to be substantial. However, when balanced with the wealth of rich data that the interview process generated in showing the wide variety of ways in which the lived experience of physical impairment could impact on psychological and mental well being, the benefits were felt to have clearly outweighed any short-term hardships. As the sample group was of a relatively small size, the two-stage interview process was, with good organisation, manageable but if working with a larger sample group the merits of using a two-stage interview approach would need to be carefully considered. In particular, if the geographical location of participants was diverse, attention would need to be paid to the factor of travelling time given that when undertaking research time constraints are likely to be an issue that requires consideration.
The Focus Group

The use of a focus group as an additional data collection method was felt to have added strength to the data collected within the interviews, in particular to the topic areas which focused on shared experiences. The focus group was considered to have worked well in the opportunity it provided for women to meet and share their experiences of mental distress and of receiving mental health support. From a researcher perspective, the focus group was felt to have worked well as, for example, within a small number of interviews women talked briefly about issues or experiences which they felt sounded odd or seemed silly and therefore did not wish to elaborate on: however, within the focus group setting, when those very issues were raised by others, women appeared able to talk with greater ease about those areas having recognised that their thoughts or experiences were not unique to them.

The organising of a focus group which met the individual needs and access requirements of a diverse group of women was again time consuming. Given the various locations in which women lived and their individual circumstances, it would have been unrealistic to achieve attendance by all twelve women. However, I was fortunate in being able to use an accessible location that was within a reasonable travelling distance for eight women. The invaluable data that I hoped to gather by holding a focus group had to be balanced with the work involved in making it possible but on reflection I firmly believe the benefits gained to have outweighed what went beforehand.

In addition, the focus group was valued by those women who attended. Following the session, women talked amongst themselves about how they had welcomed the opportunity to meet with each other and share experiences and in the weeks following the focus group I believe that supporting friendships were formed. Interestingly, when
the women were asked informally what their motivation had been for becoming involved in the study, the overwhelming response was that it had given them an opening to talk about an area of their lives that was seldom recognised or acknowledged. This was resonant of the responses of the women who took part in my 2003 study in this area when asked the same question and which arguably indicates how little headway has been made in providing spaces for such conversations since then.

Finally, many women spoke following their interviews and the focus group of how the researcher having a physical impairment had made a difference to what they had felt able to share or talk about. This, it was stated was because as a woman with a physical impairment myself ‘I would know what they meant’. The debate over whether only people with an impairment should undertake research with people with impairments has been ongoing for many years and is likely to continue as I believe there to be no definitive answer (Barnes & Mercer 1997). As this study has shown when examining the issue of people with impairments only receiving counselling from people who themselves have an impairment, there are a wide range of factors other than impairment that need to considered.

PART THREE: CONSIDERATIONS FOR FUTURE RESEARCH AND PRACTICE

Within the introduction to the thesis it was stated that in more recent decades the subject area of physical impairment and mental health has been talked about to a limited degree within the literature. However, the majority of what has been written has adopted a medical model approach and has failed to attract attention in any significant way from either academics or researchers in the field. This work has attempted to
address this omission but a number of directions in which future research could expand on what has been examined in this study are considered below.

The sample group worked with was considered to have been representative of both women with congenital and acquired impairments and comprised of women well spread across the specified age range. The group also included women who were mothers or had other care responsibilities and women without dependants. In terms of ethnic origin all women identified themselves as British White. The approaches made to a diverse range of organisations I had hoped would elicit responses from women from different ethnic backgrounds and cultures. However, there was just one response from a woman of Asian origin who initially was keen to participate but subsequent health problems prevented her from doing so. Therefore, future research in this area may necessitate efforts to identify women from a range of ethnic backgrounds either through recruitment within geographical areas with a high concentration of ethnic minorities or from organisations that work with individuals from specified ethnic backgrounds. Indeed, focused studies involving women from specific ethnic minority communities would be fruitful, given the different experiences which result from specific intersections of disability, gender and ethnicity for different groups of disabled people using or who have used mental health services.

Firstly, whilst this study has focused on the experiences of women with physical impairments, future research may wish to consider the mental health support needs of men with physical impairments who have mental health support needs. At the outset my reasons for focusing specifically on women were stated. Whilst it was considered likely there would be overlaps in the experiences of men and women, equally there were likely to be differences and consideration of both men and women would have not
enabled an in-depth study to be conducted. Also, a small number of studies had been undertaken which had focused specifically on men's experiences though these are now rather outdated. This could also be said of research studies which I identified that had examined the mental health support needs of people with visual and/or sensory impairments so renewed research within each of these areas is arguably overdue.

From this study, one of the strongest messages to emerge related to changes that women considered were needed at a service provider level in order to improve the incidence of positive reporting of using mental health services. Therefore, research that examined professional practice that was deemed to be enabling and helpful would be worthwhile. Whilst literature and studies undertaken (including this one) have talked about what is ‘wrong’ with relationships between people with impairments and the health/mental health professionals they have worked with, to examine in greater depth than has been possible here ‘what works’ would be of benefit, in particular if utilised to feed back into professional practice.

Drawing on the women’s accounts of what they had found to be helpful or not when receiving support from mental health professionals, the study highlighted how small actions could make significant differences to women’s experiences. For example, to be respected or listened to was shown as having contributed positively to women’s self image. Therefore, through building on research which identifies good professional practice, respect and humanity would arguably be restored to the individuals they are working with rather than continuing to live as a person identified by their impairment as opposed to their human existence.
The study has further emphasised the need for mental health professionals to have a good knowledge and awareness of disability and impairment. This would prove invaluable in providing a service which is helpful in addressing any mental distress that women may experience, and without which, trained professionals could potentially become part of the problem as opposed to offering useful support. It is vital that in the years to come alliances are forged between those working within the disciplines of physical impairment and mental health so that a greater understanding of the potential of physical impairment to impact upon mental health is created.
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Appendix 1.

Seeking Research Participants......

Would you be interested in talking about your experiences of disability?

I am a second year PhD research student at Birmingham University, interested in talking to women with a physical impairment aged between 18 and 65, about their experiences of living with their condition. In particular I am interested to hear about women's emotional and psychological experiences and help or services that might have been provided to help.

Taking part in the research would involve being interviewed by myself, in which a series of questions would be asked relating to your experiences. A group discussion will also take place, to which all research participants will be invited to attend. This is likely to take place at Birmingham University towards the end of 2007 after interviews have been conducted. All research participants will be paid for their involvement and any travel expenses incurred will be met.

If you think that you would like to be involved in this original research which has been granted full ethical approval, or would like further information about the study, please contact me using the details below.

Julia Smith
PhD Research student
Institute of Applied Social Studies
University of Birmingham
Edgbaston
Birmingham
B15 2TT.

Email  jls470@bham.ac.uk
Tel no 0780 368 4687
  0121 415 8032
Appendix 2.

INFORMATION FOR PARTICIPANTS.

Title of the Study:-
Mental Health Services: The experiences of women with physical impairments.

Who is Carrying out the Study:-

The study will be carried out by myself, Julia Smith. I am a second year Research Student at the University of Birmingham based within the Institute of Applied Social Studies.

My contact details are: Julia Smith
Institute of Applied Social Studies
Terrace Huts
University of Birmingham
Edgbaston
Birmingham
B15 2TT Contact telephone no 0121 415 8032
Email jls470@bham.ac.uk

What the Study is About:

The focus of my study is to talk to women about their individual experiences of seeking help from and using mental health services for women with physical impairments who have also experienced (or are currently experiencing) mental health problems. The research aims to examine whether, from the perspectives of women with physical impairments, it is felt that mental health services within the UK meet the needs of women with physical impairments who also have mental health needs.
What will I have to do?

This information sheet is being provided to outline the nature and purpose of the research that is to be carried out. If having read the information you decide that you would be willing to participate in the study you will be asked to sign a consent form. This will state that you have read and understood the information which has been provided within the sheet, and that you have been provided with an opportunity to ask any questions you may have about the study. You shall then take part in an interview that will be recorded and in which a series of questions will be asked by myself. The interview will take place at a time and place that is convenient for yourself and all interviews will take place within a setting that meets the mobility requirements of any individual. It is estimated that each interview will last between 1-1 1/2 hours but any specific needs or circumstances will be respected. For example, should you prefer an interview of a shorter time span then it will be possible for the interview to be conducted over two stages.

In addition to the interview you will be invited to take part in a focus group where you will meet with the other women who are taking part in the study. The purpose of the focus group will be to discuss issues that participants have talked about within their interviews in more depth and the focus group is also intended to provide a forum where as a group, women can talk about their experiences of mental health services. The venue for the focus group is likely to be in the West Midlands area but this is not confirmed at present. For any individual who may wish to participate in the focus group but for whom travelling may be difficult, it may be possible to arrange participation through a video link facility.

What are the Benefits of Participating in the Study?

By participating in the study you will be contributing towards what I hope will be an original and innovative substantial piece of research within a subject area where to date there has been little research done. It would be intended that the study would also provide an opportunity for all participants to talk about an aspect of their lives that is likely to have received little attention. In a study which I undertook in 2003 that examined this topic area on a smaller scale, the women stated that their decision to participate in the study was due in part to being provided with an opportunity to talk
about an aspect of their lives that was important to them but which was given little recognition among health and welfare professionals with whom they came into contact.

**Is there any Risk for me if I Agree to Participate?**

In undertaking this study there is absolutely no intention to put any participant at risk or for any person to be subjected to harm.

**Will the Study Cost Anything?**

My research study is being funded by the Economic and Social Research Council and there is no financial cost involved to any participant. The ESRC is the UK’s leading research funding and training agency addressing economic and social concerns. Further information about the ESRC can be found at www.esrc.ac.uk.

Expenses that may be incurred through attending either the interviews and/or focus group i.e. for travel or subsistence will be paid. Should you require the assistance of a carer or personal assistant to enable you to participate within the study then their out of pocket expenses will also be met. In addition as a gesture of appreciation for your involvement within the study a small payment will be made to each participant. This may take the form of tokens/vouchers, a cash payment or a donation to an organisation of your choice depending on your preference.

**What if I do not Want to Take Part?**

Participation within the study is entirely voluntary. The decision as to whether or not to take part is entirely yours and there is no obligation to do so. If you decide that you do not wish to take part in the study your decision will be respected and the reason for your decision will not be questioned.

**What Happens to the Information?**

The information that is generated both from the interviews and focus group will form a substantial part of my research study, the accumulation of which will be a PhD thesis. This will be read by a small number of academic professionals and subject to successful
completion, copies of the thesis will be held both within the University of Birmingham main library and the Institute of Applied Social Studies.

**Who else is Taking Part?**

In total 8-10 women will take part in the study. Each participant will be aged between 18-65, will have a physical impairment and will have had experience of mental health problems.

**Will any of this Effect my care or receipt of services?**

No. Taking part in the study will not effect any care or services that you are in receipt of. Maintaining the confidentiality of any research participant is of great importance to any researcher and while every effort will be made to provide an assurance of confidentiality there can be limits. The proposed conditions for confidentiality and anonymity and circumstances in which it may not be possible to guarantee total confidentiality will be discussed with each participant and made clear at the outset of the study.

With regard to any payment made for your out of pocket expenses or your involvement in the research, it will be my responsibility to ensure that this will not have an effect on any welfare benefits that participants may be in receipt of.

**What Happens if I Change my Mind and Decide to Withdraw from the Study?**

As stated above, participation in the study is entirely voluntary. Should you wish to withdraw from the study then your wish shall be respected. Throughout the time you are involved with the study your willingness to remain a participant will be checked with you to ensure that you are happy to remain involved. If you decide that you wish to withdraw from the study then it would be appreciated if you could discuss this with me at the earliest opportunity. My contact details are given on the front page.

**What if I have any Questions or do not Understand Something?**

If any participant has any questions or queries in relation to any aspect of the study being undertaken at any stage of the research process then please do not hesitate to contact myself using the contact details listed on Page 1.
What Happens at the End of the Study?

Upon completion of the study which is likely to be during 2009, a PhD thesis will be produced. Each person who has participated within the study will be provided if they so wish with a copy of the research findings.

If you have any Concerns about the Study and Wish to Contact Someone Independent you can Telephone

In undertaking this study I am being supervised by two Research Supervisors, Professor Ann Davis and Dr Harriet Clarke who are both based within the Institute of Applied Social Studies at The University of Birmingham. In the event of any concerns you can contact Dr Harriet Clarke on 0121 415 8479.
Appendix 3

Pro forma approval prior to starting a research project

NAME of Student:  Julia Smith
NAME of Supervisor:  Ann Davis and Harriet Clarke.

Dear Student,

Please read through the form fully before completing, in order to be clear about what information you are asked for at which point. For example, note within ‘background’ you are asked to summarise methods used, however the detail on this should be placed under ‘research design’.

These procedures are adapted from the Social Research Association Guidelines. Please complete each section.

It is not expected that any answer should be more than 500 words, except where there are very specific issues of ethical concern to be addressed.

**PROJECT TITLE**
This should be descriptive and give an indication of the broad area in which the research project is to be undertaken.

MENTAL HEALTH SERVICES: THE EXPERIENCES OF WOMEN WITH PHYSICAL IMPAIRMENTS.

**DURATION**
This should indicate length of time of the project, the duration of any fieldwork or data collection within that period.

The research is being undertaken as a 3 year PhD, funded by the ESRC from 1st February 2006-31st January 2009. At this stage it is anticipated that a six month period of fieldwork will be carried out commencing mid 2007.

**RESEARCHER PREPARATION FOR UNDERTAKING THIS RESEARCH PROJECT**
This should be a full statement which identifies all previous relevant learning (knowledge and skills) which has prepared you to undertake this study. E.g. modules undertaken, skills gained, development of knowledge through experience, previous experience of participant group (if any).

