

# **Rethinking Mental Health**

**A Discovery Framework**

**Prepared for the Robert Wood Johnson Foundation  
By Stefanie Olsen and Ashoka's Changemakers**

**8.11.2009**

*changemakers*<sup>®</sup>



## FRAMING QUESTION

### **How can we integrate people who experience mental illnesses more fully into society?**

Around the world, mental-health professionals and experts identify stigma as one of the largest obstacles to the detection, care, and recovery of people who experience mental illness. When affected individuals are asked to name the single largest obstacle to their recovery, stigma and discrimination are the most common answers.

In the simplest terms, stigma can be thought of as a noun embodying negative attitudes and beliefs toward people who experience mental illness. Discrimination, on the other hand, is the verb, in which people act out their negative views in ways that deprive others of respect, rights, or opportunities, such as access to fair housing, employment, or full participation in civic life.

Together, negative attitudes and discrimination can produce social distance and profound feelings of isolation among individuals affected by mental illness—isolation that can fuel the cycle of stigma by discouraging people from seeking help, which may cause their symptoms to deepen and lead to homelessness, substance abuse, or incarceration. These outcomes, in turn, can perpetuate fear and stigma in society.

Failure to seek help also can be fatal. Ninety percent of individuals who kill themselves have a diagnosable mental health problem, most commonly a depressive disorder or substance abuse disorder, according to the National Institute of Mental Health (NIMH) (1).

Individuals throughout their lifetime can experience a range of mental health disorders, but for the purposes of this project, we have identified serious mental illness as severe depression, bipolar disorder, schizophrenia, as well as other conditions that can lead to psychosis. Although the mental health field has progressed dramatically in knowledge of these mental illnesses within the last 60 years—through scientific research that brought about “the decade of the brain” in the 1990s and the development of pharmaceutical and psychotherapy treatments—millions of people affected by them still go untreated every year because of stigmas and outmoded ways of thinking about mental illness.

Using the lens of social entrepreneurship and innovation, this analysis examines several underlying barriers to social inclusion and outlines several principles that have driven successful projects, both international and domestic, to transform barriers into gateways of opportunity for social inclusion and improved care. For the purposes of this analysis, we examined a range of approaches in mental health that address severe mental illness, as well as a broader set of emotional and psychological issues and mental disorders, as a way to identify effective methods for changing attitudes and approaching early detection and intervention.

---

## CONTEXT:

**An estimated six percent of the American population—or one in 17—suffers from severe mental illness.** Worldwide, about 154 million people suffer from depression and another 25 million people from schizophrenia, according to the World Health Organization. Nationally, about 5.7 million Americans over age 18 have bipolar disorder and another 2.4 million have schizophrenia, according to the NIMH (2).

Attitudes in the United States toward mental health are mixed. In a nationally representative survey tracking changes over the last fifty years, people have said that they understand mental illness more as a medical condition and have expressed desire for government to take more action in support of mental health policies. (3) But nearly half of adults surveyed said they would be unwilling to socialize with, work with, or live near people affected by mental health issues. Studies have shown similar trends with respect to stigma internationally, in countries such as New Zealand, the United Kingdom, and Germany.

Cultural differences can also have an impact on stigma and discrimination. For example, mental illness in some Asian cultures can be seen as a poor reflection on the whole family, potentially weakening marriage and economic prospects for relatives (4). In India, where more than 20 million people required active mental health care as of the mid 1990s, there were as few as 1,000 trained psychiatrists throughout the country to attend to patients in institutions, reflecting an overall marginalization of mental illness and bias toward physical health in the country, especially among poor rural citizens (5).

Stigma is multi-faceted. It lives within individuals, among families and friends, and within the community, encompassing education, employment, housing, law enforcement, public services, and the healthcare profession. It also lives in the society at large, including government policy, religious, racial, or cultural beliefs (which can compound stigma), and images and information disseminated by media, entertainment, and advertising. For that reason, and because mental illness can be complex and produce varied symptoms in individuals, the solutions must be layered. To change attitudes and behaviors, it takes concerted, sustained action at all levels.

***“If you want to change behavior, you can’t just hit one level of the individual. It has to be at a structural community level, individual level, and on the family level,” Dianne Flannery, of U.C.L.A.’s Family Coaching Clinics.***

---

## Design Principles

## Barriers

Myths about mental illness perpetuate fear and isolation.

Available treatment options are few and fragmented.

Mental health profession is undervalued.

Authoritarian relationships reinforce fear.

Mental illness is often neither diagnosed, nor treated.

National or institutional policies undermine human rights.

Re-frame language of mental illness in the public sphere.

See Me

The Royal College of Psychiatrists

Gabor Gombos<sup>+</sup>

Nevin Eracar<sup>+</sup>

Roots of Empathy<sup>+</sup>

Use the community as medication.

Air Force Suicide Prevention Program

Family Coaching Clinics  
Denise Alves Lopez Robles<sup>+</sup>

Jose Lumerman<sup>+</sup>

Luiz de Barros<sup>+</sup>

TIPS

Daniel Becker<sup>+</sup>  
Al Etmanski<sup>+</sup>

Promote mind and body wellness in treatment and public awareness.

Adalberto Barreto<sup>+</sup>

The Institute for Family Health\*

Martin Domenech<sup>+</sup>

Mental Health First Aid

Homeless Court Program<sup>+</sup>

Normalize illness through the support of peers and mentors.

