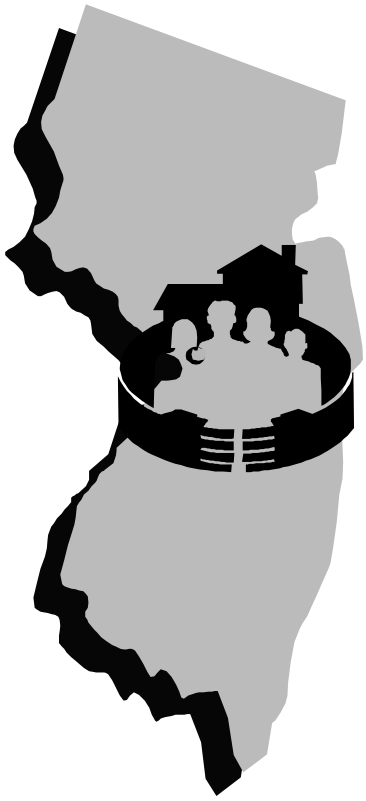
NEW JERSEY

STATE FAMILY SUPPORT PLAN



For FAMILIES of PERSONS
With a
SERIOUS MENTAL ILLNESS

NAMI NEW JERSEY
1562 Route 130, North Brunswick, NJ 08902
December 2002

ACKNOWLEDGEMENT

Through the Family Support Act for Persons With a Serious Mental Illness, New Jersey has acknowledged the vital role families play as the major source of support, care and other services for persons with a serious mental illness. Family members are the glue that keeps our system of mental health care together. They have acquired a particular expertise in dealing with mental illness that can only be obtained through a life of experiential learning. This expertise has made family members eminently qualified to determine their own needs and to select the supports that would best serve to enhance their family's quality of life.

A great debt of gratitude is due to the members of the Family Support workgroups for their untiring effort and dedication in making the ideals of the Family Support Act a reality. Members not only contributed their knowledge and insights over many months of workgroup meetings, but also were instrumental in reaching out to local family members in order to foster inclusiveness, without which such a comprehensive Plan would not have been possible. The efforts of these individuals have resulted in a Plan that is genuinely established by families for families.

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December 2002

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INTRODUCTION

In 1996 groundbreaking legislation was signed into law in New Jersey, *The Family Support for Families of Persons with a Serious Mental Illness Act*, P.L. 1995, Chapter 314. This Law 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 declared 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 shall adopt, review and revise as needed, a State Family Support Services Plan for Families of Persons with a Serious Mental Illness. The Plan shall assess needs, establish goals and set priorities for the provision of family support services. The Plan was to additionally provide for outreach and coordinated delivery of support services.

The first New Jersey Family Support Plan for Persons with a Serious Mental Illness was adopted in 1997 and submitted to the Division of Mental Health Services. The Plan has been distributed to a wide range of family members, consumers, mental health professionals and advocates. It has served as a map to guide the mental health system on the concerns of families dealing with a mental illness and has contributed to the development of a greater awareness of the vital role played by families in the care of persons with a serious mental illness. A written report has been submitted to DMHS on a yearly basis that details the progress made towards effectuating the purpose of the act. Additionally, meetings between the State Family Support Workgroup members, the DMHS Director and the Division Senior Staff has served to forge a partnership in support of families.

METHOD

Local family and advocacy groups in each of New Jersey's twenty-one counties were contacted by the Coordinator to recommend family members who were the primary caretakers of persons with a serious mental illness to serve as members on the Regional Family Workgroups. Selections were made on based on the degree to which the individuals could represent and involve family members residing in their respective counties. An effort was made to include a cross section of families representing those with children, aging in youth, siblings, spouses, parents and the dually diagnosed.

Each of the Regional Family Workgroups met on a monthly basis. Members were oriented to P.L. 1995 CHAPTER 314 and the purpose and goals of the Workgroups. Members were initially asked to provide input from family members in their counties in order to define the meaning of "quality of life" for families with an ill family member. From this input, a list of "quality of life"statements was developed. Workgroups members returned to their counties and solicited comments from family members regarding their perceived barriers to achieving a satisfactory family quality of life.

In order to reach the greatest number of family members, the survey instrument was distributed to Intensive Family Support Services (IFSS) programs throughout the state through the IFSS provider organization. The IFSS programs collaborated by distributing the survey instrument to families participating in their programs. In addition the State Family Support Coordinator conducted interviews with key informants from the service provision, academic and state government arenas in order to elicit a full range of input.

