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MENTAL HEALTH SERVICES
OVERSIGHT AND ACCOUNTABILITY COMMISSION

June 14, 2007

To the Members of the Mental Health Services Oversight and Accountability Commission:

Attached for your review is the report of the MHSA Stigma and Discrimination Advisory Committee.

As you know, this Advisory Committee met at your request over the last several months to formulate advice and recommendations. These were some of the most challenging meetings of the MHSA stakeholder process. Members struggled to identify common goals, strategies and approaches. One observer noted that issues of stigma and discrimination are so personally felt and so disempowering that work in this area by nature exposes our greatest vulnerabilities, both as individuals and as a system.

Our strategy to find meaning in these difficulties has been to listen. Advisory Committee members and the public had great deal to share: they spoke of painful experiences of stigma that have hurt them and limited their life opportunities. They spoke of systemic discrimination that has created barriers more formidable than the Berlin Wall. They detailed the ways that stigma and discrimination hurts adults and children, families and communities in almost every domain of life. It was a process filled with difficulty but it was also a very powerful process, going to the heart of the Mental Health Services Act itself.

This report is the first product of our work. It is not intended as a research paper of an academic nature; rather, it is an advocacy paper that is research-and-policy-informed. The problems, themes and often the voices and perspectives expressed are those of our stakeholders. After they articulated their views and concerns, we went to the literature in search of further evidence of the problems they raised. There we found validation of their experiences of stigma and discrimination and found that the problems they identified have been widely researched, written about and shared by others interested and involved with mental health.

This process has not led to easy solutions. Mental health advocates are not well suited to "one-size-fits-all." Our stakeholders' views sometimes contradicted one another. We did not attempt to entirely smooth out those differences of opinion, but to represent them honestly and let them stand. The finished report reflects that approach.

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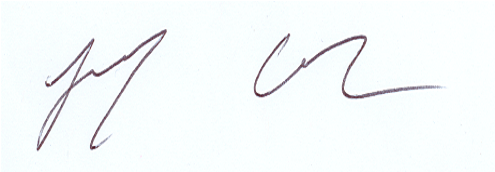
There are also those who will notice that this initial effort is long on problems and short on solutions. However, the problems of stigma and discrimination against adults and children with mental health disabilities have existed throughout history. We cannot believe that we have solved them in a few short months.

What we have accomplished is to engage in an honest dialogue that has resulted in a detailed blueprint of the problem. SAMHSA's recommendation for developing a stigma reduction initiative is to first conduct a "Situational Analysis" – this document fulfills that purpose. This comprehensive Situational Analysis can serve as the foundation of our work on reducing stigma and discrimination. In addition, we have also developed strategies to be explored and developed further as we proceed, as well as fulfilling our main task of making initial recommendations to the Commission for making a sound investment of $80 million of initial resources.

There are many people whose contribution to this work has been invaluable, and they are acknowledged at the end of the report. Special thanks are in order to Laurel Mildred, MSW, who is responsible for the writing.

Respectfully Submitted,



Jennifer Clancy, MSW
Executive Director

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MENTAL HEALTH SERVICES
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ELIMINATING STIGMA AND DISCRIMINATION AGAINST PERSONS WITH MENTAL HEALTH DISABILITIES

■ A Project of the California Mental Health Services Act ■

In today's world we are still considered disgraceful, diseased, abnormal, hysterical, even criminal in the minds of a society that, on the whole, seems to lack understanding and respect for us.

-Delphine Brody, Client Leader

Stigma is the most formidable obstacle to future progress in the arena of mental illness and health.

-United States Surgeon General

INTRODUCTION

According to the United States Surgeon General, "stigmatization of people with mental disorders has persisted throughout history. It is manifested by bias, distrust, stereotyping, fear, embarrassment, anger and/or avoidance. Stigma leads others to avoid living, socializing or working with, renting to, or employing people with mental disorders, especially severe disorders such as schizophrenia. It reduces access to resources and opportunities (e.g. housing, jobs) and leads to low self-esteem, isolation and hopelessness. It deters the public from seeking, and wanting to pay for, care. In its more overt and egregious form, stigma results in outright discrimination and abuse. More tragically, it deprives people of their dignity and interferes with their full participation in society" (U.S. Department of Health and Human Services, 1999, p. 6).

> *Inclusion and integration can be achieved only if the law recognizes that people with mental disabilities are fundamentally like other people and hence entitled to equality as well as fairness.*
>
> (Levy and Rubenstein, 1996)

If stigma represents the feelings, reactions and stereotypes that people experience when they encounter mental illness and adults and children who face it,

discrimination is action taken to deprive people of their rights, based on those feelings and reactions. Stigma demonstrates a lack of understanding, compassion and knowledge of mental illness and the people it affects. Much discrimination, on the other hand, is illegal -- a fundamental abridgement of the civil rights of people who are fully entitled to the same rights as all other citizens of the United States.

The cumulative impacts on people that result from stigma and discrimination are the central concern of this work. When those who face the challenge of recovering from mental distress, crisis, trauma and illness are shunned, avoided, deprived of employment, housing, relationships and other life opportunities, the impacts can be devastating. Stigma can lead adults and children to feel ostracized, damaged, flawed, defective, and unwanted. It can lead those who need hope the most in order to face the world each day to isolation, depression and suicide.

These impacts are not an inherent part of mental illness. They are socially constructed, the result of oppression. And although the task of changing stigma and fighting discrimination are daunting, they are also amenable to change, because people can change. It is a matter of reaching both their hearts and their minds. For those facing mental illness, it is actually often a matter of life and death that we succeed in that endeavor.

Part I. FOUNDATION

A. BACKGROUND

Historically, stigma has been a key factor in why mental health problems are poorly funded (U.S. Department of Health and Human Services, 1999), and here in California, "mental health programs are the chronic losers in budget debates" (Little Hoover Commission, 2000, p. i). However, in November of 2004 California voters approved Proposition 63, entitled the Mental Health Services Act (MHSA), making California the first state in the country to levy a special tax to finance mental health services. The tax is 1% of personal incomes exceeding one million dollars, and will result in $2.53 billion dollars over the first three years, sustainable into the future, for mental health treatment, prevention activities, development of innovative programs, investment in a crumbling infrastructure of capital facilities and technology and providing training and recruitment for the critically understaffed mental health workforce.

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It is not the funding alone that makes California's investment in the Mental Health Services Act a groundbreaking investment in mental health nationally. The funding represents about 12% of the statewide funding for mental health (California Mental Health Directors Association, 2007). It will not fully address the overwhelming need for mental health services in a state where less than 50% of children, adults and older adults who need and qualify for services receive them (California Mental Health Planning Council, 2003).

The greatest benefit of the MHSA lies in its underlying values and philosophy. The Act will not replicate old ways of doing business, but is designed to leverage funding to *transform* the old system to deliver client-driven, youth-and family-oriented services that reflect best and most effective practices and that clearly demonstrate outcomes and accountability. Clients, family members, ethnic communities, community-based agencies, providers and other stakeholders in the mental health system have become key partners in the decision-making process, meeting together to make essential decisions that were previously the domain of state and county mental health bureaucracies. This process of local decision-making is referred to as the "Stakeholder Process" and it has quickly become the first and most visible transformation accomplished by the MHSA.

> *The right to equality becomes the most critical right of all, subsuming all other rights. It means that people with mental disabilities must have the same right to liberty, autonomy, informed consent, due process as all other members of society and that qualified people with mental disabilities may not be discriminated against in housing, employment or the activities of civic life.*
>
> (Levy and Rubenstein, 1996)

The Act also established a new commission to oversee this sea change in the California mental health system. Intended to be used as a "bully pulpit" to promote mental health, to empower the voices of clients, family members and underserved populations in the process and to ensure accountability to stakeholders and to the public, the 16-member Mental Health Oversight and Accountability Commission was established in July, 2005. In keeping with their responsibilities for oversight and leadership in mental health policy, the Commission identified reducing stigma and discrimination as an essential goal of the MHSA, and approved an annual allocation of $20 million to this project, for a total initial investment of $80 million over the first four years. The Commission appointed an Advisory Committee of 26 key stakeholders and organized two public hearings to give feedback, provide guidance for the project, to draft this initial statement of the problems of stigma and discrimination and to make recommendations on strategies to employ.

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B. THEORETICAL FRAMEWORK OF A TRANSFORMED MENTAL HEALTH SYSTEM

The work of the Mental Health Services Act, as described above, is diametrically different than older models of mental health service delivery. Guided by principles and methods based in a social justice and client-driven orientation, some of the key theoretical underpinnings of the transformed mental health system are critical to the reduction of stigma and discrimination.

The Ecological Systems Model is a general organizing theory – an umbrella theory – that provides a framework for understanding the new work of the MHSA. This theory asserts that each person is located within many environments, including the family, society, culture, and physical surroundings (Anderson and Carter, 1999). In this way, the person cannot be understood separately from his or her environment (so rather than simply considering only the mind, the whole person must be considered). This "whole person" approach is sometimes also described as a "bio-psycho-social-spiritual" (mind, body, relationship, spirit) approach.

Other theories and perspectives that respond to the whole person also operate under the general organizing principle of the Ecological Systems Model and are essential to the transformed mental health system. One of the most important of these is the Strengths Perspective, which de-emphasizes labels, diagnoses and deficits, focusing instead on strengths, resiliency and potential for recovery (Shriver, 2001). The Strengths Perspective emphasizes what is important and meaningful to the client for his or her life. It is often in direct conflict with the older "Medical Model," which focuses on diagnosing and treating a "disease," and this theoretical shift represents a major transformation in the way services are designed and delivered in the mental health system.

The Wellness Perspective is related to the Strengths Perspective and is also part of the new theoretical shift, but emphasizes some additional issues. Along with the mind-body connection, this perspective is respectful of the role of spirituality in healing and recovery, and it specifically calls for reducing barriers to living with a disability (Schriver, 2001); an important foundation for reducing stigma and discrimination.

Family Theory is also important to the transformed mental health system. This theory emphasizes interaction among members of families, respects the role that both biological families and affiliative families play in people's lives, and operates in ways that strengthen families as an essential asset to a person's well-being (Cocozzelli, 1987).

Culture Theory is based in the study of the diversity and similarities of different human cultures, and grounded in respect for the protective qualities of culture in good mental health (U.S. Department of Health and Human Services, 2001). Culture Theory provides a social justice framework that acknowledges that racism, poverty, exposure to violence and other adverse social conditions are risk factors associated with mental illness. It emphasizes reducing disparities among ethnic communities and other underserved groups, and on "cultural competence,"

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providing services that are relevant, appropriate and informed by each person's cultural framework.

Finally, three related perspectives, the Empowerment Theory, the Recovery Model and the Resilience Model are at the heart of the work of the MHSA. Empowerment Theory advocates increasing political, social and economic strengths of people and communities by assisting them to develop confidence as well as control over their own lives (Lee, 2001). The Mental Health Recovery Model emphasizes that while people may not have full control over their symptoms, they can have full control over their lives by achieving stability, social rehabilitation and transcending limits to achieve their highest goals and aspirations (Mahler, Tavano, Gerard, Baber, 2001). The Resilience Model is well-adapted to the needs of children, taking into account developmental stages and focusing on cultivating factors that promote life success rather than trying to eliminate factors that promote failure (Garmezy, 1993).

Theories of course represent the ideal, and not the realities of practice. But taken together, these theories, perspectives and models represent the vision, values, hopes and dreams that we hold for California's mental health services and system, and are one of the major avenues toward reducing stigma and discrimination in our midst.

C. STIGMA AND DISCRIMINATION DEFINED

As noted above, *Stigma* refers to attitudes and beliefs that motivate individuals to fear, reject and avoid those who are labeled, diagnosed or perceived to have a serious mental illness – often anyone who is seen as "different."

Stigma also affects those who work with, advocate for or love people who are perceived as different. Family members are frequently stigmatized, especially by clinicians and the mental health system but also by society at large, judged responsible for a loved one's mental illness and treated with suspicion or disapproval. These views can be damaging to people who are already struggling under challenging circumstances, leading to isolation and a high risk of developing clinical depression themselves (Gray, 2003).

Those who work with persons perceived as different are also stigmatized. Mental health services are among the most underfunded, and mental health professionals in the public mental health system are among the most underpaid, of all the health professions (McRee et al, 2003). A severe shortage of a qualified mental health workforce is the result of these factors. Retaining qualified staff in the face of all this is equally a challenge, and the positive transformation of the mental health system is severely hampered by this dynamic.

