

**People with physical impairments and mental
health support needs**

People with physical impairments and mental health support needs

A critical review of the literature

Jenny Morris



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Introduction

Nasa Begum, who initiated the research project of which this literature review is the first part, stated in her research proposal:

Over recent years, more attention has been paid to the support needs of (a) mental health service users and (b) disabled people with physical impairments. However, the experiences and support needs of individuals who fall into *both* these categories have been overlooked by providers, practitioners, researchers and organisations of service users and disabled people. As a result there is insufficient knowledge about how to best support people with physical impairments who use (or might use) mental health services. (Begum, 2000)

Nasa's original proposal has been taken forward by a research project which had three parts to it:

- (a) a literature review of what is known about the mental health experiences and support needs of people with physical impairments
- (b) an information/resource booklet for people with physical impairments who also experience mental health difficulties. This was published and distributed by Mind¹
- (c) gathering information about the mental health experiences and support needs of people with physical impairments by postal questionnaires and in-depth interviews (Morris, 2004).

This paper presents the findings of a review of the literature on the mental health support needs of people with physical impairments. It is divided into two main parts: a review of research literature concerned with psychology, psychiatry and rehabilitation services; and a review of what is known about the mental health support needs and experiences of people with physical impairments from a social model perspective.

1 The booklet, *Disabled People and Mental Health*, is available from Mind Publications, tel. 020 8221 9666.

Part 1

**Review of research literature concerned with
psychology, psychiatry and rehabilitation services**

A literature search, using the checklist for literature reviews published by the NHS Centre for Reviews and Dissemination (2001), revealed a number of studies concerned with mental health experiences of people with physical impairments. These studies are primarily about depression and its association with specific impairments. There is also a large number of studies concerned with depression in old age but this is not an area covered by this literature review. Neither is the literature on the mental health experiences of deaf people covered. There is very little in the literature about people whose mental health support needs may have nothing to do with their experience of physical impairment. This latter issue is considered first, before looking at the more extensive literature on depression and physical impairment.

Physical impairment amongst people with mental health support needs

There seems to be very little recognition in the research literature that a proportion of people with physical impairments, as part of the general population, will experience mental health difficulties that may have nothing to do with their physical impairment. Neither is there much recognition that people with mental health difficulties may acquire physical impairments and that, in particular, those with long-standing mental health difficulties may be more likely to acquire physical impairments.

This lack of recognition coexists with some indication that there may in fact be a very strong correlation between mental health difficulties and physical impairment that has nothing to do with the psychological impact of physical impairment. There is long-standing evidence that mental health difficulties can have a detrimental effect on physical health. For example, stress suppresses the body's immune system, reduces resistance to disease and might increase the risk of coronary heart disease (Stewart-Brown, 1998). There is also some indication that people with mental health support needs are disproportionately represented amongst those who become physically impaired as a result of accidental injury. In one study of people admitted to a small spinal injury unit over the course of a year, 23 per cent (7 out of 30) had had a diagnosis of psychiatric disorder before their injury (Fullerton *et al.*, 1981). In another study of people who had sustained serious burn

injuries, 45 per cent had had psychiatric disorders before the injury (Noyes *et al.*, 1979). Both these studies highlighted that consumption of alcohol is implicated in a high proportion of accidents resulting in physical impairment.

Some people's experiences of the mental health system itself may mean they acquire physical impairments. It has long been acknowledged that there were high levels of physical illness and impairment amongst people in long-stay hospitals in the past (for example, Pryce *et al.*, 1991). There is also evidence of similar levels of physical illness and impairment amongst current psychiatric hospital patients: for example, two-thirds of long-stay patients in a psychiatric hospital in Melbourne, Australia, were assessed as having physical impairments associated with physical illness (Richards *et al.*, 1997). A US survey of people in the mental health system found that those in hospital settings were more likely to experience 'a high degree of physical health care needs' than those living in the community (Hazel *et al.*, 1991). In 1999 the Annual General Meeting of the Broadmoor Patients' Council heard that more and more people in Broadmoor Hospital have mobility impairments (Roberts, 1999). There is some indication from English research that amongst people in medium- to long-stay psychiatric hospitals, those assessed as having physical impairments have a poorer mental health outcome (Patrick and Holloway, 1990).

There are also some indications that people who are admitted to psychiatric hospitals may already have high levels of physical ill health and impairment. In one study of people admitted to hospital with major depression in Jerusalem, Israel, almost two-thirds were found to have 'concomitant physical illness' (Lerer *et al.*, 1999).

It is unclear how much this association, between using mental health services over a period of time and physical illness and impairment, is related to the side effects of medication and how much is related to other aspects of living with long-standing mental health difficulties (for example, a higher risk of homelessness – see below – or substance abuse). The use of anti-psychotic drugs is itself associated with physical impairment. As Barnes and Phillips state, these drugs cause 'a range of motor disturbances: acute extrapyramidal symptoms, including parkinsonism, acute akathisia and acute dystonia; and chronic motor problems such as tardive dyskinesia, chronic akathisia and tardive

dystonia' (Barnes and Phillips, 1998, p. 49). Newer drugs are sometimes said to have fewer physical side effects but this has yet to be properly confirmed.

High levels of social and economic deprivation are associated with both physical and mental ill health: for example, amongst homeless people there are high levels of both physical impairment and mental health difficulties. Most research that focuses on mental health difficulties of homeless people, however, only makes a passing reference to the coexistence of physical impairment, although there is some recognition that amongst the homeless population in the United States and Britain, many have serious physical impairments and health problems (e.g. Zuvekas and Hill, 2000; Crane and Warnes, 2001).

A final point to emerge from this part of the literature review is that there may be a tendency in research practice to deliberately exclude people with physical impairments if the focus of research is mental health difficulties. For example, Jeste *et al.* claim that people who have other 'medical conditions' are 'usually excluded from research studies [on schizophrenia], although they probably represent the majority of individuals with schizophrenia' (Jeste *et al.*, 1996, p. 429).

Depression and physical impairment

As already mentioned, most of the research studies found in the literature review concerned the association of depression with specific physical conditions and impairments. In these studies, the researchers are mainly asking themselves questions such as: Is depression associated with this particular impairment? What are the factors which make depression more likely? Does the experience of depression influence the way impairment is experienced? There are a few studies which look at the relevance of other factors such as race and gender and economic and social roles.

The studies are mainly quantitative rather than qualitative, and experiences are measured by instruments devised by psychologists mainly for use with non-disabled populations. The definitions and measurements of impairment and disability are those laid down by the World Health Organisation's International Classification of Impairment,

Disability and Handicap (ICIDH) and are therefore prone to the assumption, as discussed below, that impairment in itself is the primary cause of disadvantage. A final general point to be made is that there is very little on disabled people's experiences from their point of view and also very little concerning their experiences of services.

