

**'One town for my body,
another for my mind'**

‘One town for my body, another for my mind’

**Services for people with physical impairments
and mental health support needs**

Jenny Morris



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Introduction

Background

Over recent years, increasing attention has been paid to how people with mental health support needs and people with physical impairments experience services' responses to their needs. However, policy makers, service providers and researchers have tended to overlook individuals who fall into both of these categories.

People with physical impairments associated with conditions such as cerebral palsy, multiple sclerosis or spinal cord injury are as likely as the general population to experience mental health problems and, indeed, may be more likely to be users of mental health services. Possible reasons for this correlation include: higher rates of poverty and unemployment (Disability Rights Commission, 2003), which are themselves associated with poor mental health; the mental health legacy of the greater risks of abuse experienced by disabled children (Westcott and Cross, 1996; National Working Group on Child Protection and Disability, 2003); and some indications that people with mental health support needs are more likely to become physically disabled as a result of accidents or attempted suicide (Noyes *et al.*, 1979; Fullerton *et al.*, 1981). In spite of this, the National Service Framework for Mental Health for England makes no reference to disabled people as a specific group among users of mental health services (Department of Health, 1999) although the Welsh National Service Framework for Mental Health does (Welsh Assembly, 2002).

There is also evidence of a link between poor physical and mental health, and this has been more recognised. For example, the English National Service Framework for Mental Health highlighted that 'people with physical illnesses have higher rates of mental health problems' (Department of Health, 1999, p. 14). There is also increasing acknowledgement that long-term mental health problems are correlated with conditions such as heart disease and diabetes (National Institute for Mental Health in England, n.d.; Mentality, 2003).

Yet there has been little acknowledgement that some of these illnesses and poor physical health give rise to impairment. This means that needs relating to such experiences of impairment are largely unrecognised. For example, the Department of Health’s guidance on improving in-patient psychiatric services covers the physical environment generally but does not address the specific issues for those with physical impairments (Department of Health, 2002b). The guidance requires, for instance, that ‘Service users should have access to drinks and refreshments at all times’ but does not address the changes to the physical environment and the provision of personal assistance that would be required for this to be achieved for people with physical impairments. Neither do requirements relating to risk and safety consider the specific issues for this group of service users.

At the level of commissioning and providing services, there has been little recognition that a proportion of those who use physical disability services also have mental health problems, or of the consequences of this for meeting needs. Indeed, the recent national inspection of physical disability services found that not enough attention was paid to ‘emotional and mental health needs’ generally (Social Services Inspectorate, 2003, para. 7.16). Neither has it been sufficiently recognised that people with physical impairments experience unequal access to mental health services. Indeed, a literature review commissioned by the National Institute for Mental Health in England (n.d.) did not identify disability or impairment as being a relevant factor when looking at experiences of discrimination and mental health services. Nowhere in this review of literature concerning the policy, practice and user experiences of mental health services is there any mention of people with physical impairments who have mental health support needs.

Within both mental health and physical disability services there have been pressures for inter-agency and inter-disciplinary working. The Government is encouraging health

and social services to work together by its promotion of joint funding and the development of Care Trusts. However, these policy developments have not fully recognised that people who use services may have both mental health needs and physical impairments. The national inspection of physical disability services commented that links with mental health services were 'frequently poor' (Social Services Inspectorate, 2003, para. 7.49) and that a lack of a formal framework for joint working created operational problems. Yet the Department of Health itself does not always recognise that people with physical impairments can also have mental health support needs. For example, the recently issued survey that is to be carried out of users of physical disability services asks whether someone has a learning disability but not about mental health needs (Department of Health, 2003a).

The research

Our research aimed to look at how people with physical impairments, who also have mental health support needs, experienced mental health and disability services. In the first stage of the research project, a review of the literature explored the evidence concerning the relationship between physical impairment and mental illness.¹

The second stage of the research sought information from people with physical impairments and mental health support needs about their experiences of mental health and physical disability services. We gathered this information in two ways. An information booklet was published by Mind on *Disabled People and Mental Health Services*. The booklet contained a questionnaire, which asked about people's experiences of both mental health and physical disability services.

Eighty-three people returned the questionnaire. Their mean age was 45, two-thirds were women and 91 per cent were white. Almost half lived alone and a quarter with a partner

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(and no children). Fourteen per cent said they were gay or lesbian and 7 per cent bisexual. The Appendix provides more information about the characteristics of these 83 people.

Among those who returned the postal questionnaire there was a range of diagnoses causing physical impairments. Almost half recorded diagnoses such as stroke, angina or diabetes; just over 20 per cent said they had a congenital impairment such as cerebral palsy or spina bifida; 16 per cent experienced mobility impairments as a result of arthritis or back problems. Three out of the 83 respondents had multiple sclerosis, and two myalgic encephalomyelitis (ME), while, for four respondents, their physical impairments were caused by accidents and, for one, they were caused by cancer.

The most common diagnosis in terms of mental illness was depression – mentioned by 38 per cent as the main diagnosis. Seventeen per cent mentioned bi-polar disorder (or manic depression), while 11 per cent mentioned schizophrenia or psychosis. The remainder recorded a number of diagnoses such as eating disorders, obsessive compulsive disorder, personality disorder and addiction. Fifty (60 per cent) of the 83 respondents had been in-patients in psychiatric hospitals, sometimes on more than one occasion. Twenty of these had been compulsorily admitted under the Mental Health Act. Most of our respondents were long-term users of mental health services.

Twenty-five of those returning the postal questionnaire were selected for interview. These 25 interviewees were purposively sampled from the total respondents to represent a variety of individual experiences and characteristics. These included men and women from a range of ages, ethnic origin and household types, and people with a number of different medical diagnoses.

This report draws on both the questionnaire responses and the in-depth interviews. This is a self-selected sample of service users and we do not know how representative they are of people with physical impairments who also have mental health support needs. Nevertheless, this is the first research project to seek the views of this particular group of service users, and their voices need to be heard and responded to by those responsible for policy and practice.

The structure of this report

The report starts by identifying what people said they wanted from services. This draws on both positive experiences of services (which unfortunately were a minority experience) and what people said they wished for from an 'ideal service'. We then look at people's relationships with mental health services, physical disability services and GPs, before moving on to explore experiences of specific responses to needs, namely medication, 'talking treatments', self-help, complementary therapies and advocacy, and using direct payments or own resources to purchase support.

Drawing on these experiences, the report then discusses two major issues that arise from our research: the relationships between impairment, disabling barriers and mental health; and the fragmentation of needs. This chapter also looks at other sources of exclusion and discrimination. Finally, a summary of key issues that should be addressed by those responsible for policy and practice in the areas of both mental health and physical disability services are identified.

A note on terminology

This research was based on the social model of disability and the terminology used throughout this report reflects this framework for analysis.

The social model of disability uses the term ‘impairment’ to refer to functional limitations and ‘disabling barriers’ to refer to factors that are external to the individual. These disabling barriers can take the form of negative attitudes or physical, social or economic factors. To take an example: someone may have a communication *impairment*, which means he does not use speech. His ability to communicate, however, will depend on whether the necessary equipment and/or assistance is available and whether those around him facilitate his communication. An assumption that he has nothing to communicate and/or a failure to provide the necessary assistance or equipment are *disabling barriers*.

The social model of disability is an important analytical tool for understanding how the people who participated in this research project experienced services. There were many instances where they described being excluded from services, or receiving inappropriate or inadequate responses to their needs. These experiences themselves could have an important impact on their state of mental health. Some of these issues are returned to in the final chapter where we discuss the fragmentation of people’s needs and the relationship between impairment, disabling barriers and mental health. However, the primary focus of the research was people’s experiences of services. First, therefore, we look at what people wanted from services before moving on to look at how they actually experienced services and treatments.

Note

- 1 The literature review is available both as a pdf file and in print from the website of the Joseph Rowntree Foundation: www.jrf.org.uk (Morris, 2004 forthcoming).

1 What do people want from services?

In the main, the people who returned the questionnaire and those we interviewed had poor experiences of services. About two-thirds said they experienced difficulties with accessing mental health services because of their physical impairment and a similar proportion had difficulties using physical disability services because of their mental health support needs. These experiences are described in subsequent chapters. In this chapter, we use the rather sparse evidence of positive experiences, as well as what people said when asked about an ideal service, to analyse what it is that they value and want from services and the individuals who work within them.

When interviewees described positive experiences, it often concerned their contact with a particular professional. Occasionally, however, the characteristics of a service were praised. Some of these characteristics echo what most users of mental health services or physical disability services have said they want, although there are a number of ways in which such characteristics are particularly important for people with physical impairments who also have mental health support needs. Other characteristics are integral to determining whether this particular group of people receive equal access to services appropriate to their needs.

Recognition of access needs

People appreciated it when mental health professionals took account of their access needs relating to physical impairment. David, who has a mobility impairment, was positive about the psychiatrist he sees: 'She always makes sure I'm happy with going [to one of her two offices] because of access and things like that. And they normally give me an early morning appointment because there's easier parking.' Humerah praised a therapeutic community where the physical environment was suitable for a wheelchair user and her

'they normally give me an early morning appointment because there's easier parking'

personal assistance needs were recognised and responded to.

Access is also about communication and attitudes. People appreciated when professionals used accessible language and had good communication skills. Ingrid praised a community psychiatric nurse (CPN): 'He's very easy to talk to. He's quite sort of down to earth. He doesn't talk down to me or patronise me in any way.' After many years of unhelpful encounters with psychiatrists, Laura appreciated the psychiatrist she currently sees: 'He was actually helpful because he seemed normal and ordinary ... I understood what he was saying completely. He didn't use any words or terms or anything that wasn't understandable.'

Negative attitudes towards either physical impairment or mental health needs can restrict access to services. In the case of physical disability services, people wanted an understanding of their mental health needs and the implications these might have for their use of services. Unfortunately, it was more common to find that those working in physical disability services were, at best, at a loss as to how to respond to someone who also had mental health needs and, at worst, held negative attitudes, which could restrict access to and use of services.

Recognition of the impact of impairment and disabling barriers

Although people did not want professionals to assume that their mental health problems were necessarily caused by their impairment, they did want recognition that both impairment and disabling barriers may have an impact on mental health.

A few people had contact with professionals who understood that disabling barriers can be a significant influence not just on someone's physical and mental health but also on their

life chances generally. They appreciated the opportunity to talk about how negative attitudes undermine self-esteem, unequal access creates social isolation and disempowering services cause emotional distress. For example, Adam, who lives in a residential home, became very depressed when the home changed their rules about lifting and insisted on using a hoist. This was a very uncomfortable and unpleasant experience for Adam. He tried to limit the number of times he needed lifting by, for example, reducing his fluid intake so he needed to go to the toilet less often. The whole experience was described as a 'nightmare' and Adam said 'Anybody would get depressed'. The regular visits of the CPN gave him the chance to talk through these experiences, although the disabling barrier of a rigid and dehumanising interpretation of regulations remained.

Some mental health workers recognised that experiences caused by impairment, such as pain and limited mobility, can impact on a person's state of mental health. David, who has osteoarthritis and osteoporosis, appreciated that his psychiatrist 'asks how my physical problems are, when she sees me, and whether ... because I think she's aware that if my back's really bad and I'm having a couple of weeks when I can't walk very much or do anything like that ... But that really affects me psychologically, as well, so she always asks about my physical well-being as well.'

**'she always asks
about my physical
well-being as well'**

Being treated as a 'whole person'

Recognising the effect of both disabling barriers and impairment is part of being treated as 'a whole person' and this was quite a common feature of positive experiences of services. Another message was that people appreciate professionals who see them as people and not as a disease. While this is a characteristic of services appreciated by service users generally, it is a particularly important requirement for people whose needs are commonly divided by service and professional boundaries.

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Some of the interviewees described situations where a focus on only one set of needs meant that the service response was inadequate. For example, Jack felt that the support he received to take up employment was inadequate because it was not based on a comprehensive assessment of all of his needs – which include spina bifida, epilepsy and depression. In consequence, he ended up losing his job. In contrast, Caroline spoke of a psychotherapist who took a more holistic approach. She ‘had a good grasp of understanding all aspects, including my physical impairment, which we did also talk about during the sessions’. She is also now seeing a psychiatrist who ‘does seem to see me as a whole person’. She appreciates it when professionals ‘do seem to look at wider aspects of my life and don’t just see me as a body to medicate’.

