



**THE NEW JERSEY
STATE FAMILY SUPPORT PLAN
FOR FAMILIES OF
PERSONS WITH A
SERIOUS MENTAL ILLNESS**



NAMI NEW JERSEY
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2006

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Published by

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This plan is dedicated to the memory of Walter Zalenski and Robert Bulle, each of whom passed away in the past year. Both of these extraordinary gentlemen were original members of the state family support workgroup, Walter representing Passaic County in the northern region and Robert representing Middlesex County in the central region. Each had full working careers, raised families and then went on to dedicate themselves to the family movement for those who are coping with a mental illness. Walter and Robert will be missed for their warmth, always thoughtful counsel and dedication to the work of the family support workgroups.

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The New Jersey State Family Support Plan For Families of Persons with a Serious Mental Illness

The impact of the recovery concept is felt most by consumers and families. Consumers and families are energized by the message of hope and self-determination.

Mental Health: The Surgeon General's Report

INTRODUCTION

In 1996 New Jersey became the first state to pass legislation to establish a comprehensive system of supports for families coping with a mental illness. *The Family Support for Families of Persons with a Serious Mental Illness Act*, P.L. 1995, Chapter 314 declared that it is in the best interest of the State to preserve, strengthen and maintain families who have a family member with a serious mental illness. It stated that families were the major providers of support, care and other services for their family members, and that families are to be provided the support they need to sustain their family member with dignity in the community. The law further stated that a statewide family support policy for persons with a serious mental illness must acknowledge that families are able to define their own needs and select their own services; these family supports must be chosen by families, controlled by families and monitored by families. The act established a program of family support services within the Division of Mental Health Services designed to strengthen and promote families who provide care in the community for a family member with a serious mental illness. The act called for the Division of Mental Health Services (DMHS) to monitor the program of family support services. NAMI NEW JERSEY was designated to administer the program.

In order to effectuate the purpose of the Act one statewide and three regional family working groups were established to be administered through a coordinator employed by a designated statewide family advocacy organization. The coordinator in conjunction with the three regional family working groups and the statewide family working group was charged to adopt, review and revise as needed, a State Family Support Services Plan for Families of Persons with a Serious Mental Illness. The Plan assesses needs, establishes goals and sets priorities for the provision of family support services. The Plan is to additionally provide for outreach and coordinated delivery of support services.

The 2006 State Family Support Plan for Persons with a Serious Mental Illness is the third such plan to be submitted to the New Jersey Division of Mental Health Services (DMHS). Because families have been the essential cohesive element in our system of mental health care this plan, with the cooperation of DMHS, family members, consumers of mental health services and the state's provider community, will serve a vital role in informing the transformation of New Jersey's mental health system to one that is wellness and recovery oriented.

I. A SYSTEM RESPONSIVE TO FAMILY NEEDS:

The first onset of mental illness in a family is frequently a time of turmoil. Families report that they were ill prepared to deal with the initial onset of a major mental illness in their family. As is the case in the general population, these families had little prior knowledge of mental illness. Families find that not only must they deal with the upheaval that often accompanies a mental illness but that many of the natural supports that they have come to rely on are not available to them in their time of need. This is due to a great extent to a general lack of awareness concerning mental illness among the usual supports people turn to in a time of crisis such as family, friends, coworkers and clergy. The breakdown of natural support systems is compounded by a confusing and disjointed formal system of mental health care. Once a family has become aware of the mental health system they are still confronted with an array of confusing or conflicting eligibility criteria that often seem to be meant to exclude individuals with a mental illness rather than to serve them. This is magnified by the extreme shortage of resources such as housing and supported employment. For many this also extends to private mental health professionals. Many families have said that they have gone years before they have been made aware of existing mental health and supportive programs. The access to information on mental illness and appropriate resources must be greatly expanded if we are to have a system of mental health care that is responsive to the needs of families.

For families one of the most difficult aspects of dealing with a mental illness is the loss of the support of family and friends. Whether due to stigma or the turmoil that comes with the onset of a mental illness, families suffer from the loss of the natural systems that one comes to count on during a time of need. The toll that mental illness takes on families is often unspoken. Family members often neglect their own self care focusing instead on the needs of their family member with a mental illness. Many family members have found healing through family led support groups. They speak of the nonjudgmental acceptance they feel from “someone who has walked in the same shoes”. Families are able to establish relationships that are both therapeutic and normalized to take the place of “friendships” that were lost at the onset of a mental illness in the family.

New Jersey is increasingly becoming a more ethnically, culturally and linguistically diverse state. We currently rank third among the 50 states in our percentage of foreign born. To be effective with people with mental illnesses, professionals must alter their practices and the service delivery system to become compatible with the cultural patterns of those seeking help. Culturally sensitive service provision include a language and culture match between providers and clients and incorporates an understanding of the beliefs, values, traditions and practices of a culture. Family as defined by each culture is usually the primary system of support and preferred intervention. Services are best provided in ones natural community and with flexible hours and accommodation of walk-ins. When possible, mental health services should also be configured to address the social, economic, legal, and medical problems experienced by consumers and their families. In general New Jersey must do a better job in reaching the African-American, Hispanic/Latino, and Asian populations.

Medical confidentiality underpins the professional–patient relationship and ensures privacy so that intimate information can be exchanged to improve, preserve, and protect the health of the patient. It is also important to guard information that would identify an individual as a recipient of mental health services due to the stigma associated with mental illness. A problem arises

however when these principles are applied in a rote manner to interactions between professionals and families with the result being that families are excluded from the treatment process.

Significant evidence now exists that providing information to families about their relatives' illness decreases the frequency of relapse and hospitalization. Practice guidelines for the treatment of severe mental illness have integrated these findings and other evidence and now recommend involving families in all phases of routine care. Families hold a wealth of information on past response to treatment. Families are frequently the first to recognize warning signs and symptoms. Families often play an important role in medication adherence. Even though the importance of the family's role in providing support and promoting recovery is widely documented families continue to find the rigid, and frequently misinterpreted, application of confidentiality a significant barrier to receiving optimal mental health care for their family member. The advent of HIPAA has tended to make matters worse, even though HIPAA contains provisions for the disclosure of information to families that are less stringent than New Jersey law. Families report that HIPAA is blindly invoked as a justification for closing families out of all aspects of the treatment process.

