

POSITION STATEMENT
ON
STIGMA AND DISCRIMINATION
IN
MENTAL HEALTH AND ADDICTIONS



DEVELOPED BY
THE INDIANA STATE CONSUMER COUNCIL

Of the
Indiana Family and Social Services Administration, Division of Mental Health and Addiction Mental
Health Planning Council

This paper has been prepared by the DMHA Consumer Council and is not intended to reflect the views of the Division of Mental Health and Addiction, the Indiana Family and Social Services Administration, or the full DMHA Mental Health Planning Council. It is intended to reflect the Consumer Voice regarding Stigma and Discrimination and what consumers believe should be the policy of the state mental health authority and the providers of mental health services.

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Addressing Stigma and Discrimination in Mental Health and Addictions

Introduction

In many human rights circles, the last 50 years has been an era of increasing (albeit imperfect) tolerance. Those of us working in the field of mental health and addictions have seen change – from mysticizing, warehousing and criminalizing to medicalizing and psychologizing. We have moved people out of mental hospitals and into assisted living units, we have found that a range of treatment options and social supports help people recover like never before; we have spoken of addiction as an illness, not a moral issue.

But there's still the language – addict, mentally ill, schizophrenic, psycho, junkie – personless, labeling language that, even today, is so hard to shake off. And why? A person cannot choose their race or gender, or reverse a physical disability; behavior, however, is different. There is an expectation that a person should be in control of their behavior, thoughts and feelings. And though the experts have argued for, and proclaimed victory in, having mental illness and addiction viewed as health issues, for many people it remains an issue of poor self-control and character flaw.

“What if he falls off the wagon?” “What if he acts strangely?” “What if she becomes violent?” These are not health concerns; they are judgments based on stereotypes, media depictions, and lay assumptions of causality that are embedded in our culture. “Come on, pull up your socks.” “Stop trying to get attention.” “Just say no.” “If you would just get a job and get off the system. . .”

Definition of Stigma and Discrimination

Webster on stigma: a mark of shame or discredit: Stain<bore the *stigma* of cowardice> c: an identifying mark or characteristic; *specifically*: a specific diagnostic sign of a disease

Webster on discrimination: 1 a: the act of discriminating B: the process by which two stimuli differing in some aspect are responded to differently 2: the quality or power of finely distinguishing 3 A: the act, practice, or an instance of discriminating categorically rather than individually B: prejudiced or prejudicial outlook, action, or treatment <racial *discrimination*>

History behind Stigma and Discrimination

The mental health and addictions movements have historically always talked of stigma. According to the father of stigma theory, Erving Goffman, stigma is the situation of an individual being excluded from full social acceptance because of a trait that marks them as different from the so-called “normal” majority. This difference then elicits some form of discrimination from the community, such as punishment, restriction of rights, ridicule and/or social rejection.¹

¹Goffman, E. (1963). *Stigma: The management of spoiled identity*. Harmondsworth, UK: Penguin

For the ancient Greeks, stigma referred to visible marks on the body that were branded on ‘undesirables’ – slaves, criminals and traitors. Although nowadays people with Mental illness and/or addictions are not tattooed upon diagnosis, the feeling is not altogether different; the brand is just invisible.

Throughout their history and up to the present day, mental health and substance use problems have been seen as sins, crimes, behavioral problems, diseases, or some combination of these. Despite the changing frame, the perception has basically remained the same: the person is, at worst, irreparable; at best, only capable of temporary recovery through strict adherence to ‘the program,’ ‘the steps,’ ‘the medication’ ...

People with mental illnesses and/or addictions have been among the most devalued of all people with disabilities – and by extension, friends, family and professional care providers also face a kind of “stigma by association.” A major US nationwide survey of mental health consumers found that almost 80% of survey respondents had overheard people making hurtful or offensive comments, with more than a quarter often being told to lower their expectations in life.²

But the effects of discrimination go far beyond dirty looks and name-calling. Users of mental health or addictions services can be denied basic rights of citizenship, encountering both subtle and blatant discrimination when accessing housing, employment, income assistance, higher education, insurance, parenting rights, immigration status and even recreational opportunities. They are often viewed as second-class citizens by the communities and neighbors they wish to live among and befriend, by the physical health care and criminal justice systems, media, mental health and addictions professionals, other service users, and even their own friends. Rejection from social supports, resources and institutions has a significant impact on a person’s self-sufficiency, recovery and overall quality of life.

