



# **Mental Illness and Families**

## **A Handbook for Caregivers**

Compiled and written by  
NAMI Mass family members  
Updated July 2009, Seventh Edition, website version

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**Please Note:** This handbook has been produced by family members who provided guidelines and recommendations based upon their experience and research. For professional advice, please consult mental health professionals. Information on rights, rules and regulations and other legal matters should be reviewed by a lawyer before relying on it.

Many references are made to websites, especially, [www.namimass.org](http://www.namimass.org) and [www.nami.org](http://www.nami.org). If you do not have access to a computer at home, from a relative or friend, or at your local library, please call NAMI Massachusetts at 800-370-9085 and ask for the specific information you require. It will be printed and mailed to you.

Thank you to all the family members and staff of NAMI Massachusetts for their assistance in producing this booklet and its previous editions.

For information on ordering additional copies, please contact your local NAMI affiliate.

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Suggestions for future updates of this handbook are always welcome. Contact the NAMI Mass office at 800-370-9085 or email [info@namimass.org](mailto:info@namimass.org).

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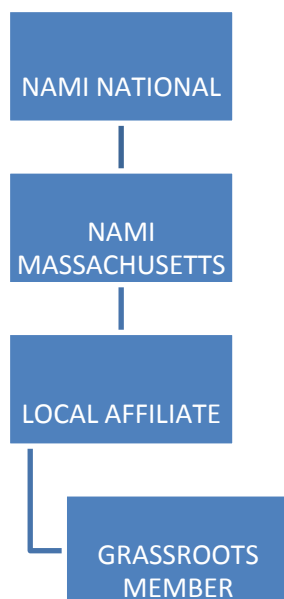
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## INTRODUCTION

If you are reading this handbook, someone in your family has been diagnosed with severe mental illness and your family members may be suffering through some hard times. This handbook has been written by members of the National Alliance on Mental Illness of Massachusetts (NAMI Mass) who have experienced unnerving brushes with mental illness and can empathize strongly with your feelings and uncertainties. We have published this guide to help your family and others cope and gain confidence and competence in your many perplexing roles: active management, quiet and loving support, steadfastness throughout the healing process, and advocacy. By helping families, we also hope to help persons with mental illness.

Each diagnosed mentally ill person will differ from every other ill person, even those sharing the same diagnosis. Each mentally ill person will follow a different path on the road to recovery. The timing and intensity of episodes will vary, as will the quality of advocacy, professional support, and mental health services.

Predicting how a mental illness will develop is difficult. Family members' roles in helping the mentally ill person may not be significant at first, but over time they may become quite influential and a steadying influence in a treatment world that is constantly changing. Who could have predicted that many large institutions for the mentally ill would disappear due to dramatically improved and continually improving medications? We have great hope. Nevertheless, progress toward recovery may be painfully slow, with awakenings, setbacks, surprises, and disappointments. There may be inappropriate behaviors, substance abuse, or rash or illegal acts as a response to inner personal tortures. As families learn to support and advocate, there may be appropriate and adequate treatment that leads the way to recovery. We, the families of NAMI Mass, wish you and your loved ones well on your journey and stand ready to help in anyway we can.



## WHAT IS NAMI?

The National Alliance on Mental Illness of Massachusetts (NAMI Mass) is a nonprofit grassroots advocacy, education and support organization. Founded in 1982 and obtaining 501(c) (3) status in 1999, NAMI Mass' mission is to provide support to individuals with serious mental illness and their families; advocate for nondiscriminatory and equitable federal, state and private-sector policies; and educate to eliminate the pervasive stigma surrounding mental illness.

NAMI Mass and 23 local affiliates are comprised of individuals with mental illness, family members and others in the mental health community, "***The state's voice on mental illness.***"

The NAMI organization operates at the local, state and national levels. Each level of the organization provides support, education, information and referral and legislative advocacy to support individuals who live with mental illness and their families.

NAMI's roots have grown from the need for knowledge and understanding, sharing of grief, relief of guilt, and mutual support. NAMI's membership is likely to be concentrated in families and individuals with mental illness needing and seeking this same solace. Family means individuals with mental illness and their parents, siblings, adult children, spouses, and other involved relatives and caregivers.