'Impairment causes depression'

There is a common general and professional acceptance that depression and physical impairment go together, especially when combined with the ageing process. As one researcher in the field of disability and ageing has written:

Research documenting an association between depression and disability in late life is intuitively understood by many lay people. 'Of course, she's depressed; she's old; she's alone; she's disabled.' To a large extent, the layperson interpretation encompasses not only the cross-sectional studies but also the more recent prospective data suggesting both that depression is a risk factor for disability and that disability increases the risk of depression. This easy acceptance of these findings belies how little we still know about the relationship between depression and disability. (Bruce, 1999, p. 8)

In an article about her experiences of the mental health system, Nasa Begum recounted how a psychiatrist told her 'If I was disabled, I'd be depressed'. She later found that the diagnosis on her medical notes was 'understandable personality disorder because of her disability' (Begum, 1999).

A large number of research studies conclude that depression is associated with impairment. One longitudinal study of people with physical impairments found that 'the disabled are at dramatically elevated risk for depressive symptoms and ... this high level of depression characterises men and women of all ages' (Turner and Noh, 1988, p. 23). A study of students with a range of acquired and congenital impairments found they reported 'higher levels of psycho-social distress' than their non-disabled peers (Hogan *et al.*, 2000). Studies of the experience of particular impairments and conditions have reached similar conclusions: for example, one study found about half of people

with multiple sclerosis experienced major depression (Sadovnick *et al.*, 1996) and high rates of suicide have also been found amongst this group (Stenager *et al.*, 1992). A review of research on long-term experience of spinal cord injury found not just higher rates of suicide but also the phenomenon of what one study called 'physiological suicide' through self-neglect (Trieschmann, 1988).

Conflicting evidence of a link between impairment and depression

Many of the research studies which find 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 social and economic factors that may accompany impairment. The assumption of this causal link persists in spite of some conflicting evidence about the coexistence of physical impairment and depression, and also in spite of evidence that existence and degree of depression do not seem to be related to extent of physical impairment. The first point is illustrated by looking at some of the large numbers of studies about the psychological status of people who have sustained a spinal cord injury. These studies present a conflicting picture.

For example, two studies on the quality of life (including emotional well-being) experienced by American veterans with spinal cord injury concluded 'that the quality of life enjoyed by SCI veterans, young and old, is relatively good, and in the case of the older SCI veterans, is actually better than similarly aged able-bodied males' (Eisenberg and Saltz, 1991, p. 520). Another study of people with spinal cord injuries, interviewed on average 20 years after initial injury, reported levels of well-being only slightly lower than in non-disabled people of similar ages (Schulz and Decker, 1985).

In contrast, a review of research concluded that 'Spinal injured persons are ... more likely to be distressed, depressed and anxious and to perceive their future as out of their control in comparison to non-spinal cord injured persons' and reported that 'suicide rates are five times that for age- and sex-specific rates for the community' (Craig *et al.*, 1997, p. 33). On the other hand, the authors concluded that research has also found 'either no differences or higher levels of self-esteem in SCI persons than in non-disabled persons' (Craig *et al.*, 1997, p. 37).

Trieschmann concludes, from her review of the literature and experience as a rehabilitation professional, that 'most depression [after spinal cord injury] disappears within weeks of the injury and therefore discharge' and that 'depression is not as severe nor as prevalent as had been suspected following spinal cord injury' (Trieschmann, 1988, pp. 79, 85). She also notes the need to take account of the 'traumatic effects of the acute treatment environment' when assessing mental health in the period immediately following injury.

There are also contradictory findings about the psychological implications of secondary impairments associated with spinal cord injury. On the one hand, a commentary in the journal *Evidence Based Mental Health* asserts that 'Depression after spinal cord injury is often associated with the occurrence of secondary complications, such as pressure sores, urinary tract infections, and contractures' (Kennedy, 1999, p. 58). On the other hand, research published in the early 1990s concluded there was no relationship between these factors and depression (Fuhrer *et al.*, 1993, p. 259).

Another factor that calls into question the causal link between impairment and depression is that a number of research studies have found that psychological distress is not correlated with degree of physical impairment. This lack of association has been found not only amongst people with spinal cord injury but across a range of conditions, including polio and post-polio syndrome (Schanke, 1997) and cystic fibrosis (Cowen *et al.*, 1984). In contrast, however, one study of people with physical impairments admitted to a residential addiction programme in Canada found that 'more severely disabled people are more likely to report attempting suicide and to express the need for mental health counselling' (Ogborne and Smart, 1995, p. 137).

'Traumatic loss' and the acquisition of impairment

The assumption of a causal link between impairment (in itself, rather than the circumstances in which it is experienced) and depression often rests on the assumption that acquisition of impairment is an experience of traumatic loss. The person concerned has to go through various stages of grieving before becoming psychologically whole again. Depression and distress are the inevitable accompaniment to physical impairment and if these are not evident then this in itself is a problem.

Occasionally, a newly disabled person does not seem to be particularly depressed, and this should be a matter of concern. In almost all instances something inappropriate is taking place. A person should be depressed because something significant has happened, and not to respond as such is denial. (Siller, 1969, p. 292, quoted by Lenny, 1993)

In the case of spinal cord injury, the group of disabled people that Siller was referring to, the experience of acquiring this particular type of physical impairment has changed over the last 50 years. As a man who was injured in the 1940s commented, 'When I was injured, I was jolly well depressed ... because I was told I would be dead in two years. I was told I would never marry. I was told I would never have a family. I was told I would be in an institution for the remainder of my life' (Trieschmann, 1988, p. 71).

Spinal cord injury is no longer a death sentence or necessarily accompanied by a loss of relationships and employment. However, this experience, and that of other causes of acquired impairments, is still commonly constructed by rehabilitation and other professionals as an experience of loss which has to be mourned (for example, Ratna, 1996, p. 240; Withers, 1996, p. 103). Roberta Trieschmann has identified how theories of loss and grieving have been applied to people who have acquired physical impairments, in a way that is often experienced as unhelpful:

many disabled persons report that the most 'depressing' thing is the expectations of the staff that they should be 'depressed'. Thus, it would appear that professionals consistently perceive more grief than the person actually experiences, which may be a further example of able-bodied people imposing the 'requirement of mourning' on disabled people. (Trieschmann, 1988, p. 85)

The effect of mental health on the experience of impairment

While there is much research that concludes that impairment in itself causes mental health difficulties, there is also research which contends that mental health difficulties influence a person's experience of impairment. One study of people with multiple sclerosis (MS) found that 'Patients with a high probability of depression ... tended to perceive their

disability [i.e. impairment] as greater than that assessed objectively by the physician' and concluded that 'Depression is common in multiple sclerosis and adversely affects patients' perception of their disability' (S.J. Smith, 2000, pp. 50, 53). There seemed to be little acknowledgement that the individual with MS may have a greater knowledge of their degree of physical impairment than that which could be achieved by a physician observing them in a clinic.