The collected responses were analyzed by the Workgroup members and categorized into domains. Over the course of several months Workgroup members prioritized the identified barriers within each domain utilizing a consensus method.

The Workgroups developed the following criteria for the selection of goals for the State Family Support Plan:

1. The accomplishment of a goal will result in something occurring that has importance.
2. The goal and its results are clearly understandable.
3. The results are clearly related to the purpose of the State Family Support Plan.
4. The goal is feasible; there is a reasonable expectation that it will be accomplished.
5. Measurable change should be expected to occur within one to three years.

A decision was made to adopt a general three year time frame for each of the plans objectives in keeping with the process utilized by the State Mental Health Planning Council in the New Jersey's submission to the federal government. This method provides for greater flexibility in achieving the Plan's objectives by relying less on arbitrary time frames. This process should result in a less static plan and allow sufficient time to achieve something meaningful. It is anticipated that there will continue to be growth within the context of the Plan. As objectives are achieved they can be revised in the Coordinators yearly report.

The State Family Support Plan that follows represents the collective recommendations of the three Regional Family Workgroups as reviewed and adopted by the State Family Workgroup.

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

ACCESS: A SYSTEM RESPONSIVE TO FAMILY NEEDS

Entry into the mental health system of care is frequently a time of turbulence for consumers and family members alike. The first encounter with the symptoms of mental illness, the involvement with police and/or hospital emergency rooms can be a harrowing and confusing experience. Families and consumers are in need of guidance, understanding and support, which is often not available. The system of mental health care must ensure timely access to diagnosis and treatment through appropriate levels of care including hospitalization. To do so calls for the close coordination of the multiple systems with which a person with a serious mental may become involved. There is a need for better coordination between programs and between public and private providers. Existing services must be more closely integrated to provide a seamless delivery system. Mental health services are needed that would aggressively reach out to those in need to ensure engagement including those living at home with their family. Service provision should accommodate the predictable ups and downs of the illness process. Once a consumer has graduated from a program, they should be allowed to return if the need arises. Consumers should not have to return to the hospital to be eligible for community programs.

Families are the major source of support for persons with a serious mental illness. Coping with the mental illness of a family member places extraordinary demands on each and every member. During the initial stages of the illness families frequently struggle alone to make sense out of an incomprehensible array of symptoms. They must learn to navigate a disjointed system of care that frequently offers as many barriers to care as solutions. The responses gathered from family members suggests a widely held perception that there is a lack of knowledge concerning mental health and generic resources to assist families who are providing care for a family member with a serious mental illness in the community. In times of distress families turn to naturally occurring community supports, families, friends and religious figures such as ministers, priests and rabbis. The lack of accurate information regarding mental illness and the community support options that are available significantly diminish the role of these informal networks to provide support. Unfortunately this lack of familiarity with existing resources does not only exist with families but extends to treating professionals, particularly general practitioners and private mental health professionals. For minority populations these problems can be compounded. Services must be delivered in a culturally and linguistically competent manner, preferably by a professional of ones own race.

For many people, their initial contact with the mental health system comes during a psychiatric emergency through a designated psychiatric screening center. As a major point of entry into the mental health system, screening centers are ideally situated to not only determine a consumer's suitability for hospitalization, but to provide linkage to the wider system of mental health care.

I. GOAL - ACCESS

New Jersey will develop policies and procedures to support families who are coping with an acute serious mental illness.

Objective 1

State designated Screening Centers will ascertain the name(s) of family members providing support to the consumer being seen by the service.

Objective 2

Screening Centers will refer families who are providing support to the consumer being seen by the service to local family support organizations and Intensive Family Support Services (IFSS) program.

Objective 3

The designated statewide family advocacy organization will develop an advocacy strategy to have intensive outreach case management provided to individuals who are assessed by a designated screening center as not meeting the criteria for inpatient commitment but *who are suffering from a significantly diminished capacity to provide self care due to an acute mental illness.*

Objective 4

Develop a strategy to promote the growth of MICA expertise in professionally and family led family support groups.

OPTIMISM FOR THE FUTURE

Family members are the primary caregivers for the majority of persons with a serious mental illness. Many of these families share the common experience that these illnesses will not be resolved quickly, but rather may become lifelong conditions. Many families share the experience of their family member dropping out of or being excluded from care. Even families who are highly satisfied with the care received by their family member are acutely aware of the often fragile connection that binds their ill family member to needed services.

