

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

People with physical impairments who also have mental health support needs have tended to be overlooked by both policy-makers and those commissioning services. Research by Jenny Morris on this group of people's experiences found high levels of dissatisfaction with services and some key areas of concern.

-  The majority of respondents said they had difficulty accessing mental health services because of their physical impairments. The majority also had difficulty using physical disability services because of inadequate recognition of mental health needs and negative attitudes amongst staff towards mental health issues.
-  In-patient experiences were often characterised by inaccessible physical environments and a lack of assistance for even simple things. There was a lack of understanding of the assistance that people needed, and staff were often too busy to provide it.
-  Medication required for a physical condition was commonly withdrawn on admission to a psychiatric ward and was not always available when needed. This caused considerable distress, particularly when the medication was required for the control of pain.
-  Community mental health services were appreciated when needs relating to physical impairment as well as mental health were addressed. However, this was unusual. Staff were often unfamiliar with needs relating to physical impairment and this could be associated with unhelpful attitudes.
-  There was commonly poor or no communication between mental health and physical disability services. Many respondents found that services accessed because of physical impairment ignored mental health issues; some staff had negative reactions to such needs.
-  Medication given for mental health needs often had an impact on physical impairment, but most people said they had not been warned about these potential effects.
-  'Talking treatments' received the highest rating of any service, but it was often difficult to find an accessible and, within the private sector, affordable therapist or counsellor.
-  When people were asked what they wanted from mental health and physical disability services, they said they wanted to be seen as "a whole person", with attention paid to both mental health needs and those relating to physical impairment. They wanted services and professionals to communicate and work together, and easy access to flexible services which could address individual needs. Above all, they wanted to be listened to and treated with respect.

## Introduction

Increasing attention has been paid to how people with mental health support needs, and people with physical impairments, experience services. However, policy-makers and service providers tend to overlook individuals who fall into both 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 include: higher rates of poverty and unemployment, which are themselves associated with poor mental health; the mental health legacy of the greater risks of abuse experienced by disabled children; 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.

There is also evidence of a link between poor physical and mental health and increasing acknowledgement that long-term mental health problems are correlated with conditions such as heart disease and diabetes. Yet there has been little recognition that such conditions can result in physical impairment (such as mobility difficulties) and the implications of this for mental health services. Amongst those commissioning physical disability services there has been little recognition that some service users also have mental health problems, or the consequences of this for meeting needs.

Within both mental health and physical disability services, there have been pressures for inter-agency and inter-disciplinary working. However, these policy developments have not fully recognised that people who use services may have both mental health needs and physical impairments.

This research asked people with physical impairments who also have mental health support needs about their experiences of accessing mental health and physical disability services. They identified a range of problems with both types of service, and their levels of satisfaction seemed to be significantly lower than that found in other surveys of mental health service users and users of physical disability services.

## Mental health services

Two-thirds of 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 amongst staff. In-patient experiences were often characterised by a lack of physical assistance for even simple things. For Caroline, who has arthritis:

**"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."**

Humerah, a wheelchair user, fell and broke her leg because of the unsuitable environment. Jane found the combination of a physically inaccessible environment and lack of assistance distressing. Although staff told her to ask if she needed help, she found that when she did, they said they were busy.

**"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. The distance down to breakfast was just about the limit of my walking, but I'd be shattered when I got there. I couldn't serve myself with the meals because it was the sort of situation where you queued 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. I couldn't manage that."**

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, painkillers were taken away from him. 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.

Community mental health workers were often unfamiliar with physical impairments, and the assistance 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. Sharon has cerebral palsy:

**"They don't know how to say to me 'What help do you need? Do you need help into the building' - simple things like that... They seem to forget that a bit of physical help into a building might make a difference."**

A number of respondents found that a lack of familiarity with physical impairment amongst mental health staff resulted in disempowering attitudes. A few people, however, praised individual workers. Laura, for example, praised a social worker from her Community Mental Health Team whose assessment covered needs relating to both her physical impairment and her mental health.

