

# A Study of Mental Health Service Users' Perception and Experience of Discrimination in Hong Kong

A joint project between The Equal Opportunities Commission and The Chinese University of Hong Kong

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## **Executive Summary**

This was a study of the subjective perception and experience of discrimination among mental health service users in Hong Kong. 757 and 50 mental health service users took part in a self-report questionnaire survey and qualitative interviews respectively. 160 respondents who attended a diabetic treatment center served as a control group for the survey. This study focused on mental health service users' own perception and first-hand experience. The word discrimination was broadly used to refer to different forms of prejudicial attitudes and/or unfair treatment that the respondents perceived as "discrimination" in multiple domains of life and over significant periods of time. It did not take the specific meaning of discrimination under the anti-discrimination law. The findings of the survey demonstrated that actual or anticipated discrimination, thus defined, was widespread among the group of mental health service users studied. The degree of reported discrimination was significantly more severe among mental health service users than outpatients with diabetes mellitus. Discrimination adversely affected multiple domains of life, such as work, family, social relationships, and professional treatment. Case studies of subjects who experienced actual discrimination confirmed that work place marginalization, family rejection, social exclusion, and suboptimal treatment conditions were damaging to patients' self-esteem, functioning, treatment adherence, and well-being. The frequency with which the side effects of psychotropic drug treatment impaired social functioning and precipitated discrimination was notably high. In order to avoid treatment-induced discrimination and to re-join the mainstream community, mental health service users often defaulted treatment at the cost of a relapse of the mental illness. Although they perceived that the media perpetuated substantial negative stereotypes about mental illness, they were reluctant to speak out for fear of the traumatic consequences of exposure. Notwithstanding the painful impact of discrimination, mental health service users adopted predominantly passive modes of coping with actual or anticipated discrimination. These included concealment, putting up with unfair handling, avoidance, and/or isolation that did not effectively rectify the discriminating circumstances or individuals. Negative emotional reactions to discrimination, such as demoralization, attempted suicide, fear of intimacy, and guilt about concealment were common, especially among female mental health service users. Because of the fear of exposure and further unfair treatment, formal complaints against individuals or institutions that were perceived to discriminate were rare. The result was patterned exclusion from equal opportunities, dejection, productivity loss, and unsatisfactory treatment of mental illness. Mental health service users suggested public education, responsible media reporting, legal measures, and improvement in psychiatric service as useful means of reducing the impact of discrimination. The limitations of the study, such as the need to evaluate the findings from the perspectives of the individuals, circumstances, and institutions that were perceived to discriminate, were discussed. Because the elimination of discrimination against mental illness required a sustained intersectoral effort, we made recommendations at the educational, employment, social, clinical and policy levels. Finally, the EOC has formulated its views on the findings of the study and the recommendations made by the researchers. They appear in Part B of this report.

**EOC Statement on**

**The Perceptions and Experiences of Discrimination of People with**

**Mental Illness in Hong Kong**

**Introduction**

A study (Study) of the perceptions and experiences of discrimination of 757 persons with mental illness in Hong Kong was jointly conducted by the Equal Opportunities Commission (EOC), the Department of Psychiatry of The Chinese University of Hong Kong and the Department of Social Work of Baptist University. It focused on the first-hand experience and perception of discrimination of respondents coming from 28 halfway houses and a public psychiatric outpatient clinic. The term, Mental Health Service Users, is used in the Study as a collective description of the respondents but the experiences and perceptions relating to discrimination are not confined to medical treatment and health care. The Study covers multiple domains of life, such as work, family and social relationships in addition to medical treatment and health care.

The results show that more than 65% of the respondents rate the psychiatric staff of psychiatric wards as “good” or “very good”. It should be emphasized that the Study profiles the perceptions of the respondents

only and covers significant periods of time, in some cases, decades. The perceptions described must, therefore, be taken in context.<sup>1</sup> This Study does not canvass the clinical reasons for specific treatment or care and no judgment is made or intended regarding these decisions. Against this background, the Study was conducted,

First, to gauge the cumulative impact of these experiences on the individual respondents as regards their perspectives and difficulties in multiple domains in life; and

Second, to document the perspectives of the demand side as distinct from the supply side of service providers, including health service providers, so as to better define users' participation in the healing process.