It is particularly common for links to be made with psychological factors when accounting for individuals' experiences of types of pain which are resistant to treatment. For example, in the case of so-called 'phantom limb' pain, 'clinicians still frequently use personality as a rationale to explain amputees' phantom limb pain' (Whyte and Niven, 2001, p. 938). In contrast, Whyte and Niven's own study of 315 people who had had a limb amputated found that 'psychological distress ... did not explain any of the variance in phantom limb pain' (Whyte and Niven, 2001, p. 944) and that 'performance difficulties' were more correlated with pain than 'negative affect' (i.e. depression).

Whyte and Niven also draw attention to the way unspoken assumptions can underpin the whole research process. They argue that research on the experience of phantom limb pain is commonly 'designed and conducted with the implicit assumption that psychological factors played a causal role in phantom limb pain' (Whyte and Niven, 2001, p. 944). This may not be surprising as such research often results from clinicians' experiences of not being able to help people who experience persistent phantom limb pain.

'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, many researchers have then looked to disabled people's attitudes to their impairment for explanation. Leger *et al.* (2002), for example, found that psychological difficulties experienced by people with a range of impairments were not correlated with degree of impairment, nor with whether the condition was degenerative, acquired or congenital. Instead, they argued, 'a lower level of acceptance [of disability] was significantly associated with more anxious and depressive symptoms' (Leger *et al.*, 2002, p. 205).

Another recent example is a study that used a measurement of 'psychological well-being' with a sample of people with rheumatoid arthritis (RA). Interviews found a range of difficulties experienced with pain, activity and mobility, medication, social support, information and work. The study also found that 'depression and lack of self-confidence were common in patients' and concluded that these were 'linked with feelings of frustration of having rheumatoid arthritis' (Read *et al.*, 2001, p. 1391). There seemed to be little attention paid, in this study (as in others), to the possibility that 'depression and lack of self-confidence' may be causally linked to the context in which someone experiences RA rather than the condition itself.

There are also assumptions within some research studies that both the cause of and solutions to psychological distress are to be found within the individual personality. One study compared blind with sighted adolescents and found a higher incidence of depression amongst the former. The authors concluded: 'Perhaps it is those blind adolescents who have not resolved the angst created by blindness that are more likely to experience depression than those who have achieved some level of acceptance' (Koenes and Karshmer, 2000, p. 277).

'Personality traits' and mental health

Psychology often looks to personality traits for explanations of both the extent to which people experience psychological difficulties and how they deal with them. One study of disabled people found that depression was positively associated with coping styles that used 'confrontation, escape or avoidance, and self-blame', and was negatively associated with 'acceptance, distancing and self-control' (de Carvalho *et al.*, 1998, p. 353). Some have argued that when people experience stress, those with a greater degree of 'mastery ... show less psychological distress than persons low in mastery ... Mastery ... concerns the extent to which one regards one's life-chances as being under one's own control in contrast to being fatalistically ruled ... [Mastery] influences one's ability to manage life's challenges competently, and is conditioned largely by one's past history of successes and failures in meeting such challenges' (Turner and Noh, 1988, p. 26). As the same authors point out, however, disabled people 'may be more likely than the non-disabled to encounter

difficulties that are relatively unresponsive to problem-solving efforts' and a sense of mastery may therefore be particularly difficult to achieve and maintain. It is also of relevance that 'mastery', according to American research, is correlated with socio-economic status and with ethnicity: black Americans are less likely to believe life chances are under their own control (Trieschmann, 1988, p. 93).

The social and economic context of the experience of impairment

A few researchers, who have found little correlation between extent of physical impairment and depression, have emphasised the importance of the social context of the experience of impairment. Fuhrer *et al.*, for example, found no relationship between degree of impairment and depression amongst their sample of spinal cord injured persons. Instead, they concluded, 'depression is associated with restrictions in social role performance that stem from the interactive influences of the environment, disability and impairment' (Fuhrer *et al.*, 1993, p. 259). Other research emphasised:

In addition to the need to maintain their health and avoid secondary conditions, [people with spinal cord injury] must adjust to family and interpersonal roles, added financial pressures, and the likelihood of temporary or permanent job loss. These changes may take an emotional toll above and beyond that resulting from the sheer magnitude of physical impairment. An individual's subjective well-being will be strongly related to the extent to which he or she successfully adapts to the changes brought about by spinal cord injury. (Krause, 1998, p. 900)

Some professionals working with adolescents with rheumatoid arthritis also argue that the existence and extent of psychological difficulties are not related to the existence and extent of physical difficulties. What is felt to be more important is the extent to which an adolescent's role is affected. 'Arthritis can disrupt one's performance in a role, and this can be particularly distressing for adolescents, who are in role transition as they move from childhood into adulthood' (Leach, 1997, p. 53).

Conclusion

Although some of the research reviewed in this first part of the literature review recognises the importance of the social and economic context of impairment, most of it is underpinned by two important assumptions: first, that impairment, *in itself*, is a cause of psychological distress; and, second, that the extent and likelihood of distress, and the solutions to it, are to be found in the individual. This is in contrast to an approach which would look at external factors, indicative of the disabling barriers faced by people with physical impairments (see Part 2).

One final point to be made is that all these studies are, of course, very dependent on the accuracy of the measurements used. The study referred to above, of people with MS (S.J. Smith, 2000), found that levels of depression varied according to the instrument used to measure it, thus accounting, it was surmised, for the large variation in the research literature in prevalence of depression amongst people with MS – between 15 and 54 per cent.

In addition, some instruments used have been criticised as inappropriate. Krause and Anson drew attention to the way that instruments used to measure psychological difficulties amongst non-disabled people are inappropriate for people with physical impairments. For example, one commonly used instrument includes ‘items which use inability to control bowel or bladder functions, or anomalous sensations such as numbness, to indicate abnormal functioning, yet these are normal conditions in spinal cord injured persons’ (Krause and Anson, 1997, p. 33). It is also quite common for ‘independence’ to be measured by functional ability (e.g. Daverat *et al.*, 1995).

It is also important to point out that the assumption that impairment itself is the problem underpins the ways of measuring the experience. When classifying people with physical impairments, most of the research studies use the definitions laid down by the World Health Organisation in both the 1960 and 2000 versions of the International Classification of Impairment, Disability and Handicap (ICIDH, now known as the International Classification of Functioning and Disability). These systems of classification contend that impairment causes ‘disability’ (i.e. functional limitation) which causes ‘handicap’ (i.e. social and economic disadvantage). Although the international disability movement was

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engaged in the revision process of the classification during the 1990s, the final classification is still underpinned by the assumption that the underlying cause of disadvantage is the individual's impairment and functional inabilities (Hurst, 2000; Pfeiffer, 2000). This limits the scope of most of the studies within the current psychology and rehabilitation literature. Part 2 of this literature review explores the implications of adopting a social rather than a medical model of disability.

