

**STIGMATIZATION AND ACCESS TO HEALTH CARE
IN LATIN AMERICA:
CHALLENGES AND PERSPECTIVES**

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Stigmatization and Access to Health Care in Latin America: Challenges and Perspectives*

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Stigma associated with mental illness produces a series of adverse conditions that can result in exclusion in health. From the perspective of health systems, however, this phenomenon has not been widely studied. Hence the purpose of this study is to establish the importance of stigma as a barrier to access to the health services, and to identify ways to reduce exclusion in health due to stigma that go beyond the protection of the rights of the individual and place it within the framework of the extension of social protection in health. To this end, the study attempts to analyze the subject on the basis of what is happening today in the countries of Latin America in relation to:

1. The characterization of exclusion in health associated with stigma and its consequences; and
2. The identification of a set of indicators to measure the various aspects associated with stigma, thereby contributing to the strengthening of social protection policies for persons with mental illness. It takes into account initiatives that have been successful in identifying and acting on stigma.

In the final analysis, the idea is to work in an area of inclusive and multifaceted policy-making that incorporates the various aspects involved in assessing the competencies of persons with mental illness, with the health system being only the starting point. This study further intends to define research lines on the subject in order to support the design and formulation of health policies that promote access to health as a social right for persons with mental illness. In addition, the identification of indicators to measure stigma will make a valuable contribution to the implementation of Essential Public Health Function No. 11, *equitable access to health (1)*.

In this work, exclusion in health is defined as the lack of access of certain groups of people to goods, services, and opportunities that improve or preserve health status and that other individuals and groups of society enjoy (2). Stigmatization, in turn, is associated with a social process or with a personal experience characterized by exclusion, rejection, accusation, or invalidation, that

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result in an adverse social judgment on a person or a group (3). In this context, UNAIDS considers stigma to be a powerful social control tool applied through the marginalization, exclusion, and exercise of power over individuals who present particular characteristics (4).

Importance and Implications of Exclusion in Health from the Psychiatric Stigma Perspective

The Pan American Health Organization/World Health Organization (PAHO/WHO) began to study and measure exclusion in health in countries of Latin America and the Caribbean at the beginning of this decade. The need to address this subject arose as a result of the impact that the economic reforms of the 1980s and 1990s had on health, and which in the majority of countries resulted in increased poverty, deteriorating income distribution, and widening of the gap between the rich and poor segments of society. In Latin America, in particular, serious questions were raised about health inequity, poverty and, in the case in study, exclusion (5).

The above-mentioned studies found that between 20% and 77% of the general population does not have access to the health system when it needs it, and that on average 78% does not have any form of health insurance (6). In global terms, around 30% of the total population of Latin America and the Caribbean (166 million people) is partially or totally excluded from access to health goods and services. Measuring exclusion is important for several reasons. The most important is that exclusion in health is in itself denial of the right to health; therefore, the imperative to act is both ethical and legal in character. In addition to the ethical and legal imperatives, today it is recognized that the satisfactory performance of the health systems - in terms of their efficiency in the allocation of resources and of the health outcomes of the population - depends to an important degree on the timely access of disadvantaged groups to health services. Timely access is the only way to avoid the enormous cost in mortality and disability generated by the lack of access to health care of these population groups – a cost borne by the State and society as a whole.

The leading causes of exclusion in health in Latin America and the Caribbean can be classified as follows (2), (7):

- *External to the health system or based on disparities or barriers to access*, such as economic barriers (poverty level, percentage of families not covered by health insurance, employment related, etc.), geographic location, ethnic and/or cultural factors, or related to the lack of public infrastructure for the delivery of basic services (water, electricity and sewerage).
- *Internal or integral to the health system itself*, either linked to the process of health care, the infrastructure of the health network, the resources assigned within the health system, or the effectiveness of coverage. Such

exclusion occurs at the final point of care, when the user makes contact with the service provider or the health service.

Persons with mental illness may be subject to any of the above variables of exclusion depending on their economic condition, cultural or ethnic origin, gender, geographic location, employment, etc. Additionally, they are vulnerable to exclusion because of the specific nature of their health problems, which isolate them socially and lead them to self-exclude in order to avoid discrimination.

