Family Support
For Families of Persons With
A Serious Mental Illness

2012 New Jersey State Plan

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

Elizabeth Golden
David MacLean
Eileen Santoro

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

Families fulfill a vital role in the planning and development of mental health services for consumers, their family members and significant others in New Jersey. The New Jersey Division of Mental Health and Addiction Services (DMHAS) has designated the New Jersey Chapter of the National Alliance on Mental Illness (NAMI New Jersey) to administer *The Family Support for Families of Persons with a Serious Mental Illness Act, P.L. 1995, Chapter 314.* This Act establishes 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. Through the Act one statewide and three regional family working groups are established. The coordinator in conjunction with the three regional family working groups and the Statewide family working groups adopt, review and revise as needed, a State Family Support Services Plan for Families of Persons with a Serious Mental Illness.

Through Regional Family Support Workgroups, members solicited feedback from family caregivers across nine domains on the barriers faced by families in providing support for their family member in the community. Workgroup members then prioritised the collected responses from which goal statements and action steps were developed.

The following State Family Support Plan for Persons with a Serious Mental Illness is the fourth such plan to be submitted to DMHAS. Because families have been the essential cohesive element in our system of mental health care, this plan with the cooperation of DMHAS, will serve a vital role in informing the transformation of New Jersey’s mental health system to one that is wellness and recovery oriented.

FAMILY SUPPORT

The New Jersey Chapter of the National Alliance on Mental Illness (NAMI New Jersey) along with 19 county affiliates provides a variety of services to support family caregivers including: education; mutual support; systems advocacy and referral services. It is contracted with the New Jersey Division of Mental Health and Addiction Services (DMHAS) additionally to these services to four separate ethnic groups through the following programs: Family to Family en Español, South Asian Mental Health Awareness in New Jersey (SAMHAJ), Chinese American Mental Health Outreach Program (CAMHOP), and the African American Community Takes New Outreach Worldwide (AACTNOW!). NAMI Basics is an education program for parents and other caregivers of children and adolescents living with mental illnesses.

The NAMI NEW JERSEY Family to Family Education course is a 12-week program for families of individuals diagnosed with serious mental illness. The curriculum focuses on the major biologically based psychiatric illnesses and emphasizes the clinical treatment of these illnesses. The curriculum also presents the knowledge and the skills that family members need when faced with the problems of mental illness. The course is now also offered to the families of veterans coping with a mental illness.
Intensive Family Support Services (IFSS) has provided professional supports to families since the first eight programs began in 1990. IFSS programs now exist in each of New Jersey’s twenty-one counties. IFSS offers a range of supportive activities designed to improve the quality of life for families with a mentally ill relative. Family members and professionals work collaboratively to provide each family with the knowledge, skills and supports they identify as useful to the family's overall functioning and sense of control.

Individual outpatient programs in the state offer support groups for family members of persons with a mental illness. The Mental Health Association of Passaic County has the Consumer Parent Support Network that works with parents with mental health issues who have children.

New Jersey’s Division of Child Behavioral Health Services within the Department of Children and Families provides funds and/or contracts for services for children and adolescents with serious emotional and behavioral disturbances and their families including parent run family support. Family Support Organizations (FSO) provide direct peer support and assistance to families of children by family members of children with behavioral, emotional and mental health challenges.
2012 STATE FAMILY SUPPORT PLAN

GOALS and ACTION STEPS

A SYSTEM RESPONSIVE TO FAMILY NEEDS

The lack of information and understanding of mental health conditions and services continues to be a major barrier to accessing care. People with mental illness may require a variety of mental health, housing and employment services as well as the support of government entitlement programs. To families experiencing the upheaval of the onset of mental illness the disjointed nature of the “mental health system” can present an impenetrable maze leaving them angry, frustrated and without the care their family members need. Families report existing programs are full or that they are turned away because their family member does not meet rigid admissions criteria. It is not uncommon for families to spend years in treatment with private practitioners without ever being aware of the services that may be available through the public mental health system. There is consensus on the need for more bilingual and bicultural providers and service provision. Above all, families felt that to successfully navigate the system required a persistent, well informed family member working on the consumer’s behalf.

GOAL 1

Promote the availability of information on mental health resources through web based and written resource manuals.
1. Three county-specific resource guides for persons with a mental illness will be developed
2. Provide training to grassroots groups on web based and social networking platforms for information sharing.

