

*Women, Disability  
and Mental Distress*

JULIA L.T. SMITH



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ASHGATE



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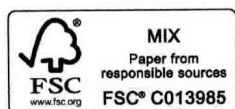
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# Introduction

Through the latter decades of the twentieth century within the UK, increasing amounts of attention began to be paid to meeting the individual support needs of both mental health service users and people with a physical impairment. Evidence of this can be found both in the expanding body of literature that had begun to examine mental health and physical impairment from a range of perspectives and the increased range of service provision offered by a growing number of health and social care providers for individuals within each group. In contrast, the mental and psychological health needs of individuals living with a physical impairment *and* who experience diagnosed mental distress have largely been overlooked by health and social care service providers, practitioners and organisations for whom the main focus or area of interest is either mental health or physical impairment. The lack of attention which historically has been paid, both in theory and in practice, to meeting the mental health needs of people with physical impairments who experience mental distress has resulted in the absence of a comprehensive knowledge base of how best to support such individuals which in turn has led to their mental health needs remaining neglected, and subsequently left unmet.

Likewise, the subject area of physical impairment and mental health had until the latter decades of the twentieth century received little attention within the academic, policy and research literatures but where it was examined, a medical approach was overwhelmingly adopted by the literature with physical impairments and mental health issues viewed as 'illnesses' or 'conditions' and with minimal focus on the individual *per se*. Predominantly, the literature has been underpinned by two key assumptions: firstly, that a physical impairment *per se* will be a cause of psychological distress and that affected individuals will need to adjust to their 'loss' in stages before they can become 'psychologically whole' again (Turner and Noh 1988); and secondly, that the solutions to an individual's mental distress are to be found within the individual and the text will examine both assumptions. In addition it will discuss literature which, in the latter decades of the twentieth century, in contrast to an entrenched medical perspective, began to examine the topic area of physical impairment and mental health from a *social* perspective. Within this literature attention began to be given to the potential for social and cultural barriers such as societal attitudes towards impairment or barriers to service provision to impact on the mental well-being of people living with physical impairments. In shifting the focus from an individual's *impairment* onto *disability*, the social model of disability (and its history and relevance within the context of women's personal experiences which will be discussed) uses the term to refer to disabling social, environmental and attitudinal barriers rather than a lack of functional ability.



The origins of my interest within the subject area of physical impairment and mental health are long held and primarily two-fold. Firstly, as a young teenager diagnosed with a spinal lesion that rapidly resulted in extensive functional paralysis, significant life changes and adjustments at both a physical and psychological level had to be made. A four year hospital admission following the onset of paralysis was punctuated by periods of both 'feeling low' and prolonged episodes of diagnosed clinical depression, but overwhelmingly any mental health or psychological needs were sidelined by medical professionals for whom the priority was the physical body and a desire to make it as 'well' and as 'normal' as possible. Thus, it was not until reaching adulthood that I was finally able to access mental health provisions which very belatedly enabled me to share thoughts, feelings and emotions about my grief and changed life circumstances.

Proceeding some years later to qualify as a social worker, my dual experiences of living with a physical impairment and experiencing mental distress proved to be invaluable in my work within an adult's physical disabilities team, working predominantly with women service users who either self-presented to seek mental health (and other) support or, having been referred by other health or social care agencies, were assessed as having mental health/psychological needs. A persistent lack of appropriate mental health provision for this group of women, combined with clear evidence of a stark delineation between physical disability services and mental health services across both the statutory and non-statutory sector was experienced both by myself, as a social care professional, and service users as being immensely frustrating and disappointing, and subsequently for large numbers of women resulted in their mental health needs being left unmet.

