

MODULE 5

ACCESS TO MENTAL HEALTH CARE

PART I: INTRODUCTION

Historically, laws have focussed on protecting society from people with mental disabilities or with mental health problems. People with mental disabilities were often *legally deprived* of their liberty and other rights. Involuntary admissions and treatment of persons experiencing mental health problems were common, and often the conditions of institutions for persons with mental disabilities were not kept up to the standards of facilities for persons with physical illnesses. In addition, society has traditionally viewed persons with mental disabilities as objects of charity and social welfare.

Today it is increasingly recognized that persons with mental disabilities are entitled to human rights and fundamental freedoms on an equal basis with others. They have a right to equality, human dignity, and a right to be free from discrimination on the basis of mental disability. As a result of this shift, legislation worldwide is being rewritten to protect and promote the human rights of persons with mental disabilities.

One of the key rights of persons with mental disabilities is the **right of access to care**. The right of access to care finds its basis in the right to health as stated in section 1 of the General Comment 14 on the International Covenant on Economic, Social, and Cultural Rights (**ICESCR**):

Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity. The realization of the right to health may be pursued through numerous, complementary approaches, such as the formulation of health policies, or the implementation of health programmes developed by the World Health Organization (WHO), or the adoption of specific legal instruments. Moreover, the right to health includes certain components which are legally enforceable.

Article 25 of the Convention on the Rights of Persons with Disabilities (**CRPD**) expands this, stating that “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”. The CRPD also requires that State Parties provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons (Article 25(a)). The inclusion of this provision is very important, requiring positive action from State Parties since it mandates the creation of these mental health services.

As is recognized in international instruments such as the U.N. Declaration of Human Rights and in General Comment 14 on the ICESCR, the right to health – including mental health – is typified by four factors: publicly funded health facilities and services must be **available** in sufficient quantity; treatment, care and information must be geographically and economically

accessible to all persons without discrimination; facilities and services must **acceptable**, meaning appropriately delivered for vulnerable or minority groups such as women, children, and ethnic or cultural minorities and respectful of medical ethics; and care must be **of good quality** (see also Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt (“*Hunt Report*”), discussed in module 3). In addition, the right to health does not simply mean delivery of health services but also includes many other factors that are related to health outcomes: socio-economic factors such as clean living conditions; non-discrimination and equal access to care; freedom from interference; access to medications; equitable distribution of care; and adequate and up-to-date training of professionals. **Most importantly, the right to health does not distinguish between physical and mental health.**

Even after mental health law reform, country legislation may focus only on institutional or structural issues such as voluntary and involuntary admissions to hospitals and the establishment of mental health tribunals to monitor admissions and patient care. While these are important procedural protections, they do not fully address access to care.

1. Barriers to Access

What are barriers to access? Barriers to access are anything, whether physical, financial or procedural that prevents a person who needs good quality mental health care or other assistance from receiving care and assistance.

Barriers can include:

- The lack of comprehensive mental health policies and legislation to enforce the rights of persons with mental disabilities.
 - A lack of good policy and law can lead to human rights violations such as abuses related to involuntary hospitalization and treatment, the lack of proper food or water, or the lack of proper medical care.
- The lack of skilled mental health workers at the primary health care level and a lack of community-based mental health care professionals, facilities and services (*e.g.* psychosocial rehabilitation programmes, day care, and residential facilities).
 - A lack of skilled mental health workers prevents persons with mental disabilities from having their conditions recognized and properly treated.
 - Mental health care is often based in urban centres, meaning that persons who live outside of the main urban centres must pay for travel and lodgings, and must take the time to travel, in order to receive care. The fact that they are far away from their own communities means they are deprived of the presence, care and support of their families and friends.
- Wrongly informed priorities
 - Governments spend their resources on large institutional care for a small fraction of persons rather than providing mental health services in the community or at a primary care level, allowing more people to be able to get care.

- Many countries spend less than 1% of their entire health budget on mental health (WHO, *Mental Health Atlas: 2005*), despite the significant burden mental disorders.
- Lack of access to medications
 - 89.3% of countries have an “essential drugs list” used as a basis for procuring therapeutic drugs or a therapeutic drug policy, but many people still lack regular access to medication as drugs may only be available in psychiatric institutions or urban centres, and supply may be erratic or scarce (WHO, *Mental Health Atlas: 2005*).
- Lack of medical insurance coverage for mental disabilities
 - In many countries mental disabilities are not covered by health insurance schemes such that many people cannot afford treatment.
- Discrimination and stigma
 - About one quarter of all countries do not provide disability benefits to persons with mental disabilities (WHO, *Mental Health Atlas: 2005*).
 - Many people with mental disabilities are targets of unfair discrimination such that access to housing, employment and other opportunities is compromised.

2. Promoting Access

Promoting access to mental health care is a basic step a government can take to fulfil its obligation to persons with mental disabilities. Access to mental health care means making mental health care:

- Affordable for all members of the population;
- Geographically accessible to people in rural as well as urban areas;
- Available on a voluntary basis to anyone who asks for it;
- Equitably funded compared to physical health care; and
- Of a similar quality as physical health care.

It is well-established that lack of access to health care leads to poor health outcomes – and it follows that lack of access to mental health care leads to poor mental health and health care outcomes. Well-formulated and implemented mental health laws and policies (or other policies and laws where mental health issues have been integrated) can help to increase access to mental health care, and thus improve mental health outcomes in the population. Policies can provide a guideline and strong statement of a government’s intentions for the development of mental health care; legislation and regulation create obligations on the government that can be legally enforced and that can push government bodies and organizations to take action to improve mental health services.