Victoria Shocrón<sup>+</sup>

Kedar Ranjan Banerjee<sup>+</sup>

Momentum for Mental Health

mothers2mothers

Like Minds, Like Mine

<sup>+</sup>Ashoka Fellow

---

## BARRIERS

*Barriers are core components of a problem that, if changed, could allow for true systems-change. Barriers are not underlying causes that merely describe a situation. They must be moveable and specific to the problem. The social entrepreneurs that we highlight are addressing these issues at key leverage points with pragmatic, innovative solutions.*

### **Barrier: Myths about mental illness perpetuate fear and isolation.**

Despite recent advances in the research of brain health, myths and unknowns about the cause and effect of mental illness persist in the popular consciousness. People in many cultures still widely believe that individuals diagnosed with a mental illness can't recover or live symptom-free. Research has demonstrated that a vast majority of individuals experience significant reduction of symptoms and improved quality of life with a combination of pharmacological and psychosocial treatments and supports (6). Yet people don't know this largely because of a lack of education or integrated mental health and primary care services, where people might learn of options and treatment success rates.

Other myths include: "mental illness typically causes violence;" "madness' is infectious;" "mental illness is the result of deliberate weakness of will and character;" or "crazy people are completely unable to make rational decisions about their lives."

These myths play out in the public sphere, whether through employment discrimination or portrayals of illness in media and entertainment (e.g., "wackos" and "psychos"). In a circular fashion, affected individuals internalize societal perceptions and can be reluctant to talk about symptoms before they worsen. Families and friends may do the same and unintentionally exert prejudice toward their loved ones.

### **Barrier: Available treatment options are few and fragmented.**

The availability of treatment options and information about treatment options is scant in many countries, including the United States. Even mental health professionals are sometimes unaware of how to quickly connect patients to the right care. A lack of transparency or support services, such as assistive housing and peer-to-peer counseling, contributes to feelings of helplessness and hopelessness.

In conjunction with the closure of many public mental hospitals in the United States, jails and hospitals have become the front-line facilities for people who experience mental health challenges. But these institutions are not designed to give people the necessary support and treatment.

Health professionals say that there is substantial evidence of effective treatment options—assertive community treatment or family psycho-education, for example—and they are available in the United States. But Americans don't use these options very often because they're not reimbursed by insurers, they're not promoted like medications, or there are few people trained in these practices. Treatment also occurs late, rather than early in the symptom phase.

**Barrier: The mental health profession is undervalued.**

One of the strongest places stigma is rooted is in the education of physicians and the training of mental health professionals, internationally and nationally, according to many mental health professionals. Some in the medical community, for example, can view psychologists, psychiatrists, or social workers as less scientific, and therefore not as rigorous in their training. Because there are medicines and treatments that work for some, but not for others, mental health care professionals are challenged to provide consistent, measurable outcomes that don't always satisfy the medical community. Furthermore, mental health professionals say that they can encounter a "guilt-by-association."

*"If people with mental illness are 'less than,' it stands to reason that those associated with them are 'less than' too," said Paul Taylor, president of San Jose-based Momentum for Mental Health.*

**Barrier: Authoritarian relationships in treatment reinforce fear.**

Feelings of vulnerability, fear, hopelessness, and isolation among patients and families can be compounded within traditional models of treatment, where caregivers and doctors are the only ones who possess knowledge. When patients are treated as passive recipients of care, without being included in the decision-making process, they can feel powerless to create change or improve their lives, especially in the face of a distant and/or inaccessible health care system. Unequal relationships between doctors and patients can undermine the patient's self-esteem and decrease the chances of social integration. Unequal relationships also cause patients to be closed off and less responsive to therapies.

**Barrier: Mental illness is often neither diagnosed, nor treated.**

Healthcare providers, including physicians, may not recognize the signs and symptoms of a mental illness or be knowledgeable about effective treatment. For example, according to a study by the NIMH, 20 percent of older adults who committed suicide had visited their primary care doctor on the same day, 40 percent within one week, and 70 percent within one month of the suicide.

Because of stigma and fear of discrimination, mental illness can be neglected for as many as 15 years before an individual gets treatment, according to NIMH. The result is that the symptoms of mental illness can progress to the point of suicide, psychotic breakdown, or violence. Those behaviors, ironically, produce more fear in family members, the community and society, thereby reinforcing stigma. To break the cycle, mental health care must move to early diagnosis and intervention.

**Barrier: National or institutional policies undermine human rights.**

Mental health care is a basic human right. But stigma and discrimination can influence the policies, practices, and cultures of large organizations, social and educational systems, as well as laws, governmental systems, and economies. As a result of stigma, people may experience difficulty obtaining housing and keeping or finding work, despite their capacity to do the job. In addition, stigma and discrimination may prevent affected individuals from fully participating in civic life. For

instance, forty-four U.S. states have constitutional language that restricts the voting rights of people if they are found mentally incompetent (7).

International policies can similarly discriminate against the mentally ill. In India, for example, mental health law forbids patients from using the services of the psychiatric wards of general hospitals, psychiatric day hospitals, or community care after a stipulated 30 days of treatment, immediately after an individual shows sign of mental illness (8). In Brazil, government health services do not effectively reach the poorest populations that are most in need because of inadequate facilities or low-paid health professionals, among other problems.

To alter institutional discrimination, many social entrepreneurs target training programs to employers, schools, law enforcement, and medical professionals.