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Finally and most importantly, the shame and blame of society's discomfort with the differentness of mental illness lands squarely upon those most vulnerable – those struggling to have meaningful lives while coping with the symptoms and effects of mental illness.

Discrimination is no less egregious than stigma, but may have impacts that are even more damaging. Discrimination occurs when people and societies *act* upon their feelings of rejection and discomfort with mental illness by depriving those associated with it the rights and life opportunities that are afforded to all other people. And many of its most common manifestations are illegal, for example, depriving people of housing, employment, education and opportunities for civic life.

Abuse is another form of discrimination which is illegal but which occurs all too frequently. Unnecessarily violent responses from police often lead to death and severe injury of people in mental distress. Children struggling with emotional disturbance are shunned by peers and taunted or beaten up by bullies in their schools and neighborhoods. People in crisis and admitted to involuntary "treatment" settings have been illegally strip searched or subjected to sexual abuse. They have been strapped into restraints and left for hours as punishment or as a strategy to manage staff shortages (Mildred, 2002). These are not examples from the dark ages. They are part of the very real dangers that people with mental illnesses face when they are stripped of power, choices and civil rights.

Most people do not face such experiences or dangers in the course of their everyday lives. Unfortunately, these most dangerous outcomes accrue to children and adults of all ages who are already burdened by mental illness, and vulnerable to harm and exploitation. Understanding the consequences of stigma and discrimination is the first step toward redressing these injustices and reducing the preventable harm they cause.

Part II: PEOPLE

A. A FIRST-PERSON PERSPECTIVE: LIVING WITH STIGMA AND DISCRIMINATION

It is important to note that while there is a substantial amount of research, theory and opinion about stigma and discrimination, people have personal experiences and actually live with it every day. They frequently report that the cumulative effects of isolation, alienation and denial of equal opportunities for life happiness can be more devastating than the illness itself.

Over a three-year period, the California Network of Mental Health Clients conducted twelve confidential focus groups in the Bay Area, surveying the experiences and opinions of 249 mental health clients on the topics of stigma and discrimination. The results reveal that frequently the

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subjective experience of living with stigma and discrimination differed from the opinions of mental health professionals and other mental health stakeholders.

In particular, clients in this study noted that they felt that they experienced the greatest stigma and discrimination from the mental health system, as well as members of their families, followed by police officers (Brody, 2007). Many of the clients in this survey disagreed with often-cited anti-stigma messages, especially the notion that "Stigma is a problem in that it deters people from seeking treatment." They felt that this message promotes a notion of stigma based in the medical model, rather than a client empowerment model, and deflects attention away from environmental factors, traumatic experiences and the underfunding of essential voluntary services and supports. One client noted that anti-stigma messages of the "broken brain" school of thought may evoke pity, but do not promote client inclusion in society (p. 24).

> *I'm told that I've socially expired – I'm history. I've been given a social death sentence.*
> -Mental Health Client
> (Brody, 2007)

For these clients, the key effects of stigma and discrimination were "prejudice, labeling, intolerance, segregation, exclusion, the problematic concept of 'normal,' the harmful effects of the 'medical model' and the loss of personal freedom" (Brody, 2007, p. 33). The remedy, as one client stated simply: "Treat people equally" (p. 31).

B. CHILDREN AND ADULTS INTERNALIZE STIGMA

Children and adults with experience of mental illness are at high risk of internalizing stigma and suffering diminished self-esteem, feelings of confidence and mastery in their own abilities (Corrigan, 1998, Link, 1987). The low self-esteem that results from internalized stigma is often experienced as shame, and interferes with a person's life goals and quality of life (Corrigan, 2004). This low self-esteem and demoralization from constant reinforcement that one is shameful and devalued has been associated with failing to pursue work or independent living. In the view of one researcher, "It is undoubtedly threatening and personally disheartening to believe that one has developed an illness that others are afraid of" (Link et al, 2001, p. 1621).

Internalized stigma is also related to willingness to engage in treatment: "Consumer advocates have argued, and research seems to support the idea, that many psycho-social and medical treatments disempower people, and as a result, people in need decide not to fully participate in services" (Corrigan, 2004, p. 620). This research indicates that effective services that are defined useful by persons with mental illness and are also non-shaming can reduce stigma and internalized stigma, increasing the willingness of people to utilize and engage in those services.

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This type of self-stigma can also exacerbate isolation. Fear of stigma and rejection can lead people to act less confidently, more defensively, or to avoid social contact altogether. It can lead to strained and uncomfortable social interactions with those perceived as potential stigmatizers. It can also lead to limited social supports, poor life satisfaction, unemployment or loss of income (Link et al, 2001).

The combined effects of societal stigma internalized by adults and children with mental illness can lead to substance abuse and suicide. According to the Surgeon General, as many as half of people with serious mental illnesses develop alcohol or other drug use problems at some point in their lives. Substance use exacerbates symptoms, hospitalization, depression, suicide, incarceration, family friction and costs of treatment. It also exposes people to negative life outcomes and to health risks such as violence and sexually transmitted diseases (U.S. Department of Health and Human Services, 1999). However, despite the high association of substance abuse and mental illness, substance abuse treatment for persons with mental illness is scarce. Exacerbated by separate delivery systems that are both underfunded, an estimated 500,000 mental health clients in California with co-occurring mental health and substance abuse disorders need substance abuse treatment to move forward in recovery, but do not receive it (Little Hoover Commission, 2000).

Suicide is most tragic outcome of mental illness and is integrally connected to internalized stigma. Societal messages that one is devalued, of little worth and has little opportunity to contribute, love, connect, experience success and feel happiness can become a vulnerable person's reality: suicide results from despair. According to the Little Hoover Commission, an estimated 3,430 Californians committed suicide in 1997 – the leading cause of preventable death. Thousands more struggle with suicidal feelings as an ever-present reality.

Research suggests that two of the most effective strategies to combat internalized stigma are empowerment and recovery. Empowerment includes peer support and self-help, advocacy, economic development projects, protest and participation in the system. Recovery is the individual journey of personal growth that supports better management of symptoms, healthy life choices and an improved quality of life. "Neither of these strategies make the world fairer, but they strengthen people's ability to withstand stigmatizing attitudes, to fight against discrimination and to stand up for their rights" (Everett, 2007).

C. PEOPLE FACING MULTIPLE OPPRESSIONS

Racial and ethnic minorities face multiple barriers involving stigma and discrimination that increase their risk of mental health problems, reduce their access to treatment, and make it less likely that treatment will be helpful to them.

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In addition to the stigma experienced by all persons facing mental distress, racial and ethnic minorities also experience racism, poverty, language barriers, clinician bias and inappropriate services. These conditions have resulted in enormous disparities, leaving the populations who are at the highest risk of mental health problems the most underserved. These disparities operate in all health care, but are particularly severe in the mental health system.

The social conditions that put minorities at high risk for mental illnesses include racial discrimination in housing sales and rentals (Yinger, 1995) as well as hiring practices (Kirscheman and Neckerman, 1991). According to the General Social Survey of 1990, minorities experience higher financial stress as a result of racial bias. And recent studies link the experience of racism to poorer mental and physical health. Research has shown that major incidents of discrimination are associated with psychological distress and major depression, and the day-to-day grind of everyday incidents of discrimination is linked to generalized anxiety and depression. The Surgeon General concludes, "Racism and discrimination are clearly stressful events that adversely affect health and mental health and place persons of color at risk for mental disorders." (U.S. Department of Health and Human Services, 2001, p. 38).

WHITE PRIVILEDGE:

A term denoting a variety of advantages, for example, in housing, salaries, healthcare, employment, education, opportunity and life expectancy that white persons have come to expect but that are commonly unavailable to non-whites. These privileges are often "invisible" and taken for granted by those who benefit from them.

(Tatum, 1997, McIntosh, 1989)

The lack of appropriate language services is one of the major barriers to accessing the mental health system. The number of Californians age five and over who speak a language other than English was 12.1 million in 2000, with Spanish, Vietnamese, Cambodian, Laotian, Hmong, Armenian, Cantonese, Korean, Russian, Farsi, Mandarin and Tagalog among the major languages spoken. This snapshot does not capture the full complexity of the language barriers, however – just among the sub-group of Asians and Pacific Islanders, there are 43 subgroups and 100 languages. The fastest growing group of non-English speakers is the Latina/Latino population – in some counties such as Colusa, Imperial and Monterey, over 50% of Medi-Cal beneficiaries reported Spanish as their primary language (Bloom et al, 2005). Federal and state laws, including the Civil Rights Act of 1964, grant rights to equal access to services and require that language services be provided free of charge. But despite these protections, discrimination in access because of language barriers continues to be a significant roadblock to treatment in the mental health system.

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Another significant barrier to mental health services for people of color is differential treatment and poor quality of care. While underserved in the voluntary community system of mental health care, minority groups, particularly African-Americans and Native Americans, are overrepresented in coercive services involving involuntary inpatient hospitalization (U.S. Department of Health and Human Services, 1999; Snowden & Cheung, 1990).

> *Legally sanctioned discrimination and exclusion of racial and ethnic minorities have been the rule, rather than the exception, for much of the history of this country.*
>
> -U.S. Surgeon General, 2001

In particular, African-Americans are disproportionately diagnosed with schizophrenia in many cases where a correct diagnosis is depression or bipolar disorder, resulting in incorrect treatment. Physicians are also less likely to prescribe the newer generation antidepressant or antipsychotic medications to African-Americans who need them (New Freedom Commission on Mental Health, 2003) and as a result they suffer from tardive dyskenesia, the irreversible movement disability caused by neuroleptic medications, at twice the rate of whites. People of color receive higher doses of high side-effect medications, are subject to more involuntary medications and are subjected to restraints at significantly higher rates than whites. Longstanding federal anti-discrimination laws prohibit this treatment, but they have rarely been used to challenge practices in the mental health system (Levy & Rubenstein, 1996).

> *A Latina woman in her 30's was referred to a clinic for mental health services. She requested a Spanish-speaking therapist but her request was dismissed and she was referred instead to an English-speaking therapist. After six months of clinical services in English, the therapist informed the client that she did not speak English well enough to continue, and suggested that the client improve her English before returning for mental health services.*

Stigma also presents such a barrier in some communities of color that people never receive services at all, suffering mental distress for a lifetime without any of the treatment that mental health services can offer. Asian Americans, for example, are only one-quarter as likely as whites to have sought outpatient treatment. In some Asian cultures mental illness is thought to reflect poorly on the entire family, and as such it diminishes the marriage and economic prospects for other family members (Sue & Morishima, 1982).

Culturally competent services are essential to reducing the burden of social oppression and mental illness for racial and ethnic minorities. According to the Surgeon General, "culturally competent" services incorporate respect and understanding of ethnic and racial groups as well as their

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histories, traditions, beliefs and values systems (U.S. Department of Health and Human Services, 2001). Cultural competence is not a "program," but rather a systemic approach to changes that embeds integrated cultural approaches into all levels, reduces disparities, provides linguistic access and high quality of care. The five essential elements of cultural competence include valuing diversity, cultural self-assessment, honoring the dynamics of difference, formalizing and disseminating cultural knowledge at all levels, and adapting to diversity (Guerrero, 2006). This vision for a respectful, accessible and quality mental health system that reduces stigma and discrimination is central to the MHSA.

People who are lesbian, gay, bisexual, transgender or questioning their sexual orientation (LGBTQ) also experience multiple forms of oppression, frequently becoming the target of stigma and discrimination due to their sexual orientation. This puts them at high risk of mental health problems.

Homophobia is the fear of and prejudice against homosexuality and is rooted in the same historical and social processes as white supremacy, racism, patriarchy and sexism. "They are all systems of bigotry that classify and degrade human beings on the basis of presumed, internal, biological characteristics" (Platt, 2000, p. 2). "For most of the history of this country, homosexuals have been killed for their sexual orientation, had their children taken away, gone to jail, been forced into treatment, been hospitalized against their will, been hassled and beaten by the police, denounced in religious institutions and forced out of jobs" (Platt, 2000, p. 1).

LGBTQ teens are subject to harassment, threats and violence on a daily basis, hearing anti-gay slurs such as "homo," "faggot" and "sissy" about 26 times a day, or once every 14 minutes. Thirty-one percent of gay youth were threatened or injured at school in 2000.

