



THE CYRUS AND PRIYA VANDREVALA FOUNDATION

MENTAL HEALTH INITIATIVE, INDIA

Background Document

When we started out with a mission to improve mental health in India over a year ago – we were hoping to be able to write cheques to a couple of NGOs, be able to review their results four times a year and pat ourselves on the back for making a difference.

What further ensued was a discovery into the dark corners of disease, the discrimination and the realization that we had no idea as to what we were trying to achieve, let alone now. We have tried to articulate a mission of where we are heading, borrowing heavily from the Canadian Senate Committee Report “Out of the Shadows at Last – *TRANSFORMING MENTAL HEALTH, MENTAL ILLNESS AND ADDICTION SERVICES IN CANADA*” that was *published in May 2006*.

‘In no other field, except perhaps leprosy, has there been as much confusion, misdirection and discrimination against the patient, as in mental illness... Down through the ages, the mentally ill have been estranged by society and cast out to wander in the wilderness. Mental illness, even today, is all too often considered a crime to be punished, a sin to be expiated, a possessing demon to be exorcised, a disgrace to be hushed up, a personality weakness to be deplored or a welfare problem to be handled as cheaply as possible.’

These words were written nearly half a century ago, but nowhere is this problem more real and fierce than in India today.

The challenge for the mentally ill is that the only way to get prompt psychiatric care is to commit a crime or attempt suicide. That in itself, should be a crime.

The Foundation's first point of attack is the provision of high quality medical care. Whilst most of the Western world has evolved into providing good frontline medical care, including general awareness, high quality family support and if needed, very medically qualified rehabilitation centres for the severely addicted, depressed or ill, in India, the situation has not moved forward. There are 43 mental health hospitals in India, none of which were set up after 1947 (Source WHO Country Profiles: India 2001). Most of them are abysmal, similar to jails and they are one of the reasons most people are frightened to call a hospital in case they end up in one. National Human Rights Commission study reveals that there are two types of hospitals:

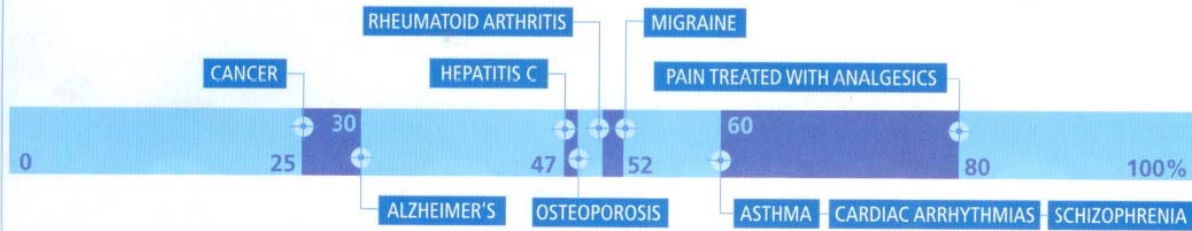
- "The first type does not deserve to be called 'hospitals' or mental health centers. They are 'dumping grounds' for families to abandon their mentally ill member, for either economic reasons or a lack of understanding and awareness of mental illness. The living conditions in many of these settings are deplorable and violate an individual's right to be treated humanely and live a life of dignity. Despite all advances in treatment, the mentally ill in these hospitals are forced to live a life of incarceration."
- The second type of 'hospitals'," the NHRC report continues, "are those that provide basic living amenities. Their role is predominantly custodial and they provide adequate food and shelter. Medical treatment is used to keep patients manageable and very little effort is made to preserve or enhance their daily living skills. These hospitals are violating the rights of the mentally ill persons to appropriate treatment and rehabilitation and a right to community and family life".

The Foundation is, therefore, providing high quality medical care, with a group of 12 psychiatrists, several very well respected, free of cost to anyone who calls in and cannot afford one. 60% of people suffering from mental illness or addiction simply do not seek help.

Aggressive follow up is planned because the drugs that are now available to treat mentally ill patients are so advanced that very little innovation is now required. It is simply a matter of execution.

The Real Dismal Science

Modern medicine is still little more than a crapshoot. The numbers below are patients' response rates to a major drug in closely controlled trials for these diseases. In the real world, patients often don't take their pills; the fault is also in doctors' inability to precisely diagnose the root causes of disease: genetic, infectious or something more mysterious. Only when we can make precise diagnoses will we get consistently effective care.



Source: Brian Spear, Trends in Molecular Medicine.

It is startling to note that if you have cancer, a drug works 25% of the time; if you have a headache, an analgesic works 80% of the time and if you have schizophrenia, the drugs work 100% of the time. The idea of the helpline is to demonstrate the power of medicine in situations that were previously considered irreversible. So to now say my brother is 'mad' is replaced by my brother is 'manic-depressive' and has not had a psychotic outbreak for three years – changes the patient's life from a failure to a disorder.