International legal standards

Article 12(1) of the **ICESCR** states that “[t]he States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”.

Article 25 of the **CRPD** is more comprehensive and states that:

“States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a. Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b. Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c. Provide these health services as close as possible to people's own communities, including in rural areas;
- d. Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- e. Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- f. Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

3. Legislating Access

Well-written and well implemented legislation can help increase access to mental health care by:

- improving funding allocation in mental health care – for instance, by mandating parity of funding with physical health care and thus influencing resource distribution;
- re-organizing services to improve geographic access – for instance, by integrating mental health and general health services so that mental health care can be obtained in all places along with general health care;
- promoting community care and de-institutionalization – for instance by making mental health care a part of primary health care and available in general hospitals, and mandating community-based services;
- establishing non-medical rehabilitative programs and social support programs;
- improving resource allocation to underserved populations; and
- improving access to medication, psychosocial interventions, and health and other insurance.

The purpose of this module is to inform and enable students with respect to legislative tools and changes that can be used to increase the accessibility of mental health care.

PART II: ACCESSIBILITY AND FUNDING

Legislation can indirectly encourage **increased funding** in many ways such as ensuring that mental health services receive equality with physical health services, creating legal obligations to develop mental health services, redirecting funding by promoting community based care and creating new funding for statutory bodies.

Legislation can also promote the **re-allocation** of existing funding to increase the efficiency of mental health care services. This is a particularly useful and effective tool in countries with limited resources.

By providing for government funding of mental health care, legislation promotes the **financial accessibility** of mental health care for those who cannot otherwise afford it. In countries where health care is not publicly funded or only partly publicly funded, legislation can also provide that private **health insurance** plans or drug insurance plans be non-discriminatory.

1. Improving funding allocations

Almost one third of countries do not have a specific public budget for mental health. Of the 101 countries with a mental health budget, 21 countries spend less than one percent of their total health budget on mental health (WHO, *Mental Health Atlas, 2005*). Mental health in low-income countries faces a double disadvantage: the poorest countries spend the smallest proportion of their already scarce resources on mental health. Including provisions for funding in mental health legislation, or writing provisions into already existing legislation, can help to improve the available funding for mental health care resources.

Legislation can improve funding allocation to mental health in two ways. First, legislation can directly provide for the resourcing and funding of mental health care services. Secondly, it can also indirectly put pressure on government to increase the amount of funding available for mental health care. For example legislation can:

- State that there must be parity of funding between mental and physical health services.
 - For instance, stipulate that mental health services have to be funded so that they are just as available and offer just as high quality of care as physical health services.
- Mandate that specific obligations be met in the provision of mental health services to pressure the government to ensure that the obligations are met by providing facilities or funding.
 - The law could mandate a minimum level of quality of care.
 - For instance, the law could state that mental health patients must have a minimum amount of personal space, when living in an institution, adequate, food, clothing etc.;
 - The law could state that people have the right to be treated in primary health care and in general hospitals;
 - The law could state that mental health care is made available to people living in remote or rural areas

- Indicate where mental health resources should be spent.
 - For instance on community mental health care initiatives, prevention programs, rehabilitation services, or a plan on increasing access to psychotropic medicines (see section 3, below).
- Reallocate funding by shifting responsibility from hospital-based mental health care to community-based mental health care.
 - This strategy will be discussed in greater detail, below.

2. Re-allocation of funding

Funding of mental health care is often allocated to hospital-based services and in-patient care. This method of allocation not only results in mental health care being accessible only to a small fraction of persons with mental disabilities, but is also financially inefficient. Reallocating funding from institutional care to community-based services and to primary care has the double result of increasing access by reaching a greater number of people, while remaining financially viable.

It must be noted that reallocation of funding must be planned and systematic so that a viable and accessible network of community services are in place before other institution-based services are phased out. Otherwise, there is a risk of simply draining – rather than reallocating – mental health care funding.

Restructuring mental health care service delivery in Brazil

In the 1980s, in response to criticisms of a hospital-centred model of mental health care, Brazil restructured mental health care delivery by building a network of community health care services to replace the institutional network. From 1992 to 2001 these “community and primary health care services” (CAPS) grew from a network of 23 centres providing mental health care to 295. In 2001 the “Paul Delgado law” was introduced: a legal realization of mental health care reform. The CAPS network expanded, more than doubling to 689 CAPS in 2005. This was accompanied by a progressive and carefully planned reduction of hospital beds, by 42%. Together, these initiatives dramatically increased community access to care.

(Source: Human Resources and training for mental health. Geneva, WHO 2007)

There are several ways in which funding can be reallocated. Firstly, legislation can create **structural changes** in the mental health care system, so that mental health care delivery is made more efficient. Legislation can, for instance, integrate mental health care with primary care by stating that mental health care should be available at any primary care institution and in general hospitals, or by making mental health care diagnosis and treatment a required component of education and training programs for health care professionals. Legislation can also create community care facilities, and de-institutionalize the delivery of mental health care services.

Funding can also be reallocated by **redirecting** funding from institutional care to other programs. In order to increase geographic accessibility, funding can be redirected to historically underserved populations by creating mental health care services in rural or poor and vulnerable groups and communities. It can also be directed to make medication more accessible by amending legislation or regulations to include mental health medication in existing strategies to promote access to medicines or as a part of health insurance or drug insurance benefits. For countries with an “essential drugs” list, amendments can be introduced to include essential psychotropic drugs on the list. Funding can also be redirected towards mental health care promotion and education programs for the general population and for health care professionals, alike. Finally, legislation can provide for the creation or the funding of psychosocial rehabilitation programs and other community-based preventative or support programs for persons with mental disabilities.