Prior to this research project I have acquired both the academic skills and personal experience that are required to undertake research within my specified subject area. In October 2005, I successfully completed at Birmingham University an MA degree in Social Research (Social Policy). This one year degree course included substantial research training with modules that focused on both basic and advanced qualitative and quantitative research methods. In addition, modules in which the focus was
social policy related concerns were completed. To meet the requirements of the MA dissertation, a review of the literature that examined the subject area of physical impairment and mental health was undertaken in which I was able to utilise knowledge and skills gained from undertaking the research modules.

In terms of personal experience within my specified project area, I have ten years experience of working as a social worker with women with physical impairments, many of whom were assessed as having mental health needs but for whom service provision was not available. In addition, as part of a MA in Disability Studies (Leeds University 2003) I undertook a dissertation which used qualitative methods to carry out a small scale study that focused on access to and the provision of mental health services for women with physical impairments.

### RESEARCH QUESTION

This should identify the overarching question which the proposed research seeks to answer. Sub questions can be stated if appropriate.

**Main Research Question.**

Do mental health services in the UK respond appropriately to the support needs of women with physical impairments?

**Subsidiary Research Questions**

a) Do women with acquired and congenital impairments differ in their personal analysis of the relationship between physical impairment and mental distress/mental ill health?

b) To what extent do women with physical impairments perceive social disability as a source of mental distress/ill health?

c) Do women with a range of physical impairments who have experienced mental health problems identify a shared set of barriers to mental health services?

d) Do women with physical impairments who also have experience of mental health problems believe that mental health services within the UK could meet their needs more appropriately, and if so, how?

### PURPOSE OF STUDY

This should set out the aims and objectives of the study. You should include an indication of the policy and/or practice context and outline the pertinence of the subject for academics, policy makers and/or practitioners, the population being studied, and, where applicable, wider society.

Over recent years an increasing amount of attention has been paid to the individual support needs of mental health service users, and people with a physical impairment. Evidence of this can be seen both through the literature that focuses on mental health or physical impairment from a wide range of perspectives and an increased range of service provision for individuals within both groups. However, the support needs of people with physical impairments who also have mental health support needs have largely been overlooked by service providers, academics, practitioners and both mental health and physical impairment organisations and charities. As a consequence of the lack of attention that has been paid to this area, there exists insufficient knowledge as to how the support needs of people with physical impairments who access or may wish to access mental health services can best be met.
The research will examine specifically the experiences of using mental health services both within the statutory and non-statutory sector for women with physical impairments aged 18-65 who also have (or have had) experience of mental health problems. This approach therefore has breadth which may enable a common set of experiences (including barriers faced) to be identified across a diverse sample of women; the project also seeks depth by providing a space for women’s voices to be heard. This is vital as previously within the literature and in research undertaken within the area of physical impairment and mental health, attention has been drawn to the fact that there has been little focus on the experiences of people with physical impairments from their point of view. This is the case with regard to both their experiences of services as well as their wider day to day experiences (Morris 2002). In undertaking my research the overarching aim is to produce a study in which the central focus is the experiences of women with physical impairments from their own perspectives, within an area where to date I have been unable to identify any studies (other than my own MA dissertation research) that focus specifically on women.

Continued….  

**RESEARCH BACKGROUND**
This should introduce why the research is being proposed. It should therefore provide the rationale for the study. For example, does it repeat or complement a study done previously and, if so, why repeat it? What research methods are to be used?

The topic of physical impairment and mental health, as stated above, has received little attention within the literature and there exists a minimal amount of research that focuses on this topic. A national inspection of physical disability services in 2003 concluded that not enough attention was being paid to the mental health needs of people with physical impairments (Social Services Inspectorate 2003) and there was little recognition that people with physical impairments experience unequal access to mental health services. Within a literature review commissioned by the National Institute for Mental Health in England (NIMHE) which was concerned with the policy, practice and service user experience of mental health services, there was no reference to people with physical impairments who may have mental health support needs. In addition, neither disability nor impairment were identified as being a relevant factor when looking at experiences of discrimination and mental health services. A study by Morris, one of a minority of authors who has undertaken research within this area, concluded that the majority of respondents had experienced difficulties in accessing mental health services because of their physical impairments and that the evidence of positive experiences was disappointingly sparse (Morris 2004).

The small number of studies undertaken that have focused on the mental health experiences of people with physical impairments are primarily concerned with the incidence of depression and its association with specific impairments and there exists little in the literature about people whose mental health support needs may have nothing to do with their experience of physical impairment. Studies which have found increased rates of depression amongst people with physical impairments make an assumption that the causal link is to be found in the experience of impairment and functional limitations rather than the social and economic factors which may accompany impairment (Turner & Noh 1988, Hogan et al 2000). The assumption of this causal link has persisted in spite of conflicting evidence about the co-existence of physical impairment and depression and also in spite of evidence that existence and degree of impairment do not seem to be related to extent of mental distress (Morris 2002).
Most research that looks at physical impairment and mental health is therefore underpinned by two assumptions; firstly that impairment in itself is a cause of psychological distress and secondly that the solutions to it are to be found in the individual. This is in contrast to an approach which would look at external factors that are arguably indicative of the disabling barriers faced by people with physical impairments.

Given the minimal amount of work that to date has been undertaken within this area, a study which focuses specifically on the mental health experiences of women with physical impairments will be innovative and original in addition to being of importance to policy and practice (and from many women's perspective possibly well overdue). The study shall set out to expand on a small scale study which I previously undertook that examined the experiences of a small group of women with physical impairments in accessing and/or using mental health services (Smith 2003). From this study, a number of themes emerged that participants identified as being important in ensuring that their mental health needs were met. These were:

- That based on their personal experiences of accessing and using services, the women did not feel to varying extents that their mental health needs were adequately met.

The time constraints of the study meant that there was not sufficient scope to examine whether the reported differences were related to whether the women had acquired their physical impairment or whether it had been present from birth. This research will therefore seek to explore in greater depth whether women's experiences of using mental health services are related to this factor.

- All of the women reported that mental health professionals with whom they had contact made an assumption that the mental health problems they had experienced (or were experiencing) were as a direct consequence of living with their physical impairment. In addition, mental health professionals were often perceived as being reluctant to consider some of the women's beliefs that their mental health problems were unrelated to their physical impairment.

This theme will be further developed within my study by exploring the reasons why women might feel that mental health professionals routinely assumed a link between the presence of a physical impairment and a susceptibility to mental health problems.

- Each of the women reported that external factors such as accessibility issues and attitudes within society towards physical impairment played an important role in the potential they created to impact on mental health.

Within the doctoral study I shall aim to examine in greater depth why women who have physical impairments believe that external factors create the potential for impacting on mental health and in what ways this may manifest itself. Women who participated in the 2003 study made reference to a recognition that with the staged implementation of the Disability Discrimination Act 1995, they were beginning to witness both improved access within society generally i.e. to public places and a positive shift in attitudes towards physical impairment. This theme will be explored further in the light of implementation of Part III of the DDA in 2004 and whether this has had an effect on the perceived impact of the role played by external factors on mental health.

- That there were a variety of changes needed in order for women with physical impairments experiences of mental health services to be viewed in a more positive way, i.e. attitudes of mental health professionals, improved access to buildings, in-patient units etc.
This theme will be developed within the study by examining more precisely the changes that women who have physical impairments believe are needed. It will seek to establish both the reasons why they are needed and why women believe that such changes would lead to a more positive experience of mental health services.

The proposed research shall examine each of the areas outlined above and the research questions outlined aim to explore at a deeper level the themes that clearly emerged from the 2003 study and which it is believed warrant further attention.

Please refer to key literature within this section and follow it with a list of key resources cited (references/bibliography not to be included in word count limit)

List of References cited above:


RESEARCH DESIGN
Describe briefly:
- Overview of what will be done
- What sample is sought (empirical work); How will relevant resources be sourced (literature based analysis)?

If conducting fieldwork…
- What will participation involve for research participants?
- What data-collection method(s) will you be using?

Empirical and literature work…
- Analysis methods should be indicated.

Note: We expect that draft information leaflets, draft consent forms and draft interview schedules/questionnaires or other research tools to be attached as appendices.
In undertaking work on the research design, my aim has been to devise a design which has a clearly defined purpose, that demonstrates a coherence between the research questions and the methods proposed and which generates data which is valid and reliable. A good qualitative study research design is, according to Ritchie & Lewis (2003), one which is realistic, conceived with due regard both for practical constraints of time and finance and for the reality of the research context and setting. That research design is a continuing process which calls for constant reviews of decisions and approaches and is not a discrete stage of the research process which is concluded in the early life of a study, is also emphasised (Ritchie and Lewis 2003).

Since February 2006, as the first stage of this research project I have undertaken a comprehensive review of the literature on physical impairment and mental health. For the fieldwork stage of my research, a sample group of 8-10 women aged between 18 and 65, who have a physical impairment and who have either requested help from or had experience of using mental health services are sought. The nature of the individuals' physical impairment or mental health problem will not be specified as my aim is to identify a sample group which encompasses women with both a range of physical impairments and mental health problems. As I am interested to look at whether experiences of using mental health services differ between women born with their impairments and those who acquire them, I shall endeavour to identify 4-5 women within each category. I aim to identify a group of women whose composition reflects both a spectrum of the age range specified and women who are either mothers or have child or other care responsibilities and those who do not have dependants.

At this point in time two possibilities are being considered with regard to from where/ which location women who meet the criteria for the study will be accessed. Each is outlined briefly below;

1.The small scale research study undertaken in 2003 (referred to on pg 2) examined the experiences of women with physical impairments in accessing and/or using mental health services. The length and time constraints of this study meant that there was insufficient scope to explore in greater depth a number of areas that emerged from the interviews undertaken. Some of the women who participated in the study (none of whom were known to me previously) have expressed a keen interest in being involved in further research which as stated aims to encompass recurring themes that emerged from the study undertaken.

2. Through my personal experience of living with a physical impairment for over two decades, I have been involved for fifteen years with a number of organisations of disabled people both within a professional capacity and at personal level. Through this involvement I know many women with a range of physical impairments who would meet the criteria for the study being proposed and have expressed an initial interest in involvement with the fieldwork. One aspect of informed consent is that it is based on an understanding of participation being entirely voluntary. This may require particular emphasis where research is being conducted by people who have a professional (or personal) relationship with sample members which may lead to feelings of obligation or gratitude (Holloway & Wheeler 1996). The existence of power relationships within research are highlighted by Stevens and Manthorpe (2003) who believe that service users may well experience feelings of confusion and powerlessness when invited to work ostensibly on an equal basis alongside social work (or mental health) professionals who may previously have been influential over their lives through their ability to make moral or legal judgements i.e. removing children or depriving a person of liberty.

Within this study it is not my intention to undertake interviews with women that I had previously worked with in a social work capacity so I do not believe that these issues will arise. Since submitting the ethics application in May initial contacts have been made with a number of local disability organisations. The purpose and nature of
the research has been outlined and to date has received a positive response so that presently it is anticipated that a large majority if not all of the participants will be people who I have not known previously.

In conducting the fieldwork with a sample group of 8-10 women I believe that this size of sample will provide a sufficient level of diversity within which the varying influences of different factors that the study wishes to address can be explored. A sample of this size will enable myself as the researcher to examine issues in depth while also being of a sufficient size to allow comparisons to be made between individuals. Based on previous experience of undertaking research and the volume of rich data that this generated, I am keen to ensure that my sample group is not of a size that by virtue of time limitations would prevent research questions being able to be explored in depth. A larger sample group may also potentially generate data that would neither be sufficient in depth nor which would enable analysis to be carried out at a level that will be required of a doctoral thesis. In addition, as the study is seeking to provide an opportunity for women’s voices to be heard, if participants are to be truly given scope to talk about their experiences in depth and from their own perspectives, then I believe that a sample group of this size is both justifiable and realistic.

In conducting the fieldwork, my aim is to undertake semi-structured interviews, using a set of semi-structured questions. These in particular will focus on sub questions a) and b) both of which are more personal in their focus. The decision to use semi-structured interviews as a research method has been based on this approach being used successfully in my previous research in that the interviews produced data that was highly relevant to the research questions that were being addressed and was rich in detail. Through the use of semi-structured interviews it is intended that the opportunity will be presented in which each of the participants can provide responses based on thoughtful consideration of their detailed experiences whilst simultaneously providing a structure that allows for comparisons to be made between individuals. In generating data, Ritchie and Lewis (2003) claim that key features of individual interviews are their ability to provide an undiluted focus on the individual and permit an in depth understanding of the personal context within which the research phenomena are located.

The importance of the role the researcher has to play in directing the interview process is emphasised by Legard et al (2003) as is the researcher being clear about how to ‘stage manage’ the interview effectively so as to meet the purposes of the research. The stages involved in conducting an in-depth interview, i.e. the organisation of practical arrangements, interview venues and recording arrangements are outlined usefully by Robson (2002). Within my study the number of interview sessions for each participant may vary depending on their individual needs/circumstances, but the intention would be to not exceed two interviews for any member of the sample group.

In addition to using semi-structured interviews, my intention is to hold a focus group. This is because, based on the research questions that the study wishes to address I believe this approach could be highly stimulating and would bring real insight into the subject area being examined. A focus group would be particularly pertinent to sub questions c) and d) in which the focus is shared experiences and concerns among this group of women. Additionally, I believe that a focus group will be of value in that, if used correctly it has the potential to generate discussion between women with physical impairments who may have similar mental health experiences but which they may not wish to share within the confines of a one to one interview. Also, given that traditionally in society there is arguably some reluctance among people to talk about mental health problems they may have experienced, some participants may feel able to be more open within a group setting. In allowing participants to hear from others, a focus group will also provide an opportunity for
reflection and refinement which can deepen respondents' insights into their own circumstances, attitudes or behaviour.

My intention is to hold a focus group after the interviews with participants have been conducted with the purpose of exploring issues generated through the interviews at a more strategic level. My decision to hold the focus group at post interview stage is based on some personal experience of both being involved in and with the setting up of focus groups. As noted above, given that the subject area that participants are being asked to talk about may be deemed as sensitive, my experience has shown that people may feel more comfortable and able to talk about their views or experiences within a setting where they feel that they now 'know' the researcher/group facilitator.