For families that have been the glue to keep their family member connected to needed services or who have provided for their ill family member when needed resources are not being received there is an ever present concern with what will happen to their ill family member when they are not there to provide or oversee care. A NAMI NEW JERSEY survey conducted in the year 2000 found the average age of a parent providing care to a son or daughter to be 65 years of age. Aging caretakers cannot be expected to provide care for their ill family members into the indefinite future

Of the various "burdens" that have been associated with family care giving, worry for the future appears to be the most intractable. The needs assessment conducted by the three Regional Family

Support Workgroups identified a worry regarding who will replace the care giving parent after that parent has died and a corresponding worry about the general lack of social connectedness of their ill family members as the primary future concerns of family caregivers.

Family members have expressed a desire for an organization(s) that has the ability to deliver a range of individualized services over time to consumers and has also developed credibility with family caregivers. Educational programs on future needs planning and special needs trusts have been very well received by families and should be continued throughout the state. Strategies should continue to be developed to increase the social connectedness of persons with a serious mental illness. Peer to peer outreach is a particularly attractive strategy as it also provides positive rolls for consumers to fill.

II. GOAL - OPTIMISM FOR THE FUTURE

Promote strategies to strengthen the capacity of families to provide for planned lifetime assistance to their family member with a serious mental illness.

Objective 1

The Regional Family support workgroups will collaborate with Intensive Family Support Services (IFSS) programs to develop a list of resources to assist families in future planning.

Objective 2

Increase the number of families enrolled in future planning organizations by promoting awareness of these organizations.

Objective 3

Future planning workshops will be given on an annual basis in each county by Intensive Family Support Services (IFSS) programs and/or local family support organizations

Objective 4

The designated statewide family advocacy organization will collaborate with future planning organizations to identify additional sources of funding for future planning service delivery.

HEALTH

Having a serious mental illness is associated with increased risk of cardiovascular disease, diabetes, hypotension and weight gain. Persons with a serious mental illness are three times as likely to smoke cigarettes as the general population. As the baby boom generation ages, the largest number of people with a serious mental illness are entering a stage of life when they will be experiencing an increasing number of health problems.

A psychiatrist is either the most frequently or only medical practitioner seen by many people with a serious and persistent mental illness. Because of this it is the feeling of Workgroup members that Provider Agencies funded by DMHS are in an integral position to act as primary care physicians in

the coordination of physical health care. The use of advanced practice nurses has reportedly increased the attention to the physical health care of mental health consumers on a limited basis. New Jersey is in a period of transition to managed somatic health care for Medicaid recipients. For those mental health consumers who are Medicaid recipients, there is the promise of increased access to health care, including dental, as well as medical case management. Because mental health care for these individuals remains carved out, the coordination of somatic and mental health care will require scrutiny to determine if the coordination of care has improved. In the interim strategies can be adopted that promote healthy living and that also recognize that the there is an aging consumer population in New Jersey.

III. GOAL - HEALTH

Promote the somatic health of persons with a serious mental illness.

Objective 1

Identify strategies to deliver "In Vivo" health services to consumers of mental health services who are unwilling or unable to access traditional health services.

Objective 2

Promote wellness programs that encourage exercise, weight reduction, a healthy diet and smoking cessation.

EDUCATION

The availability of accurate, timely information regarding serious mental illnesses is consistently identified as a significant barrier by families who are coping with a serious mental illness. Families first presented with a mental illness are generally ill prepared to deal with the tumult that that frequently results. Natural supports such as family, friends and religious affiliations that are generally available to families undergoing a crisis are frequently not available to families experiencing an mental illness because of a lack of knowledge concerning a mental illness, inaccurate information and stigma. Where professional supports such as educators, physicians and mental health professionals are informed about serious mental illness, too frequently there is a lack of knowledge about the range of services available to support a person with a mental illness and their family. For many families seeking help becomes a long process of trial and error.

Both family run and professionally led family support services are now available in each of New Jersey's 21 counties. Although highly regarded by family members of persons with a serious mental illness, only a portion of the families that could benefit from these services are aware of them. A dual strategy of outreach to both the general public and through the public and private mental health provider system should be expanded to ensure that all those who could benefit from a family support service are aware of them. The capacity of the system of family support to meet this need must assured.

School systems are strategically positioned to promote a better understanding of mental illness and the benefit of early intervention. The needs assessment conducted by the Family Support Working Groups suggested that there is a substantial need for the dissemination of information on mental illness to parents, students, teachers and school administrators. With nearly 600 school districts and

an additional 55 charter schools, reaching all of New Jersey's schools in a consistent manner is particularly challenging.