Despite the close relationship between health exclusion and stigmatization, the latter is not included in research or doctrine as a variable of exclusion along with the other social determinants of income, education, gender, ethnic group or race. This is noteworthy for two main reasons: First, because, like all variables of exclusion, stigmatization exists in the pyramid of discrimination to access and is in fact one of the main arguments used in the defense of the human rights of persons with mental illness. Research conducted for the present study found that although doctrine and jurisprudence have made important advances in the defense of the personal rights of individuals with mental illness, stigma as a cause of exclusion - from a health facility, for example - has not been considered with the same intensity. One of the most significant studies in terms of the objectives of the present paper was carried out in Chile in 2003, in relation to the utilization of the mental health services (8).

Second, stigmatization in mental health involves an element of diminished social integration, which is central to social exclusion (6).^[3]In this case, stigmatization plays a key role in exclusion in health, which then encourages exclusion in other spheres of activity throughout the life of the individual, notably in the educational system and the workforce. Stigma as a cause for exclusion impacts on the development of skills and subsequent income generation, thereby increasing the likelihood of poverty in persons with mental illness. The circle of poverty does not stop with the individual; it also affects the family since in many instances it falls to the family to provide the resources to maintain the person with mental illness at the basic subsistence level. As a result, in addition to the costs of long-term care and lost productivity, it can be argued that mental disorders contribute to increased levels of poverty (9).

The low significance that the health system attaches to the care of mental and behavioral disorders, and the lack of priority given to them, in turn results in failure to identify alternatives to allow persons with mental illness to enter into the mainstream of education and work, and thus perpetuates the cycle of damage and poses a threat to the social capital as a whole. The additional costs

^[3] Exclusion in health may be regarded as a component of social exclusion. The British Government has defined exclusion as something that can occur when people or areas suffer from a combination of related problems such as unemployment, lack of skills, low income, poor dwellings, high crime environments, poor health, and the destruction of the family structure. Text for the creation of the Unit of Social Exclusion by the English Prime Minister. Page of Social Exclusion of the British Government. Cited in PAHO/WHO-AIDS. *Exclusión en Salud en países de América Latina y el Caribe*. Serie No. 1. Extensión de la Protección Social en Salud (Reviewed edition, 2004).

generated by young people with behavioral disorders between the ages of 10 and 27 years go beyond health care and impact on the education and justice systems (8).

The failure to include stigma among the variables of exclusion could be due to several reasons. One has to do with the higher weight given to other variables, for example ethnicity and race. This is an important consideration when one considers that the indigenous population of Latin America is estimated to be between 33 and 40 million, divided into approximately 400 ethnic groups, and that, with the sole exception of Uruguay, every country in the subregion has an indigenous population. There are some 150 million persons of Afro-Latin and mestizo background, or roughly 30% of the regional population. This population is mainly concentrated in Brazil (50%), Colombia (20%), and Venezuela (10%) (10).

Another reason has to do with civil rights. The lack of representation of persons with mental illness makes it difficult for them to make claim to inclusion policies and to demand the nondiscrimination guarantees enshrined in international instruments as well as the human rights principles incorporated into constitutional texts. Add to this the synergistic effect of mental illness-stigma and you find these groups caught at the bottom of the economic and cultural ladder, further diminishing their ability to act. (11).

Finally, the historic marginalization of psychiatric care and mental health from core health and social services has contributed to the exclusion of the stigma variable. The low priority conferred on mental health illness by the majority of health workers is evidenced in both budget allocation and in planning that does not provide for care at the same level as for other health conditions (12). This marginalization impacts not only the health system, but also increases the burden of mental illness on the economic and social system. Even though cost estimates are not available for all mental disorders, let alone for all the countries, comparisons are still possible based on studies carried out in Great Britain and the United States, where in 1990 mental health illness was responsible for 2.5% of the Gross National Product (GNP). In the countries of the European Union, the average percentage was 2% of the GNP (9). An estimate of the overall burden of lost disability-adjusted life years (DALYs) shows that mental and neurological conditions are important contributors. For example, in 1999 they represented 11% of the DALYs lost due to disease and injury. By 2020 it is expected that the number of people with mental illness will have increased and the consequent burden of disease will have risen to 15% of the DALYs lost per year (12).