Naomi, a long-term user of mental health services who sustained significant physical injuries in a car crash, struggled with the lack of communication between mental health services and those professionals dealing with the impact of her injuries. She described the CPN who she saw before her accident and for a brief period afterwards as ‘the only person who saw the whole of me’. She also expressed a high level of satisfaction with counselling services: ‘It’s looking at me, not a symptom or a particular injury or a particular illness ... It’s the only space where I try and look at everything, mental and physical ... [I] didn’t feel as if I was going in with any big label that just said this is the disease.’

‘She looks very carefully at any medication to make sure it doesn’t conflict with the medication I’m already taking for my pain control for arthritis’

Very few respondents found that mental health professionals took account of medication prescribed for a physical condition or illness when treating mental illness. David was one of these few and said of his psychiatrist, ‘She looks very carefully at any medication to make sure it doesn’t conflict with the medication I’m already taking for my pain control for arthritis’. As will be seen in subsequent chapters of this report, the lack of a holistic approach to medication had a significant impact on many of our respondents.

Ingrid was among a number of people who used complementary therapies and valued the way that they were treated holistically. She said of homeopathy: 'I like the fact that they treat you as a whole person.' This was an approach that people often wished for when they talked about their ideal service. Laura, for example, wanted assessments carried out by professionals to be more holistic: 'I'd like to see an assessment which doesn't just do physical disability or mental health or whatever. That looks at the whole.'

'I'd like to see an assessment which doesn't just do physical disability or mental health or whatever. That looks at the whole'

For some people, being treated 'as a whole person' would, they felt, require one professional to act in a co-ordinating role to ensure that services co-operated and complemented each other. Eileen was particularly keen on this, as she is also a parent and found that not only did adult services fail to work together but also there were then major problems when children's services got involved. Service and professional boundaries, and the failure to communicate across them, meant that fragmentation of people's needs was one of the major issues to arise from this research and this is explored in more detail later in this report.

Flexible services that respond to individual and changing needs

As it was common for people to find they had to fit into services, rather than services responding to their specific circumstances, it was very much appreciated when this did not happen. For example, although Jack was initially offered only 12 weeks' counselling, this was extended when it was clear he needed more. The service was run by a local voluntary organisation and he described it as 'very person-centred and open-ended'. It was also able to respond to his request for a male counsellor. As many people with physical impairments have difficulty finding accessible mental health services, it is particularly important that those that are accessible are also flexible and responsive to individual need.

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Ann found that the attitude at the hospice she goes to was 'non-judgemental ... They accept you as you are.' It was also flexible: 'One day you might need help for cancer and one day you need help because of the trauma [of childhood abuse].' Daisy, who has multiple sclerosis, received counselling through a multi-disciplinary neurology service. Initially, she saw the psychologist to help her manage her pain but then continued to work with her to tackle her depression: 'We've built up a good level of trust and we work really well together. And I'm so glad ... if that hadn't been going on, I don't know where I'd be.'

'He sees me as a real person. I respect him'

Sharon has cerebral palsy and has often found that anti-depressants have a significant impact on her physical impairment, while drugs prescribed for spasm, affect her mental health. Since she developed vertigo following an undiagnosed viral infection, her GP has offered her a monthly appointment to discuss her treatment for both her physical and mental health. 'I usually have the last appointment of the day. And he's a talker, as well, so ... I can be there half an hour ... I can throw whatever I want at him ... this is the problem or that is, or we can just have a laugh about it. He sees me as a real person. I respect him.' She also feels confident that, if she says she is not managing to cope with her depression, he will respond.

David, who has osteoarthritis and osteoporosis as well as a diagnosis of psychosis and depression, expressed a good deal of satisfaction with the physiotherapy treatment he received. He said, 'they've really been as helpful as they could be in several ways'. Not only were they flexible in terms of timing of appointments but also the physiotherapists were able to respond to his particular, and changing, needs.

Ingrid appreciated her local Out of Hours mental health service. 'Say if it's late at night and you can't sleep and you're wandering around and perhaps thinking about doing things, you ring them and they'll say "well, we think you should take ten milligrams of this". And then they ring you back in half an

hour. You can ring them every half an hour if you want and they'll just keep talking through the evening and advise you what to do.' She said it was particularly helpful that the person on the other end of the phone would 'advise you how to relax. And [ask] "What do you normally do?" And remind you of what you normally do.'

Some people received practical support – through either mental health or physical disability services – which was flexible and responsive to their particular needs. Felix, for example, receives six hours a week of help from a support worker employed by a voluntary organisation: 'On Fridays we go [into town] to shop ... and on Mondays we do things around the house or around [the neighbourhood] ... They help people like myself with shopping, with going out the house, with general life skills.' Laura had a 'befriender': 'We had a common interest in horses. We had a lot of common interests so it was nice sort of going out with her.'

While flexible and responsive services are appreciated by all service users, those who have both mental health support needs and physical impairments are particularly likely to be disadvantaged by services that are inflexible and do not respond to varying individual needs.

Being listened to and treated with respect

When people were asked (in the postal questionnaire) what was the most important thing that mental health services could do, a number responded with comments such as 'Listen, accept and believe the way I see my distress'; 'Listen to what I say'; 'Be more understanding'. A few people who were interviewed felt that some service providers did listen to their views and treat them with respect. Ingrid said: 'The GP I've got now is brilliant ... she talks to me like I'm a person. Listens to what I have to say. You know, she takes what I say on board, quite seriously. She sort of seems to respect my point of view ... She sort of values my opinion which is quite empowering in a way.'

'She sort of seems to respect my point of view ... She sort of values my opinion which is quite empowering in a way'

‘She takes from me what my interpretation of things are and doesn’t assume that because I was born with an impairment that that’s the source of all my problems’

While being listened to and treated with respect is a characteristic of services appreciated by all service users, there are particular issues for people with physical impairments who also have mental health support needs. For Adam, who does not use speech, a failure to respect his communication needs means that all too often he is denied a ‘voice’ and people do not listen to his concerns. In one instance, however, after waiting for 18 months, he started psychotherapy with someone who addressed the barriers to communication and he found it very helpful. Others find, as discussed later in this report, that therapists all too often impose on them their own views and feelings about impairment. In contrast, Humerah was very positive about her current therapist – ‘She’s a star. She takes from me what my interpretation of things are and doesn’t assume that because I was born with an impairment that that’s the source of all my problems.’

Sometimes it is negative attitudes that get in the way of listening to people with physical impairments and treating them with respect. In contrast, when people are accepted and respected, this is very affirming. For example, Patricia said that, ideally, she would like to have group therapy with other people who have physical impairments. She had had this kind of experience in the past and their acceptance of her had helped a lot: ‘I found being with a group of people [with physical impairments], and seeing that they treated me really quite the same as everybody else, helped my confidence quite a lot.’ This common acceptance was also a key part of people’s appreciation of self-help groups, which is discussed later.

Easy access to services, including preventative and early intervention services

Hugh said that his ideal service would be ‘via a computer’, by which he meant ‘being able to press a button’ and find out what services were available for depression or relating to

physical impairment. He also wanted accurate online information about benefits. David would have appreciated it if, every time he accessed either mental health or physical disability services, the professional concerned could call up information about all his needs, which was already held by services, instead of having to explain everything anew each time he contacted services. This is an issue that is often mentioned by service users but, for people with both mental health support needs and physical impairments, the process of explaining everything anew can be even more burdensome.

A number of people mentioned that they would particularly appreciate easy access to a residential service when they were having a crisis. Christine said she could ring up and book herself into a respite care facility when she was having a mental health crisis: 'Short-term, you can go there. You don't have to be referred. There's no waiting and uming and arring.' Others mentioned a need for somewhere to go on a day or residential basis in order to prevent a crisis. Again, although this is a type of service wanted by many mental health service users, there are particular issues for those who also have physical impairments. Humerah, for example, has for many years had her need for respite recognised in her care plan. The Community Mental Health Team, however, has never been able to find a service that could meet both her mental health support needs and her needs relating to physical impairment.

The Community Mental Health Team, however, has never been able to find a service that could meet both her mental health support needs and her needs relating to physical impairment

Summary

These, then, are the characteristics of services that people felt would meet their needs. They did not want to be excluded from mental health services because of their access needs or from physical disability services because of their mental health needs. They wanted services that saw them as 'a whole person', addressing both mental health needs and those relating to physical impairment. They wanted services

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and professionals to communicate and work together, and easy access to flexible services that could address individual needs. Above all, perhaps, they wanted to be listened to and treated with respect. The next three chapters look at how people experienced mental health and physical disability services, and GPs.

2 Mental health services

Almost 20 years ago, American research concluded there are 'several major barriers to adequate mental health services for people with "severe physical disabilities"' (Pelletier *et al.*, 1985). However, there would appear to have been little recognition of this issue on this side of the Atlantic. Anecdotal evidence suggests that both attitudes and inaccessible environments create barriers to accessing mental health services. Nasa Begum, for example, wrote: 'I was refused accommodation in several supported housing projects for mental health service users because of my physical condition' (Begum, 1999).

Both hospital and community mental health services are covered by the Disability Discrimination Act. Service providers discriminate if they fail to make 'reasonable adjustments' to their policies, practices or procedures so as to make the service accessible to disabled people. They may neither refuse to provide a service to disabled people, nor provide a lower standard of service. From October 2004, there will be a duty to carry out physical adjustments to buildings to make them accessible. In the meantime, services should provide alternative means of access unless they can justify not doing so.

This chapter explores people's experiences of mental health services, both as in-patients and in the community. Among those who returned the postal questionnaire, two-thirds reported difficulties with using these services because of their physical impairment. The two most common problems were that there had been little or no recognition of their needs relating to physical impairment (mentioned by almost four out of five of those reporting difficulties) and negative attitudes held by staff (mentioned by two-thirds). Over half of those reporting difficulties (58 per cent) said that personal assistance and/or equipment was not available and half (49 per cent) said that buildings were inaccessible. Only a minority (23 per cent) identified negative attitudes among

other service users as a problem. This chapter looks first at people’s experiences of being an in-patient in a psychiatric hospital and then at community mental health services.

In-patient psychiatric hospital experiences

‘The loneliest place in the world is a psychiatric ward’

A total of 50 people who returned postal questionnaires had been in-patients in psychiatric hospitals, sometimes on more than one occasion. Forty-six had experiences of being admitted on a voluntary basis while 20 had been admitted on a section. Six out of ten rated their in-patient experiences as either poor or very poor. In interviews, people talked of the same kinds of difficulties that other mental health service users have highlighted about psychiatric wards (e.g. Sainsbury Centre for Mental Health, 1998). Ingrid, for example, said, ‘The loneliest place in the world is a psychiatric ward’, while Caroline told us, ‘It wasn’t the sanctuary I’d hoped to find. It was chaotic and upsetting.’

However, people with physical impairments can also experience additional difficulties when they are admitted to psychiatric hospitals. Those participating in this research spoke of difficulties caused by physical environments and how these problems could be made worse by staff attitudes and responses. Some of those who required personal assistance found this was not available. People also commonly experienced problems in accessing medication and treatment related to their physical impairment.

Jane, who has a mobility impairment, found that:

‘The psychiatric hospital just wasn’t geared up for people with physical impairments at all’

The psychiatric hospital just wasn’t geared up for people with physical impairments at all. The room I had had an incredibly heavy door. The shower was lethal: there was no alarm, no handrails or anything, and it was very slippery. It was really difficult to get in and out of. And the distance down to breakfast was just about in the limit of my walking, but then I’d be absolutely shattered when I got there. I

couldn't serve myself with the meals because it was the sort of situation where you queue up, picked up your meal and then took it over to your table, put your dishes away afterwards, and went to somewhere different to get your drink. And I couldn't manage that. There were lots of things I couldn't manage.

