

NEW JERSEY STATE FAMILY SUPPORT PLAN



For FAMILIES of PERSONS With a SERIOUS MENTAL ILLNESS

June 2016

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

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ACKNOWLEDGEMENT

In memory of

Ed Von Lindern

Donald Saull



Whose selfless dedication to the ideals of family support for those affected by a mental illness serves as a model for those who follow in their footsteps

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INTRODUCTION

In 1996 Governor Christine Whitman signed landmark legislation into law for family caregivers, The Family Support for the Families for Persons with a Serious Mental Illness Act, PL1995, C. 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. NAMI NEW JERSEY was designated to administer the program through a coordinator. 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 are 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 in the state.

The 2016 Plan is the fourth such plan to be adopted. Through presentations to the leadership of the New Jersey Division of Mental Health and Addiction Services (DMHAS), county mental health departments and additional stakeholders the Plan serves as a map to guide the mental health system on the concerns of families dealing with a mental illness. It 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 and additionally has served to forge a partnership with members of the mental health community in supporting families in their vital caretaking role.

METHOD

In the course of surveying family members for their need for family support over the past twenty years, the collected responses have taken on a pattern that allowed them to be categorized into a number of life domains. From these domains a survey instrument was developed in order to elicit barriers that family members found in achieving a satisfactory quality of life in each of these areas during the course of caring for a family member with a serious mental illness. Surveys were distributed to family members through NAMI New Jersey groups and Intensive Family Support Services (IFSS) programs, professional led programs funded through DMHAS.

Family Support Workgroup members met over the course of several months to review and through a consensus process prioritize the barriers that were identified by the survey. The workgroups then developed goals and action steps to address the prioritized barriers.

The Family Support for the Families of Persons with a Serious Mental Illness Plan

As recently as four decades ago, most individuals with a serious mental illness would have resided in state psychiatric hospitals, some staying their entire lives. Today family caregivers play a critical role in our health and long term care system by providing a significant proportion of the care for both the chronically ill and aging. This is nowhere more true than in our system of mental health care in New Jersey where estimates of people with a mental illness living at home with their family range from 27% to 62% depending on the length of time from a discharge from a psychiatric hospital. Family members assume roles they had not anticipated because the illness often demands that someone acts as a case manager, a medication monitor, a financial planner and a housing coordinator. Generally, that "someone" is a relative of the patient. Family members are a critical and hard to duplicate resource.

Because family members of people with serious mental illnesses also experience ignorance and stigma, as well as the difficulties of caring for a loved one, self-help support groups are a key resource to help them cope. Families need information about mental illness and its treatment, the mental health system, providing care to their family member, community resources, and how to cope with, and adapt to, their relative's needs and circumstances.

Family members are also successful advocates for improved treatment, increased funding, and ongoing research and education initiatives designed to improve the lives of all people with serious mental illnesses. Many advocates believe that recovery involves the nurturing of relationships with families to take advantage of natural community and supports. It should therefore be a guiding principle that the family members of the person with a mental illness should be involved and engaged in a collaborative treatment process to the greatest extent possible.

Access to Services

People with serious mental illnesses and their families face significant access barriers to health and mental health care services. These include knowing where to find services, what services are available, long waiting lists for services, difficulty scheduling and maintaining appointments and the overuse and misapplication of the HIPAA privacy law.

One of the most difficult barriers for people with serious mental illnesses is a lack of coordination among the many community programs and services designed to meet their multiple and complex needs. People with serious mental illnesses require a broad range of housing, health and mental health care, and social services, all of which typically are handled by separate agencies. The burden of coordination for many falls on the family members, but fragmented services are difficult for family members to negotiate and especially for individuals with serious mental illnesses to negotiate unaided. Though outreach is now considered to be a key element in an integrated system of care for people with serious mental illnesses, especially those who are homeless or at risk of homelessness, the availability of these programs is limited both in number and duration of service.

A SYSTEM RESPONSIVE TO FAMILY NEEDS

GOAL: Welcome and Discharge Packets containing information on Mental Health and Substance Use treatment resources, entitlements and mutual support organizations will be distributed to consumers and their families upon admission and discharge from all DMHAS licensed programs.