***“All persons with a mental illness, or who are being treated as such persons, shall be treated with humanity and respect for the inherent dignity of the human person... There shall be no discrimination on the grounds of mental illness.” U.N. Principles for the Protection of Persons with Mental Illness, 1991.***

---

## PRINCIPLES

*Design principles are insights and strategies we distill from the work of leading social entrepreneurs. They do not encompass tools (like technology or education) nor do they name specific organization-level approaches. They are clarifying ideas and insights that identify levers of change.*

### **Principle: Re-frame language of mental illness in the public sphere.**

To reduce stigma and discrimination, the public must begin to understand that mental illness, especially severe illnesses such as bipolar disorder and schizophrenia, are brain disorders, much the way cancer or multiple sclerosis are medical conditions with less blame. The blame should be placed on the illness, not the individual, mental health professionals say. The public also must understand that affected individuals respond well to treatment.

One of the primary ways to reduce stigma and discrimination is through public education and awareness campaigns, working with the media, advertising, and entertainment industries to change popular language and sensitize people. Some citizen sector organizations are working to reshape the language of mental illness, including consumer movements that are taking back the word “crazy” and using it with pride. And yet others are working to promote transparency through databases and collections of information on mental illness that can be accessible to the public.

***“A lot of the challenge to reduce stigma is to help the public understand them as medical disorders and not mental disorders,” said Dr. Thomas Insel, director of National Institute of Mental Health (NIMH).***

*The Like Minds, Like Mine program, based in New Zealand, is one of the longest-running public education and anti-stigma programs worldwide. Independent research has shown a significant shift in attitudes toward mental illness since it began its campaign in the late 1990s. In 2006, a study noted a 20 percent increase in positive attitudes, if someone with a mental illness moved into a person's neighborhood. It believes its programs are a catalyst for national social change, as well as policy change. For example, since its groundbreaking work, all mental health workers in New Zealand must learn improved communication skills to help people address stigma and discrimination.*

(Editor's note: This report adopts one method for re-framing mental illness, by referring to people "who experience mental illness" or "who are affected by mental health challenges" as a way to combat stigmatizing labels that can lose sight of the whole individual in other contexts of his or her life.)

### **Principle: Use the community as medication.**

Traditionally, medical and mental health providers have believed that services must be targeted at an identified patient and that he or she should be isolated for care. But considering the individual within the context of family and other important relationships can empower individuals and families to manage recovery themselves, as well as foster self-direction in patients.

Along with family-centered services, social entrepreneurs may target mental-health awareness throughout touchstones of their community—churches, schools, primary care offices, law enforcement, and employers. They may take a multi-disciplinary approach to rehabilitating an individual—from social support, to psychotherapy, to physical activities and meditation—or they might team specialists with leaders in public environments to help them recognize signs of mental illness. So-called social therapists can reach broader populations by not relying on doctors and psychiatrists. These various approaches can improve understanding and compassion in the community for people experiencing mental health challenges. In turn, patients can receive treatment in an integrated setting.

*"For pain to go away, it must be shared by the culture."-Unknown.*

### **Principle: Promote mind and body wellness in treatment and public awareness/detection.**

Many studies have shown that physical and mental health are intertwined, and between 11 and 36 percent of people visit primary care physicians because of an underlying mental health issue (9). By combining these two disciplines and treating the mental and physical health of an individual, people begin to pay more attention and respect to their mental health. With a more holistic view of health, caregivers can also have an easier time making appropriate early diagnoses and interventions, perhaps avoiding neurological degeneration from a lack of treatment and ensuing consequences such as suicide, loss of relationships, jobs, and legal issues. This approach can be integrated into the training of professionals, as well as promoted widely in the public.

*"If it wasn't for my doctor and my therapist, I wouldn't be here today," said a 48-year old African-American/Puerto Rican patient of the Family Health Institute in New York. "I lost all of my faith when my depression got the best of me, but they believed in me. They called me, got me to come to the office when I felt my worst, and as time went on, I got better."*

## **Principle: Normalize illness through the support of peers and mentors.**

There seems to be nothing more powerful to people experiencing mental illness than the stories and personal contact of individuals who have already recovered and transformed their lives. Media campaigns targeting stigma typically feature celebrities or everyday people giving personal accounts of their experiences, but many innovative programs designed to help people recover and rejoin society involve the training and hands-on work of former patients. These people in the community are closer to the ground and can act as leaders to present valuable information, social support, and hope to those affected. This very act takes away the stigma from mental illness. It helps both parties open up about their experiences and perpetuates understanding.

*“If you’re going to have social change, it has to be led by people with mental illness,” said Darryl Bishop, Program Leader, “Like Minds, Like Mine” Population Health Directorate, New Zealand Ministry of Health.*