In using this method, consideration will need to be given to a range of practical issues including individual needs and the geographical location of participants in addition to accessibility of the venue. This will be essential both for interviewees and for myself as an interviewer with a physical impairment. I will stress to individual participants the importance of maintaining confidentiality within the focus group, which involves creating a safe space for sharing of experiences (and additionally allowing participants not to share some aspects of their experience which they have highlighted in the interview stage).

Data Analysis.

What 'analysis' actually means is complex and often contested by qualitative researchers. Coffey and Atkinson (1996) suggest that there is no single or most appropriate way to analyse qualitative data as just as there are many ways to undertake the analysis of data, analysis in general means different things to different people. Analysis, according to Tesch (1990), is a cyclical process and a reflexive activity and that the analytic process should be comprehensive and systematic but not rigid. Tesch maintains however that analysis is not a structureless process that can be done inattentively but that qualitative data analysis requires methodological knowledge and intellectual competence. Likewise, analysis it is argued is not the last stage of the research process and that it should be seen as part of the research design and of the data collection (Coffey and Atkinson 1996).

In undertaking data analysis, early analysis is recommended by Miles and Huberman (1994) based on a belief that it helps the researcher move back and forth between thinking about existing data and generating strategies for collecting new and often better data. By undertaking data analysis as a separate stage of the research process, it is argued that this approach rules out the possibility of collecting new data to fill in the gaps or to test new hypotheses that emerge during analysis. In addition this approach can make analysis into a somewhat overwhelming task that demotivates the researcher and reduces the quality of the work produced (Miles & Huberman 1994).

Data that is generated from the fieldwork will be analysed using the Analytic Method Framework as outlined in Ritchie et al (2003). In adopting the matrix based analytic method, rigorous and transparent data management will it is claimed be facilitated, such that all the stages involved in the ‘analytical hierarchy’ (Ritchie et al Ch 9) can be systematically conducted.

Whilst recent decades have seen a significant increase in computer software for undertaking qualitative data analysis (CAQDAS) with a general agreement among commentators that their advent has been beneficial to the analytical process, other analysts have outlined their reservations. The benefits of the speed that CAQDAS methods offer the researcher handling large amounts of data and the ability of the software to assist with the conceptualisation of data and theory building are acknowledged by Spencer et al (2003) while Weitzman concludes that 'the very ease, speed and power of the software have the potential to encourage the researcher to take shortcuts' (2000 pg 807). As the researcher, when undertaking my data analysis, careful consideration will need to be given to the benefits or otherwise of an over reliance on CAQDAS methods.
RESEARCH TIMETABLE
This should provide an overview of the time allocated to each phase of the research.

February 2006-February 2007. The emphasis of the work undertaken over the past year has been to carry out a comprehensive review of the literature that examines the subject area of physical impairment and mental health. A full first draft of the literature review was submitted to my Research Supervisors in early March 2007. In addition work has been undertaken on developing a theoretical framework for the thesis and working on the research design and research questions.

NB. Please note that time scales given for the research phases below are presently provisional.

March 2007-mid 2007. This stage of the study will concentrate on preparing for the fieldwork to be conducted by identifying research participants and constructing interview schedules. This stage shall also focus on making the required practical and administrative arrangements for undertaking the research interviews and focus groups.

Mid 2007-early 2008. The focus of this period will be conducting the fieldwork and will commence with a pilot study. Upon completion of the interviews with participants, it is my intention to hold a focus group.

February 2008-February 2009. The final year of the study will be devoted to comprehensive analysis of the data and writing up of the thesis. An updated review of the literature will also be undertaken over this period.

POTENTIAL BENEFITS AND HAZARDS: RESEARCH PARTICIPANTS

- What risks to research participants are entailed by their participation?
- Are there any potential physical, psychological or disclosure risks that can be anticipated?
- What is the balance of possible benefits and potential harms?
- What procedures have been established for the care and protection of research participants i.e. insurance or medical cover and the control of any information gained about them?
  - Note University will act as sponsor to majority of student projects
- Some indication of potential power relations that may arise in the conduct of the research and how they are to be mitigated should also be indicated

In undertaking this research study there is no intention to induce harm to participants but as ESRC makes clear, risk in social research can be broadly defined including social factors such as personal standing, privacy and personal values and beliefs. Ethical guidelines also draw attention to the fact that it may often be difficult or impossible to quantify or anticipate risk in full prior to the start of a research study. If in the course of preparing for fieldwork a risk is identified, then in line with ESRC guidelines this will be discussed with the participant in order that informed consent can be secured (ESRC 2005). In accordance with published guidelines, for the duration of the research study risk identification and risk management will be an ongoing concern.

Ritchie and Lewis (2003) state that it is useful for the researcher at the design stage to give thought as to how they can give something in return for the assistance, time and thought given by research participants. The contribution that service users can make can be recognised and valued in a range of ways from being thanked for
their involvement to being provided with a copy of the research findings or by providing payment (DoH 2006). Within my study and in accordance with the Principles of Good Practice for reimbursing study participants (DoH 2006) out of pocket expenses i.e. for travel and subsistence will be met in full to ensure that participants are not left out of pocket or put at risk of being financially worse off as a result of their involvement in the study. If the assistance of a carer or personal assistant is required to enable an individual to participate then the expenses of that person will be met also. In addition it is my intention to offer to each participant as a token of appreciation for the time and thought that they have given, a small payment which will be in the form of tokens/vouchers, cash payment or a donation to an organisation of the participants choice. The prominent ethical concern that 'money may induce people to participate in research by compromising the voluntary nature of their decisions or their willingness to explore the risks and benefits of the study' (Dickert et al 2002 p368) is not felt to apply within this study. Whilst there is a need to be aware of the potential that offering payment may have on informed consent I believe there to be a variety of reasons why people may choose to participate in research such as the opportunity it may provide to share their experiences with other participants, to gain new skills or to provide a sense of purpose or that of belonging to a group (Faulkner 2004).

Within my previous research within this area women stated their primary reason for participating was due to the opportunity that was being provided to talk about an area of their lives that was important to them but which was routinely neglected. Within the study participants were not paid for their involvement but given the longer time span of this fieldwork that participants will be required to be involved for, I believe that a payment of some form is justified. In addition payment for research participation can help to emphasise a distinct change in the relations of power between the researcher and the participant, whereby it signifies a change in their role from client/service user to research participant (Ungar & Teram 2000) and also acknowledges the real contribution being made by the participant to the project (SURGE 2003). The process for and the form of payment to be made will be agreed at the outset so as to avoid any future uncertainties or problems and all monies paid out will be signed for. Monies paid by the ESRC in the form of the Research Training Support Grant will be partly used for reimbursement of expenses and payments to participants.

Consideration will need to be given to the level of cash payments made to participants who may be in receipt of welfare benefits to ensure that they are not penalised in any way by receiving payment. Therefore in order not to contravene the current £5 weekly disregard amount permitted to maintain benefit levels, payment will be made on a weekly basis and the reasons for this method of payment will be highlighted to participants.

By taking part in the research there is a possibility that this may raise questions for the participants themselves, create a level of distress or lead to a felt need for further support. Whilst as a researcher I will not be offering an advice service, I will however seek to provide further contacts (e.g. disability and mental health organisations; telephone helplines) to participants in the form of a 'thank you' leaflet: this will state 'what happens next' (to the data) and 'useful contacts'.

**PROTECTION FROM HARM**

Identify how you will respond to any concerns for participants' well being, including how you will respond to identification of concerning, dangerous or illegal behaviours towards or by participants.

Prior to participation within the research context, the informed consent of all participants will be obtained. (see pg 16 for further details relating to this) Potential participants will be provided with an information sheet (see attached) which outlines honestly and explicitly the nature and purpose of the research.
Interviews can have a certain seductive quality and while participants may appear comfortable and disclose information apparently willingly during an interview, they may later regret having been so open and participants may be left with feelings and thoughts stirred up long after the researcher has moved on (Lewis 2003). Given the potentially sensitive nature of the subject, as the researcher such considerations need to be borne in mind. Sensitive topics are likely to be best addressed through clear and direct questions so that people are not drawn through ambiguity or confusion into subjects they would wish to avoid.

In participating within the research project, confidentiality and anonymity will be guaranteed to all participants unless there are clear and overriding circumstances to do otherwise (BSA 2004). Should such a situation arise, any concerns shall be discussed with research supervisors at the earliest opportunity. Circumstances in which it may be felt that confidentiality and anonymity could not be guaranteed would be made clear to all participants at the start of the research process. (see page 17) In the event of any behaviour deemed to be dangerous or illegal occurring during the fieldwork process, the interview would be suspended and if necessary the research process with the individual would be terminated.

POTENTIAL HAZARDS: RESEARCHERS
What risks to researchers are entailed by the project? What risk assessments have been made? What procedures have been established for the care and protection of research participants?

From the outset of the study, arrangements should be made to minimise risk and assessing risks is an important element of preparation for fieldwork (Social Research Association 2001). In order to ensure the safety and wellbeing of both the research participants and the researcher, contact will be arranged in advance on all occasions. Written confirmation of arrangements made between the researcher and the participant i.e. date, time, place will be provided in advance of arranged meeting times and interviews will take place at a location agreed between the researcher and participant. As the researcher it shall be my responsibility to ensure that a third person is aware of arrangements and that they are provided with a contact telephone number should any concerns arise.

RECRUITMENT PROCEDURES
How will research participants be recruited? Is there any sense in which their participation might be felt to be ‘obliged’ e.g. as students, prisoners, patients, service users, employees, people already known to the researcher?

With regard to recruitment of participants refer to page 8/9. In conducting this research, although women who are known to me from previous research undertaken may possibly participate in the study, (this is not confirmed at present) it shall be made clear to each individual that there is no obligation to do so based purely on this reason. Should women with whom I have a pre existing knowledge and/or relationship become participants, I shall remain aware of the need when conducting social research to maintain boundaries between myself as the researcher and interviewees. For the duration of the interview, participants will be given the space to share different views and experiences and the interviews will not be used to rehearse previously ‘shared’ knowledge about the participants experiences and perspectives. Women who participated in my previous study expressed a wish to do so partly because it was felt that they were being provided with an opportunity to talk about a
topic area that was important to them but which was given little recognition among health and welfare professionals with whom they had contact.

**INFORMED CONSENT**

Please state how you will gain informed consent from participants, including how you will inform people what participation means and their right to withdraw.

- Where appropriate, consent of participants must be requested, preferably in writing, and participants given an information sheet setting out the reasons for the study, the benefits of their participation and how the data is to be stored.
- Copies of the consent forms to be used should be appended.
- Where written consent may not be possible or considered appropriate please provide justification.
- Where covert research methods are to be used, there should be a brief justification of how the interests of those being observed will be protected.

From the outset of the research project, it will be necessary to obtain the freely given informed consent of all participants and there shall be no coercion of prospective participants to participate in the study. This will entail providing information in an accessible format, in appropriate detail and in terms meaningful to participants. The information sheet will outline:

a) What participating in the research project entails
b) What the nature of the research is
c) Why the research is being undertaken
d) Who is undertaking and funding the research
e) How the completed study is to be used and disseminated (BSA 2002)

In addition to being provided with a written information sheet, prospective participants will be given the opportunity to ask verbally any questions they may have in relation to the study. If having read the information provided and been given the opportunity to ask questions etc individuals decide they would like to participate then it shall only be at this stage that a consent form will be signed by both parties.

Both the ethical guidelines of the Economic and Social Research Council (2005) and Social Research Association (2003) clearly state that in all cases of research, researchers have a duty to inform subjects both of their right to refuse to participate or withdraw from the study being undertaken whenever and for whatever reason they wish. Should a participant express a wish to withdraw from the study during the course of the research process, then their choice will be respected. However, in order to minimise the potential for any participant expressing a wish to withdraw at an advanced stage of the research process i.e. during the writing up phase, the informed consent of all participants will be reconfirmed with them throughout the data collection process and transcripts of interviews will be shared with participants.

**DATA PROTECTION**

- Please state how you intend to meet the requirements of the Data Protection Act.
- Consider how data will be stored and how anonymity will be protected.

During the data collection process, data that is stored electronically will be stored securely and will be encrypted where possible. Any tape recordings, interview notes and written documents that are collected and used in the research process will be stored in locked storage within the home or within a locked cabinet at University. Tapes and transcripts will be labelled such that anonymity will not be compromised and identifying information i.e. sampling documents will be stored separately from data. In storing data in this way, this is intended to meet the requirements of the Data Protection Act 1998.
CONFIDENTIALITY AND ANONYMITY
What steps are to be taken to safeguard the confidentiality of records and the identity of research participants?

In undertaking research, maintaining the confidentiality of research participants is a vital ethical issue and one that signifies respect to participants (Faulkner 2004). As previously stated, while efforts will be made to offer assurances of confidentiality, there are limits to confidentiality and anonymity and it will be ensured that participants are clear about these limits (BSA 2004). Proposed conditions for anonymity and confidentiality will be carefully considered and made clear to participants from the outset of the research.

In accordance with the ethical guidelines of the BSA (2002), care will be taken to prevent data from being published in a form that would permit the actual or potential identification of participants without their prior written consent. For potential participants, in particular those who may possess a combination of attributes that make them readily identifiable, there will be a reminder that it may be difficult to disguise identity without introducing an unacceptably large measure of distortion into the data.

The widespread use of computers in research is now often regarded as a threat to individuals due to the methods it provides of disclosing and linking identified records. By contrast, the guidelines of the Social Research Association (2003) suggest that it may be possible for social researchers to exploit the impressive capacity of modern information technology to disguise identities and to enhance data security (SRA 2003). For participants who may wish for their identification to be disclosed in order to maintain ‘ownership’ of the data (Grinyer 2002) as the researcher it shall be my responsibility to present to participants the potential disadvantages of removing anonymity though ultimately the researcher can not be held responsible for participants who choose to disclose their identities themselves. By contrast in the event of such disclosures leading to a failure to preserve the anonymity of other subjects who do not wish their identification to be disclosed then the researcher should resist such requests to disclose identification.