GOAL: ENCOURAGE EACH COUNTY TO DEVELOP A DESCRIPTIVE HANDBOOK OF MENTAL HEALTH SERVICES /RESOURCES.

INDICATOR: A county level mental health resource manual will be prepared for each county by a county level mental health advocacy program or organization.

GOAL: ADVOCATE FOR CHANGES IN NEW JERSEY CONFIDENTIALITY LAWS TO PROMOTE APPROPRIATE FAMILY INVOLVEMENT.

INDICATOR: A position paper on confidentiality based on New Jersey regulations and HIPAA requirements will be prepared and distributed within the mental health advocacy community.

II. OPTIMISM FOR THE FUTURE

There is a new optimism about both genuine recovery from mental illness, and about our ability to manage mental illnesses in ways that make it possible for people to live their lives with increased meaning and purpose. Research has yielded important advances in our knowledge of mental illness and helped to develop more effective treatments and service delivery strategies. With this promise, the fragmented nature of programs and funding makes accessing integrated, state of the art services a challenge. Narrowly drawn admission criteria exclude large numbers of individuals from needed mental health services. Some may become disconnected from mental health services when they are "graduated to independence". Other may be excluded from programs due to a reoccurrence of acute symptoms. Families have been under recognized as the safety net and case managers that hold the mental health system together when formal services fail.

Families have learned from experience that recovery from mental illnesses is neither a linear nor a short-term process. A distinct characteristic of mental illness is its unpredictability. Relapse is

to be expected, and individuals may require long-term follow-up support. Some individuals with a serious mental illness may only need occasional help managing their everyday affairs and others for many months or years.

Substantial numbers of adults with a mental illness are now being cared for by their aging parents and will need to turn to the public service system to meet their needs in the near future. For families who have experienced difficulty in accessing services or whose family member's services have been disrupted this raises a dilemma that is ever present. This is voiced most frequently as "what will happen to my loved one when I am gone?" Without a dramatic shift in public resources for community care, the needs of many adults with disabilities will go unmet.

A system of mental health care should be one that forms longitudinal partnerships with persons with a mental illness based on education, support, and proactive planning. Long term supports should be offered to help navigate the often fragmented bureaucracies that provide their benefits, to advocate for their service needs, and to assist them when problems arise. These services should include consumer self-help and advocacy. In addition consumers may also be employed as staff in more traditional mental health services. Consumer positions most commonly include peer counselors, peer job coaches, case managers, outreach workers, and housing assistants. Such services engender recovery for consumers and stimulate hope in family members.

GOAL: PROGRAMS FUNDED BY DMHS WILL INCLUDE PERMANENCY PLANNING FOR FINANCES, HOUSING AND PROFESSIONAL AND SOCIAL SUPPORTS IN THE TREATMENT PLANNING PROCESS.

INDICATOR: The Family Support Coordinator will propose enabling language during the adoption of DMHS program regulations and grant solicitations that stress permanency planning.

III. EDUCATION

Stigma and a lack of understanding regarding mental illness continue to present the most significant barriers to treatment for people who need help. There is a widespread lack of awareness regarding mental illness among the general population. This may extend to those in professional helping roles or to those who as a result of their profession can have a significant impact on the lives of persons with a mental illness. This is compounded by an even greater lack of awareness regarding available services. Understanding and negotiating the complex system of services and supports is a challenge to all.

Mental health care was once based exclusively on institutional care and isolation. Since the 1970's the system has shifted its emphasis almost entirely to the provision of community-based support for individuals with mental illness. Not surprisingly organizations that have not traditionally specialized in mental health are taking on an increasingly more important role in the care of those with a mental illness.

The majority of people with mental health problems who seek help from a health professional will initially do so from their general practitioner rather than from a mental health professional.

Primary care providers carry much of the burden for the diagnosis of mental illness but due to a lack of training the rates at which they recognize and properly identify disorders often are low. General practitioners are additionally ill equipped to fulfil the case management roles that are so crucial for persons with a mental illness. In order to effectively provide and coordinate mental health care it is, therefore, necessary for general practitioners to understand how to access appropriate supportive services.

Only 20% of children with mental disorders are identified and receive mental health services, leading to school failure, substance abuse, involvement with the juvenile justice system, and suicide. Parents caring for children with mental illness have had to evolve their own information, skills, strategies, and supports. New Jersey is currently in the midst of a major reform of the children's system of care, but a great deal remains to be done in the educational system. School professionals must be trained to recognize the early warning signs and symptoms of mental illnesses. Educational programs that bring up to date information about mental illness to school personnel and students have shown promise and should be replicated.

The community acceptance of persons with a mental illness may have increased in recent times. Many churches and synagogues make space available for support and self-help groups. Even with this many families continue to report an uneven reception at their places of worship. With a proper understanding of mental illness religious communities are in a unique position to provide a message of acceptance and hope. Faith communities can reach out to individuals and families affected by mental illness in many helpful ways. Congregations can promote workshops and forums to educate members about serious mental illness.

People with mental illness are encountering the criminal justice system with growing frequency. Studies indicate that rate of serious mental illness among individuals in jails and prisons is at least three to four times higher than the rates of serious mental illness in the general population. Nearly half the inmates in prison with a mental illness were incarcerated for committing a nonviolent crime. Increasingly law enforcement officers, prosecutors, public defenders, and judges are the people responsible for making decisions that affect the lives of persons with a mental illness. A consensus is forming that the early identification of persons with a mental illness and referral to a treatment program would be beneficial in divert individuals from the criminal justice system.

GOAL: PROMOTE STRATEGIES TO BRING MENTAL HEALTH INFORMATION TO POLICE, EDUCATORS, PHYSICIANS AND CLERGY

INDICATOR: The State Mental Health Authority will develop a web based directory of mental health services.

IV. LEISURE

Recovery involves the growth of interdependent social relationships- being connected through families, friends, peers, and neighbors in mutually supportive and beneficial ways. Everyone requires a social network to satisfy the human need to be cared for, accepted, and emotionally

supported, particularly in times of stress. Research has demonstrated that strong social support may significantly improve recovery from both physical and mental illnesses.