All components of NAMI declare:

- Together we can give each other strong support;
- The illness is treatable as any other illness;
- You can survive as an intact family;
- It's not anyone's fault;
- You don't need to explain anything– we already know; and
- With dedication and unity, we have enormous strength through which we can accomplish constructive change.

### **WHAT IS MENTAL ILLNESS?**

Mental illness refers to a group of disorders which cause severe disturbances in a person's ability to think, feel and relate. Untreated, they can result in a greatly diminished ability to cope with the ordinary demands of life. Mental illness can affect individuals of any age – children, adolescents, adults and elders. Every year more than five million Americans experience an acute episode of one of five major mental illnesses: schizophrenia, bipolar disorder, major depression, obsessive-compulsive disorder or panic/anxiety disorder, including 12% of children under the age of 18. The cost to society is high due to lost productivity and treatment expenses. **Mental illness is more common than cancer, diabetes or heart disease.**

Other mental illnesses include Asperger's Syndrome, Attention-deficit/hyperactivity disorder, Borderline Personality Disorder, Eating Disorders, Personality Disorders, Post-traumatic Stress Disorder, Schizoaffective Disorder, and Tourettes Syndrome.

For more information about specific disorders please contact the NAMI Mass office at 800-370-9085, email [info@namimass.org](mailto:info@namimass.org) or contact your local affiliate for an informational pamphlet. You can also visit the website [www.nami.org](http://www.nami.org), click on "Inform Yourself then choose "Severe Mental Illnesses." There is a Fact Sheet about each illness with symptoms,

treatments, and links to other sites.

### **CAUSES OF MENTAL ILLNESS**

The cause of biologically-based brain diseases is not well understood, although it is believed that the functioning of the brain's neurotransmitters is involved. Many factors may contribute to this disturbed functioning. Heredity may be a factor in mental illness as it is in diabetes and cancer. Stress may contribute to the onset of mental illness in a vulnerable person.

Recreational drugs or alcohol may also contribute to onset, but are unlikely to be the single cause. Family interaction and early child training were once thought to cause mental illness; however, research does not support that theory any longer.

### **WARNING SIGNS OF POSSIBLE MENTAL ILLNESS**

(For use as an informational guide not a tool for diagnosis which needs to be performed and documented by a licensed and trained mental health professional)

- Sitting and doing nothing; rocking or pacing
- Friendlessness; abnormal self-centeredness
- Dropping out of activities; decline in academic/athletic performance
- Inappropriate hiding
- Loss of interest in once pleasurable activities
- Frequent or sustained crying for no apparent reason
- Expressions of hopelessness; extreme pessimism about everything
- Excessive fatigue or sleepiness, or persistent insomnia
- Inability to concentrate or cope with minor problems
- Irrational statements and/or peculiar use of words
- Excessive fears or suspicions
- Bursts of emotion unrelated or out of proportion to the situation
- Hostility from a person formerly passive and compliant
- Indifference in important situations
- Apparent inability to cry or express joy
- Inappropriate laughter
- Unexplained severe anxiety or fearfulness
- Changes in eating habits; gorging, purging, starving
- Hyperactivity or inactivity or both
- Deterioration in personal hygiene or grooming
- Extreme washing, checking, or counting
- Noticeable or rapid weight gain or loss
- Hair pulling or other forms of self-mutilation
- Unusual involvement in automobile accidents
- Drug or alcohol abuse
- Forgetfulness or loss of valuable possessions
- Frequent moves or hitchhiking trips; running away
- Bizarre behavior; skipping, staring, or strange posturing
- Extensive, sustained hoarding
- Excessive sensitivity to noises, light, clothing, or smells
- Obsession with and collection of guns, knives, explosives, etc.
- Violence directed towards objects, animals, others, or self
- Reports of hearing voices or seeing sights unknown to others
- Beliefs that are obviously contrary to fact

- Delusions of grandeur or persecution (paranoia)
- Suicide ideation

**Please note: If a person starts talking about suicide, it's important to call a doctor, crisis services or 911 immediately. Crisis information is available on our website (see the red Crisis Info tab on our home page), [www.namimass.org](http://www.namimass.org). If you are not sure what to do, contact the Samaritans at 1-877-870-4673 and they will talk you through it.**

Please also note: Some of the above symptoms can be caused by another illness so it's important to rule out other illnesses by standard medical tests and a physical examination performed by a primary care physician.