Within the focus group setting in which discussion will take place among a group of people, inevitably there will be sharing of information. Within the group, in order to allay any concerns for confidentiality group members will be asked to treat what others say as confidential and not to be repeated outside of the group. This is likely to be of particular importance to individuals who may know each other on a one to one level or as part of a wider network.

In the event of participation being arranged either by or through a third party, anonymity may be compromised. Though I do not currently envisage participation being arranged by or through a third party, in such cases absolute guarantees of anonymity could not be given and the participant would be informed who will be aware of their participation.

DEBRIEving OF PARTICipANTS
Please state how you will ensure that participants will have an opportunity to discuss participation following involvement in the research, how the researcher will be contactable, and how participants will be informed of the research outcomes.

Upon completion of the interviews with participants, each will be given the opportunity to ask any questions or make comments about either the research itself or the research process. This will apply equally as the focus group is drawn to a close. Each participant will be provided with the contact details of the researcher should they have reason to make contact during the duration of the research project.
and participants will be informed of research outcomes it is envisaged through a Summary paper or a similar document.

**DEBRIEFING OF RESEARCHER**

*Please state* any arrangements to provide you with the opportunity to debrief following engagement in fieldwork.

Both during and after the fieldwork stage of the research, debriefing will be discussed with my supervisors during scheduled supervision sessions. Should any concerns arise between supervision sessions which I feel that I would wish to discuss, then email or telephone contact would be made with supervisors.

**DISSEMINATION OF FINDINGS**

*What is the anticipated use of the data, forms of publication, etc?*

Data obtained from the fieldwork stage of the research process will be used principally towards completion of the PhD thesis. It is anticipated that I shall write a summary report of the research findings which will be available to research participants and organisations or bodies who may have registered an interest in the subject area. As my research is funded by the ESRC, the research council requires that findings or data that have resulted from the study are made available to them and in turn to a wider research community.

At present there are no plans to publish in a format other than the thesis but this is likely to be discussed with my supervisors as the research progresses.

**SENSITIVITY AND DIVERSITY**

*Please provide a statement on how you are approaching issues of diversity within your research (e.g. gender, sexuality, age, disability, mental health).*

*Note: this approach should also be reflected in your account above* i.e. integral to your research plan.

The research as stated is focusing on women aged between 18 and 65 years who have a physical impairment and who have had experience of mental health problems. The age range chosen was determined to a large extent by service provision in that services are frequently categorised to persons under 18, adults between 18 and 65 years and persons over 65 years of age. In choosing to focus on women, this is not to disregard the experiences of men with physical impairments who may require support from mental health services but evidence from the limited literature available suggested that their needs were likely to be different from those of women. My decision was based on wishing to focus on women's experiences in some depth rather than attempting to additionally cover issues relevant to men which would potentially lead to areas not being covered in sufficient depth. As stated my sample group aims to encompass a group of women across a wide age range whose physical impairment may be either congenital or have been acquired. I also aim to have within the group women from different ethnic backgrounds and who may be mothers or have other caring responsibilities or women who do not have dependants.

By focusing solely on physical impairment this is not to ignore any mental health experiences of people with learning disabilities or those with a visual or sensory impairment. My concern however, was that by expanding the research to other groups of people, there would be a risk of the research study becoming too diluted.
OPENNESS AND HONESTY
Please demonstrate how you will ensure maintenance of openness and honesty within your research.
Note: this approach should also be reflected in your account above i.e. integral to your research plan.

By providing an information sheet which outlines fully to participants the nature and purpose of the research being undertaken, it is my intention to provide a foundation for a research process that is open and honest from the outset. At any stage during the research process participants will be able to ask questions they may have regarding the study and as the researcher it is my responsibility to ensure that participants are reminded of this throughout the research process. At no stage shall any attempt be made to mislead participants and through the use of semi-structured interviews and a focus group, the aim is that each participant will be encouraged to be active in the research process.

STUDENT TO CONFIRM THAT THEY HAVE CONSIDERED ETHICAL IMPLICATIONS OF RESEARCH IN RELATION TO:

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
<th>NOT APPLICABLE</th>
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</thead>
<tbody>
<tr>
<td>Ensuring informed consent</td>
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<td></td>
</tr>
<tr>
<td>The nature of power relationships in the proposed study</td>
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<td></td>
</tr>
<tr>
<td>Right to withdraw from the study</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Responding to potential detrimental effects on participants</td>
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<td></td>
</tr>
<tr>
<td>Confidentiality</td>
<td>x</td>
<td></td>
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<td>Protection from harm of vulnerable participants</td>
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<td></td>
</tr>
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<td>how to respond to harmful or illegal behaviour</td>
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<td></td>
</tr>
<tr>
<td>Justifying subterfuge in research design</td>
<td></td>
<td></td>
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</tbody>
</table>

FUTURE ETHICAL PROCESSES TO BE UNDERTAKEN
Please detail any further ethical review processes required before undertaking fieldwork.

None. No women will be recruited via health or social care services.

TO BE SIGNED BY THE STUDENT APPLICANT:

I confirm that I have read the University Guidelines for Research and agree to abide by them:

I confirm that I have read the Social Research Association Guidelines or Guidelines of my professional association, the Economic and Social Research Association and agree to abide by them:
I confirm that I have discussed the proposed study with a member of IASS staff (e.g. supervisor).

Should the research project change in a significant way from that previously approved, I accept that it is my obligation to discuss those changes with my supervisor who will advice whether I should bring those changes back to the IASS Student Research Ethics Committee for approval. I also undertake to report promptly any adverse events:

Signedé é é é é é é é é é é é é é é é.

Dateé é é é é é é é é é é é é é é é é é.

TO BE SIGNED BY THE SUPERVISOR

Before submitting, your supervisor must have read your proposal and given approval for submission. NOTE THAT YOUR SUBMISSION WILL NOT BE REVIEWED WITHOUT THE SIGNATURE OF A SUPERVISOR TO CONFIRM APPROVAL.

I have read this proposal and give approval for submission

Signature of supervisoré é é é é é é é é é é é é é é é é é é é é é é é é é é é é é é é é é é.

Where two supervisors are involved in postgraduate research the signature of one supervisor indicates that both supervisors have given approval.

APPENDICES REQUIRED

Please refer to attached.
Information Leaflet for Participants
Consent Forms
Draft Topic Guide(Interviews)
Draft Topic Guide (Focus group)

References.


Bibliography.


Appendix 4.

Title of Research Project:--
Mental Health Services: The experiences of women with physical impairments.

Name of Researcher:--
Julia L. Smith

Address and Telephone Number of Researcher:--
Institute of Applied Social Studies
Terrace Huts
University of Birmingham
Edgbaston
Birmingham
B15 2TT

Contact telephone no. 0121 415 8032

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions. YES/NO

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without having to give any reason, and without my care or legal rights being affected. YES/NO

3. I agree to take part in the above study. YES/NO

____________________  ______________ ___________________
Name of Research Participant                Date                                        Signature

____________________  ______________ ___________________
Name of Researcher                                Date                                        Signature
<table>
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<tr>
<th>NAME</th>
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<th>EDUCATION</th>
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<td>CHARCOTTE MARIE TOOTH SYNDROME-GENETIC CONDITION DIAGNOSED AS YOUNG CHILD</td>
<td>MAINSTREAM EDUCATION SPECIALIST COLLEGE FRO F.E.</td>
<td>LIVES WITH HUSBAND WITH CARE SUPPORT PROVIDED BY TEAM OF CARERS</td>
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<td>43/ 1960'S</td>
<td>SPINAL CORD INJURY-ACQUIRED IMPAIRMENT AT AGE 13</td>
<td>SPECIAL EDUCATION FROM AGE OF 13</td>
<td>LIVES IN ADAPTED PROPERTY WITH FAMILY-24HOUR LIVE IN CARE</td>
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<td>MAINSTREAM EDUCATION</td>
<td>LIVES WITH PARTNER WHO PROVIDES ANY SUPPORT REQ'D</td>
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<td>Disability/Impairment Details</td>
<td>Education</td>
<td>Living Arrangement</td>
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<td>STROKE - ACQUIRED IMPAIRMENT AT 55</td>
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<td>LIVES IN ADAPTED BUNGALOW WITH 24 HOUR CARE SUPPORT</td>
</tr>
<tr>
<td>LOUISE</td>
<td>39/1960'S</td>
<td>SPINAL LESION-ACQUIRED IMPAIRMENT AT 14</td>
<td>MAINSTREAM AND SPECIAL SCHOOL EDUCATION</td>
<td>LIVES IN ADAPTED BUNGALOW WITH 24 HOUR CARE SUPPORT</td>
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<tr>
<td>CARLY</td>
<td>18/1980'S</td>
<td>BORN WITH IMPAIRMENT</td>
<td>MAINSTREAM- F.E. EDUCATION IN SPECIALIST COLLEGE</td>
<td>LIVES AT HOME WITH FAMILY- CARE PROVIDED BY MOTHER, CARE PROVIDED DURING TERM TIME BY CARE TEAM AT COLLEGE</td>
</tr>
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Appendix 6a

Research Participant 1. Katy

Katy is 43 years of age and lives in central England. Katy has brittle bone disease and has used a powered wheelchair since childhood. Katy lives in her own adapted property with 24 hour care support. She has an older sister who lives nearby and her elderly mother who she sees every week lives five miles away.

Katy received most of her education within a special school setting before spending two years in the mid 1980's at a residential college of further education for students with physical disabilities. She graduated with a Diploma in Applied Social Studies from the Open University in 1994 and since then has been involved in disability awareness training and with a number of disability organisations in her home county. In her spare time Katy enjoys going to the theatre, spending time on her computer and swimming.

Appendix 6b

Research Participant 2. Alison

Alison is 39 years of age and was born in the Yorkshire area. Alison was born with Spina Bifida and has always used a wheelchair for her mobility. For the past twenty years she has lived in an adapted bungalow in a rural village. Alison's parents who own a farm live nearby as does her younger brother and she sees her mum on a regular basis.

After spending many years as a boarder at a special school, at the age of 16 Alison spent two years at a residential college for students with physical disabilities. Upon leaving college in 1987 Alison returned to Yorkshire and took up employment as a secretary with a large national company where she remained for 7 years. Whilst working as a secretary Alison organised what she described as her dream wedding but feels she married too young and separated from her husband after five years. For the past 12 years Alison has worked within a bank call centre in a local town and now works four days a week.

Alison receives care support from a care agency through the Direct Payments Scheme and also has help with everyday activities from her mum. Alison has an adapted vehicle which she is able to drive independently and uses this both for work and leisure purposes. Alison enjoys spending time with friends and likes to travel.
Appendix 6c

Research Participant 3. Pippa

Pippa is 35 and lives in a small town in the West Midlands. She lives in an adapted bungalow with her parents and has one older brother. Pippa has cerebral palsy and has used a powered wheelchair from an early age. Care support is provided predominantly by Pippa’s mother as she had a number of poor experiences of using private care agencies.

Throughout her school years Pippa went to different special schools and colleges before enrolling for an Undergraduate degree at university in 1998 from where she graduated in 2002 with a degree in Computer Science. Upon graduating Pippa took up employment at a large car manufacturing company in Warwickshire where she has now worked for the last five and a half years as a Training Administrator.

Pippa describes herself as a sociable person who likes to balance her work life with a wide range of leisure activities and she recently completed a parachute jump through which she raised a large amount of money for a disability charity.

Appendix 6d

Research Participant 4. Lisa

Lisa is 45 years of age and lives in the Birmingham area. As a young child Lisa was diagnosed with the same genetic progressive condition that had affected her father and for the past fifteen years has used a powered wheelchair. Lisa lives with her husband and is supported by a team of carers one of whom is her mother who lives nearby.

Lisa attended mainstream school until the age of 17 before spending two years at a college of Further Education for students with physical disabilities. For many years Lisa was a keen swimmer and she participated in the Olympics during the 1980s. Lisa then took up employment in a number of clerical positions and during the 1990s was involved in working with a number of disability organisations in the Birmingham and West Midlands area. More recently Lisa has focused on doing voluntary work and occasional disability consultancy which she finds is more suited to her fluctuating health symptoms. In her leisure time Lisa enjoys getting out and about in her adapted vehicle and meeting friends. In particular she enjoys foreign travel and would like to travel around the world.
Appendix 6e

Research Participant 5. Maria

Maria is 51 and lives in Warwickshire with her husband. Maria has three children—two sons in their twenties and a daughter in her late teens. Maria’s daughter has a learning disability but has received all her education in a mainstream school with academic support and has recently enrolled for a university degree. Maria’s youngest son has enduring mental health problems and has spent long periods within a residential psychiatric unit.

After finishing school at the age of 16 Maria started working in a bank where she remained until she was no longer able to continue working. Maria was diagnosed with Multiple Sclerosis she thinks when she was in her early thirties having now lived with the condition for nearly twenty years. During the past two years Maria says her condition has progressed significantly and she now relies on care support to meet all her care needs and mobility requirements. Prior to the decline in her health Maria enjoyed reading and sewing and had a number of hobbies that she no longer feels able to pursue. Maria says she now derives most pleasure from getting out and about but relies heavily on the support of a friend and the availability of accessible transport to be able to do this.

Addendum.

Maria passed away in July 2009 following a prolonged period of ill health. Maria’s family were aware of her involvement and keen interest in the study. They stated that it would have been Maria’s wish that the material gathered from her interviews and involvement in the focus group would be used in the study.

Appendix 6f

Research Participant 6. Jackie

Jackie is 43 years of age and has lived in Warwickshire for the past twenty years. At the age of 13 Jackie was involved in an accident, acquiring a significant spinal cord injury and has now been a wheelchair user for thirty years. After spending two years at a national college of further education for students with disabilities in the mid 1980’s Jackie got married and had a daughter who is now in her twenties. From 1987 Jackie worked across a number of departments within a local authority before retiring due to ill health in 2006.