In addition to my involvement at both a personal and professional level with physical disability and mental health service providers over two decades, the origin of this text is founded upon a recent research study (Smith 2010) which examined the experiences of a group of women with physical impairments who had experienced mental distress. As users of mental health services, the research sought to determine from the women's personal viewpoints, whether mental health and allied professionals and the services and organisations in which they worked, had been effective in meeting their mental health needs. Additionally, the study endeavoured to identify whether women with congenital impairments and women with acquired impairments differed in their personal analysis of the relationship between physical impairment and mental distress whilst also examining whether they perceived social disability, for example, the attitudes of a majority able-bodied society towards physical impairment, to be a source of mental distress. Further, the study examined whether women with a range of physical impairments who had experienced mental distress, identified a shared set of barriers to accessing mental health service provision and finally, sought to determine whether mental health services in the years ahead could meet their mental health needs more appropriately, and if so, how?

In undertaking the study, a unique approach was utilised through incorporating both the experiences of physical impairment and mental distress of 12 women



aged between 18 and 64, each living with a diagnosed permanent physical impairment. Additionally, each woman had previously been diagnosed on one or more occasions with a mental health condition for which treatment of some form had been received (and which for two women was ongoing). Women who had acquired a physical impairment as a consequence of mental distress, for example, paralysis resulting from a suicide attempt or, women with a history of mental distress prior to acquiring their impairment were not included within the selection criteria. All women were of British white ethnic origin, with six women born with their impairments and six living with acquired impairments. In seeking to recruit a sample group which reflected a spectrum of physical impairments and mental health conditions, neither the nature of the impairment or mental health condition was specified and subsequently included women living with spinal cord injuries, spina bifida and a spinal tumour whilst experiences of mental distress included acute clinical depression, self-harm, stress and anxiety and an eating disorder. Women who were mothers or had other care responsibilities and women who were single or had no dependents were all represented within the group.

In conducting the fieldwork stage of the study a mixed methods approach was used: face-to-face semi-structured interviews were conducted over a four-month period (with a minimum of two interviews per person), with a focus group having been held one month after completion of all interviews, its purpose being to explore issues that been generated through the interviews at a more strategic level (Hollis et al. 2002). In wishing to explore any regional variations in mental health provision, endeavours were made to recruit participants from across the UK whilst simultaneously balancing the time constraints for conducting fieldwork and practical travelling considerations for myself as a wheelchair-user researcher. Consequently, all participants lived within a 100-mile radius of Birmingham where the study was based.

In authoring a text which I consider to be both needed and long overdue, the book is seeking to be innovative in providing an in-depth discussion of a to date largely neglected area of personal experiences and in doing so it will hopefully additionally ignite discussion and meaningful debate about the subject area of women, disability and mental distress. In focusing on the subject area of physical impairment and mental distress, it is hoped the text will make an original and welcomed contribution to knowledge in relation to both policy and practice whilst simultaneously aiming to be of benefit and interest to a wide spectrum of health and social care professionals working within the fields of physical disability and/or mental health. Additionally, I hope it will become a valued text for both academics within the specialisms of counselling, social work, psychology, medicine, nursing, disability studies or mental health and to undergraduate and postgraduate students across these realms. Furthermore, placing the emphasis on a service user perspective will, I hope, position the text as an informative and helpful resource for women with physical impairments who seek support for mental distress. Whilst the text focuses predominantly on the personal experiences of disabled women, there exist many overlaps between women's experiences of working with mental



health and allied professionals and the experiences of disabled men, and therefore it is hoped that the book will have worth for men with physical impairments also. Finally, whilst based on the findings of a UK study, I believe that much of the book's content will have relevance for other Western countries.

Chapter 1 will begin with an examination of a historical and widely held assumption within medical and psychology literatures that have examined the topic area of physical impairment and mental health, that individuals living with a physical impairment will inevitably experience mental distress (on one or more occasions) by virtue of living with an impairment. By providing evidence from the research undertaken, the chapter will highlight the problematic nature of the assumption of a causal link between living with a physical impairment and experiencing mental distress (overwhelmingly assumed to be depression). Secondly, the study's findings relating to the perceived potential of factors such as society's attitudes towards physical impairment, or the representation of disability within the media to impact on women's mental well-being and self-image will be discussed before finally examining the diverse ways in which women experienced their relationships with significant people in their lives within the context of their personal experiences of mental distress.

