

## Greater needs, limited access

With the recent ratification of the United Nations Convention on the Rights of Persons with Disabilities by the United Kingdom, Kathryn Senior reports that access to health care for people with mental health disorders is one area that leaves room for improvement.

Eleven years after being diagnosed with schizophrenia, Marita's daughter Mandi experienced severe headaches and began to fall over for no reason. Mandi and her parents described the worsening symptoms to her doctors for more than four years, yet neither a computed tomography (CT) scan nor any other investigation was ever done. "Mandi's symptoms were explained away as a result of her medication, or a progression of her condition, without any evidence that this was the case," recalls Marita.

The general practitioner (GP) who called at Mandi's home after she collapsed one morning prescribed paracetamol and diazepam; and asked Mandi to come to the surgery the following Monday. "On Monday, Mandi's life-support machine was switched off after the brain tumour that filled half her skull had haemorrhaged," says Marita.

After Mandi's death, Marita obtained her medical records and complained formally to the Healthcare Commission in England, which ruled in her favour. "The GPs blamed the psychiatrists and vice versa; no-one would take any responsibility either before Mandi's death or since. None of them

ever listened; one psychiatrist spent the entire consultation looking at the floor," says Marita.

Marita's experience is not unusual. Liz Sayce, chief executive of the Royal Association for Disability and Rehabilitation in the United Kingdom, reports that there is a growing body of evidence from small-scale studies and personal testimony that people with mental health disorders, such as schizophrenia and bipolar disorder, die prematurely and unnecessarily. "This stimulated the United Kingdom's Disability Rights Commission, now part of the Equality and Human Rights Commission, to undertake a larger formal investigation into inequalities in health-care access and their impact on people with mental health disorders and/or learning disabilities," says Sayce. The research involved analysis of eight million primary health care records, consultation with more than 1000 people with mental health problems and/or learning disabilities, their carers, health professionals and representatives of advocacy groups.

The investigation's report, entitled *Equal treatment: closing the gap*, concluded that people with learning disabilities or mental health disorders in England and Wales were more likely to

have significant health risks and major health problems such as obesity, high blood pressure and diabetes. "People with schizophrenia are more likely to have coronary heart disease than other citizens and are more likely to die of it before the age of 55. Yet they are less likely to be screened for cholesterol or to be prescribed statins, the main evidence-based treatment," says Sayce.

Reasons for the inequalities are complex. They include social deprivation – but this factor on its own does not explain the limited access that such people have to primary health care and to specific screening and treatment.

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*Marita (whose daughter died from an undiagnosed brain tumour)*

The investigation found that health-care providers viewed disability access almost entirely in terms of physical access to premises and considered many problems were associated with the individual – and not issues that they could remedy. Many patients with mental illness either had difficulty using the appointment system (such as needing to phone for an appointment at a particular time) or could not easily remember and travel to appointments; or they did not trust the service, due to prior experience of not being treated with dignity and respect or distorted perceptions about the way they have been treated, which can be symptomatic of their illness.

"Sometimes patients couldn't understand or cope with the implications of the medical advice they had been given," says Sayce. "But there did not seem to be any strategies in place to support these patients."

Diagnostic overshadowing was identified as another barrier, whereby clinicians attribute symptoms or behaviours of a person to their mental disorder and under-diagnose or miss the co-existing physical illness. "The



Rethink, Mental Health Charity

Health-care professionals need to spend more time listening in consultations with patients with a mental illness.

cognitive skills of the clinician are important,” says Dr Taghi Yasamy, from the department of Mental Health and Substance Abuse at the World Health Organization (WHO). “Bias or even discrimination against people with mental illness may also play a role.”

Robert, diagnosed with bipolar disorder 17 years ago, has experienced the impact of diagnostic overshadowing personally. “Early on, I had a very unsympathetic GP who would not take my severe stomach pains seriously – he didn’t appear to feel it was important to investigate them,” says Robert. When he stopped taking antibiotics prescribed for another condition, the pains stopped. He realized that his symptoms were due to the drug reacting with his other medication. “I would have expected the GP to be aware of the possibility of adverse drug reactions, but he never offered this as a possible explanation,” says Robert. For the next eight years he struggled with suboptimal treatment that left him debilitated from musculoskeletal pain. “It is also important for doctors not to overlook the fact that physical disorders can also be symptoms of a mental illness not being treated effectively,” he says.

There are also specific risk factors for people with mental health disorders, such as the impact of medication for psychiatric conditions (that can cause weight gain and associated health impacts such as diabetes) and patient lifestyle including high smoking rates, which among people with schizophrenia are approximately twice those of the general population.

According to Yasamy, complications of unmonitored treatment and the poor organization of health services are likely to be the major contributors

to the poorer health of people with mental illness. “People with mental disabilities require even better access to quality health care [than the general population] but this is not the case in most situations even in high-income countries,” he says. “The majority do not receive appropriate medical examination or treatment.”

The United Kingdom investigation recommended improved monitoring of medication impacts in primary care to enable individuals to make informed choices; for example, the trade-off between mental health gain and negative physical impacts; and the range of strategies to mitigate adverse effects, from changes of medication to lifestyle changes.

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*Dr Petre Jones*

Reduced access to health care for people with mental health disorders is a global phenomenon. In the United States of America, 17–28% of people with mental disabilities have no health insurance but are much more likely than the general population to report poor physical health. Alana Officer, co-ordinator of Disability and Rehabilitation at WHO, says that “the evidence from all countries, be they resource-rich or resource-poor, indicates that people with disabilities experience poor health care and have many unmet health needs”. It is clear that, worldwide, people with disabilities are not receiving the same range of mainstream health-care services, such as screening, even though early assessment of health conditions can reduce long-term negative health impacts and subsequent costs to health systems, adds Officer.

According to a global survey conducted by the United Nations Special Rapporteur on Disability, 74% of 114 responding countries said they had taken action to make medical care accessible to people with disabilities; however, the population covered by



Liz Sayce, chief executive of the Royal Association for Disability and Rehabilitation (the United Kingdom).

such services remains unknown and only 49% of the countries had legislation in place to enforce this. And there is lack of concrete data on the provision of medical services specifically for people with mental disabilities.

Dr Petre Jones, a GP in Newham, London, is highly proactive in establishing systems that give greater accessibility to disabled patients, including those with mental health or learning disabilities. Jones advocates specific training for receptionists and support staff to help people fill out registration forms and his practice offers longer, more flexible appointments if needed. Some patients are more comfortable using health-care facilities that offer “drop-in” visits without requiring an appointment or may benefit from appointment reminders sent as text messages.

Improving the access of disabled people to good physical and mental health care requires long-term commitment, but Jones recommends one change in behaviour that all health professionals could adopt tomorrow with no cost implications. “Studies have shown that a GP lets a patient speak for an average of 18 seconds before interrupting them. When I train GPs, I tell them to just say nothing for at least a minute – 2 or 3 minutes for someone with a mental problem. Listening to what a patient can tell you is the greatest window into their needs,” he says. ■



Courtesy of Petre Jones

Dr Petre Jones, a London GP, is proactive in supporting patients with mental illnesses.