Although staff told her to ask if she needed help, she then found that, when she did, 'It was "Oh, we're busy"'.

When asked why she thought staff were not very helpful, Jane said:

I think, partly, because they didn't understand, partly because they were used to people being very demanding and maybe they saw me as being demanding. I don't think they could get their head round the fact that I could walk around with my stick some of the time, but needed my chair for longer distances. I think they saw everybody as either in a wheelchair or not in a wheelchair, and this was very confusing for them. And I just think they didn't understand. And they were ... Well, they were kind of busy.

David needed physical assistance in order to have a bath. However, he was told that 'there was no staff who could help 'cos they weren't able to do anything for the physical person because they were psychiatric nurses and so it wasn't in their job, what they were able to do within their job description'.

Caroline, who has arthritis, also found that staff did not understand her physical needs and were reluctant to respond to her requests for assistance. She was an in-patient on a ward that was physically accessible and even had a hoist in the bathroom, but it was staff attitudes that created disabling barriers:

I found it almost impossible to get personal assistance from nursing staff. They thought I should be able to cope

'It was very difficult to get across to staff that I just needed a hand out of bed in the morning ... I just needed a little bit of help to sit up'

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because I live alone. But at home I have aids and adaptations to assist with bathing, getting out of bed, etc. ... I found it very demoralising to have to explain every time why I needed that extra assistance because, to them, I probably looked OK ... Even things like squeezing toothpaste out of the tube, getting out of bed in the morning, lifting teapots and using the dining room, I needed a little bit of extra help ... It was very difficult to get across to staff that I just needed a hand out of bed in the morning ... I just needed a little bit of help to sit up. They seemed to have no understanding of how I may have those kinds of needs ... I was usually told to wait. ‘Well can’t you do it yourself?’ Or, ‘Well, don’t you manage at home?’ I got that kind of response. Perhaps, then, help was grudgingly given. But it wasn’t easily forthcoming.

Humerah also told of how staff on a psychiatric ward questioned ‘how do you manage at home?’ when she asked for personal assistance to transfer on and off the toilet. ‘They didn’t say outright “you won’t get it” but they just made it difficult to obtain, like staff weren’t available, or saying “hang on”, or “can’t you manage?”’ Because assistance was not forthcoming she fell and broke her leg. ‘They thought I had done it deliberately, they thought I had self-harmed, and they didn’t X-ray it for 24 hours and it was quite a bad break.’ Even then, with her leg in plaster, she found it difficult to get assistance, although ‘there was one member of staff – a male nurse – who was really good and, though he was male, I didn’t mind him helping me because he was fine. He even worked out a way of enabling me to have a bath with my leg in plaster.’

‘They were just more about me as an equal person. I didn’t get derogatory comments’

Humerah had a more positive experience when she had two planned admissions to a therapeutic community. At the first admission, nursing staff met her personal assistance needs: ‘It was the only place where I haven’t had an argument about my personal assistance needs.’ The second time, her personal assistance needs were met by agency staff from outside the hospital, paid for by social services. Interestingly,

this hospital was also Humerah's only experience of being asked whether she wanted to fast during Ramadam. 'I did fast for two weeks and they accommodated that, by waking me up in the morning before sunrise and giving me some toast.' Generally, she said, staff attitudes were very positive about her as both an Asian woman and a disabled person: 'They were just more about me as an equal person. I didn't get derogatory comments.'

In contrast, Daisy, who has multiple sclerosis and uses a wheelchair, felt that staff on a psychiatric ward pathologised her access needs: 'The dining room was miles away. And for me, it just wasn't worth the energy of getting there, sitting there and then getting back, to have a meal ... But they couldn't understand that. They thought I was isolating myself.' She relied on her partner to come into the hospital to provide the assistance she needed. 'The pressure was on me to adapt my disability to the facilities ... And I think I would have got on much better if I hadn't had to worry about having a shower, getting to the loo, all that sort of thing, on top of what was going on anyway.' Day care services were held on a floor of the hospital that was not served by a lift.

Day care services were held on a floor of the hospital that was not served by a lift

Some people said that their physical impairments were interpreted by hospital staff as being part of their mental health difficulties. Ken, for example, said that, when he was in a psychiatric hospital, 'the fact that I said I had [asthma and arthritis] was seen as an aspect of mental illness'. Lee felt that staff in the psychiatric hospital ignored his needs relating to his physical impairment: 'As far as they're concerned they're there to look after you mentally. And if you've got a physical problem that needs medication you should be seeing the GP or somebody like that. You shouldn't be bringing that problem to hospital with you.'

Sometimes, when people are compulsorily admitted to hospital, those admitting them do not ensure that any equipment they need accompanies them to the hospital.

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'They would tell me when I could have a painkiller ... [and I] was left in pain to carry on'

Hugh, for example, was admitted without his stick: 'The ambulance came ... just got a wheelchair and carted me out ... So I arrived with no stick. So basically, I couldn't walk very far.'

People commonly found that medication they needed for their physical impairment was withdrawn on admission and was not always made available when they needed it. If the medication was needed for pain, this withdrawal and lack of control caused significant distress. When Lee was admitted, the painkillers that he took for his problems with his back were taken away from him: 'They would tell me when I could have a painkiller ... [and I] was left in pain to carry on.' The only way he could control his pain while in hospital was to ask his mother to bring his medication in for him, which she did without the staff knowing.

Caroline was not allowed to keep the analgesia that she used at home to treat her pain:

If I needed analgesia I would have to ask the nurse, who would then have to go and find the person who'd got the key ... I was often asked to wait ... On one particular occasion I remember that they found they hadn't got any of my medication on the trolley. And I had to wait for pharmacy to deliver, which was about six hours later by the time I actually got it. And I'm used to just taking painkillers at home when I need them ... It caused me quite an amount of distress because the longer you wait for painkillers the worse you imagine your pain becomes ... And feeling a burden: I used to feel a real nuisance when I was asking for something that other patients weren't asking for ... It caused me to become quite agitated and depressed.

Although interviewees talked about unhelpful attitudes held by staff about the assistance they needed, none identified negative attitudes among fellow-patients; as Caroline said: 'I didn't have any negative attitudes from other patients on

the ward.’ It was, however, neither always possible to rely on other patients for physical assistance, nor did people necessarily want to do this. Jane said:

Some of the patients were really helpful and when I got to know them a bit more particularly helpful. But there was other people that were really, really ill at that time so not everybody kind of wanted to help, you know, at the point they were at. So it was very tricky.

A number of people commented that a failure to meet their physical needs while in hospital created considerable stress. Some also felt that their physical impairment or condition worsened. Daisy, for example, felt that her physical condition deteriorated following her time in hospital. She has multiple sclerosis and says: ‘I have noticed that when I’m put under extreme stress that I do tend to respond with a relapse.’

Community mental health services

Generally, people’s experiences of both accessing and receiving community mental health services were poor. The only service praised by a majority of service users was private psychotherapy or counselling. Nineteen (59 per cent) of the 32 people who used this type of service rated it as either good or very good while four out of ten who used NHS ‘talking treatments’ rated them as good or very good. Experiences of ‘talking treatments’ are discussed in more detail in Chapter 6. The services that received the poorest ratings were crisis services (81 per cent of 32 respondents said they were poor or very poor); employment support (69 per cent of 26 respondents) and residential home – which could include respite care (65 per cent of 17 respondents). Personal assistants or agency workers funded by direct payments or people’s own resources were also very poorly rated: 70 per cent of 17 respondents said the service they received was either poor or very poor. Experiences of, and issues relating to, this way of meeting needs are discussed in Chapter 7.

'One town for my body, another for my mind'

More details concerning the rating of specific services are given in the Appendix.

Among those people we interviewed, a few praised individual workers (such as community psychiatric nurses, psychiatrists or social workers). It was particularly appreciated when a professional saw the service user as 'a whole person', taking into account all their needs. Laura, for example, is a wheelchair user and praised the social worker/care co-ordinator from her local community mental health team who visited her and her husband regularly. She felt that his mental health training had equipped him to work in a sensitive way that was helpful for both her and her husband. He carried out an assessment that covered both her mental health and physical needs and, indeed, resulted in direct payments so that she could meet both sets of needs.

'They seem to forget that ... a little bit of actual physical help into a building might make a difference'

However, needs relating to physical impairment were not always recognised or responded to in mental health community services, and this could make services themselves difficult to access. Sharon, who has cerebral palsy, said: 'They don't know how to say to me "What help do you need? How can we help? Do you need help into the building?" ... You know, "Would it help if somebody was at the door when you arrived?" Simple things like that ... They seem to forget that ... a little bit of actual physical help into a building might make a difference.' Lee attends a work programme at a day centre but finds a similar lack of sensitivity to his needs relating to physical impairment. He finds the chairs at the centre difficult to sit on for any length of time and needs a more suitable seat, but he said, 'I don't think there's really any money available to provide those facilities'.

It can be very distressing when services are physically difficult to access. Daisy, who uses a wheelchair, was offered occupational therapy (OT) for her mental health needs. She described how disempowering the physical experience of getting there was:

Because they want to encourage my independence, they'll send me transport. So they send an ambulance. And the bloke came out of the ambulance, pushed me up, shoved me into the ambulance, strapped me down ... You know, I'm completely covered in these shackles in this ambulance – a solitary little bod in the ambulance – hurtling towards [the next town]. Get to the OT department, which is across a huge bridge so I can't self-propel that far. The door's narrow, there's a lift, and we get into this building. And the place where the OT is, I can't get my wheelchair in so I have to leave my wheelchair in a nearby office and peg it ... And so I finally get in there and sit there. And there's four of us doing clay models. And I thought there was going to be some kind of, you know, a rota of activities. But, after four sessions of doing clay, I thought ... It's actually so exhausting to be shoved around like that and then to get there and try and do what you're meant to do.

Laura described a relatively common experience of difficulties in physically accessing a community mental health service when she talked about going to see a psychiatrist:

There is a main entrance so if you use a wheelchair you go round the side. And there's an arrow so you go down. But it's not clearly sort of stated so you go down and down before you find where you go – and you go round and round. Then you've got to ring a bell. But then you had to go back to the front door because the bell wasn't working or something. So then you sit there and wait till someone goes round the other way to come to let you in. And then there were boxes of photocopying things and that in the way so you knew that that entrance was not used very often ... And then people were apologising because there were chairs in the way and ... You know, it wasn't set up. Although it had ... it did have a wheelchair access, it wasn't set up and it wasn't the norm for it to be used.

‘One town for my body, another for my mind’

‘The Community Psychiatric Nurse [CPN] allocated to me was so overwhelmed by the physical difficulties I was having and also how her service couldn’t offer anything to me’

If mental health professionals are unfamiliar with physical impairment, this can result in disempowering attitudes and can be very distressing for the service user concerned. Daisy talked of how ‘The Community Psychiatric Nurse [CPN] allocated to me was so overwhelmed by the physical difficulties I was having and also how her service couldn’t offer anything to me. I just think that she couldn’t hack it.’ Caroline, who has arthritis, said that the mental health professionals she has been in contact with:

... have a very limited understanding of my physical condition and how pain affects me. I don’t think they understand the nature of chronic pain. I think perhaps they can understand, where you have a headache, you take a tablet and then it goes away. But they don’t have an understanding of pain that’s there 24 hours a day, and how that can have a grinding-down effect.

People often talked about mental health service professionals making decisions in ways that didn’t involve them. Jack, for example, who had received support from community mental health services after leaving a psychiatric hospital, said: ‘I was summoned to a meeting ... really on the pretext of reviewing my care. And, basically, the upshot was “Oh, you don’t need this care any more. It’s the end.”’ He also felt that his concerns about personal relationships were not being taken seriously: ‘I was lonely and I was trying to make inroads into meeting people and so on.’

Lack of involvement in treatment decisions is an experience that many non-disabled users of mental health services have long complained about. However, for disabled mental health service users, there are additional consequences if they are not involved in decisions about their care. These include the effects of medication on physical impairment (as discussed later in this report), and difficulties in accessing and using services if needs relating to impairment are not recognised or addressed. Moreover, mental health professionals

sometimes make assumptions about causes of distress without consulting the person concerned. This can lead to inappropriate responses and can sometimes exacerbate distress.