## **Stigmatization**

Of the many vulnerable groups in Hong Kong, perhaps those with mental illness form the most misunderstood group. They are generally perceived to be violent, suicidal, unpredictable and incapable of rational decision. Stigmatization has resulted in alienation of those with mental illness from the community when acceptance and inclusion are most needed to promote wellness. Doubts regarding their decision-making abilities have also made them vulnerable to possible non-consensual medical treatment and confinement.

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<sup>1</sup> There have been improvements in medical services over the years and that there could be clear clinical reasons for specific treatment or care.

## **Coordinated and Holistic Approach**

This Study shows that stigmatization attached to mental illness can be regarded as worse than having the illness itself. Typically there is a history of concealment and social exclusion which prevents early detection and timely treatment. To counter stigmatization, a committed and coherent program of education, support and redress is necessary. Such a program must encompass the promotion of community and family care, and the respect for the rights of the mentally ill. The well being of the mentally ill and the realization of their rights require acceptance of the community as well as the entrenchment of their rights in law and the recognition of these rights as enforceable values by the institutions providing services to them.

This Study provides an in-depth understanding on the perception and experience of discrimination, stigmatization and alienation faced by persons with mental illness. Through this Study we hope to increase the public's understanding of the plight of the mentally ill. This Study is but a first step and must be followed by larger studies on the provision of medical and health care services to those with mental illness, their legal position and the perception of the public.

Mental illness can affect one in five of our population at different times, in different forms and with varying degrees of severity. Mental health in times of economic downturn is of particular concern. The success of mental health care services hinges on many factors – public acceptance;

effective health service; availability of effective medication; accessibility to support and legal services, provision of occupational, vocational and rehabilitation services; etc. Although many of these are beyond the remit of the work of the EOC, they are inter-related and require a coordinated and holistic approach.

### **Mental Health Council**

The Study makes a number of important recommendations, of which, the key is the establishment by government of a Mental Health Council as a multi-disciplinary and cross sectorial body to coordinate policy formulation, program delivery, research and public education in the area of mental health and to safeguard the rights of those with mental illness. We support this recommendation and request its consideration by the Health, Welfare and Food Bureau.

### **EOC's WORK RELATED TO MENTAL ILLNESS**

Up to 30 September 2002, 16% (290) of the complaints lodged under the Discrimination Disability Ordinance were related to mental illness<sup>2</sup>. 192 (66%) of these complaints were in the employment field involving job arrangement, hire and fire (154), harassment in work place by co-workers (35) and victimization (3). The remaining 98 (34%) were in the non-employment field relating to discriminatory treatment (70), harassment

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<sup>2</sup> Among the complaints, 14% are still under investigation, 56% discontinued for various reasons provided under the DDO, 15% conciliated successfully, 13% conciliation unsuccessful, 3% reached an

(19) and victimization (2) in the course of provision of goods and services, and vilification (7). Among the service-related complaints, 2 were on taking out of insurance policies, 28 on health/dental care service, 7 on education. The figures do not represent the actual situation as aggrieved persons are reluctant to lodge complaints out of fear that revealing their identity can draw further stigmatization or lack the skill or knowledge to lodge and handle complaints.

Completed programmes relating to mental illness are described in the Annex. A further discussion paper on the health and legal rights of those with mental illness is under preparation and we highlight several areas under study below.

### **Human Rights and Medical Ethics**

There has been a coming together of the fields of human rights and medical ethics. Patient/clinician relationships are changing. Increasingly they are being defined according to human rights standards and to provide for maximum personal autonomy. Models of best practices now include principles such as the rights to best available treatment, to give or withhold consent, to privacy, to information, to advocacy, to appeal compulsory treatment orders and to the use of least restrictive alternatives where compulsion is needed.

The Hospital Authority states that the Patients' Charter is designed to inform patients of their rights and responsibilities, leading to the development of beneficial relationships with healthcare providers, and by doing so enhance the effectiveness of the health care process. This statement reflects an understanding that recognition of human rights complements other elements of health care.