The case has been made that, due to discrimination, mental health and addictions systems are chronically under-funded – particularly when measured against the toll these conditions take on families, workplaces, and the health care and criminal justice systems.³

Background

Twenty-three percent of all American adults (18 and older) suffer from a diagnosable mental disorder in any given year and one out of every five young persons (before the age of 18) suffers from some form of emotional disturbance.⁴ Yet many people still believe the adage “It can’t happen to me.” And, since many people hide their problem and/or treatment out of embarrassment, mental illness might appear to be less common than it actually is. The reality is that mental disorders are as common as physical ailments and are equally debilitating. The irony of the discrimination of mentally ill persons is that mental illness does not discriminate.

²Wahl, O.F. (1999). Mental health consumers’ experience of stigma. *Schizophrenia Bulletin*, 25(3), 467-468

³Gross, C.P., Anderson, G.F., and Powell, N.R. (1999). The relation between funding by the National Institutes of Health and the burden of disease. *New England Journal of Medicine*, 340(24), 1914-15.

⁴*Facts and Figures about Mental Illness*; National Alliance for the Mentally Ill (NAMI); January 2001

Perceiving mental disorders as “real medical illnesses” reduces stigmatizing attitudes among the general public, as does having contact with a person suffering from a mental disorder. Study results suggest that previous studies on this topic have suggested that prejudice decreases when the public are given biogenetic causal explanations for mental diseases, such as when schizophrenia is promoted as “an illness like any other.”⁵

The often socially-accepted negative associations of mental illness – which mentally ill persons are “crazy” or “mad” – make it difficult for some people to get past these connotations and to see conditions such as post-partum depression and seasonal affective disorder (SAD) as legitimate ailments. The fact is, an estimated 5 million young females suffer from eating disorders each year and eating disorders are the deadliest mental illness claiming more lives than any other illness.⁶ The outdated images of “lunatics” in asylums sometimes overshadow the fact that most mental disorders can be effectively treated with medication or counseling. Educating the public on the nature of mental illness and the importance of mental health is the cornerstone of advocacy groups. An acceptance and understanding of mental conditions is necessary to facilitate a “comfort zone” wherein people suffering from those conditions feel safe enough to seek help. Cutting through the stigmas that prevents people from seeking effective treatment is an important first step in addressing mental health as a public health issue.

Organizations such as the national Mental Health America (MHA), with its *Campaign for America’s Mental Health*, are working to raise awareness through education and public outreach. More information on MHA’s program is available www.MentalHealthAmerica.net.

Over six percent, or 14 million, Americans (12 and older) used illegal drugs in 2000.⁷⁻¹⁰ In 1998, an estimated 1.6 million Americans abused prescription drugs.⁸ And more than 12 million Americans (12 and older) have reported a history of heavy drinking.⁹ And more than 2 million Americans suffer with gambling addiction and millions more with gambling problems.¹⁰

The fact that addiction is a disease recognized by the medical community has not entirely ended negative attitudes toward those with addiction problems. It can be argued that alcoholism is genetic or inherited. It can be argued that those who abuse drugs, while initially choosing to use, are predisposed to a compulsion to continue using. Addiction and dependence are not weaknesses or character flaws; research shows physiological effects that produce lasting changes in both brain chemistry and neurological function.

Treatment and recovery is, by most accounts, a matter of “One day at a time,” and different efforts work for different people. Still, treatment can be highly successful, and those in the recovery community are fully capable of leading productive lives. Those still struggling with their addictions should be treated the same as anyone else with a chronic illness.

⁵*Summary of Findings from the 2000 National Household Survey on Drug Abuse, DHHS Publication No. (SMA) 01-3549, Rockville, MD: Office of Applied Studies, Substance Abuse and Mental Health Services Administration (SAMHSA); 2001*

⁶⁻¹⁰*Prescription Drugs: Abuse and Addiction, National Institute on Drug Abuse Research Report Series, NIH Publication No. 01-4881, Rockville, MD: National Institute on Drug Abuse, National Institutes of Health (NIH), U.S. Department of Health and Human Services (HHS); April 2001.*

The U.S. Department of Health and Human Services' (HHS) Substance Abuse and Mental Health Services Administration's (SAMHSA) Center for Substance Abuse Treatment (CSAT) published a report entitled *Changing the Conversation: The National Treatment Plan Initiative to Improve Substance Abuse Treatment* in November 2000. The intent of this report was to "change the (national) conversation" about substance abuse and treatment to stress that addiction is a treatable disease.