ACTION STEPS

- Promote the development of Welcome and Discharge Packets during Division of Mental Health and Addictions Services (DMHAS) Family Monitoring Workgroup.
- Local NAMI groups, IFSS programs and family advocates will work with county mental health boards to promote welcome and discharge packets in local psychiatric hospitals.

OPTIMISM FOR THE FUTURE

People living with mental illness need their family, friends, and professionals to remain optimistic and to nurture the belief that recovery is possible - particularly when they are ill and their situation feels most bleak. Recovery in this context does not mean ‘cure’ but being able to achieve ones full potential beyond the limitations of illness. Families know that hope is critical to recovery, but they can lose optimism in the face of repeated illness and its losses. At times of crisis when the support of the mental health system is most crucial, consumers may become disengaged from service providers as a result of their symptoms or “noncompliance”. This experience causes families to worry more about their loved one and the possible recurrence of illness, adherence to treatment, social isolation, and who will play the role of the family as case manager when families are no longer alive to “pick up the pieces”. As a result, the mental, emotional, and physical health of the family suffers. Their dreams and hopes for the future may be shaken and the quality of life of the family may slip away.

Reforming a system of care that remains episodic and crisis oriented to one that comprehensively engages in lifetime or future planning remains an elusive goal. In the interim families could benefit from better knowledge and connections to those long term entitlements that could support individuals with a mental illness over their lifetime.

GOAL: Develop informational material on programs and entitlements that offer long term support to individuals with a mental illness.

ACTION STEPS

- Regional Family Support Workgroups will compile existing material on programs and entitlements that offer long term supports.
- The Family Support Coordinator will elicit support from DMHAS to make the collected information available to the public.

EDUCATION

The onset of mental illness most commonly occurs during the ages when young people are beginning to develop their adult roles. During this time, they are completing their education that prepares them to work, developing relationships that create a social network, and learning their rights and responsibilities within their communities. The onset of a mental illness disrupts this process. Once disrupted, it is very difficult to resume. For many however the path to recovery involves resuming one's education. Through supported education programs and the educational accommodations that are now available to individuals with a mental illness as a result of the Americans with a Disabilities Act (ADA) there has been increases in educational program participation by students with a mental illness and in competitive employment.

GOAL: Develop a resource guide to educational accommodations for individuals with a mental illness.

ACTION STEPS

- Regional Family Support Workgroups in collaboration with other advocacy groups will compile existing material on educational accommodations for individuals with a mental illness.
- The Family Support Coordinator will elicit support from DMHAS and the Children's System of Care (CSOC) to make the collected information available to the public.

LEISURE

Social relationships are important for anyone in maintaining health, but for people with a mental illness it is especially important. The stigma associated with mental illness however creates huge barriers to socialization. Persons with mental illness may experience social isolation as a symptom of their mental illness. Social isolation can be both a cause and an effect of mental illness. As a result it is the families of people with mental illness that often provide the most continuous and enduring sources of support. Families report that due to a lack of appropriate social outlets for their family member that the responsibility for finding social/recreational outlets for their family member frequently falls entirely on them.

GOAL: Promote closer collaboration between local family support organizations and consumer self-help/wellness centers in order to foster increased social opportunities for consumers and families.

ACTION STEPS

- Promote an annual planning meeting between county based family support organizations and consumer self-help/wellness centers.

- County based family support organizations and consumer self-help/wellness centers will develop an annual schedule of increased social opportunities for consumers and families.

LEGAL

In a mental health crisis, people are more likely to encounter police than get medical help. As a result, 2 million people with mental illness are booked into jails each year. Nearly 15% of men and 30% of women booked into jails have a serious mental health condition. The vast majority of the individuals are not violent criminals—most people in jails are have not yet gone to trial, so they are not yet convicted of a crime. The rest are serving short sentences for minor crimes.

Once in jail, many individuals don't receive the treatment they need and end up getting worse, not better. They stay longer than their counterparts without mental illness. They are at risk of victimization and often their mental health conditions get worse.

After leaving jail, many no longer have access to needed healthcare and benefits. A criminal record often makes it hard for individuals to get a job or housing. Many individuals, especially without access to mental health services and supports, wind up homeless, in emergency rooms and often re-arrested. At least 83% of jail inmates with a mental illness did not have access to needed treatment. (NAMI)

GOAL: Through local, state and Federal advocacy, promote the growth of programs that divert individuals with a mental illness from the legal system to appropriate treatment.