---

## **OBSERVATIONS**

- **Are we overmedicating in the United States?** In the five decades since the development of psychotherapeutic medications, a \$25 billion market in the United States, the treatment of the mentally ill has not improved much by measure of employment rates, suicide rates, and prevalence rates of people who experience mental illness, according to the NIMH’s Director Dr. Thomas Insel. Can we balance the impact of pharmaceuticals with the impact of family or other non-pharmaceutical approaches by promoting alternative solutions?
- **Can the occurrence of violence lead us to prevention?** One of the main causes of stigma is the threat of violence associated with serious mental illness. People in medical health advocacy don’t want to talk about it, but the reality is that there is some truth to exhibited violence in people experiencing severe mental illness, even though the act is more likely self-directed (i.e., suicide) rather than directed toward others. Mental health professionals say that this violence is restricted to those who go untreated—an idea that must be circulated so that people get serious about treatment and early detection. People exhibiting symptoms and signs of serious mental illness are more likely than others to be arrested by the police, and prisons turn into the primary holding areas. Can we shift this dynamic by focusing on early detection, supportive housing, and family psycho-education?
- **Can we view mental illness from the lens of creativity?** By exploring the relationship between art and the psyche, we may be able to shift our focus away from illness to ability. Artists such as Jackson Pollock, Virginia Woolf, and Pablo Picasso experienced mental disorders and yet were perceived as geniuses. What factors supported their development? Class difference? Does spirituality play a role in experiencing mental illness?
- **Should cultural and class differences play a larger role in raising public awareness and treatment?** Various cultures experience mental illness and stigma differently, according to studies. For example, Caucasians are four times as likely to seek outpatient

treatment than Asians (10). Another study found that African Americans did not soften in stigmatizing attitudes after contact with those living with mental-health issues (11). Citizens in rural areas of the world are often the most neglected in terms of mental health care services. By understanding these dynamics better, we can target groups with ingrained or multiple stigmas, and ultimately, with better services.

## RECOMMENDATIONS

- **Promote better institutional policies through partnerships, advocacy.** Over the years, anti-stigma campaign leaders have found that education is not enough to significantly reduce levels of discrimination. As a result, campaigns have evolved to become more multifaceted, including efforts to change employment, housing, and health care policies and laws. Often, the most effective ways of achieving these goals are through the combined efforts of nongovernmental organizations, social entrepreneurs, aid agencies, and the private sector.
- **Focus on mental health as a human right.** Laws in the United States, such as the Federal Fair Housing Act and the Americans with Disabilities Act, outlaw discrimination in employment, housing, public services, and transportation for people experiencing mental health challenges. But it can be hard for people to hire legal aid or establish evidence to fight discrimination, as well as to file a lawsuit. Congress' recent passage of Mental Health Parity Act in 2008 requiring the equal treatment of mental health by insurance carriers and employers may go a long way to help people with mental illness, but the public conversation should shift to one of human rights and public awareness. Investigations into compliance with anti-discrimination laws may be another step toward achieving parity.
- **Target youth mental health and youth as leaders against stigma.** Half of all diagnosable cases of serious mental illness begin by age 14, and three-fourths of all cases start by age 24, according to the NIMH. Prevention, early detection, and social awareness must begin in youth because children with social, emotional, or behavioral challenges are vulnerable to peer exclusion, social isolation, bullying, and other forms of abuse that can exacerbate their symptoms. Programs in schools and those like the Family Coaching Clinics can go a long way to promoting compassion and sensitivity. Also, youth can be influential leaders in the fight against stigma, given that they often haven't absorbed the same negative attitudes about mental illness until they are taught those ideas.
- **Streamline detection, care, and recovery through integrated approaches.** Promote integrated services that focus on early detection and outpatient social support, employment training, and other creative activities. Holistic approaches to care involving family, friends, and the community have proven instrumental to people's recovery—and to encourage voluntarily participation. Similarly, integrated healthcare that offers immediate identification or diagnosis of a mental illness can streamline patients into support groups, and other outpatient services. Training and integrating an individual into the work world can be incredibly effective toward building his or her self-esteem and creating normalcy, for example.
- **Champion a national or global cooperative online effort** between mental health professionals, the medical community, and individuals and families who experience mental

illness in order to share information about mental illness, including symptoms, early detection and preventative interventions, treatment options, new scientific discoveries, and support forums. A national database for mental healthcare, for example, might cast every patient into the role of research partner so that practitioners could track symptoms and build evidence to clarify issues and form insights.

## **APPENDIX**

### **1. Mental Health First Aid, Australia**

First Aid is known around the world as training to assist people with medical problems. Yet that training does not factor in mental health, a categorical split that reflects people's general lack of skills to support someone coping with a mental health problem.

Created in 2000 by professors Tony Jorm and Betty Kitchener of the ORYGEN Research Centre at the University of Melbourne, the Mental Health First Aid Program is a training program for citizens in how to support someone who is having a mental health crisis or who is developing a mental disorder. Recommended for teachers and police officers, the 12-hour training course and certification is designed to assist in early intervention and on-going community support of people with mental illness, as a first step before obtaining professional help. The course teaches the symptoms, causes, and evidence-based treatments for depression, anxiety disorders, psychosis, and substance-use disorder. In controlled tests, the program has been shown to increase knowledge of mental health, reduce stigmas, and boost supportive actions for those in need. It has even been shown to improve the mental health of people administering the first aid.

Mental Health First Aid has spread to several countries, including Canada, England, Finland, Japan, Ireland, and the United States. Also, in an effort to intervene at the earliest stages of developing disorders, the group has developed a Youth Mental Health First Aid Program aimed at adults who have frequent contact with young people. It emphasizes the mental disorders and the crisis situations that are most common in this age group and includes additional modules on eating disorders and deliberate self-harm.

### **2. Like Minds, Like Mine, New Zealand**

New Zealand's Like Minds, Like Mine is one of the longest-running national programs designed to combat stigma and discrimination associated with mental illness. Founded in 1997 by the New Zealand Ministry of Health, the program has drawn praise and success for its comprehensive, long-term approach. The program is a collaborative effort involving agencies, mental health service providers, consumer-controlled organizations and networks, and non-governmental organizations.