IV. GOAL - EDUCATION

Increase the awareness of serious mental illness on the part of children, parents, teachers and administrators in New Jersey's Public schools.

Objective 1

Determine the current curriculum standards for disseminating information on mental illness in public schools.

Objective 2

Investigate model programs for teaching about mental illness in the public schools.

Objective 3

Develop strategies to educate students and school personnel regarding mental illness

EMPLOYMENT

In today's society, one's status or worth is often correlated with one's employment or educational attainment. For persons with a serious mental illness, employment engenders a sense of self-worth that has been eroded during the course of a mental illness.

People with severe mental illnesses are both the largest and the fastest growing population within both the SSI and SSDI programs. Employment assistance is critical for people with severe mental illnesses to regain independence, dignity, and purpose. The passage of the Work Incentives Act has allowed people with disabilities to return to work while maintaining their much needed medical coverage, thus mitigating a significant barrier to employment. The number of people disabled by a serious mental illness who return to work and leave social security remains very small. While Supported Employment is highly regarded by consumers and family members, the percentage of consumers receiving this service is miniscule, less than 1% of those served by the Division of Mental Health Services. As therapeutic services must be individualized to achieve the optimum benefit, so to must rehabilitative services be based on each consumer's abilities and aspirations. It is not enough to merely place individuals in entry level service positions, employment like recovery must take into account future opportunity and growth. A wider range of employment opportunities is needed.

For many individuals the effects of a serious mental illness commence in late adolescence or early adulthood resulting in the disruption of their schooling. Being able to resume the educational process can be the first tangible step towards recovery. There is strong sentiment among consumers and family members that supportive education has been a highly effective strategy and should be expanded. The sense of accomplishment and self worth that is engendered among those who take part, make the participation for those who choose to do so, a highly desired outcome of mental health care. Because some consumers function best in individualized or small group settings, independent study can be a useful educational option.

V. GOAL - EMPLOYMENT

A vocational or educational opportunity commensurate with ones abilities and preference will be available to each consumer of publicly funded mental health services in New Jersey.

Objective 1

Promote strategies that expand individualized vocational and educational opportunities for persons with a serious mental illness.

HOUSING

Decent, safe, affordable housing for persons with a serious mental illness, when coupled with supportive services, have been associated with increased community tenure and improved quality of life. It is widely understood that housing has consistently ranked as a leading priority for consumers of mental health services and their families. However, less than 2 percent of all individuals with a mental illness in New Jersey reside in a DMHS funded residential program.

Advocates for people with disabilities are becoming more concerned about people with disabilities living with aging parents. This is particularly true for persons with a mental illness where approximately 60% of the discharged from state psychiatric hospitals are discharged to their family. An even greater number of individuals have avoided hospitalization due to the supports that have been provided by their family. Now these parents are in their 70s and 80s and community-based housing is desperately needed for their adult children.

A lack of a comprehensive understanding of the scope of the housing crisis for people with a serious mental illness in New Jersey has hindered advocacy efforts to marshal resources. The Developmental Disabilities community has done a more affective job in assessing the need for housing and implementing a plan to meet the need.

VI. GOAL - HOUSING

Identify and promote strategies to increase the availability of decent, affordable housing with supports for persons with a serious mental illness.

Objective 1

Advocate for assessing the residential needs of each individual entering a Division of Mental Health Services (DMHS) funded program.

Objective 2

Make the residential need data available to advocacy and planning bodies on the state, county and local level.

Objective 3

Advocate for creating a state funded housing priority for consumers of mental health services who are living with aging caregivers.

FINANCIAL

The economic consequences of mental illness cannot be overstated. Consumers of mental health services as a group are among the most economically disadvantaged segments of our population. Poverty exists as one of the most debilitating aspects of having a serious mental illness.

Nearly 50 percent of individuals with severe mental illnesses receive either Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI). With an average monthly SSDI benefit of $704 and SSI benefit of just over $500 a month, persons struggling with these disorders are among the lowest income households in the country. In fact, the average income of an individual on SSI is only 24 percent of the average American living on one income. New Jersey has not increased its contribution to SSI in more than 20 years. Between 85 percent and 95 percent of persons with treatable severe and persistent mental illnesses are unemployed. People with disabilities who are unable to work and must rely on entitlements such as Supplemental Security Income (SSI) can find it virtually impossible to find affordable housing. Not a single housing market area in the United States exists where a person with mental illness receiving Supplemental Security Income can afford to rent even a modest efficiency apartment. For many people with a mental illness this translates into living in substandard housing, homelessness and incarceration. Poverty has also been associated with negative healthcare outcomes and exposure to violence and abuse.