"*Changing the Conversation* envisions a society in which people with a history of addiction, people in recovery, and people at risk for these problems are valued and treated with dignity, and where stigma, accompanying attitudes, discrimination, and other barriers to recovery are eliminated. We envision a society in which substance abuse/dependence is recognized as a public health issue, a treatable illness for which individuals deserve treatment. We envision a society in which high-quality services for addiction problems are widely available and where treatment is recognized as a specialized field of expertise."¹¹

About one in five British Columbians is living with some form of mental disorder or addiction, but two-thirds will not seek help. This is not due to lack of mental health resources or even effective treatments, but too often because people fear being labeled according to age-old stereotypes of people with mental health problems.

Even clinical depression, which has arguably received the most media attention this past decade, is still stigmatized. A 2005 Australian study noted that around one quarter of the people felt depression was a sign of personal weakness and would not employ someone with depression. Nearly one third felt depressed people "could snap out of it," and 42% said they would not vote for a politician with depression.

Addiction, which is a chronic and disabling disorder, is also often thought of as a moral deficiency or lack of willpower, and there is the attitude that people can just decide to stop drinking or using drugs if they want to. The study of the effects of stigma on substance use disorders is a still fairly undeveloped area, but research is revealing that social stigma and attitudes towards addiction are preventing people from seeking help.

Even the helpers aren't immune from the silence of stigma. More than 40% of family doctors, who are in a good position to detect substance abuse problems early, admit in a US survey that they find the topic difficult to talk to patients about – more than double the discomfort they admit feeling for depression.

The reality of discrimination has a very real and direct effect on the course of treatment of a person's mental health or substance abuse problem. Among the top three reasons why people don't seek help were that they are too afraid to ask, or are afraid of what others would think.¹² Prejudice and discrimination have also been shown to influence treatment behavior, from attendance at self-help or therapy groups to compliance with medication.

Discriminatory attitudes can also affect people's access to treatment for substance use problems.¹³ Someone with a problem may be reluctant to seek help (even through 'anonymous' support groups) for fear of society's reaction if they were found to have substance use problem. Another example is if someone commits a petty theft to get money to buy drugs or alcohol: the criminal behavior is usually the focus, when what the person really needs is treatment for their addiction.

¹¹⁻¹³*Changing the Conversation: The National Treatment Plan Initiative to Improve Substance Abuse Treatment, DHHS Publication No. (SMA) 00-3480, Rockville, MD: Center for Substance Abuse Treatment, SAMHSA; November 2000.*

There is also evidence to suggest that community attitudes and discriminatory behaviors toward mental disorders and addictions may help determine a person's degree and speed of recovery.¹⁴ For example, researchers have found that schizophrenia has a better prognosis, or outcome, in developing nations not because of better medical treatment but because of societal reaction and integration of the person into the community.¹⁵

The shame and discrimination associated with mental illness is the legacy of an era when individuals with mental illness were locked away in insane asylums, sometimes for the rest of their lives. Because of a lack of effective treatments, people with mental health needs were regarded as "mentally defective" and incurable.

Change began in the 1960's with the introduction of powerful antipsychotic medications and advances in psychotherapy. As treatments began to offer relief from the more severe symptoms of mental illness, patients were deinstitutionalized across the country and treated on an outpatient basis or in a hospital for short periods.

And yet, a 2001 Canadian study of people with schizophrenia still found that social withdrawal had a "great impact" on their lives while the hallucinatory and delusional symptoms of their illness – thanks to advances in therapy and medications – had the 'least impact' on their lives.¹⁶ As a society, we have done much to alleviate major clinical symptoms of mental illness, but little to alleviate the symptoms of societal discrimination.

The most common ways people with mental illness or addiction cope with the effects of shame or stigma are by hiding it, educating people individually, or withdrawing from potentially stigmatizing social situations. These are not only generally ineffective but can be emotionally costly because they affect interpersonal relationships and perpetuate one's social isolation. They also increase fears and worries of being discovered, and maintain a person's negative self-image.

A 2005 study of patient attitudes towards depression found that 29% of people felt their families would be disappointed to know about their depression, 46% would be embarrassed if their friends knew, and 67% felt their employers should not know about their conditions. The study even found that more than a quarter of young adults surveyed did not accept their physicians' diagnosis of depression.

These findings apply to individuals across the societal spectrum. Physicians, for example, often deny their own mental health needs and addiction issues and hide their conditions to protect their careers. A study of medical students revealed that concerns about confidentiality, stigma, notation on academic record, and forced treatment were among the top barriers to mental health care and addiction treatment for those in the medical community. As a result, the rate of completed suicides among physicians is much higher than in the general population.

¹⁴Johnson, T.P., Booth, A.L. & Johnson, P. (2005). Physician beliefs about substance misuse and its treatment: Findings from a US survey of primary care practitioners. *Substance Use & Misuse*, 40(8), 1071-1084

¹⁵Jorm, A.F., Christensen, H., & Griffiths, K.M. (2005). Belief in the harmfulness of antidepressants: Results from a national survey of the Australian public. *Journal of Affective Disorders*, 88(1), 47-53.