The Mental Health Ordinance (Cap. 136) provides to a patient the right to see a District Court judge or a magistrate before a compulsory order is made. The Hospital Authority, in response to the concerns that we raised, has from 10 September 2001 made arrangements whereby patients who are admitted involuntarily to a mental hospital under s. 31 of the Mental Health Ordinance are informed of their right to see a District Court judge or magistrate.

After commencement of the new arrangements, a total of 513 patients were admitted to mental hospitals under s. 31 of the Mental Health Ordinance between 10 September 2001 to 9 December 2001. 109 patients requested to see a District Court judge or a magistrate and out of this, 11 were not ordered by the District Court judge or magistrate to be admitted to a mental hospital. This snapshot serves to highlight how the system is working and no implication is drawn or intended as regards the clinical decisions taken in the 11 cases referred to.



## **Human Rights and Legal Rights**

The upholding of the human rights of those with mental illness depend on the availability and accessibility of advice, advocacy, representation and redress to those with mental illness. Without advocacy and representation, it is unlikely that many would feel able to pursue their rights as they usually lack the skill or the capacity to seek redress.

## **THE PROBLEMS UNCOVERED BY THIS STUDY**

### **Those Affected**

For many respondents, living with social stigma was an overwhelming experience. They were being evaluated against unfounded myths. Social stigma eroded a person's confidence, resulting in low esteem, self-stigmatization and concealment of the condition and deprived them of their dignity and participation in life.

The double disadvantage faced by women with mental illness was also evident. The World Health Organization Report of 2001 points out that the multiple roles that women are expected to fulfill, as wives, mothers and carers of other family members, put them at greater risk of experiencing mental disorders. Twice as many women suffer from depression as men.

## **Detection and Treatment**

The average mental patient in Hong Kong seeks treatment from a psychiatrist two years from the onset of symptoms<sup>3</sup>. The lack of general awareness of mental illness and fear of stigmatization are the major causes of delay in seeking treatment among many respondents.

Raising the awareness level of the public and the medical profession can help improve early detection, assessment and intervention. Making mental health treatment more available in primary care clinics and reducing the segregation between general and specialist care where practicable can help to increase detection and reduce the labeling effect feared by many. For those who are in employment and have difficulty taking leave to attend follow-up treatment in daytime, extending outpatient service beyond office hours will also help to accommodate their needs.

## **Support to Family**

The family remains the principal source of support for many individuals. However, the present survey shows that family members can also be a source of stigmatization. A sense of frustration and helplessness on the part of family members often arise from misunderstanding the illness and the needs of the mentally ill. Families need to be educated in the knowledge and skill for caring of individuals with mental illness.

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<sup>3</sup> An experience revealed by the Secretary of Health and Welfare in his speech delivered at the MINDSET Initiative on 21 June 2002.

Community and professional support to families, such as parenting skill and group counseling, is essential to create a wider community-based care system. Respite and carer services, as recommended in the Study, are useful in relieving families that are temporarily unable to attend to their family members with mental illness.

### **Evidence-based and Customer-centered Approach**

Some respondents reported unhappy experiences with health care workers in the treatment process. These represented the perception of the respondent only and there could be clinical justification for the ways things were handled at the material time. Nevertheless, there are allegations of illness of a physical nature being regarded as a mental problem. These areas should be carefully considered to see if they resulted from any stereotypical assumptions in the course of providing health care services.

### **New Drugs**

Four dimensions need to be considered in respect of the right to health: availability, accessibility, acceptability and quality of service and care.

While recognizing every psychiatric drug may have its side effects, as reported by the respondents, the conventional drugs create greater disruption to the daily activities of an individual. Medication

represents only a small part of the total treatment cost of serious illness. The greater acquisition cost of the new generation psychiatric drugs is more than compensated by the decrease in clinical care (e.g. the shorter duration of hospitalization) and other indirect costs (e.g. unemployment benefits and longer rehabilitation process). More fundamentally these drugs create fewer side effects making those with mental illness less of a hostage to stigmatization which leads to concealment and non-treatment.