Part 2

**A social model perspective on the mental health
support needs and experiences of people with physical
impairments**

Introduction

'Impairment' and 'disability'

The starting point of the social model of disability is the separation of the two terms 'impairment' and 'disability'. In contrast to the medical model, the social model of disability does not use the term 'disability' to mean impairment but to refer instead to the disabling barriers of prejudice, discrimination and social exclusion. The following definitions are therefore used:

- *Disability* is the disadvantage or restriction of activity caused by a society that takes little or no account of people who have impairments and thus excludes them from mainstream activity. (Therefore, *disability*, like racism or sexism, is discrimination and social oppression.)
- *Impairment* is a characteristic, feature or attribute within an individual which is long-term and may or may not be the result of disease or injury and may
 - 1 affect that individual's appearance in a way which is not acceptable to society, and/or
 - 2 affect the functioning of that individual's mind or body, either because of or regardless of society, and/or
 - 3 cause pain and/or fatigue, affect communication and/or reduce consciousness.
- *Disabled people* are those people with *impairments* who are disabled by society.

Finkelstein and French (1993) use the distinction between impairment and disability to also make a distinction between the psychological aspects of impairments/functional limitations and the psychological aspects of disability/oppression. Impairment, they say, may be associated with specific psychological experiences: prolonged pain, for example, can in itself cause anxiety and depression, as can fatigue. The experience of pain and fatigue can make it difficult to engage in work,

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social and other activities and thus lead to social isolation. However, they also identify that anxiety, depression and social isolation can be part of what they call the psychology of disability (i.e. of oppression):

Disabled people may feel negative and depressed about their situation because they have absorbed negative attitudes about *[impairment]* both before and after becoming disabled, and much of the depression and anxiety they feel may be the result of social factors such as other people's attitudes, poor access, non-existent job prospects and poverty. (Finkelstein and French, 1993, p. 31)

Micheline Mason and Richard Reiser explored 'internalised oppression' in their resource for schools, *Disability Equality in the Classroom* (Mason, 1992; Reiser, 1992). Carol Thomas takes the analysis further in her assertion that what she calls the 'psycho-emotional effects of disablism' 'are just as much a part of disability [i.e. oppression] as "restrictions of activity" in domains such as employment, housing and independent living' (Thomas, 1999, p. 60).

The distinction between impairment and illness

It is also perhaps important to make clear the distinction between impairment and illness. Corker, in criticising mainstream counselling models for treating impairment as the cause of all the difficulties experienced by disabled individuals, also identifies that there is a tendency to 'conflate impairment (for example hearing, visual, speech and mobility impairment) and illness (for example multiple sclerosis, chronic fatigue syndrome, HIV/AIDS)' (Corker, 2002, p. 50). It is possible, therefore, that a person with a physical impairment may experience distressing experiences associated with impairment, illness *and/or* disability (i.e. disabling barriers/oppression). The source of the distress will have implications for identifying an appropriate response. It is also particularly important to distinguish impairment from illness in the context of the debates on 'physician assisted suicide' or 'euthanasia' (see below).

Disabling barriers and mental health support needs

What follows is a summary of evidence of the contexts and factors that seem to be related to the mental health experiences and support needs of people with physical impairments. Much of this evidence is anecdotal (an indication of the paucity of research from this perspective), but is used to highlight issues which may warrant further research. It is also important to preface this discussion with the recognition that physical impairment and disability may not be the only or the most important aspect of someone's experience that influences either their mental health support needs or how they are treated by mental health support services. Race, gender and sexuality, social and economic circumstances, childhood experiences – all these factors are likely to be part of the whole experience of mental health and it may indeed be difficult for researchers, professionals and individual disabled people to separate out such factors.

Disabling attitudes

Many disabled people have written about difficulties in their everyday interactions with non-disabled people (Murphy, 1987, pp. 90–103; Morris, 1989, pp. 73–8; Morris, 1991, pp. 17–34; Keith, 1996). Most social interactions are a process of negotiation. People bring preconceived ideas and knowledge to each interaction and these may be challenged and modified in the process of the interaction. People with physical impairments interact with non-disabled people in many situations where they are seen as negatively different and dependent. Impairment may be unfamiliar, and can also be feared. Disabled people have drawn attention to assumptions held by professionals and the general public that a life with physical impairment may be of such poor quality that it is not worth living. For example, within the debate about the ethics of 'euthanasia' or 'physician/doctor assisted suicide', some people seem to assume that 'incurably disabled people are right to want to die and should be helped to kill themselves while apparently able

abled people are wrong to want to die and should be helped to live' (Davis, 1994, p. 53; see below also).

Awareness of these attitudes can be stressful and undermining. As Nancy Mairs says, 'To know that one arouses dismay and fear and pity simply sickens the spirit of anyone, whether sound of limb and mind or not' (Mairs, 1996, p. 103). To experience this more or less every time a person ventures outside their front door must, we might surmise, have some impact on mental health. For those who acquire their impairment, there may also be the grief, bewilderment and, sometimes, anger, of recognising that friends, acquaintances and family react in ways which can be painful and disaffirming (Murphy, 1987; Morris, 1989).

A number of individual disabled people have written about how they respond to these types of pressure. A few research studies have also focused on the interactions of disabled people with non-disabled people from the point of view of the disabled person. A common theme which emerges is that disabled people have to continually struggle to assert their own reality and self-definition, and how damaging this can be sometimes to a person's state of mental health.

Tighe's small-scale study of the meaning of health and disability for women with physical impairments, for example, concluded that 'the most compelling feature of their narratives was the pressure to define their health by able-bodied standards' (Tighe, 2001, p. 511). The 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 pitiable. At the same time, this meant that it was hard to acknowledge actual experiences of illness or physical difficulties. Veronica Marris's study of women experiencing chronic illness also highlighted how 'silenced' they felt, how difficult it was for women to articulate their 'physical pain and weakness' without colluding with a sense that their lives were 'not worth living' (Marris, 1996).

Whereas mental health and medical professionals have tended to see denial of impairment as a reaction to loss of physical function, disabled people themselves have identified that, where there is such denial, it may be in reaction to other people's attitudes towards impairment.

Sally French, who has grown up with a visual impairment, argues that many disabled people 'deny' their impairments 'for social, economic and emotional survival and we do so at considerable cost to our sense of self and our identities; it is not something we do because of flaws in our individual psyches'. She identifies a number of reasons for minimising or denying her own visual impairment:

- To avoid other people's anxiety and distress.
 - To avoid other people's disappointment and frustration.
 - To avoid other people's disbelief.
 - To avoid other people's disapproval.
 - To live up to other people's ideas of 'normality'.
 - To avoid spoiling other people's fun.
 - To collude with other people's pretences.
- (French, 1993, p. 77)

Many disabled people hide their feelings about their experiences of impairment and disabling barriers, sometimes because they feel a pressure to reassure others, sometimes because they feel that acceptance is conditional. Michele Wates, who has multiple sclerosis, describes her need to hide her true feelings after she has fallen down: 'She badly needed to cry and howl and shake, but instead she cast about for something ordinary to say in something that she hoped was close to her usual tone of voice. Needing to reassure, needing not to be rejected' (Wates, 1994, p. 92).