Within the limited literature to date which in recent decades has examined the topic area of accessing and using mental health services for disabled people, consistently it has highlighted the barriers that individuals had encountered and that the overall process of gaining access had been fraught with difficulties. Furthermore, where mental health services had been accessed, individuals had considered any provision to have been inappropriate for their needs (McKenzie 1992, Begum 1999, Morris 2004). Based on the study findings, Chapter 2 will therefore offer a detailed examination of women's experiences of both gaining access to and using mental health services across the statutory and non-statutory sectors. In particular, it will highlight how factors such as lengthy waiting times for initial assessments, difficult to access service information and a lack of psychological support within hospital rehabilitation units had affected women's ability to access service provision. Likewise the chapter will show how the professional's level of understanding and awareness of disability and impairment, and the length of contact time offered to an individual by a service or mental health professional, were clearly linked to women's rating of their experiences of using mental health services and their effectiveness in addressing their mental distress.

Over recent decades within the UK, the use of counselling as a form of treatment or psychological support has expanded significantly alongside the emergence of a growing body of literature which has examined the processes of counselling when working with diverse client groups or circumstances. Within the sample group, the majority of women had received counselling as part of their treatment for their mental distress but in comparison with other client groups, the body of counselling literature that focuses on working with people with physical impairments has historically been, and remains small. In Chapter 3, the counselling approaches that counsellors, psychologists and allied professionals have typically



used when working with disabled clients will be examined, whilst the key criticisms, which over recent years have been directed at counselling responses to disability which predominantly have been founded upon loss theories such as their disempowering nature and their role in reinforcing the medical model of disability, will be discussed. In responding to the criticisms levelled at established theories of loss, recent years have witnessed the emergence of alternative approaches to loss, each of which have been presented as offering a more accurate and realistic explanation of how individuals respond to physical impairment and the merits of two key alternative approaches will be outlined. The concept of loss will then be considered from the viewpoints of the study participants.

Historically, the lack of counselling approaches which are informed by the social model of disability and which recognise the potential for oppression within the counsellor–client relationship has been widely claimed to have led to the long held stereotypes and prejudices around physical disability being left unchallenged. The final part of the chapter will thus consider counselling approaches which, in recent years, based on their core principles, have been advocated for use when working with disabled clients in addition to considering the potential benefits or otherwise of a disability counselling approach.

Further evidenced by the study data was the strong preference expressed by the large majority of women to work in counselling with a same gender counsellor and, within the context of the counselling process both being viewed positively and as having beneficial outcomes, a same gender counsellor was considered to be of significant importance. Chapter 4 will therefore firstly discuss the issue of gender, highlighting from the women's perspective the considered advantages and disadvantages of counsellors being the same gender as their clients. Secondly, the recently emerged and continuing debate (initially amongst disabled academics primarily, but more recently with welcome contributions from disabled people themselves (for example, Smith 2003, Reeve 2004, Jack 2009)) as to whether people with physical impairments are best served by working with counsellors who themselves have a physical impairment (or have either lived experience or a good understanding of physical impairment), as opposed to an able-bodied counsellor with no lived experience of impairment will be discussed. However, several women drew attention to the need to consider factors and attributes beyond gender and impairment which were believed to be equally important within the context of women's experiences of the counselling process such as the counsellors personality or character traits and their ability to listen to and communicate with their client and each of these factors will be considered. Finally, whilst Chapter 1 considered the impact (or potential impact) of factors such as societal attitudes towards impairment or the representation of disability in the media to affect women's mental well-being, Chapter 4 will finally examine women's recollections of their experiences of distress and the personal circumstances relevant to those experiences.