In the year 2001-2002, the Government provided additional funding to 2500 patients with new psychiatric drugs. The effectiveness of the scheme should be evaluated and made public.<sup>4</sup>

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<sup>4</sup> This information is important. Under the drug prescription scheme now put on trial by the Hospital Authority New Territories East Cluster, new generation psychiatric drugs is considered as 'non-essential' drugs that has to be bought from community pharmacy. According to the Hospital Authority, the three guiding principles in classifying non-essential drugs are: (1) drugs without comprehensive evidence base in its treatment effects; (2) drugs with comparatively less side effects, of marginally better efficacy but the cost is extremely high; and (3) life style drugs such as slimming pills or those drugs purely for preventive uses. (Hospital Authority Press Release dated 21.8.2002)

In some countries, new generation psychiatric drugs are now recommended to be prescribed as first-line treatment for schizophrenia. For example, in UK, it is recommended that new generation psychiatric drugs be considered in the choice of first-line treatments for individuals with newly diagnosed schizophrenia, and for individual currently receiving old drugs and experiencing unacceptable side effects. In Malaysia, new generation psychiatric drugs are on the national formulary list. Physicians are allowed to prescribe them as first-line treatment. In Korea, some new generation psychiatric drugs can be prescribed as first-line treatment. In Taiwan, the former restrictions imposed on doctors in prescribing second-generation psychiatric drugs has recently been lifted and doctors can prescribe new drugs under the national health insurance scheme without having the patients try out the typical drugs in the first place.

## **THE WORK OF EQUAL OPPORTUNITIES COMMISSION (EOC) RELATED TO MENTAL ILLNESS**

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### **Policy Advice on Rights to See District Court Judge / Magistrate**

In 2000, the EOC received one complaint regarding the patient's right to see a District Court Judge or Magistrate under section 31 of the Mental Health Ordinance when application for compulsory detention of a patient was made. We wrote to the Hospital Authority and the former Health and Welfare Bureau urging that arrangement be made to assist patients in exercising this right. Such arrangement was later introduced in September 2001. As a follow up, we also urged the Hospital Authority to monitor the situation and keep relevant statistics.

### **Litigation on Discrimination Case on Ground of Mental Illness**

The EOC had granted legal assistance to three young persons who were deprived of employment because of their relatives' mental history. Judgment was given on 27 September 2000. The Court found that the recruitment policies of the Fire Services and the Customs and Excise Department were unlawfully discriminatory under the Disability Discrimination Ordinance.

The court judgment on the cases, K & Others v. Secretary for Justice could be downloaded from EOC's homepage at:

<http://www.eoc.org.hk/CE/rulings/rulings/Fire%20Services%20Department.htm>

### **Surveys on Public Perceptions and Needs of Persons with a Disability**

Since our establishment, the EOC had commissioned several surveys to identify problems faced by persons with a disability including those with mental illness. The findings are helpful to highlight service gaps and areas for improvement.

*“Baseline Survey on Employment Situation of Persons With A Disability in Hong Kong”*

The survey, conducted in 1997, studied the employment situation of five disability groups in Hong Kong. It was found that persons with mental illness experienced difficulty in seeking jobs and maintaining employment:

- About 30% of persons with mental illness were unemployed at time of survey, while the overall unemployment rates for different disability groups ranged from 25% to 50%.
- Health problems and dismissal were the most frequently cited causes for changing jobs by persons with mental illness.

The survey highlights could be downloaded from EOC’s homepage at: <http://www.eoc.org.hk/CE/research/employ97/index.htm>

*“Baseline Survey on Public Attitudes towards Persons with a Disability”*

The survey was conducted in early 1998 to elicit the views of the public towards persons with a disability in six disability groups including mental illness. Major areas covered in the survey included employment, public access, services and facilities, social interaction, and education and training.

The survey found that people in general would avoid and had limited contacts with persons with mental illness:

- Only 13% of the respondents thought that employers would be willing to hire persons with mental illness. Safety was believed to be the main reason for not offering employment.
- 41% of the respondents thought that colleagues would not accept persons with mental illness as co-workers, and safety was again believed to be the main reason.
- Only 35% of the respondents thought that people would like to make friends with persons with mental illness.
- Only 13% of the respondents had friends, colleagues, relatives and service targets with mental illness.