Trieschmann has argued that 'the message sent by the [American] rehabilitation and social welfare system, reinforced by the success stories presented by the news and entertainment media [is], no matter what the cost, people can overcome their difficulties if they work hard enough' (Trieschmann, 1988, p. 285). She identifies what she sees as the emotional cost to disabled people of this attitude:

the person has to work out strategies to deal with the anger, frustration, fatigue, pain and grief that may accompany the disabled experience on a daily basis. Suppression of emotions, cognitive minimization of difficulties and eventual repression of most feelings can be the long-term result of chronic disability ... Putting on a 'good face' especially in front of non-disabled people, becomes such a

habit that the person may lose contact with the essential features of the self and not realize that it is happening. However, this manner of coping is consistently reinforced by society, since non-disabled people don't know how to react when [disabled people] get upset. (Trieschmann, 1998, p. 256)

While disabled people have increasingly spoken up about the disabling attitudes they face every day, there has been less articulation of the feelings that these attitudes invoke. The experience of disabling attitudes, and anticipation of these experiences, can cause anger and distress, feelings of rejection and, sometimes, persecution. It can feel unremitting but there is little recognition in any of the literature of the short- or long-term psychological consequences.

Sally French hints at some of the consequences when, in almost a passing remark in a piece of writing about her experience of equal opportunities policies, she says, 'It seemed to be assumed that I was using my disability [ie. impairment] as a tactic to avoid work. I still don't know how to resolve the intense anger I feel about this' (French, 1994a, p. 155).

Disabling environments

People with physical impairments not only face physical obstacles to going about their daily lives, but are often segregated from the rest of society. This segregation may be short-lived (such as being forced to occupy 'special places' in a cinema or theatre) or experienced over a long period of time (such as segregated schooling or residential care – see below). There is little research on the psychological consequences of these types of experiences.

Lois Keith conveys some of the daily, unremitting stress that comes with living in a physical environment which can sometimes seem designed to exclude.

I'm always nervous about going somewhere new. This anxiety is rarely a social one, it isn't about meeting new people or feeling shy. I had thirty-five standing up years to deal with that one. This 'normal' anxiety is displaced for me by the sheer physical concern of going to

a place about whether I can get out of the car straight on to the pavement, whether there will be kerbs. It's anxiety about asking a total stranger (if there is a total stranger to ask) to help me in some way. It's the fear that there will be some obstacle no one has told me about – a step, a bollard, a pothole, a locked door. (Keith, 1994, p. 62)

Keith then goes on to describe the experience of arriving at the venue which she had been assured was accessible, only to find it 'Completely inaccessible':

A dark, rainy night, nowhere to park, no way to get in. Huge bollards, an unbelievably steep and cambered concrete slope, chicken wire fence and no one there. I telephone again. From the car I could see lights on, lots of people in the building. No reply. 'Don't cry', I said to myself firmly. 'Don't cry, you're not to cry.' It never works. (Keith, 1994, p. 63)

People with physical impairments face daily experiences of environments which exclude or which are only accessible if the disabled person enters through a back door, or is confined to a particular part of a venue. Like disabling attitudes, the experience of disabling environments must have some impact on mental health. Yet there is little research that explores this issue, and it does not seem to figure in either the rehabilitation literature or the mental health literature generally.

Segregation

The segregation of disabled people from the rest of society was, and in some circumstances arguably still is, considered to be legitimate and inevitable. Segregated education in Britain was enshrined in legislation and is, still, considered acceptable if parents 'choose' segregation for their children or if non-disabled children's education is considered to be jeopardised by the presence of a disabled child in their school. Community care policy in Britain assumes that it is legitimate to institutionalise disabled adults if it would cost too much to support them in their own homes (Morris, forthcoming).

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There is very little recognition of the short- and long-term effects on disabled children of daily experiences of being separated from their non-disabled siblings and peers. What does it mean for children when they are 'bussed' to schools many miles away, excluded from 'mainstream' leisure activities and venues, and sent to be looked after by other people because their parents need a break (Oswin, 1984)?

It can be particularly hard when a child has to deal with more than one source of discrimination. As Nasa Begum writes:

As a child it was difficult for me to accept that there were two distinct ways I was different from the majority, not like the people I saw on the TV, in the comics and books I read ... [when I started school] I soon learnt what it meant to be black in a predominantly white establishment. I used to get very upset at the relentless name-calling, 'blackie', 'nigger', 'paki', but grassing on anyone was not on so I had to learn to live with it. (Begum, 1994, p. 49)

The most extreme form of segregation is where a child or adult lives in a residential setting. A few disabled adults have articulated distressing experiences of childhoods spent in residential special schools (Morris, 1995; French, 1996). There is very little recognition of the effects of institutionalisation on disabled children's and adults' mental health. Some disabled writers have highlighted the isolation, dependency and powerlessness associated with living in a residential home (Hannaford, 1985; Morris, 1993; Smith, 1998). Some disabled people have written about their individual experiences of adult residential care: Ruth Bailey, for example, describes it as 'a stripping of souls' (Bailey, 1996). Earlier academic research argued that, when a disabled person entered residential care, this meant they lacked 'any actual or potential role that confers a positive social status in the wider society' and that this was 'tantamount to being socially dead' (Miller and Gwynne, 1972, p. 80). This research analysed the way in which rejection by society, family and friends can have a significant psychological effect on the disabled individual. However, they also concluded that this was an inevitable part of the experience of physical impairment (see Hunt, 1981 and Morris, 1991 for critiques of this research). A social model approach would obviously challenge this.

While there is much research about the psychological and emotional difficulties experienced by non-disabled children placed in residential care and separated from their families, there is very little recognition of disabled children's similar experiences. Neither is there much recognition of the emotional legacy for disabled adults of segregation in childhood, or of the difficulties young disabled people go through in making the transition to adulthood. Disabled adults may experience, as Ann Macfarlane puts it in her poem entitled 'Loss', 'almost a lifespan of isolation, of painful separations' and a need to grieve 'for the loss of touch, love, sexuality, personal growth' (Macfarlane, 1994a, p. 100). Disabled people's needs for physical and sexual intimacy are often not recognised and, where they are, are commonly experienced as problems for services which assist them in daily living (Earle, 1999; Brown and Croft-White, 2000). There is little acknowledgement of the long-term consequences for mental health of a denial of physical affection, intimacy and close relationships.

Disabling services

Ken Davis (1993) and others have written of the unequal relationship between professionals and disabled people, where the former have the power to define the needs of the latter and how they will be met. The process of getting basic needs met is rarely experienced as other than difficult, lengthy and uncertain. From the disabled person's point of view, it is characterised by all-powerful professions and their organisations determining the nature of an individual's impairment, the needs associated with it and the level and type of assistance for which the individual qualifies. Powerlessness is all too often the key characteristic of the relationship for the disabled individual.

Paradoxically, people with physical impairments, while experiencing general social pressures to deny the extent of physical dependency, find that in order to obtain assistance to go about their daily life they have to stress weakness, lack of ability and a failure to cope. People with physical impairments often have to spend large amounts of time and energy seeking information about how best to meet their needs and advocating to get these needs met. The bureaucratic and attitudinal barriers that they encounter can be stressful and create feelings of anger and helplessness (Olkin, 1999, pp. 251–3).