Many people with mental illnesses have difficulty developing and maintaining comfortable social relationships. This can lead to loneliness and isolation, as well as conflicts with employers, landlords, neighbors and within the family. For many, changes in society have diminished the traditional support once offered by neighbors and families. This becomes heighten in the case of mental illness due to a general lack of awareness and the pervasive stigma associated with a mental illness.

Day treatment programs have traditionally played a role in meeting the need for social contact by developing socialization components to their programming. As an alternative, mutual aid groups and self-help centers have sprung up throughout the state. Groups provide an opportunity for positive, mutual support and fellowship. Self-help groups provide a meaningful structure for participants, one that is not imposed from the outside but rather is generated from the members themselves. Self-help works as the result of the change in role from "helpee" to helper, where interactions are mutual. Participants in a group can share coping strategies. They are able to form a network based on common experience and overcome their isolation. Self-help centers should not be conceived as the sole locus of leisure activity for persons with a mental illness, but rather a springboard to fuller participation in activities that include persons with a mental illness and activities that do not.

Families are an integral part of the social fabric of an individual's life. Many persons with a mental illness live at home with their family, are supported in the community by their family or return to their family around times of acute illness. Families provide a "safety net" when no other program or resource is available. For most people a family can play a very positive role in the road to wellness. The caregiving members of the family are often involved in treatment and support issues but they need regular breaks to maintain their own health and well-being. Respite care is one of the few direct services available with a primary focus on supporting family caregivers. The majority of families identify a need for greater quality, quantity, variety and flexibility in respite provision, one where trust has been built up over time among the family, the consumer and the respite provider. Adequate outreach and support services should be made available to increase caregiver awareness about available respite options and community resources.

GOAL: INCREASE AWARENESS OF CONSUMER SELF-HELP CENTERS IN NEW JERSEY

INDICATOR: Each county will have a mental health resource manual listing the consumer self-help center.

GOAL: EXPLORE SUCCESSFUL OVERNIGHT RESPITE PROGRAMS IN NEW JERSEY FOR PERSONS WITH A SERIOUS MENTAL ILLNESS AND THEIR FAMILIES

INDICATOR: Conduct a survey of Intensive Family Support Services programs to identify promising practices in the provision of respite services.

V. LEGAL

Persons with severe mental illnesses are at greater risk for arrest and incarceration than the general population. Most offenses are minor, and the association between violence and mental illness is weak. A number of factors have been proposed to explain why a mentally ill person is arrested rather than taken to a hospital. A person who appears mentally ill to a mental health professional may not appear so to police officers, who, despite their practical experience, have not had sufficient training in dealing with this population. Also, mental illness may appear to the police as simply alcohol or drug intoxication. Still another factor is that in the heat and confusion of an encounter with the police and other citizens, signs of mental illness may go unnoticed.

Even if the police consider the problem to be mental illness, the mental health option can involve a number of problems. There may be long waiting periods in emergency rooms during which police officers cannot attend to other duties. Law enforcement officers may be more inclined to take mentally ill persons to jail if they believe no appropriate community alternatives are available.

Detainees with a mental illness who have committed minor crimes, such as trespassing and disorderly conduct, should be diverted to the mental health system entirely, or at minimum for treatment. For instance, mental health teams should be readily available for consultation to the arraignment courts and especially to the municipal courts, where many acutely ill individuals appear with very minimal criminal charges. Only a small number of jails have diversion programs for detainees with a mental illness. It has been found that court-mandated and -monitored treatment in lieu of jail is effective in obtaining a good outcome for severely mentally ill persons who committed misdemeanors. Other Recommendations include mental health consultation to police in the field; formal training of police officers; careful screening of incoming jail detainees; assertive case management and various interventions, such as outpatient commitment.

There is also a corresponding lack of understanding about the workings of the criminal justice system among families, consumers and mental health advocates. Families are frequently overwhelmed by the multiple layers of the criminal justice system, a system that is more complex and less welcoming to families than the mental health system. In addition the majority of attorneys who specialize in working with persons with a mental illness only work in civil matters. There are few criminal defense lawyers who specialize in defending persons with a mental illness.

GOAL: PROMOTE STRATEGIES TO BRING INFORMATION ON MENTAL ILLNESS TO THE LEGAL COMMUNITY

INDICATOR: A reference manual for persons with a serious mental illness who are arrested will be developed.

VI. FINANCIAL/EMPLOYMENT

Mental illnesses are costly burdens for individuals, families, and states. If persons with mental illness are not poor to begin with, they are likely to become poor, and poverty factors become important in explaining common outcomes, such as quality of life. SSI supplement programs

are meant to help people with mental illnesses and other disabilities who otherwise could not afford health care or to pay rent. Unfortunately, although nearly one-half of the States provide SSI supplements, few supplements are large enough to raise one out of poverty.

The onset of a mental illness may have an adverse impact on a person's educational attainment and educational level is likewise an important factor in employment. Education also dictates the types of jobs a person can seek. Lower educational attainment is associated with entry-level jobs known for rapid turnover—the same types of jobs that persons with serious mental illness frequently take. People with serious mental illnesses have a harder time securing and keeping a job, although studies have found that most would prefer to work if afforded the opportunity and certain incentives to do so.

There has been a promising shift in orientation in psychiatric treatment towards rehabilitation and recovery models. By providing treatment, supports, and employment services, many persons with mental illness can sustain employment, become more self-sufficient and contribute to society. Expanding supported education programs would also go a long way toward improving the work lives of persons with serious mental illness. Consumers of mental health services have indicated that recovery is enhanced through engaging in meaningful life activities such as employment or education. Filling these roles can provide a sense of identity and mastery.

Another factor affecting employment is the ability of persons with mental illness to retain benefits. Unfortunately, there is much misinformation and misunderstanding surrounding the retention of benefits upon employment for this population. Recipients need to know what benefits they are entitled to, how many hours a week they can work without losing coverage, and what that coverage includes.

GOAL: UNDERTAKE ACTIVITIES THAT PROMOTE EMPLOYMENT AND ECONOMIC SELF-SUFFICIENCY

INDICATOR: Presentations will be held in each county to increase awareness of existing supportive employment/education programs and incentives to return to work

VII. RESIDENCE

Over the years families have consistently identified housing with supports as a primary need for their family members who are coping with a mental illness. A stable housing environment, a place to call home, has consistently been shown to play a vital role in recovery.