Jackie lives in an adapted bungalow with her parents and daughter and has had live in care for the last eleven years funded through Direct Payments and the Independent Living Fund.

Jackie now undertakes voluntary work with a number of council organisations and is involved in training young adults with learning disabilities to use public transport and to become more independent. In her spare time Jackie enjoys spending time with her daughter, travelling and going to the theatre.
Appendix 6g


Carly is 18 years of age and lives in the North of England with her parents and younger sister and has two older sisters who live in the area. Carly was born with cerebral palsy and uses a powered wheelchair for her mobility. For her primary and secondary education Carly attended mainstream schools but is now studying for a BTec National in Social Care at a specialist residential college for students with physical disabilities. On completion of her two year course Carly hopes to progress to University and would like to follow a career in social work. In her spare time Carly enjoys listening to music, watching films and spending time with family and friends.

Appendix 6h

Research Participant 8. Helen

Helen is 41 years of age and spent her childhood years in southern counties and has lived on the South coast for the past twenty years. Helen was born with cerebral palsy and has used a wheelchair for mobility from birth. Helen is the youngest of five children and has an elderly father who lives in the North of England. For her primary and secondary education Helen attended special school then at the age of 17 enrolled at a residential college for students with physical disabilities where she spent four years before moving to live on the South coast. Initially Helen spent fourteen years living within a residential setting but for the past six years has lived in an adapted bungalow with 24 hour care support.

Helen is a trustee of a local advocacy organisation, is involved with a number of local mental health organisations and undertakes voluntary work in a range of capacities. In her spare time Helen enjoys eating out and spending time with friends.

Appendix 6i


Elisabeth is 63 years of age and was born during the second world war in Wales but grew up in Warwickshire before spending many of her formal education years at a rural boarding school. Elisabeth was born with a joint malformation condition and also has a visual and a hearing impairment. Elisabeth has two younger siblings and her mother is now resident in a nursing home. At the end of her school years Elisabeth spent eleven years at home before enrolling for further education at a specialist college for students with physical disabilities where she spent three years studying for O and A levels. This was followed by three years at university studying for a degree in Philosophy and a further two years of postgraduate study. Between 1984 and 2006 Elisabeth worked across the country undertaking a range of disability related work.

Elisabeth now lives in the West of England in an adapted property and lives with the support of personal assistants funded through Direct Payments. In her leisure time Elisabeth enjoys reading and poetry and likes to spend time in her sensory garden.
Appendix 6j

Research Participant 10. Judith

Judith is 62 years of age and was born and grew up in the Black Country area of the West Midlands and has lived in North Birmingham for the past twenty years. Judith has two younger sisters and her elderly parents live in South West Birmingham. At the age of 15 Judith left school to start work and continued to work full time until seven years ago when she suffered a severe stroke. Judith got married in her early twenties and has a grown up son and daughter—she has lived alone following her divorce.

Judith now lives in adapted accommodation within a sheltered housing complex and receives support with daily living and personal care from family and a carer. Judith enjoys spending time outdoors and uses a mobility scooter for her outdoor mobility. She attends a social luncheon club three times a week and a stroke support group fortnightly. For leisure Judith enjoys going to the theatre and has enjoyed travelling to a number of different countries over the past eighteen months.

In 2005 Judith was diagnosed with cancer and spent four months in hospital undergoing treatment which was successful and she is currently in remission.

Appendix 6k

Research Participant 11. Frankie

Frankie is 26 and was born and grew up in the West Midlands with her parents and younger brother. Frankie attended mainstream primary and secondary school before enrolling for a four year Chemistry degree at a local university in 1999. Currently Frankie is entering the fifth year of her PhD study which she hopes to complete in 2009/10.

As a child Frankie was diagnosed with juvenile arthritis but the diagnosis was reassessed in 2001 when she was diagnosed with a genetic condition, hypermobility syndrome which affects the joints and causes significant levels of pain. Assistance with aspects of daily living is provided by Frankie's partner with whom she has lived for the past five years and currently she requires assistance with mobility and uses a walking aid.

Away from her studies Frankie says that she enjoys cooking, is a keen reader and when her condition is stable likes to drive and travel.
Appendix 6I

Research Participant 12. Louise

Louise is 39 years of age and has lived most of her life in the West Midlands area. Louise comes from a large extended family but currently lives alone in an adapted property in North Birmingham with the support of private carers who provide round the clock assistance with all aspects of daily living.

As a child Louise attended mainstream primary school and began her secondary education at a private boarding school which she attended for two years before acquiring her impairment. Much of Louise's teenage years were spent in hospital during which time she intermittently attended a local special school. Having left hospital after a period of four years Louise moved into residential care and subsequently resumed her studies at a local Sixth Form college before progressing to University education. From the early 1990's Louise worked in a number of social work related roles but due to difficulties associated with her physical impairment and mental health difficulties she made a decision to leave work in 2001 and now undertakes consultancy work on an ad hoc basis in disability related areas.
When not working Louise enjoys reading and spending time at home.
Appendix 7

TOPIC GUIDE-SUMMARY SHEET. (Interviews)

♦ Introduction
♦ Present Circumstances
♦ Details of Life History
♦ Physical Impairment
♦ Mental Health
♦ Accessing and Using Mental Health Services
♦ Role of External Factors
♦ Suggestions for the future
♦ Drawing Interview to a close
Appendix 8

Topic Guide. Interview Schedule (DRAFT)

MENTAL HEALTH SERVICES: THE EXPERIENCES OF WOMEN WITH PHYSICAL IMPAIRMENTS.

Objectives of study

- To produce a study in which the central focus is the experiences of women with physical impairments from their own perspectives.

- To determine, from the perspectives of women with physical impairments who have experience of mental health problems, the extent to which mental health services within the UK meet the needs of women with physical impairments.

- To examine the experiences of accessing and using mental health services for women with a range of physical impairments.

- To examine whether women with a range of physical impairments perceive social disability to be a source of mental distress.

- To examine whether women with physical impairments believe that mental health services could meet their mental health needs more appropriately, and if so, how.

Introduction

- Introduce self as researcher to participant to refamiliarise.
- Ensure that participant is happy with interview arrangements and that setting meets any specific requirements.
- Confirm with participant purpose of study, by whom research is being funded, how research will be used.
- Check whether participant has any questions prior to commencing and is ready to proceed.

1. PRESENT CIRCUMSTANCES.

- Name, (likes to be called by what name)
- Age
- Ethnic origin
- Place of residence

2. DETAILS OF LIFE HISTORY. (To use with aim of providing background information and establishing relationship with participant)

- Childhood & family background
-- Place of birth, where person has grown up & lived
-- Family composition/ circumstances

• Schooling & education

-- Where participant attended school
-- Experiences of school- good, bad, happy, mixed
-- Experiences of further education and/or studying for qualifications
-- For people who have acquired their impairments was their experience of/progress in education affected by the onset of impairment?

• Post school education/employment

-- What participant has done since leaving school/college- current status ie. employment status. Undertaking studies etc

-- Work, further studies, employment training, attendance at day care, voluntary work

-- Other information relevant to participant ie. leisure interests/ hobbies etc

3. PHYSICAL IMPAIRMENT.

• Background to participants physical impairment.

Nature of the physical impairment-congenital or acquired

-- If congenital, at what age did person become aware/conscious of impairment
-- If impairment was acquired, at what age, circumstances leading to onset of impairment
-- Effect of physical impairment on day to day living-ie. ask participant to describe in their own words how/if impairment affects everyday activities

• Contact with/Use of service provision.

-- Are there needs relating to physical impairment that are met through using services? Ie. through health services- physiotherapy, district nurses, wheelchair services, GP, hospital services, complementary therapies?
-- What services are used ? ie. Home care provision, day care, respite care services.
-- Frequency?
-- Women's experiences of using services-more general or specific comments
-- Does participant feel that needs relating to physical impairment are being met?
-- Level of satisfaction with services being provided overall ie. relating to provision of care support, thoughts re communication between services
-- Other comments/opinions on provision of services relating to physical impairment

4. MENTAL HEALTH.

• Research relating to Physical Impairment and Mental Health.
Studies undertaken that have examined physical impairment and mental health, have for the majority concluded that depression among persons with a physical impairment is often associated with the trauma of the experience of impairment and believe that a level of depression is almost inevitable when living with a physical impairment.

--Participants views/thoughts about this

In addition in the limited studies in which people with physical impairments have recalled their experiences of mental health problems, individuals have described how mental health professionals with whom there has been contact, have routinely assumed that the mental health problems being experienced are a result of living with a physical impairment.

--Views/thoughts on this
--Why women think/believe that health professionals frequently assume a link between experiencing mental health problems and the presence of a physical impairment

- Participants thoughts re the concept of 'loss' and their thoughts as to whether they feel they have experienced a sense of loss or not. Do participants think that 'loss' (if they think it does happen) is experienced differently for women who acquire their impairments compared to those who are born with them?

- Experience of Mental Health problems.

--Participants experiences of mental health problems/ emotional or psychological difficulties
--Have mental health problems been diagnosed, if so by whom?
--Agreement or otherwise with diagnosis given

5. ACCESSING AND USING MENTAL HEALTH SERVICES.

--Currently using mental health services, previously used?
--Community based services or in-patient? ie. Psychologist, Community Psychiatric Nursing, Counselling services, Support groups

--Recollection/description of experiences of accessing/using mental health services

--If difficulties were experienced what were they?

--Barriers to using services-structural or other? ie. Inaccessible buildings, lack of personal assistance available, cost of counselling services if having to access privately

--How would describe experiences ie. positive, negative, mixed?

--Mental health needs adequately met?

--Any other comments in respect of receipt of services

--Thoughts of participants as to whether as a woman with a physical impairment they would prefer to receive counselling from a person with a disability or someone who has had direct experience of disability themselves?
--Do they think it matters or not? Reasons why?

--In addition as a woman would participant prefer to receive counselling from a woman? Reasons? Do they think they would have a choice?

6. ROLE OF EXTERNAL FACTORS.

- Refer to previous study and literature describing how women with impairments have attached importance to issues such as barriers to accessing the environment and attitudes in society towards impairment and the potential such factors create to impact on mental health.

--Views, thoughts of participants about this ie. agree, disagree
--Why?

If social factors are thought to play a role in impacting on mental health

--How does this/could this manifest itself? ie. affect on self image
--Participants thoughts re impact of physical impairment upon relationships with friends, family, partners, spouses etc

- With implementation of the Disability Discrimination Act in recent years:-

--Any changes witnessed within society generally ie. improved access to public places, shift in attitudes towards impairment as people have become more 'visible'

--If participants thought external factors had played a significant role in potential they created to impact on mental health, have changes of recent years altered views on this?

--Have changes benefited participant personally?

7. SUGGESTIONS FOR THE FUTURE.

--Does participant think that mental health services within the UK could meet the needs of women with physical impairments in a more appropriate way?
--& if so, how? Why?
--For participant personally, if anything what changes would like to be seen?
--How would this make experience of using mental health services more positive?
--Any other thoughts/comments?

8. DRAWING INTERVIEW TO A CLOSE.

--Any other comments participants would like to make, questions to ask of researcher
--Thank participant for time given and talking about their experiences
--Confirm contact details should points/issues raised within interview require clarification etc.
Appendix 9

Topic Guide. Revised Interview Schedule

MENTAL HEALTH SERVICES: THE EXPERIENCES OF WOMEN WITH PHYSICAL IMPAIRMENTS.

Objectives of study

- To produce a study in which the central focus is the experiences of women with physical impairments from their own perspectives.

- To determine, from the perspectives of women with physical impairments who have experience of mental health problems, the extent to which mental health services within the UK meet the needs of women with physical impairments.

- To examine the experiences of accessing and using mental health services for women with a range of physical impairments.

- To examine whether women with a range of physical impairments perceive social disability to be a source of mental distress.

- To examine whether women with physical impairments believe that mental health services could meet their mental health needs more appropriately, and if so, how.

Introduction

--Introduce/re-introduce self as researcher to participant to refamiliarise.
--Ensure that participant is happy with interview arrangements and that setting meets any specific requirements.
--Confirm with participant purpose of study, by whom research is being funded, how research will be used.
--Check whether participant has any questions prior to commencing and is ready to proceed.

1. PRESENT CIRCUMSTANCES.

- Name, (likes to be called by what name)
- Age
- Ethnic origin
- Place of residence

2. DETAILS OF LIFE HISTORY. (To use with aim of providing background information and establishing rapport with participant)

- Childhood & family background

-- Place of birth, where person has grown up & lived
-- Family composition/ circumstances

- Schooling & education

-- Where did you go to school?
-- What were your experiences of school- good, bad, happy, mixed
-- Experiences of further education and/or studying for qualifications
-- For people who have acquired their impairments was their experience of/progress in education affected by the onset of impairment?

- Post school education/employment

-- What participant has done since leaving school/college- current status i.e. employment status, undertaking studies etc
-- Work, further studies, employment training, attendance at day care, voluntary work
-- Do you have any hobbies or leisure pursuits?

3. PHYSICAL IMPAIRMENT.

- Background to participants physical impairment.

Nature of the physical impairment-congenital or acquired

-- If congenital, at what age did person become aware/conscious of impairment
-- If impairment was acquired, at what age, circumstances leading to onset of impairment
-- Effect of physical impairment on day to day living-i.e. ask participant to describe in their own words how/if impairment affects everyday activities

- Contact with/Use of service provision.

-- Are there needs relating to physical impairment that are met through using services? i.e. through health services- physiotherapy, district nurses, wheelchair services, GP, hospital services, complementary therapies?
-- Women's experiences of using services-more general or specific comments
-- Does participant feel that needs relating to physical impairment are being met?
-- Level of satisfaction with services being provided overall i.e. relating to provision of care support, thoughts re communication between services
-- Other comments/thoughts on provision of services relating to physical impairment

4. MENTAL HEALTH.

- Research relating to Physical Impairment and Mental Health.