The next point of our attack on the illness has to be the removal of stigma and discrimination. Most people suffering with mental illness will experience stigma and discrimination in every aspect of their lives solely because they had been diagnosed with a mental illness or lived with an addiction. Most people are being criticised not because they have done anything wrong, but because of fear and ignorance in society. Our Foundation's goal is to help remove the stigma to spread awareness that this is a disease mostly treatable. Only by changing society's perception and removing the social stigma and understanding more about mental illness, can we as a society begin to improve the treatment and care provided to the people who suffer from a mental disorder. Further, if a patient shows up with a mental disorder, it is usually brushed under the carpet or left to deal with 'when the patient feels better'. The healthcare profession, in itself, is not very comfortable with any 'one of its own' even having a mental disorder. We have now launched a special helpline for doctors to call in and speak to a Psychiatrist – so if they are told, I am

sad; depressed; anxious; suicidal – what does the doctor do next? We are trying to help the medical profession with real tools to strengthen our frontline attack.

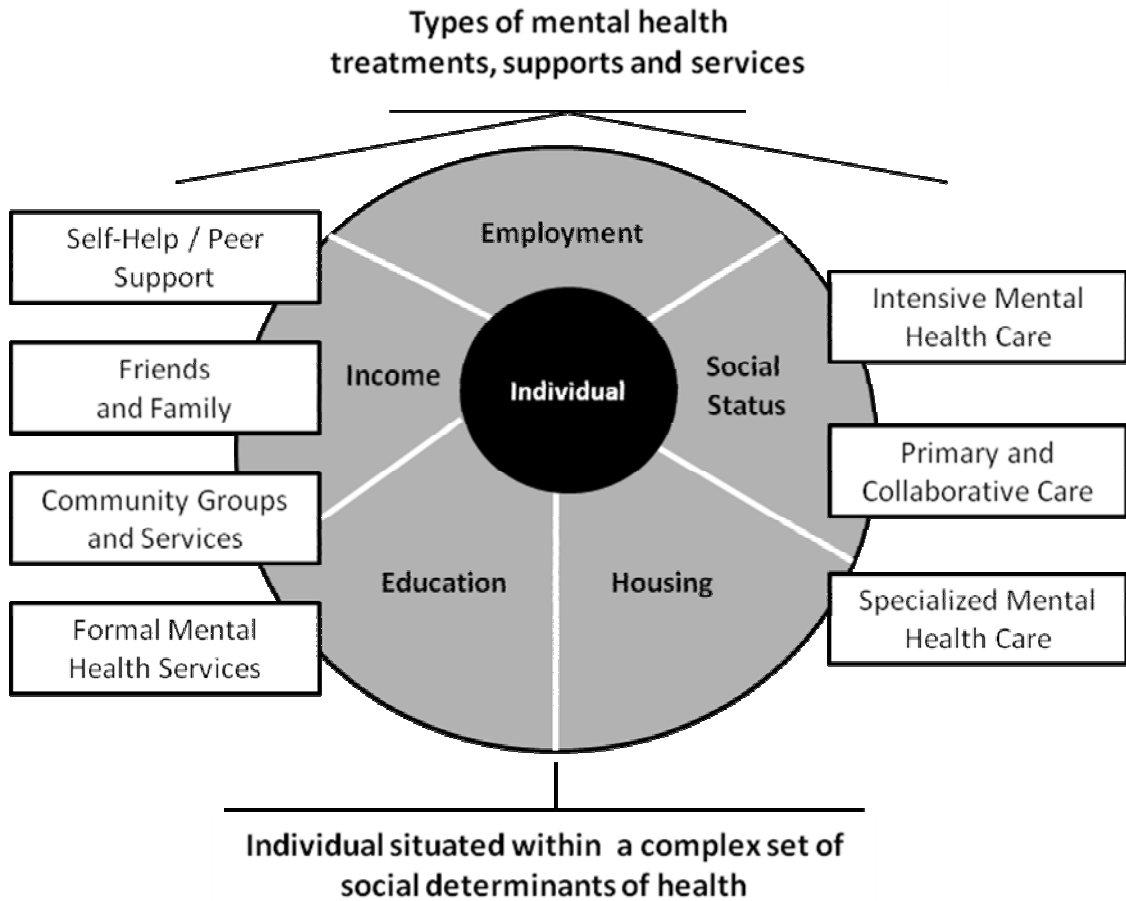
The Foundation also aims to reduce the stigma and shame of mental illness created by the media. Film and television have used mental illness to add drama to their productions by suggesting the character may be, or is, suffering from an illness, regardless of whether or not the character's behaviour could be attributed to other causes, either emotional or physical. The industry must be alerted to the damage these actions are inflicting on the mentally ill, and the harm they are doing in stigmatizing persons with a mental illness. More media coverage on the reality of mental illness, as opposed to the sensationalism and stigmatism of it, would be beneficial. People need to be taught that people with mental illness are not homicidal maniacs, as depicted on TV, but are friends, neighbours, professionals, etc.

Lastly, the recognition that mental illness is a physical illness, not some disease that enters the mind of the weak or the characterless. Like cancer, it can happen to anyone. Let us start treating 'mental' illnesses as what they are. Devastating diseases!