The New Freedom Commission's Subcommittee background paper on Housing and Homelessness stated, "Housing is more than a basic need. Living in one's own home also brings new freedoms and responsibilities and marks the transition to adulthood in contemporary American culture. Finding and maintaining a home is a fundamental indicator of success in community life."

Individuals with mental illness must have the option of living in decent, stable, affordable, integrated, and safe housing that reflects individual choice and available resources. Options

should maximize opportunities for participation in the life of the community and promote self-care, recovery, wellness and citizenship. Individuals should not be required to change living situations or lose their place of residence if they are hospitalized and they should be able to choose their living arrangements from among those living environments available to the general public.

In New Jersey the high cost of housing often leads persons with a mental illness to live in substandard housing. For many others the only residential alternative offering even a modicum of support services are residential health care facilities or class C boarding homes. The Division of Mental Health Services funds the majority of the service based housing for persons with a mental illness through contracts with nonprofit organizations. Each of the States 21 Counties has at least one contracted agency that provides housing to county residents. In general state contracts specify the number of individuals a contract agency must admit from a State or County hospital thus creating a heavily weighted admission priority for these individuals. This criterion has had a deleterious effect on a significant portion of the population. A large number of individuals still either live with their families or are supported in the community by family members. This has become a more precarious situation as the state's population has aged. A 2001 NAMI NEW JERSEY study places the average age of parent caretaker at 65 years of age. This represents a residential problem in both the near and long term. As the cohort of persons with a mental illness similarly age, consideration must be given to delivering specialized medical supports to individuals who reside in what has traditionally been mental health housing.

GOAL: PROMOTE THE ESTABLISHMENT OF ELIGIBILITY CRITERIA THAT WOULD MAKE HOUSING NEEDS BASED NOT EVENTS BASED

INDICATOR: A needs based criteria will be established for housing developed from the Special Needs Housing Trust Fund.

VIII. HEALTH

Research, has consistently confirmed that persons with a mental illness have high rates of physical illness, much of which goes undetected. Mortality rates for recipients of mental health services are significantly higher than those for the general population. As a result each New Jersey Family Support plan has called for health professionals to be more aware of these findings and for better medical screening and treatment of patients with a mental illness.

Several factors impede people with mental illness from receiving good physical health care. People with a mental illness are less likely to report physical symptoms spontaneously. Some symptoms of the consequences of mental illness, cognitive impairment and social isolation may contribute to patients not seeking care, or adhering to treatment. When they do present themselves the stigma of mental illness may make it less likely that they receive good care. A fragmented healthcare system, the difficulties in accessing care and the lack of practitioners who accept Medicaid have exacerbated the problems.

People with a serious mental illness are at increased risk from a variety of medical diseases, including respiratory illnesses, infectious diseases, obesity, diabetes, and cardiovascular disease. Although clinicians are now able to target the different phases of mental illness with a broad

variety of mood stabilizers, antidepressants, and atypical antipsychotic agents, it has become increasingly clear that the many efficacious medications have potentially serious side effects. The health risks associated with some agents can be significant. The clinician must therefore be continuously vigilant to ensure minimal weight gain and avoid obesity-associated metabolic complications by matching patients with the safest agent(s), especially since these patients may often require combination pharmacotherapy. Only by balancing physical and psychiatric health management to minimize morbidity and mortality can good clinical and functional outcomes be achieved.

The prevalence of smoking among persons with a mental illness is significantly higher than among the population as a whole. People with a mental illness are at two to three times the risk of developing tobacco-related medical illnesses. Mental health treatment programs have a history of reinforcing tobacco usage and using tobacco to modify behavior. These treatment settings have many staff that smoke and endorse the belief that tobacco helps their patients manage their psychiatric disorder. Under recognition and under treatment of tobacco addiction in persons with a mental illness continues to be common despite the availability of effective management approaches. Smokers with a mental illness are a broad treatment population that requires specifically tailored treatment. Nicotine replacement medication, and modified psychosocial treatments can improve outcomes. The effective model programs and system changes that have begun to address tobacco need to be replicated throughout the state.

**GOAL: PROMOTE SMOKING CESSATION PROGRAMS IN
SELF-HELP CENTERS AND PARTIAL CARE PROGRAMS**

INDICATOR: A smoking cessation program for persons with a mental illness will be available in every county in New Jersey.

IX. EMPOWERMENT

Historically, families have viewed service providers as operating from a position of strength when interacting with families. This imbalance is due to their control over services, their access to information, and their expertise. Empowerment has emerged in reaction to this imbalance and inadequacies in the systems of care for persons with serious mental illness. Empowerment is based on the principle that consumers of psychiatric services and their families can gain control over their lives, interact collaboratively with professionals, and take action on their own behalf.

Family members can contribute unique insights to the administrative and policy decisions which affect persons with a mental illness and their families due to the wealth of experience they have with the mental health system. In addition families often devote time, energy, and resources for advocacy to improve services and opportunities for their family members. Family advocacy on a local level might include organizing to improve local mental health services, or to redress grievances with service providers. On the state and national level, groups work to influence legislation and to support research and education initiatives. As we look to transform our system of mental health care it becomes more crucial that the outcomes we seek are based in the values of those served by the system. Families have consistently favored measures that stress not only the remediation of symptoms but also those that embody full participation in life such as those based on employment and social connectedness.

Families have made gains in system participation. Families are prominently represented on the State Mental Health Planning Council. At least one family member serves on each county mental health board. Families regularly participate in the program reviews conducted by the Division of Mental Health Services' Bureau of Licensing and Inspection. Family monitoring programs are underway in each of the four state psychiatric hospitals. State regulations (N.J.A.C.10:37D-3.1) also prioritize family members for inclusion on provider agencies' governing boards and advisory committees. On the individual level various state regulations and best practice support the involvement of families in treatment.