ACTION STEPS

- Workgroup members will identify programs that divert individuals with a mental illness from the legal system to appropriate treatment in their county
- Workgroup members will join in local and statewide groups advocating for the growth of programs that divert individuals with a mental illness from the legal system to appropriate treatment.

FINANCIAL

People with mental illness often live in chronic poverty. A NAMI New Jersey survey found that 86% of the respondents had an annual income that was lower than the Council on Affordable Housing (COAH) very low income guideline, 30 percent or less of the county median income. Many people with a mental illness therefore rely on social security as their primary source of income yet these rates are significantly lower than what is needed to cover the cost of basic necessities, such as food, clothing, and housing. The average rent for a studio apartment in New Jersey is 136 percent of the average Supplemental Security Income (SSI) payment, making housing unaffordable for adults living with serious mental illness who rely on SSI.

Some States supplement the Federal SSI benefit with additional payments. This makes the total SSI benefit levels higher in those States. The amount of the state supplement ranges from \$10 to \$200, depending on the state. In New Jersey, the state with the nation's 42nd highest cost of living, the state supplement is \$31.25. Neighboring New York adds \$87 a month or an additional \$669 a year.

GOAL: Identify and provide support to organizations and coalitions that are advocating for an increase in the New Jersey Social Security subsidy.

ACTION STEPS

- Workgroup members will identify organizations and coalitions that are advocating for an increase in the New Jersey Social Security subsidy.
- Workgroup members will report to their Workgroup on the efforts of organizations and coalitions that are advocating for an increase in the New Jersey Social Security subsidy.
- Efforts of organizations and coalitions to advocate for an increase in the New Jersey Social Security subsidy will be brought to the statewide family advocacy organization for its support by the Family Support Coordinator.

EMPLOYMENT

No single social activity conveys more of a sense of self-worth and identity than work. For people with a serious mental illness, employment is an important stepping-stone to recovery. Employment not only provides a paycheck, but also a sense of purpose, opportunities to learn and a chance to work with others. Most importantly, work offers hope, which is vital to recovery from mental illness.

Individuals with a mental illness are a diverse group of people, with a wide range of talents and abilities. For too long employment services for people with a mental illness involved segregated settings or training on menial tasks. In contrast, today there is supported employment an evidence-based practice that helps people with mental illness work in jobs that pay competitive wages in integrated settings in the community. Rather than promoting extensive prevocational training, supported employment helps people find jobs that align with their interests and strengths.

The enthusiasm for the many new developments in the field of supported employment is tempered by a general lack of awareness regarding these programs, their limited availability and the lack of public understanding of government incentives for returning to the workforce.

GOAL: Advocate for increased availability of supported employment programs that are able to match employment opportunities to the abilities of individual consumers.

ACTION STEPS

- The Coordinator will request that the Department of Psychiatric Rehabilitation and Counseling Professions at the Rutgers - School of Health Related Professions provide information on supported employment programs that are able to match employment opportunities to the abilities of individual consumers.
- The Family Support Workgroups will work in coalition with the Mental Health Coalition Advocate for increased availability of supported employment programs that are able to match employment opportunities to the abilities of individual consumers.

RESIDENCE

The lack of Affordable Housing that is appropriate, accessible, and affordable has been considered by family members to be the number one barrier to successful community living for people with serious mental illnesses. In addition, housing subsidies, a key to helping people with serious mental illnesses maintain residential stability, are in short supply. As a result, many people for whom SSI is their only source of income are forced to live in overcrowded and often substandard living environments that place them at physical and emotional risk. Others are living with aging parents or relatives, many of whom are also living on fixed, low incomes.

Through the Affordable Care Act New Jersey is drawing down a considerable amount of federal dollars to provide Community Support Services to provide supportive services for individuals in the community. Although this has great promise, the availability of housing for individuals on an SSI income is extremely limited due to New Jersey being the fifth most expensive state in the U.S. for renters. The fair market rent for an efficiency apartment in New Jersey is equal to 129% of an SSI income in the state.