Characterization of Exclusion in Health Associated with Stigma

The characterization of exclusion in health associated with stigma requires that the reasons that keep people away from health services be

identified. To characterize stigma as an exclusion variable, this study considers three scenarios: 1) *the individual scenario*, related to self-exclusion or the rejection of psychiatric care; 2) *the institutional scenario*, in terms of the response of the health system and its health workers; and 3) *the community scenario*, when referring to the attitudes of the other users of the health system in light of the social worth they assign to the mental health patient.

Self-exclusion or rejection of psychiatric care

The most common reason for rejection of psychiatric care is the belief that there is no effective treatment for mental illness. To this is added the fear and shame associated with the stereotyping of mental illness, both at work and in the social ambit (13). These fears are largely a result of the negative reactions that individuals themselves perceive, both social and economic. In the latter case in particular, the mere inclusion of questions relating to psychiatric or psychological therapy of any type or form generates fear. Private insurance schemes based on health maintenance organizations (HMOs) and other individual insurance plans contribute to the sense of stigma by setting limits on reimbursements for mental health care and often increase premiums for persons who declare a mental health problem. The same may be said about questions directed at identifying mental illness on applications to educational institutions (12) or in the job market.

There is general agreement on the effects of self-exclusion as a health care barrier. Self-exclusion creates an expensive pattern of health service demand due to the over-utilization of emergency and hospital services. It can also manifest itself in abandonment of treatment with subsequent psychotic deterioration, and even suicide. However, research for the present study found little importance given in Latin America to the impact of stigma on access to services. Only two references were found on this issue. In the first case, a study conducted in Costa Rica in 2004 reveals the impact of stigmatization related to mental illness on aspects associated with social and work environments: isolation or social rejection, difficulty in finding employment, problems with being accepted as a couple, exclusion from participation in sports, and discrimination in the daily routine, such as in public offices and health care centers (15).

A 2004 Chilean study dealt with the subject of self-exclusion in greater detail. It concluded that stigma represents an important barrier to access to treatment. It is one of the few studies that characterizes the problem. One third of the persons considered in the sample, which included 2,987 participants with a level of response of 90.3 per cent, claimed that stigmatization was an important barrier in their use of the psychiatric services. The most important deterrent to seeking access was found to be the fear that others might find out that they had sought psychiatric care. The socioeconomic and educational levels of the participants were a major factor in their responses, with the fear of stigmatization rising in inverse proportion to their levels (8).

Stigmatization associated with the health care system

Conditions associated with stigma (stereotyping, discrimination, and fear, among others) have consequences for the access of persons with mental illness to the general health services, in terms of the negative perception that the health team may have of this type of patient. It would be useful to explore in depth how the system reacts with effective coverage, length of wait times, and demand satisfaction when the person with mental illness requires care that is not psychiatric-related. This information is not readily available for Latin America and the Caribbean.

Stigmatization derived from the community of users

In this case, stigmatization is associated with the way in which other users of the health services perceive mental health patients in terms of their contribution to the social and economic good, for example, to the generation of income. It is based not only on the perception of the person with mental illness as a disruptive element in the health care service – myths associated with violence and unpredictable behavior, or the association of mental illness with mental retardation - but also involves the element of responsibility to contribute to social growth. That is, it can create in the collective mind of the group the idea that the contribution of the person with mental illness to the economic chain is negligible or non-existent. As a result, the group may demand priority for others who can make a more meaningful contribution, such as for patients who are gainfully employed.

Data sustaining this stigma variable are scarce. However, generally speaking, the argument for this scenario is: *I have to go to work, they don't; they can wait because they have the time and I don't*. The same argument can be made to justify relative access to drugs, where the economically productive population feels that priority should be given to treatment of their health conditions. The negative assessment made of persons with mental illness in terms of their contribution to society places their health needs squarely at the bottom of the priority scale. This is even more evident in Latin American societies, which are historically constructed on a social hierarchy that places men who work and provide for their families at the top of the priority scale.

Indicators that Support the Characterization of Stigmatization as a Barrier to Care

The premises for this analysis are:

- a) Stigmatization acts as a barrier to access to the health services for persons with mental illness and is therefore a cause of exclusion.
- b) It is possible to identify indicators that are a good parallel for this phenomenon.