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Disabled parents have reported particular stress caused by the difficulties they experience in getting access to services which enable them to look after their children (Maternity Alliance, 1993; Keith and Morris, 1996; Department of Health, 2000). Some disabled parents find that they can only get access to assistance if their children are classified as 'children in need' and fear that this may lead to their children being taken away (Wates, 2002, p. 2).

People with communication needs find it particularly difficult to get their needs met and this may have significant consequences for their state of mental health. Many young disabled people who do not use speech to communicate reach the end of their schooling without proper assessment of, or provision to meet, their communication needs (Morris, 2001). People with communication impairments may spend almost all their time in environments where those around them do not enable them to communicate. As one woman who lives in residential care communicated:

They [staff] don't spend the time, and they don't let me take my time. They don't pay attention. They worry about themselves, not me. I end up having to work twice as hard at communicating because they won't spend the time. It's frustrating – I despair and I want to cry sometimes. (Hemmings and Hooper, 2002, p. 13)

Some disabled people react to a denial of communication by behaving in a way which is then labelled as 'challenging behaviour' or by withdrawing completely (Morris, 2001). There is often little recognition of how people's behaviour may be a reaction to the situations in which they find themselves. A common response to people whose behaviour is interpreted as bizarre, frightening or incomprehensible is to see them as somehow not fully human (Myers, 1995). There is also evidence that people who are given a 'challenging behaviour' label are often prescribed anti-psychotic drugs (Qureshi, 1994).

The medical and associated professions sometimes treat people with physical impairments in ways that are potentially damaging to their mental health. This is particularly the case when physical conditions are not recognised. For example, many people with myalgic encephalomyelitis (ME) have experienced a failure to recognise the

physical nature of their symptoms (Burne, 2002) and, for some, the way they have been treated by professionals has created significant emotional distress and mental health problems. One young woman described her experiences:

The doctors didn't believe me when I tried to tell them how ill I felt. They made me feel so small when I went to the doctor. They were so superior and it was a really degrading experience every time. They kept doing blood tests which didn't show anything. I thought I was going mad ... I took all their comments to heart and stopped believing in myself. I hated myself because I thought I was imagining everything. I became suicidal and secretly used to cut my body with razors and burn myself with hot water. I had to give myself a reason for being in such pain – although I don't think I knew it at the time. My physical health continued to deteriorate until it got to the point where I couldn't cope at all at school. I returned to the doctor and was treated for depression, which made me worse. I then saw a psychiatrist who said that there was nothing psychologically wrong with me, but that I had ME. I was so relieved that I wasn't going mad; the self-abuse stopped instantly. (Morris, 1999a, pp. 42–3)

Race and gender may affect the relationship between the disabled person and health services: for example, Carol Thomas's research on disabled women's experiences of health services found that women were sometimes dismissed as 'neurotic' or 'hysterical'. She argues that both disability and sexism operate within the health service and can result in some very distressing experiences for disabled women (Thomas, 2001). There is also evidence that racist attitudes may influence medical and nursing staff's responses towards pain experienced by people with thalassaemia or sickle cell disorder (Atkin and Ahmad, 1998).

Some disabled adults have described their experiences of not being believed as children when the first symptoms of a medical condition emerge. Carole Harrison, for example, wrote about acquiring juvenile rheumatoid arthritis at the age of two and of not being believed until she was four or five.

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I constantly complained when any walking was to be done. My mother would regularly march me round to our GP, looking for reassurance. That always ended in a smack because of mum's frustration at being told there was nothing wrong with me other than being a spoilt, miserable child. (Harrison, 1997, p. 52)

Like many children who acquire physical impairments Carole was also forced to do physical activities which were difficult and painful.

Disabled children are particularly vulnerable to adults' reluctance to listen to experiences from the children's point of view. How many disabled children have had, and continue to have, the experience of Nasa Begum when she says, in a passing remark: 'It wasn't until I went away to boarding school that anyone acknowledged that my lack of writing skills was due to my physical condition rather than to an inability to study' (Begum, 1994, p. 48)?

Other common childhood experiences that disabled adults have described as distressing, and which sometimes cause lasting trauma, are painful operations and procedures and frequent hospitalisations. Sometimes these result from adults' pressure on the child to be more 'normal', for example to walk rather than use a wheelchair. Disabled adults also talk about the fear created by not being told what is happening to them and, for example, the trauma of being treated like an object by roomfuls of professionals: 'When I used to go up to London to the specialist, there used to be a room full of students and the professor would be saying "feel this" because I used to get a lot of spasm and stuff. He wanted the students to feel what it was like. It was quite horrible really' (Morris, 1999a, p. 101).

Glenn Smith's study of young men growing up with chronic illness highlighted how hospital treatment, by ignoring the emotional and social dimensions of their experience, caused 'psychological distress in the present and future' (R.G. Smith, 2000, p. 152). When services *have* acknowledged psychological needs they have found this an important issue for disabled people. For example, Leeds Young Adult Team seeks to provide a holistic service to young disabled people between the ages of 16 and 25 and has found that the help they are able to give with psychological issues is a very important part of their service (Chamberlain and Rooney, 1996).

A final point to be made under this heading is that some neurological conditions may be misdiagnosed as mental illness. There are documented instances, for example, of neurometabolic genetic diseases such as Niemann-Pick disease being misdiagnosed as schizophrenia (Shulman *et al.*, 1995; Campo *et al.*, 1998). It is also common for people with new variant Creutzfeldt-Jakob disease to initially be given a psychiatric diagnosis (Douglas *et al.*, 1999).

Disabling mental health services

Almost twenty years ago, an American piece of research concluded there are 'several major barriers to adequate mental health services for people with severe physical disabilities', including 'transportation, finances, attitudes and professional training' (Pelletier *et al.*, 1985, p. 422). However, there would appear to have been little recognition of this issue since then. Anecdotal evidence from individual disabled people themselves indicates a division between mental health and disability services which results in a failure to meet the needs of people with physical impairments who also have mental health needs. Nasa Begum writes of her experience:

I was refused accommodation in several supported housing projects for mental health service users because of my physical condition, and all the usual services for disabled people wouldn't take me because I self harmed. The voluntary sector was not much better. I couldn't go to a self harm survivors' conference because of the lack of access, and a Mind counselling service didn't feel they had the experience to work with a disabled person. (Begum, 1999)

Anecdotal evidence also suggests that mental health professionals' reactions to physical impairment can get in the way of recognising mental health needs. Impairment can have a powerful meaning for non-disabled professionals and this can influence their interaction with people for whom they provide a service. Most people fear physical dependency. People fear, and are often disgusted by, incontinence. Communication impairment is often assumed to mean cognitive impairment. The historical segregation of disabled people means that many people working in the mental health field are unfamiliar with physical impairment. Curiosity and fear can get in the way of normal professional practice.