Many of these re-allocation issues will be discussed in more detail below, as access to health is not only contingent on the adequate funding of mental health services but also depends highly on the kind and quality of services offered. In other words, increasing funding is not sufficient to increase access: access is not only about money, but is very much about where money is spent.

3. Equal access to health insurance.

One must also consider that cost is a barrier to access for many patients and their families. The cost of care can be made greater by things such as: cost of travel to and from a mental health service provider; cost of lodging where travel to a mental health service provider takes a long time; cost of missing work if a person must be accompanied by another family member to a place where they can get treatment; and cost of medication. In most cases, where people are poor the sheer expense is a significant reason that people and/or their families choose not to seek care (James et al. 2002).

In many countries, social insurance (19% of countries worldwide), voluntary health insurance (2%) and tax-based arrangements (60%) are used to pool risk such that health care benefits are redistributed to people with the greatest need when such need arises. Although these funding systems are both effective and equitable, some countries (16%) continue to rely on out-of-pocket payments to finance mental health care; in fact, more than a third of low-income countries rely on out-of-pocket payments as a primary source of financing for mental health care services. This is a stark contrast to the 3% of high-income countries who finance health care through out-of-pocket payments. While out-of-pocket payments are an immediate, flexible and low-maintenance source of revenue, the “user pay” approach only serves to decrease the financial accessibility of mental health care services (Saxena et al., 2007). As a result, many people choose not to seek care until their need for care is critical, leading to higher costs to the patient, the patient’s family, and to society (WHO, *Investing in Mental Health*). Early detection and care means that: caregivers have a lower burden leading to lower stress, fewer workdays lost and less loss of income; employers have a more stable working environment with reduced absenteeism leading to higher efficiency and productivity; and the economy and therefore the country benefits.

As not all countries have publicly funded mental health care that is available to all, individuals may need to purchase health insurance in order to obtain health care. In such cases, a person without insurance would, on top of travel and other costs, have to pay for mental health care services. In such countries, health insurance can be and often is regulated using legislation. Such legislation should provide for the needs of persons with mental disabilities as well as persons with physical disabilities. Legislation should:

- Include anti-discrimination provisions so that people with mental disabilities are able to obtain mental health care insurance benefits that are on par with the health insurance benefits for people with physical health problems.
 - For an example, see the U.S. Mental Health Parity Act (1996) and compare it with the Paul Wellstone Mental Health and Addiction Equity Act (2008) (see “International Resources”, below).
- Account for the chronic nature of some mental disabilities, leading to a regular need for treatment and medication.
 - Chronic illness is often considered a liability for insurers, and private insurers might choose to refuse coverage or remove coverage from a person who has developed a mental disability. Legislation can ensure that a person with mental disabilities cannot be refused insurance solely on the basis that he or she has a recurring or chronic illness.
- In some countries, people with mental disabilities find it difficult to obtain other forms of insurance, such as income or mortgage protection insurance. Such discrimination may require protection by the law.

4. Conclusion

Legislation can be used to change how mental health care is financed. It can help to improve overall funding allocations to mental health care within a government budget, and it can also re-allocate funding by shifting spending priorities. Finally, legislation can help to create a health care regime that puts the least amount of pressure on persons who are unable to afford care, and can ensure that insurance plans are more accessible to and less discriminatory against persons with mental disabilities.

However, using legislation to increase or re-allocate funding to mental health care and taking steps to minimize the cost of care to individuals is only part of increasing access to care. Other important access issues are discussed below.

PART III: INTEGRATION IN PRIMARY CARE AND GENERAL HOSPITALS; COMMUNITY-BASED CARE, AND DE-INSTITUTIONALIZATION

(Note: Students should be aware that WHO has developed a report on Integrating Mental Health into Primary Health Care (3 launched Oct 2008) which can be accessed at the following WHO website http://www.who.int/mental_health/policy/en/)

1. Introduction

This section covers the integration of mental health care in primary care and general hospitals. It also discusses community care and de-institutionalisation. These methods are key ways to increase access to mental health care.

Psychiatric institutions around the world continue to provide “treatment and care” that can only be described as inhumane and degrading. Patients are sometimes subject to horrific physical or sexual abuse. Some are secluded for long periods of time with no human contact or are forced to spend hours or even days alone in caged beds or tied down to beds with restraints. Others lack proper clothes, clean water, healthy food, and proper toilet facilities. Furthermore, large institutions tend to be located in major urban centres, leaving other areas with very limited or no mental health services at all. In other words, mental health care is significantly less accessible when it is provided through institutions than when care is more diffuse.

Mental health institutions cannot, however, be closed without first ensuring that alternative modes of service provision are in place (see generally WHO, *Organization of Services for Mental Health*). Integration of mental health into general health care, the development of community mental health care services, and de-institutionalization are complimentary strategies that are key for increasing geographical and financial access to mental health services. Delivery of mental health care through general health care and community care increases accessibility to underserved populations that may presently have access to primary care but not to mental health care. It also has the benefit of also better including family and community members in mental health service delivery, and decreasing stigma against mental disabilities. Placing care within the community enhances the ability of family to understand and support persons receiving treatment and services. By bringing mental health care “home”, the strangeness of mental health disabilities is somewhat diminished. Finally, providing integrated services, community care, and decreasing the role of institutions is in keeping with respect for the human rights of people with mental disabilities by applying the principle of the “least restrictive alternative”, and by upholding the right to live independently and to be included in the community.