Managed and staffed by people who have personal experience with mental illness, the program combines a national media campaign that includes TV and radio advertising; public speaking engagements by people with first-hand experience of mental health challenges, including major sport figures; and media advocacy to disseminate positive personal stories and guidelines for journalists to encourage nondiscriminatory reporting. It also has 26 regional programs that provide training and support to people in their local communities. The organization's work at the community level, which it calls "the power of contact," ensures that the relationship between caregiver and individual is equal. Leaders of the regional offices work to change people's perception

of mental illness by ensuring that those who share personal stories are professional and transformed by their treatment and journey.

### **3. See Me, Scotland**

A national program in Scotland, See Me targets public perception about mental illness through the media and community work around the country. Founded in 2002, the program is an alliance of five mental health organizations in Scotland and is fully funded by the Scottish Government. It targets media campaigns, including TV and radio ads, and a network of local community advocates that support citizens with mental health problems. The campaign features close-up pictures of individuals with mental health challenges, with the slogan "see me.... I'm a person not a label." The campaign also has incorporated an effort to advocate for more accurate media portrayals of those with mental health challenges.

### **4. Family Coaching Clinics, Diane Flannery (A project of U.C.L.A.'s Semel Institute Global Center for Children and Families)**

Preventive physical health care is assumed to be a basic necessity, yet the need for preventive mental health care is largely unrecognized.

Working to normalize mental health services in the community, the Family Coaching Clinics offer a new model of preventative mental health care for children and families. Located inside shopping malls so that they're more accessible and easy to use, the clinics provide convenient yet targeted, action-oriented education and coaching to help families with young children or teens handle everything from simple to complex childhood issues. Health care workers are trained to screen kids for mood disorders, anxiety, and autism, for example. The clinics use cognitive behavioral strategies within services called modules, delivered in 4 to 6 coaching sessions and which include coaching sessions, group sessions, and self directed materials designed to help families create a plan, identify support, and integrate behavior change into sustainable family lifestyles. They also offer broad community education on the same topics. The clinics work to teach families to "self-treat" early, preventing the development of later dysfunction with much higher costs to individuals, families, and society.

### **5. Steve Binder, Homeless Court Program (Ashoka fellow, 2005, California)**

The Homeless Court Program (HCP), a nonprofit based in San Diego, California, tailors the criminal justice system to the special needs of the homeless, who can often be mentally ill or face the same type of discrimination. HCP helps prosecutors and judges transform fines and jail time for misdemeanors into feasible sentences that contribute to the individual's rehabilitation: life-skills classes, chemical dependency meetings, computer training or literacy classes, employment training, counseling, or volunteer work with service agencies. Through this action, HCP attempts to alleviate the additional "scarlet letter" that an individual receives through a conviction by empowering the person on the road to integrate with society. The HCP works to reduce stigma by helping the prosecution in court focus on the individual and not the offense, turning the court to the person's accomplishments rather than his or her offenses. Through the program, as many as 90 percent of cases are dismissed to reduce stigma associated with conviction. The group plans to next help returning veterans and the stigma associated with admitting to traumatic brain injury, which some have cited as a factor that might compromise opportunities for advancement within their careers.

## **6. The Institute for Family Health, New York**

Many people are reluctant to seek help because of the social stigma attached to mental health diagnoses. That's why the Institute for Family Health, founded in 1983, developed an integrated electronic health record system to keep track of the identification and treatment of depression in the context of primary care. The citizen-sector organization runs 16 family health centers across the state of New York. In 2004, in coordination with physicians, mental health care providers, and technology staff, the Institute pioneered depression screening test scores that can be recorded as lab values—or an abnormal lab value—in the electronic health record, enabling the network of primary care providers to make depression screening and treatment a routine part of care. An abnormal lab value would prompt doctors to take action where they otherwise wouldn't, causing a cultural shift among caregivers that leads to greater sensitivity to mental illness and a more holistic approach to health services.

According to the team, the electronic record helps to “dramatically reduce instances of untreated depression through annual, routine screening of adult patients.” The routine screening helps identify patients early on and offers them onsite treatment services that are managed collaboratively by their primary care physician, a mental health clinician, and a psychiatrist.

## **7. Adalberto Barreto, (Ashoka senior fellow, 2008, Brazil)**

Adalberto Barreto, a physician and psychiatrist, created a methodology that puts the community in the center of mental health care services in Brazil, helping to normalize mental health for citizens. Called Community Therapy, the scientifically proven methodology combines societal and academic knowledge in order to create forums where people can express themselves without fear of judgment or stigma. Helping people who suffer from alcoholism, depression, and societal pressures, the methodology includes collective therapy circles, led by trained health professionals, art education for children, and a more individualized service that helps people with stress, insomnia, and depression. The Live Pharmacy—a project developed with the University of Ceara—provides curative herbs. Another knowledge-sharing center is the Memory House, which keeps videos and tapes of radio programs developed throughout the years about several topics such as alcoholism, depression, stress, child abuse, etc. Because the community helps take on responsibility for individuals, the approach reduces the need for hospital and medical treatment.

More than three million people have attended Barreto's community therapy sessions, and nearly 90 percent have experienced improvement in dealing with their problems through community therapy. Two French cities have already adopted the methodology.

## **8. Jose Lumerman, (Ashoka fellow, 1996, Argentina)**

Jose Lumerman, who runs the Instituto Austral de Salud Menta, attempts to combat the traditional Argentine system of mental health care that hospitalizes people in large institutions, isolating them from their family and community.