Due to the stigma associated with mental illness the privacy of treatment information has traditionally been closely guarded. The passage of the Health Insurance Portability and Accountability Act (HIPAA) in 1996 provides federal protections for personal health information held by covered entities and gives patients an array of rights with respect to that information. At the same time, the Privacy Rule is balanced so that it permits the disclosure of personal health information needed for patient care and other important purposes.

Many providers do not understand the law, have not trained their staff members to apply it judiciously, or are fearful of the threat of fines and jail terms. The law itself says that

health care providers may share information with others unless the patient objects, but does not require them to do so. Disclosures are voluntary and health care providers are left with broad discretion. Families have consistently reported that many health care providers apply HIPAA regulations overzealously, leaving family members and caretakers stymied in their efforts to play a supportive role in their family member’s recovery.

GOAL 2

*Educate providers and families regarding HIPAA and Family Involvement.*

1. Five presentations on HIPAA and family involvement will be made in each of the next three years.
2. Partnerships will be developed with provider agencies to bring accurate information on HIPAA and family involvement to mental health professionals.

OPTIMISM FOR THE FUTURE

As the population ages, concerns mount regarding the future of adult children with serious mental illness who will continue to require financial oversight and medical/mental health care and planning. Many caregivers are aging; and many have been the primary caregivers of their adult children for the entirety or greater portion of their own adulthood.

The Primary concern for these caregivers are the provision of a safe, secure environment and the level of support needed to assure that those with a mental illness have a high quality of life long after family members are no longer there to provide it. The increase in consumers who live on their own or in supported living situations is welcomed; but has also contributed to the concern of many families about the assurance of appropriate long-term care.

Families are aware of the shortage of appropriate clinical outpatient programs, residential housing, vocational programs and support services that are available. In addition the episodic nature of a mental illness can jeopardize a consumer’s standing in these programs. Far too many consumers are discharged from mental health programs when their illnesses become acute. For aging parents the main issue is; Who will maintain contact with their family member and see that they are connected to appropriate mental health and supportive services should the need arise after they are gone?

To its credit New Jersey has a commitment to provide highly innovative and effective consumer and family operated services, supports and interventions. Recovery coaches work with individuals to provide outreach, long-term support and linkage to professional treatment. The Peer Recovery WarmLine is a peer-run service providing ongoing telephone support to mental health consumers as they work towards their recovery. NAMI Connection (Consumer Support Groups) is a weekly recovery support group for people living with mental illness in which people learn from each others’ experiences, share coping strategies, and offer each other encouragement and understanding. These
provide non-stigmatizing environments where individuals can share a common concern or similar life experience. They offer outreach to persons who may need additional support and services in a non-stigmatizing and cost effective manner. CONTACT, in various parts of the state, provides a free daily outreach service to senior citizens who live alone. REASSURANCE Volunteers phone clients once each day to check on their well-being.

Programs such as these offer examples of low intensity methods of maintaining connections to individuals with a mental illness living independently in the community. They are respectful of a consumer’s autonomy while at the same time offering a “lifeline” to professional services should the need arise.

**GOAL**

*Advocate for the expansion of peer and family networks that foster long term connections to supportive networks for individuals with a mental illness.*

1. Develop a network of constituency groups who are interested in this issue. Year one
2. In conjunction with allies, develop a position paper on “low intensity long term supports” for persons with a mental illness. Year two
3. Advocate for the adoption of the policy position. Year three

**EDUCATION**

The transition from high school to college; and from adolescence to legal adulthood, can be problematic for any teenager. Late adolescence or young adulthood is a time when major psychiatric disorders commonly begin. For the increasing number of young people who arrive on campus with diagnoses of serious mental disorders the passage can be particularly disconcerting. For parents, the anxious pride at seeing children go off to college is often tinged with fear that their child might fall apart, spiraling into mental illness.

For many consumers the process of establishing a healthy life includes the pursuit of formal higher education. Higher education is a socially accepted means by which we pursue our life goals and meaningfully participate as productive members in society. Yet, individuals with mental illness may have difficulty accessing and completing post-secondary education.