## Physical disability services

Two-thirds of respondents said they had difficulties with using physical disability services. There was often inadequate recognition of mental health needs and negative attitudes amongst staff towards mental health issues. These problems were compounded by generally poor communication between physical disability and mental health services.

Naomi had used mental health services before a car crash in which she sustained serious injuries. She found that medical and rehabilitation services focused almost entirely on her physical injuries and did not communicate with mental health services. She also felt that her experience of depression was now assumed to be because of the accident, and there was no acknowledgement of her pre-existing mental health support needs.

One interviewee, who lives in a residential home, described how once he developed mental health problems some of the care staff "wouldn't have anything to do" with him. Others had also experienced hurtful reactions from care workers.

When people had to go into hospital for reasons relating to their physical health or impairment, their mental health history sometimes influenced the way they were treated and they had difficulties getting an appropriate response to their mental health needs. Ingrid, for example, broke her leg 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."**

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. She felt that lack of familiarity with mental health needs meant that "there was a fear" amongst staff "because they didn't know what to do, or how to respond..."

## GP services

Almost half (48 per cent) of respondents said that their GP's response to needs relating to physical impairment was either good or very good; a third (35 per cent) said it was either poor or very poor. This situation was 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.

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 addressed. 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. She is due a cervical smear test but has not managed to have one.

Some people found that mental health issues were not taken seriously by GPs or that they 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 and long-term depression, "she said everybody has off days. She said go home and I would be better tomorrow". Adam's parents tried unsuccessfully to call out the GP when Adam was trying to harm himself. The GP said she didn't know enough about cerebral palsy and mental health.

Some people felt having a mental health diagnosis meant that GPs – together with other health professionals - did not take physical symptoms seriously.

**"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 appreciated it when GPs made time for them, listened to them and respected their rights to be involved in treatment. Ingrid felt fully involved by her GP:

**"She lets me sort of make my mind up about things."**

## Medication

Almost sixty per cent of respondents reported that medication given for mental health needs had an impact on their physical impairment, while over forty per cent 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 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.

Humerah has been disabled since birth. She experienced significant side-effects from psychiatric medication:

**"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. 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 that they took me off all the medication at once and my physical functioning 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.

Few people experienced a co-ordinated approach by GPs or psychiatrists to the prescribing of medication for mental health needs and physical impairment. Regular reviews of medication appeared uncommon.

### 'Talking treatments'

Privately funded counselling or therapy received the highest rating of any mental health service amongst respondents. However, high levels of poverty and unemployment amongst disabled people meant that such a service was 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 mental health and 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.

### Direct payments

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 which many respondents said they valued. However, there was a high level of dissatisfaction with the services purchased by using either direct payments or their own resources, particularly amongst 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.

If direct payments are to remain an integral part of community care policy, this research indicates that more attention must be paid to how people with physical impairments who also have mental health support needs can be supported to use them.

### Conclusion

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". 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.

When the researchers asked what they wanted from services, people said they wanted to be seen as "a whole person", and for services to address both mental health needs and those relating to physical impairment. They wanted services and professionals to communicate and work together, and easy access to flexible services which could address individual needs. Above all, they wanted to be listened to and treated with respect.

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.

### About the project

The research covered England and Wales and was carried out by independent researcher Jenny Morris, in partnership with Mind. Eighty-three people who have physical impairments and mental health support needs returned a postal questionnaire and in-depth interviews were carried out with 25 people.

### How to get further information

The full report, 'One town for my body, another for my mind': Services for people with physical impairments and mental health support needs by Jenny Morris, is published by the Joseph Rowntree Foundation (ISBN 1 85935 193 X, price £15.95). A literature review relating to this project, **People with physical impairments and mental health support needs**, will be published on 21 June at <http://www.jrf.org.uk/bookshop/details.asp?pubID=595>.