Summary

The majority of our respondents said they had difficulty accessing mental health services because of their physical impairments. They talked not only of inaccessible physical environments but also of unhelpful attitudes among staff. In-patient experiences were often characterised by a lack of physical assistance for even relatively simple things such as sitting up in bed or squeezing a tube of toothpaste. Medication required for physical conditions was usually withdrawn on admission and was not always available when people needed it. Community mental health workers were often unfamiliar with physical impairments such as cerebral palsy and this could get in the way of responding to mental health needs. The help that people required to access services (which could be as simple as help with opening doors, a higher chair or more appropriate timing of appointments) often went unrecognised.

Most of our respondents were also in contact with physical disability services and the next chapter looks at their experiences of these services.

3 Physical disability services

Two-thirds of respondents to the postal questionnaire said that they had difficulties with using physical disability services. Among these, two-thirds experienced inadequate recognition of mental health needs and negative attitudes of staff towards mental health issues. Half of those who experienced difficulties said that assumptions or judgements made about their mental health needs had prevented them from using a disability service. A third experienced negative attitudes from other service users.

The highest ratings were received by physiotherapy services: 46 per cent of the 46 respondents using this service rated it as either good or very good. Self-help groups/services and advocacy services also received positive ratings from about four out of ten users. However, other services accessed for reasons relating to physical impairment received poorer ratings. The lowest ratings were received by employment support (87 per cent of 32 respondents said their experience was either poor or very poor) and home care services (66 per cent of 36 respondents).

A number of respondents said that those working in disability services did not recognise or understand mental health support needs. Adam saw his care manager once a year for a review of his residential placement and felt that she didn't try to either understand his mental health needs or respond to them. Naomi found that 'All the physical stuff just completely took dominance' once she became disabled. She had used mental health services before a car crash in which she sustained serious injuries. Her experience of rehabilitation services was: 'It was almost like the mental health stuff didn't matter, didn't come into it ... since this has happened, everything's been sort of physical.' A report on recent neurological tests had included 'one line' about 'severe depression' but 'it was just like a line and they completely ignored that'. She also felt that her experience of depression is now assumed to be because of the accident and the resulting loss of employment and physical impairment.

'It was almost like the mental health stuff didn't matter'

On the other hand, she found that, although the physiotherapists and occupational therapists had changed over the months she saw them, the service itself had been consistent and ‘they’ve just got a better idea about who I am and what’s me ... I think they recognise ... that the level of mobility I’ve got is affected by what’s going on in my head, in terms of emotional and mental health stuff’. She contrasted this with ‘most of the medics ... who just look and they go “Oh your leg’s this” or “The X-ray’s showing this”. They don’t know who I am.’

Caroline was among a number of interviewees who experienced a lack of understanding of mental health issues from a service she accessed to meet her physical needs. She sometimes put off having new wrist splints made or seeking other treatment for her arms (relating to her physical impairment) because of reaction to the scars caused by self-harm.

If I go along with a problem with my arms and a physiotherapist or occupational therapist has to look at them, they will make a comment. And I don’t want to have to explain what’s happened, but I feel a need to ... I was offered physiotherapy recently and I delayed it because of that. I feel that I’m not ready to have to explain everything to a physiotherapist again because it’s always somebody different you see. They don’t tend to read your notes.

Having blood tests also provokes remarks from the person taking blood – and ‘it’s never a private room ... and ... you don’t want to have to go into discussions when there are other people in the room’.

When someone working in physical disability services has had some mental health training, this can make a big difference. Laura had a good experience of a physiotherapist who she thought had a good understanding of mental health issues because she had had some relevant training: ‘I think it’s made her, perhaps, aware that you listen to what the

‘mental health services seem, in this area certainly, not to be available to people with disabilities’

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patient is saying and that they are an expert on their own body ... she looks at you holistically.’ On the other hand, she received the general impression from the physical disability section of her social services department that ‘mental health services seem, in this area certainly, not to be available to people with disabilities’.

Adam, who lives in a residential home, found that, once he developed mental health problems, some of the care staff ‘wouldn’t have anything to do’ with him. Other people had also experienced hurtful reactions from care workers – Daisy, for example, has care workers from an agency to provide her with personal assistance to get up in the mornings: ‘One day I was still in bed when she came and she said “You must feel like killing yourself when you’re feeling like this”.’ This comment upset her very much: ‘I’ve never felt so ill that I’m going to kill myself. And, you know, that level of belief about somebody that you’re working for is quite, I found it quite damaging really.’

‘They provide services for disabled people that aren’t expected to achieve a lot’

Services for disabled people can be disempowering if they have low expectations of disabled people and this, in itself, can have an impact on mental health. Some of our respondents had been assisted into employment as a person with a physical impairment but found that they were stuck in jobs that under-used their abilities. This experience then exacerbated mental health difficulties. As Patricia said: ‘It was the same thing day in, day out. There was very little to do. Some days I knew, when I left work that day, there would be nothing to do when I got in the next day. And, in the end, I hated it. I was so bored. I was just sat at my desk, trying to look busy. It made me ill actually.’ She found her experience of physical disability services to be generally disempowering: ‘They provide services for disabled people that aren’t expected to achieve a lot ... I’ve never fitted in anywhere.’ This added to her low self-esteem and lack of confidence. Other services can be similarly disempowering, particularly when they segregate disabled people from the rest of society. In the residential home where 27-year-old Adam lives, most

people are older than him. Many of them have progressive conditions and become unable to leave their beds. 'It becomes a very sad place.'

It was clear from the literature review that needs relating to physical impairment are sometimes responded to in ways that are disempowering and this can contribute to and exacerbate mental health problems. This was also the experience of our respondents. Most people also found that physical disability services were unfamiliar with mental health issues and that there was poor communication between physical disability and mental health services. As Laura put it:

There is no joined-up thinking, as far as I can see, in the [Social Services] Department, as to the fact that people have multi sort of needs and that you can't just be classified as having a physical disability, you may have sensory disabilities, you may have mental health needs. They should be looking at you holistically but, I'm afraid, they're not.

Hospital experiences

When people have to go into hospital for reasons relating to their physical health or impairment, their mental health history sometimes influences the way they are treated and there are difficulties in getting an appropriate response to their mental health needs. Ingrid, for example, broke her leg very badly and was in hospital for four weeks. She did not tell the hospital staff to begin with that she had bi-polar disorder but, when she did, 'they started treating me differently. It was very, very hard ... They didn't listen to anything I said ... and I didn't get any painkillers when I needed them. And I told them about when I started to go high how I self-medicate – that's what I always do. And they brought a psychiatrist in to see me.' She asked to be given the tranquillisers that she

'It was very, very hard ... They didn't listen to anything I said ... and I didn't get any painkillers when I needed them'

'One town for my body, another for my mind'

usually took when she was high – 'But it never happened. I used to ask for them and they'd say, "Oh, no, it's not due till ten o'clock. It's not due till two o'clock." And so, by the time I'd get them, I'd be completely wound up. And it was like they didn't understand anything at all about what was going on.' Another psychiatrist then 'gave me this massive high dosage of tranquillisers. So then I was completely out of it, completely blotto.' Yet another psychiatrist then cut down the dosage of tranquillisers and also suggested that she try to come off the sleeping pills that she had taken for years.

So then I was supposed to ask if I needed a sleeping pill. But then the nurses decided they were actually going to stop all these pills. So when I asked for things, they said, "Oh, no, we're going to see if you can manage without them. You seem OK to us. You don't seem too bad so we're going to leave it for now. If you need it later on, we'll give you it." You know, the whole thing, it was awful really.

Humerah was transferred to a general ward after she broke her leg while an in-patient on a psychiatric ward. Although the two buildings were next door to each other, she had no contact with the psychiatrist who had been responsible for her care on the psychiatric ward: 'They washed their hands of me until it came time to transfer me back,' she said. She felt that lack of familiarity with mental health needs meant that 'there was a fear' among staff 'because they didn't know what to do, or how to respond ... Every time I got upset – and I did get upset because I was in a lot of pain – they wanted to give me medication to calm me down, sedating medication.' She felt that staff were frightened that she would harm herself and that they also assumed that she could cope with pain because she had a history of self-harm. She didn't feel that they took her requests for pain relief seriously, 'and if I was upset they just gave me sedatives'. While on the general ward, the only time she saw a psychiatrist was when it came time to transfer her back to the psychiatric ward, when the duty psychiatrist came to see her.

Summary

A lack of familiarity with mental health issues among many staff in physical disability or general hospital services created difficulties for most of our respondents. Negative attitudes towards people with mental health support needs were also reported by some. These difficulties were compounded by generally poor communication between physical disability and mental health services. A number of interviewees also mentioned the low expectations that, for example, employment services have of people with physical impairments, and how physical disability services themselves can be disempowering and can have a negative impact on mental health.

4 GP services

The postal questionnaire asked about people's experiences of GPs' responses to both their mental health needs and their needs related to physical impairment. Almost half (48 per cent) of the 75 people who responded said that their GP's response to needs relating to physical impairment was either good or very good and a third (35 per cent) that it was either poor or very poor. This situation was more or less reversed when they rated their GP's response to mental health needs – 45 per cent said it was either poor or very poor while 36 per cent said it was either good or very good. This higher rating of GP response to physical care compared to mental health needs was also found in research concerning people with 'severe mental illness' (Bindman *et al.*, 1997), although our respondents had lower levels of satisfaction with their GP on both counts compared to this earlier research.

People appreciated it when GPs made time for them, listened to them and respected their rights to be involved in treatment. Ingrid found it was not a battle to see her GP urgently if she really needed to see her. 'If I ring and say I really need to see the doctor today, they will fit me in.' The GP will also do telephone consultations. Ingrid also felt fully involved in her treatment: 'She lets me sort of make my mind up about things.'

However, GP surgeries were not always physically accessible and several interviewees felt that GPs and receptionists did not always take physical access needs seriously enough. Patricia, who uses a wheelchair, reported that 'The front entrance door is very heavy. You really have to push on it really hard. The reception desk is very high ... The waiting room's in the middle of the building and there's a very narrow corridor all the way round it to all the different GPs' surgeries.' On one occasion, 'there was a line of chairs right across the middle of the waiting room so I couldn't get from where I was sitting, once my GP had called me, through the other door to

**'They had to move
all the chairs for me
to get through'**

go to her surgery. They had to move all the chairs for me to get through.’ When Patricia complained to the GP, the GP asked her to write to the Primary Care Trust because, as the GP said, ‘We really need to move to bigger premises’.

Daisy’s GP is ‘on the third floor of a building that’s not wheelchair accessible so I can’t go in to see her’. Her GP will come out to see her but Daisy has to first persuade the surgery’s receptionist that a home visit is needed: ‘I have to lay it on very thickly, each time I ring.’ She is due a cervical smear test but has not managed to have one.

Access to help from a GP is not just about physical barriers. Some people found that mental health issues were not taken seriously or that GPs seemed out of their depth when faced with someone who had both a significant physical impairment and mental health needs. When Adam, who has cerebral palsy, went to his GP about severe depression, which he had experienced over a period of years, ‘she said everybody has off days. She said go home and I would be better tomorrow.’ Adam stays at his parents’ home each weekend and his parents have on occasions tried unsuccessfully to call out the GP when Adam was trying to harm himself. The GP said she doesn’t know enough about cerebral palsy and mental health.

‘she said everybody has off days. She said go home and I would be better tomorrow’

Some of those interviewed felt that having a mental health diagnosis means that GPs – together with other health professionals – do not take physical symptoms seriously. As one respondent wrote, ‘When you have a history of mental illness it is frequently wrongly assumed that your presenting physical symptoms are really psychosomatic and treatment may be therefore delayed or mis-prescribed because of this judgemental attitude.’ People with mental health support needs are not only just as likely to experience physical ill health as anyone else, they also are in fact more likely to experience physical conditions such as heart disease, respiratory illness and diabetes (National Institute for Mental Health in England, n.d, p. 3).