While universities grapple with how to serve the growing number of students with mental disorders, students are taking the initiative by helping one another. The National Alliance on Mental Illness has 30 campus affiliates, with 18 more in formation, groups that are set up as student clubs and are financed by school activity budgets and fund-raisers. Active Minds, a student-led mental health advocacy organization founded in 2001 at the University of Pennsylvania, now has 56 chapters at schools nationwide.
Effective and coordinated programs are needed to support the aspirations of consumers for further education. Families and consumers are often unaware of federal and state laws, regulations and programs that can support individuals in entering or resuming higher education. A comprehensive and accessible source of information is needed to support people who want to pursue education.

**GOAL**

*Develop a guide to resources on educational accommodations for mental illness*

1. Conduct a survey of existing material on educational accommodations  
   Year one
2. Assimilate the results for an attorney’s review  
   Year two
3. Publish and distribute a guide  
   Year three

**LEISURE**

Recreation and leisure are a vital to wellness and essential ingredient to recovery. Like anyone else, persons who have serious mental illnesses need a sense of belonging and a feeling of satisfaction with their lives. Recreational and leisure involvement promotes health by providing a buffer for stress and creating a sense of balance.

Many people with a serious mental illness however experience difficulty in developing and maintaining social relationships outside of the contact they have with professionals and family members. Their interactions with others can be quite limited; and as a result, many report spending the majority of time alone.

Just as such individuals may benefit from a job/work coach, they may also benefit from leisure coaching or recreation groups that would help them identify and explore personal interests. Such activities could help individuals develop or refine skills needed to pursue personal interests, and locate community resources that support their involvement in community recreation. Most importantly, this could help remove barriers to participation in community and social life. These programs may be nontraditional. Support can be provided by non-professionals such as by community volunteers or by members of self-help, mutual support, or consumer-run programs. The use of these natural supports may also be more mutual and normalizing, less expensive, and lead to greater community integration than social skills programs provided by rehabilitation professionals.

**GOAL**

*Compile “promising practices” in the provision of leisure activities for consumers of mental health services.***

1. Conduct a survey among NAMI groups  
   Year one
2. Conduct a survey among Intensive Family Support Services Programs  
   Year two
3. Conduct a survey among Self-help centers  
   Year three
LEGAL

Persons with serious mental illness are overrepresented in America’s criminal justice system. Police are increasingly becoming front-line respondents to people with severe mental illnesses who experience a crisis in the community. Police are usually the first and often the only community resource called on to respond to crisis situations involving persons with mental illness. As a result, officers are expected to act as the primary gatekeepers for both the criminal justice and mental health systems. They must either recognize an individual’s need for treatment and divert that person to an appropriate mental health facility; or make the determination that the individual's unlawful activity is the primary concern and that the person should be arrested. Yet some officers in New Jersey may have received as little as two hours of training on individuals with “special needs” only a portion of which may cover mental illness.

Programs such as the NAMI New Jersey Law Enforcement Education Program and Crisis Intervention Training (CIT) have shown considerable promise in New Jersey. However, there continues to be strong sentiment among family members that education about mental illness must be expanded to all levels of the judicial and legal systems. Judges, lawyers, police officers, correctional officers, parole and probation officers, law enforcement personnel, court officers, and emergency medical transport and service personnel should be required to complete training about these disorders. Consumers and family members should be a part of this educational process.

GOAL

*Develop strategies to expand mental health training to law enforcement and judicial personnel.*

1. Identify mental health training that is currently being provided in New Jersey
2. Evaluate current requirements and training that is being provided
3. Recommend a strategy to mental health advocacy organization(s)

FINANCIAL OR EMPLOYMENT

People with a mental illnesses want and need to work. This is true whether their illness is disabling or not. Employment is an important stepping-stone to recovery. It is a normalizing factor that provides not only daily structure and routine, meaningful goals, improves self-esteem and self-image, but also increases finances, alleviates poverty, provides opportunities to make friendships and obtain social support, enriches quality of life and decreases disability. However, despite their desire and ability to work, people with psychiatric disabilities have the highest rate of unemployment of any group with disabilities. People with psychiatric disabilities are eligible for and may receive employment-related services from the mental health, vocational rehabilitation, and/or public workforce systems. Unfortunately they frequently do not receive the type of evidence-based services that would help them succeed at work, such as Supported
Employment. The employment services that are received through the mental health system often focus on “work as therapy” rather than competitive employment.