## **TREATMENT AND RESOURCES**

### **Can Mental Illness be Prevented or Cured?**

While we don't know the causes of these brain disorders, we do know that people can recover. With early intervention and necessary evidence-based treatment and support, individuals with mental illness can live successful lives.

An expanding range of medications and therapies are available that markedly reduce symptoms for many but no one medication or therapy is better than another. Each individual has to determine what best helps him/her. As is the case with most chronic illnesses a balanced diet, regular exercise, adequate sleep, and stress management techniques contribute to a healthier life. Some examples of therapies include: Electroconvulsive Therapy (ECT); Cognitive Behavioral Therapy (CBT) and Dialectical Behavioral Therapy (DBT). Supportive counseling, peer-led support groups and community rehabilitation programs promote recovery and build self-confidence. In addition housing and employment services enable some people to develop independent living skills, hold a job, and achieve a fulfilling life. Others may need more support for most or all of their lives. Helping people achieve a sense of dignity with the highest degree of independence, productivity, and satisfaction with life is the goal.

Early recognition is crucial. Mental illness may show up in childhood, adolescence, young adulthood or later. Teachers and guidance counselors can alert parents of personality or behavior changes and aid in finding a therapist or psychiatrist. Sometimes, however, the illness erupts suddenly, precipitating a crisis.

### **Crisis Intervention**

When a mental illness is suspected and a severe crisis in behavior occurs, family members are often at a loss as to what to say and do. It is most important to defuse the situation by establishing that you are genuinely concerned for your loved one's welfare. Know what is most significant and valuable to the ill person. If you see that one approach is not working, back off and try another. Do not expect to know all the answers. Remember, because you are a family member, your experience with the person is extremely valuable. The following are suggestions for preparing yourself and members of your family for a possible crisis situation:

Keep a diary or thorough notes about:

- (1) the ill person's diagnosis and medical conditions;
- (2) medications being taken as well as medications not tolerated; and
- (3) specific behaviors and actions that preceded and followed the crisis.

You should provide a copy of this information to the Crisis Team, to mental health professionals or the police. Plan and think ahead. Know what steps to take if the mentally ill individual gets out of control. Locate available sources for help such as the mental health crisis team, the individual's therapist, helpful friends or neighbors and your local NAMI affiliate. Keep these numbers posted by your telephone. Note: You can locate the crisis services that serves your community by using the NAMI Mass website, [www.namimass.org](http://www.namimass.org) and click on the red **Crisis Info** button on the home page. (See page 19 for more info.)

Consult ahead of time with your loved one's social worker or psychiatrist or with the nearest Community Mental Health Center so you will know how to obtain services when you need them. As you deal with the situation, keep in mind that the mental illness is not your fault nor is it the fault of the person who is in crisis. Mental illness involves a biochemical disorder of the brain, and it is diagnosed by its symptoms. The ill person may not be able to articulate how the mental pain is affecting them.

Learn about your local Crisis Team and how it operates (see pg.12 for more info). Call them before a full-blown crisis develops. You will then be able to evaluate the situation and ask for help when really needed. The Crisis Team and/or law enforcement officers should be called for threat of suicide or danger to any person or property. If your psychiatrist or the Crisis Team deems it necessary, the ill person may be hospitalized. Therefore, it is prudent to plan for voluntary hospitalization or emergency commitment. Call your local NAMI support group to help you put the situation in perspective and to carry on your personal life.

Selecting an appropriate person to treat your mentally ill loved one may be a disconcerting process of trial and error. Often more than one professional is involved in the process. These professionals are known as the Treatment Team. The treatment team often consists of:

- Psychiatrists: physicians who assess, diagnose, and prescribe medications and possibly other treatment and aftercare. A surprise to most families new to psychiatric care is that frequently the psychiatrists who treat patients in the hospital are not the same ones who treat them as outpatients;
- Psychiatric nurses: are specially trained and usually have major responsibility for treatment in hospitals, day programs, or medication clinics;
- Therapists and Social Workers: are trained as counselors, and work with doctors, patients, and family members in the development of on-going treatment and discharge plans and provide help accessing community resources;
- Clinical psychologists: may be involved in administering diagnostic tests, conducting individual or group sessions for patients, and planning care both inside the hospital and after discharge; and
- Mental Health Counselors: have a Master's Degree and two years of supervised work.