Using a clinic that he established years ago in the city of Neuquén as his base of operations, Dr. Lumerman trains groups of general practitioners to serve as team leaders in various small towns and cities across Argentina. Lumerman's approach includes diagnosis, treatment, and rehabilitative services provided by the team of health service providers, led by a trained general physician. The role of the psychiatrist is limited to the provision of training and consulting services. People with

disorders receive needed treatment on an outpatient basis in their own communities, where they enjoy the support of family, friends, familiar surroundings, and various community services. Patients receive "holistic care," responsive to both mental and physical ailments. The clinic also serves as the locus for continued monitoring and assessment of the treatment provided by the general physicians and their teams, and for various social activities that are an integral part of the program's treatment and rehabilitation services.

#### **9. mothers2mothers, South Africa**

An estimated one percent of pregnant women are HIV-positive worldwide, and about 95 percent of these women live in Sub-Saharan Africa. Without proper medical attention, nearly a quarter of these women will transmit the virus to their newborns. A major obstacle to programs for the prevention of mother-to-child transmission (PMTCT) can be the shame, discrimination, and hopelessness that HIV-positive mothers experience—mothers simply don't want to come forward.

In 2001, Dr. Mitchell Besser, a gynecologist, founded mothers2mothers from a single support group in Cape Town. He enlisted new mothers living openly with HIV/AIDS to become "mentor mothers," in order to connect with and educate their pregnant peers. These mentors then comprise a team of caregivers and educators for other HIV-positive mothers and become an integral element of clinical PMTCT care. M2M works alongside PMTCT treatment programs in antenatal clinics, maternity wards, post-delivery clinics, and hospitals that offer medical treatment to women living with HIV. Through support groups, individual counseling, education, and daily social gatherings, M2M promotes empowerment and companionship, while assisting women to deal with fighting stigma within their families and communities and preventing their child from contracting HIV.

#### **10. Momentum for Mental Health, San Jose**

A private nonprofit organization based in San Jose, Momentum for Mental Health offers a holistic set of residential and outpatient treatment services for people who experience mental illness. MMH offers residential treatment programs in the individuals' homes or an in-home like environment. It will also help people re-enter their community through employment services, training programs, and coaching. The organization also hosts advocacy events annually where it will host a speaker—such as the former Miss Arizona—in the recovery process, and talk about how mental illness will touch one in four people in the participant's lifetime. Because the organization believes everyone breathes in these ideas of stigma, it also proactively educates its own mental health professionals against stigma.

Paul Taylor, the director of MMH, has found that the most potent approach to reducing stigma is through its panel members of consumers and family members, which travel to meetings, service clubs, and high schools to tell their own personal story. "We found meeting a person that has a serious mental illness, who is coherent and can tell a story of what it was like, first hand, that is most effective."

#### **11. Mary Gordon, Roots of Empathy (Ashoka fellow, 2002, Canada)**

A recent study in Canada showed that 51 percent of boys aged 4 to 11 years can't concentrate for long, and 45 percent of girls between those ages exhibited the same behavior. According to Mary Gordon, founder of Roots of Empathy, this is an early indicator of poor mental health. More than a decade ago, she developed Roots of Empathy to address the social and emotional competence of

children in this age group. Each class "adopts" a baby who visits the classroom along with a parent and a trained ROE instructor once a month for the duration of the school year. The instructor meets with the class before and after each family visit for a total of 27 sessions. Instructors work with the students to recognize the baby's emotions, and, as they become more comfortable identifying and labeling the feelings of others, they are able to explore and discuss their own feelings. The developed "emotional literacy" helps them recognize the feelings of their peers and understand how violent actions (such as bullying) affect others. Through understanding, people develop a huge capacity for inclusion, she said. Her program has been successfully launched in 133 Canadian schools, directly affecting some 4,450 children.

## **12. The Royal College of Psychiatrists, Changing Minds and Time to Change, U.K.**

The U.K. Royal College of Psychiatrists started taking a proactive approach in the late 1990s toward challenging attitudes about mental illness in the public sphere and within the employment and medical profession. In 1998, it launched Changing Minds, an anti-stigma program that urged the public to "Stop! Think! Understand!" and included multiple levels of public education to fight stigma, with a special focus on family education. It targeted doctors, children, employers, and the media with a substantial toolkit of materials such as books, leaflets, booklets, fact sheets, and comic books for young children. (Surveyed results of the campaign showed a reduction in stigmatized attitudes, but they varied for disorders—stigma had been reduced for depression—and showed needed targeting for 16 to 19 year olds.) An updated mandate at the College called Fair Deal focuses on anti-discrimination and stigma within the medical profession and empowerment of patients.

In early 2009, several advocacy groups, with the help of the College, launched a large national program called Time to Change to challenge attitudes toward mental illness. The program, funded with tens of millions from national grants, includes public activities and events (e.g. a celebrity walk-a-thon and street art), a Web site and social marketing campaign on Facebook, as well as community projects, education for teachers and doctors, and a legal effort seeking test cases around discrimination. The program, which aims for a 5 percent reduction in discrimination by 2012, aims to raise awareness of mental health, reducing discrimination against those affected by mental health problems, and an overall improvement in the mental wellbeing of the population through physical activity.