New Jersey's Olmstead initiative has demonstrated that coupling rental assistance with supportive mental health services has proven to be successful and sustainable strategy for overcoming the barrier of affordability.

GOAL: Encourage families to lend their support to organizations advocating for increasing the number of housing vouchers that are available to people living with a mental illness.

ACTION STEPS

- The Family Support Workgroups will identify organizations advocating for increasing the number of housing vouchers that are available to people living with a mental illness.
- The Family Support Workgroups through the coordinator will promote advocacy efforts by making information available to family support groups and programs on advocacy initiatives to increase the number of housing vouchers that are available to people living with a mental illness.

HEALTH

The 1999 Surgeon General's report on mental health recognized "the inextricably intertwined relationship" between mental health and physical health. This has gained increased attention as studies have shown that individuals with a serious mental illness have both shorter life spans and are more likely to have comorbid medical conditions than the general population. Barriers to people with a mental illness receiving appropriate health care include the limited number of physicians who accept Medicaid, stigma towards these individuals, limited self-care ability and lack of transportation.

While best evidence-based practices for the prevention and diagnosis of medical conditions among people with mental illness such as Behavioral Health Homes are being developed in New Jersey, families seek the full integration of health and mental health care. This entails that screening for mental and physical health disorders be standard operations in general medical and mental health specialty practices so that conditions can be detected early and care provided in ways convenient and accessible to those in need.

GOAL: Advocate for the expansion of programs that integrate physical and mental health care.

ACTION STEPS

- Develop an overview of approaches to integrating physical and mental health care.
- Identify advocacy and planning bodies that are able to promote integrated physical and mental health care.
- Identify, monitor and provide advocacy on legislative and regulatory measures that promote integrated physical and mental health care.

STIGMA

Over 60 million Americans are thought to experience mental illness in a given year, and the impacts of mental illness are undoubtedly felt by millions more in the form of family members, friends, and coworkers. Despite the availability of effective evidence-based treatment, only about 40% of individuals with serious mental illness receive care and many who begin an intervention fail to complete it.

The desire to avoid public stigma causes individuals to drop out of treatment or avoid it entirely for fear of being associated with negative stereotypes. Stigma can also affect those closest to individuals with mental illness, including family, and caregivers. Families may be blamed, feared or shunned because of their connection with their relative. In many instances stigma inhibits people from receiving the natural supports on which they would rely under other circumstances causing them to become socially isolated.

Stigma makes it difficult for people affected by serious mental illnesses to find housing and jobs, maintain social networks, and become accepted in their communities. In addition, stigma

surrounding serious mental illnesses negatively affects the public's willingness to pay for services and treatment.

GOAL: Raise the public awareness of the deleterious effect of stigma towards those with a mental illness by promoting anti-stigma coalitions throughout the state.

ACTION STEPS

- Identify anti-stigma efforts that are taking place in New Jersey
- The Family Support Workgroups working in coalition with other like-minded groups will promote the various anti-stigma activities taking part in the state.

OTHER - Shortage of culturally/linguistically competent services

New Jersey is a one of the top 3 most diverse states in the US with respect to racial/ethnic and foreign born populations. In 2011, racial/ethnic minorities made up over one-third (44 percent) of the total estimated population of New Jersey. This rich diversity presents a challenge to health professionals. In general, racial/ethnic minorities are less likely to seek professional help for behavioral health issues than white, native born population. Diverse populations bring different attitudes, expectations, beliefs and communication styles to each health encounter. Health professionals must be sensitive to these complex issues if they are to be successful. In the health care setting, this can require organizational change as well as more skilled one-on-one patient interactions.

GOAL: As a part of a Division of Mental Health and Addictions Services (DMHAS) review, agencies will demonstrate that interpreters are available, linguistically proficient and trained to work in the mental health field.

ACTION STEPS

- In meetings with DMHAS the workgroup members and the coordinator will advocate for regulations that require that the agencies with which DMHAS contracts/licenses demonstrate that interpreters who are linguistically proficient and trained to work in the mental health field are available to consumers and their family members.

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

GOALS and OBJECTIVES

A SYSTEM RESPONSIVE TO FAMILY NEEDS

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FAMILY SUPPORT WORKGROUPS

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