‘When you have a history of mental illness it is frequently wrongly assumed that your presenting physical symptoms are really psychosomatic’

On the other hand, some people felt that physical impairments seem to take precedence over mental health issues. Naomi praised her GP for his involvement in her treatment for the physical impairments caused by a car crash but 'it's like he doesn't remember' that she has a long-term experience of depression, which pre-dated her physical impairment. 'Even if I go in and I think I'm going to talk to him this time about the depression ... I don't do that because we focus on, you know, "I've had a letter from the spinal consultant and he said this". Or, "This has come through from plastics ... I've got this file from social services that says you're having so and so done" ... in a way he responds to what's in front of him. And the physical stuff tends to be the stuff at the forefront.' When she does mention her depression to him, 'He usually says something like "Oh, you're doing quite well really" ... It's almost like it's a non-issue ... Anything that I say about that would be ascribed to a physical problem.'

Summary

GP surgeries were not always physically accessible. Some respondents appreciated the adjustments that GPs made in such situations but others reported that their access requirements were not responded to. While people gave a more positive rating to their GP's response to needs relating to physical impairment, many had difficulties with responses to their mental health support needs and wanted more recognition of these needs. Some respondents felt that physical symptoms were not taken seriously because of their mental health diagnosis. Those who praised their GP appreciated being listened to and treated with respect.

5 Medication

Medication given for mental health needs can have a significant impact on physical impairment but people were rarely warned about this and the effect was not always recognised or responded to. In the case of medication given for reasons relating to physical impairment, this can also have an effect on mental health but, again, people were rarely warned about these possible effects.

People with physical impairments experience the same range of difficulties with, and benefits from, anti-depressants and anti-psychotic medications as those without physical impairments. Ann, for example, spoke of how it turned her into a different person: 'It's horrible! And you get a terrible hunger where you want to eat and eat and eat and eat. Pacing, pacing, pacing, pacing, and that isn't me. You're totally something else.' Ann also found that one drug's side effects included tinnitus and disturbed vision. Milan experienced devastating side effects from an anti-depressant, although he also says 'I'm not as much against medication as I once was. It depends what works for people.'

However, people with physical impairments can also find that medication given in response to their mental health needs can exacerbate existing physical difficulties. Fifty-eight per cent of respondents to the postal questionnaire said that medication prescribed for mental health needs had had a negative effect on their impairment, and most of these people (83 per cent) said they had not been warned that this might happen. More than half (56 per cent) reported that the negative effect was not recognised by GPs or other professionals.

A smaller percentage – 45 per cent – reported that medication related to their physical impairment had had a negative effect on their mental health. Again, most (77 per cent) had not been warned this might happen and half (51 per cent) reported the effect was not recognised.

‘Psychiatric medication has had major detrimental effects on my physical functioning, so much so that I fell and broke my limbs several times’

Humerah, who uses a wheelchair, said, ‘Psychiatric medication has had major detrimental effects on my physical functioning, so much so that I fell and broke my limbs several times. I became so weak that I needed two people instead of one person to assist me and I could not manage going to the toilet independently, which I had been able to do before.’ Humerah – who has been disabled since birth – was on so much medication while on one psychiatric ward that, she said, ‘I physically began to stop functioning, so much so that they thought I had a neurological disorder ... I couldn’t even push myself in my wheelchair’. She also became very confused. However, ‘it didn’t occur to anyone that it was the medication which caused all this. It was only when I took a major overdose and ended up in a general hospital, they took me off all the medication at once and my physical functioning just became amazingly better.’

Jack, who has spina bifida and epilepsy, found that some medication prescribed to meet his mental health needs had an impact on his co-ordination and balance, which ‘weren’t A1 to start with’. Daisy spoke of the way that the weight gain and fatigue caused by anti-depressants exacerbated her impaired mobility caused by multiple sclerosis: ‘with amitriptyline ... I was slowing down completely, I was falling asleep during the day and I was putting on an enormous amount of weight ... I couldn’t get around and I couldn’t look after myself.’ She did not find her GP was very sympathetic – ‘I think that’s what doctors are for, just handing out medication. I don’t think they’re treating people at all.’

As with weight gain, other side effects of medication given for mental health reasons can have a more significant impact on people with physical impairments. Adam, for example, who has athetoid cerebral palsy, found that the nose bleeds that were a side effect of an anti-depressant caused major problems. He could not wipe the blood up himself, he swallowed it and it caused him to vomit. This was not a side effect that he had been warned about, although it was in the small print on the instructions accompanying the tablets. The

GP who prescribed the anti-depressants had not considered whether potential side effects would create particular difficulties for someone with Adam's impairment.

Caroline said that she always looked up medication she had been prescribed and, on one occasion, found she had been given one drug that should not have been prescribed in combination with another she was taking. 'I contacted the pharmacist who said "no, you can't take these two together". I then got back in touch with the GP who changed it to something different.'

Few people experienced reviews of long-term use of medication or of the effect of the combination of different medications. Four people interviewed had good experiences: in one case, a psychiatrist oversaw all the medication prescribed and monitored the effects, while, in another, their GP fulfilled this role. Jack said that now his GP takes care over both the medication required for his physical impairments and that prescribed for depression. 'He works it out with me what I should take ... And he includes me in treatment, you know, in my treatment.' He felt that the GP now recognised the impact of medication on physical impairment. Eileen described how the 'medication for my physical condition has been built up through specialists and GPs and ... then I went to the psychiatrist and he gave me the medication for my mental problems'. She also said, however, 'They've sort of worked together, really, 'cos they have to look what I'm on'.

Few people experienced reviews of long-term use of medication or of the effect of the combination of different medications

Felix felt that long-term use of painkillers had an effect on both his mental and physical health:

I think the services, and particularly the GP, could have looked at my situation in a bit more detail. I was very much treated as a lifetime patient. It was considered that, due to my back problem, I would need certain large doses of painkillers every day of my life, for the rest of my life. The fact that taking those painkillers was causing more

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problems than the actual back problem was obvious. Years ago it was apparent, almost right from the beginning, but nothing was ever done about it. The prescriptions just kept on flowing through.

'My GP thinks that I'm difficult because I'm careful about what medication I take'

And, yet, Daisy said: 'My GP thinks that I'm difficult because I'm careful about what medication I take and I see what side effects it has and I weigh up whether they're worth the positive effects and if they're not then I don't want to take them.'

When she was in a general hospital, Ingrid was denied the medication she was usually on to treat her bi-polar disorder

When people are being treated in psychiatric hospitals, staff do not always acknowledge or provide medication required for physical impairment, while staff in general hospitals do not always acknowledge or provide medication required to treat a mental illness. This issue has been covered in the chapters on experiences of psychiatric hospitals and of physical disability services. One key factor in either setting is whether a person's knowledge and experience of what medication they need is respected. When she was in a general hospital, Ingrid was denied the medication she was usually on to treat her bi-polar disorder and had to resort to subterfuge. 'It was ridiculous because I knew if I didn't have the drugs I'd become hyper ... In the end I got my sister to get some from home and bring them in. So I actually had some hidden in the hospital so I was dosing myself with it. I mean I was very careful with them. I kept a piece of paper ... and I wrote down when I took them.' Even when she was then prescribed the medication, she found that she wasn't always given them at the time needed. 'I've had this illness, or whatever you want to call it, for 30 years and, by and large, I've managed my own medication. So I know what I need.'

Some interviewees felt that they were denied the medication they needed because of poor communication between professionals and different services. David, for example, said:

When you go into a psychiatric unit, they should be able to look at your records and see that you've got a physical health problem, what that is, and what medication you need for that. It's always been very difficult. Both times that I was admitted, it took between three and five days to actually get re-prescribed with my painkillers.

Summary

Almost six out of ten respondents reported that medication given for mental health needs had an impact on their physical impairment, while over four out of ten said medication relating to physical impairment had a negative impact on their mental health. Most reported that they had not been warned about these potential effects. Some people found medication had a significantly negative impact on their physical abilities, while others found that existing physical impairments meant that side effects, such as weight gain, were particularly difficult to deal with. Very few people experienced a co-ordinated approach by GPs or psychiatrists to the prescribing of medication for mental health needs and physical impairment. It also seemed that regular review of medication was uncommon.

6 'Talking treatments'

People with mental health support needs have for a number of years argued that counselling and psychotherapy are the preferred form of treatment for many of them. This positive view of 'talking treatments' was also reflected in this research in that counselling and psychotherapy were the most highly rated of mental health services among those who returned the postal questionnaire. Four out of ten who received such treatment through the NHS rated the service as either very good or good; six out of ten rated private counselling or psychotherapy as either good or very good.

'The process of trying to find an accessible and affordable therapist has been a nightmare'

However, for people with physical impairments, it can be very difficult finding an accessible therapist. As Humerah said, 'The process of trying to find an accessible and affordable therapist has been a nightmare, yet I believe that this is the one resource that, if it was available over a period of years rather than months, would make a huge difference to my emotional survival.'

'They assume I'm not happy because I can't accept my impairment and if I deny it it's proof that I'm in denial'

People with physical impairments can also experience disempowering attitudes on the part of counsellors, psychologists, etc. As Rhoda Olkin (1999) and Donna Reeve (2000) have argued, those who offer 'talking treatments' are no more immune from negative and prejudicial attitudes than the rest of society. Disability equality does not figure in professional training in the way that race and gender equality increasingly does. Many 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). Negative attitudes can mean 'there is sometimes oppression within the counselling room' (Reeve, 2000, p. 669). One form that this can take is, as Humerah said, 'assuming that my impairment is the source of all my problems. They assume I'm not happy because I can't accept my impairment and if I deny it it's proof that I'm in denial.' She went on to say, 'I said to my current therapist that if I had a wonder drug I wouldn't want

to be non-disabled, and I wouldn't want to be white, but I would want to not have mental health problems.'

Caroline, who has arthritis, talked of a group therapist who 'makes an issue' of her need for a chair that is higher than those sat on by other members of the group. The other group members 'don't feel awkward ... It's just a slightly higher chair that's easier for me to get up from. But the psychotherapist makes something out of nothing. Everything has some hidden meaning.' She also felt there was a lack of recognition of the effect of physical impairment and a tendency to assume that it was only mental health that explained people's behaviour:

'If I felt physically unwell then that couldn't be taken at face value'

I was always reluctant to ring up and cancel a session because, you know, it's something in your mental state that means you don't want to be ... It's not the fact that you're aching too much and don't want to get out of bed today. You don't want to get out of bed because you don't want to face things. You know, there was always hidden meanings to things. If I felt physically unwell then that couldn't be taken at face value.

Counselling or therapy provided by the NHS is often time-limited and this was not always helpful. As Jack said: 'The counsellor said "Right, we'll have six sessions. It will be on this date" ... and it was sort of over very quickly ... you know going through the motions.' Other interviewees had found that 12 counselling sessions were all that were available through the NHS. Milan, on the other hand, praised the two sessions of 'crisis counselling' he received: 'Because they listened. You know, he was a good counsellor. I only had two sessions, but it was good. And I was quite desperate.' However, a number of people mentioned needing counselling during a crisis but having to wait too long to receive such support.

People with physical impairments experience higher levels of unemployment and poverty, and are therefore less likely

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to be able to afford private counselling or psychotherapy. Ann reported that the psychotherapy that she paid for herself was very helpful but, as she said, ‘I paid a lot of money to go’. When Christine sought private therapy she found it would cost £40 per session and she couldn’t afford it.

Hugh, who has had a physical impairment since birth, valued his counsellor’s approach in comparison with his previous experiences of professionals:

Because the counsellor’s job is to listen, of course, not to moralise, not to say ‘You should be doing this, you should be doing that’ and all that ... All my bloody life I’ve had ‘You should have this, you should do this, you should do that’. And I was pig sick of it.

‘It was somebody helping me to see the wood from the trees, in terms of what I was feeling about everything’

When someone is living with both mental health problems and the effects of physical impairment, counselling can be an important way of addressing all these issues. Naomi appreciated this about the counselling service she received: ‘It was somebody helping me to see the wood from the trees, in terms of what I was feeling about everything.’ She also felt reassured because she felt ‘there was some monitoring going on because it was regular and you could look at the progress ... but also that monitoring didn’t immediately lead to “Well, we’ll increase this drug” or “We’ll decrease that”. It was much more.’