The survey highlights could be downloaded from EOC's homepage at: <http://www.eoc.org.hk/CE/research/attitude/index.htm>

*“Survey On Obstacles To Persons With A Disability In Non-Employment Fields In Hong Kong”*

The survey was conducted in 1998 to identify key obstacles or discrimination faced by persons with a disability in education, access to goods, services and facilities, housing and accommodation, participation in sports and community activities, etc. The survey found that persons with mental illness generally experienced negative feedback in community life:

- Only 15% of students with mental illness reported no problems encountered at school. For those who had encountered problems, the major problems were catching up with the curriculum, lack of support from teachers and social interaction.
- 10% of persons with mental illness claimed to experience problems with doctor's attitude.
- Poor relationship with neighbours was frequently reported by persons with mental illness.

The survey's executive summary could be downloaded from EOC's homepage at: <http://www.eoc.org.hk/CE/research/obstacle/index.htm>

*“Baseline Survey of Students' Attitudes toward People with a Disability”*

The survey was conducted in 2000 to gauge the students' level of acceptance and recognition of people with a disability. The survey provided useful information for future comparison and formulation of effective strategies in advocating equal opportunities principles among students. Major findings related to mental illness included:

- Students showed the least acceptance toward those with intellectual impairment or mental illness. This finding was very much in line with the findings in international literature.
- Persons with a disability were perceived to be deviant, accident prone and appropriate for repetitive work and mental illness were assumed to be violent.

The survey's executive summary could be downloaded from EOC's homepage at:[http://www.eoc.org.hk/CE/research/student\\_att/disability.htm](http://www.eoc.org.hk/CE/research/student_att/disability.htm)

## **Public Education**

### Seminars for media

Two seminars on news reporting and mental illness, held in February 2001 and April 2002 respectively, aimed at encouraging media organizations to adopt an objective reporting style and portrayal of mental illness, to avoid prejudice and stereotyping of persons with mental illness. Each seminar was attended by over 250 participants. The second seminar particularly targeted young reporters and students of journalism to raise their awareness of the issue.

Conference papers and relevant information for both seminars could be downloaded from EOC's homepage at:

[http://www.eoc.org.hk/CE/conference/Med\\_Sem/med\\_sem\\_b.htm](http://www.eoc.org.hk/CE/conference/Med_Sem/med_sem_b.htm)

### Focus groups meetings

12 focus group meetings and 12 talks for over 500 people were conducted during the year of 2000/2001 to raise awareness of the legal rights for persons with mental illness under the Disability Discrimination Ordinance.

### Pamphlets informing rights under the law

*"The Disability Discrimination Ordinance and People with a Mental Illness/Ex-mental Illness"* informs the public on rights for persons with mental illness under the Disability Discrimination Ordinance.

The pamphlet could be downloaded from EOC's homepage at:

[http://www.eoc.org.hk/CE/rights/ddo&I/ddo&I\\_b5.htm](http://www.eoc.org.hk/CE/rights/ddo&I/ddo&I_b5.htm)

*"How a Person Recovered from Mental Illness Can Adjust to a Work Environment"* suggests concrete accommodations to cope with mental illness at work.

The pamphlet could be downloaded from EOC's homepage at:

<http://www.eoc.org.hk/CE/individual/employment/mental/index.htm>



### Other promotional programmes

Community roadshows were staged in April 2000 and November 2001 to promote equal opportunities for persons with mental illness. At the roadshow in 2001, a discussion panel on “Understanding and Accepting People with a Mental Illness” was dedicated to promote acceptance for the mentally ill.

“Equal Opportunities Expo” is the EOC’s annual programme to encourage people to act against discrimination and to raise public awareness of the need of persons with disabilities. Acceptance for persons with mental illness was a theme highlighted at both of the kick-off programmes for the Expo 2000 and Expo 2002 events.

Funds were granted to projects which aimed to enhance understanding and acceptance of persons with mental illness. Up to 30.9.2002, 19 projects involving more than HK\$300,000.00 were approved under the EOC’s Community Participation Funding Programme. This represents 6.1% of all projects and 6.7% of total fundings approved.

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