Families also deal with the economic consequence of a mental illness. Families must cope with lost wages due to an individual's inability to work or from days lost while providing care for an ill family member. Many families have expended thousands of dollars towards the care of their ill family member. Many individuals still do not have full insurance coverage for the treatment of a mental illness. New Jersey continues to have the most onerous laws in the nation in placing liens on patients of state and county psychiatric hospitals and some of their family members for the full cost of institutionalization.

Economic strategies must be included in service provision if there are to be meaningful improvement in the outcomes of mental health care.

VII. GOAL - FINANCIAL

Promote strategies to mitigate the financial hardships associated with having a serious mental illness.

Objective 1

Identify potential partners with whom to advocate for an increase in the New Jersey SSI rate.

Objective 2

Investigate the New Jersey Department of Developmental Disabilities voucher program for families.

Objective 3

Advocate for the reform of the New Jersey Statutes that require liens to be placed on individuals hospitalized at state or county psychiatric hospitals and certain members of their families.

LIESURE / SOCIAL CONNECTEDNESS

For the majority of people in the general population, family and friends provide their major source of social support. Social support describes the informal networks that people turn to in a time of need. Having a social network engenders a sense of belonging, a sense that someone cares about me and I in turn care about them. These social networks play a large part in an individual's ability to contend with an illness or the stresses of daily life. The nature of serious mental illness frequently results in the disruption of these networks leading to isolation and a diminished ability to cope. A number of consumers have spoken about the value of consumer operated drop in centers or consumer providers outreach. The ability for consumers to have reciprocity in their relationships, "to give back", can both engender a feeling of worth and also help to maintain a connection to a supportive mental health network during times of relapse.

The access to and the availability of leisure activities that are chosen by the participant enhance one's quality of life. Consumers and their family members have expressed a preference for the availability of social outlets that include consumers and outlets that are not specifically for consumers of mental health services. For family members, leisure time for caregivers is likewise important. It can significantly reduce family burden. The provision of respite services is a more complex issue than would at first seem apparent. The level of subjective comfort that families and consumers feel with the concept of respite, and the individuals and agencies providing the care, play a significant role in the utilization of respite services. A study of the conditions that would make families comfortable using respite care would be valuable.

VIII. GOAL - LIESURE / SOCIAL CONNECTEDNESS

Increase the opportunities for individuals with a mental illness to develop supportive social networks.

Objective 1

Identify best practices to create opportunities for people with a serious mental illness to become involved with activities that include people with a mental illness and people without a mental illness.

Objective 2

Determine the amount and type of respite that is being received by families caring for a relative with a mental illness in the community.

Parents with mental illness report that existing services may be largely irrelevant to their specific family needs. While the experiences of parents with mental illness are similar to those of all parents in many ways, the literature has emphasized their unique circumstances and, most commonly, their deficits and failures. Parents with mental illness must cope with reproductive issues, custody loss,

and past and present victimization, oftentimes with little or no support. They worry about the impact of their mental illness on their children but the stigma of mental illness and the pervasive assumption that parents with mental illness will fail keep many parents from seeking help. Parents with a mental illness are acutely aware that they are quite vulnerable to losing custody of their children. Once placed, maintaining relationships with children living with relatives or in foster care may be difficult. Visits may be stressful to both parent and child.

Separations may undermine parents' recoveries. Mothers with mental illness describe themselves as needing help getting their children returned to them, and in dealing with sadness about being apart from their children. Parents explain that when their parental rights are terminated, the pain never goes away. To fail as parents may be quite traumatic.

Objective 3

Investigate and report on support programs for parents with a serious mental illness who are raising children.

EMPOWERMENT/SYSTEMS ADVOCACY

Empowerment measures the ability of mental health care to enhance the capacity of consumers and family members to effect changes in their lives on both an individual and systems level. Empowerment engenders a sense of mastery that is frequently lost during the advent of a serious mental illness. Consumers and family members increasingly see a need to be able to effectively intervene at all levels of the decision making process, including increased political activism. Self-advocacy training and consumer and family lead self-help participation are viewed as empowering. Outcomes that would reflect systems empowerment would include the "meaningful" participation of consumers and family members on agency Board of Directors and mental health system deliberative bodies, as measured by the percentage of members who are consumers or family members. Additional measures of systems empowerment would include the degree to which consumers and family members are involved in the design, collection and analysis of outcome measures. Strategies that facilitate the participation of consumers and family members include scheduling meetings to accommodate their schedules, providing transportation, and providing stipends for their participation and travel.