Article 19 of the CRPD emphasizes the right of people with disabilities to community-based services and to live independently in the community. Article 19 also requires State Parties to facilitate people with disabilities' full inclusion and participation in the community. In particular, the CRPD recognizes the right of all people with disabilities to choose their place of residence and to have access to “in-home, residential and other community support services, including

personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”. Furthermore, community services and facilities for the general population must be available on an equal basis to persons with disabilities (Article 19) and all habilitation and rehabilitation services must support inclusion in the community (Article 26).

Article 19 of the Convention on the Rights of Persons with Disabilities

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- b. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

In Article 26 of the CRPD, State Parties are obligated to take measures to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. In particular, habilitation and rehabilitation services must be available to persons with disabilities as close as possible to their own communities, including in rural areas. Under Article 3, respect for autonomy is stated as a General Principle of the CRPD. The profound importance of this principle cannot be overemphasized. As will be discussed, throughout the world people are placed in custodial facilities where services enable the person to remain alive but do not allow for the development of the individual’s potential or encourage the individual’s return to the community. By recognizing a right of every person to services that maximize independence and full inclusion in all aspects of life, the CRPD raises expectations to a level that cannot be met by custodial care alone. Strategies for implementing this principle are discussed below.

2. The “Least Restrictive Alternative”

The principle of the “least restrictive alternative” is the **least intrusive service or treatment that can effectively and safely address the patient’s needs and stated preferences**. This principle originates from the UN Principles for the Protection of Persons with Mental Illness (MI

Principles)¹ a resolution of the General Assembly. Legislation can state the right to the least restrictive alternative and when deciding on treatment options, the least restrictive alternative is always the most respectful of human rights, including the rights to:

- Choose where to live, whether independently, with family or friends, in a group home, or in an institution;
- Be an active and contributing member of the community, for instance to attend educational or vocational programs or participate in community activities; and
- Have access to enabling and support services, such as home care or therapeutic services.

Accessible mental health care is key to ensuring that the least restrictive form of care is available to persons with mental disabilities. By making preventative and early care available, by providing mental health services in communities, and by including mental health care in primary care, reliance on institutions is decreased and the ability of persons to continue to live independently in their communities while receiving care is increased.

3. Why implement the least restrictive alternative?

Institutional care is the most restrictive kind of care; alternatives include mental health service delivery through primary care, general hospitals, and care in the community. People with health problems have a right to the least restrictive alternative care and persons with mental disabilities are no exception to this rule. Furthermore, alternatives such as integration in primary care and community-care facilities significantly increase the accessibility of care to persons in need.

There are many other reasons that the least restrictive alternative is a good approach when providing treatment options:

- Removing stigma: Locating mental health programs in the community integrating helps to remove the stigma of mental illness as people become more familiar with mental health issues. Integrating mental health care with primary care also removes the stigma of mental versus physical ailments.
 - Removing stigma encourages people to seek care and increases accessibility.
 - For example, James et al. (2002), report that after three months embarrassment at seeking treatment decreased where there was community care available.
- More family and community involvement: Locating mental health in an accessible place provides an opportunity for more community and family involvement in care programs.
- Improved physical health outcomes: There is very high comorbidity between mental and physical disabilities, including both infectious and non-communicable diseases and it is common for people with depression and anxiety to present with somatic symptoms when

¹ *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*. UN General Assembly Resolution 46/119 of 17 December 1991 (MI Principles). For more information on international human rights instruments, see modules 2 and 3.

seeking help for physical health problems from general health care services. Given the links between mental and physical health, it is very likely that improved mental health of a population leads to improved physical health (see Funk et al, 2005; Prince et al., 2007).

- Mental health services can also be integrated into existing special programs such as reproductive and child health programs, HIV/AIDS programs, or domestic violence programs, thus providing a feasible and affordable way of implementing mental health programs.
- Infant and child mortality can be reduced through improved treatment of postnatal depression.
- HIV/AIDS infection rates for the 17-24 year-old age group can be reduced as improved mental health reduces unsafe sex and drug use.
- There is better adherence to treatments for other ailments (e.g. tuberculosis, HIV/AIDS, hypertension, diabetes and cancer treatments) when mental health is improved.

(See generally, WHO, *Investing in Mental Health*, 2003)

- Earlier intervention means fewer crises: Mental health as a part of primary care ensures that groups who may be vulnerable to mental health problems that could lead to depression or anxiety have access to adequate and quality support networks. An integrated service encourages early identification and treatment of mental disability thus reducing the risk of acute problems.
- Decrease in abuse of persons with mental disabilities: Specialized institutions are, unfortunately, an arena for physical, mental, and sexual abuse and associated with these and many other forms of human rights violations, such that the WHO has called for the eventual closure of all such institutions.

4. Primary care and general hospitals

Integration of mental health care services in general hospitals is one way of increasing accessibility to care while also taking the emphasis away from specialized hospitals or other institutions. Legislation can mandate that mental health outpatient departments and other similar facilities be created in already existing general hospitals. Legislation can also provide for the creation of psychiatric wards in general hospitals.

Legislation can also introduce mental health interventions into primary care. Primary care is the “front line” of health care. Equipping primary care professionals with basic mental health awareness and skills ensures that this essential component of health is systematically integrated into patient care for the purposes of early detection and also of prevention. As mentioned above, mental health services at the primary care level increases geographic and financial accessibility and can also increase acceptance and understanding of mental disabilities by the community.