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As Rhoda Olkin (a disabled psychotherapist) and Donna Reeve (a disabled counsellor) have argued, those who offer 'talking treatments' are no more immune from negative and prejudicial attitudes than the rest of society. Consequently, 'there is sometimes oppression within the counselling room' (Reeve, 2000, p. 669). Disability equality does not figure in professional training in the way that race and gender equality increasingly does. Disabled people who seek or are offered 'talking treatments' may experience increased psychological distress as a result of being turned away (because services are not accessible to them) and/or because the attitudes of the counsellor or therapist may be oppressive. At the very least, most disabled people who seek counselling or therapy from so-called 'mainstream' services find they have to 'educate' the counsellor or therapist about impairment and disability (Withers, 1996; Olkin, 1999; Reeve, 2000).

Mairian Corker sums up anecdotal evidence of disabled people's experiences of 'talking treatments':

we are perceived as sick, tragic, incompetent, dependent, incomplete *per se* and, importantly for the purposes of counselling, to be in need of rehabilitation, cure or care to help us to 'normalize' or feel better about ourselves, *whether this matches our own perception or not.* (Corker, 2002, p. 50; emphasis in original)

People with physical impairments who have mental health support needs will also be affected by the social stigma attached to being a user of mental health services. One blind person who uses mental health services writes:

I notice when I am in hospital I meet many users of the service who are also blind or have other impairments. It makes you wonder how many people with physical and sensory impairments, or learning difficulties, are 'in the closet' about their experience of psychiatric impairment. And why – because the physical impairment camouflages the psychiatric impairment, or because it is so difficult to take on potential multiple discrimination? (Parshad-Griffin and Sayce, 2002)

While people with physical impairments have seen moves towards identifying disability as a civil rights issue, people who have mental health support needs have seen less progress and, arguably, more stigma. As Peter Beresford points out, 'The "Mental health" debate has been dominated by a small number of high profile homicides linked with mental health service users', a perception that 'care in the community' has failed, and an increased emphasis on the 'dangerousness and "otherness" of mental health service users' (Beresford, 2000, p. 168). These perspectives are likely to make it harder for people with physical impairments to articulate their mental health support needs.

Abuse and violence

Mental health difficulties are often associated with childhood experiences of abuse, and it is now recognised that there are higher levels of physical and sexual abuse, and neglect, amongst disabled children than amongst non-disabled children (French, 1994b; Westcott and Cross, 1996; Stallibrass, 1997; Morris, 1999b; Sullivan and Knutson, 2000; Reeve, 2001; National Working Group on Child Protection and Disability, 2003; RNIB Focus Factsheet, n.d.). However, there has been little attention paid to the implications of this experience for the mental health support needs and experiences of disabled adults. A few disabled adults have spoken of the legacy of their experience of abuse in childhood (French with Swain, 2000). Some feel that professionals may be reluctant to recognise emotional and physical abuse involving a disabled child: 'I can't believe that they didn't know. They knew I was in grave physical danger as a baby and they knew that things weren't right throughout my childhood but they didn't have the guts to do anything. I thought emotional and physical abuse was normal' (Morris, 1995, p. 11). One young man, who was taken into residential care as a baby, spoke of the lack of affection, the physical cruelty and the racism he experienced throughout his childhood. Like many young disabled people, his transition to adulthood was a lonely experience with very little support or recognition of the psychological legacy of his childhood: 'Eventually I got in a complete mess. I had a nervous breakdown and went into hospital' (Morris, 1995, p. 19). Some disabled adults find that it takes many years before they are able to articulate their experience of abuse. In her poem 'Watershed', Ann Macfarlane describes how, 50 years ago, at the age of nine, she watched another child being drowned in a bath in a long-stay hospital, concluding:

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Nearly fifty years later, this scene comes and visits me.
Then, we knew we must stay silent.
Now I speak it for all the Marys
In institutions, in hospitals, in segregated schools
And for my nine-year-old self, who had no choice
But to sit and watch.
(Macfarlane, 1994b, p. 100)

There is also evidence that disabled adults, and particularly disabled women, are vulnerable to abuse. In America, 'advocates and researchers document alarmingly high rates of abuse and violence against women with disabilities' (O'Toole and Brown, 2003). In a sample of 1,876 disabled people, drawn from databases held by American state vocational rehabilitation agencies, 39 per cent of women and 29 per cent of men reported being victims of alcohol- or drug-related physical violence (Li *et al.*, 2000, p. 64). This study concluded that disabled women 'are at greater risk of being victimized by violence than both [disabled men] and [non-disabled] women. However, the reasons for this may have less to do with the functional limitations of disability [i.e. impairment] than with social stigma and discrimination' (Li *et al.*, 2000, p. 69).

A large-scale study in America that compared the experience of physical, sexual and emotional abuse amongst women with and without physical impairments found comparable levels of abuse in both groups (62 per cent reported some level of abuse in their lives) but that disabled women were likely to experience abuse for a longer period of time than non-disabled women (Young *et al.*, 1997).

Small-scale studies, such as that by Hendey and Pascall (1998), indicate that disabled women have a high risk of their lives being limited by the fear of violence and this makes social isolation more likely. Women in their study were 'fearful of physical violence on the streets and in public places and thus of going out' (Hendey and Pascall, 1998, p. 426). Young women were deterred from leaving the parental home and those who had were likely to feel restricted by concerns about safety.

The association of physical impairment with other factors correlated with mental health difficulties

Physical impairment is associated with other material factors which correlate with mental health difficulties – poverty, unemployment, poor housing, and also alcohol and drug abuse. Despite anti-discrimination legislation in a number of countries, unemployment rates remain high, particularly for those who grow up with physical impairment. People who acquire physical impairment in adulthood face not just a threat to their financial and employment situation, but also a possible undermining of their previously established social roles. As one counsellor, writing about the experiences of people with spinal cord injury, states:

The experience of spinal-cord injury, therefore, cannot be understood in terms of purely internal psychological or interpersonal processes, but requires a whole range of other material factors, such as housing, finance, employment, the built environment and family circumstances, to be taken into account. (Lenny, 1993, p. 238)

There are also some quite specific experiences that may be correlated with physical impairment which have to be taken into account in both explaining and treating mental health needs. For example, there is some evidence from America that drug and alcohol misuse is higher amongst disabled people than amongst non-disabled people (Substance Abuse Resources and Disability Issues Program, n.d.). This issue is better researched in respect of those with spinal cord injury: for example, one survey of people with spinal cord injury in the USA found a much higher incidence of alcohol abuse (one in four) than in the general population. The study reported that those who abused alcohol identified themselves as having poorer health, were more depressed and experienced more stress in their lives than those who did not abuse alcohol (Young *et al.*, 1995). A report on disabled clients of alcohol and drug services in Ontario, Canada, found that relatively few agencies provided services tailored for disabled people and that ‘resources for physically disabled clients were not available in many addiction programs’ (Tyas and Rush, 1993, p. 275).