For individuals with psychiatric disabilities who return to work, an increase in monthly earnings may negatively impact their ability to receive either cash assistance or health insurance through Medicaid or Medicare. This acts as a disincentive to seeking employment because many jobs do not offer health benefits, which may be critical to helping an individual receive the ongoing services they need to sustain their ability to work. Further, individuals may not be fully informed about the work incentives that are designed to allow people with disabilities to work without losing important public benefits.

In light of these significant barriers to work, several Federal agencies—including the Social Security Administration (SSA) and the Centers for Medicare & Medicaid Services (CMS)—offer both programs and resources that can help.

GOAL

*Expand awareness of programs/entitlements that promote employment of individuals with a mental illness*

1. Compile information on programs/entitlements that promote employment of individuals with a mental illness
2. Develop a fact sheet and resource list of programs/entitlements that promote employment of individuals with a mental illness
3. Promote presentations on programs/entitlements that promote employment of individuals with a mental illness

RESIDENCE

Individuals with a serious mental illness and their families identify housing as an important factor in achieving and maintaining recovery. Housing means much more than shelter. Whether it is a room of one's own, an apartment, or a house, a home offers stability and a chance to create community. However, many live in substandard accommodations that are physically inadequate, crowded, noisy and located in undesirable neighborhoods.

Access to decent, safe, and affordable housing remains a tremendous challenge for adults with severe mental illnesses. In virtually every part of New Jersey people with a serious mental illness struggle to find good-quality housing they can afford. Many people with the most severe and disabling mental illnesses also need access to appropriate services and supports so that they can successfully live in community-based housing, which promotes their independence and dignity. Long waiting lists or exclusionary admission criteria limit access to housing as well as the lack of a centralized, user friendly clearinghouse for information on housing resources.
GOAL

*Develop a guide to housing resources for individuals with a mental illness and their families*

1. Conduct an environmental scan of existing housing options for individuals with a mental illness
2. Compile information on financial resources that may support housing for individuals with a mental illness
3. Identify resources in order to develop a guide to housing resources for individuals with a mental illness

HEALTH

Since the 1950s, there has been evidence that individuals with schizophrenia suffered from a variety of medical and metabolic disorders at rates higher than the general population. Although the introduction of the atypical neuroleptics has resulted in significant clinical advances, several of these agents have a variety of significant metabolic health risks associated with them. Concern for these side effects has prompted the US Food and Drug Administration (FDA) to issue a warning for all of the atypical neuroleptics, indicating that hyperglycemia and diabetes may result from the atypical neuroleptics.

Clinicians should therefore carefully consider the health risks associated with psychopharmacologic interventions, first utilizing those agents that maximize clinical response while minimizing health risks in already vulnerable individuals. A detailed monitoring process for the metabolic syndrome risk factors that include family history of metabolic disorders, waist circumference/BMI, blood pressure, fasting blood sugar, and lipid profile of consumers prescribed antipsychotics should be performed on a regular basis. This would promote medical care directed towards prevention, early detection, and chronic disease management.

GOAL

*Promote the use of protocols that evaluate the presence of metabolic syndrome among consumers of mental health services.*

1. Identify potential allies
2. Select an appropriate protocol to evaluate the presence of metabolic syndrome

STIGMA

Stigma towards individuals with a mental illness has been identified as a major obstacle to recovery, limiting opportunities and undermining self-esteem, relationships and job opportunities. Consumers and their family members indicate that stigma undercuts the natural support system of relatives, co-workers and friends that people typically rely on
during times of illness, compounding the burden of coping with a mental illness. Additionally stigma is recognized as a significant barrier to seeking help for mental health treatment.

In the previous State Family Support Plan the Family Support Workgroups reviewed stigma reduction strategies. There is evidence that individuals who possess more information about mental illness are less stigmatizing than individuals who are misinformed about mental illness. This supports public education programs such as those that have been conducted by the Governor’s Council on Mental Health Stigma, an effort that prior to a budget reduction had put New Jersey at the forefront of public efforts to reduce mental health stigma.