In Latin America as in the rest of the world, there are initiatives that successfully address the elimination of stigma as a cause of exclusion not only in the social and work settings but also in terms of the variable under study. One of these initiatives relates to HIV/AIDS. There are parallels between exclusion due to stigma associated with mental illness and exclusion due to HIV/AIDS, such as unfounded fears resulting from ignorance about the disease and the existence of effective treatment, association of the disease with low productivity and absenteeism in the workplace, association of the disease with religious myths, or generational castigation. Therefore, in the development of indicators to identify stigma as a cause of exclusion in health for those with mental illness, the typologies utilized for HIV/AIDS have been taken into consideration (16).

The typology of indicators however, does not exist in a vacuum. That is, the indicators cannot be applied in the abstract, but must also be analyzed in the context of other socioeconomic variables, such as poverty (or social vulnerability), geographic location (rural or urban), education, family structure (in terms of its ability to strengthen the self-esteem of the individual and his/her ability to deal with rejection associated with stigma) and the various factors associated with cultural patterns (for example, of indigenous communities or populations of African descent). These factors accentuate or diminish the potential for stigma associated with mental illness to become a barrier to access of the health services. Results of studies of the characterization of exclusion in health carried out by eight counties of the region, as well as two studies at the state level, indicate that poverty, indigenous origin, rural environment, working in the informal sector or unemployed, and illiteracy or monolingualism in a language other than Spanish are factors that increase the potential for stigma associated with mental health problems to become a barrier to access to health services (6).

Indicators to measure self-exclusion

Self-exclusion indicators can be developed by taking into consideration both individual and collective perceptions, the latter mainly in terms of the collateral impact on family members and associates.

At the level of the individual:

- Number of persons who do not seek attention for fear of social rejection
- Number of persons who believe that there is no effective treatment for mental health illness and thus perceive the risks associated with seeking out the health services to be greater than the benefits
- Number of persons who do not seek care for fear of confidentiality breaches (by professionals and institutions and with regard to the new automated procedures for maintaining clinical histories)
- Number of persons who do not declare having received psychiatric care on their job applications, requests for insurance, or admission forms for academic institutions

- Number of people who do not seek care for fear of losing some authority role (family, religious community)

At the collective level:

- Number of people who do not seek care for fear of bringing shame on their families

Based on these perceptions, the suggested indicators are:

- Percentage of patients with mental illness who drop out of treatment
- Percentage of persons with mental illness who, having been ill or injured during the last three months, do not seek medical care for fear of being discriminated against or mistreated, or out of fear that they will lose authority or confidentiality

Indicators to measure exclusion associated with the general health care system

For the construction of these indicators it is suggested that the attitudes of health personnel towards persons with mental illness be considered in terms of:

- Fears associated with violent reactions
- Perceptions of power associated with the undervaluation of the person with mental illness – they are doing a favor in caring for him or her
- Incorrect correlation between psychiatric disorders and physical conditions – attention to the physical aspects may generate a crisis that provokes violent behavior
- Belief that persons with mental illness are unable to follow treatment or therapeutic recommendations

Based on these perceptions, the suggested indicators are:

- Length of wait periods for persons with mental illness compared with those for the general population
- Cost of premiums for individual health insurance plans for persons with mental illness versus the premiums for similar population groups not having these problems
- Percentage of individual health insurance plans that consider mental illness as a preexisting condition
- Percentage of the population with mental illness affiliated to individual health insurance plans compared to the general population
- Percentage of public health expenditure appropriated for the diagnosis and treatment of mental illness
- Percentage of primary and secondary health care staff trained to address the general health needs of persons with mental illness

Indicators to measure exclusion by the community of users

For the construction of these indicators it is recommended that the attitudes of the members of the community towards persons with mental illness be considered in terms of:

- Disruption (cause problems, do not follow a predictable behavioral pattern)
- Do not contribute to the chain of production and are therefore not deserving of priority
- Do not have family obligations

Based on these perceptions, the suggested indicators are:

- Percentage of persons in a community who think that rendering health services to persons with mental illness is a waste of resources

Additionally, it is recommended to include an indicator showing the concern of the society for the subject, in terms of the existence, or lack thereof, of legal mechanisms to protect the rights of access to health care for people with mental illness.