Dual diagnosis services are treatments for people who suffer from co-occurring disorders- mental illness and substance abuse (drugs or alcohol). Research has strongly indicated that to recover fully, a person with mental illness with a co-occurring disorder needs treatment for both problems; focusing on one does not ensure the other will go away. Dual diagnosis services integrate assistance for each condition, helping people recover from both in one setting, at the same time. Dual diagnosis services include different types of assistance that go beyond standard therapy or medication: assertive outreach, job and housing assistance, family counseling, even money and relationship management.



The Program of Assertive Community Treatment (PACT) is an effective, evidence-based, outreach-oriented, service-delivery model for people with severe and persistent mental illnesses. Using a 24-hours-a-day, seven-days-a-week, team approach, PACT delivers comprehensive community treatment, rehabilitation, and support services to consumers in their homes, at work, and in community settings. It is not available in every area. For detailed information to help you decide if the PACT model is available for you and right for your family, visit [www.namimass.org](http://www.namimass.org) and type "PACT" in the search box. The individual with the mental illness has to be eligible and apply for the PACT program through the Department of Mental Health. There are a limited number of slots and there may be a waiting list.

### **Massachusetts Department of Mental Health (DMH)**

DMH launched a new application process designed to streamline eligibility determinations and speed service delivery. The revamped procedure simplifies paperwork; facilitates a user-friendly application system focused on individual goals; and efficiently links consumers and family members with appropriate services.

Massachusetts residents will now use simplified forms to apply for DMH services, but the eligibility requirements remain the same, following existing regulations and statutory requirements. The agency improvements also feature early personal interaction between DMH staff and mental health consumers. In past years, DMH sent a letter to applicants notifying them that the agency had received their applications. With the goal of accelerating patient engagement, staff will now contact each applicant or his or her designated guardian by telephone within seven days to conduct individual assessments and collect information necessary to make eligibility determinations promptly and appropriately.

Individuals with a mental illness can obtain a "request for services" forms — one for children and adolescents and another for adults — by visiting the DMH website, [www.mass.gov/dmh](http://www.mass.gov/dmh), and clicking on the Key Resources/Service Application Forms link. Application materials are also available at all DMH Area and Site Offices, acute inpatient psychiatric facilities and at many community programs. DMH offers translators and other assistance as needed. Completed forms should be delivered, mailed or faxed to the appropriate regional DMH Area or Site Office. In order to determine where an application should be sent, please call the DMH Information and Referral Line toll-free at 1-800-221-0053.

The Community Based Flexible Supports (CBFS) initiative represents a major transition for the Department of Mental Health (DMH) and its role in the public mental health system. DMH is shifting to an agency that sets standards, provides oversight, and monitors the services that are being provided to everyone who currently has them.

DMH had 170 vendors that provide adult mental health services in the communities throughout the Commonwealth. On July 1, 2009 this changed and the number of DMH vendors providing services will be 46.

DMH funded community services for adults will include Community Based Flexible Supports (CBFS), Program of Assertive Community Treatment (PACT), clubhouses, respite care, peer operated programs and DMH case management services.

Community Based Flexible Supports increases the focus on recovery and include such services as:

- interventions and supports that manage psychiatric symptoms in the community;
- restore or maintain independent living in the community;
- restore or maintain daily living skills;
- promote wellness and the management of medical conditions; and
- assist clients to restore or maintain and utilize the skills necessary to undertake independent employment.

DMH case management services will remain the duty of DMH staff.

If a mental health consumer wants to receive CBFS services, they must first apply to DMH and meet the clinical criteria to receive DMH services and then if appropriate DMH may refer them to a CBFS vendor. Upon completion of an initial screening by the CBFS vendor, a client may be enrolled in CBFS.