There is also convincing evidence that increased contact with persons with a serious mental illness is associated with lower stigma. These contacts need not be of prolonged duration and may take place in a “mental health” or similar setting. The opportunity for members of the general public to see consumers in a positive role, describing their recovery has been shown to engender more positive attitudes towards consumers of mental health services. This approach has the added benefit of counteracting self-stigma, an individual’s negative view of their own mental illness. This is a chance for a consumer to mine the value of their past experience, affirm their recovery and to” give back” to others.

GOAL

Promote opportunities for the public to interact with individuals who are recovering from mental illness
1. Identify local mental health advocacy groups who are promoting anti-stigma efforts.
2. Identify opportunities to provide anti-stigma presentations
3. Evaluate effort to provide opportunities for the public to receive anti-stigma information
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:

<table>
<thead>
<tr>
<th>Confidentiality</th>
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<tbody>
<tr>
<td>Long wait times/ not enough programs</td>
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<tr>
<td>Lack of awareness/information on illness/treatment</td>
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</table>

- Hard to obtain services for “undiagnosed”
- Services geared to crisis intervention.
- Lack of adequate services
- The system asks for family input yet does not use it.
- Lack of coordination between hospitals, physicians, social workers.
- Difficulty gaining access to information even with patient approval.
- Many providers do not know about NAMI NEW JERSEY
- Confidentiality issues
- Insurance does not take into account my relative’s needs.
- Lack of services for children
- Lack of services for dual diagnosis, mental illness/developmental disability
- Inconsistency of services availability across counties.
- Minor consent (over 14) to health treatment/HIPAA
- Privacy laws preclude sharing and giving vital information
- Programs not available in the suburbs, only the cities.
- Qualify/educate on HIPAA law
- Push agencies for additional family inclusion
- Promulgate the Resource Guide
- Understand that persons struggling with mental health issues are not rational and not capable of decisions that can be more effectively referred to their caregivers.
- Family should have additional rights in care decisions
- Educate care givers regarding required and proper documentation that should be readily available when seeking help from the system.
- Educate care givers regarding Power of Attorney requirements – how to develop documentation.
- Plans to privatize public hospitals.
- Getting return calls from service providers—sometimes never!
- Lack of social workers.
• Difficulty getting an appointment with a doctor.
• Unfamiliarity on the part of new people encountering the system.
• Communication between patient, family and doctors is often blocked.
• Family members often cannot speak to psychiatrist or other professional even with permission of patient.
• Getting a professional/service provider to listen to you can be difficult.
• Programs are often scheduled at inconvenient times for consumers/caregivers.
• Confidentiality restricts the flow of information.
• Insurance companies determine how long someone should be in the hospital.
• Not enough support groups for consumers or family members.
• Long wait times for access to treatment.
• When my son was young I was never told that I could have availed myself of respite care. Public schools should be trained to educate parents of classified children.
• Hard to find services.
• Disapproval of family involvement.
• Denial of service.
• Loved one does not share information with us.
• Confidentiality laws preclude us from providing and receiving input from health care professionals.
• Lack of help in finding quality medical help.
• Inappropriate use of HIPAA.
• Records don’t travel with the patient. No info on what worked and what didn’t in the past.
• Hospitals are not responsive to the regular “pre-crisis” psychiatrist.
• Got no information or diagnosis from doctor and no direction to NAMI.
• No continuity of care from institution to institution and even within an institution.
• Need better access to treatment and at an earlier age.
• Loved one refuses help and medication.
• Not knowing where to begin.
• Not enough knowledge of available resources.
• Bureaucracy minimizes clients.
• Collaborations with school based services is nil.
BARRIERS TO OPTIMISM FOR THE FUTURE

| “Who will take care of my loved one when I am gone?” |
| Lack of SERVICE coordination/permanency |
| Some consumers do not accept that they have an illness |