Of course, just as a certain percentage of people with physical health problems need more intensive care than an out-patient unit in a primary care setting can provide, so too will there be a number of people with mental disabilities who need more intensive care than can easily be provided through primary care services. However, having psychiatric services available in general hospitals or in community mental health facilities can meet the needs of the vast majority of people. While there is a small percentage of people who may need long-term mental health care, it is cruel, unnecessary, and expensive to keep them in large, dedicated mental health institutions. Accommodation in small, protected facilities as close as possible to their communities and family members is the best means of treatment.

Community-based models of care show improved clinical outcomes and cost savings

A systematic review of community-based models of care for adults with depression, schizophrenia, panic disorder, and bipolar disorders in low-income and middle-income countries found that community-care models improve clinical outcomes, with some cost savings. Evidence indicates that, in low-income and middle-income countries, support for primary health care workers with training, assistance, and supervision by available specialist mental health staff, is the best way to extend mental health care to the population. (Source: Saxena et al., 2007)

5. Community care and de-institutionalization

Community-based mental health care can be broadly defined as **any type of care, supervision and rehabilitation of patients with mental disabilities outside of a hospital by health and social workers based in the community** (WHO, *Organization of Service for Mental Health*). Specialized and centralized mental health institutions, on the other hand, frequently consume a large proportion of scarce mental health resources (budgets, beds, and staff) and have higher costs than care in the community in addition to the isolation, stigma and abuse associated with such institutions as discussed above. In addition to the economic advantages of community care, the CRPD requires all State Parties to take measures to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

Despite these advantages and legal obligations of community versus institutional care, only about half of the countries in Africa, the eastern Mediterranean, and southeast Asia provide community-based care; overall, 52% of low-income countries and 97% of high-income countries provide community-based care (Saxena et al., 2007). However, it can be the case that even when community care is provided it is made available only in a few areas.

As previously mentioned, accessibility can be significantly increased by shifting resources to community-based care schemes and away from de-institutionalization. Firstly, as with integration of mental health into primary health care and general hospitals, placing mental health care in the community means makes care more geographically accessible. People are more easily able to go to a community-based clinic for care than to travel to a far away institution, and inconvenience is one common barrier to mental health care (James et al., 2002). Secondly, it

gives people the ability to both receive treatment and continue their regular lives as much as possible. People with mental disabilities can then maintain family relationships, friendships, and jobs, all of which contribute to maintaining good mental health. Third, community-based care reduces the stigma of mental disabilities because mental and physical health care are treated in similar ways and because – unlike specialized institutions – community care facilities do not segregate persons with mental disabilities. When mental health care is more socially acceptable, it is easier for people to step forward to use it rather than avoid care in order to avoid stigma. Reducing stigma thus increases accessibility of care. Fourth, community-based care protects and promotes social integration and psychosocial rehabilitation of persons with mental disabilities. Finally, of course, community-based care promotes the right of persons with mental disabilities to the least restrictive alternative.

It should be noted, however, that deinstitutionalization cannot take place without a coordinated shift of resources to create or augment community care alternatives. Care in the community requires access to mental health resources that might, in an “institutional system”, only be located in large psychiatric institutions. Without accessible care and support in communities, persons with mental disabilities risk suffering from neglect, leading to related problems such as homelessness. Moving care to the community thus requires a re-allocation of resources, as mentioned above.

Legislation can be used to shift mental health care from institutional to community-based care, thus increasing accessibility. Legal reform can specify services that need to be created, and where such services should be available. When drafting legislation and regulations, law-makers should be aware that there may be competition between hospital and community-based services which can hinder the transfer of human and financial resources to community care centres, and plan the legislation accordingly.

6. Underserved populations

Underserved populations are groups that have lower accessibility to adequate mental health care service. These groups can face additional barriers leading to low access to services, or lack of appropriately delivered mental health services:

- Psychosocial stressors such as poverty and unemployment are correlated with the onset of adult mental health disabilities. Poor communities, however, may not have as much access to mental health care, whether because it is financially inaccessible or because there are not sufficient resources allocated to providing care in poor communities.
- Gender can also play a role – many studies indicate that women are at a higher risk of reporting symptoms of anxiety and depression (Saxena et al., 2007).
- Inequity of access to scarce resources is especially pronounced for children and adolescents with mental illnesses. Mental health services must take into account the special needs of youth (see also WHO, *Child and adolescent mental health policies and plans*).
- Refugee populations may need counselling and settlement services that are culturally appropriate, and in some cases that are sensitive to trauma situations. Similarly, immigrant

groups, and ethnic and religious minority groups can face a lack of access to care to culturally appropriate services. Presently, mental health care strategies do not equitably deliver care to all ethnic and religious minority groups (Saxena et al., 2007).

- Rural communities often have inadequate access to mental health care because of geographic location as, in most low-income and middle-income countries, mental health care professionals live in or around large urban centres. Studies have found that rural populations are under-represented among mental health outpatient services (Saxena et al., 2007).

Legislation can create criteria for the needs-based allocation of services by stating that mental health care services must be provided equitably to all persons regardless of geography, gender, ethnicity or other status traditionally associated with discrimination. Legislation can also include specific criteria to account for the needs of minors, women, minorities, refugees or other groups in society who lack access to good quality mental health services.