‘Nobody actually said “What’s the matter? Tell me, in your own words, what’s the problem”’

However, not everyone who received ‘talking treatments’ felt that issues relating to their physical impairment were adequately understood. Sharon, who has had a physical impairment since birth, has recently acquired further physical impairments that have significantly curtailed her life. She feels that assumptions made about her pre-existing physical impairment and mental health difficulties got in the way of recognising the psychological consequences of her new experiences. When she had her last mental health crisis: ‘Nobody actually said “What’s the matter? Tell me, in your own words, what’s the problem.” There were often

assumptions about what the problem was. Nobody bothered asking.' She tried talking to a counsellor about her feelings of 'isolation and loss of independence' but 'she sort of said:

Well, I can't do anything about that. I said I'm not saying you can do anything about it, but you could meet me where I am, you can let me talk through the issues ... It has been quite a marked change in my life, and nobody's helping me address that. You know, I went from, yes, having a physical disability, through cerebral palsy, but being able to use public transport, to not going out at all unless I [have someone with me] which is a big difference.

Summary

Privately funded counselling or therapy received the highest rating of any mental health service among our respondents. However, high levels of poverty and unemployment among disabled people mean that such a service is beyond many people's means. People also experienced difficulties finding a physically accessible therapist in either the private sector or the NHS, and NHS 'talking treatment' was often time-limited. Sometimes, unhelpful assumptions were made about links between their mental health and their physical impairment. When people valued the support they got from a counsellor or therapist, it was usually because they felt treated as 'a whole person', and because their perspective was both listened to and respected.

7 Purchasing support using direct payments or own resources

Currently, the main focus of community care policy for people with physical impairments is to increase the take-up of direct payments (cash payments in lieu of community care services) so that people can purchase the support they need to go about their daily lives. The Government also wishes to extend the use of direct payments to groups of service users who have, up until now, been under-represented among direct payments users. This includes people who use mental health services and a number of the organisations that received funding from the Department of Health's Direct Payments Implementation Fund are specifically targeting this group.

In theory, having the resources to purchase your own support should create more choice and control over how personal assistance and other support needs are met. Certainly, people with physical impairments have long campaigned for direct payments and generally express a high level of satisfaction with the difference this makes to their lives.

However, among our respondents who used either direct payments or their own resources to purchase personal assistance, there was a surprisingly high level of dissatisfaction. Twenty-one people purchased their own support to meet needs relating to physical impairment by employing a personal assistant (PA) or using an agency. A third of the 21 people concerned rated the service as either good or very good while just over half rated it as either poor or very poor. Seventeen purchased their own support in order to meet their personal assistance needs relating to mental health and, of these, 70 per cent said the service was either poor or very poor.

**'I feel much happier,
much more fulfilled'**

An example of the positive difference that direct payments can make was that given by Laura, who had previously been reliant on her husband but who now employs her own helpers to assist with both her physical and her mental health support needs:

Purchasing support using direct payments or own resources

I can go shopping again, I can buy presents for my grandchildren, my family. And, also, the house can be different. And if I want to try a recipe or something then I can do it with my PA. And it's doing things again. I can be in charge of any of the things that I used to be in charge of. I'm not necessarily doing them myself, but I'm controlling what is going down. And I feel much happier, much more fulfilled. And I feel there's not a lot that I can't do now, that I could do before. Well, you know, within obvious restrictions, I feel that it's there if I wanted to do it.

A comprehensive assessment (which covered mental health as well as personal assistance needs) by her social worker had also picked up that she and her husband needed a break from the day-to-day stresses of their life together. She had been able to use direct payments not only to have a break from each other but 'also we've been able to go away together and make creative use of respite. That's been brilliant.'

Daisy, on the other hand, used a combination of direct payments and her own resources, and experienced a number of difficulties. First, she found the administration of direct payments a daunting task: 'I've had a real struggle with doing the direct payments and employing staff and all that sort of thing.' She is hoping that she will get help from a local organisation: 'There's a woman working for them, now, who's going to help me to recruit somebody for the mornings to get over this ... And I'll talk to her about recruiting for the evening as well. But I don't have the confidence to recruit someone to do my personal care.' Second, she felt disempowered by the unhelpful attitudes towards her mental health difficulties held by some of the people she employed. And, third, she has had a lot of problems with using agencies, as they often do not send workers at the time that she wants them and the workers themselves are not always suitable.

'I've had a real struggle with doing the direct payments and employing staff and all that sort of thing'

These are problems that have also been highlighted by other users of direct payments. There are also specific issues for people with mental health support needs that need to be

‘If they come out to see you when you’re not doing too bad and they cut your hours, what happens when you go down?’

addressed in the implementation of direct payments (Davidson and Luckhurst, 2002; National Centre for Independent Living, n.d.). For example, if someone’s state of mental health improves, then there is a tendency to assume they’ve ‘got better’ and for support services to be withdrawn. People like Ingrid and Humerah, however – both of whom use direct payments to meet their mental health support needs – feel that it is ongoing support that enables them to function, just as ongoing physical assistance may be required if someone needs help with transferring in and out of a wheelchair. Ingrid is worried that, if her state of mental health seems to have improved, then her hours will be cut and she won’t have the support she needs. ‘I think I’m due for a review. I’m always thinking, “oh god, what if they come, what if they cut my hours?” ... If they come out to see you when you’re not doing too bad and they cut your hours, what happens when you go down?’

‘when my mental health support worker is here I lie in the bath for about an hour, and we chat or we listen to music’

It may also be the case that it is particularly difficult for people with mental health support needs to get the type of support they require if they use agency staff. Yet poor mental health may also make it more difficult to deal with all the hassles that go with recruiting and employing support workers, so people with mental health support needs may be more likely to use agencies. Patricia refused direct payments because she didn’t feel able to manage them. In contrast, Humerah receives support from a voluntary organisation to recruit support workers who are then paid by the organisation, so Humerah does not have to deal with the practicalities of being an employer. At the same time, this enables her to recruit people who she judges will be able to give her support to meet her mental health needs. For example, Humerah described the different qualities she needs from the support workers whom she recruits to meet her mental health needs in comparison with the workers sent by an agency to meet her physical needs. She uses both types of worker to assist her having a bath but ‘with the agency worker it’s literally just in the bath, cleaned, out the bath or maybe just soak for about five minutes. Whereas when my mental health support

worker is here I lie in the bath for about an hour, and we chat or we listen to music ... it's the only way I relax and it helps my head with the voices.'

However, other users of direct payments among our respondents either relied on agency workers or recruited and employed their own staff with little or no support. This may account for the high levels of dissatisfaction with direct payments.

Summary

For people with both physical impairments and mental health support needs, direct payments – in theory – offer the type of flexible and holistic response to needs that many of our respondents said they valued. However, there was a surprisingly high level of dissatisfaction with the services purchased by using either direct payments or own resources. This may have been related to the use of agency services and to a lack of appropriate support to administer direct payments. If direct payments are to remain an integral part of community care policy, more attention needs to be paid to how people with physical impairments who also have mental health support needs can be supported to use them.

8 Self-help, advocacy and complementary therapies

A number of interviewees spoke of turning to self-help or complementary therapies because of the inadequacies of mental health and disability services, and GPs. Some had also used advocates to help them articulate their needs to statutory services and/or to make complaints.

About half of those returning the questionnaire had used self-help groups. Among these, about a third rated them as either good or very good and a similar proportion either bad or very bad, with the remainder scoring them as average. Those who were interviewed were not representative of this mixed experience of self-help groups, as none of them recounted negative experiences.

‘There’s a natural understanding there when you go to a self-help group, most times’

Milan said he appreciated self-help groups ‘because they allow people to talk ... There’s a natural understanding there when you go to a self-help group, most times. People do understand what you’re talking about ... And I think at the very least they can bring you from the point of despair and fed-upness and depression and anxiety, where it’s crippling to where actually you can cope much better and make you laugh about things and get on with things.’ He contrasted the more equal relationship between service users with the relationship between professionals and service users: ‘People understand each other and it’s not us and them ... There’s much less hierarchy there.’

‘each person’s just been accepted’

Rabani, who was very pessimistic about the ability of mental health services to help him, was more positive about self-help groups, which he described as ‘very good, they try to help’. He regularly visited the offices of a local disability organisation and found them helpful and welcoming. For the last seven years, Caroline has facilitated a weekly support group, together with a CPN. ‘We’ve had a number of people with different impairments in that group. And each person’s just been accepted. There’s never been any issue made of their particular impairment. And the building’s pretty

accessible. And there's never been a problem.' In the past, she has attended other self-help groups where 'they've just accepted me quite openly and my physical problems have never been an issue'.

Laura felt more peer support should be funded, especially to help people use direct payments. She is involved in a local disability organisation that runs a peer support group for people using direct payments: 'And that is very well attended. And, especially for people new to direct payments, it's really the experience of others that they find that they can relate to that's better than anything else.'

The key characteristic that people appreciated about self-help groups was that they felt accepted and listened to. This was also a characteristic appreciated of complementary therapies. Partly, this was related to such services generally being ones that people chose to pay for and, partly, to the more holistic approach used by complementary therapies. However, as with self-help groups, not everyone had good experiences by any means.

Thirty-seven people who returned the postal questionnaire said they had used complementary therapies or treatment for reasons relating to their physical impairment (45 per cent of the total). Thirty-seven per cent rated their experience as either good or very good and almost the same number as either bad or very bad. Twenty-five said they had used complementary therapies or treatment for reasons relating to their mental health. Among these, more people had bad or very bad experiences (44 per cent), while 32 per cent rated their experience as good or very good. Again, the sample who were interviewed did not reflect this pattern of experiences of complementary therapies in that the experiences they told us about were almost entirely positive.

Patricia gave the highest ratings to aromatherapy and homeopathy in terms of responses to her physical impairment. She thought it was important that they are

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‘They were helpful. But it was very costly, I can’t afford it’

‘mainstream services that anybody can access. They’re not specifically for disabled people so I fit in with that better than if it was specifically for disabled people ... I’ve had aromatherapy just by going, like anybody else would go, to a salon.’ For others, however, the cost of such services was prohibitive. Rabini, for example, had tried complementary treatments and said: ‘They were helpful. But it was very costly, I can’t afford it.’

‘my experience of using advocacy services was positive and empowering’

Advocacy services were the other type of non-statutory service that we asked about. About four out of ten respondents used such services and just over 40 per cent of these rated the experience as either good or very good. Again, some of the interviewees illustrated what they appreciated from advocacy services. Caroline described an experience where advocacy services were both accessible and empowering:

I contacted the local advocacy service and asked if an advocate would accompany me on a visit to my GP in order to help me request the treatment I wanted to try. I met the advocate at their office, which was fully accessible. In fact, several of the advocates were themselves disabled people. I explained what I wanted to ask for and said why I found it difficult to get my point across to my GP. The advocate was helpful in suggesting ways to approach the situation. When I attended my GP’s surgery the advocate went with me and prompted me as necessary so that I could make my request for treatment. She gave me the confidence I needed and appeared to have a good understanding of mental health issues. She was there to support me and did not try to take over the situation by speaking for me. She checked with me before we left the surgery that I felt I had been listened to by the doctor. Thus my experience of using advocacy services was positive and empowering.

Milan described the help he received from an advocate in making a complaint: 'He just preserved my self-esteem. He stuck up for me and that's what I needed.' David praised the tenacity of his advocate: 'He was willing to sit down and hit the phone and hammer away, at anyone and everyone, until he got reassurances that I would be seen to, that I would receive help.'

Hugh said of the advocacy service he used: 'They're brilliant because it's a one-to-one advocacy ... And it takes all the strain off. It's really a positive thing.' He also appreciated that many of the people working for the advocacy service were disabled themselves, 'so they understand'.

Summary

There were mixed experiences of self-help groups, complementary therapies and advocacy services among those responding to the postal questionnaire. This chapter has highlighted what interviewees appreciated about these services but their positive experiences are not representative of the majority of respondents.