IX. GOAL - EMPOWERMENT/SYSTEMS ADVOCACY

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 in New Jersey.

Objective 1

Develop strategies to increase the participation of family members on state, county and local planning bodies and mental health agency boards.

Objective 2

Promote methods to enhance the membership and infrastructure of family led support groups.

Objective 3

Clarify the "conflict of interest policy" for family members sitting on County Mental Health Advisory Boards.

LEGAL

Without access to community mental health treatment and other public services, people with mental illnesses are increasingly incarcerated. They have a 64% greater chance of being arrested than those who are not mentally ill committing the same offense. The US Department of Justice Statistics reports that persons with a mental illness make up approximately 16% of all inmates in federal and state prisons and county jails. Once in jail or prison, these men and women are even less likely to receive adequate treatment—both because the criminal justice system lacks the capacity to deliver comprehensive mental health services and because jail settings are the antithesis of a therapeutic environment.

When persons with mental illness or their families are confronted with the criminal justice system, the pressure and intimidation can be overwhelming. Jails and courts operate under various jurisdictions, municipal, county, state and federal. The criminal justice system(s) is multi-layered and can be confusing to those coming from the mental health system. Not only is there a lack of understanding on the part of consumers of mental health services and their families regarding the roles of probation, parole and the Intensive Supervision Program (ISP), but there is also a lack of direction or assistance in learning to negotiate the criminal justice system. Many families are unaware of the legal organizations that assist persons with a mental illness, and when they are, they find that the resources of these organizations are stretch well beyond their limits.

X. GOAL - LEGAL

Increase the capacity of families to effectively interact with the legal/criminal justice system.

Objective 1

Investigate sources of information that would serve to guide families in interacting with the legal/ criminal justice system within the Division of Mental Health Services, the Department of Corrections, the Department of Law and Public Safety and the New Jersey Judiciary.

STIGMA

Stigma is a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group. Several reasons explain why stigma is such an important consideration. It adds to the illness burden in various ways, and it may delay appropriate help seeking or terminate treatment for treatable health problems. For diseases and disorders that are highly stigmatized, the impact of the meaning of the illness may be as great a source of burden as the symptoms of the illness.

There is considerable agreement that a great deal of outreach/ public information is needed to combat the stigma faced by persons with a mental illness and their families. Inasmuch as health information and programs that aim to reach a large segment of the public must be simple, and because health policy related to stigma may be highly complex, there is less agreement on the course programs to counter stigma should take. In the effort to formulate effective strategies and public health communications, research is needed to distinguish simple and effective public health strategies from simplistic approaches that may be counterproductive. Assessment of the effects of interventions on stigma helps to distinguish effective from ineffective approaches and to guide policy.

XI. GOAL - STIGMA

To reduce the debilitating effects of stigma on the consumers of mental health services and their families by promoting the positive portrayal of persons with a serious mental illness.

Objective 1

Investigate programs that have demonstrated effectiveness in reducing stigma.

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

GOALS and OBJECTIVES

I. GOAL - ACCESS

New Jersey will develop policies and procedures to support families who are coping with an acute serious mental illness.

Objective 1
State designated Screening Centers will ascertain the name(s) of family members providing support in the community to the consumer being seen by the service.

Objective 2
Screening Centers will refer families who are providing support in the community to local family support organizations and Intensive Family Support Services (IFSS) program.

Objective 3
The family support organization will develop an advocacy strategy to have intensive outreach case management provided to individuals who are assessed by a designated screening center as not meeting the criteria for inpatient commitment but *who are suffering from a significantly diminished capacity to provide self care due to an acute mental illness.*

Objective 4
Develop a strategy to promote the growth of MICA expertise in professionally and family led family support groups.

II. GOAL - OPTIMISM FOR THE FUTURE

Promote strategies to strengthen the capacity of families to provide for planned lifetime assistance to their family member with a serious mental illness.

Objective 1
The Regional Family support workgroups will collaborate with Intensive Family Support Services (IFSS) programs to develop a list of resources to assist families in future planning.

Objective 2
Increase the number of families enrolled in future planning organizations by promoting awareness of these organizations.