(Bart, 1998, Chase, 2001)

Up until 1973, homosexuality was defined as a mental illness by the American Psychiatric Association's Diagnostic and Statistic Manual of Mental Disorders (DSM). This regulated societal stigma and homophobia toward LGBTQ people by categorizing them as "mad, not bad." These efforts set up LGBTQ people for psychiatric "cures" for their homosexuality. The year 1951 was the last known example of the use of the lobotomy to "cure" homosexuality in the U.S., but hospitalization and other treatments such as aversion therapy remained common throughout the 1960s and beyond (Mind, 2007). Discrimination against LGBTQ people in the mental health system continues today. Research has shown that between 25 – 65% of LGBTQ people seek counseling at some stage of their lives, and up to 50% report discontent with their experience, noting their counselor's negative and prejudicial attitudes toward homosexuality (Rudolph, 1988). Research is emerging that emphasizes the importance of tailoring services to the special needs of gay,

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lesbian and bisexual mental health service users to improve the efficacy of services for LGBTQ clients (Cabaj & Stein, 1996).

LGBTQ people are also at high risk of becoming victims of violence. Along with African-Americans, gay men are subject to the greatest number of hate crimes (deGiere, 2004). Gay and lesbian youth are especially vulnerable to harassment and violence in school, often subjected to such intense bullying that they are unable to receive an adequate education, dropping out at a rate of 28%, three times the national average. These youth are frequently too embarrassed or ashamed to report the abuse, and feel that they have nowhere to turn for help.

The advocacy organization Mind notes that being gay is not in itself a mental health problem, but coping with the effects of discrimination can be highly detrimental to the mental health of LGBTQ people, reflected in high rates of depression, substance abuse and especially suicide. In 1989, the United States Department of Health and Human Services reported that "A majority of suicide attempts by homosexuals occur during their youth, and gay youth are 2 to 3 times more likely to attempt suicide than other young people." The report estimated that LGBTQ youth comprise up to 30 percent of the estimated 5,000 completed youth suicides annually (U.S. Department of Health and Human Services, 1989). Kevin Berrill, Director of the Anti-Violence Project of the National Gay and Lesbian Task Force at the time of the report, welcomed its release, stating, "The increased risk of suicide facing these youth is linked to growing up in a society that teaches them to hide and to hate themselves. We welcome this report and hope it will lead to action that will save lives" (Blumenfeld and Lindop, 1995).

D. FOSTER YOUTH

Children and youth in foster care and adolescents transitioning from foster care to independent living are another group heavily burdened by stigma and discrimination. Each year about 40,000 children in California are removed from their homes because of abuse or neglect (Little Hoover Commission, 2003). Being in the foster care system itself carries a heavy burden of shame and stigmatization; in addition, about 60% of children in foster care are estimated to have moderate to severe mental health problems, compounded by trauma of family separation and frequent and stressful relocation.

A University of California study found that 50% of these children with mental health problems are not receiving appropriate mental health services. Societal racism also intersects with stigma and discrimination in this population. Children of color face removal to foster care and longer stays in foster care than their white peers. Finally, an issue peculiar to the problems of mental illness occurs when loving parents are sometimes forced to relinquish custody of their children with serious mental illnesses because they cannot afford the expensive care that they require (Rita, 2002).

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Foster care was originally intended to serve as a temporary haven for children who had been abused or neglected. However, it has evolved into a complex "system" that often exposes children to further trauma and abuse, uncertainty, instability and impermanence. For approximately one out of four California children who enter the system each year, foster care is not temporary, but a "heartless limbo -- childhoods squandered by an unaccountable bureaucracy" (Little Hoover Commission, 2003, p. 1) and children who are exposed to this system develop mental illnesses at high rates (Packard Foundation, 2004).

> *In high school, I didn't share my status as a foster youth with anyone. That was a secret kept in my family.*
>
> -Former Foster Youth
> (Sanchez, 2004)

In addition, the children of racial and ethnic minorities are disproportionately overrepresented in the foster care system. Children of color represent 33% of children under the age of 18 in the United States, but comprise 55% of the children in foster care. Studies have documented that "there are no differences in the incidence of child abuse and neglect according to racial group," (Packard Foundation, 2004, p. 79), but African American and Latina/Latino families are more likely than white families under similar circumstances to be reported for child abuse and neglect and to have children removed from the home. High poverty rates exacerbate this trend. African American children are most seriously affected, constituting about 45% of children in public foster care and more than half of all children waiting to be adopted. Native American children are in foster care at double their percentage rate in the general population (U.S. Department of Health and Human Services, 1999).

Research also indicates that children of color are treated differently inside the child welfare system, receiving fewer contacts with caseworkers, fewer written case plans, fewer developmental or psychological assessments and fewer family visits. They also tend to remain in foster care placement longer than their white peers. And although it has been found that a culturally sensitive environment can provide a nurturing and protective foundation that children can draw upon in times of distress, many children of color become disconnected from those benefits when they enter and remain in the foster care system.

In addition, federal Medicaid policies sometimes force loving parents to give up legal custody of their children because they cannot get mental health services for them in any other way. Protection and Advocacy reports that thousands of children who need mental health care cannot access it because their families do not qualify under Medi-Cal guidelines and cannot afford intensive treatment on their own (Rita, 2002). These children end up in foster care, group homes, hospitals, juvenile halls or the Youth Authority, where their care is paid for with state and local funds. This institutional out-of-home treatment is far more expensive than it would be to provide services to children in their own home, and is a disastrous outcome for children and their families.

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The failures of the foster care system are paid for by youth when they turn 18, who age-out of the system with multiple burdens of stigma and discrimination. They are often dumped out of the system with no family or supports, and in addition must face the stigma and discrimination of mental illness. Approximately 1/3 of children aging out of foster care fail to complete high school, and few enter college. Twenty-five percent become homeless, and 50% experience unemployment (Little Hoover Commission, 2003). These children who grow up as the responsibility of the state face the stigma and discrimination of both the foster care system and the mental health system, and ultimately end up quite alone in trying to overcome these burdens.

As my life got bigger, my illness got smaller.

-Transition Age Youth
(Clark, 2000)

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E. FAMILY MEMBERS AND CAREGIVERS

Family members and caregivers of persons with mental illness are also frequently treated with stigma and discrimination. Known as "stigma by association," parents, partners and spouses, caregivers, siblings, and other relatives who care about a person with mental illness often face obstacles and barriers that are associated with the problems of mental illness, and the struggle to navigate a disconnected and poorly funded mental health system. The NAMI Family-to-Family peer support and education program introduces family members to the challenges of stigma and discrimination: "If someone has never been subjected to the systematic discrimination which occurs in mental illness, they cannot remotely imagine how terrible it feels, how it mitigates against the hope and optimism we need to take risks and move on with our lives . . . this is the bizarre aspect of recovering from mental illness. It requires us to endure public scorn while we try to heal" (NAMI, 1998, p. 11.1).

My teenage daughter was being released from the hospital after a mental health crisis. I fought for her to have services at home but I was told that the only option was for her to enter a group home, where I would not be able to contact her at all for the first three weeks.

The social worker said to me, "You've done your job, now we'll clean up the mess."

-A Mother

The issues facing family members and caregivers date

back to the early origins of psychiatric theory. With little known about mental illness, early theorists promoted the concept that parents were to blame for mental illness in children. Not surprisingly, mothers came in for particular criticism: schizophrenia was thought to be caused by a "schizophrenogenic mother" who was cold and aloof (U.S. Department of Health and Human Services, 1999). These views reflected a lack of understanding of the biological basis of mental illness, as well as the unfair and inappropriate societal views of women and the superhuman expectations and responsibilities for which they are held accountable. Fighting such prejudices was one of the driving factors in the emergence of family member organizations in the mental health system. Despite many advances, these attitudes influence the way family members and caregivers are treated today by mental health professionals.

> *What other resources can you tap after you've already mortgaged your house? When you are too "rich" to qualify for Medi-Cal and too poor to cover the thousands of dollars for hospital fees, ambulance fees, doctor bills and medications for your family member?*
>
> -A Mother

Also a central concern of these organizations was the struggle to access care from disparate and uncoordinated public agencies (U.S. Department of Health and Human Services, 1999). In California, then-Governor Ronald Reagan began to de-institutionalize the state hospitals with a promise that the resources from the state hospital system would be re-directed to support people with mental health disabilities to live in the community. However, he subsequently vetoed the bills that followed-through with this funding. With no community system of care in place, family members watched their loved ones struggle in the community without adequate care, services or resources. Combating stigma and discrimination by advocating for system resources to provide services and prevent human suffering has been one of the major purposes of the family and caregiver movements.

The issues that affect family members and caregivers are not limited to advocacy, but often have a direct affect on their own health and well-being. Informal (unpaid) caregivers provide nearly two-thirds of all home-and-community-based care in the United States (Liu, Manton & Aragon, 2000). Despite this key role, caregivers struggle with stress, anxiety, and financial burdens that result in very high rates of depression themselves (Gray, 2003). Thirty to 59% of caregivers report depressive disorders or symptoms (Cohen et al, 1990, Family Caregiver Alliance, 2001). These high rates of depression put family members and caregivers at risk of the direct stigma and discrimination of mental illness, as well as to stigma by association. In addition, high rates of depression also put many caregivers at risk for chronic health conditions such as coronary heart disease, cancer and diabetes (Cannuscio et al, 2002). Focusing on their family member with mental illness, juggling caregiving with a job and other responsibilities, and financial stress often lead caregivers to neglect their own well-being and deplete their inner resources (Gray, 2003).

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The physical and mental exhaustion faced by caregivers is often exacerbated by financial burdens. Family caregivers (of all kinds, not just for persons with mental illness) provide an estimated $257 billion dollars' worth of unpaid care in the United States, and this care helps to prevent expensive and inhumane institutionalization. Yet families rarely receive any payment for these services and are often in difficult financial circumstances as a result of their caregiving (Commonwealth Fund, 1999).

Programs that would support families, lighten financial burdens, support caregiver mental health and provide respite for stressed families and caregivers are practically non-existent in the underfunded mental health system. Programs that appropriately acknowledge the contribution of family members and caregivers are essential to reducing stigma, preventing discrimination and supporting the well-being of those with mental illness as well as their families and support systems.

> *If I came in to work today and said my child was hospitalized with a diabetic coma last night, people would bring casseroles. But because my child was "committed" to a psychiatric hospital, I cannot even mention what is happening with my family.*
>
> *It is a source of shame rather than an occasion for community support.*
>
> -A Parent

PART III: SYSTEMS

A. STIGMA AND DISCRIMINATION IN THE MENTAL HEALTH SYSTEM

Historically, people with mental disabilities have been subject to grave abuses in institutional settings: sometimes starved, tied to beds, beaten, and subject to inhumane practices such as lobotomies, electroconvulsive shock treatments, and immobilizing medications. In fact, California led the country in forced sterilizations between 1909 and 1950, responsible for about 80% of nationwide involuntary sterilizations that were performed under state auspices (Lombardo, 2003).

Today, despite the closure of many of the state hospitals, each year there are people who still remain in state hospitals for weeks, months and sometimes years. In addition, at least 100,000 Californians are involuntarily committed to acute psychiatric facilities in the community each

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year (Mildred, 2002). "In this age of deinstitutionalization, a great many people find themselves institutionalized." (Levy and Rubenstein, 1996, p. 285.) These modern institutional settings remain controlled, restrictive and often excruciatingly boring, with severe sanctions for noncompliance, including being placed in restraints.

> *We want and deserve better treatment. We want people to know many of our friends are locked up and don't have equal rights.*
>
> -Mental Health Client
> (Brody, 2007)

Although the image of patients wearing straightjackets, locked in a tiny room or tied to a bed in four-point restraints are seen as the legacy of the distant past, institutional violence, abuse and injuries are "far more common than is reasonably acceptable" (Levy and Rubenstein, 1996, p. 285). According to the American Civil Liberties Union, "To the general public, [those images] are no more contemporary than the shootout at the OK Corral. Unfortunately, the public is wrong. Seclusion and physical restraint remain the wild west of institutional psychiatry" (p. 300).

In 1998, the Hartford Courant reported on wide-scale deaths from the use of seclusion and restraints. These reports found patients became comatose, suffered broken bones, were hit in the face, bruised, needed stitches or were bleeding as a result of being placed in seclusion and restraints. In the worst cases, patients died of causes that included asphyxiation, strangulation, cardiac arrest, fire or smoke inhalation, blunt trauma, drug overdoses or interactions, and choking (Mildred, 2002).

Protection and Advocacy reported in 2003 that California follows the national trend: despite extensive federal reforms, 22 deaths occurred between 1999 and 2003 to people who were in seclusion and restraints (California Senate Select Committee on Developmental Disabilities and Mental Health, 2003). A report by the California Senate Office of Research found California's oversight of these practices in facilities to be a "regulatory maze that impedes accountability and progress," stating that piecemeal standards have resulted in a condition where "the only meaningful measure of seclusion and restraints in California is when people die" (Mildred, 2002).