With these gains family involvement has not been fully integrated across New Jersey's mental health system. Care providers may under appreciate the importance of treatment approaches that involve families. On a systems level there remains a shortage of family representation on advisory and decision making bodies. To an extent this is due to the constraints on time and energy that come with being a family caretaker. Day to day coping can be demanding. A truly transformed system however must shift power to families and consumers by paying attention to creating positive circumstances for their participation. Successful strategies such as advocacy training and mentoring have been developed to maximize the meaningful participation of families. As Family members become proficient with advocacy skills, they are better able to positively impact the planning and provision of mental health and support services at the state and local levels.

GOAL: ENHANCE THE ABILITY OF FAMILIES CARING FOR A RELATIVE WITH A SERIOUS MENTAL ILLNESS TO INFLUENCE THE PROVISION OF SERVICES TO PERSONS WITH A SERIOUS MENTAL ILLNESS

INDICATOR: Advocacy training will be provided to families in each region of the state.

X. STIGMA

Stigma refers to a cluster of negative attitudes and beliefs that motivate the general public to fear, reject, avoid, and discriminate against people with mental illnesses. Stigma and discrimination associated with mental illness and its treatment have substantial negative impact on the lives of individuals, families, and communities. The Surgeon General's report concluded that despite the existence of effective treatments for mental disorders, the fear of stigmatization often deters individuals from acknowledging their illness and seeking treatment.

The stigma attached to mental illness is a main obstacle to a better quality of life for people with a mental illness and for their families. The life opportunities of people with mental illness are undermined by stigmatizing attitudes and discriminatory behavior. 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 leads to low self-esteem, isolation, and hopelessness.

Families often experience stigma in the form of blame for causing their family members illness due to their own behavior or bad parenting. Families also experience blame if the relative

with a mental illness fails to adhere to the treatment regimen or relapses.

People with mental illness are, many times, not described accurately or realistically in the media. Movies, television and books often present people with mental illnesses as dangerous or unstable. News stories sometimes highlight mental illness to create a sensation in a news report, even if the mental illness is not relevant to the story. The stigma associated with mental illness dehumanizes individuals and in so doing it contributes to lack of investment in the mental healthcare system. It deters the public from seeking care and contributes to the persistent underfunding of services for people with a mental illness.

Initiatives aimed at reducing the stigma of mental illness are risk reduction strategies that increase opportunities for people with mental illnesses to live, work, and socialize in their communities. Public awareness campaigns, including information provided through the media, education of school children, and presentations by advocacy groups about the causes and symptoms of mental illnesses, can help reduce discrimination against people who have serious mental illnesses.

Perhaps the most effective way to reduce stigma is to ensure that people with mental illnesses have opportunities to live, work, study, and socialize alongside people who do not have mental disorders. When their neighbors and coworkers get to know people with mental illnesses as individuals, negative stereotypes tend to diminish.

GOAL: PROMOTE EDUCATION AND AWARENESS PROGRAMS THAT SENSITIZE THE PUBLIC AND PROVIDERS ABOUT THE IMPACT OF STIGMATIZING ATTITUDES

INDICATOR: Education and awareness programs featuring consumers and family members will be presented statewide.

NEW JERSEY FAMILY SUPPORT PLAN FOR PERSONS WITH A SERIOUS MENTAL ILLNESS

I. A SYSTEM RESPONSIVE TO FAMILY NEEDS:

GOAL: ENCOURAGE EACH COUNTY TO DEVELOP A DESCRIPTIVE HANDBOOK OF MENTAL HEALTH SERVICES /RESOURCES.

INDICATOR: A county level mental health resource manual will be prepared for each county by a county level mental health advocacy program or organization.

GOAL: ADVOCATE FOR CHANGES IN NEW JERSEY CONFIDENTIALITY LAWS TO PROMOTE APPROPRIATE FAMILY INVOLVEMENT.

INDICATOR: A position paper on confidentiality based on New Jersey regulations and HIPAA requirements will be prepared and distributed within the mental health advocacy community.

II. OPTIMISM FOR THE FUTURE

GOAL: PROGRAMS FUNDED BY DMHS WILL INCLUDE PERMANENCY PLANNING FOR FINANCES, HOUSING AND PROFESSIONAL AND SOCIAL SUPPORTS IN THE TREATMENT PLANNING PROCESS.

INDICATOR: The Family Support Coordinator will propose enabling language during the adoption of DMHS program regulations and grant solicitations.

III. EDUCATION

GOAL: PROMOTE STRATEGIES TO BRING MENTAL HEALTH INFORMATION TO POLICE, EDUCATORS, PHYSICIANS AND CLERGY

INDICATOR: The State Mental Health Authority will develop a web based directory of mental health services.

IV. LEISURE

GOAL: INCREASE AWARENESS OF CONSUMER SELF-HELP CENTERS IN NEW JERSEY

INDICATOR: Each county will have a mental health resource manual listing the consumer self-help center.

GOAL: EXPLORE SUCCESSFUL OVERNIGHT RESPITE PROGRAMS IN NEW JERSEY FOR PERSONS WITH A SERIOUS MENTAL ILLNESS AND THEIR FAMILIES

INDICATOR: Conduct a survey of Intensive Family Support Services programs to identify promising practices in the provision of respite services.

V. LEGAL

GOAL: PROMOTE STRATEGIES TO BRING INFORMATION ON MENTAL ILLNESS TO THE LEGAL COMMUNITY

INDICATOR: A reference manual for persons with a serious mental illness who are arrested will be developed.

VI. FINANCIAL/EMPLOYMENT

GOAL: UNDERTAKE ACTIVITIES THAT PROMOTE EMPLOYMENT AND ECONOMIC SELF-SUFFICIENCY

INDICATOR: Presentations will be held in each county to increase awareness of existing supportive employment/education programs and incentives to return to work

VII. RESIDENCE

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INDICATOR: A needs based criteria will be established for housing developed from the Special Needs Housing Trust Fund.

VIII. HEALTH

GOAL: PROMOTE SMOKING CESSATION PROGRAMS IN SELF-HELP CENTERS AND PARTIAL CARE PROGRAMS

INDICATOR: A smoking cessation program for persons with a mental illness will be available in every county in New Jersey.