¹⁶Kealey, E.M. (2005). Variations in the experience of schizophrenia: A cross-cultural review. *Journal of Social Work Research and Evaluation*, 6(1), 47-56.

Many people do not want an official record that identifies them as having mental illness or an addiction. They fear others might find out, treat them differently and judge them based on these problems. Sadly, in many cases, they are right. Subtle and overt discrimination against mental disorders and addictions continues to be documented by social scientists in the arenas of employment, education, housing, parenting, criminal justice, immigration, and other areas of social and community life.

For some people who are recovering, this can lead to feelings of emptiness, alienation and rejection.¹⁷ The isolation and loneliness may even trigger a depression, substance abuse problems, or a relapse. This drives up the personal cost of mental illness, which is already too high. Prejudice and discrimination are based largely on ignorance, myth and intolerance.¹⁸

The best antidote is targeted, community-based education coupled with direct positive contact with individuals who have experience with mental illness and/or addictions.¹⁹ The knowledge that people can recover from these illnesses and contribute to society can help dispel society's fears and misconceptions about them and encourage more people to open up their hearts to themselves and others who develop a mental disorder.²⁰

It's also time to start calling stigma what it is – prejudice and discrimination.²¹ Stigma implies there is something wrong with the person while discrimination puts the focus where it belongs: on the individuals and institutions that practice it. Liz Sayce, a researcher from UK's Mind charity who has written extensively on the topic of social exclusion asks why the mental health movement would be any different from other human rights movements; it's not as if we talk about the "stigma of being black – no, we talk of racism." People with mental health and addictions and their families have been blaming themselves for far too long. It's time to put that energy towards examining society's attitudes, structures and policies.²²

Facts about mental illness²³

- Mental illness affects people of all ages, educational and income levels, and cultures
- Mental illness affects a person's thinking, feeling, judgment and behavior
- Mental illness is not contagious
- Although there are no cures for mental illness, treatments can reduce the symptoms and help people lead productive and fulfilling lives.

¹⁷⁻¹⁸Link, B.G. Mirotznic, J. & Cullen, F.T. (1991). The effectiveness of stigma coping orientations: Can negative consequences of mental illness labeling be avoided? *Epidemiology of Mental Disorders*, 32(3), 302-320.

¹⁹Markin, K. (2005). Still crazy after all these years: The enduring defamatory power of mental disorder. *Law & Psychology Review*, 29, 155-185.

²⁰Rasinski, K.A., Woll, P. & Cooke, A. (2004). Stigma and substance use disorders. In P.W. Corrigan (Ed.), *On the stigma of mental illness: Practical strategies for research and social change* (pp. 367-380). Washington, DC: APA.

²¹Sayce, L (1999). *From Psychiatric patient to Citizen: Overcoming Discrimination and Social Exclusion*. New York, NY: St. Martin's Press

²²⁻²³Schizophrenia Society of Canada. (2001). *Schizophrenia: Youth's greatest disabler*. A report on psychiatrist and patient attitudes and opinions towards schizophrenia. Markham, ON: Author.

- The onset of most mental illnesses occurs during adolescence and young adulthood
- A complex interplay of genetic, biological, personality and environmental factors causes mental illnesses
- Persons with mental illness can and do recover

Persons with mental illness need caring support: these illnesses can place enormous emotional and financial strains on the person with the illness and their family and friends.

Facts about addiction²⁴

- Addictions occur in people of diverse ages, education levels, socio-economic situations, and culture
- Addiction is not caused by moral weakness, or lack of self-control or willpower
- No one knows what causes addiction, but there are many factors that increase a person's risk of experiencing problems with substance use: these include biological factors, family situation, school/peer group influences, other social factors, and what sort of tools a person has to cope with stress or other life difficulties
- Many people with addictions can't "just stop" using drugs or drinking – they need treatment
- Persons with addictions can and do recover

Recovering persons need support from their families, friends, workplaces, and other community groups. Support can help with recovery and decrease the chances of relapse.