National leadership and statewide legislation have endeavored to reform institutional practices; however, between 2002 and 2005 the United States Department of Justice (DOJ) launched investigations into four California state hospitals. Under the authority of the Civil Rights of Institutionalized Persons Act of 1980, the U.S. DOJ found system-wide deficiencies in nearly every category of care, finding that standards in most areas were "well below professionally-accepted standards of professional care" and that staff at the hospitals used seclusion, restraints and medications in the absence of adequate treatment or as a punishment, violating the civil rights of state hospital patients.

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PAI testified to the California Senate in 2005 that the DOJ reports validated their experience of problems in the state hospitals, including misdiagnosis, overmedication, lack of treatment planning, poly-pharmacy, aversive behavioral therapy, inappropriate use of seclusion and restraints, no discharge planning, and for children and youth, the failure to educate and prepare them for life in a non-institutional setting (California Senate Select Committee on Developmental Disabilities and Mental Health, 2005).

In May of 2006, the U.S. DOJ and the state of California reached a settlement concerning civil rights violations at the four hospitals, and agreed to a 5-year Consent Judgment that requires extensive reforms (California Department of Mental Health, 2007). The agreement includes provisions for the department to make quarterly reports to the Legislature on implementation of the reforms.

> *Stigma is not only a barrier to treatment; it is part of treatment as well.*
>
> -Mental Health Client
> (Brody, 2007)

Although the U.S. Department of Justice investigations were focused on state hospitals, persons with mental illness are subject to stigmatizing and discriminatory treatment practices in the community as well. Seclusion and restraints, forced medication and other institutional abuses are also utilized in psychiatric hospitals, group homes and skilled nursing facilities. In addition, persons labeled as mentally ill are sometimes subjected to bias and discrimination by mental health providers whose role is to help people to achieve recovery.

Studies have shown that many health care professionals harbor unconscious negative feelings about their clients (Tate, 1991). Although under the recovery philosophy the client-physician relationship is more appropriately conceptualized as a partnership, stigmatizing attitudes, including devaluing statements, are sometimes endorsed by mental health professionals (Perlick et al, 2001). Psychiatrists sometimes perpetuate biased and stigmatizing attitudes, and the way that psychiatry is structured tends to reinforce the status quo (Fink and Tasman, 1992). Research has shown that the impact of perceived stigma may be even more powerful in non-mental health settings that provide treatment for depression, such as primary care (Sirey et al, 2001). One general practitioner summarized his views: "[Mental health clients] take up far too much of our time and energy – people complaining, miserable, depressed, neurotically whining about how unhappy they are, pouring out all their problems in the [office] and dumping them on my doorstep. It would be really unbearable if I was actually listening to them." (Farrell, 1999, from Byrne, 2000, p. 66). When people encounter stigmatizing attitudes from helping professionals, it has a negative impact on their willingness to seek and continue treatment. Together, fear of the abuses of the mental health system and negative responses from healthcare professionals are two of the most frequently cited reasons that people reject mental health treatment and seek to "go it alone," feeling that the cure is worse than the disease.

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The mental health system has paid scant attention to the central experience of physical and sexual abuse in women's lives. In one recent study 45 percent of women in an outpatient clinic for people with mental illness had been sexually abused, 51 percent had been physically abused and 22 percent had experienced childhood neglect.

Women who have experienced abuse report that clinicians either ignore their history of abuse or ascribe a woman's emotional problems to an entirely different cause.

-Levy and Rubenstein, 1996

B. IMPACTS OF STIGMA AND DISCRIMINATION ON ACCESS TO MENTAL HEALTH AND HEALTH SERVICES

Peter Byrne has written that negative attitudes toward people with mental illness start at playschool and endure into adulthood (2000). These attitudes often discourage people from seeking help for mental health problems or continuing mental health treatment they have begun (U.S. Department of Health and Human Services, 1999). Although the Surgeon General has estimated that about one in five Americans experience a mental disorder in the course of a year, a large-scale epidemiological study shows that less than 30% of people with psychiatric disorders seek treatment (Regier et al, 1993). "Public identification as 'mentally ill' can yield significant harm" concludes one researcher (Corrigan, 2004, p. 616), and many people reject or drop out of services to distance themselves from being labeled and devalued as "mentally ill" (Sirey et al, 2001, Perlick, 2001, Corrigan, 2004). Concerns with labeling apply to children and adolescents as well as adults – research shows that adolescents who are more likely to endorse the stigma of mental illness are less likely to seek care when it is needed (Corrigan et al, 2000). The effects of being labeled with mental illness have been shown to be much more severe than the labeling of people with other health conditions (Corrigan et al, 2000), making the instinct to avoid treatment understandable.

Stigma has become a marker for adverse experiences – first among these is a sense of shame. Mental illness is perceived as an indulgence, a sign of weakness.

-Byrne, 2000

Stigma also interferes with recovery when people do receive treatment. To be devalued and discriminated against can impede the restoration of self-esteem, a sense of purpose and a better quality of life (Perlick, 2001). At its best, mental health recovery is a journey of healing and transformation that enables a person with a mental health problem to live a meaningful life in a

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community of his or her choice while striving to achieve his or her full potential (SAMHSA, 2006). Stigma and discrimination subvert these aims, interfere with treatment and recovery and add an unnecessary burden to those who can ill-afford to bear it.

Another barrier to treatment access is the range of discriminatory insurance policies that do not adequately cover mental health treatment. Private sector insurance coverage for mental health care lags significantly behind coverage for physical health conditions. Despite California's "parity" law, intended to ensure equal physical and mental health benefits, significant disparities in insurance coverage of mental health treatment persist. Attempts at the federal level to pass a parity law have failed thus far, despite research supporting its' cost-effectiveness.

Ironically, both private insurance and federal Medicaid programs provide better access to high-cost institutional services than to more effective, recovery-oriented community services, which are severely rationed. As an example, institutionalization rates for children skyrocketed during the 1980's because of these perverse trends – nationally, the average daily census of children in psychiatric hospitals and residential treatment centers increased 60% between 1983 and 1986 (Levy & Rubenstein, 1996). This "institutional bias" of funding affects all age groups, and results in ignoring opportunities to support recovery in the community and offering services only on the far end of the spectrum when people decompensate into acute crisis. These public and private insurance practices run counter to the U.S. Supreme Court's landmark 1999 decision *Olmstead vs. L.C.*, which decreed that people must be treated in the least restrictive setting possible, in the community instead of institutional settings whenever feasible. Private sector insurance coverage as well as federal Medicaid policies must be aligned with the *Olmstead* decision in order to provide access to cost-effective, recovery-oriented community services that are both more effective and greatly preferred by people with mental health needs.

Accessing physical health care is another barrier for people who are labeled with mental illness. They experience significant disparities in physical health care, receiving fewer medical services than those without that label (Desai et al, 2002). This is especially concerning because medications used in mental health treatment frequently cause side effects that endanger a person's health, such as obesity. This often leaves people with mental illness at high risk of diabetes, hypertension, heart disease, cancer and other life-threatening physical health conditions, but with very little access to physical healthcare to address these illnesses.

Problems of access to services are especially acute for racial and ethnic minorities. According to the Surgeon General, "the U.S. mental health system is not well-equipped to meet the needs of racial and ethnic minority populations" (U.S. Department of Health and Human Services, 2001). As these groups grow, the lack of access to mental health services for people of color is tantamount to a public health crisis.

In 2003, the President's New Freedom Commission on Mental Health gave serious attention to the problems of lack of access to mental health services for people of color. This high-profile

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commission noted that among many barriers, societal stigma is a key factor. The lack of culturally competent services, as discussed previously, was reported as a contributing factor, including language competency and respect and understanding of the histories, traditions, beliefs and values of minority groups. For example, in many traditional societies, mental health problems can be viewed as spiritual concerns and as occasions to renew one's commitment to a religious or spiritual system of belief (U.S. Department of Health and Human Services, 1999). Mental health services that do not respect and understand these issues as part of the client's cultural framework are ineffective and provide a significant barrier to access.

The New Freedom Commission also cited the significant underrepresentation of minority populations in the mental health workforce as a barrier to access, as well as mistrust and fear of treatment, different cultural ideas about illnesses and health, differences in help-seeking behaviors, language, communication, racism, varying rates of being uninsured, and discrimination by individuals and institutions. In addition, we know that problems with the mental health system are even more pronounced for recent immigrants (Sue et al, 1994).

The Commission stated that as a result of these factors, Native Americans, African Americans, Asian Americans and Pacific Islanders, Latinos and other racial and ethnic minorities bear a disproportionately high burden of disability from mental illness – not because of a higher prevalence or severity of illness in these populations, but from receiving less care and poorer quality of care. The Commission reported that misunderstanding and misinterpreting behaviors have led to tragic consequences, including inappropriately placing minorities in the criminal and juvenile justice systems (New Freedom Commission, 2003).

Steven, 28, has bipolar disorder. He maintains a family and a job as a landscaper. He had never had problems with the law or any history of violent behavior, until one night while he was driving the police signaled him to pull over. He heard voices telling him to keep going. He did, and was apprehended, shot in the hand, bitten by police dogs and arrested. He spent four months in jail without the medication that had kept him stable. Eventually, he was found "not guilty by reason of insanity" and was hospitalized. The charges were dismissed.

-The Bazelon Center for Mental Health Law, 2007

Stigma is a significant factor in this intersection between mental illness and the criminal justice system. The criminalization of adults and youth with mental illness occurs when police, rather than the mental health system, respond to mental health crises (Watson, Ottati et al, 2004), and it is among the worst outcomes of the lack of access to appropriate mental health services. According to the Little Hoover Commission, "The criminal justice system is too often the only resource – the only safety net – available to mental health clients and their families in time of

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crisis" (Little Hoover Commission, 2000, p. xii). People exhibiting symptoms and signs of serious mental illness are more likely than others to be arrested by the police (Teplin, 1984), and people with mental illness tend to spend more time incarcerated than those without mental illness (Steadman et al, 1989). Of the 30,000 seriously mentally ill people in California jails and prisons, the majority are thought to be nonviolent, low-level offenders who landed in the criminal justice system in part because they did not receive adequate community treatment (Little Hoover Commission, 2000, p. xiii). Once people are in the criminal justice system, their mental health needs are usually unmet (The Bazelon Center for Mental Health Law, 2007), and they are likely to recycle through the mental health, substance abuse and criminal justice systems over and over again (New Freedom Commission, 2003).

According to the President's workgroup, these problems are equally pressing for youth: "Recent research shows a high prevalence of mental disorders in children within the juvenile justice system. A large scale, four-year, Chicago-based study found that 66% of boys and nearly 75% of girls in juvenile detention have at least one psychiatric disorder. About 50% of these youth had substance abuse issues" (New Freedom Commission, 2003, p. 32). According to the Little Hoover Commission, 50 – 90 % of the children in the juvenile justice system in California need mental health care, and a great many do not receive any services (2001). Studies also show that as youth progress further into the formal juvenile justice system, rates of mental disorders increase (The Bazelon Center for Mental Health Law, 2007). The New Freedom Commission called for appropriate treatment and diversion to be provided in juvenile justice settings, followed by routine and periodic screening.

For youth as well as adults, the Commission noted that too often the criminal justice system becomes the primary source of mental health care due to lack of access to appropriate services, and that the added stigma of a criminal record is an additional hardship for many people with mental illness. Cost studies suggest that taxpayers can save money by increasing access to mental health programs instead of placing them in jails and prisons (New Freedom Commission, 2003). Better access to mental health services on the front end, and appropriate diversion and re-entry strategies once people with mental illness become involved with the criminal justice system, are essential to avoid the criminalization and extended incarceration of non-violent adult and juvenile offenders with mental illness.

C. EDUCATIONAL SYSTEMS

Discrimination in access to a public education is one of the fundamental abridgements of civil rights, and the struggle for educational access for children with disabilities has followed a similar path to the groundbreaking struggle of ethnic minorities to establish their rights to a free and public education.

The importance of education to life success is well understood. In *Brown v. Board of Education*, the U.S. Supreme Court wrote:

> [*Education] is a principal instrument awakening the child to cultural values, in preparing him for later training, and in helping him to adjust normally to his environment. It is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education.*

Achieving the benefits of a free and public education for children with disabilities has been a long struggle. Prior to 1975, at least one million children with disabilities, including those with mental and emotional disabilities, were denied access to public education. Four million others were segregated from mainstream schools and students (Disability Rights Education & Defense Fund, 2007). To remedy these inequalities, Congress passed the Individuals with Disabilities Education Act (IDEA) in 1975. The IDEA reformed educational access and practices for children with disabilities, guaranteeing them a free and appropriate education in the least restrictive environment. Under the IDEA, children in special education are entitled to mental health services that are required in order to allow them to benefit from a special education program. The IDEA utilizes Individualized Educational Programs tailored to each child's need, along with special educational and supportive services, to provide children with disabilities with educational rights.