7. Links between primary and secondary facilities and intersectoral links

The need for good linkages between primary health care and secondary mental health facilities is crucial, and is promoted in the 1978 Declaration of Alma Ata where it states that primary care must be “sustained by integrated, functional and mutually supportive referral systems.” Simply including mental health care in primary health care services and creating community care services are not sufficient to ensure adequate access to care. Community and hospital-based services work best when they are coordinated with each other and with primary health care services. The structure and procedure of referral and consultation between primary and secondary facilities, minimum time delays for referrals and transfers of patients between facilities, and a funding structure to ensure the various facilities work in cooperation, can be broadly provided for in legislation with the details in regulations. In many cases, several levels of government or administrative bodies (for instance, local, regional, or provincial) will need to be consulted to ensure that linkages between primary and secondary services are well constructed (WHO, *Organization of Services for Mental Health*).

In addition to links between different mental health care programs and facilities, there must also be coordinated collaboration between mental health services and other community resources in non-health sectors. These can include education, social welfare, justice, family, and employment programs based in agencies such as housing services, employment/vocational counselling, income support services, and others. Community resources may also include traditional, indigenous and alternative health-care systems. In addition, it should be recognized that NGOs, religious leaders and other support networks are key to successful re-integration and independence. NGOs can be a particularly important resource as 88% of countries have at least one NGO that is active in mental health (Saxena et al., 2007). Commonly, these NGOs are involved in advocacy, health promotion, prevention, rehabilitation, and direct service provision related to mental disabilities. It should be noted, however, that NGOs are not always able to reach the entire population or provide a comprehensive range of services. Effective collaboration

with the government and support of NGOs is, thus, an important part of increasing accessibility of care.

Rural adolescents in Australia prefer counseling support from the school

In one study, Australian university students who were from rural areas were interviewed about their high school experiences with mental health support services. Access to help was primarily school-based. A preference for supportive counseling from school-based helpers was voiced, over structured interventions. (Source: Boyd et al. (2007) 15 Aust J Rural Health 196)

8. Training, supervision, and support of mental health professionals at all levels

Support must be provided to mental health professionals in order to ensure that primary and community care programs effectively deliver care. Legislating integration and community care initiatives cannot increase access to mental health care if health professionals do not have adequate training and supervision. However, worldwide, only 59% of all countries have facilities to train primary health care workers in mental health care (Saxena et al., 2007).

Training can be mandated for professionals who are specialized in the area of mental health - for instance, psychiatrists, psychologists, psychiatric nurses, and specialized social workers. In addition, mental health training can be mandated for the staff of community-based health clinics or other community-based facilities that assist persons with mental disabilities. A mental health component can be included in curriculum for a range of non-health professionals for whom such a component may be relevant to their work. This can include social workers, vocational and educational staff including teachers and counselors, spiritual leadership training, and so on. Training should not be restricted to those with formal education – indigenous practitioners are an important resource for patients and should also be sensitized and trained with respect to mental disabilities (James et al.). Once training is completed it is important to provide continued supervision. Mental health training received in the course of formal education may be short and theoretical, with only a brief practical component. Furthermore, such practical components are not likely to be community-based but will take place within the structure of the educational institution. Follow-up of trainees is essential to ensure continued education with respect to new ideas and issues in mental health, as well as field-based supervisory visits. Legislation can provide for a program including staff and transport, to ensure continued education of health and non-health professionals, and to act as a supervisory group to whom primary care staff can go for advice or guidance. Finally, it is essential to provide adequate support to primary health care staff. This can be done by investing in additional primary care staff – in many countries, primary care staff are overburdened as they deliver multiple health care programs. Legislation can also mandate that there must be adequate infrastructure, equipment, and availability of psychotropic medication and psychosocial rehabilitation programs.

9. Conclusion

The right of access to care is based on the right to health found in Article 25 of the CRPD and section 1 of the General Comment 14 on the ICESCR. State Parties are required by the CRPD to create free or affordable mental health services for people with with the same range, quality and standard of free or affordable health care and programmes as provided to other persons. These services must be provided in a manner that maximizes independence and full inclusion in all aspects of life.

Applying the principle of the “least restrictive alternative” means offering that the least intrusive service or treatment that can effectively and safely address the patient’s needs and stated preferences. Using a least restrictive alternative approach also increases accessibility to care, as well as addressing many other issues related to access to care such as stigma, family and community involvement, improvement of physical health outcomes, early intervention, and cost. Key ways to increase accessibility are to integrate mental health care in primary care and in general hospitals, and to promote community care over institutional care. It is also important to ensure that underserved populations have access to appropriate mental health care services. Implementation of such programs must be done in concert with the creation of strong links between primary and secondary care facilities, and between health and non-health sectors. Finally, programs must be put into place to ensure that primary health care, community caregivers, and others have access to adequate training, support, and supervision.

Legislation can help to implement these objectives by including reference to the principle of the “least restrictive alternative”, ensuring that proper support is available for people to live and receive treatment in their communities. For example:

- Italy’s law on *Voluntary and Compulsory Health Treatments* (Law No. 180, 1978) states that hospitalization is only allowed when community-based treatment is not feasible or has failed.
- Portugal’s Mental Health Law 36 (1998) states that “the provision of mental health care is undertaken primarily at the community level...”
- Laws can state that there is a preference for community care.
- Laws or regulations can delineate the responsibilities of community mental health services. These can explicitly include outpatient duties, rehabilitation services for outpatients, supervised home care, and services promoting mental health.
- Law can mandate creation of community-based facilities.
- Laws can prohibit involuntary admissions for periods longer than is absolutely necessary in the circumstances.
- Legislation can mandate accessible aftercare and rehabilitation services.
- Legislation can clearly outline mental disabilities training programs as a part of other educational or community-based instruction programs.
- Legislation can delineate intersectoral approaches and partnerships for delivery of psychosocial mental health programs.