Evidenced consistently both within the research study's findings and within the limited available literature was how any positive experiences of working with counsellors or other mental health professionals had been closely linked



to other factors such as a good working relationships between professional and client, the professional's level of understanding and awareness of disability and impairment related issues and their willingness to both listen to and value the disabled client's perspectives concerning their mental distress. Within Chapter 5 the focus will be an examination of mental health provisions in the years and decades ahead for women (and men) with physical impairments requiring mental health support, considering in detail a range of changes to the professional training courses of mental health and health and social care professionals who work, or may potentially work, with disabled clients. The importance of factors such as the inclusion of teaching both around the social model of disability and disability equality training within professional training courses, both within the context of the support provided by mental health professionals and the approaches used when working with people with physical impairments of either gender will also be discussed. Based on the study findings, the need for mental health professionals to have a greater awareness of the problematic representation of disability in the media and its potential to impact on mental well-being, alongside an awareness of the positive ways in which recent changes in disability legislation may have impacted on the mental well-being of disabled people was a widely shared view and both topics will be discussed.

In reaffirming that disabled people have historically encountered both in gaining access to and using mental health services over several decades, the final part of the chapter will discuss both the structural and organisational changes which women widely believed needed to take place in endeavouring to improve disabled people's experiences of accessing and using services and additionally to observe higher incidences of positive reported experiences of receiving appropriate mental health support which had been effective in addressing an individual's mental distress.

In bringing together the key themes and findings which emerged from the topic areas discussed within and across the individual chapters, the final chapter will consider the potential outcomes for mental health and allied professionals working within statutory and non-statutory sector organisations and services, and for the women (and men) with physical impairments with whom they work, if the changes which were identified as needing to take place, became reality. It will discuss how an increased awareness of the intersections between physical impairment and mental health could potentially result in the years ahead in significant positive and welcome changes to both service provision and service delivery and hopefully could steadily impact positively on the lives and mental well-being of women with physical impairments who experience mental distress.

Finally, before proceeding, a few words of explanation in relation to the language and terminology used within the book may help any readers who may question the use of some terminology which is used interchangeably throughout the text. Firstly, across the group there existed a broadly shared agreement of how *disability* and *impairment* were defined and therefore, for the purposes of this book, 'disability' will be defined as:



The functional limitations within the individual caused by physical, mental or sensory impairment.

Oliver 1996

Whilst the term 'impairment' will be defined as:

The functional limitation within the individual caused by physical, mental or sensory impairment.

Oliver 1996

Physical and social barriers are referred to as:

Those that prevent the full participative citizenship of disabled people that marginalise and segregate people in every aspect of social life and that deny access to and participation in organisations and that preclude equal rights.

Swain, French et al. 2004

The terms 'people/women with physical impairments' and 'disabled people/women' are used interchangeably as, whilst some women described themselves as 'a woman living with a physical impairment', others referred to themselves as 'a disabled woman'. Likewise, within the focus group, some women expressed a preference for the term 'a group of women with physical impairments', whilst others felt that, gathered together, they were 'a group of disabled women' so efforts have been made to accommodate the preferences of all research participants.







# Chapter 1

## Living with a Physical Impairment: Is Mental Distress Inevitable?

### Introduction

Within this chapter the focus will be on three related areas. Firstly, it will discuss assumptions which, within some areas of the psychology and medical bodies of literature, have long been held relating to the inevitability of women (and men) who are living with physical impairments experiencing mental distress. Predominantly founded upon an assumption of a causal link between living with a physical impairment and experiencing mental distress, the problematic nature of an assumed causal link will be discussed, providing evidence from both my research and empirical studies which within recent decades have rejected a causal link between a lived experience of physical impairment and experiencing mental distress. Secondly, the chapter will discuss findings from the research with regard to the perceived potential of factors such as societal attitudes towards physical impairment and the broad representation of disability within the media and its potential to affect the mental well-being and self-image of disabled women in the early twenty-first century. Finally, the diverse ways in which individual women experienced their relationships with significant persons in their lives within the context of their experiences of mental distress will be examined.

