Paths of Medicine

by Norman Sartorius
sartorius@normansartorius.com

> Croat Med J. 2007;48:396-7

Stigmatized Illnesses and Health Care

Being disabled because of a disease or injury can lead to invalidity benefits – a pension, for example, or a reserved parking space. In some instances, the benefits are very attractive but, in most countries of the world, the disabled have no access to any governmental help, and insurance premiums are so high that only a minority of the population can participate in disability compensations schemes. In some situations, disability due to a war injury or to some other situation that confers hero status can also bring social respect and moral prestige to the disabled person.

For the vast majority of disabled people, however, the disadvantages of disability are much more important than its advantages. A restriction of the possibility of participation in normal social life and limitations in the pursuit of personal happiness are often grave and depressing for the person with an impairment that causes a disability.

When the disease or the situation that has produced impairment is stigmatized, the limitations of functions are aggravated and the possibility of compensating disability is significantly reduced. There are a number of diseases that are stigmatized – mental disorders, AIDS, venereal diseases, leprosy, and certain skin diseases. People who have such diseases are discriminated in the health care system, they usually receive much less social support than those who have non-stigmatizing illnesses and – what is possibly worst – they have grave difficulties in organizing their life if their disease has caused an impairment that can lead to disability and handicaps.

Mental disorders probably carry more stigma (and consequent discrimination) than any other illness. The stigma does not stop at the persons who are suffering from a stigmatized illness. Their immediate and even remote families often experience significant social disadvantages. The institutions that provide mental health care are stigmatized. Stigma reduces the value of the persons who have a mental disorder in the eyes of the community and the government. Medications that are needed in the treatment of mental disorders, for example, are considered expensive even when their cost is much lower than the cost of drugs used in the treatment of other illnesses: they are not considered expensive

because of their cost but because they are meant to be used in the treatment of people who are not considered to be of much value to the society.

The awareness of the fact that stigmatization is one of the major – if not the major – obstacles to the improvement of care for people with stigmatized illnesses is gradually growing. In a number of countries governments, non-governmental organizations, and health institutions have launched campaigns to reduce stigma related to illness. They display posters and distribute leaflets, as well as organize radio and television programs. Sometimes parliaments introduce legislation that helps to reduce discrimination in the labor market, in housing, and in other walks of life.

There is, however, an important sector employing many individuals that does not participate very actively in the reduction of stigma and in efforts to eliminate the discrimination that follows it. It is the health sector – which, by its definition, could gain from the reduction of stigma almost as much as the individuals who have the stigmatized illness. The managements of general hospitals, as well as heads of various medical departments often refuse to have a department of psychiatry and, if they accept it, they usually assign the worst accommodation for it – in a remote corner of the hospital grounds, for example, or in the lowest (sometimes partly underground) floor. In the order of priority for maintenance or renovation work departments of psychiatry come last although they are often in a pitiful state. Doctors who are not involved in mental health care participate and sometimes excel in making fun of the mentally ill, of psychiatrists, and of mental illness. They will often refuse to deal with physical illness in a person with a mental disorder and send such patients to their psychiatrist, although they are better placed to deal with the physical illness than the psychiatrist.

Nor are the psychiatrists and other mental health care staff doing as much as they should about the reduction of stigma. They seem unaware of the stigmatizing effects of their use of language – they speak of schizophrenics when they should say a person with schizophrenia and about misbehavior or lack of discipline when they should make it clear that behavioral abnormalities are part of the illness they are supposed to recognize and treat. In some countries they requested and received longer holidays or somewhat higher salaries saying that they deserve this because they deal with dangerous patients – although they have publicly proclaimed that mental illness is a disease like any other. They often disregard complaints about the physical health of people with mental disorders and do not do much about them, thus providing suboptimal care and contributing to the tendency to dismiss whatever people with mental illness may be saying. In their teaching activities, stigmatization as well as the prevention of discrimination and its other consequences often receive only minimal attention.

Perhaps it is impossible for the health care workers themselves to launch large anti-stigma programs: what, however, they should and can do is to examine their own behavior and activity to ensure that they do not contribute to stigmatization and consequent discrimination. They should also participate in the efforts of others to reduce stigma and its nefarious consequences, or initiate such efforts whenever possible. Doing nothing about stigma and discrimination that follows it is no longer an acceptable option.