PART IV: MAINTAINING MENTAL HEALTH: MEDICATION AND PSYCHOSOCIAL INTERVENTIONS

1. Introduction

Access to treatment for mental disabilities must be complemented by access to more regular care in order to maintain good mental health. Persons with chronic mental disabilities require chronic care. With access to mental health care and services they are able to continue being capable and contributing members of their communities and of society as a whole, enjoy a higher degree of independence from caregivers, and thus meet their full potential. Maintenance of mental health is aided by regular and guaranteed access to medications and availability of psychosocial interventions.

2. Improving access to psychotropic medication

The use and availability of psychotropic medication can significantly contribute to reduced hospitalizations, and also enables community-based care by helping to control some of the more adverse effects of mental disabilities. Thus, when essential medicines are unavailable, mental health treatment is constrained. However, in many countries there continues to be limited access to medication because necessary medicines are unavailable in the country or, when available, are only available at institutions and not in local clinics such that supply in many regions of a country is non-existent or irregular. This is very problematic as effective pharmacological treatment for many mental disabilities requires reliable and continuous access to medication over extended periods of time. In some cases, access to medication may be blocked because no health professional is available to prescribe or dispense them. Finally, all medications are costly and the more so when they are bought on the private market rather than via a public health care system.

In other words, access to medication depends on which medications are considered essential, the affordability of the medication, whether there is sustainable financing for the purchase of medications, and whether there are reliable supply and health systems in place to ensure that medicine is available in adequate amounts, at all times, in appropriate dosages and of assured quality (WHO, *Improving access and use of psychotropic medicines*, 2005). Each of these components is essential, but none alone are sufficient, to ensure adequate access. In addition, the calculated cost of treatment must take into consideration that mental disabilities are often chronic, and thus require long-term treatment or repeated treatments, and that certain drugs are subject to abuse and may need to be designated as “controlled substances”. Most importantly, it must be emphasized that there is already an obligation under article 15 of the ICESCR to give everyone the right “to enjoy the benefits of scientific progress and its applications.”

Legislation should enhance adequate access to essential psychotropics. It can ensure the availability of psychotropic medicines by mandating that medications for mental and physical health issues be equally available, or by specifically stating that adequate provision must be

made for psychiatric medications on a country's essential drugs list – as was done in Brazil (Order of Service No. 1.077, 2001). Legislative provisions should include safeguards to ensure that medications are of acceptable quality, and that they are not only available but also distributed and used appropriately at all times. Laws should define the responsibilities and authority of manufacturers, importers, wholesalers and distributors to ensure timely delivery, safe storage, and quality control. Persons who can sell, store, and prescribe medications should also be defined. In countries where mental health care service delivery is primarily done locally via primary care, legislation and regulations should ensure that the appropriate persons are given the authority to prescribe, dispense, and administer medicines as a psychiatric specialist may not always be available. A regulatory body should be established to oversee this process.

3. The importance of psychosocial intervention

Medication alone is not sufficient to treat most mental disabilities. Other interventions such as counselling, specific psychotherapies and vocational training are equally important. These interventions help to enable persons with mental disabilities to live independently in the place of their choosing, as active and contributing members of the larger community. Improving access to such interventions requires policy initiatives as well as legislative action. In addition to psychosocial rehabilitation and habilitation, all persons have a right to education (see the ICESCR). This means that persons with mental disabilities have a right to education taught in an accessible manner. This also includes specific mental health education so that people can learn about how to cope with mental disabilities. Finally, persons with mental disabilities have an equal right to employment, a right which enables all people with mental disabilities to live independently as stated above.

In many countries there is limited or no access to such programs. Psychosocial intervention programs may be restricted to certain geographical areas, may be privately run and financially inaccessible to some people, or may not exist because of a lack of trained staff to provide psychosocial services. Access to these interventions can be increased by including psychosocial intervention in mental health legislation. For example, the *Law on Mental Health* in Tunisia, passed in 1992, states that “Any person suffering from a [mental disability] shall have the right to appropriate medical care and physical treatment as well as, to the extent possible, instruction, training and rehabilitation that will aid him to develop his capacities and skills.” Such legislative statements ensure that policy makers and government are aware of and must account for the creation and accessibility of these services.

Articles 26 and 27 of the Convention on the Rights of Persons with Disabilities

Article 26 – Habilitation and Rehabilitation

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services

and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;

b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.

3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

Article 27 - Work and employment

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;

b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;

c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;

d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;

e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;

f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;

g) Employ persons with disabilities in the public sector;

h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;

i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;

- j) Promote the acquisition by persons with disabilities of work experience in the open labour market;
 - k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.
2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

4. Conclusion

Legislation must not only ensure that persons with mental disabilities have access to adequate care, but also that there is continued access to the medications and programs that are necessary to enable persons with mental disabilities to maintain the maximum mental health and to continue to be contributing and active members of their communities. This is necessary in order to comply with international human rights instruments, such as the CRPD. Psychotropic medications and psychosocial interventions are a part of long-term treatment of persons with chronic mental disabilities and help to lower the incidence of acute illness that could lead to institutionalization. Access to essential psychotropic medications and to psychosocial interventions is therefore a very important part of ensuring the success of community-based treatment programs and the application of the principle of the least restrictive alternative.

READING MATERIALS

1. Core Reading

WHO Resource materials

Books

WHO, *Improving access and use of psychotropic medicines* (Geneva: World Health Organization, 2005). Online: http://www.who.int/entity/mental_health/policy/services/10_improving%20access_WEB_07.pdf.