### Women with Physical Impairments and Mental Health

Since the latter decades of the twentieth century, the body of literature concerned with women and mental health has grown significantly and within which the diverse needs of different groups of women within society have received both increased attention and recognition (Perry 1993, Brockington 1998, Doyal 1998, Ashurst 1999, Smith and Cox 1999, Kohen 2000, Barnes, Davis et al. 2002, Gido and Dalley 2008). In contrast, any specific focus or discussion within the literature concerning the mental health needs or requirements of disabled women who experience mental distress remains small with only a small number of women having published in this area (Begum 1990, 1995, Morris 1991, Keith 1994, Marris 1996, Thomas 1999). In a study which examined the experiences of using mental health services for a group of people with physical impairments living across the UK, (two thirds of whom were women) Morris (2004) drew attention to how needs relating to physical impairment had commonly being unrecognised



within mental health services, with some services structurally inaccessible to people with significant mobility impairments due to a failure to comply with the Disability Discrimination Act by making reasonable adjustments. Additionally, poor experiences both of gaining access to, and using community mental health services were reported by individuals with privately funded counselling the sole provision that had been viewed positively (Lonsdale 1990, Morris 2004).

Where the topic area of physical impairment and mental health has, until recent decades, been examined within mental health and psychology literature, the predominant perception of disabled people was for their situation to be characterised by a medically informed personal tragedy perspective (Thomas 1999). Likewise, it was routinely asserted that an individual's disability had likely arisen through his or her circumstances, shortcomings and/or medical condition, with the physical condition viewed as 'a problem for the individual' or as a 'tragedy for which a cure was required' (Fillingham 2012). Within the studies, a clear link has been made between physical impairment and mental health and founded on a premise that a level of depression will automatically be experienced by someone living with a permanent physical impairment. Mostly, two assumptions underpin the literature:

- i) that a physical impairment per se is a cause of mental or psychological distress;
- ii) that the extent and likelihood of distress, and the solutions to it are to be found within the person.

With studies routinely asking questions such as:

- i) Is depression associated with this particular impairment?
- ii) What are the factors that make depression more likely?
- iii) Does the experience of depression influence the way that impairment is experienced?

Furthermore, much of the literature has suggested that individuals (both women and men) living with a physical impairment will need to make psychological adjustments at a number of stages if they are to fully come to terms with their impairment and to live as a 'psychologically whole being'. A discussion of stage theories and the associated concept of loss will be discussed in more depth within Chapter 3.

Studies which sought to examine a link between living with a physical impairment and experiencing mental distress overwhelmingly assumed the causal link to be found in the experience of impairment per se and the consequential functional limitations, additionally looking at the potential for specific conditions, for example Multiple Sclerosis or Spinal Cord Injury, to impact on mental health and well-being and focusing predominantly on depression as opposed to any other mental health condition (Craig et al. 1997, Kennedy 1999). In a study which



examined the incidence of depression among a group of people diagnosed with Multiple Sclerosis (two thirds of whom were women), almost half had experienced a major episode of clinical depression (Sadovnik 1996) whilst Stenager's study (1992) of 50 people living with Multiple Sclerosis discovered high rates of suicide attempts or suicidal ideations when experiencing episodes of decline in functional abilities. Other studies (for example Zarb and Oliver 1987, Craig and Hancock 1997) which identified relatively high rates of depression among physically disabled people, likewise assumed a causal link between an individual's experience of physical impairment and coping with functional limitations but with all having attracted criticism at a number of levels.

Foremost, studies undertaken were criticised for their failure to consider a range of social and economic factors which may accompany, or be associated with physical impairment, such as added financial pressures, potential relationship difficulties and/or the likelihood of temporary or permanent loss of employment for those of a working age. Any potential relevance of factors such as ethnicity, gender or economic and social roles critics claimed to have been considered within only a small number of studies and further drew attention to the lack of consideration given to the disabled person's experience from their personal perspective, which was a fundamental element of my work. An assumption that people living with a physical impairment would experience depression as a response to, or as part of an adjustment to living with their impairment, whilst other forms of mental distress or mental health conditions were seldom considered was further criticised, in addition to the lack of differentiation made when assuming a causal link between individuals born with their impairments, and those who acquired their impairment at some stage during their lives.