## **13. Daniel Becker, Centro de Promoção da Saúde (CEDAPS) (Ashoka fellow, 2003, Brazil)**

In 1993 Daniel Becker, a pediatrician with a background in public health, founded the Center for Health Promotion with a team of professionals in order to show poor Brazilians how to solve their health problems within the framework of participative planning. He shifted the health system model from requiring marginalized populations from distant neighborhoods to visit a faraway clinic for medical attention, to empowering a general internist (family doctor) in communities across Brazil, with support of a community health agent and a social assistant. CEDAPS uses participatory methods that build capacity and create networks of youth, women, community leaders, health professionals, and educators. These actors, in turn, work through partnerships with businesses, government agencies, and community and nonprofit groups to improve the lives of more than 500,000 people in 120 poor urban communities.

The positive results of this model caught the attention of Rio de Janeiro's Secretary Ministry of Health, who invited Daniel to design and implement the first national Family Health Program.

Together with other groups, Daniel helped the program to grow and reach the Ministry of Health. Now national policy, the program has changed the lives of millions of people in the country.

#### **14. Kedar Ranjan Banerjee, (Ashoka fellow, 1990, India)**

Dr. Kedar Banerjee, who in the 1990s was one of India's only 1000 psychiatrists, has developed a preventive and rehabilitative approach to the growing problem of drug addiction and mental disorders in India through his organization, the National Institute of Behavioral Sciences (NIBS). Kedar pioneered the development of Medical Aid Camps in rural areas to sensitize medical and para-medical personnel to the importance of mental health and the use of drugs. By organizing periodic drug detoxification and rehabilitation camps, his organization promotes family participation in organizing mental health services, encouraging them to help with care and rehabilitation.

#### **15. Victoria Shocrón (Ashoka fellow, 1994, Argentina)**

Victoria Shocrón, who in 1992 founded the nonprofit organization the Foundation Disabled with Art (DISCAR), works on two levels: to integrate young people with disabilities into the work world, and to raise public awareness about what it's like to live with a disability. To this end, she has developed a set of programs that involve agreements with employers, such as McDonalds-Argentina, to train and hire young men and women with disabilities, as well as a series of public awareness campaigns, including a cable television series that introduces its audience to the true-life stories of disabled youths. Shocrón also uses the public school system (a program called "education in schools" that teaches kids to avoid labeling others, for example) and mass media to sensitize the public and transmit the message that individuals with disabilities, like all other citizens, have first and last names, families, hobbies, likes and dislikes, dreams, projects, and long-term aspirations. Her work has had an impact on stigma related to employment hiring-practices, family and individual prejudices, and the collective public conscience. Kids gain more self-confidence and a sense of responsibility.

Her foundation offers free workshops in dance, drama, music therapy, and body mechanics to children with disabilities to help develop their communication and coordination skills.

#### **16. Luiz de Barros (Ashoka fellow, 1997, Brazil)**

Luiz de Barros developed a network of autonomous, decentralized self-help groups for psychiatric patients and their families throughout Brazil. To establish a self-help group, Luiz combines four people/elements—the individual, a family member, a health professional, and an institution (such as a church, hospital, university, business, or other association). Once he has joined at least these four, he provides a framework for conducting the self-help group, usually facilitating the first several sessions and catalyzing the process of acceptance of the mental illness and development of long-term maintenance strategies. The groups are linked to a São Paulo-based service center that will address administrative and technical needs as well as take on the public role of defending mentally disabled people's human rights. The center also serves as a resource for up-to-date information regarding mental health treatment.

### **17. TIPS (Norway)**

TIPS, a project in Rogaland County and Oslo County in Norway, as well as parts of Denmark, is working to detect and treat serious psychiatric illnesses as early as possible. Its main goal is to reduce the time it takes from patients with psychosis to develop symptoms until treatment is started, and to test whether this has an impact on the patient's long-term prognosis. To this end, it educates the community, including doctors, teachers, and families, with information campaigns in connection with serious psychiatric illnesses. One of the elements in the treatment program for psychotic patients is psycho-educational family work. Through the Tips program, with community outreach and hotline, people exhibiting signs of mental illness are immediately connected with an outpatient clinic and assigned a regular doctor, a nurse who makes house calls, and a day-care worker who checks to see if the individual requires assistance in managing daily life.

### **18. Nevin Eracar (Ashoka fellow, 2003, Turkey)**

Autism affects 4 in 10,000 people. In Turkey, people who are disabled are excluded almost completely from mainstream society. For this reason, Nevin Eracar founded the Turkish Autism Association to conduct training, raise public awareness, and provide help and support to families with autistic children. The cornerstone to her approach is the establishment of Autistic Integration Camps, which provide opportunities to increase social development in peer groups. Not only do the camps allow the children to experience life in an integrated setting, they also serve to educate parents and supporters, who return to their own professional circles and neighborhoods to educate and campaign for greater awareness and services, or to create their own camps. She also works with journalists and appears in the media, providing information to the public on disabilities, particularly autism and schizophrenia. Finally, the group advocates for laws that guarantee rights for people with autism and other disabilities.

### **19. Gabor Gombos (Ashoka fellow, 2001, Hungary)**

In 1993, Gabor Gombos organized the Psychiatric Interest Defense Forum, a 300-member consumer-run organization that advocates for better mental health policy, runs support groups and clubs of patients, and promotes a training curriculum for doctors, nurses, and social workers in mental health care. It also has the support of the National HealthCare Council. Additionally, Gabor has developed a training curriculum for institutional workers designed to raise empathy towards and understanding of psychiatric patients.