- Families are often not part of the therapeutic process
- Lack of funding to make services available
- Limitations in medication, housing and job prospects.
- Poor economy
- “All those setbacks”
- Not being able to participate in the plans for treatment for our son.
- Uncertain about care for loved one when we are gone
- Lack of insight
- “Who will bail him out from the consequences of his bad choices?”
- “When I am gone, who will steer him to agencies and services?”
- Seek better housing
- Follow up on needed care
- Find ways to stop having to requalify/reevaluate when mental health provider changes
- Seek extended mental health care for consumers without insurance
- SSI Issues –
  - Case workers at Social Security should have additional training on how to handle mental health situations.
  - Determine why some SS regulations do not accommodate mental health needs
- Clean up Ancora Psychiatric Hospital – Less promises – more positive action
- Listen to consumers as they express their needs
- Some services are being cut.
- Not enough programs
- The consumer is often unaware about his/her responsibilities after the caretaker is gone.
- Opportunities are not always taken advantage of by consumers.
- A lack of funding exists for programs.
- A lack of coordination exists among mental health groups.
- Programs closing instead of opening.
- Fear of loss of companionship.
- Need to improve the treatment system
- No help and sound guidance
- Who is going to care for my son when I’m gone?
- Who is not taking advantage of him and his finances?
• I worry about who will care for my son and I know he does too.
• Unless one accepts his illness, things do not look too optimistic.
• Need better medication with fewer side effects.
• Need longer hospital stays at inpatient units until patient is more stabilized.
• Loved one refuses help and medication.
• Lack of housing choices when we are gone.
• Will my child get arrested for being abusive?

BARRIERS TO EDUCATION

| Information on educational accommodations |
| Lack of awareness of programs that can pay for education |
| Lack of understanding in the schools about mental illness |

• Transportation
• Finances
• Accommodations to illness.
• Lack of understanding about mental illness
• More help with online courses needed
• More help for families needed on the help that is available
• Unless the consumer is high-functioning, education does not happen.
• The consumer’s illness (especially paranoia) impedes education.
• Colleges need to address the need for more help for consumers.
• Special education colleges are needed with more hands-on training.
• Nobody explained the illness to the family in the beginning.
• Standards of schools and colleges are too strict.
• Not much knowledge about mental illness among the public
• Cost of Education
• Social Stigma
• Doctors don’t understand difficulties.
• Transportation
• School districts unwilling to make modifications
• Funds and opportunity
• Competent teachers who speak good English
• Severely depressed teenagers cannot attend high school so the educational system should encourage home education
• How can we teach society that mental illness is only an illness?
• I don’t think anyone truly understands mental illness unless you live with it.
• Grants only for full time students
• I rarely go away because my son never answers the phone and I am constantly worried.
• My son feels he would be stigmatized because of his mental illness if he were to go back to college.
• Cannot focus. There is no special education for people with a mental illness.
• Social life in college revolves around drinking.
• Can’t carry a full load.
• Need education immediately upon diagnosis at a doctor’s or therapist’s office.
• School system unwilling to make modifications.

BARRIERS TO LEISURE

<table>
<thead>
<tr>
<th>Lack of opportunities to socialize</th>
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<tr>
<td>Lack of transportation</td>
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<tr>
<td>Lack of leisure for caregivers</td>
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</table>

- Fear of an “incident” in public places
- Financial resources go for essentials, e.g. treatment, housing etc.
- Respite not affordable
- Lack of transportation
- Lack of recreational programs
- Inability to drive
- Lack of friends
- Lack of opportunities for people with a mental illness to socialize
- No one to care for my ill relative.
- I worry about what will happen when I am away or on vacation
- My family member not interested in activities with other consumers.
- Family member needs help in making friends.
- Family member is reclusive due to illness, avoids social activities.
- Trouble finding respite to get away for a few days.
- Contact agencies to determine availability of field trips for consumers.
- Promote Winifred Chain’s youth group. (AACT)
- Develop a Consumers’ Guide to advertise availability of resources
- Form a “Citizen’s Advocacy Group” for new members.
- Explore a meeting place for consumers – party, dance, time with “normal” people
- Very limited or no leisure for caregivers.
- The caregiver fears what will happen later.
- Very limited leisure activities exist for consumers. Consumers can get upset and have fear when parents leave for vacation, etc.
- Where to go?
- Lack of funds
- Some cannot cope by themselves.
- Frequent need for help and support.

- My son feels people avoid him
- Transportation
• Domestic stress from mental illness
• My family member does not want to participate in leisure activities.
• Always have to be around loved one. Can’t leave them for a long period of time.
• Dating – These days groups go out at 9 or 10, he’s going to bed.
• Refuses help, always delusional and hallucinating.
• No leisure, always worried and on guard for something bad to happen.
• My daughter has no place to make friends.