IX. EMPOWERMENT/SYSTEMS ADVOCACY

GOAL: ENHANCE THE ABILITY OF FAMILIES CARING FOR A RELATIVE WITH A SERIOUS MENTAL ILLNESS TO INFLUENCE THE PROVISION OF SERVICES TO PERSONS WITH A SERIOUS MENTAL ILLNESS

INDICATOR: Advocacy training will be provided to families in each region of the state.

X. STIGMA

GOAL: PROMOTE EDUCATION AND AWARENESS PROGRAMS THAT SENSITIZE THE PUBLIC AND PROVIDERS ABOUT THE IMPACT OF STIGMATIZING ATTITUDES

INDICATOR: Education and awareness programs featuring consumers and family members will be presented statewide.

BARRIERS TO ACHIEVING A SATISFACTORY QUALITY OF LIFE

The State Family Support Workgroup is assessing the barriers faced by families that are coping with a serious mental illness. Please review the list of topics below and list the barriers you face in trying to achieve a satisfactory quality of life for you and your family member with a mental illness

BARRIERS TO A SYSTEM RESPONSIVE TO FAMILY NEEDS

- I can't get information on my mentally ill son's condition and diagnosis to be able to help him recover
- There are not enough professionals who can help mentally ill people who are indigent and provide support for their families/friends
- Long wait for services
- Not enough help out here
- Give families of mentally ill persons the opportunity to choose HMO
- Need the "police" to help place people in hospitals or "homes"
- Frustration with the knowledge of realizing that the system is inefficient
- I found that group therapy doesn't help – counselors listen but don't offer much help
- Disconnect between Family Doctor and the Mental Health System.
- Doctors unaware of help available to families- no referrals.
- People do not know about NAMI, IFSS, etc.
- Families do not know where to start. Many phone calls are required before help is obtained.
- Extensive turn over in Mental Health workers. Low pay issues.
- General exclusion of families in treatment. HIPPA restraints. Families are not consulted, even when a consent form exists.
- Consumers over 18 years of age are considered adults- Families are not advised.
- Doctors fear liability – do not share information.
- System review Committee of County Agencies should be strengthened. (Gary Miller's quarterly meeting) This exchange should move to flow and problems, and what is changing in the county.
- Consumer should have a central file. New Doctors and agencies require a restart and a total update. This is also a problem when seeking help from the same agency- e.g. VA patient info is not readily available if the person is treated by another Medical Center.
- Problems of consumers who have no family for support.
- Difficulty in understanding and meeting criteria to get a patient into the system. (Medicare, Medicaid, etc.)
- How do I know which agency has the contract to handle my problem?
- How do I deal with a person who has no insight into their illness: "I'm not sick!"
- How do we get the entire system to collaborate?
- Slow getting to see a psychiatrist and getting a diagnosis
- Very limited resources for follow-up care after hospitalization (example: a "very active" day program)
- Overzealous regarding confidentiality without advocating for consumer to sign a release; confidentiality inhibiting free access to doctors who then can be "used" by some consumers to restrict flow of information to loved ones
- Long waits for service; more one-on-one time with therapist

- No follow-up if treated outside of the “system
- Little help for parents who have lost custody of their children to maintain contact
- Insurance limiting hospital stays to 3 to 4 days
- Right now inpatient commitment is the only option for incapacitated individual
- “Confidentiality” prevented knowledge of son’s whereabouts
- Long waits for services
- Family member refuses treatment
- Lack of/inadequate/long wait for services
- Include family in evaluation, families not taken seriously
- Confidentiality rules too strict
- Need help before “dangerousness”
- Need enforced follow-up treatment
- Time limit in ICMS
- Extend ICMS to more people
- Restrictions on day treatment to consumers receiving PACT services
- Waiting lists too long, treatment too short
- Restrictive use of confidentiality
- How do we know what services exist, where to turn for help?
- Waiting for more intensive services

BARRIERS TO OPTIMISM FOR THE FUTURE

- Less opportunities
- Encourage legislatures and senate to please provide adequate SS for the future
- Past failures → low self esteem
- Who will look after my family member when I am no longer able?
- Who will take care of my family member when I am gone? (4)
- Funding shortages – New Jersey budget gap.
- Lack of good jobs.
- Inadequate training available.
- Public’s ignorance regarding mental illness.
- We are not diagnosing and treating illness in the young. The problem worsens.
- The consumer asks: “What is to become of me?”
- Utilization of Plan New Jersey is expensive.
- What happens to folks who can’t afford this type of support?
- Mental Health Consumers are intelligent. They are discouraged when they see others advance and have quality lives.
- Feelings of “I don’t fit! I’m different!”
- Problem of going out of state or out of county to obtain services. This creates an unequal treatment opportunity.
- Trauma of mental illness often fractures family dynamics. Parents ability to function in their workplace becomes an issue.
- Not enough concern for the mentally ill among everyone involved
- Family members need support groups—no cutbacks
- Limited reasonable housing and employment assistance
- Inadequate coordination between family services and consumer services
- Loved one is provided for financially, but maybe not spiritually

- Early intervention often is restricted, making preventative measures harder and inhibiting recovery
- “ball gets dropped” within the system
- I can’t seem to help my family member with her despair
- I worry about her living in poverty for the rest of her life
- Won’t have children, afraid of passing illness on to them
- No affordable programs to provide services after parent’s death
- Side effects lead to discontinuing meds and relapse
- Many years of little progress leads to hopelessness
- Not enough outlets for people with a mental illness to have a useful life
- People stuck in poverty
- Who will take care of my love one when I am gone?
- What services exist for the elderly?
- Fear family member will lose his benefits
- Too easy for people to be dropped from programs
- Families need support/assistance now to be prepared if something happens
- If my son doesn’t improve enough what will happen to him?