To share with participants. Studies undertaken that have examined physical impairment and mental health, have for the majority concluded that depression among persons with a physical
impairment is often associated with the trauma of the experience of impairment and believe that a level of depression is almost inevitable when living with a physical impairment.

--What are participants views/thoughts about this?

In addition in the limited studies in which people with physical impairments have recalled their experiences of mental health problems, individuals have described how mental health professionals with whom they have had contact, have routinely assumed that the mental health problems being experienced are a result of living with a physical impairment.

--What are participants views/thoughts on this?
--Why do women think/believe that health professionals frequently assume a link between experiencing mental health problems and the presence of a physical impairment?

- What are participants thoughts/views about the concept of 'loss'
- Do they feel they have experienced loss? Yes or no? Why?
- Do participants think that 'loss' (if they think it does occur) is experienced differently for women with acquired impairments compared to those with congenital impairments?

- Experience of Mental Health problems.

--Can you tell me about your experiences of mental health problems/ emotional or psychological difficulties
--Were mental health problems diagnosed, if so by whom?
--Was participant in agreement with diagnosis given?

5. ACCESSING AND USING MENTAL HEALTH SERVICES.

-- Are you currently using mental health services, have previously used?
-- Can you tell me what types of services these were? i.e. Community based services or in-patient? For example, Psychologist, Community Psychiatric Nursing, Counselling services, Support group

--Can you recall/describe any of your experiences of accessing or using those mental health services

--If you experienced difficulties can you tell me what those were?

-- Fr example- Barriers to using services-structural or other? I.e. Inaccessible buildings, lack of personal assistance available, cost of counselling services if having to access privately

--How would you describe your experiences overall of using mental health services or of receiving mental health support? Were they positive, negative, mixed?

--Do you feel that your mental health needs were adequately met?

As a woman with a physical impairment do you have any preferences in respect of working with an able bodied counsellor or a counsellor with a physical impairment?
--Do participants think this matters? Reasons why?
--Do participants have any thoughts with regard to the gender of the counsellor?

--Is there anything else you would like to say in respect of the services you received/are receiving?

6. ROLE OF EXTERNAL FACTORS.

- Refer to previous study and literature describing how women with impairments have attached importance to issues such as barriers to accessing the environment and attitudes in society towards impairment and the potential such factors create to impact on mental health.

--What are participants views, thoughts on this? Agree? Disagree ?
--Why?

If social factors are thought to play a role in impacting on mental health

--How does this/could this manifest itself? ie. affect on self image
--Participants thoughts re impact of physical impairment upon relationships with friends, family, partners, spouses etc

- With implementation of the Disability Discrimination Act in recent years:-

--Have participants witnessed any changes within society generally? I.e. improved access to public places, shift in attitudes towards impairment as people with physical impairments have become more 'visible'

--If participants thought external factors had played a significant role in potential they created to impact on mental health, have changes of recent years altered views on this?

--In what way have the changes benefited participant personally?

7. SUGGESTIONS FOR THE FUTURE.

--Does participant think that mental health services within the UK could meet the needs of women with physical impairments in a more appropriate way?

--& if so, how? Why?

--For participant personally, what changes would like to be seen?
--How would this make experience of using mental health services more positive?
--Any other thoughts/comments?

8. DRAWING INTERVIEW TO A CLOSE.

--Any other comments participants would like to make, questions to ask of researcher
--Thank participant for time given and talking about their experiences
--Confirm contact details should points/issues raised within interview require clarification etc.
Appendix 10

TOPIC GUIDE-SUMMARY SHEET (Focus Group)

♦ Introduction
♦ Individual Introductions
♦ Mental Health
♦ Research relating to Physical Impairment and Mental Health
♦ Role of External Factors
♦ Suggestions for the future
♦ Drawing Focus Group to a close
Appendix 11

**Topic Guide. (Focus Group).**

MENTAL HEALTH SERVICES: THE EXPERIENCES OF WOMEN WITH PHYSICAL IMPAIRMENTS.

**Objectives of study.**

- To produce a study in which the central focus is the experiences of women with physical impairments from their own perspectives.

- To determine from the perspectives of women with physical impairments who have experience of mental health problems the extent to which mental health services within the UK meet their needs.

- To examine the experiences of accessing and using mental health services for women with a range of physical impairments.

- To examine whether women with a range of physical impairments perceive social disability to be a source of mental distress.

- To examine whether women with physical impairments believe that mental health services could meet their needs more appropriately, and if so, how.

**Introduction-Scene setting and ground rules.**

--Once group is complete make start to session with personal introduction to refamiliarise myself with participants/vice versa; ensure participants are satisfied with venue etc

--Provide outline of the research topic and reiterate purpose of focus group- why it is being held

--Give background information on purpose of the study and who it is being funded by

--Stress confidentiality to group members and give explanation of what will happen to data

--Give indication to participants of expected roles

--Explain that session will be in form of a discussion and that participants do not need to wait to be invited before speaking

--Also important to stress that there are no right or wrong answers-all views are of interest as group aims to hear as many thoughts as possible

--Explain the need to record discussion in order to ensure that researcher has a full account of everything that is said.

--Check for any participant questions, queries etc before proceeding. Ensure recording equipment is switched on

1. **INDIVIDUAL INTRODUCTIONS.**

- Ask each participant to introduce themselves in turn- giving name and telling other group members a little about themselves. This to be left to participants to decide as they may not wish to say very much until a later stage when the group is more established.

- Researcher may choose to jot down spatial diagram of names, brief background details etc for use as an aide-memoire.
- Having completed personal introductions, consider making a few comments re composition of group as a whole, ie may wish to highlight differences that have been revealed, pointing out benefit of this for contrasting views and experiences in forthcoming discussion.

Or, maybe note similarities, particularly as a prelude to exploring a sensitive issue in depth. May help to reinforce a feeling of now being 'a group'- one in which all group members are included.

2. MENTAL HEALTH.

- Experience of Mental Health problems.

--Ask group members if they would be willing to share/ talk about their experiences of mental health problems
--Have mental health problems been diagnosed? Satisfaction with diagnosis given?
--Was getting a diagnosis/ being given 'a name' to the problem being experienced important to you?

- Accessing and Using Mental Health services.

--Discussion re services currently being used or previously used ie. CPN, Support groups, Counselling services
--Discuss/share experiences of accessing mental health services
--Any difficulties experienced in doing so? What were they? ie. structural barriers, lack of personal assistance available
--Discuss/share experiences of using services
--How would experiences be rated? Positive? Negative? Mixed?
--Did service provided meet needs?
--Any other comments in respect of receipt of services

3. RESEARCH RELATING TO PHYSICAL IMPAIRMENT AND MENTAL HEALTH.

To share with group members. Studies undertaken that have examined physical impairment and mental health have mostly concluded that depression among people who have a physical impairment is often associated with the trauma of the experience of impairment. These findings could suggest that a level of depression is almost inevitable for people living with a physical impairment.

--Ask group members to discuss/share their thoughts/opinions about this-ensure that all group members are given opportunity throughout to contribute, offer encouragement
--Note agreements, disagreements, uncertainties between group members

Expand on discussion- In addition, in the limited number of studies in which people with physical impairments have recalled their experiences of mental health problems, individuals have described how mental health professionals with whom they contact, have routinely assumed that the mental health problems being experienced are a result of living with a physical impairment.
--Group members thoughts on this
--Have their own experiences of using mental health services borne this out
--Why do women think/ believe that mental health professionals often assume a link between experiencing mental health problems and the presence of a physical impairment?

--Have group members had experience of their physical impairment being viewed as a 'tragedy'? (either by themselves or others)
--Does this happen particularly when the individual has acquired their physical impairment and had previously been able bodied?

4. ROLE OF EXTERNAL FACTORS.

- Make reference to own previous study undertaken and draw attention to literature that has shown how women with impairments have attached importance to issues such as barriers to accessing the environment and attitudes in society towards impairment and the potential it is felt such factors create to impact on mental health.

--Discuss views/thoughts of group members about this
--Agree, disagree? Why?

*If it is believed that social factors do play a role in impacting on mental health*

--How does or could this manifest itself?

- With implementation of Disability Discrimination Act in recent years

--Share thoughts/views on any changes witnessed within society generally i.e. improved access to public places, a shift in attitudes in society overall towards impairment as people have become more 'visible'.

--If group members believe that external factors have played significant role in potential they have created to impact on mental health, have changes in recent years altered their views on this?

--Share thoughts/experiences on how changes have brought benefit at a personal level

5. SUGGESTIONS FOR THE FUTURE.

--Discuss views/ thoughts of group members on whether mental health services in the UK could meet needs of women with physical impairments in a more appropriate way
--& if so, how and why?
--Changes that group members would like to see
--In what ways this would make experience of using mental health services more positive
--Any other thoughts?
6. **DRAWING FOCUS GROUP TO A CLOSE.**

--Facilitator to indicate moving towards bringing group to a close
--Establish if there are other comments group members would like to make, questions to ask?
--Express thanks for time given to share thoughts and talk about experiences-stress how discussion has been helpful
--Confirm own contact details should anyone wish to make contact
--Draw group to a close, check practicalities i.e. transport arrangements for group members.
<table>
<thead>
<tr>
<th>Topic</th>
<th>Theme</th>
<th>Participant</th>
</tr>
</thead>
</table>
| 1. Personal details - outline of personal circumstances etc.  
   a) Experiences of mainstream or special school education | | |
| 2. Physical Impairment  
   a) nature of, effects of physical impairment on everyday activities  
   b) any care or support services provided  
   c) satisfaction with service provision relating to physical impairment | | |
| 3. Mental Health  
   a) Research relating to physical impairment and mental health  
   --suggestion that experiencing depression is inevitable when living with a physical impairment  
   --assumptions frequently made by medical & mental health professionals that experience of mental health or psychological difficulties are as result of living with physical impairment. | | |
| 4. Loss - thoughts of women participants around the concept of loss. | | |
| 5. Experience of Mental Health problems  
   a) experiences of accessing/using mental health/psychology services | | |
| 6. Counselling for women with physical impairments  
   -thoughts re disabled Vs non disabled counsellors/ male or female counsellor | | |
7. The role of external factors  
   a) Discussion of how women have attached importance to issues such as barriers to accessing the environment &  
   b) Attitudes in society towards impairment and the potential that such factors create to impact on mental health/ emotional well-being  
   c) The impact of physical impairment upon relationships with family/friends/spouses etc  

8. Implementation of the Disability Discrimination Act  
   a) Perceived impact of DDA - improved access  
   b) Changes in attitude towards impairment within society  

9. Suggestions for the future  
   a) Participants thoughts/views as to whether mental health/counselling services within UK could meet needs of women with physical impairments in a more appropriate way-  
   b) Any changes personally that participant would like to see that would make experience of using services more positive  

10. Any additional thoughts or comments.
Appendix 3.

As I say my first had experience of depression was when I was at boarding school and was bullied and then this turned to panic when I was really down as there was nobody to turn to and just thought I wouldn't be listened to but I wouldn't be believed as that was the sort of culture that existed there. By the time I left the school mentally and psychologically I was at a pretty low point. Since then I've had episodes of depression on and off of which some have been more severe than others and then I've tended to be on antidepressants for a while over the years I've had counselling also a couple of times at hospital that specialises in rehab. Now most of it are thing that I've done with work since then but the last year I was off work due to severe back pain for about 4-5 weeks and around this time developed a more depressive episode... I began to talk to the GP about my depression and discuss....
Experiences of Mental Health problems

I think in the initial months after my accident that was when I was most depressed because when I first had the accident and I suppose being so young I was quite naive and thought the use in my arms and legs would come back and that using the wheelchair was a temporary thing but once it was explained to me that wasn't the case well yes I remember that I did go into myself. In later years though I have in a strange way thought myself lucky that my accident happened at the age it did because I was at an age when I hadn't really made a decision about a career or anything like that and I could almost rethink my strategy where as there were people on the spinal unit who maybe already had jobs, homes and families and for them it was like

I was depressed I never got to the stage where I felt suicidal and didn't totally shut myself off from everyone, well not for any length of time anyway & everyone on the ward you were all pretty much in the same boat & so you helped each other through as there was no such thing as counselling in those days all the treatment was practical based and around getting you mobile and independent again. Any emotional or psychological difficulties you had weren't really seen as a problem and I think maybe it was a way that was why I came out with the attitude that I did... came out fighting almost and thinking I want to live! it was a matter of me wanting to live rather than think that I had sat at home all these years watching daytime telly or gone to a day centre and done some mundane activities that would have brought me to a really low point I'm sure of that. That's why when I had to finish work that I was in such turmoil and got so down because I was really anxious about the impact it would have on me psychologically and it was also accepting a decline in my health that wasn't going to be reversible. So that was when someone suggested to my mum that I might benefit from counselling, to talk to someone about how I was feeling as I just become so anxious and couldn't sleep yet found I couldn't talk to anyone around me as I didn't think they would understand the way I was feeling.

As I said when I was given the diagnosis of MS I took it quite badly and went into myself and felt quite depressed and that has repeated itself when there have been quite big changes in my condition so I think in some ways there has been a pattern sometimes though I don't know whether I'd call it an internal depression or whether it's more feeling very sad and then I get quite irritable. I think MS is a frustrating condition and I certainly have my moments when I think why or for what have I done to deserve this but no and it doesn't get you anywhere or achieve anything & you just have to make the most of what you have got. Potential being ill I was always quite a positive person & so I still try to keep that going... try to do things that are good for me mentally. I have been indoors for a while with no stimulation or company really gets me down over a period of time so that's why I find it is important to get out of the house and just see other people. In some ways even if it's only a small thing I think it's why ever recent months I've been more down as there have been a lot of changes and now I'm totally reliant on someone else just to even get out of the front door...
A DISCUSSION OF THE LINKS BETWEEN THEORETICAL WORK ON GENDER, DISABILITY AND MENTAL HEALTH AS APPLIED TO THE EXPERIENCES OF THE STUDY PARTICIPANTS

INTRODUCTION

Drawing on my literature review, I will highlight the key theoretical points made by Jenny Morris and Carol Thomas who have theorised on gender and disability, Eileen McLeod in relation to feminist counselling and therapy, Jane Ussher as regards gender and mental health and Donna Reeve, relating to anti-discriminatory counselling and disabled people. I will then give consideration to the intersections between them and finally give consideration to how this helps to theorise the experiences of women in my research study.