LEGAL BARRIERS

<table>
<thead>
<tr>
<th>Need for police training and jail diversion programs.</th>
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<tbody>
<tr>
<td>Improve the education of lawyers and judges regarding mental health issues.</td>
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<tr>
<td>The cost of legal assistance</td>
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• Trying to get the criminal justice system to recognize and get help for people with mental illness is difficult.
• Being shunted to the criminal justice system instead of treatment.
• Cost of legal assistance
• Representation hard to find for caretakers.
• Family member has been handcuffed while transported to screening though not arrested.
• Minor consent (over 14) to health treatment/HIPAA
• Initiate police training in county townships
• Promulgate recent clarifications to the HIPPA Act
• Determine why Community Health Law Project is unresponsive to phone inquiries.
• Expand Jail Diversion Program
• Have “In our Own Voice” group make presentation at Bar Association
• Initiate/ Expand contact with Law Schools and Paralegals
• No legal services advertised for mental health issues.
• The agency has to respond.
• Some police are still not informed about mental illness issues.
• Arrest in lieu of treatment.
• Cost of legal advice.
• No one else seems to care.
• Can’t find a mental health lawyer to explain my situation
• In New York there are separate courts for persons with a mentally illness. I wish New Jersey would implement this. My son has a $500 fine for sleeping in an abandoned building when was homeless.
• High cost of legal advice and representation.
• People with a mental illness should receive treatment not jail.
- His Hagedorn stay comes up on his credit check
- Very costly if Legal Aid won’t help
- Law enforcement not sensitive to issues.
- Can’t find a lawyer with expertise in mental illness.
- Working poor don’t have access to legal services.

**FINANCIAL OR EMPLOYMENT BARRIERS**

<table>
<thead>
<tr>
<th>Supported Employment programs need to be expanded</th>
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<tr>
<td>Discrimination towards individuals with a mental illness</td>
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<tr>
<td>Social Security rate is below the poverty level</td>
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- Navigating the entitlement system (appointments, forms) for someone with a mental illness can be a “deal breaker”
- Stigma
- Limited academic or vocational training.
- Lack of satisfactory, well paying jobs.
- Lack of work history
- Discrimination in the workplace
- Low employment rates
- Raise level for consumers at SSI and SSDI
- Eliminate marriage penalty
- Educate and clarify facts on losing benefits when resuming work
- Educate employers regarding talents of mentally ill persons
- Examine rights of Mentally Ill persons under Disability Act
- Explore potential for volunteer work – eg. library
- Just about no jobs available.
- The fear that some people on the job are making fun of the consumer.
- The consumer is paranoid over stigma.
- It is financially difficult to take care of loved ones with a mental illness.
- SSI is below the poverty level.
- Supported employment programs need to be expanded.
- Consumer anxiety.
- Insensitivity of some employers.
- Not enough money to care for someone who is ill.
- Social stigma with employers.
- With the inability to hold a job, money gets tighter and tighter.
- Insufficient training
- Transportation
- People who are not aware of the urgency (life and death) issues
- It takes too long to get social Security and even longer to get Medicare.
- Lack of availability of supported employment.
• Social Security is below the poverty level.
• Cost of therapy can be prohibitive.
• Reduce the cost of name brand medications.
• Education breaks stops insurance coverage.
• Goes through Social Security money in a few days and expects me to supply money for the rest of the month.
• Not enough employers willing to take a chance on people with a mental illness.
• No jobs or very low paying if available.
• Transportation

RESIDENCE BARRIERS

Prioritization of the limited state funded housing for those being discharged from state hospitals
Long waits/closed lists for rental assistance
NIMBY (Not In My Backyard)

• Many places don’t accept pets
• Not enough income for an apartment
• Only people coming from a state hospital are prioritized for a small number of residential programs.
• Rental Assistance lists are closed in most counties.
• Not available
• Lack of supportive housing
• Lack of low cost independent housing.
• Restrictions on housing eligibility.
• Long waits
• More flexible “housing first” needed.
• Not in my back yard (NIMBY)
• Loved one always seems to fall between the cracks, not severe enough but still in need of assistance.
• Section 8 vouchers are too hard to obtain
• Families are not aware of housing opportunities as they become available.
• Eliminate “Group Home” terminology and replace with “Cooperative Living” or other less stigmatizing term.
• Additional Section 8 housing in good neighborhoods.
• Explore dormitory-style housing –promulgate options available from mental health providers
• Fight “NIMBY” and “NOPE” (Not On Planet Earth)
• Lengthy waiting list for Section 8 housing and group homes.
• Paperwork too cumbersome.
• Too little housing—a lot more needed.
• Where can you live with such little income?
• Social stigma with neighbors.
• Little low cost housing.
• Insufficient housing to provide support
• Not functioning house mates living with alcoholics
• We need more decent, clean housing for the mentally ill
• There are not enough housing opportunities for people with a mental illness.
• There is a lack of instruction in life skills (cleaning, cooking etc.).
• Little housing for single males.
• Waiting lists are long or closed.
• Limited housing for dual diagnosis (mental illness/substance abuse).