### **20. Denise Alves Lopez Robles (Ashoka fellow, 1999, Brazil)**

Denise Robles has established both direct services and financial support systems to address issues of mental health. Through her Programa Social de Gotas de Flor, psychological treatment and life skills classes are offered within small groups of parents and children who would otherwise lack access to such resources because of geographic or socioeconomic factors. Participants are then placed in a standardized stream of social, education, health care, and employment support services, with preventative and rehabilitative measures. Robles also implemented an alternative funding strategy by linking Gotas de Flor with "godparents," higher-income residents who sponsor children personally.

## **21. Air Force Suicide Prevention Program**

The Air Force Suicide Prevention Program was a community-wide public health approach developed in the 1990s to counter a precipitous rise in suicides among Air Force personnel. Among other goals, it sought to modify the culture of the USAF community to remove the stigma of seeking help for a mental health problem, because it believed that many of the suicides came after a long road of personal suffering. The program included leadership involvement (USAF Chiefs of Staff sent periodic service-wide messages promoting the importance of coming forward and of support services); community education through "buddy care" training for military personnel; required-training curricula that covered suicide risk factors, intervention skills and referral procedures; and requirements that all Air Force installations have a multidisciplinary team to respond to traumatic events, including suicides; and an online database enabling the Air Force to track risk factors.

Still active, the program was ultimately responsible for a 33 percent reduction in Air Force suicides between 1996 and 2002, during a time when other military services did not experience similar changes.

## **22. Al Etmanski, Planned Lifetime Advocacy Network (Ashoka fellow, 2003, Canada)**

An estimated 16 million children and adults live with disabilities in North America, but only a small fraction of their families have taken steps to protect them from an uncertain financial future, largely because of economic issues. But in the next decade close to six million families in North America will be caring for their aging relatives with a disability, and the number of people over the age of 60 that have mental handicaps will double in both the U.S. and Canada by 2030.

So-called guardianship in Canada, the standard legal fallback provision for protecting a disabled person, does not protect quality of life, including relationships, home, choice, contribution, and (sufficient) wealth. Through his organization Planned Lifetime Advocacy Network (PLAN), Al Etmanski offers a new way of thinking about disabilities and citizenship through the lens of a good life. In order to combat isolation, for example, PLAN contracts with facilitators with broad community connections to find people who share interests with the disabled person. The Personal Networks usually number about 10 people, including some family members, who commit to being part of the disabled person's community for her lifetime, with PLAN's support when necessary as a guarantee. His organization also gives seminars to lawyers and financial planners on disability law, better preparing them to serve families with disabled relatives.

## **23. Martín Domenech (Ashoka fellow, 1997, Argentina)**

Martin Domenech, a clinical psychologist, was upset by the inability of modern medicine to address the emotional, spiritual, and physical needs of HIV patients, drug addicts, and people with mental disorders. So, in 1990, he founded the Hospital of Life to combine traditional and Western medicines, and restore the mind, body, and spirit of its participants in treatment and recovery. Working to broaden the Argentine's traditional concept of appropriate care, the program helps to rebuild patients' self-esteem, their connection between body and spirit, and their hopes for the future. He also founded a School for Mental Health Professionals to train former patients to provide therapeutic support for people suffering from drug addiction, AIDS, and mental disorders. This component of the program provides a vehicle for recovered patients to continue as productive members of society and provides a basis for ongoing support.

## FOOTNOTES:

1. National Institute of Mental Health. In *Harm's Way: Suicide in America*, 2003.
2. NIMH (Kessler RC, Chiu WT, Demler O, Walters EE. Prevalence, severity, and comorbidity of twelve-month DSM-IV disorders in the National Comorbidity Survey Replication (NCS-R). *Archives of General Psychiatry*, 2005 Jun; 62(6):617-27. ) Based on 2004 Census residential estimates of the U.S. population age 18 and older.
3. *General Social Survey: Americans' Views of Mental Health and Illness at Century's End: Continuity and Change*, 2000.
4. *Report: the mental health of Asian Americans*. San Francisco, CA: Jossey-Bass, 1982.
5. According to documentation of Ashoka Indian fellow Ratnaboli Ray, <http://www.ashoka.org/fellow/2602>.
6. Two studies based on a recovery model by Courtney Harding, PhD., defined recovery as:
  - having a social life indistinguishable from your neighbor
  - holding a job for pay or volunteering
  - being symptom free, and
  - being off medication.Dr. Harding's data in a recovery oriented system in Vermont point to recovery or significant improvement in 62 percent to 68 percent of people studied. Harding. C. *The Vermont Longitudinal Study of Persons with Mental Illness I*, *American Journal of Psychiatry*, 144, 718-726
7. "No Right is More Precious: Voting Rights and People with Intellectual and Developmental Disabilities" College of Education and Human Development, University of Minnesota, 2000.
8. According to documentation of Ashoka Indian fellow Ratnaboli Ray, <http://www.ashoka.org/fellow/2602>.
9. American Psychiatric Association, study from 1998.
10. "The mental health of Asian Americans." San Francisco, CA: Jossey-Bass. Sue, S. & Morishima, J.K., 1982.
11. Ethnic and racial differences in perceptions of dangerousness of persons with mental illness. *Psychiatric Services*, 48, 1328-1330. Whaley, A. L., 1997.

The analytic process behind the Discovery Framework is the property of Ashoka.  
For more information regarding this report or the Discovery Framework, please contact Ashoka's  
Changemakers at [connect@changemakers.com](mailto:connect@changemakers.com)

*changemakers*<sup>®</sup>