THE GENDERED CHARACTER OF DISABILITY

Whilst disabled women have written on disability since the formative years of the Disabled People’s Movement, writings about the relationship between gender and disability are, within Disability Studies, relatively new (Barnes, Mercer & Shakespeare 2003). Building on the work of Campling (1981) and Lonsdale (1990), over the past two decades Morris (1989,1991,1998) has worked to show that forms and impacts of disablism are invariably refracted in some way through the prism of gender locations and that being disabled is a gendered experience.
In order to fully understand the experience of disability it is necessary to consider the interaction between gender and disability as social constructs. Gender is defined by Morris as concerning what it is to be male or female in a particular social context whilst disability concerns the way that a society reacts to impairment. Whilst the concept of gender is central to understanding the different social, economic and political experiences of women and men, the concept of disability explains the social, economic and political experiences associated with impairment (Morris 1996).

As a renowned writer on the gendered nature of disability and the life experiences of disabled women, Morris (1991, 1996, 1998) argued that personal experience has been missing from the political agenda of the Disabled People’s Movement (DPM). Morris and other disabled women (French 1994, Crow 1996) called for a renewed social model of disability which took account of personal experience and so allowed for integration of impairment into approaches to the lived experience of disability. Exclusion of experiences of the body within disability studies were seen by Morris as being tantamount to a patriarchal rejection of personal experience, and failure to acknowledge its importance for understanding physical and emotional well being. Calls for a renewed social model attracted criticism from traditional social modellists such as Oliver (1990) and Finkelstein (1996) who argued that a focus on the experiences of impairment risked diverting attention from oppressive social barriers and represented a backward step.

In response, disabled feminists argued that adoption of an anti-experiential position risked ignoring the social and political gains that had been made by the women’s movement which had placed personal experience at the very heart of its theoretical concerns and political actions (Morris 1991, Crow 1996). Morris also
highlighted how the socio-structural barriers which had been prioritised by the DPM tended to be those of greater significance to men with physical impairments. In contrast, barriers that were of particular relevance to women with impairments and associated with gendered role responsibilities in the domestic family domains were, overall, ignored (Morris 1996).

According to Morris, the way in which gender is viewed as a social construct influences both women’s and men’s experiences and can have an impact on whether or how impairment related needs are responded to by health and social care professionals. Further, she argues that the recognition of impairment in men and women can often itself be influenced by gender. For example, Morris illustrated how rehabilitation services can often be influenced by gender: whilst a focus on men’s role as paid workers means that rehabilitation for men predominantly focuses on building strength and fitness, women’s employment needs are typically given much less attention. In addition, just as gender can influence the experience of impairment and disability, Morris claims that impairment and disability can influence the experience of being a woman (or man). In terms of gaining access to services, difficulties that disabled women may experience in getting help with activities that are central to their roles as mothers or carers, (e.g. help with childcare) is highlighted (Morris 1996).

Feminism and Disabled Women

Whilst feminism has fought to challenge society’s rigid gender roles, it has been seen to embrace (or at best not challenge) the personal tragedy representation of women with physical impairments as incapable of performing ‘normal’ female roles: Morris has been instrumental in criticising non-disabled feminists for their failure to address disability issues (Morris 1998). Despite their
disappointment with mainstream feminists, Thomas (1999) highlighted how Morris and other disabled feminists (Begum 1990, Keith 1994, Crow 1996) have got on with the task of applying feminist ideas in analysing disability.

Whilst ‘bringing in the personal’ has been a hallmark of feminism generally, Thomas highlights its particular importance in giving a voice to women who had previously been unheard and in so doing gave rise to new ways of understanding what knowledge is and how it is produced. This, according to Thomas, has repercussions for the development of disability theory through serving as a reminder that all knowledge is situated and that knowledge is a social product bearing the marks of time, place and social positioning. Therefore, Thomas believes that Disability Studies could learn a great deal of value from feminist insights on questions of epistemology (Thomas 1999).

In writing about their life experiences, Morris highlighted a need for disabled women to take control of representation of the personal experience of disability including the negative parts; she believed that in an attempt to challenge the personal tragedy models of disability there had been a tendency to deny the personal experience of disability. Whilst calling upon disabled women to assert their right to be integrated within communities Morris stated her belief in the importance of women also being explicit about the ways in which they are not like the non-disabled world. Morris encouraged disabled women to take pride in their own abnormalities and differences and ‘celebrate their difference’ (Morris 1991). More recently, Thomas (1999) has called for a further extension of the analysis of ‘difference’ claiming that, by Morris speaking for disabled women, differences that do exist between disabled women may themselves become obscured. Barnes & Mercer (2003) also highlighted how a ‘celebration of difference’ may be
problematic for those women whose impairments are debilitating, painful or associated with premature death and that such individuals may not feel easily able to celebrate and take pride in their difference.

Drawing on the accounts of women in her study who shared their experiences of living with a physical impairment, Thomas highlighted the significance of their narratives. Firstly, they offered a powerful illustration of the intersection between gender and disability and secondly the women’s accounts only acquired meaning when reference was made to the gender norms that made up their social worlds (Thomas 1999). In considering how the intersection of gender and disability should be theorised Thomas referred to Fine & Asch’s (1988) work which highlighted the differences both between the lives of disabled and non-disabled women and disabled women and men and illustrated how the lives of disabled women were overwhelmingly at odds with gender norms. Whilst not rejecting the validity of Fine & Asch’s findings, Thomas’s study placed more emphasis on the ‘sameness’ or ‘shared’ features of non-disabled and disabled women’s lives: whilst trying to illustrate the differences that disability and impairment bring into women’s lives, women’s stories brought attention to the ‘ordinariness’ of disabled women’s lives and therefore endeavoured to illustrate difference in the context of sameness so that disabled women are not ‘othered’ (Thomas 1999). Writers who had previously attempted to theorise the intersection of gender and disability have, according to Thomas, taken a ‘double handicap’ or ‘double oppression’ approach, with women viewed as doubly disadvantaged in a layered sense by the impact of disablism and sexism.

Morris explicitly rejected what she saw as an over-simplified ‘double whammy’ approach for the way in which it served to individualise disability and shifted
attention away from non-disabled people and social institutions as being the problem and onto disabled women as passive victims of oppression. Morris argues that it is only through full recognition being given to the experience of gender that experiences of both disabled women (and men) will be clearly represented and explained (Morris 1998).

Materialism, Gender and Disability

The theorisation of the intersection of disability and gender from a materialist perspective is viewed by Thomas as a largely unchartered territory and that a theoretical challenge requires the analysis of the materialist roots of disability to a feminist critique (Thomas 2007). Whilst non-disabled feminists of a materialist persuasion have largely ignored disability and the lives of disabled women, work which has considered the material and cultural locations of disabled women in contemporary industrial society has drawn attention to disabled women being more disadvantaged than disabled men or non-disabled women: attention is drawn to their marginalized social positions in work, in relationships, education and other ranges of cultural domains.

Whilst historically women’s lives in general were, and continue to be, bound up with the performance of household labour and child care, recent decades have seen significant changes in women’s social position with large scale entry of women into paid work and further and higher education being witnessed. However, Thomas claims that little is known of how disabled women have fared in these gender transformations, thus creating space for the opening of a renewed research agenda with a need to theorise the current social position of women with physical impairments in connection with both production and reproduction whilst
also giving attention to the cultural and ideological dimensions of their oppression (Thomas 2007).

For many social analysts today, Thomas claims that the historical materialist perspectives have been relegated to dustbins of history with post-modernists and post-structuralists regarding the grand narratives of the modernist epoch in western culture as no longer relevant in today’s society. Whilst Foucault’s work on post-structuralism has been viewed by some as providing a welcome relief from what were perceived to be the narrow constraints of a dominant materialist social model, it is the overwhelming emphasis on culture together with the freeing of cultural processes from any kind of material foundation that Thomas finds problematic (Thomas 1999). However, post-modernist and post-structuralist approaches have, she believes, assisted in bringing attention to the existence and importance of powerful discourses such as medicine, welfare agencies or education which undisputedly play a key role in shaping disabled women’s (and men’s) life experiences.

Thomas’s discussion of both materialist and post-modernist perspectives and their applications in Disability Studies therefore arguably highlights more difficulties than similarities: whilst materialists have sought to explain the material foundations of disability in relations of production and have highlighted the socio-structural barriers which exclude people with impairments, they have tended to downplay the role of cultural practices in disablism and matters of personal experience and gender differences. In contrast, post-modernists have sought to describe the social construction of (gendered) categories such as ‘disabled’ and ‘impaired’ and have analysed the cultural processes of a constitutive ‘othering’. They have however, largely ignored the real materiality of bodies and the reality that in today’s society
life remains a struggle for existence for a great number of disabled women (and men) alike.

Thomas considers whether Disability Studies should seek a synthesis of these (and other) theoretical approaches so that all features—socio-structural, experiential and cultural are addressed but does not consider this an option given the incompatibility of their philosophical, epistemological and ontological foundations. Furthermore, she believes that the accommodation of a range of theoretical perspectives and purposive and intellectual engagements between those adopting different approaches can only serve to enrich Disability Studies (Thomas 1999).

A Social-Relational Definition of Disability

Whilst the social model of disability had defined disability as a form of social oppression, since the late eighties there have been varying interpretations of this definition which has led to heated debates centring on whether disability has anything to do with impairment. Thomas’s introduction of a social relational definition of disability in Female Forms (1999) was partly an attempt to clarify the muddle between disability and impairment through its clear identification of both the structural and psycho-emotional dimensions of social oppression: this provides a starting point for endeavouring to show the importance of the psycho-emotional dimension of disability within the lived experiences of women (and men) with physical impairments. Whilst disability studies has become well rehearsed over recent years in theorising structural disabling which affects what women (and men) with physical impairments can do, disabling factors which affect people at the psycho-emotional level have overwhelmingly been relegated to the domain of personal troubles. Whilst studies have begun to acknowledge the personal
impacts of internalised oppression and dealing with the prejudicial reactions of others, it is an area that in contrast remains largely under-theorised (Thomas 1999). The psycho-emotional dimension of disablism has also to date failed to attract due attention from researchers and academics in the field (Reeve 2008) and my study has been an attempt to make a small contribution to filling in that gap.

WOMEN'S EXPERIENCES OF FEMINIST THERAPY AND COUNSELLING

McLeod outlines how the cornerstone of feminist therapy and counselling has been to locate the origins of widespread emotional suffering amongst women in the gendered nature of social relations which construct, reproduce and reinforce women's subordination. Developing out of the critique of the treatment of women in a sexist society, writers in feminist therapy have tried to map out to the furthest reaches of women's psyche how subordination through gender is at the fulcrum of women's emotional development.

Despite its egalitarian intent, critics have highlighted how inherent shortcomings in feminist therapy mean that is unlikely to resolve the inequalities implicated in women's distress. Whilst Ussher was critical of what she perceived to be the hierarchical nature of feminist therapy, McLeod highlighted its failure to take account of other sources of social inequality that women may be experiencing. Whilst her study concluded that the significance of other sources of oppression such as race, disability or sexuality was registered within feminist therapy, she argues that they were neither seen as a main focus of the therapeutic process nor treated as being of particular importance (McLeod 1994).
Benefits and limits of feminist therapy and counselling

Despite criticisms that have been levelled at feminist therapy and counselling, McLeod’s study (1994) illustrated a range of ways in which women believed they had benefited from receiving feminist therapy/counselling. For example, women spoke of valuing therapy in which they felt listened to and in which their emotional needs were seen as being important. In addition women spoke of valuing longer term involvement: each of these factors were identified by women within my study as being central to a strong and positive counselling relationship.

McLeod discusses her belief in the need for women therapists to have direct experience of different aspects of inequality in order to be able to respond appropriately to women’s needs, claiming that without this shared experience aspects of women’s suffering could be neglected through a lack of awareness and understanding. The issue of counsellors and their clients sharing direct experience of inequality has been widely debated: for example Burstow (1992) argued that it was possible for counsellors to respond in a useful way through awareness and sensitivity to whatever the conditions might be even if they lacked first hand experience. Conversely, evidence in writings from lesbian women (e.g. Perkins 1991) and black women (e.g. Shah 1989) stated that it was only through women organising on shared experiences of social divisions other than gender that its significance for shaping the emotional well being of the women themselves starts to emerge. The significance or otherwise of shared experiences within a counselling relationship was discussed within my study and will be discussed in the final section.

Whilst acknowledging the positive outcomes women could achieve from feminist therapy, McLeod stated that greater benefits could be achieved by
tackling the wider social conditions implicated in women’s emotional well-being and called for action beyond feminist therapy to tackle this. McLeod highlighted how, just as feminist disabled women have called for gendered assumptions about disability to be challenged, that there was a need to undertake work which is explicitly concerned with women’s mental health and allied to action which uncovers and dissolves social inequality in all its forms running throughout society. Findings from my study illustrated the women’s unanimous view that whilst counselling played a central role in addressing their mental distress there were wider social issues that needed addressing.

**GENDER AND MENTAL HEALTH**

In discussing gender and mental health Ussher (1991) states that in madness acting as a signifier, it clearly positions women as the ‘other’ as ill, outside and second rate, and that in order to understand women’s madness there is a need to deconstruct the concept of madness itself. Her analysis highlights how from a feminist position women are positioned as ill as a result of individual oppression and that madness is not some individual pathology within the woman. Attention is also given by Ussher to the significance of the Victorian era in marking a change in the discursive regime which confined and controlled women, and that during this era madness became firmly conceptualised as mental illness under the scrutiny and control of medical establishments where it remains today (Ussher 1991).