The Foundation is limited in its focus and does not devote its attention to substance abuse issues, or on Government policy issues.

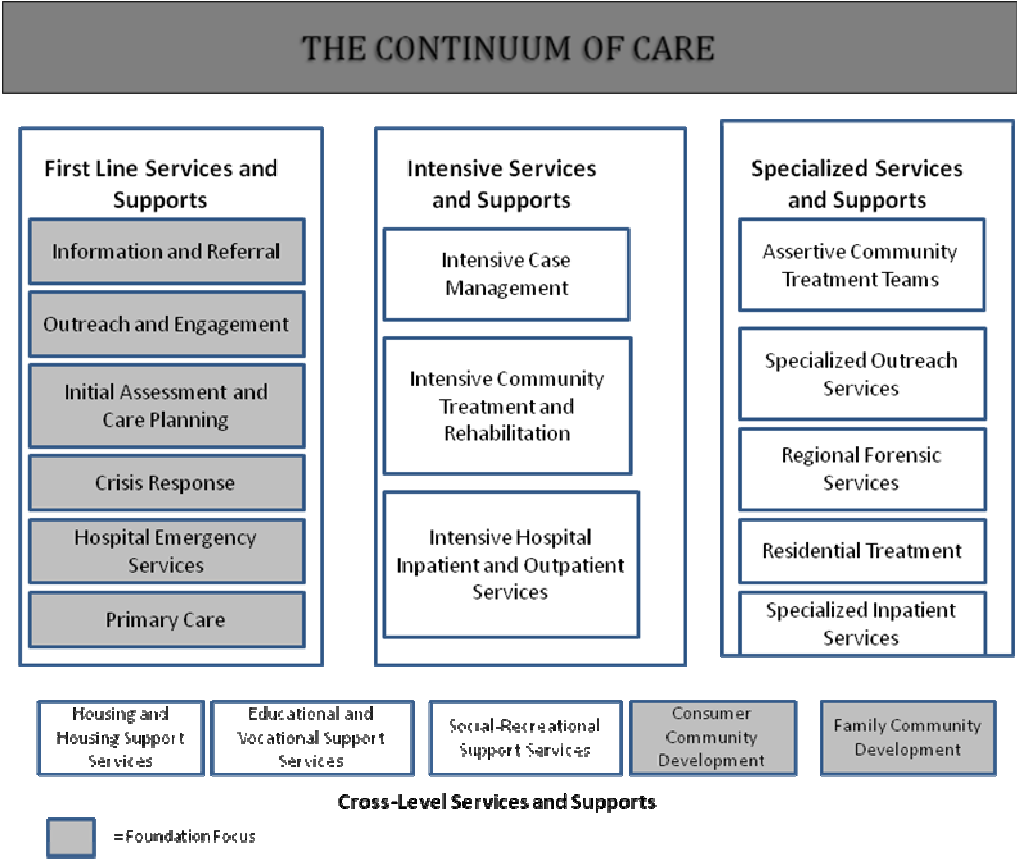
Figure 1

Source: Adapted from New Brunswick Department of Health and Wellness, *Community Mental Health Care Centres: Programs and Services*, p. 3, accessed at: <http://www.gnb.ca/0055/cmhcs-e.asp>



The Foundation is hoping to provide services across the continuum of care.

- (a) First-Line – first-line refers to prevention, assessment and treatment provided by frontline providers. The idea is to ensure that front-line care, which is either the primary care doctor, nurse, or our helpline are accessible and respond to a wide range of needs; to be extremely sensitive to the confusion, fear and concern of those experiencing symptoms of mental illness, perhaps for the first time.



Specialized refers to highly specialized mental health programs provided in community or hospital settings that focus on serving people whose serious mental illness is characterized by complex and unstable mental disorders

(b) Intensive – Intensive refers to mental health assessment, treatment and support services that are provided in community or hospital settings for people with serious mental illness. People living with serious mental illness will often require ongoing, long-term support from service providers, but not necessarily daily contact. Intensive services and supports are designed to provide continuous contact and support for people who, without them, would be a risk for repeated or prolonged institutionalization in health care or correctional facilities. The needs of most people living with a serious mental illness should be met by

community-based intensive services and supports. This is not an area of current focus, although it is critical to improve and the Government has allocated 1000 crores in its budget to do so. We urge immediate action in this area.

People living with mental illness say that the most devastating impact on their lives came not from the illness itself, but from the way others began to treat them.

Self-help and peer support counteract stigma and providing people a place where they are safe and welcome. Families also bear the brunt of stigma.

People are spoken of as addicts, schizophrenics or depressive. They have become their illness. Indeed, it is this personal experience that has caused us to regard our work on this much more than just another job to us, it is truly a calling.

We know how difficult it will be to improve the lives of people living with mental illness. We know it will be tougher still to change deep-seated public attitudes and reduce the stigma and discrimination they face. To put each of them on the road the recovery will be an extraordinary challenge.

Yet we are optimistic that the time has come when meaningful change can, and will, be made. We are willing to help make change a reality, the help bring people living with mental illness into the mainstream of society.