However, despite these protections, children with emotional disorders face many barriers to receiving an education. According to a report sponsored by the California Endowment and conducted by the Disability Rights Education & Defense Fund (DREDF), "California has failed to effectively monitor the delivery of mental health services to children" (DREDF, 2001, p. 1). As a result, the state lacks an effective service delivery system to provide mental health services required by state and federal law to thousands of children with disabilities. This leaves some of California's most vulnerable children at risk for dropping out of school, unemployment and incarceration.

The Surgeon General has reported that half of the children in the United States who require mental health services receive them, if at all, through the public school system (U.S. Department of Health and Human Services, 1999). In California, it was estimated in 2001 that up to 864,000 children diagnosed with emotional disorders do not receive the services that they need. Parents of children who need these services report that they are rarely informed of their children's rights to special educational services, that lack of coordination between schools and mental health agencies creates the "run-around" instead of allowing access to services, and that these barriers are so severe that hiring an attorney is often the only way to gain access to the educational rights to which their children are entitled by law (DREDF, 2001). Responding to these barriers, DREDF itself has given great emphasis to assisting parents of children with disabilities to become capable self-advocates, in order to obtain the special education and supportive services their children require.

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DREDF's broader recommendations for remedy of educational discrimination against children with emotional disorders include better state monitoring of children's mental health services, greatly improved interagency collaboration, preventing schools from "passing the buck," and maximizing available funding. The central strategy to ensure educational access to children is the Children's System of Care, a successful model of integrated care delivery for children that the state of California developed and implemented for over 20 years, but which it gradually de-funded and eventually eliminated completely in 2004 due to state budget pressures.

The Children's System of Care (CSOC) provided funding for counties to provide coordination, integration and individualized treatment planning for children with mental health needs. It recognized that children and youth with emotional disturbances will be more likely to have problems at home, in school and in the community at large (Hendrickson, 1995). The CSOC model views parents as partners in treatment, rather than adversaries or the cause of the child's problems, operates from a strengths-based model, acknowledges the need for culturally competent services and views institutionalization of children as the exception rather than the rule (DREDF, 2001). The Children's System of Care provided a bridge between different agencies with responsibility for children's mental health care (such as mental health agencies, schools and the juvenile justice system) in order to maximize collaboration and resources, coordinate care and develop effective, comprehensive treatment and follow-through.

The Children's System of Care was a foundational model for the Mental Health Services Act and was designated as the key approach for developing children's mental health strategies. However, state actions and regulatory interpretations have prevented it from being funded through the MHSA after the state eliminated all general fund support for the program. These dilemmas have prevented the funding of this successful model program since 2004, negatively impacting educational access for children as well as their access to other necessary services and supports.

Transition-age youth and adults also experience barriers to educational access because of stigma and discrimination. According to a 2006 report conducted by the University of California, university students are presenting mental health issues with greater frequency and complexity. These issues have been reported to be equally urgent for the California State University System and for students attending California Community Colleges. However, system-wide, diminished funding has resulted in longer student wait-times, difficulty retaining staff, huge student-to-counselor ratios and decreased services and supports. These factors have resulted in a dearth of appropriate support for students who are faced with significant developmental challenges, emotional stressors and mental health risks. They put students at high risk of suicide and mental health issues and they are another example of system problems that leave those who are at great risk to cope without preventive supports until they are in crisis (University of California Student Mental Health Committee, 2006).

Students have unique mental health needs that are growing in scope and complexity. Nationally, nearly half of all college students report feeling so depressed at some point in time that they have

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trouble functioning (Kadison & DiGeronimo, 2004). In addition, late adolescence and young adulthood are periods of high risk for "first break" episodes of psychosis as well as the onset of eating disorders and substance abuse issues, and most concerning, suicide. The UC system has seen rises in student suicide, as well as significant rises in suicide attempts. Suicidal behaviors at UC San Diego have doubled over the past four years. A large survey in 2000 found that over 9 % of students had seriously considered suicide. Only 20% of those students were receiving mental health services – *80 % of students who were thinking of suicide received no mental health services at all* (University of California Student Mental Health Committee, 2006).

Racial and ethnic minority students, gay and lesbian students and graduate students are at particularly high risk because of the multiple challenges they face. Scarce resources have diminished the ability of higher education to provide assistance to those students and to others who are not so acute but who are also dealing with concerns of a more "traditional" nature such as homesickness, questions of identity, relationship issues and concerns over career choice.

The lack of resources for mental health services in higher educational institutions in California leaves young adults and adults on college and university campuses vulnerable to suicide, substance abuse, poor educational outcomes and other mental health risks.

PART IV: COMMUNITY

A. VIOLENCE: MYTHS AND FACTS

According to the Surgeon General, stigma and discrimination against persons with mental illnesses persists and is stronger than it has been in the past in large part because of the perception that people with mental illness are dangerous (U.S. Department of Health and Human Services, 1999). Research debunks these stereotypes. The MacArthur Community Violence Study demonstrated that there is no significant correlation between mental illness and violence in the absence of substance abuse (substance abuse affects rates of violence in the general population as well as among those defined as having a mental illness) (Steadman et al, 1998). In fact, "the overall contribution of mental disorders to the total level of violence in society is exceptionally small" (Swanson, 1994 from U.S. Department of Health and Human Services, 1999, p. 7).

There is a significant body of research which concludes that people with mental disabilities are actually much more likely to be victims of crime. According to an extensive assessment conducted by the University of California, people with disabilities are targeted as victims of violent crime at much higher rates than the general population, and that these crimes are dramatically underreported. The research suggests that people with disabilities are often

victimized because of stigma and discrimination -- because they engender fear and hostility, guilt, or have visible traits that are different than others (deGiere, 2004).

This vulnerability to violent crime is most evident among those who are homeless. According to a California Department of Justice Report in 2002, 66 percent of homeless people surveyed said that they were victimized in the previous year, "suggesting an estimate of over 66,0000 homeless persons victimized in California in 2001" (Mallory, 2002, p. v-vi). Of these, 72 percent said they were victimized on multiple occasions, and 75 percent stated that the crime was assault -- 23 percent of the assaults were rapes. In 2004 the National Coalition for the Homeless reported that between 1999 and 2003 there was an alarming increase in reports of homeless men, women and children being killed, beaten or harassed. In California, the Coalition documented 39 of these incidents, resulting in 17 deaths over the five year period (deGiere, 2004).

> *We need to support fundamental change that will ultimately transform our image of people living with mental illness from community liabilities into an accurate reflection of those individuals as our neighbors, family members and loved ones.*
>
> -Toby Ewing
> (Little Hoover Commission, 2000)

Children are also subject to violence and bullying at school because of stigma and discrimination. Children diagnosed with Serious Emotional Disorders (SED), as children's mental illnesses are referred to, face much greater risks of violence at school than their peers. Thirty-three percent of special needs children who attend mainstream schools are targets of bullying, compared to 8 percent of their classmates (Garrity and Barris, 1996). Bullying behavior is an ongoing, pattern of physical or psychological aggression that is threatening, coercive, relentless and leaves the victim feeling powerless (Goodman, 2000). Effective interventions to protect these children need to be comprehensive, focusing on the child who bullies, on the victim, and on the peer culture as well as home and school environments (Garrity, et al, 1996). However, the programs that exist to prevent bullying tend to overlook the special risks, vulnerabilities and needs of children with serious emotional disorders.

Older adults with mental illnesses are also vulnerable to violence and abuse. A 2003 report by the Public Law Research Institute reports that elder abuse is a serious and growing problem in California, and it is a "crime that often accelerates a senior's death" (Hydorn, 2003, p. 3). In a 13-year longitudinal study, only 9% of abuse victims survived, compared with 40% of elders who were not abused – the mortality rate for elders who were abused was three times higher (Beers and Berkow, 2000). Mental health issues make older adults very vulnerable to physical, sexual, and financial abuse, especially when combined with physical frailty. Exacerbating these vulnerabilities is the low rate of mental health services this population receives -- only 15% who need services receive them (California Mental Health Planning Council, 2003).

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People in mental distress are also at high risk for dangerous or deadly confrontations with police. In November, 1999 the Los Angeles Times reported that from 1994 – 1999 the Los Angeles Police Department had shot and killed 25 people who were exhibiting mental or emotional distress, using "questionable tactics and the use of deadly force." The Times reported that based on standards agreed upon by nationally recognized authorities on policing and mental illness, officers took actions that helped push confrontations to fatal conclusions (Senate Health and Human Services Committee, 2000).

In May, 2000 the federally-mandated organization Protection and Advocacy, Inc. (PAI) addressed police violence against persons with mental illness, investigating the shooting deaths of Charles Vaughn of Monterey County and Marvin Noble of Mendocino County. PAI found that neither man presented a threat of danger that would call for law enforcement intervention, let alone the use of deadly force, and found that inadequate training, policies and procedures led to the deaths (Duryea and Hughes, 2000).

Amnesty International has also singled California out for concern about deaths related to the use of deadly force by police. Danny Dunn, a "mentally disturbed" man, died in the Kern County Jail after being physically restrained by three deputies who knelt on him, pepper-sprayed him and placed him in a choke hold, according the Rights for All Campaign, which reported on numerous cases of concern. The autopsy report established the cause of death as a torn liver due to compression trauma to the abdomen. Sacramento County was also singled out for the use of a four-point restraint chair in the local jail, after it was implicated in egregious abuses (Amnesty International, 1999).

These high profile cases did garner the attention of policymakers, and the California Legislature passed AB 1718 (Hertzberg), Chapter 200 of 2000, requiring the Commission on Peace Officer Standards and Training to establish a continuing education course on law enforcement interaction with persons with mental and developmental disabilities, designed to avoid such preventable tragedies. However, the course is completely voluntary and optional; the only required training of law enforcement in how to interact with persons with mental health disabilities is six- hours of basic instruction in police academy curriculum.

Los Angeles County instituted a major reform project that is thought to have yielded some improvements (Senate Health and Human Services Committee, 2000) and a number of counties around California have adopted the Memphis, Tennessee model of Crisis Intervention Teams, which are seen as a promising collaborative model of training. However, newspaper stories persist around the state of incidents of dangerous restraint procedures, stun devices and pepper spray and shootings that result from a relatively innocuous incident or a person who is suicidal. These urgent and preventable tragedies indicate the need for consistent tracking, reporting and investigation of these incidents and mandatory rather than voluntary training requirements.

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Finally, family violence is sometimes an issue associated with mental illness, as it is in society in general. Even among those who labor together in this effort of implementing the Mental Health Services Act, the topic of family violence is painful and difficult to discuss. Family members advocating for access and care for their loved ones have shared that there have been times when their loved one's behavior has been violent or abusive in the home, sometimes prompting the necessity of police intervention. And client advocates who have struggled to become empowered and find their voice in recovery have shared many experiences of violence and abusive treatment by their families of origin.

As leaders together in this effort, we can only strive to honor the courage of those who struggle to speak their truth under difficult circumstances, to be kind to one another, and to hope that our efforts to address these issues will help to prevent painful experiences of family violence for others.

B. DISCRIMINATION IN HOUSING

Homelessness may be one of the most visible outcomes of mental illness, and it was an important motivation for passing the MHSA. Homelessness is considered one of the major consequences of the state's de-institutionalization efforts; an estimated 57% of homeless adults have a mental illness (Little Hoover Commission, 2000). Homelessness is also a result of the poverty that is caused by having a mental illness (Dohrenwend et al, 1992).

In addition to those forced to live on the streets, thousands of people with mental illness are warehoused in loosely regulated Board and Care homes. A 2004 report examining Board and Care homes by the California Network of Mental Health Clients related experiences of verbal, physical and sexual abuse, over-medication, lack of privacy and respect and nowhere to turn to report abuses without retaliation. They frequently reported a lack of adequate food and poor quality of food (Hosseini, 2004). People who live in Board and Care facilities are not considered as "institutionalized" because technically they are living in the community, and they are largely forgotten by society and even within a mental health system that

> *[Living in a Board and Care] was such a horrible experience. We were only allowed to shower twice a week . . . the food was atrocious. We ate lots of Spam, no fresh fruit ever, no vegetables ever, lots of spaghetti, rice, hot dogs. Lunch would routinely be two stale pieces of bread with a thin layer of peanut butter. I lost a whole lot of weight there. I was always hungry . . . we were not allowed in the kitchen.*
>
> -Charles, Age 54
> (Hosseini, 2004)

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largely responds to people in crisis.