Olkin reviewed rehabilitation research of the 1980s and 1990s and concluded that disability services in the USA have been very slow to recognise alcohol and substance abuse amongst disabled people, and

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that substance abuse programmes and services did not usually cater for people with physical and/or sensory impairments (Olkin, 1999, pp. 259–62). In summarising the reasons that research studies claim to have found for increased substance abuse amongst disabled people, Olkin emphasises the social context in which impairment is experienced. The reasons are thus a list of disabling barriers, rather than physical impairment in itself. They include:

- the stress and frustration of facing daily discrimination and stigma
- increased social isolation
- reduced rates of employment
- increased likelihood of a history of sexual abuse
- decreased attention of service providers to a history of abuse
- overmedication
- easier access to medications
- a belief amongst others that life with impairment is so intolerable that drug abuse is an unsurprising reaction
- chronic pain
- high rates of pre-impairment substance abuse in, for example, those with spinal cord injuries
- use of medication in childhood amongst those who grew up with impairments.

There is also a need to recognise the interrelationship/coexistence of physical impairment and mental health needs in certain contexts such as, for example, amongst refugees and victims of torture. Both groups may be more likely to experience physical impairment, and experiences of losing their homes or being tortured may also result in lasting mental health difficulties (James and Dawood, 2000). This was an issue raised when the Greater London Association of Disabled People held a

conference in 1997 on how the disability and psychiatric survivors' movements can work together (Greater London Association of Disabled People, 1998, p. 4).

The impact of impairment in itself

The social model of disability does not ignore the experience of impairment. Rather, by making a clear distinction between impairment and disabling barriers, it becomes possible to pay proper attention to impairment and its impact. However, it is difficult to assess, from the existing literature, how people who acquire physical impairments feel about their changed bodies, and what is the effect on their mental health experiences and support needs. Most of the rehabilitation literature imposes theories of psychological pathology that do not allow space for the disabled person's voice to be heard. Most literature written by disabled people themselves focuses on the disabling barriers, external to the individual, that undoubtedly have a significant impact on how impairment is experienced but which allow little room for an exploration of whether impairment *in itself* may impact on mental health. When disabled people do talk about the experience of impairment it is difficult, if not impossible, to separate out social context from individual experiences, as illustrated by one young woman talking about acquiring a mobility impairment following an accident:

'Disabled' means to me being weaker and more defenceless, being unpleasantly different. I was a person who very much enjoyed physical activity and now I feel as if a large and important part of the person I was no longer exists. After seven years, I still haven't come to terms with this absence, like a sudden death. (Morris, 1989, p. 79)

It is difficult to disentangle here the effect of the disabling attitude about what being disabled means from the emotional distress about the loss of physical activity. We also need to know more about how people who were born with physical impairment experience their bodies, and what physical limitations mean to them.

Some of the physical experiences associated with impairment may have implications for a person's state of mental health. It is recognised, for example, that chronic pain is associated with depression but individuals

do not always have good experiences of professional response to their pain. The medical profession and health services generally often find it difficult to know what to do with people whose pain does not respond to treatment. We have already referred to evidence of unhelpful attitudes towards people with so-called 'phantom limb' pain. As Rhoda Olkin says, 'Instead of being viewed as a failure on the part of the medical system, [people with long-standing pain] are usually seen as being "treatment resistant"' (Olkin, 1999, p. 245). More helpful responses include the Arthritis Self-Management Programme, which originated at the Stanford Arthritis Center in the USA. Evaluation of a pilot programme in England found that this 'patient education programme' increased people's ability to control pain (Barlow *et al.*, 1998). One of the key aspects of this initiative was that the people running the courses were people who had arthritis themselves. This model of self-management and 'user-led training' is now promoted by the Expert Patients Programme, supported by the Department of Health, which launched 26 pilot projects in 2002 (Department of Health, 2001).

Fatigue is another factor associated with some conditions, such as multiple sclerosis. It can affect how someone functions intellectually and emotionally as well as physically. However, there is anecdotal evidence that some people who experience incapacitating levels of fatigue meet scepticism and undermining attitudes from some professionals. Olkin, for example, warns that, when someone with a physical impairment makes clear their needs relating to fatigue (or pain or functional limitations), psychotherapists and psychologists often look for other motives for making such demands – 'It is another way in which we overpathologize people with disabilities out of ignorance of the norms for such persons' (Olkin, 1999, p. 250).

Other physical experiences associated with some physical impairments, such as incontinence or spasms, may be inherently distressing. However, the social context in which they are experienced will also inevitably have an impact on their implications for mental health. There is little research, however, on these experiences from a social model perspective, or of the implications for mental health support needs.

While everyone experiences a change in physical abilities as they get older, these changes may be particularly pronounced and may have more significant consequences for people with physical impairments. The physical effect of most conditions worsens over time, even if the condition is not, in itself, a progressive one (Morris, 1989, Ch. 9; Zarb and Oliver, 1993; Olkin, 1999, p. 241). Fear of dependency and vulnerability is particularly felt if the disabled person has already had experience of institutional care. As one woman who spent ten years in residential care before managing to live in her own home said, in contemplating old age:

the growing dependency I will have on other people is very frightening. Mentally, I cannot cope with the idea of getting frail and going into any institution. If I had no responsibility to loved ones, I would take the coward's way out and take a correct overdose. I could not suffer the indignities of institutional care again; once was enough. (Morris, 1989, p. 142)

Many people with physical impairments also find that pain increases with growing older. These are all issues which will affect both mental health experiences and mental health support needs.

Conclusion

Nasa Begum concluded her account of her experiences as someone with both a physical impairment and mental health support needs by saying, 'The time has come for disabled people to start talking about our mental health support needs and for policy makers and practitioners to listen to what we have to say. We need to start changing things' (Begum, 1999).

A number of issues emerge from this literature review which may warrant further research and/or attention from service providers. They can be divided into four main headings:

- 1 The incidence of physical impairment amongst users of mental health services, the causes of physical impairment, and the implications for service providers.
- 2 The effect of disabling barriers of prejudicial attitudes, inaccessible environments and segregation on the emotional and mental health of people with physical impairments, and the implications of these causal factors for services.
- 3 The meaning and experience of impairment from the point of view of people with physical impairments. The implications of needs relating to physical impairment for mental health services.
- 4 The experiences of other sources of oppression (including racism, sexism, heterosexism and ageism), how these interrelate with experiences of disabling barriers, and the implications for service providers.

It would be inappropriate to draw conclusions from the existing research about any of these issues. Not only has there been inadequate attention paid to these issues, but the perspective of people with physical impairments is underexplored. One of the clearest messages from the mental health system survivors' movement in recent years has been that services and treatments can only be truly helpful if professionals are able to hear and respond to service users' own definitions of their experiences. For example, people who self-harm insist that this is not attention-seeking or manipulative behaviour but a way of dealing with

extreme emotional pain (for example, Harrison, 1996). If services are to be helpful to people with physical impairments they will similarly need to listen and learn about the experience of impairment and disabling barriers from disabled people themselves. Research has a key role to play in this but will only be empowering if people with physical impairments set the research agenda and research methods are adopted which enable their voices to be heard.

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