The later decades of the twentieth century saw an increasing range of drugs becoming available as emphasis moved from long term institutions to care in the community with mental health support provided by a range of mental health professionals. During the latter decades of the twentieth century there was a growing recognition that medical and drug treatment was not the only option and
later decades of the twentieth century saw an expansion of non-medical professional roles and therapy services.

Ussher also argues that therapy is often not gender neutral but based on patriarchal principles with helping professions seen as agents who coerced women into accepting situations they neither wanted nor were happy with. By teaching women to see their misery as illness and to direct their attention for a cure at themselves means that women fail to look at factors outside themselves and using madness as an explanation for women’s unhappiness began to be challenged in the 1970s (Ussher 1991).

In her refute of the concept of women’s madness as illness Ussher asserts the need to move away from the long held pathological explanations for women’s madness. The medical psychiatric approach which has treated women as mad has according to feminists been a result of women’s position in society, their subjective experiences of their gendered identity and not the result of a biological vulnerability. Ussher (1991) highlights how the explanations for women’s madness the theories, remedies and critiques combined make a complex jigsaw: it is only when all the pieces are assembled that the picture becomes clearer. Both Ussher and McLeod believe that madness can only be fully understood by looking beyond the individual and to the whole discourse which regulates woman. However, Ussher (1991) and McLeod (1994) highlight the need to look beyond the category of woman to the reality of distress which is a part of many women’s experience.

ANTI-DISCRIMINATORY COUNSELLING

Whilst the British Association of Counselling & Psychotherapy (BACP) has in recent years claimed to see disability issues as an important topic, the starting
point for understanding disability within counselling remains predominantly as a condition of the individual caused by their impairment (Swain, Griffiths & French 2006). Counselling theories that have been based on non-disabled people’s attitudes and prejudices have led to a proliferation of loss models and counselling approaches which fail to acknowledge the effects of living with discrimination and oppression. Improvements across counselling training, practice and theory are all highlighted by Reeve as being necessary if real anti-discriminatory counselling is to be provided (Reeve 2000).

Reeve drew attention to the lack of teaching around disability on counselling training courses which has resulted in stereotypes about disability within society not being challenged or exposed within counselling courses in the same way that other areas of social inequality are. In striving for anti-discriminatory counselling for people with impairments, Reeve highlights the necessity for Disability Equality training to become a mandatory part of all counselling training so that counsellors can comprehensively learn about the social model of disability. DET would also enable counsellors to understand disability as a social construct rather than being caused by a person's impairment (Reeve 2004), a view which was mirrored in my study’s findings.

Using a social model approach within counselling must have as its first principle, Reeve argues, counselling services which meet fully the access needs of people with physical impairments. Further, anti-discriminatory counselling, using a social model approach, is about the inclusion of disabled counsellors as well as disabled clients.

To achieve anti-discriminatory practice, counselling training must also include a social model approach to disability that focuses both on the structural barriers
dimension and the psycho-emotional dimensions of disability and considers their potential to impact on emotional well being. Additionally, by counsellors moving away from working within a ‘personal tragedy’ model in which impairment is interpreted as having only negative impacts on an individual’s life, then this would benefit individuals who were receiving counselling (Reeve 2004).

Whilst a social model approach to counselling would be fundamental to achieving the goal of anti-discriminatory counselling, Reeve does not consider this to be sufficient: two possible solutions are proposed both of which would recognise the potentially oppressive nature of counselling whilst also seeking to redress the power imbalance in a counsellor/client relationship.

Firstly, Reeve advocates a disability counselling approach which recognises oppression within the counselling room and incorporates the social model of disability as its cornerstone. With the social model at its centre, disability counselling would be profoundly social and political as well as personal and individual and would enable disablist attitudes and prejudices to be challenged in the same way that trans-cultural counselling challenges institutionalised racism within the counsellor.

Secondly, Reeve considers the use of counselling approaches which, over the past decade, have begun to adopt a social and political rather than psychological stance. Through aspiring to achieve comprehensive anti-oppressive practice that offers counselling which is empowering for all, irrespective of race, gender or sexuality Reeve (2004) believes that such approaches have much to offer individuals with physical impairments who enter into counselling.
Reeve however reflects on whether disability counselling approaches have the potential to be divisive and she acknowledges that counselling which emphasises the disabled dimension of an individual could in itself be seen as discriminatory. Indeed, findings from my study clearly illustrated how women wanted counsellors (and other mental health professionals) to see their impairment as just one facet of their identity: whilst many women voiced a preference to work with a counsellor with an impairment, particularly where the issues to be addressed were impairment related, the majority of women wanted access to the same range of services as able-bodied people as opposed to 'special'counselling services.

A CONSIDERATION OF THE EMERGENT INTERSECTIONS

Having outlined the positions of key authors I now indicate the learning from this work as a whole which provides a base from which to account for the conceptual implications of my findings:

- **Women’s voice within gender focused analyses – the contribution of non-disabled and disabled women:** As the women’s movement grew through later decades of the twentieth century women increasingly began to exert their expertise in different areas of their lives and the emergence of women’s accounts served to illustrate how they were the experts in their own health and bodies. The work of non-disabled feminist scholars came to intersect with that of feminist scholars towards the end of the 20th and into the early 21st century with Morris and other disabled feminists calling for disabled women to assert that they were the experts on their lives and that it was not for others (non-disabled people) to make judgements about the value of their lives.

- **Bringing together the structural and the emotional:** The feminist movement strongly asserted that it was factors external to the individual that created the
potential to impact on women's well being both on a physical and emotional level. Within their work both Morris and Thomas called for a greater understanding and awareness of the potential for structural barriers to impact both on physical and/or mental well being thus mirroring the claims made by feminist scholars about the ways in which structural factors in society shaped women's individual health and well being.

- **Psycho-emotional implications of oppression**: Both Thomas and Reeve have in recent work called for greater recognition of the psycho-emotional dimension of disability within the lived experiences of disabled women (and men). Factors such as attitudes in society towards disability and impairment and difficulties in accessing the environment, whilst having the potential to create individual distress, are issues that need to be addressed on a wider scale.

- **Women's bodies and the medicalisation of both distress and disability**: Ussher highlights feminists rejection of the biological reductionist model which located women's madness within their genes; treatment which focused on the body was seen as central to curing women's madness. Women's madness was in stark contrast seen by feminists to be a result of women's oppression in society. Similar themes are highlighted in Morris's work and that of other disabled women who described how medical professionals, typically doctors saw their impairment as being the problem; surgical treatment was advocated for the potential opportunity it provided to offer a cure and to make the individual normal. Thus, medically based solutions were proposed which focused on the individual as opposed to looking at wider changes in society which could be made to eradicate some of the difficulties that women (and men) with physical impairments faced in their daily lives i.e. barriers to access.
• Gender, Distress and Therapeutic Interventions – acknowledging the structural and personal intersection: Feminist scholarship claimed that forms of intervention which were meant to assist the individual actually compounded the problem because they were founded on ways of understanding women that were oppressive. An aim of feminist therapy was to offer women interventions which addressed personal unhappiness but in a way that was shaped by the knowledge of women’s collective position within social structures. Reeve’s work on counselling demonstrated how established counselling approaches based on loss models were oppressive because they saw disability as a problem located within the individual, as opposed to being a problem of society. Reeve therefore proposes counselling approaches which recognise disability as a social construct rather than a problem of the disabled individual.

• Therapy and counselling in the context of multiples sources of inequality and oppression: In her analysis of feminist therapy and counselling, McLeod’s work intersects with that of Morris and Thomas who have highlighted the gendered nature of disability and how the experience of one form of oppression (being disabled) is interwoven with another form of oppression (being a woman). McLeod was critical of feminist therapy and counselling’s failure to acknowledge the significance of other sources of oppression that may be central to women’s lives e.g. concerning race, sexuality or disability. Whilst a key aim of feminist therapy and counselling was to address women’s pain at an individual level, McLeod highlighted the need for wider social inequalities not only to be acknowledged within therapy and counselling, but to be tackled outside of it, believing that addressing women’s distress at an individual level was only a partial solution. Reeve, in her work highlights the need for counsellors working with individuals with physical impairments to acknowledge the significance of
different forms of oppression within the lived experience of the disabled woman (or
man). Also, like McLeod, Reeve stated that counselling approaches which focused
solely on the individual did not offer a whole solution to the difficulties they were
experiencing and that counsellors needed to consider a wide range of factors that had
the potential to impact on health and well being.

THE RELEVANCE OF THE INTERSECTIONS TO THEORISING THE EXPERIENCES
OF WOMEN IN THE STUDY

- **Women's Voices within Gender Focused Analysis:** For two decades Morris
  has argued that disabled women were the experts in their own lives and called for
disabled women to assert their own values on their lives: the experiences of the women
in my study illustrated how women considered themselves to be the person best placed
to talk about their lived experiences of disability and impairment.

A key finding of my study was women's wish for the health/mental health professionals
they had contact with to listen to them and to respect their views. Whilst some women
considered their impairment to have been a contributory factor to their experience/s of
mental distress, it was seldom the sole reason and women in the study considered it
vital for mental health professionals to consider a range of factors that may have the
potential to impact on mental well being. The research has, through its methodology,
enabled both the shared and individual experiences of impairment and disability to be
voiced, with a focus on women's experience: the approach, however, has relevance for
the development of a gender aware research stream in disability studies which attends
to both structural and personal accounts of disability and distress.
• **Bringing together the Structural and Emotional:** Just as the feminist movement highlighted the significance of external factors to impact on health and well being, my study has shown how women wanted non-disabled people, public and professionals alike to recognise and appreciate the significance of factors outside of the individual to impact on their lives. The study showed how for older women in the study barriers to access had impacted significantly on different areas of their lives and their life opportunities: poor access had also led to them feeling excluded from society (and had an impact on emotional well being). Attitudes towards impairment and prejudices towards disability were also described as having impacted on mental well being.

In contrast, the experiences of younger women in the study (approx aged 40 or below) highlighted how by wider social issues having been tackled (i.e. changes in attitudes towards impairment and improved environmental access) this had created a sense of greater inclusion and impacted positively on mental well being. However, the study showed that there was still progress to be made in relation to improved environmental access, better access to transport and so on: structural features of disability are still an important area of concern impacting on the inclusion of disabled people, mental well being, and access to services.

• **Psycho-emotional Implications of Oppression:** My study highlighted that whilst some women saw their impairment (directly or indirectly) as being a contributory factor to their experiences of mental distress, it was often factors external to themselves that played a significant role in their mental distress: for example, the attitudes of others towards impairment, structural barriers to the environment. Women’s experiences highlighted their belief of the need within counselling for a focus on the psycho-emotional dimension of their lived experiences of disability and for counsellors to recognise that their mental distress was not just about living with an impairment:
distress was linked to the attitudes of others towards you and how people treated you. However, some women described how pain and fatigue that were a consequence of their impairment could lead to mental distress, demonstrating the importance of including the emotional impact of bodily experience in an understanding of distress.

- **Women’s Bodies and the Medicalisation of Both Distress and Disability.** Women in the study identified the negative and positive impacts of the medicalisation of both their distress and their impairment/disability experience. The study illustrated how older women in the study who were born with significant mobility impairments were viewed by medical professionals as having lives of little worth. Therefore, this experience of medicalisation was a potential hazard to women’s wellbeing. Some women underwent, over several years, surgery to “make them normal.” In more recent years women who had undergone impairment related surgery spoke of how this had been with the aim of improving quality of life rather than reflecting a “normalising” approach, as attitudes in society were considered to have now changed with people being more accepting of difference. Change over time is crucial to consider and has been made possible through the inclusion of women of different ages in the study; continuity in the prevalence of a medicalised approach can also be identified.

- **Gender, Distress and Therapeutic Interventions: acknowledging the structural and personal intersection:** The study showed that for the majority of women who had received counselling the experience had been a negative one. Negative experiences were attributed to counsellors working within approaches that saw their impairment as a “tragedy” and as a “loss” that needed to be adjusted to. Also, the majority of women’s experiences highlighted a belief that their counsellors had little understanding and/or awareness of disability and impairment and saw the woman’s disability as located within the individual: in failing to give consideration to wider social
issues the majority of women found the counselling process to be an unhelpful one. The study showed how, in contrast positive experiences were reported in two instances where the counsellors worked within a social model approach and were prepared to listen to the woman’s views about their lived experiences of physical impairment and mental distress.

Experience of inequality or oppression outside the arena of intervention was understood as having implications within it. Some women expressed the view that given a choice their wish would have been to work with a counsellor with an impairment, this preference being based on a belief that a counsellor with a physical impairment themselves would have a better understanding than a counsellor who was able-bodied or had no direct experience of impairment. Other women did not consider that shared experience was of major significance to them and that working with someone who had understanding/awareness would be more beneficial. The study also highlighted how the large majority of women expressed a preference to work with a woman, again based on a belief that women would have a greater understanding of the difficulties they were experiencing (in particular if their distress was gender related)

- Therapy and Counselling in the context of multiple sources of inequality and oppression: the experience of participants illustrated the women’s belief that undergoing counselling was only a part of the solution to their experiences of mental distress: issues at a societal level such as attitudes towards impairment and negative stereotyping of/prejudices towards disability all needed to be tackled. This study therefore speaks to debates within counselling and psychotherapy arenas where there is recognition amongst more psychosocial or critical workers that there is a need to move the focus away from the individual if intervention is not to replicate social oppression.
In undertaking this study my work has engaged with the significant issues in debates concerning the personal experience of disability and sources of mental distress. By focusing solely on women I have aimed to contribute towards work which highlights the gendered nature of mental distress. The methodology employed, it is hoped provides a model for engaging with lived experience whereby women can voice their experience of disability, impairment and mental distress. Further, given the changing social context in which disability is experienced, the importance of exploring distress in the context of individual life stories and changing social practices has been demonstrated.

**Additional sources cited in the Addendum**


**Additional Bibliography**