## **MEDICATIONS**

Medications have been found to be very useful in helping people who are mentally ill to think more clearly and gain control of their thoughts and actions. Words such as "psychotropic" or "psychoactive" (affecting mood, thought, emotions, and behavior) are generally used more or less interchangeably. They refer to certain drugs prescribed by a licensed physician, preferably a psychiatrist. Prescription writing power has been extended to nurse practitioners and psychiatric nurse mental health clinical specialists provided the nurses' prescriptions include the name of a physician with whom the nurse has signed an approved guideline agreement.

The effectiveness of a particular medication may help determine a doctor's diagnosis of a patient's mental illness. Each person reacts differently to a medication or combination of medications. Dosages should be individually tailored and may need to be adjusted from time to time. Most drugs may take several weeks or more to become fully effective. Do not be dismayed at the number of different medications that are prescribed concurrently. The taking of several different medications at the same time is known as "polypharmacy" and it is not unusual.

All psychotropic medications have side-effects and have risks; sometimes a stay in the hospital, with thorough monitoring, may be necessary until stabilization is achieved. Side-effects may be temporary, continual or appear only after long-term use. Dosages should be carefully checked and adjusted/fine-tuned to be most effective and yet minimize side-effects.

The patient or a family member should keep records of medications taken, dosages, and dates begun or terminated. Each drug has both a trade or commercial name and a generic name.

The ability of people who are mentally ill to handle their "meds" should be weighed and watched by family, friends and clinicians. The use of alcohol could seriously impair a patient's rational use of medication and therefore is discouraged. If the person stops taking his or her medications or overdoses, this should be noticed and reported to the physician promptly. Quick action may be required to avert a crisis or deal with adverse reactions or regression in the absence of medications. Some mentally ill people in the community may need extra help or stronger measures to make sure they take their medications properly. People with mental illness can devise clever ways to fake taking their medications. Furthermore, "life style" agents such as caffeine or nicotine can interfere with desired effects. Do not be discouraged

if medications do not seem to be helping, new drugs and new uses for existing ones are continually being tested and reported. Better treatments are on the way!

For a detailed description of a particular medication, including side-effects, type its name into your browser's search engine, or [www.google.com](http://www.google.com). Pharmaceutical companies have web sites that give extensive information about the medications they manufacture, as well the side-effects. Again, type the name of the pharmaceutical company into your search engine to get to the website.

"Ask the Psychiatric Pharmacist" is a section of the NAMI Web site where board-certified psychiatric pharmacists write and answer questions that they experience in the course of their work with individuals with mental illness. These questions are provided by members of the College Psychiatric and Neurologic Pharmacists (CPNP) ([www.cpn.org](http://www.cpn.org)), who also write NAMI's medication fact sheets ([http://www.nami.org/Template.cfm?Section=About\\_Medications](http://www.nami.org/Template.cfm?Section=About_Medications)) CPNP is pleased to provide this service to mental health consumers and caregivers and welcomes your input for future columns by emailing [info@cpnp.org](mailto:info@cpnp.org).

### **Access to Medications**

NAMI has developed a story bank for individuals with mental illness and their families who have been supported in their recovery by access to medications as well as those whom have been challenged in their recovery by lack of access to medications. Shared stories shed light on the challenges individuals with mental illness and their families face—putting a human face on the tragedy of failed access and the hope for recovery that access supports is one of the most effective ways NAMI can advocate for our mission. Please share your story with other mental health consumers and families in Massachusetts and other advocates with whom you are working. The story bank will support the NAMI Massachusetts Campaign for the Mind of America in securing access to medications and treatment in its advocacy efforts. Contact the NAMI Mass office 800-370-9085 or e-mail [info@namimass.org](mailto:info@namimass.org) if you would like more information or want to share your story. You will be asked if your story can be used for testimony during a public hearing for a legislative bill to preserve access to medications.

### **DAILY LIVING**

Medications cannot do it all. People suffering from mental illness continue to need respect, support and love of friends and family, who can also help and encourage optimal use of medications. In order to best fulfill their helping role, families should try to maintain contact with therapists or social workers, in hospital as well as community settings. Do not be afraid to ask questions about medications and discuss what you have read in books, and other publications.