There has been some recognition of the value of self-help groups and peer support in recent years. For example, the publication of *The Expert Patient: A New Approach to Chronic Disease Management* (Department of Health, 2001) marked an official recognition that people living with chronic conditions (whether associated with physical or mental illness) benefit from better information, training in self-management and peer support. By January 2003, 144 Primary Care Trusts had joined the Expert Patients Programme and were planning or running training in self-management programmes for people living with a variety of chronic conditions.

'One town for my body, another for my mind'

Other forms of self-help have not received such official recognition and the more traditional types of self-help groups continue to struggle for existence and funding. A review of self-help interventions found that, while self-help approaches are popular with many people with mental health support needs, there is insufficient evidence to draw firm conclusions about their efficacy (Lewis *et al.*, 2003). Unfortunately, our research does not provide firm evidence one way or the other of the value of such interventions for people with physical impairments who also have mental health support needs.

9 Issues arising

Fragmentation of needs

People experienced a fragmenting of their needs across physical disability and mental health services. Sometimes this was a stark physical division of services – as one interviewee said, ‘I have to go to one town for my mind, another for my body’. However, this fragmentation also took the form of a failure of mental health services to take account of needs relating to physical impairment, and a corresponding failure of physical disability services to take account of mental health experiences and support needs. There was also a lack of communication between the two types of services.

‘I have to go to one town for my mind, another for my body’

Caroline had recently been admitted to a general ward for a blood transfusion. She needed support in terms of her mental health but, although the mental health service and general ward are on same site, they are run by different health trusts and there was no communication between them. Naomi also found a lack of communication between mental health and medical services. She would have been happy for there to be communication between the medical and rehabilitation services that treated her following a car crash, and the community mental health services that she had been using at the time of her accident. ‘I don’t understand why they didn’t,’ she said. The fact that there was no communication also, she felt, meant that mental health services ‘didn’t know enough [about the effects of her physical injuries] to be able to help me to think things through’.

When the disabled person is also a parent, there can be an even greater fragmentation of needs and response. Eileen, who has a degenerative physical impairment and who had post-natal depression after the birth of her third child, described her family’s experience. ‘We got referred to the Mental Health Team, they brought in the Adult Social Services Team to cope with my needs, and then we had to bring in the Child Care Team to cope with my baby’s needs. And nobody

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worked together to think of the family's needs.' She found it very frustrating that the different services didn't communicate with each other:

Nobody talked to each other about anything that was set up or organised so we were finding that things were repeated a lot and there was a lot that people didn't know. We tried to organise meetings with everyone together, and because I had like a mental health advocate and the health visitor, it's so hard to get people ... together so that it becomes quite impossible sometimes.

'That's not in our remit. We don't do that'

The division of responsibilities has meant that some professionals and service providers have said to her: 'That's not in our remit. We don't do that.'

One person who returned the postal questionnaire wrote of how difficult some health professionals seem to find it to respond in a holistic way: 'Doctors in particular seem to want patients to have either a physical problem or a mental health problem, but not both. Psychiatrists I have seen have tended to ignore my physical difficulties, or they have focussed on them as the cause of all my problems.' Another respondent wrote: 'It is very difficult when one has mental and physical health needs. The mental health team do not acknowledge the physical and the physical team do not acknowledge the mental. Both act on each other to make a very difficult life.'

'My care manager doesn't seem to know anything about mental health services or how I can access them'

Poor communication and co-ordination between physical disability and mental health services can also create barriers to accessing services. One interviewee described being stuck in the 'silo' of physical disability services: 'My care manager doesn't seem to know anything about mental health services or how I can access them.' Another asked his social worker from the Community Mental Health Team if she could refer him for an assessment from the physical disability team, because there are times when he needs help with getting up and dressed, only to be told: 'you don't look disabled enough'.

Other sources of exclusion and discrimination

Nine per cent of respondents to the postal questionnaire gave their ethnic origin as African-Caribbean, Asian or mixed parentage. Fourteen per cent said that they were gay or lesbian and 7 per cent bisexual. Two-thirds were women.

Some of our respondents mentioned factors other than physical impairment or mental health needs that they felt influenced their experiences of services. Rabani, for example, was strongly of the view that his religion and culture had significant implications for his state of mental health, and did not feel that either mental health or disability services understood this. Humerah experienced racial stereotyping in terms of service providers' assumptions about her family's involvement in her care: 'They thought my family must be involved with looking after me and should therefore have access to information about me and that was a real problem because self-harm and attempted suicide are such a cardinal sin within the Muslim community.'

'They thought my family must be involved with looking after me and should therefore have access to information about me'

Daisy reported that a care worker reacted negatively to her lesbian relationship and she felt that, when she was an in-patient, her partner was not accorded the same recognition that a heterosexual partner would have been. A number of respondents felt they were discriminated against on the grounds of their age. Christine, for example, said that one disability service had an upper age limit of 45 and, at 54, 'I was told I was too old for treatment'. Almost 40 per cent of our respondents were aged over 50 and only 7 per cent were 30 or under.

'I was told I was too old for treatment'

There has been some attention paid to these sources of unequal treatment in recent years. People with physical impairments who are from black and minority ethnic communities are likely to experience the same discriminatory treatment within mental health services, as has been

highlighted in recent reports (Sainsbury Centre for Mental Health, 2002a; National Institute for Mental Health in England, 2003). The recent consultation and implementation guidance on a strategy for women’s mental health recognised that gender influenced experiences of services and that there is a need to develop gender-sensitive services (Department of Health, 2002c, 2003b). Disabled people who are gay, lesbian or bisexual are also likely to experience the prejudice and discrimination described in Mind’s recent study (King and McKeown, 2003). The Government has itself recognised that discrimination on the basis of age occurs within mainstream health services (Department of Health, 2002d), although there has not been the same attention paid to this issue within either mental health or disability services.

It is also important to emphasise that experiences and needs relating to physical impairment are particularly relevant to black and minority ethnic communities, women and older people, as levels of physical impairment are higher among these groups than among the general population. Similarly, poor mental health is more commonly found among women and older people, gay men, lesbians and bisexuals, and among some minority ethnic groups in comparison with the general population. The failure of services to adequately meet the needs of people with physical impairments who also have mental health support needs therefore has a particular impact on these groups.

Impairment, disabling barriers and mental health

There is a complex relationship between people’s experiences of impairment and disabling barriers, and their state of mental health. Although some people found that service providers recognised the influence of negative attitudes and unequal life chances (i.e. disabling barriers) on their mental health, it was more common for assumptions to be made about a link between impairment *in itself* and

depression, and generally people found these assumptions unhelpful. In addition, services themselves were sometimes delivered in ways that were disempowering and that created or exacerbated distress.

Sharon was one of a number of respondents who felt that mental health professionals made inappropriate assumptions that her mental health difficulties were linked to impairment. She has limited mobility as a result of cerebral palsy and said 'There is a desire on the part of medics, psychiatrists, psychologists to link, I think too readily, my physical disability with mental health needs.' You know, I'm depressed because I have a physical disability ... How the hell do they know! They never ask! ... I'd quite like to get a gang of them, really, in a room and say, "Look, you know, I'm quite independent, I'm sort of reasonably articulate ... and by the way, my brain's not in my backside".' Humerah said that she wishes that professionals did not 'assume my physical impairment is the source of my distress ... For me my physical impairment does not cause pain or discomfort other than created by attitudinal, environmental and institutional barriers, whereas my mental health impairment is excruciatingly painful and is the thing that stops me functioning and makes the roof fall in over and over again.'

'There is a desire on the part of medics, psychiatrists, psychologists to link, I think too readily, my physical disability with mental health needs'

Respondents did, however, talk of a link between their state of mental health and their experiences of the disabling barriers of negative attitudes and unequal access. For some people, their experience of disabling attitudes had a clear impact on their mental health. Adam, who has cerebral palsy and does not use speech, used to have a 'breakdown' each October before the start of (mainstream) college and university because of the anticipation of exclusion: his experience was of '300 students just looking away'. Hugh was one of a number of people whose childhood experiences of discrimination left a legacy of anger and distress. 'I had a lot of crap, you know, both mentally and physically, from people,' he said, and felt that he needed help to get at 'what is inside you ... [so] you're not so angry at the injustices.'

‘One town for my body, another for my mind’

Jack had been in special schools since the age of two-and-a-half and linked this experience to his history of depression and anxiety.

Lack of educational and job opportunities can create mental health difficulties, as can a lack of close relationships. There was a feeling among some people that professionals had low expectations of disabled people in all these areas. Patricia felt that, if she had had the same opportunities as a non-disabled person, she wouldn't experience depression associated with lack of self-esteem and self-confidence. 'I just think if I had had a better education ... I'd be doing something and I'd be with people that I could have a conversation with on my level, and achieve things, and do good things, and then feel that I was a valuable member of society.'

Naomi had severe and long-term depression before a car crash left her with significant physical injuries. She feels, however, that her mental illness is now seen as a consequence of her accident:

When things have been bad, it's always like a ready-made excuse for it ... before when I had periods of depression ... I saw mental health services and things ... and now when I have what I know is very similar to what I used to have, then people don't see that as problematic ... They just see it all as part and parcel of the results of the accident.

‘Once you acquire a disability that control thing is so difficult to get your head around’

For some people, bad experiences of services exacerbated their physical impairment and/or their state of mental health. Having choice and control over how assistance is provided is key to independence for people with physical impairments. Being denied choice and control over assistance can create or exacerbate anxiety and depression. As Daisy said, 'All these things have just been taken completely out of my control. Once you acquire a disability that control thing is so difficult to get your head around.' It is not necessarily being unable to do things for yourself that causes the distress but the denial of

control over the assistance needed. 'My idea for establishing my independence', said Daisy, 'was I wanted somebody from 7.00 till 9.00, five days a week, and 8.30 to 10.00, two days.' However, although the agency contracted by social services started off by providing assistance at these times, they then changed the rota. When Daisy complained, their reaction was 'Like it or lump it, take it or leave it, that's the best we can do'. As Humerah said, mental health services need to recognise 'that when things are hard with your physical assistance care package it can knock you for six emotionally'.

Adam experienced depression when the residential home he lived in changed their rules so that he could no longer be lifted in the way he preferred. Instead a hoist was used, which created physical difficulties and caused considerable distress. Adam does not use speech and, since the age of two, relied on a word board for communication. In his twenties, he finally received an assessment for a communication system but this was not without its difficulties. One of his mental health crises came at the point when the communication system for which he had been waiting for such a long time arrived without an essential part. It took him a year before he was willing to risk giving it another try.

It was quite common for people to feel that their experiences of physical difficulties or illness were not believed and were put down to their state of mental health. Wendy spoke of how 'My physical experiences are seen as delusions'. In the case of Ann, her symptoms of breast cancer were interpreted by the mental health team as 'delusional'. Ken said that, when he was admitted to a psychiatric hospital, pain associated with arthritis and migraines were 'interpreted as mental health' problems.

Many of our respondents had similar experiences and found that their physical impairment, or aspects of it, were interpreted as part of their mental illness. Having experienced this for years, Laura was relieved when she met a psychiatrist who did not make such an assumption:

'My physical experiences are seen as delusions'

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He was helpful because he had a certain understanding of things like ME [myalgic encephalomyelitis]. And he could understand why I wanted a diagnosis. And I was also wanting to know, at the time, if I could really make a difference, if I was really subconsciously wanting this ... I really wanted to know if [I had] a sort of need perhaps to be ill or whatever. But he didn't think so at all, which was very nice. He also said that he thought I was coping very well ... He made me think, 'yes I am alright. I'm not doing it to myself.'

Some physical experiences associated with impairment, particularly pain, can impact on mental health support needs. However, this is not always recognised by mental health services. Ken spoke of how ‘you get irritable and angry and bad tempered’. In contrast, when pain relief works, he said, ‘I become relaxed and get things more in proportion because I'm not having to fight my own body’. A number of respondents experienced pain, which, if untreated, deprived them of sleep and this could cause and exacerbate distress. The inadequate treatment of pain when people were admitted to psychiatric hospitals – as discussed previously in this report – could exacerbate a mental health crisis.