GOAL - OPTIMISM FOR THE FUTURE (continued)

Objective 3
Future planning workshops will be given on an annual basis in each county by Intensive Family Support Services (IFSS) programs and/or local family support organizations.

Objective 4
The designated family support organization will collaborate with future planning organizations to identify additional sources of funding for future planning service delivery

III. GOAL - HEALTH

Promote the somatic health of persons with a serious mental illness.

Objective 1
Identify strategies to deliver "In Vivo" health services to consumers of mental health services who are unwilling or unable to access traditional health services.

Objective 2
Promote wellness programs that encourage exercise, weight reduction, a healthy diet and smoking cessation.

IV. GOAL - EDUCATION

Increase the awareness of serious mental illness on the part of children, parents, teachers and administrators in New Jersey's Public schools.

Objective 1
Determine the current curriculum standards for disseminating information on mental illness in public schools.

Objective 2
Investigate model programs for teaching about mental illness in the public schools.

Objective 3
Develop strategies to educate students and school personnel regarding mental illness

V. GOAL - EMPLOYMENT

A vocational or educational opportunity commensurate with ones abilities and preference will be available to each consumer of publicly funded mental health services in New Jersey.

Objective 1
Promote strategies that expand individualized vocational and educational opportunities for persons with a serious mental illness.

VI. GOAL - HOUSING

Identify and promote strategies to increase the availability of decent, affordable housing with supports for persons with a serious mental illness.

Objective 1
Advocate for assessing the residential needs of each individual entering a Division of Mental Health Services (DMHS) funded program.

Objective 2
Make the residential need data available to advocacy and planning bodies on the state, county and local level.

Objective 3
Advocate for creating a state funded housing priority for consumers of mental health services who are living with aging caregivers.

VII. GOAL - FINANCIAL

Promote strategies to mitigate the financial hardships associated with having a serious mental illness.

Objective 1
Identify potential partners with whom to advocate for an increase in the New Jersey SSI rate.

Objective 2
Investigate the New Jersey Department of Developmental Disabilities voucher program for families.

Objective 3
Advocate for the reform of the New Jersey Statutes that require liens to be placed on individuals hospitalized at state or county psychiatric hospitals and certain members of their families.

VIII. GOAL - LIESURE / SOCIAL CONNECTEDNESS

Increase the opportunities for individuals with a mental illness to develop supportive social networks.

Objective 1
Identify best practices to create opportunities for people with a serious mental illness to become involved with activities that include people with a mental illness and people without a mental illness.

GOAL - LIESURE / SOCIAL CONNECTEDNESS (continued)

Objective 2
Determine the amount and type of respite that is being that is being received by families caring for a relative with a mental illness in the community.

Objective 3

Investigate support programs for parents with a serious mentalm9illness raising children.

IX. GOAL - EMPOWERMENT/SYSTEMS ADVOCACY

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 in New Jersey.

Objective 1
Develop strategies to increase the participation of family members on state, county and local planning bodies and mental health agency boards.

Objective 2
Promote methods to enhance the membership and infra structure of family led support groups.

Objective 3
Clarify the "conflict of interest policy" for family members sitting on County Mental Health Advisory Boards.

X. GOAL - LEGAL

Increase the capacity of families to effectively interact with the legal/criminal justice system.

Objective 1
Investigate sources of information that would serve to guide families in interacting with the legal/ criminal justice system within the Division of Mental Health Services, the Department of Corrections, the Department of Law and Public Safety and the New Jersey Judiciary.

XI. GOAL - STIGMA

To reduce the debilitating effects of stigma on the consumers of mental health services and their families by promoting the positive portrayal of persons with a serious mental illness.

Objective 1
Investigate programs that have demonstrated effectiveness in reducing stigma.

BARRIERS TO ACHIEVING
A SATISFACTORY QUALITY OF LIFE

BARRIERS TO A SYSTEM RESPONSIVE TO FAMILY NEEDS:

- Frequent changes of treatment staff, high case loads.
- Lack of programs for "higher functioning" consumers.
- Confusing and restrictive eligibility criteria for programs.
- Program waiting lists or lack of availability.
- Confidentiality that frequently appears to be a "shield" for the agency/hospital rather than for the benefit of the consumer.
- Lack of support from extended family.
- Lack of MICA programs.
- Consumers diverted into the criminal justice system due to lack of MH & MICA programs.
- Lack of information and publicity about available programs and supports.
- System does not respond unless there is an emergency.
- Denial on the part of consumers.
- Lack of integration among police, hospitals (stays too short) and treatment programs result in many consumers falling between the cracks.