It will not help to argue or deny that what your relative is seeing, hearing and feeling is real. Instead, assure him/her of your love and understanding, that what they are experiencing is real only to them, and that you want to help. Honesty is always essential. Your relative needs to know that he/she can trust you. Discuss commitment if this is a possibility. Do not make threats unless you plan to follow through.

Do not be discouraged if your loved one does not comprehend what you are saying when he/she is psychotic. Even though the thoughts of the person who is ill are disordered, he/she may perceive and remember later.

In extreme circumstances, you may have to get a court order to assist you in managing your ill family member. If the order is violated, you may have in hand the only certain way to get help from the Crisis Team and other authorities.

### **HOSPITALIZATION: VOLUNTARY OR INVOLUNTARY**

The current trend is to send patients to general or psychiatric hospitals for acute care as the number of state hospitals has decreased. If the ill person presents a severe danger to himself/herself or to others, a locked ward will be needed. Private hospitals usually keep the patient for a limited stay, depending on health insurance coverage. At the end of this time, the ill person may have to be transferred to a long term care facility such as a state psychiatric facility or discharged.

While hospitalized in a safe environment, the mentally ill person will be observed and diagnosed; proper medication will be determined (in part by trial and error) and therapy offered individually, in groups or with the family. When the patient is discharged, the family will be an important therapeutic element. The family will need to prepare by keeping close contact with the psychiatrists, social workers, support groups and the case manager, in order to learn as much as possible about the medication and the necessary home therapy environment. If it is determined that the family may not be able to deal with the situation, then the discharge may be to a halfway house or group residence, rather than to the family home. The family can benefit during this whole process by connecting with the support groups through the hospital or through a local NAMI affiliate.

In an emergency situation when the patient is deemed to be a danger to herself/himself or others, it is oftentimes necessary to arrange for involuntary hospitalization.

For information about the legal considerations of an involuntary hospitalization, consult the "FAQ" section on the NAMI Mass website [www.namimass.org](http://www.namimass.org).

The Mental Health Legal Advisors Committee has prepared a Mental Health Law Guide, a collection of pamphlets that discuss the rights of people with respect to hospitalization, their rights while an inpatient in a mental health facility, their rights with respect to medication, and other matters. A copy of the Guide (out of date at the moment) can be obtained using their website. Call 1-800-342-9092 for further information or visit their web site: [http://www.mhlac.org/Order\\_Publications.htm](http://www.mhlac.org/Order_Publications.htm).

### **HOSPITALS AND PROGRAMS IN THE COMMUNITY**

**General hospitals** provide acute care services (usually limited to a maximum stay of 21 days). Or they may have a Psychiatric Services Agreement with another hospital. Be sure to inquire about this.

**Private hospitals** provide short-term, intermediate and long-term care services, at a higher cost, with the need for prior approved insurance coverage or guaranteed payment. Some questions you should ask when considering a private hospital are:

- What is the treatment philosophy of the hospital? You must be the judge as to whether you think the facility is appropriate.
- How much is it going to cost?
- How does the hospital view the role of the family in relation to the patient?

- What kind of relationship does the hospital have with the community in terms of resources (housing, day programs, outpatient treatment, etc.)? This can be critical when the patient is discharged and needs access to community programs.
- Does this hospital have a locked unit?
- Is this institution a member of the Massachusetts Association of Psychiatric Hospitals? If so, who is the ombudsperson?

Ideally, treatment for dual diagnosis should be provided in integrated settings, where all patients receive education to make better decisions about substance use in the context of their ongoing psychiatric treatment, and where addicted patients can receive intensive addiction treatment geared for individuals with psychiatric disabilities.

**Community Mental Health Centers** provide emergency assessment and services, community placement, medical supervision, treatment and case management in the community for people with mental illness. They may also provide information and services to families. Community Mental Health Centers (CMHCs) are federal and state funded facilities that provide out-patient treatment for persons with mental illnesses. Some communities have private and/or publicly-funded drop in centers to supplement out-patient or therapy services, as well as temporary shelters or safe-homes for adolescents. Not all Massachusetts cities and towns have CMCHs (see <http://www.massleague.org/HealthCenters-ByCityTown.htm>) but many have community clinics whose services are paid through clients' Medicaid (MassHealth).