Many more opportunities are required for people themselves to articulate what impairment, disability and mental health difficulties mean to them, and what would help. Humerah said that services ‘need to acknowledge and work from our starting point rather than making assumptions and judgements about us based on the fact that we have physical impairments. Our lives and histories are complicated and therefore a solely medical or social model approach is unhelpful. The crucial question must be what things mean to us and what impact it has on our emotional life.’

Conclusion

In recent years, there have been various policy developments that address separate aspects of our respondents' experiences. There has, however, been little recognition that an individual can have both mental health support needs *and* physical impairments.

This compartmentalising of policy has had clear implications for those who participated in this research project. Two-thirds of people returning the questionnaire said they experienced difficulties using mental health services because of their physical impairment and two-thirds said they had difficulties using physical disability services because of their mental health problems. They identified a range of problems with both types of service and their levels of satisfaction with these services seem to be significantly lower than either mental health service users generally (Rose, 2001) or users of physical disability services generally (Social Services Inspectorate, 2003).

Negative attitudes were a particular problem, experienced across the whole range of services. People felt that, because they had both physical impairments and mental health support needs, service providers were even less likely to respect their knowledge and opinions. Yet it seemed from the interviews that most people had quite a lot of insight into their needs and how to meet them.

Needs relating to physical impairment were commonly unrecognised within mental health services. Some services were physically inaccessible and there was a clear failure in a number of instances to comply with the Disability Discrimination Act by making 'reasonable adjustments'. Sixty per cent of those returning the postal questionnaire had experienced in-patient psychiatric care and, in many cases, the failure of acute services to meet needs relating to physical impairment was particularly shocking. People often had considerable problems in terms of the physical environment of psychiatric hospitals and the facilities within them. Some also had difficulty getting their personal assistance needs

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met, and this was often because of staff attitudes. Medication related to physical impairment was usually withdrawn on admission and was not always made available when they needed it. If the medication was needed for pain relief, this withdrawal and lack of control caused significant distress.

There was also a high level of reported dissatisfaction with physical disability services and a general feeling that service providers do not recognise or understand mental health support needs. Services could themselves be disempowering and exacerbate mental health problems. There was little evidence of good communication between physical disability and mental health services.

GP surgeries were not always physically accessible, and respondents reported that GPs and receptionists do not always take physical access needs seriously enough. A number of respondents found that mental health issues were not addressed or that GPs seemed out of their depth when faced with someone who had both a significant physical impairment and mental health needs. Some people felt that having a mental health diagnosis meant that GPs and other health professionals did not take physical symptoms seriously.

There was a surprisingly high level of dissatisfaction with the support that people received when they used either direct payments or their own resources to either employ personal assistants or use an agency. This was particularly the case among those who used such sources to meet mental health needs. People were discouraged from using direct payments because of the administrative tasks associated with being an employer, and using agencies did not always provide an adequate alternative.

Perhaps the clearest message across all services was that the attitudes of individual workers could make all the difference. Some people experienced attitudes that robbed

them of their dignity and denied their experience of their bodies and minds. Fear or ignorance often dominated response to needs and there was a corresponding reluctance to acknowledge disabled people's own expertise. A failure to acknowledge or meet access needs could mean that people were literally shut out of services or at best received poorer quality services.

In contrast, positive attitudes could enable someone to use a service even in spite of an inaccessible environment. Recognition of needs relating to both mental health and physical impairment could mean that a service made all the difference to someone's life. Yet individual workers who made this difference were often struggling to do this against significant barriers created by structures, procedures and environments.

The experiences of those who participated in this research highlight some key issues for policy makers and service providers. We conclude this report by identifying some action that urgently needs to be taken in order to ensure that services enhance the quality of people's lives.

Key issues for consideration

- Mental health services should recognise that a proportion of their service users have physical impairments. Needs relating to physical impairment must be taken into account in order to ensure equal access to services and treatments, and to adequately address mental health needs. Compliance with the Disability Discrimination Act should be monitored across all mental health services.
- Urgent action is required to address the needs of people with physical impairments in acute psychiatric services. Attention needs to be paid not just to the physical environment but also to other 'reasonable adjustments' to the service provided, and to the treatment of physical conditions and symptoms (especially pain) while someone is on a psychiatric ward.
- 'Talking treatments' and other mental health services such as crisis and residential services must be made accessible to people with physical impairments. This would involve addressing the physical environment, providing personal assistance where required, as well as training to counter harmful attitudes among professionals and to encourage more helpful responses.
- When the Commission for Healthcare Audit and Inspection, the Commission for Social Care Inspection, the Care Standards Inspectorate for Wales, the Health Advisory Service and other organisations review and monitor mental health services, the standards applied need to take into account the fact that a proportion of service users will have physical impairments. Inspections and reviews should assess the extent to which this group is afforded equal access to services.
- There is an urgent need for changes in practice concerning the prescribing of medication for people with physical impairments who also have mental health support needs. Those prescribing, whether in a primary care, specialist or acute service setting, should be more aware of the possible

effect on physical impairment of medication prescribed for a mental illness, and vice versa. Attention also needs to be paid to possible problems caused by combining medications. It is important that services recognise and act on the need for careful review and co-ordination of medication. Professionals also need to recognise the limits of their knowledge and seek advice and information where appropriate. They should pay particular attention to service users' experiences of medication.

- Front-line physical disability services, such as social work/care management teams, day centres and rehabilitation services, need to work much more closely with mental health services in order to meet the needs of those service users who also have mental health support needs. Care managers and other workers require local protocols for joint working, and information about mental health services and how to access them.
- Those involved in designing and delivering pre- and post-qualifying training for health and social care workers should recognise that service users may have a range of needs, and this should be reflected in course content and delivery. All training should promote an acknowledgement of service users' expertise about their needs. Disability equality training should be a basic requirement for those working in health and social care.
- People with physical impairments who also have mental health needs stress that it is unhelpful if professionals make assumptions about the relationship between mental health and physical impairment. Sometimes there is a connection and sometimes there isn't. Many times it is the experiences of negative attitudes and social exclusion that have a bigger effect on mental health than physical impairment in itself. Mental health and disability professionals should seek information from service users about the effect of their impairment – such as pain or reduced mobility – on their state of mental health, and vice versa.

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Appendix

Summary of results from the postal questionnaire

Eighty-three people returned completed questionnaires about their experiences of using services as people with both physical impairments and mental health support needs. Questionnaires were returned from people living in England and Wales.

Characteristics

The mean age of people returning questionnaires was 45. The largest group of people were those aged between 50 and 59, who made up a third of the total. Roughly a quarter were aged between 30 and 39, and another quarter aged between 40 and 49. Only 7 per cent (six people) were less than 30 years old and 5 per cent (four people) aged 60 or over.

Only a third (36 per cent) of those returning questionnaires were men.

The majority gave their ethnic origin as white (82 per cent), while seven people (9 per cent) gave their ethnic origin as African-Caribbean, Asian or mixed parentage. Seven people ticked the box marked 'other' but it would appear, from the information they then gave about what this meant, that they were 'white' (e.g. white European, white Welsh).

In terms of household type, about half (48 per cent) lived alone, and a quarter with a partner and no children. Three lived on their own with children (4 per cent), while six (8 per cent) lived with a partner and children.

Over two-thirds (70 per cent) responded that they were heterosexual, 14 per cent that they were gay or lesbian and six people ticked 'other'.

In terms of physical impairment, there was a wide range of diagnoses and conditions, and it was difficult to classify them. Nineteen (22 per cent) out of 83 (16 per cent) respondents had a congenital impairment such as cerebral palsy or spina bifida. Another 14 experienced mobility impairments as a result of arthritis or back problems. Three had multiple sclerosis and two ME. For four respondents, their physical impairments were caused by accidents and, for one, they were caused by cancer. The remainder (40) recorded a range of diagnoses, some of which – such as diabetes and angina – may have been associated with long-term mental illness and associated factors.

We asked respondents about what mental health diagnosis they had been given. Thirty-two people recorded depression as the main diagnosis, 14 mentioned bi-polar disorder (or manic depression), while nine mentioned schizophrenia or psychosis. The remainder recorded a number of diagnoses such as eating disorders, obsessive compulsive disorder, personality disorder and addiction.

Experiences of using disability services

We asked whether people had experienced difficulties in accessing or using services for disabled people because of their mental health support needs. About two-thirds said they had. Of these:

- over two-thirds said this was because there had been little or no recognition of their mental health support needs
- almost two-thirds identified negative attitudes among staff
- half felt that assumptions or judgements about their mental health support needs prevented them from using a disability service

- just under half said that they didn't use disability services because they were either not available or could not afford them
- a third identified negative attitudes among other service users as a problem.

People were asked to indicate which services they used and to rate them on a scale 1 to 5, where 1 was very good and 5 very poor. Of those who had a care manager, social worker or key worker from a disability service, half rated the service as poor or very poor, and almost one in five as very good. The services that the greatest proportion of respondents rated as good or very good were:

- physiotherapy services (46 per cent of 46 respondents)
- advocacy services (44 per cent of 43 respondents)
- self-help groups or services (40 per cent of 45 respondents).

The services that the greatest proportion of respondents rated as poor or very poor were:

- employment support (87 per cent of 32 respondents)
- home care services (66 per cent of 36 respondents)
- residential homes (which could have included respite care) (60 per cent of 15 respondents)
- supported housing (56 per cent of 23 respondents).

The most mixed views were received from those who had purchased their own support by employing a personal assistant or using an agency. A quarter (24 per cent) of the 21 people concerned rated the service as very good, while 43 per cent rated it as very poor.

Experiences of using mental health services

We asked whether people had experienced difficulties in using mental health services because of their physical impairment/disability. Two-thirds (68 per cent) said they had. Of these:

- 79 per cent said that there had been little or no recognition of their needs relating to physical impairment
- two-thirds (66 per cent) identified negative attitudes held by staff
- over half (58 per cent) said that personal assistance and/or equipment was not available
- half (49 per cent) said that buildings were inaccessible
- fewer than half felt there were difficulties because of assumptions made about their impairment (45 per cent)
- 36 per cent said that mental health services either were not available to them or they could not afford them, and 23 per cent said that they had experienced negative attitudes from other service users.

In terms of how people rated the mental health services they used, the services that the greatest proportion of respondents rated as very good or good were:

- private therapy or counselling (59 per cent of 32 respondents)
- alcohol/drug rehabilitation services (45 per cent of 11 respondents)
- advocacy services (44 per cent of 41 respondents)
- NHS psychology or counselling services (42 per cent of 60 respondents).

The services that the greatest proportion of respondents rated as very poor or poor were:

- crisis services (81 per cent of 32 respondents)
- PA or agency funded by direct payments or self (70 per cent of 17 respondents)
- employment support (69 per cent of 26 respondents)
- residential home (65 per cent of 17 respondents).

The most mixed views were received from those who had used advocacy services where a quarter (27 per cent) of the 41 people concerned rated the service as very good, while 24 per cent rated it as very poor; and from day centres or drop-ins, where 20 per cent of the 45 people concerned rated the service as very good, while 38 per cent rated it as very poor.

Experiences of GPs and medication

We asked about people's experiences of their GP's responses to both their mental health needs and their needs related to physical impairment. Almost half (48 per cent) of the 75 people who responded said that their GP's response

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to needs relating to physical impairment was either good or very good and a third (35 per cent) that it was either poor or very poor. This situation was more or less reversed when they rated their GP’s response to mental health needs – 45 per cent said it was either poor or very poor while 36 per cent said it was either good or very good.

Fifty-eight per cent of respondents said that medication prescribed for mental health needs had had a negative effect on their impairment, and most of these people (83 per cent) said they had not been warned that this might happen. More than half (56 per cent) reported that the negative effect was not recognised by GPs or other professionals.

A smaller percentage – 45 per cent – reported that medication related to their physical impairment had had a negative effect on their mental health. Again, most (77 per cent) had not been warned this might happen and half (51 per cent) reported the effect was not recognised.