Some common signs of prejudice²⁵

- Stereotyping people with mental illness or addiction issues (treating them as a group rather than as individuals)
- Trivializing or belittling people with mental illness or addictions issues through insults
- Patronizing people with mental illness or addiction issues by treating them as less worthy than other people
- Reinforcing common myths about people with mental illness or addiction issues: for example, saying they are dangerous, weak, beyond hope, etc.
- Labeling people by their diagnosis; the concept of the person as an individual is lost, and the illness is the only relevant characteristic when terms such a paranoid schizophrenic, manic depressive and bulimic are used
- Using slang words such as "insane," "schizoid" and "psycho," which are often used in news headlines to grab readers' attention
- Sensationalizing or accentuating myths about mental illness: for example, a headline such as "Psychotic Bear Kills Camper" links wild animal behavior with mental illness

²⁴Semple, S.J., Grant, I & Patterson, T.L. (2005). Utilization of drug treatment programs by methamphetamine users: The role of social stigma. *American Journal on Addictions*, 14(4), 367-380.

²⁵Statistics Canada. (2003, September 3). Canadian Community Health Survey: Mental health and well-being, 2002. *The Daily*.

Position Statement

This statement proposes a four-point approach to reduce stigma and change attitudes about people at risk for, in need of treatment for, or in recovery from mental health and addictive diseases. Family, significant others, support networks, and allies are also included in this model, which comprises the following recommendations:

1. Conduct science-based marketing research (i.e., polling, surveys, focus groups) to provide the basis for a social marketing plan. This effort should begin with a language audit to determine problems or opportunities inherent in the language currently used in the field and in public discussions.
2. Based on the results of the marketing research and language audit, develop and implement a social marketing plan designed to change the knowledge, attitudes, beliefs, and behavior of individuals and institutions to reduce stigma and its negative consequences. One goal of the plan should be to develop a commonly accepted, clear worded taxonomy to describe mental health, alcoholism and drug addiction and the treatments and services available.
3. Facilitate and support grassroots efforts to build the capacity of the recovery community to participate in the public dialogue about mental health and addiction treatment, and recovery.
4. Promote the dignity of and reduction of stigma and discrimination against people in treatment and recovery by encouraging the respect for their rights in a manner similar to people who have suffered from and overcome other illnesses.

Action Steps

1. The Consumer Council recommends that the Indiana Division of Mental Health & Addiction consider adopting this position statement on Stigma and Discrimination in Mental Health and Addiction for the Statewide Plan.
2. The Consumer Council recommends that DMHA consider funding to the Indiana State Consumer Council to provide stipends and travel reimbursement for those persons in recovery to be part of a Speaker's Bureau to present statewide Indiana's plan to eliminate stigma and discrimination in mental health and addiction treatment. The Speaker's Bureau would consist of those persons' stories of recovery to show the benefits of eliminating stigma and discrimination. The possibility of public service announcements to educate the public about mental health and addiction issues would be considered.
3. The Consumer Council recommends a partnership with the DMHA, Indiana State Mental Health Planning Council, the Indiana State Addictions Planning Council, the Community Mental Health Centers, State Hospitals, Advocacy organizations and the Community Addiction Treatment Centers to pool their resources and grant opportunities to display bill boards strategically placed throughout the state to bring to the public awareness that mental health issues and addiction is at everyone's backdoor.

4. The Consumer Council recommends that DMHA and the Council be poised to design, develop, implement and evaluate these action steps in support of 1) Facilitate and support grassroots efforts to build the capacity of the recovery community to participate in the public dialogue about mental health and addiction treatment and recovery. 2) Promote the dignity of those in treatment and recovery related to mental health and addiction. Reduce the stigma and discrimination toward these persons in treatment settings by encouraging the respect for their rights in a manner similar to those people who have other long term medical needs.

History and Accomplishments

1. The Division of Mental Health & Addiction needs to be commended for their efforts at supporting the capacity of the recovery community. The DMHA Workgroups and Advisory committees are consistently working in support of any viable recommendations, through membership inclusion, through education at many levels, to policy and legislation.
2. Indiana's DMHA works to promote any recommendations that will ultimately impact consumers and families, professionals, clinicians and the public to reduce and eliminate stigma statewide, through education and advocacy in multiple levels and organizations.
3. The Division is strategically positioned to advance and sustain any efforts toward the reduction of stigma and discrimination through policy and legislation efforts.

The purpose of these recommendations and action steps is to educate the public, professionals, administrators, and clinicians that stigma and discrimination do impede the course of recovery for many individuals in mental health and addiction treatment. The Council feels the responsibility to do something about the effects that stigma and discrimination have on everyone. Full recovery and acceptance is just not possible with stigma and discrimination lurking behind every door.

This Position Statement on the Effects of Stigma and Discrimination on Mental Health and Addictions has been written with the intent of providing information about stigma and discrimination that may be used throughout the system transformation process for public education and policy development. The Consumer Council stands ready as a partner with the State to educate the service providers, clinical professionals, and the general public about the effects stigma and discrimination have on a person with mental health and/or addiction issues.