WHO, *Investing in Mental Health* (Geneva: World Health Organization, 2003). Online: www.who.int/entity/mental_health/en/investing_in_mnh_final.pdf.

WHO, *Mental Health Atlas: 2005* (Geneva: World Health Organization, 2005). Online: www.who.int/entity/mental_health/evidence/atlas_id_2007.pdf.

WHO, *Organization of Services for Mental Health*. (Geneva: World Health Organization, 2003). Online: www.who.int/entity/mental_health/policy/services/4_organisation%20services_WEB_07.pdf.

WHO, *WHO Resource Book on Mental Health, Human Rights and Legislation*. (Geneva: World Health Organization, 2005).

- Available online in various languages at: www.who.int/mental_health/policy/essentialpackage2/en/index.html.

Other materials

Integrating mental health services into primary health care. Geneva, World Health Organization, 2007 (www.who.int/entity/mental_health/policy/services/3_MHintoPHC_Infosheet.pdf).

Human resources and training for mental health. Geneva, World Health Organization, 2007 (www.who.int/entity/mental_health/policy/services/4_Humanresource&training_Infosheet.pdf).

The optimal mix of services. Geneva, World Health Organization, 2007 (www.who.int/entity/mental_health/policy/services/2_Optimal%20Mix%20of%20Services_Infosheet.pdf).

Academic publications

Funk et al. (2005) "A Framework for Mental Health Policy, Legislation and Service Development: Addressing Needs and Improving Services" 6 *Harvard Health Policy Review* 57.

James et al. (2002) “Demand for, Access to and Use of Community Mental Health Care: Lessons from a Demonstration Project in India and Pakistan” 48 *International Journal of Social Psychiatry* 163.

Knapp et al. (2006) “Economic Barriers to Better Mental Health Practice and Policy” *Health Policy and Planning (Advance Access)*.

Prince et al. (2007) “No health without mental health” 370 *Lancet* 859.

Saxena et al. (2007) “Resources for Mental Health: Scarcity, Inequity and Inefficiency” 370 *Lancet* 878.

United Nations Resources

United Nations Universal Declaration of Human Rights

- www.un.org/Overview/rights.html
- More general resources on human rights can be found at www.un.org/rights/.

United Nations Convention on the Rights of Persons with Disabilities

- This is available in html and pdf format in several language at: www.un.org/disabilities/default.asp?navid=12&pid=150
- The UN webpage on disability rights is also a useful additional source of information on international standards.

Articles 12 and 15, International Covenant on Economic, Social and Cultural Rights (ICESCR)

- www2.ohchr.org/english/law/cescr.htm

General Comment 14 of the U.N. Committee on Economic, Social and Cultural Rights

- This comment is an interpretation of article 12 of the ICESCR which establishes the right to health care. It is available for download at www2.ohchr.org/english/bodies/cescr/comments.htm. Please note that it is available in several languages, including English (under “E”) in PDF form.

Principles for the protection of persons with mental illness and the improvement of mental health care, General Assembly Resolution 46/119 (17 December 1991)

- <http://www.unhchr.ch/html/menu3/b/68.htm>

Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt

- The report and four addenda are available online in various languages:
 - i. First Report: unbisnet.un.org:8080/ipac20/ipac.jsp?session=12K08VK436768.103237&profile=bib&uri=full=3100001~!767099~!7&ri=1&aspect=power&menu=search&source=~!horizon

- ii. Addendum 1: unbisnet.un.org:8080/ipac20/ipac.jsp?session=12K08VK436768.103237&profile=bib&uri=full=3100001~!765916~!10&ri=1&aspect=power&menu=search&source=~!horizon
- iii. Addendum 2: unbisnet.un.org:8080/ipac20/ipac.jsp?session=12K08VK436768.103237&profile=bib&uri=full=3100001~!765006~!11&ri=1&aspect=power&menu=search&source=~!horizon
- iv. Addendum 3: unbisnet.un.org:8080/ipac20/ipac.jsp?session=12K08VK436768.103237&profile=bib&uri=full=3100001~!766954~!9&ri=1&aspect=power&menu=search&source=~!horizon
- v. Addendum 4: unbisnet.un.org:8080/ipac20/ipac.jsp?session=12K08VK436768.103237&profile=bib&uri=full=3100001~!768284~!6&ri=1&aspect=power&menu=search&source=~!horizon

International resources

U.S. Mental Health Parity Act (1996).

- A summary of the act is at: www.dol.gov/ebsa/newsroom/fsmhparity.html.

The Paul Wellstone Mental Health and Addiction Equity Act, passed in 2008

- The Act as passed by the House is available at:
www.govtrack.us/congress/billtext.xpd?bill=h110-1424

2. Additional reading

Jacob, K.S. (2001) "Community Care for People with Mental Disorders in Developing Countries: Problems and Possible Solutions" 178 *British Journal of Psychiatry* 296.
<http://bjp.rcpsych.org/cgi/content/full/178/4/296>

Patel, V. (2000). Culture, Health Systems and Psychiatric Disorders. *Social, Community and Public Health Psychiatry*, 13, 221-226.

WHO documents

WHO, *Child and adolescent mental health policies and plans* (Geneva: World Health Organization, 2005). Online: http://www.who.int/mental_health/policy/services/9_child%20ado_WEB_07.pdf.

Nursing matters: Developing nursing resources for mental health. Geneva, World Health Organization, 2007 (www.who.int/entity/mental_health/policy/services/Nursing%20Matters%20Infosheet.pdf).

Additional materials are available at: www.who.int/mental_health/policy.