BARRIERS TO EDUCATION

- Family physicians do not know about family support organizations that can help families and friends of the mentally ill. The same goes for ministers/priests/rabbis, school social workers, etc.
- Help – he is only a freshman. School is not equipped for mental illness
- Money
- Mental focusing
- High school age appropriate, lack of choices in county
- His own raised barriers to success in programs
- Had to hire a lawyer to fight school district to place my child in an out of district placement in therapeutic day program for high school
- Many people do not understand mental illness
- Transportation and Funding are lacking.
- Long wait for Department of Vocational Rehabilitation Services.
- This organization is focus on physical disability – not mental illness.
- College Disability offices do not understand mental illness.
- Agencies should offer more options as modern medications make consumers more functional.
- Getting a G.E.D. can be an undertaking.
- Persons with mental illness cannot carry a full college workload. Yet, 12 credits are needed to qualify for benefits. e.g. dorm rooms, tuition assistance. There should be a process to set a realistic credit workload for the consumer.
- Peer pressure – Not understanding that completion of studies will take longer.
- Guidance Counselors do not understand Mental Illness.
- Fellow students poke fun of consumer – consumer leaves college.
- Medicaid should allow education in partial care programs.
- High schools need additional attention – expand “Breaking the Silence”.
- Stop putting mentally ill persons in jail! Give them the treatment they need.

- Hard to find special education programs or information
- Schools are not always set up to accommodate
- It is really up to us to constantly seek education everywhere possible and share all of that information
- Lack of funding
- Uninformed school officials; school systems still in the dark about mental illness—more education programs needed in schools and in the workplace
- Can't get ex to supervise kid's homework
- Feels "safer" in a program than in a new and challenging setting
- Lack of information or funds
- Mood swings
- No education in hospitals
- At first had no idea where to turn
- Need more public information on mental illness and where to get help
- How can loved one return to college?
- Need supportive education
- Lack of money to pay for college
- Need more access to computers
- Educate the public to reduce stigma
- Will teachers and students understand?
- Still learning about resources for mentally ill
- Need to know more about resources for returning to college

BARRIERS TO LEISURE

- There is insufficient mental health support facilities in the county so that care givers can do other things such as attend concerts, take classes, etc.
- We worry about what will happen if I go away for a few days on vacation
- Feeling isolated
- My family member needs a place to make friends and social opportunities (2)
- Inadequate funding- Limited transportation.
- Perceived lack of interest
- Learn from successes in other counties.
- Need family involvement to get leisure activities started. Once running, the consumers should manage their own program.
- Develop a list of desirable and range of leisure activities.
- Fear of venturing forth.
- Lack of friends.
- "Schizophrenia Anonymous" type organizations are needed.
- Money drain to support smoking habit.
- Get feed back from consumers: "What do they want?"
- Consumer needs to have someone to talk to on phone- sharing or conferring with a person going through the same difficulties.
- Desire of consumer to be with "normal" people, "I don't want to always be with sick persons".
- "Why do I have to explain myself to people?"
- You feel that you must always be available for your loved one.

- You feel uncomfortable giving them their freedom
- Lack of support groups
- Lack of respite facilities
- Worried about going on vacation with spouse and leaving mentally ill loved one on his own
- Can't afford leisure items or places
- Loss of friends and relationships
- Guilt of leaving family member alone
- Worried when we go on vacation
- I sometimes feel over whelmed by constant care of my family member
- My daughter is a mother of two and works (must watch her absences). Not enough time for everything
- No friends or social contacts
- Lack of transportation
- Need recreational programs, gym, physical fitness
- Day programs do not provide enjoyable activities for high functioning individuals
- Need more opportunities for volunteer work
- Lack of respite care
- Illness makes it hard to maintain friendships
- Opportunities to socialize where people who understand mental illness
- Worry about what will happen if I go away for several days
- Illness is too consuming to consider leisure
- Relies on me for everything, I feel stressed out
- Either my wife or I have to be home at all times

LEGAL BARRIERS

- The justice system is a de facto mental illness system.
- More resources need to be marshaled to divert mentally ill people from the justice system and place them in appropriate treatment with medication
- Privacy Act
- Pay legal reps to defend clients
- Law – need to help place people in hospitals or “homes”
- Rights of the mentally ill harm the potential for treatment.
- We keep system that has gone too far in rights
- Trying to decipher what is the illness and not having adequate court representation if behavior is because of illness
- Mental Health Courts are needed. Persons determined to have a mental illness should not have to go through the normal court system.
- Judges need education on Mental illness.
- Consumers need a place to go to get legal help.
- Burlington County has no help for certain legal issues.
- Jails are used to replace mental hospitals.
- “Who do I call when I am faced with Jail?”
- Law is defective in getting a mentally ill person help.
- Need change in involuntary commitment law.

- Correction Officers need training regarding the mentally ill. Correction Officers are not trained social workers. It is unfair to ask them to act in that capacity.
- Parole and Probation officers need training regarding mental illness.
- Fear and timidity of care giver to seek help.
- Secure parity between medical and mental health insurance coverage.
- Mental Health “Legal Aid”
- Perception in legal profession that consumers are not equal to other clients
- More police education needed; still too many “bad apples” in police forces
- Legal service cutbacks
- Legal advocacy is often hard to find and is costly
- Can’t afford a lawyer
- She can shut me out with the HIPPA laws
- Lack of knowledge of available legal assistance
- Increased problems with the law and not enough services to help
- Arrested for minor offenses
- Risk of outpatient commitment will prevent people from seeking services
- There should be a list of Mental Illness advocacy lawyers
- Legal help too expensive
- The justice system is not trained to deal with the mentally ill

FINANCIAL OR EMPLOYMENT BARRIERS

- The social security system needs to be reviewed to support mentally ill people. People who are trying to get back on their feet and get employment are often discouraged due to the loss of benefits.
- Low level employment
- Level of support to return to work
- No place to go for help
- Money talks all others walk
- Reduction for insurance for employers
- Workability programs is very needed
- Help in money for school
- Help with transportation
- Lack of availability of supported employment
- Medicare allow only 190 LIFETIME days of treatment. What comes after that?
- Public transportation limits job potential.
- If I mention that I have a mental illness at work I am treated differently. This also puts some requirements on the employer. The prevailing result is job termination.
- Mentally Ill people have to lie about their illness to get hired.
- People do not understand Medicare and Medicaid benefits and hoe to access them.
- There’s higher co-pay for mental illness than for a physical illness. (\$25 vs. \$15)
- Fear of earning too much money to pay for medications.
- Loss of Medicaid, Social Security and other assistance when the mentally ill person is employed.
- Laws are confusing.
- Where do you go to get correct information? Information gained over the phone is often contradicted when the mentally ill person arrives at the agency.