The assumption of a causal link has persisted in spite of conflicting evidence both about the co-existence of physical impairment and depression and that existence and degree of depression do not appear to be linked directly to the extent of physical impairment (Morris 2002), and where called into question by the research evidence, some researchers have looked to disabled people's attitudes towards their impairment for an explanation. In an examination of the attitudes of a group of disabled people (women and men) towards their impairments, Leger (2002) concluded that the psychological differences which individuals experienced were neither correlated with degree of impairment nor with whether the impairment was acquired or present from birth, whilst a lower level of acceptance of disability was seen to be significantly associated with more anxious and depressive symptoms. This view was supported by Pilgrim (2005) who claimed that people will differ in their psychological adaptation to losing, or losing the use of limbs, and that whilst some people will develop a prolonged grief reaction to their loss or their individual personality is affected, others will not react in the same way.

Research which has found little correlation between the extent of physical impairment and the level of depression experienced has additionally emphasised the social context of the experience of impairment. For example, Fuhrer's study (1993) which examined incidences of depression among a group of people living



with varying levels of functional abilities having acquired spinal cord injuries found there to be no relationship between the two and instead concluding that experiences of depression were associated more with restrictions in social role performance that stemmed from the interactive influences of the environment. Furthermore, in a study which examined the impact on daily life for a group of people living with acquired spinal cord injuries, emphasis was placed on how, in addition to individuals need to maintain their physical health and avoid secondary infections, adjustments often had to be made to family and interpersonal roles. In addition, added financial pressures and a likelihood of temporary or permanent job loss are considered to each have potential to take an emotional toll exceeding that resulting from the sheer magnitude of physical impairment itself (Krause 1997).

In responding to the criticisms levelled at studies undertaken from a medical model perspective, recent decades have witnessed the emergence of studies which in considering the mental health experiences of disabled people (women and men) have adopted a greater social perspective. Such studies, in contrast, began to draw attention to the diversity of factors which disabled people themselves identified as having impacted on (or as having long-term potential to) impact on mental well-being, for example, how the attitudes of able-bodied people towards those who are not can affect self-worth, and how efforts to adopt a positive self-image can be impeded by the devalued status that has historically been ascribed to disabled people. In contrast to the medical model of disability, the literature adopting a social model approach shifts the focus from *impairment* onto *disability*, using the term to refer to disabling social, environmental and attitudinal barriers rather than a lack of physical ability. Similarly, emerging literature began to challenge a prevalent assumption throughout much of the twentieth century that living with a permanent physical disability equated to a life of both poor quality and worth and highlighting its potential to impact on the mental well-being of disabled people (Morris 1991, Vasey 1992). Whilst such experiences have been shown to invoke feelings of anger and rejection amongst disabled people (Campling 1981, Greeley 1996), the psychological consequences of such experiences have yet to be noticeably documented within the literature with the exception of the work of a small minority (for example Thomas 1999, 2004, Reeve 2003, 2004, 2008, 2012) who have called for an extension of the social model of disability which recognises not solely the effect of structural barriers on what disabled people can *do*, but also recognises psycho-emotional disablism and the ways in which this can impact on who disabled people can *'be'*. Calls for a renewed social model of disability have also been made over the past two decades by those who consider the original model to be outdated (for example Finkelstein 2001, Shakespeare and Watson 2001) or who wish for a model which includes the personal experience of impairment (Crow 1996) and the arguments for and against which have been, and continue to be, widely debated within disability studies circles and literature. Therefore, whilst my research (Smith 2010) highlighted as one of its key findings the need for teaching around the social model of disability to be widely included within the curriculums of mental health professionals training courses (to be