**HEALTH BARRIERS**

*The prevalence of metabolic syndrome is not adequately addressed
Need to improve self care
A number of physicians do not accept Medicaid or Medicare*

• Medical providers not prepared to deal with mental health consumers
• Fear, lack of trust in the health care system
• Poor self care
• Heavy smoking
• Ailments such as diabetes and heart disease are more common for people with a mental illness.
• Side effects of medication leading to eight gain and other health problems.
• Physical illnesses caused by meds.
• Weight gain
• My family member does not see a doctor regularly
• Use of aversives and restraints
• Shortened life expectancy for people with a mental illness
• Side effects of medications present additional challenges.
• Parity didn’t help since insurance plan never covered mental health.
• People are more at risk because medical providers are not trained about mental illness and do not view the person as in need of special considerations.
• High cost of medications for uninsured– complicated by: multi-state involvement, consumer’s working and non working periods, SSI rules.
• Explore ways around physicians/Mental Health professionals not accepting MEDICARE/MEDICAID.
• Educate consumers regarding mental health – “Hearts and Minds”
• Health and hygiene issues are not addressed as they should be; consumers are thought of as person who does not know what is going on.
• Poor consumer self-care.
• Consumers may forget about all the things you taught them about self-care.
• Consumer smoking because of stress.
• Consumer self-medicating,
• Some consumers lack cooking skills.
• What to do with people who do not cooperate.
• Smoking

• Needs a big push to exercise. Weight gain associated with medication
• Severe arthritis
• We need more doctors that will accept Medicaid patients
• There are no shower facilities at community hospital in the crisis unit. Makes it tough if you are there for three days.
• Comorbid illnesses
• Physical illnesses such as diabetes are often caused by side effects of medications.
• Poor diet and hygiene
• My stress is overwhelming, constant worry, can’t sleep.

**STIGMA**

| The public remains ill-informed about mental illness | Stigma reduces support from family and friends |
| Stigma leads to denial and/or people not seeking treatment |

• Much has been done, but still much to do
• If your child has a “physical” illness you receive compassion/empathy, but not with mental illness.
• Still must keep mental illness a secret because to the rest of the population it is still very scary.
• Mental illnesses are sensationalized in the media.
• Old friends no longer associate with my family member
• Appearance, poverty
• People say they understand, but still stay away.
• Still hear many derogatory comments about mental illness.
• Respond immediately when stigma is noticed – Letters, phone calls etc.
• Meet newly-elected county Freeholders
• Contact Freeholders to explain NAMI FACE position on Buttonwood Hospital
• Invite Freeholder to NAMI FACE meeting
• Share ideas with public – Speakers on Mental Health
  o Rotary Clubs, Business Women Clubs, Chamber of Commerce, etc.
• Use Community Bulletin Board message on Cable TV channel
  o Expand distribution of the Resource Guide

• Still held against the consumer.
• Family “reporting back.”
• Stigma feeds into denial.
• Fear of disclosure to friends and others by family and consumer.
• Few friends
• Embarrassment with both neighbors and relatives
• Even other close family members do not care.
• It is real - need more education of society
• Does not annoy me
• Ongoing struggle
• People do not understand mental illness and associate it with murderers.
• People are frightened by mental illness because they don’t understand it.
• The stigma (thankfully) is getting better
• Causes shame and isolation.
• What do you tell a friend?
• Says he has Social Security for a back problem, not mental illness.
• Stigma has many consumers not admitting they are ill and therefore refusing medication.
• Public ignorance is overwhelming.
• Blaming parents for child’s illness.
**FAMILY SUPPORT WORKGROUP PARTICIPANTS**

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