BARRIERS TO OPTIMISM FOR THE FUTURE:

- Who will care for consumer when the parents are gone?
- Lack of social connectedness of the consumer, job, friends, mate.
- Need for more long-term programs that will keep a consumer connected to appropriate treatment.
- Lack of treatment responsiveness.
- History has shown that there will be relapses that disconnect the consumer from treatment. Only family members are there to pick up the pieces.
- Ongoing stigma.
- Consumer's lack of financial resources, poverty.
- Lack of a clear assessment of consumer's abilities.
- Patients in the community have no role except as patients.
- Lack of access to meaningful employment.
- Denial on the part of consumers
- Safe, affordable housing.

BARRIERS TO EDUCATION:

- Lack of knowledge of available programs.
- Negative symptoms of mental illness, lack of motivation.
- Need more college and job training programs tailored to people with a mental illness.

BARRIERS TO EDUCATION (continued)

- Lack of financial resources.
- Lack of transportation.
- Lack of knowledge/understanding on the part of school personnel regarding mental illness.
- Lack of supports for education, tutors, counselor etc.

BARRIERS TO LIESURE:

- Sometimes can't leave consumer alone because of illness. No vacations.
- Illness takes away the 'joy for life".
- Lack of transportation.
- "What leisure!"
- Consumers, especially in hospitals, are left to sit around. There are few recreational programs or social groups.
- Lack of money.
- Activities for consumers are often demeaning.
- Few activities on the weekend.

LEGAL BARRIERS:

- How to get needed treatment and maintain the consumer's human rights?
- Lack of a comprehensive system to divert people with a mental illness from jail.
- Lack of responsiveness of the criminal justice system to family caretakers.
- Legal assistance programs for the poor and those with a mental illness are overwhelmed and under funded, especially in South Jersey.
- Legal services are frequently unavailable to caretakers.
- Need for low cost consultation.
- Lack of understanding on the part of police and the courts of those with a mental illness.
- Exclusion of family caretakers from decision making and planning.
- Adequate representation in custody hearings.

FINANCIAL BARRIERS:

- Cannot work, need to be a caretaker.
- Social security payments are well below the poverty level.
- Lack of access to appropriate and supported employment.
- Lack of child support for the children of a person with a mental illness.
- The two year wait for Medicare.
- Liens for psychiatric hospitalization in state and county hospitals.
- The cost to families of paying for a consumers expenses when they are not covered by a government program (i.e. medication, rent, car, insurance etc.).
- Denial of an illness makes a consumer ineligible for benefits.
- High cost of living in NJ.

FINANCIAL BARRIERS (continued)

- Entitlement disincentives to working.
- Shortage of rental assistance.
- Many doctors and psychiatrists do not accept Medicaid and Medicare.
- The cost of a catastrophic illness in medical and/or other bills.

RESIDENCE BARRIERS

- Scarcity of suitable, affordable housing
- Need supportive services so consumer can live independently, permanently
- Caretakers cannot move away from ill relative
- Residences are too expensive
- How to find out what is available?
- Need someone to assist in having consumer move out on his own
- Long waiting lists for residential programs and rental assistance
- Lack of transportation limits potential residences
- Hard to find apartments where the rent qualifies for rental assistance
- Many places that qualify for "low income" are dirty and run down
- No assisted living option for people with a mental illness
- Stigma and nimbyism
- Very little housing for people who also have physical health needs
- Lack of supports for caretakers with an ill relative at home
- Lack of group homes for those who need the structure
- Who takes care of the home and bills when the consumer is ill.

HEALTH BARRIERS

- Poor self care, especially with those abusing drugs and alcohol
- Lack of attention by mental health programs to physical health
- Increasing age of caretakers and consumers
- Some mental illnesses are not responsive to treatment
- Unavailability of affordable dental care
- Lack of choice with doctors who accept Medicaid
- The stress/burden of care taking is causing health problems.
- Heavy smoking
- Frequent misdiagnosis
- Family must pay out of pocket to get good care
- Self medicating
- Lack of parity with medicare
- More knowledge of resources needed
- Doctors often don't want to or are unable to deal with a patient with a mental illness
- Needs in-home assistance taking medication or with physical health care
- Expensive medication
- Difficulty in making a differential diagnosis, are ailments psychosomatic?
- Insurance companies seeking to limit coverage
- Weight gains with psycho tropic medications

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