- Mental Illness in the family can have a devastating impact on the family bread winner. They are drain from their effort within the family and their performance at their workplace suffers.
- Respite needed or family care members.
- Medicines are very expensive and the little of the cost is covered by insurance
- Employment needed for consumers
- SSDI only allows \$2,000 in savings—not able to save for later on
- Limited supportive employment programs
- Not enough pay for the support workers
- Stigma still exists in the workplace
- Fear of family member losing social security by refusing or being unable to follow through
- Liability for uncovered medical expenses. Who's responsible?
- Supported employment under funded, lack of “clubhouse programs”
- Disability benefits are below the poverty level
- Personal Needs Allowance \$72 a month
- Disclosure makes it hard to be hired
- Little understanding about reasonable accommodations for mental illness
- Need to find an employer who is understanding about mental illness
- Many of the jobs are minimum wage
- SSI barely allows for anything more than the bare essentials
- Working helps self-esteem but may lead to loss of benefits
- Lack of availability of supported employment
- Social security payments are below the poverty level
- Too many companies refuse to hire someone with a mental illness
- Does not budget money wisely

RESIDENCE BARRIERS

- Housing for mentally ill persons is sorely lacking and/or its availability is not widely known
- End homelessness
- Lack of housing, a given known fact resources needed in budget
- Low representation
- Not enough good housing available
- Rental assistance lists are closed in most counties
- Houses are not available
- NIMBY
- No new Section 8 houses available for many years.
- Federal budget squeeze complicated with state funding shortfalls.
- No affordable housing for working poor.
- Moorestown-Mount Laurel area has started a limited housing venture. We need more!
- Some housing has been promised – but it is too slow in coming.
- Patients are retained at Ancora Psychiatric Hospital because there is no housing available for them after their treatment is completed.
- There are few options for high functioning persons who want to go into a group home.
- Older mentally ill persons go on waiting list for group homes.

- Not enough housing and supervision for the ones who need it
- Sometimes lack of community cooperation regarding location (NIMBY syndrome)
- Lack of state support
- Existing housing is expensive with long waiting lists; boarding homes often are substandard
- Do not eliminate Section 8 for those who are in institutions
- MH housing often in bad areas
- Conflicts with roommates
- Safe, affordable and not only clumped together with other people with mental illness
- Rental assistance list closed
- Hard to share an apartment, living alone too costly
- Pets not allowed
- Living conditions poor in Residential Health Care Facilities (RHCF)
- Are there residential programs for people who are partially functioning?
- Residential programs are too restrictive
- Need information on obtaining mental health housing
- If he was in a group home I would feel more secure.

HEALTH BARRIERS

- New medications often have significant side effects such as weight gain
- Poor self-care
- Weight gain as a side effect to medications
- Heavy smoking
- The cost is high.
- Medicare does not pay enough.
- There is limited formulary available in prescriptions.
- My Doctor keeps changing. Persons treated by Residents lose their physician when the Doctor completes this phase of study.
- Poor integration between physical and mental health treatment.
- Continuity of care is a problem.
- Heavy smoking – cost of cigarettes.
- Danger of persons smoking in bed.
- Parity of insurance.
- Difficulty in obtaining dental care.
- Personal hygiene issues.
- Consumer will not believe they have mental health problems.
- Weight gain on some medications.
- Blood tests not given as required.
- Lack of follow up.
- Limited MICA facilities.
- No homeless shelters in the county.
- Prevalence of smoking or drug abuse making treatment impossible until abuse is corrected;
- lack of insight in mental health community as to the dangers of smoking and substance abuse
- Lack of empathy and understanding from primary care physicians; they need to

be more involved

- Many medications still have unattractive side-effects, discouraging compliance
- Health consequences of psychiatric medications, obesity, diabetes, heart disease
- Can't see a doctor due to lack of funds
- Smoking
- Restrictions of doctors accepting Medicare/Medicaid patients, or insurance only
- No effective smoking cessation program
- Doesn't take medication for high cholesterol
- Lack of dentists
- Not enough providers accept Medicaid
- Physical concerns need to be integrated with treatment for mental illness
- Lack of proper nutrition
- Lack of insurance without Medicaid or Medicare
- Somatic complaints not taken seriously by physicians due to mental illness
- Motivating family member to get "check-ups" is hard
- Family member doesn't trust doctors
- Heavy smoking
- Cost of medication
- He is careless about his health and doesn't reach out to medical services
- Reluctant to adopt healthy habits
- My son's teeth were neglected.

STIGMA

- Society fears mentally ill people through years of movie and media negativity
- Hollywood - almost always portrayed in the worst possible way
- People think, how can a crazy person tell me what to do/think?
- Friends that will not understand the down sides of mental illness
- Family members own idea of mental illness stigma
- My co-workers not as understanding of my medical emergencies for my son. I think would be more understanding if they saw illness as they see other illnesses
- Mental illness used in advertising joked about on radio and television
- Mental illnesses are often sensationalized in the media
- Reluctance to enter treatment due to stigma
- Lack of family support
- Family reluctance to acknowledge illness
- TV and Radio personalities make fun of illness – this comes in both intended and unintended forms due to improper use of language.
- Isolates family and consumer due to fear of "family finding out".
- Dilemma of letting the world know – If help is sought I will be penalized and suffer emotional or financial damage.
- Need for more understanding in different cultures.
- Spanish, Chinese, Korean and other groups need help.
- Impedes employment- "I can't work more hours because of my illness" results in getting fired.
- Loss of acquaintances or friends
- Stigma still exists everywhere, especially in Government

- If we come into contact with stigma, we all are the best teachers
- Workplace and schoolroom stigma still inhibits openness
- TV, movie, and media depiction of mental illness still often relies on “shock value” and labeling
- must hide illness to get a job
- I want the world to see her, not her illness
- Stress and heartache in dealing with others when family member is going through an unstable time
- NIMBY
- actually more sharing would help
- Old friends are no longer around
- Self stigma, not good enough
- If hired, disclosure may make a person feel inferior
- Mental illness often sensationalized in the media
- There are almost no friendships maintained.
- My family does not want to have anything to do with my ill family member.
- Neighbors won’t speak to me after police took my son to the “psych ward”.

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