Indicators for stigma as a barrier to access of the health services may be organized in the following manner:

Stigmatism indicators as a barrier to access of the health services

Category	Indicator
<i>Self-exclusion</i>	<ul style="list-style-type: none"> -Percentage of persons with mental illness who, having been ill or injured during the last three months, do not seek medical care for fear of being discriminated against or mistreated, or out of fear that they will lose authority or confidentiality - Percentage of patients with mental illness who drop out of treatment
<i>Exclusion associated with the general health care system</i>	<ul style="list-style-type: none"> - Length of wait periods for persons with mental illness compared with those for the general population - Percentage of public health expenditure appropriated for the diagnosis and treatment of mental health illness - Cost of the premiums for individual health insurance plans for persons with mental illness versus the premiums for similar population groups not having these problems - Percentage of individual health insurance plans that consider mental health illness as a preexisting condition - Percentage of the population with mental illness affiliated to individual health insurance plans compared to the general population - Percentage of primary and secondary health care staff trained to address the general health needs of persons with mental illness
<i>Exclusion in health provoked by attitudes of the community</i>	<ul style="list-style-type: none"> - Percentage of persons in the community who think that rendering health care to persons with mental illness is a waste of resources
<i>Legal framework for the specific protection of the rights to health of persons with mental illness</i>	<ul style="list-style-type: none"> - Exists/ does not exist - Applied/not applied

Methodologies for Measurement

Techniques should be developed to measure the problem quantitatively (package of independent indicators) and qualitatively (focus group and interviews with key sources or information).

Given the fact that the majority of the questions needed to identify stigma are not currently found in household surveys, agencies interested in researching the problem should conduct their own surveys or advocate for the inclusion of the questions presented in this study in surveys carried out by the Ministry of Health or others.

Since exclusion in health is a multi-causal phenomenon, it is important to bear in mind interactions between the variables, such as poverty, ethnic origin,

gender, place of residence, and stigmatization. If stigmatization is to be emphasized, it would be necessary to go back, on a case-by-case basis, to analyze the basic components in order to determine the weight of the stigma variable in relation to the incidence of exclusion in health.

Strategies

Access to health for persons with mental illness is not yet an explicit priority for the health systems in the majority of the countries of the Latin American and the Caribbean region, where the health agenda is focused on fulfillment of the Millennium Development Goals. Three strategies are proposed in order to put this issue on the political and health agenda of the countries:

1) Give visibility to the role that stigma plays in the access to health care of persons with mental illness and to the social and economic costs that this implies for States and societies. In order to achieve this, information and evidence must be collected. It thus becomes urgent to formulate and develop a platform of initiatives to research the subject.

PAHO/WHO has defined social protection in health as *society's guarantee, through the public authorities, to meet the health needs and demands of individuals or groups of individuals, by providing quality, timely, and dignified access to services regardless of ability to pay (5)*. In this context, the development of policies, and strategies aimed at extending the social protection in health to persons with mental illness is reinforced by an analytical-operational approach based on the following steps:

- a) Know the causes of the exclusion in health for this population, in particular the role that stigmatization plays as a barrier to access
- b) Understand the factors that perpetuate stigmatization
- c) Identify alternatives aimed at improving health protection for the excluded groups that are more relevant to the particular conditions of a country or territory
- d) Identify interest groups involved in the implementation of such alternatives
- e) Define, plan, and implement interventions

2) Availability of information will make it possible to pass to a second stage, focusing attention on advocacy for the rights of these persons in the countries and incorporation of the topic into the public agenda. In this context, activities to disseminate information should include social dialogue as a means of involving citizens in the debate.

3) Finally, the design and formulation of policies aimed at eliminating stigma as a barrier to access to health services for people with mental illness should include the education and training of health workers at the primary care level, also community leaders in the appropriate attention needed to address the

health needs of this population - the latter to include the drafting and dissemination of charters of the rights to health of persons with mental illness that clearly spell out their rights and responsibilities in relation to health care. The strengthening of legal mechanisms to render effective the exercise of these rights should be central to the implementation of these policies.

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