Still others with mental illness live under precarious circumstances, "languishing in the back bedroom" or "couch surfing" in the home of relatives or friends because they have no other options. Taken together, an estimated 75,000 people with mental illness needed housing in California in 2000 (Little Hoover Commission, 2000). In addition, people who do have housing but who go through a mental health crisis are at extremely high risk of losing both their job and their housing in the first year afterward, increasing the need for additional housing each year.

In addition, families of children with serious emotional disturbances are housed under precarious circumstances as children's behaviors, which are frequently symptoms of their disorders, threaten to result in the family's eviction from settings where neighbors do not want them around and landlords are not inclined to assist them. Eviction is also a possibility when parents' ability to pay for housing is compromised by their inability to work regularly because of the extensive needs of their SED children.

The responses to people with mental disabilities who seek to rent an apartment or move as a group into a neighborhood have become virtual mantras of discrimination:

- *Sorry, we don't rent to "handicapped" people.*
- *You've been in a psychiatric hospital – we just can't take a chance on leasing you an apartment.*
- *Is this area of town really safe for you?*

(Levy and Rubenstein, 1996)

Adequate and affordable housing is essential to solving these problems and providing the basic foundation of a safe home for persons with mental illness. However, stigma and discrimination create serious barriers to safe, quality housing. Landlords frequently discriminate by refusing to rent to individuals and families because of a perceived mental illness. In addition, neighborhoods and communities routinely band together to kill housing projects for people with mental illness. These community exercises of discrimination, called NIMBYism (Not in My Back Yard) are especially destructive, increasing the cost and difficulty of building desperately-needed housing.

Both individual and community discrimination are prohibited under the federal Fair Housing Act Amendments of 1988. The Fair Housing Act protects those with physical or mental disabilities from discrimination on the basis of disability when buying or obtaining financing for a house, a cooperative or a condominium or when renting an apartment. It prohibits conditional leases. It also protects families and caregivers with a minor child who has a serious emotional disorder from discrimination in housing.

The Fair Housing Act also covers the actions of zoning boards and other land-use regulators who are the most frequent enforcers of local NIMBY efforts. It protects against discriminatory

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zoning or other land use decisions, and prohibits special licensing, health or safety restrictions are not required for other housing. These provisions have been found by the courts to rule out many common forms of discrimination:

- It does not allow special distance requirements, such as a rule that requires special housing project from being located a certain distance from one another.
- It prohibits occupancy limits, or rules that allow only four, five or six unrelated people to live in a home.
- It prohibits special procedural requirements such as conditional use permits.
- It does not allow onerous health and fire safety rules that do not apply to other housing.
- It does not allow rules that require the operator of a residence for people with disabilities to provide advance notice to neighbors about the project.
- It prohibits restrictive covenants in deeds.
- It prohibits decisions about housing projects that are based on neighborhood opposition.

However, "Localities, often at the behest of neighborhood associations, continue to discriminate against people with mental disabilities through land-use powers. Only concerted advocacy, together with information about rights, can overcome it" (Levy and Rubenstein, 1996, p. 188).

C. DISCRIMINATION IN EMPLOYMENT

The Americans with Disabilities Act (ADA) has been called "the most comprehensive civil rights law in a generation," and affects every aspect of civil life (Levy and Rubenstein, 1996, p. 154). It outlaws discrimination in public services, transportation, communications technology and public accommodations. It also prohibits discrimination in public and private employment.

People with serious mental illness experience unemployment at rates of 80 – 90 % although a majority of them wish to work (Little Hoover Commission, 2000). Existing research as well as accounts of personal experiences suggests that stigma and discrimination in employment are pervasive and contribute significantly to the extremely high rate of unemployment among persons with mental illness. Research indicates that stigma and bias in employment against people with psychiatric disabilities is greater than against any other disability group (Levy and Rubenstein, 1996).

Adults who are parents of children with serious emotional disturbance also encounter difficulty obtaining and retaining employment. Employers are reluctant to hire a worker with a family member who may compete for the worker's time and energy. Many employers are also reluctant to accommodate a parent who needs to miss work to attend treatment sessions and other meetings designed to address the special needs of his or her family.

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Working is a successful strategy for reducing stigma and discrimination, highly valued for its potential to generate financial independence, social status, to reduce isolation and increase opportunities for personal achievement and contribution to the community In addition, paid employment has been found to reduce the symptoms of mental illness (U.S. Department of Health and Human Services, 1999).

> *Mental health professionals should convey that recovery is possible and that working at every level is possible. They should re-examine the predominant belief that people with severe mental illness are best suited for low-wage, unchallenging jobs.*
>
> (Russinova and Ellison, 2000)

The ADA defines a "qualified person with a disability" as one who is able to perform the essential functions of job, either with or without a reasonable accommodation. The accommodations requested most by persons with mental health disabilities are training of supervisors, onsite support and flexible work schedules, which are generally inexpensive to accommodate (U.S. Department of Health and Human Services, 1999).

However, practical difficulties arise in accessing these rights. The law protects prospective employees from disclosing a disability to help protect them from the potential effects of discrimination. But disclosure is required in order to get a "reasonable accommodation." The practical contradiction this creates is left to the person with a disability to navigate. The skill to negotiate a "reasonable accommodation" to receive needed support is uncharted territory in which a person with a mental health disability must frequently depend on the "good will" of the employer, because practical methods of accessing this right are undeveloped. Knowledge, training and practical tools to ask for and receive an appropriate "reasonable accommodation" are areas that require serious attention if persons with mental health disabilities are to be successful in joining the workforce.

Another barrier to employment is the counterproductive policy of the Social Security Disability system, which punishes people for trying to move off of Social Security and into competitive employment. These rules are especially unworkable for persons with mental illness, whose symptoms are cyclical and may come and go. If a person receiving Social Security Disability benefits tries to go to work, he or she risks losing essential health benefits that cover treatment and medications. If people are well now and go to work but become symptomatic at a later time, they experience a long delay in re-gaining benefits. And if their initial attempts to work aren't successful immediately, they have lost their benefits and must suffer destitution while they await a long delay for their benefits to resume.

However, despite such difficult barriers and persistently high rates of unemployment, research shows that people with mental illness can be successful in employment and in fact are employed at all levels. A 2000 research study by the Center for Psychiatric Rehabilitation of Boston documented persons with mental illness holding high-level, demanding jobs. A non-

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representative sample of 501 people showed people employed at all levels, including lawyers, managers, engineers, physicians, nurses and other professionals. Seventy-eight percent of participants had been hospitalized for mental illness, 25% in the past three years. Study participants came from all major psychiatric diagnoses – 11.5% had been diagnosed with schizophrenia or schizoaffective disorder, 43.5 percent with bipolar disorder, 29 percent with major depression, 16 percent with PTSD and other disorders (Russinova and Ellison, 2000).

There are a number of successful strategies for assisting people to enter the workforce, including client-run and client-owned vocational programs and independent businesses which have begun to flourish, supported employment models which utilize ongoing support to work in competitive employment, and employing persons with mental illness to work in the mental health system.

Consumer employment in the mental health system is an important strategy in California as the MHSA expands services and places an unprecedented value on the healing potential of personal experiences as a unique expertise when shared on a peer-to-peer basis. Employment of consumers in both administrative and direct service positions infuses the public mental health system with a viable workforce, while at the same time providing consumers with an opportunity to live outside of poverty or dependence upon public supports. It is also effective to reduce stigma in the workplace through thoughtful design and implementation of services that create a supportive workplace for people with mental illness, for those who experience mental illness in their family, or those who choose to keep their experience secret out of fear of being isolated in the workplace.

Currently, consumer and family member employment is clustered among a few counties in the state and within the adult system of care (California Mental Health Planning Council, 2003). There are few entry-level educational pathways for consumers to utilize opportunities and no financial incentives designed to attract them into the workplace. Addressing these issues is one of the essential tasks of the MHSA, and is critical to supporting consumers in employment and independence.

Research indicates that the greatest factor in reducing discrimination in the workplace is a track record of hiring and working with people with mental illness; such personal contact contradicts stereotypes and promotes understanding and acceptance of mental illness and increases willingness to continue to engage in non-discriminatory hiring practices (U.S. Department of Health and Human Services, 1999). Opening up employment opportunities is a time-honored civil rights strategy, and it is central to breaking down the barriers of stigma and discrimination that face those who live with the challenges associated with mental illness.

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D. STIGMATIZING MESSSAGES IN THE MEDIA

Portrayals of mental illness in newspapers, radio, television, novels and the movies have an enormous impact on stigma and discrimination in the public consciousness. A 1990 survey conducted by the Robert Wood Johnson Foundation found the primary source of information about mental illness for survey respondents was the mass media (SAMHSA, 2006). However, media representations of mental illness are widely inaccurate and distorted. The University of Pennsylvania's Annenberg School for Communication studied network television dramas over a 25-year period and found that "mentally ill" characters were portrayed as the single most violent group on TV (Schraiber, 1995). Seventy percent of characters in prime-time drama are portrayed as violent, and more than one in five are shown as killers (SAMHSA, 2006). Only two out of 10 of the characters identified as mentally ill were considered good characters, while about six out of 10 of the "normal characters" were depicted as good (Schraiber, 1995).

> *The relentless framing of mental illness in the context of violence and criminality is amplifying, sustaining and legitimizing a largely false picture of mental health . . . We should be honest enough to acknowledge that in doing so, we are helping to perpetuate deep-rooted and largely unjustified public attitudes which make the lives of the vast majority of peaceable, de-institutionalized mentally ill people more difficult than they already are.*
>
> -Patrick Smellie
> Bazelon Center for Mental Health Law, 1999

At the other end of the spectrum, movies and television utilize mental illness as comedy, usually laughing at rather than laughing with the characters, or portray people with mental illness as victims, pathetic characters or the "deserving mad" (Byrne, 1997).

Newspaper reporting is also a potent source of stigma, displaying bias toward reporting crimes by persons with mental illness. According to Otto Wahl, a professor of psychology at George Mason University in Virginia, "Crimes connected to mental illness are more likely to lead the news or be on the front page, and there is more multiple, ongoing coverage of crimes involving mentally ill people – arrest, trial, verdict and sentencing." In Wahl's opinion, "the media teach people to fear, devalue, and distrust people with mental illness. So people who need understanding are met with rejection and isolation, as well as discrimination" (Levin, 2001, p. 10).

In addition to conditioning the public to mistrust persons with mental illness, these messages have a powerful affect on those personally affected by mental illnesses. Media messages are an ever-present reinforcement of social rejection that can lead people to internalize stigma, feeling loneliness, alienation, hopelessness, anger and despair.

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Because of the influence of the media and the pervasiveness of the stigmatizing messages it delivers, media reporting and portrayal of mental illness present a powerful opportunity for change. The Substance Abuse and Mental Health Services Administration's Eliminating Barriers Initiative (EBI), launched in 2003, is a national stigma campaign that focused attention on stigma reduction efforts in general, and on working with media gatekeepers to eliminate stigma. The EBI offered advice on successful strategies, including understanding reporters' needs, developing relationships with them, showing respect for them and for their role, exercising patience, developing opinion pieces, tailoring materials to suit unique situations, developing quotable sound bites, publicizing events, and establishing partnerships (U.S. Department of Health and Human Services, 2006). Patrick Smellie of the Bazelon Center for Mental Illness also emphasizes the importance of the first-person experience in developing accuracy and balance in reporting: "Reporters should be exposed to the notion that people with a history of mental illness are capable of being reliable sources" (Bazelon Center for Mental Health Law, 1999, p. 9).

The Entertainment Industries Council, Inc., works along similar lines to influence movies, radio, television and novels – trying to impact those involved in the entertainment industry to use their powerful creative medium to educate, develop empathy, and to eradicate negative, stereotypical portrayals of mental illness. In 2005, SAMHSA launched the Voice Awards in Los Angeles, intended to acknowledge successes in this key arena. The high-profile awards ceremony recognized film, television and radio writers and producers whose work has given a voice to people with mental illnesses by incorporating dignified, respectful and accurate portrayals into their work (SAMHSA, 2006). Among the works honored in the first year were "The Aviator," "ER," "Huff," "Larry King Live," and "Monk." The Voice Awards continue as an annual event that set the standard for success in reducing stigma in the entertainment industry.

PART V: STRATEGIES AND RECOMMENDATIONS

A. FRAMEWORK

The ACLU publication The Rights of People with Mental Disabilities outlines eight strategies for combating stigma and discrimination. They include negotiation, education, consciousness raising, publicity, demonstrations, organization, lobbying and persuasion, and legal action (Levy & Rubenstein, 1996). All of these strategies may be utilized in addressing the problems of stigma and discrimination, leveraging existing opportunities and materials to avoid reinvention wherever possible.

While the initial efforts of the Advisory Committee did not encompass comprehensive strategic planning, this blueprint of the problems and issues that has been developed constitutes a

"Situational Analysis," a detailed assessment of the problem. Developing a Situational Analysis is recommended by SAMHSA as a first step in developing a stigma and discrimination campaign (SAMHSA, 2006). Future planning efforts should build upon the framework of identified issues developed in this Situational Analysis.

FRAMEWORK OF IDENTIFIED ISSUES:

1. PEOPLE
    - 1A. Internalized Stigma in Children and Adults
    - 1B. People Facing Multiple Oppressions
    - 1C. Foster Children
    - 1D. Family Members and Caregivers
2. SYSTEMS
    - 2A. The Mental Health System
    - 2B. Access to Health and Mental Health Services
    - 2C. Educational Systems
3. COMMUNITY
    - 3A. Violence Myths & Abuse Prevention
    - 3B. Housing
    - 3C. Employment
    - 3D. Media

B. STRATEGIC PLANNING

In the process of assessing the problem and making initial funding recommendations, many valuable ideas and approaches for addressing stigma and discrimination were encountered in the academic literature, discussed in the Advisory Committee and public hearings, and explored in a meeting held to solicit the advice of a grassroots communications expert. The work of ensuring that the list of strategies is comprehensive and of subjecting them to critical analysis, the Logic Model, integrating them into existing MHSA activities, and defining focus and priority was beyond the scope of this initial report, and has not yet been undertaken. Those activities will be central to developing a comprehensive ten-year strategic plan (see Recommendation 2, page 42, below). However, it is worthwhile to capture the initial thinking of the group on strategies to address the issue areas they previously identified. This repository of potential strategies can serve as a basis for the work of strategic planning, and is attached to this report as Appendix A.

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C. DETAIL AND JUSTIFICATION FOR SPECIFIC FUNDING RECOMMENDATIONS

Through a process of agreement between the Mental Health Services Oversight and Accountability Commission, the California Mental Health Directors Association and the state Department of Mental Health, funding in the amount of $20 Million annually for a total of $80 Million over the first four years has been designated for activities to reduce stigma and discrimination associated with mental illness in California.

These are the recommendations for initial funding:

1) Anti-Stigma and Discrimination Activities Targeting Children and Youth

Efforts in these areas would be addressed within K-12 and higher education, and blended and combined with other funding resources to support the MHSA Student Mental Health Initiative, described separately. These are the stigma and discrimination activities that the Student Mental Health Initiative will provide. (Please see Student Mental Health Initiative for full details of that proposal.)

K-12 Violence and Bullying Prevention

These activities would focus on education campaigns and training for school-age children to develop empathy and create norms around appropriate, accepting and respectful behavior that would act as a preventive measure against school violence and bullying.

$2.5 Million Annually
$10 Million Total

Peer-to-Peer Support on Higher Education Campuses

This project would be part of a multi-pronged matching grant program for California Community Colleges, California State University and University of California campuses. The activities would focus on mutual support, promoting acceptance of cultural diversity, disability, empowerment strategies, and reduction of the stigma associated with mental illness. It would address issues of trauma, loss, identity, relationships, homesickness, and achievement pressure and would provide mental health and emotional support that are defined useful by students themselves.

$2.5 Million Annually
$10 Million Total

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2) Empowerment Strategies Targeted To Adults

Intended to address the problems of internalized stigma, these strategies "do not make the world fairer, but they strengthen people's ability to withstand stigmatizing attitudes, to fight against discrimination and to stand up for their rights" (Everett, 2007).

Consumer Empowerment and Personal Contact Strategies

This project has two prongs. First, it would fund existing and new peer self-help and self-advocacy organizations to provide client empowerment through training, mutual support and advocacy. The activities would focus on promoting acceptance of cultural diversity, disability and the reduction of internalized stigma associated with mental illness.

Second, based on the "Stamp Out Stigma" model developed in Belmont, California, these peer-run programs would be funded to develop consumer-driven advocacy and educational outreach programs designed to make positive changes in the public perception of mental illness and to inform the community about the personal, social, economic and political challenges faced by people living with mental illness through personal contact strategies. Consumers would be trained to participate in interactive panels to share personal stories at conferences, workshops, Boards of Supervisors, in television and radio, schools, colleges and professional schools, police and fire departments, and with physicians, hospital administrators and mental health professionals. These "personal contact strategies" would compliment the work of the External Influence Campaign.

$5 Million Annually
$20 Million Total

3) External Influence Strategies

Stigma and discrimination are consistently identified as major barriers to improved use of mental health programs and recovery by people with mental health problems, their families, friends and mental health providers. These barriers tend to be more pronounced in ethnic, historically underserved communities. A public education campaign can improve the public's awareness of unmet needs and reduce the harmful effects of stigma and discrimination. Successful campaigns will require enormous collaboration with community based organizations, community leaders, and the media industry. Outreach, engagement and grassroots support of ethnic, underserved communities should be a key component of public education campaigns.

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Campaigns challenge the harmful stereotypes about people with serious mental illness and promote accurate portrayal of individuals experiencing mental illnesses. Since negative views are held by many people—teachers, landlords, providers, religious leaders, etc—a strategic communications campaign can change the stereotypes held by diverse stakeholders and significantly improve the quality of life of people with mental illness. The accurate reporting of and portrayal of people with mental illness must be culturally and linguistically sensitive to diverse audiences. Given the diversity of California's population, public education materials should be developed in languages other than English and those materials should be developed by ethnic media representatives who come from ethnic communities themselves. Messages that are designed for the general public should be culturally and linguistically tailored for ethnic communities and to the level of health literacy of historically underserved populations.

An efficacious campaign needs community member participation and input. Community members, especially from underserved communities, are key in determining the most pervasive and harmful stereotypes of people with mental illness, as well as the language/messages/images that need to be tailored in order to change such views in their particular population. This campaign would be targeted toward specific areas identified as particularly relevant to stigma and discrimination, where a potentially significant change could be effected through a strategic communications strategy.

The campaign would be developed and implemented through a contract with an expert professional communications firm, who would be expected to sub-contract for appropriate message development, strategies and input with ethnic community communications experts and ethnic media outlets who are members of ethnic communities themselves. Activities would include planning, conducting focus groups, developing high impact messages and strategic approaches, polling, media testing, grassroots organizing, conducting a press strategy and buying advertising tailored to diverse audiences, as called for.

Five key issue areas are suggested for this communications strategy, with potential strategic outcomes. Based on advice we will garner from the communications experts, we would expect only one of these topic areas to involve an initial large public media campaign. In the other four issue areas we would expect to utilize much more focused communications techniques to reach specialized decision makers to impact system change through making an impact on key leaders.

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EXAMPLE:

FIVE SAMPLE THEMES FOR EXTERNAL INFLUENCE CAMPAIGN

**** 1. Employing People with Mental Health Disabilities**
Potential issue for a public media campaign – a possible outcome would be public support for legislation supporting the employment of people with mental health disabilities in the workplace.

2. Accessing Quality Mental Health Care through Primary Care
Potential strategies may include disseminating quality of care and anti-stigma and discrimination materials to primary care doctors, as well as communicating with potential patients through creative means, such as educational videos in doctors' waiting rooms.

3. Education
Potential strategies may include communicating on a regular and ongoing basis with school principals on relevant mental health issues.

4. Law Enforcement
Potential strategies may include talking to key informants in law enforcement on strategies for collaboration, training, communication, education and violence prevention in encounters between people in mental distress and law enforcement officers.

5. Media
Potential strategies may include developing information, relationships, strategies and rapid responses to influence media reporting on mental illness to be more accurate, fair and less biased towards persons with mental illness.

Total Proposed Budget for External Influence Campaign
$10 M Annually
$40 M Total

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D. SPECIFIC RECOMMENDATIONS FOR COMMISSION CONSIDERATION

These specific measures are recommended as the initial activities to launch the MHSA Stigma and Discrimination Campaign:

RECOMMENDATION 1

The Commission should generate a special report on the impacts of stigma and discrimination on racial and ethnic communities, modeled on the Surgeon General's 2001 break-out report on Culture, Race and Ethnicity.

RECOMMENDATION 2

The Commission should develop a comprehensive ten-year Strategic Plan to guide MHSA activities to reduce stigma and discrimination (see Appendix A).

RECOMMENDATION 3

The Commission should develop a public policy agenda that addresses stigma and discrimination through legislative and regulatory policies (see Appendix B).

RECOMMENDATION 4

The Commission should take ongoing steps to ensure that messages utilized in MHSA stigma and discrimination campaigns do not increase stigma and discrimination.

RECOMMENDATION 5

The Commission should fund K-12 Violence and Bullying Prevention Strategies at $2.5 million annually over the first four years of the MHSA.

RECOMMENDATION 6

The Commission should fund Peer-to-Peer Support on Higher Education Campuses at $2.5 million annually over the first four years of the MHSA.

RECOMMENDATION 7

The Commission should fund Consumer Empowerment and Personal Contact Strategies at $5 million annually over the first four years of the MHSA.

RECOMMENDATION 8

The Commission should fund and oversee a contract with an expert communications firm for a Strategic Communications Campaign to develop and

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manage external influence strategies at $10 million annually over the first four years of the MHSA.

RECOMMENDATION 9

The Commission should be guided by stakeholder input to finalize a list of 5 focus areas for the Strategic Communications Campaign, selected from the eleven core issues identified by the Stigma and Discrimination Advisory Committee:

1. **PEOPLE**
   - **1A. Internalized Stigma in Children and Adults**
   - **1B. People Facing Multiple Oppressions**
   - **1C. Foster Children**
   - **1D. Family Members and Caregivers**
2. **SYSTEMS**
   - **2A. The Mental Health System**
   - **2B. Access to Health and Mental Health Services**
   - **2C. Educational Systems**
3. **COMMUNITY**
   - **3A. Violence Myths**
   - **3B. Housing**
   - **3C. Employment**
   - **3D. Media**

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YOU AND ME

If you're overly excited
You're happy
If I am overly excited
I am manic.
If you imagine the phone ringing
You're stressed out
If I imagine the phone ringing
I'm psychotic.
If you're crying and sleeping all day
You're sad and need time out
If I am crying and sleeping all day
I'm depressed and need to get up.
If you're afraid to leave the house at night
You're cautious
If I am afraid to leave my house at night
I'm paranoid
If you speak your mind and express your opinions
You're assertive
If I speak my mind and express my opinions
I'm aggressive.
If you don't like something and mention it
You're being honest
If I don't like something and mention it
I am being difficult.
If you get angry
You're considered upset
If I get angry
I am considered dangerous.
If you over-react to something
You're sensitive
If I over-react to something
I'm out of control.
If you don't want to be around other people
You're taking care of yourself and relaxing
If I don't want to be around other people
I'm isolating myself and avoiding.
If you talk to strangers
You are friendly
If I talk to strangers
I'm being inappropriate.
For all the above you're not told to take
A pill or are hospitalized, but I am.
--Debbie Sesula

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APPENDIX A

IDEAS TO BE CONSIDERED IN STRATEGIC PLANNING

1. PEOPLE

1A. Strategies for Addressing Internalized Stigma in Children and Adults

- Fund client empowerment strategies through existing peer self-help and peer self-advocacy organizations.
- Employ strategies to reduce isolation and alienation among children and adults with mental illness.
- Focus on improved service delivery, client-led training and contact strategies for mental health professionals to reduce negative attitudes that tend increase internalized stigma.
- Create "contact" programs in the community at large that take the person who has experienced or is experiencing mental ill health out of the "other" category (such as the Stamp Out Stigma program based in Belmont, California).
- Promote suicide prevention, including awareness of the California Youth Suicide Prevention Plan -- **http://www.cde.ca.gov/ls/cg/mh/suicideprevres.asp**.
- Work with youth groups like the YMCA and Boys and Girls clubs to provide mental health awareness campaigns.
- Foster mutual support programs and societal acceptance for the issues facing family members of persons with mental illness.
- Dedicate appropriate resources to ensure that stigma and discrimination efforts are designed in a culturally and linguistically appropriate manner to address California's diverse population.
- Implement the five essential elements of cultural competence in all mental health programs: valuing diversity, cultural self-assessment, honoring the dynamics of difference, formalizing and disseminating cultural knowledge at all levels, and adapting to diversity.

1B. Strategies for Addressing Stigma and Discrimination Associated with Multiple Oppressions

- Modeled on the work of the Surgeon General, consider developing a report to supplement this general overview, focused on a more detailed analysis of stigma and discrimination in racial and ethnic communities and its impacts on mental health outcomes for those populations.
- Create interaction between agencies that work with racial and ethnic communities and high school counseling services.
- Foster mutual support programs and societal acceptance for the issues facing family members of persons with mental illness.
- Create linkages between suicide prevention and stigma reduction efforts for LGBTQ youth.

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- Dedicate appropriate resources to ensure that stigma and discrimination efforts are designed in a culturally and linguistically appropriate manner to address California's diverse population.
- Implement the five essential elements of cultural competence in all mental health programs: valuing diversity, cultural self-assessment, honoring the dynamics of difference, formalizing and disseminating cultural knowledge at all levels, and adapting to diversity.
- Employ ethnic and racial minority consultants, media outlets, and firms to assist in the development of stigma and discrimination campaigns.
- Make assertive efforts to outreach and include underserved populations into all aspects of the MHSA stakeholder process.
- Promote understanding of the multiple barriers faced by ethnic and racial communities in accessing mental health care, tailored to each community's needs, and design methods for reducing the barriers through culturally appropriate services.

1C. Strategies for Foster Children

- Assist foster children aging out of the system in dealing with employment and housing in preparation to exit the foster care system.
- Collaborate with the child welfare system to reduce the inappropriate removal of children of color from their homes by promoting cultural understanding.
- Work to increase access to mental health services for foster youth and their families as well as youth and families at risk of child welfare interventions.
- Dedicate appropriate resources to ensure that stigma and discrimination efforts are designed in a culturally and linguistically appropriate manner to address California's diverse population.
- Implement the five essential elements of cultural competence in all mental health programs: valuing diversity, cultural self-assessment, honoring the dynamics of difference, formalizing and disseminating cultural knowledge at all levels, and adapting to diversity.

1D. Strategies for Family Members and Caregivers

- Foster mutual support programs and societal acceptance for the issues facing family members of persons with mental illness.
- Dedicate appropriate resources to ensure that stigma and discrimination efforts are designed in a culturally and linguistically appropriate manner to address California's diverse population.
- Implement the five essential elements of cultural competence in all mental health programs: valuing diversity, cultural self-assessment, honoring the dynamics of difference, formalizing and disseminating cultural knowledge at all levels, and adapting to diversity.

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2. SYSTEMS

2A. Strategies for the Mental Health System

- Promote strategies to shift involuntary services to services that are voluntary in nature.
- Provide training and education to empower consumers to understand what quality mental health services involve and what they may expect from mental health care.
- Monitor abuses in institutional settings and develop collaborations to protect mental health clients from abuses, including seclusion and restraints.
- Monitor the state's compliance with the federal CRIPA Consent Judgment regarding abuse and discrimination in state hospitals.
- Design interventions to ensure that when a person is hospitalized s/he does not lose his or her home, children, employment or belongings.
- Inform people who are homeless of their right to keep their belongings if they are hospitalized, using a Possessions Advanced Directive to prevent hospital staff from throwing away a person's belongings.
- Provide training to providers in the public mental health system as well as the primary care system about provider bias and reducing stigma and discrimination in treatment settings.
- Make assertive efforts to outreach and include underserved populations into all aspects of the MHSA stakeholder process.
- Dedicate appropriate resources to ensure that stigma and discrimination efforts are designed in a culturally and linguistically appropriate manner to address California's diverse population.
- Implement the five essential elements of cultural competence in all mental health programs: valuing diversity, cultural self-assessment, honoring the dynamics of difference, formalizing and disseminating cultural knowledge at all levels, and adapting to diversity.
- Promote understanding of the multiple barriers faced by ethnic and racial communities in accessing mental health care, tailored to each community's needs, and design methods for reducing the barriers through culturally appropriate services.

2B. Strategies for Creating Access to Health and Mental Health Services

- Provide training and education to empower consumers to understand what quality mental health services involve and what they may expect from mental health care.
- Provide client-led trainings for mental health professionals and service providers.
- Design interventions to ensure that when a person is hospitalized s/he does not lose his or her home, children, employment or belongings
- Inform people who are homeless of their right to keep their belongings if they are hospitalized, using a Possessions Advanced Directive to prevent hospital staff from throwing away a person's belongings.
- Provide training to primary care providers to improve their diagnosis, responses and treatment of mental health problems.

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- Make assertive efforts to outreach and include underserved populations into all aspects of the MHSA stakeholder process.
- Dedicate appropriate resources to ensure that stigma and discrimination efforts are designed in a culturally and linguistically appropriate manner to address California's diverse population.
- Implement the five essential elements of cultural competence in all mental health programs: valuing diversity, cultural self-assessment, honoring the dynamics of difference, formalizing and disseminating cultural knowledge at all levels, and adapting to diversity.
- Promote understanding of the multiple barriers faced by ethnic and racial communities in accessing mental health care, tailored to each community's needs, and design methods for reducing the barriers through culturally appropriate services.

2C. Strategies for Educational Systems

- Partner with advocates for special education to promote appropriate access to a free and public education for all children with disabilities.
- Provide teachers with in-service training and materials about mental health education.
- Reduce bullying of emotionally disturbed students at school through collaboration with the California Dept. of Education's "Health Education Content Standards for California Public Schools."
- Provide teachers and administrators with pertinent information and guidelines about bullying.
- Create a kindergarten through grade twelve curriculum in conjunction with the California Department of Education's new "Health Education Content Standards for California Public Schools" for the content area "Mental, Emotional and Social Health."
- Create interaction between agencies that work with racial and ethnic communities and high school counseling services.
- Create client "contact programs" for graduate education schools in the areas of primary care, mental health care and alternative care.
- Dedicate appropriate resources to ensure that stigma and discrimination efforts are designed in a culturally and linguistically appropriate manner to address California's diverse population.
- Implement the five essential elements of cultural competence in all mental health programs: valuing diversity, cultural self-assessment, honoring the dynamics of difference, formalizing and disseminating cultural knowledge at all levels, and adapting to diversity.
- Discourage educational institutions from expelling students with a mental health issue.

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3. COMMUNITY

3A. Strategies for Addressing Myths About Violence and Preventing Abuse

- Reduce bullying of mentally afflicted students at school through collaboration with the California Dept. of Education's "Health Education Content Standards for California Public Schools."
- Provide teachers and administrators with pertinent information and guidelines about bullying.
- Create "contact" programs that take the person who has experienced or is experiencing mental ill health out of the "other" category (such as the Stamp Out Stigma program based in Belmont, California).
- Partner with older adult advocacy organizations to prevent elder abuse.
- Develop collaborations with other civil rights and disability organizations to address areas of mutual concern (such as police violence).
- Ensure that all law enforcement agencies have training in dealing with crisis situations, either using the CIT or similar models.
- Raise awareness of violence toward persons with mental disabilities, including the homeless, LGBTQ persons and other high-risk populations. Develop and support a violence prevention agenda.
- Dedicate appropriate resources to ensure that stigma and discrimination efforts are designed in a culturally and linguistically appropriate manner to address California's diverse population.
- Implement the five essential elements of cultural competence in all mental health programs: valuing diversity, cultural self-assessment, honoring the dynamics of difference, formalizing and disseminating cultural knowledge at all levels, and adapting to diversity.
- Develop collaboration with law enforcement agencies.
- Provide media guidelines on reporting/portraying mental illness, using advice similar to that of the American Foundation for Suicide Prevention (AFSP) or the World Health Organization (WHO).
- Provide course instruction for college training programs of future media professionals.

3B. Strategies for Addressing Discrimination in Housing

- Develop strategies to reduce discrimination in permanent housing, including efforts targeting private landlords, housing authorities, nonprofit supportive housing managers and master tenants in shared rentals.
- Develop strategies to reduce discrimination in emergency shelters for adults and families and transitional housing programs, including domestic violence shelters and "safe houses" for runaway youth.

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- Target efforts at decreasing community opposition to siting of housing for persons with mental illness.
- Develop collaborations with other civil rights and disability organizations to address discrimination in housing.
- Dedicate appropriate resources to ensure that stigma and discrimination efforts are designed in a culturally and linguistically appropriate manner to address California's diverse population.
- Implement the five essential elements of cultural competence in all mental health programs: valuing diversity, cultural self-assessment, honoring the dynamics of difference, formalizing and disseminating cultural knowledge at all levels, and adapting to diversity.

3C. Strategies for Addressing Discrimination in Employment

- Provide training for mental health clients in techniques to pursue competitive employment, to secure a "reasonable accommodation" for their disability, and to thrive in the workplace.
- Provide pre-employment training, ongoing training and supports for clients to enter the mental health workforce.
- Provide training for county mental health departments on hiring and retaining clients in their workforce.
- Establish strategies to educate officials and work to change county personnel policies that are not supportive of consumer employment.
- Create incentives for counties to hire clients for the mental health workforce.
- Create "contact" programs aimed at employers that take the person who has experienced or is experiencing mental ill health out of the "other" category (such as the Stamp Out Stigma program based in Belmont, California).
- Dedicate appropriate resources to ensure that stigma and discrimination efforts are designed in a culturally and linguistically appropriate manner to address California's diverse population.
- Implement the five essential elements of cultural competence in all mental health programs: valuing diversity, cultural self-assessment, honoring the dynamics of difference, formalizing and disseminating cultural knowledge at all levels, and adapting to diversity.
- Provide a training program for businesses to be given through local chambers of commerce associations utilizing the Open Minds/ Open Doors employer literature -- **http://www.openmindsopendoors.com/upload/EmployerGuide.pdf**.
- Create an awards program that recognizes California state businesses that have the best record in hiring and/or retaining people who have experienced or are experiencing mental health problems.

3D. Strategies for Addressing Stigma in the Media

- Promote suicide prevention, including awareness of the California Youth Suicide Prevention Plan -- **http://www.cde.ca.gov/ls/cg/mh/suicideprevres.asp**.

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- Create "contact" programs aimed at the media that take the person who has experienced or is experiencing mental ill health out of the "other" category (such as the Stamp Out Stigma program based in Belmont, California).
- Dedicate appropriate resources to ensure that stigma and discrimination efforts are designed in a culturally and linguistically appropriate manner to address California's diverse population.
- Implement the five essential elements of cultural competence in all mental health programs: valuing diversity, cultural self-assessment, honoring the dynamics of difference, formalizing and disseminating cultural knowledge at all levels, and adapting to diversity.
- Employ ethnic and racial minority consultants, media outlets, and firms to assist in the development of stigma and discrimination campaigns.
- Provide media guidelines on reporting/portraying mental illness, using advice similar to that of the American Foundation for Suicide Prevention (AFSP) or the World Health Organization (WHO).
- Provide course instruction for college training programs of future media professionals.
- Develop and disseminate materials depicting people with mental health issues from a positive, strengths-based perspective.

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APPENDIX B
DEVELOPING A PUBLIC POLICY AND ADVOCACY AGENDA

A powerful method for addressing structural stigma and discrimination is to develop a public policy agenda in order to promote systemic changes. As the MHSA moves from the initial start-up phase and the Mental Health Oversight and Accountability Commission develops capacity, it may wish to adopt a public policy agenda. The Advisory Committee identified these initial public policy issues to reduce stigma and discrimination at the systemic level:

Public Policy Initiatives:

- Promote compliance with and enforcement of existing laws, including Americans with Disabilities Act, the Supreme Court's *Olmstead* decision, the Fair Housing Act, and the Civil Rights Act among others.
- Educate policymakers on the association between stigma and discrimination and the under-resourcing of the mental health system, and work toward appropriate funding of the system.
- Support pending legislation on mental health parity, including California's AB 423 and the pending federal mental health parity act (HR 1367 and S 558 being considered in the current Congress).
- Explore options for changing the "double bind" regulatory decisions that have prohibited the funding of the Children's System of Care with MHSA funds.
- Explore legislation that supports hiring and retention of persons with mental health disabilities.
- Advocate for increased oversight and higher standards in community board and care facilities.
- Support statewide legislation to reduce the effects of NIMBYism.
- Advocate to improve mental health and supportive services to children in the foster care system.
- Develop a federal policy agenda to reduce discrimination, including challenging the institutional bias of Medi-Cal and Social Security Disability system rules that discourage employment.

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