**Community Residences** (also known as half-way houses) provide housing with varying degrees of support. The goal is to match the level of support with the individual needs of the client. Some community residences require "high intensity" staffing. Staffing and programs provided in these residences provide intensive treatment and supervision as well as social and vocational rehabilitation in a less restrictive environment. They are generally considered among the most effective ways of treating long-term forms of mental illness. Questions to ask about each potential housing program:

- For whom is the housing appropriate?
- Is the housing transitional or long-term?
- How many hours of supervision are given per day or week?
- Are residents required to be in a day program activity?
- Does it supervise the taking of medication?
- Who pays for it?

Many former patients need some kind of day program, activity or job. Communities vary as to what services they provide. Some provide psychosocial centers that teach skills of independent living. Others have psychiatric day programs linked to hospitals or community mental health centers. These programs offer structured programs that serve as a transition from hospital to community.

**Case Management Services** assist individuals in assessing and making choices about opportunities and services in the community. They can facilitate arrangements for an appropriate array of living arrangements and services for each client's needs.

**Social Clubs, Clubhouses or Drop-In Centers** offer services by and for consumers. Services include peer self-help, advocacy, respite care, hot-lines, socializing, food banks,

supported employment opportunities and similar non-clinical services. To find out more about clubhouses visit <http://www.massclubs.org/>, The Massachusetts Clubhouse Coalition website.

**Psychosocial Rehabilitation Programs** include the following: employment-related training and services, social and recreational skills training, and support in the development of skills necessary for independent living. Limited services are available through Community Mental Health Centers, some Social Clubs and through some private hospital programs. See the Appendix B for some resources, the NAMI Mass website [www.namimass.org](http://www.namimass.org) and contact your local affiliate for more information.

**Educational Programs and Supported Education**: Many colleges have programs for disabled students. Due to the disruptions caused by both the illness itself as well as side-effects of medications, people with mental illness might need the following services: privilege to take fewer courses and still be classified as a full time student, tutoring, academic support, peer counseling and learning aids such as word processors, note takers, untimed tests, tape recorders and computers. Contact the Disability Services Dept. at the college or university for more information.

The Boston Public Library maintains complete information services on higher education and preparation for the General Education Development (GED) test for a high school equivalency diploma. Telephone 617-536-5400 or visit the website [www.bpl.org](http://www.bpl.org).

Getting financial aid for an education program may not be easy, especially when a mentally ill person first embarks on this effort. Success in the first year or term may qualify one for some assistance. Another not much publicized route is called Plan for Achieving Self Support (PASS), available to disabled recipients of Social Security assistance. For help in applying for this program or for other forms of assistance in pursuing higher education, call or visit your local Social Security Office. (<http://www.ssa.gov/>)

## **EMERGENCY SERVICE PROGRAMS**

**Emergency Services have been redesigned and there are significant changes you should note effective June 30, 2009.** There will be 21 locally based Emergency Service Programs (ESPs) covering every city and town across the Commonwealth. Seventeen of the ESPs are managed by Massachusetts Behavioral Health Partnership (MBHP), and four are operated by the Department of Mental Health in the Southeast Region. Please see our website for an the “ESP Directory,” a list of the ESPs, the areas they serve, the cities and towns included in each area, and contact information, such as addresses and phone numbers.

The ESPs provide behavioral health crisis assessment, intervention, and stabilization services, 24 hours per day, seven days per week, 365 days per year. Each ESP offers the following service components, which will make emergency behavioral health services accessible in the community, offering alternatives to hospital emergency departments (EDs) for individuals seeking behavioral health services when use of the ED may be avoided and/or is not voluntarily sought.

- **Mobile Crisis Intervention (MCI):** MCI is one of the new Children’s Behavioral Health Initiative remedy services required by the Rosie D lawsuit. MCI is the youth-serving component of the ESP for all MassHealth-enrolled youth up to the age of 21. This service mobilizes to the home or other site where the youth is located. MCI provides a short-term service (24/7) that is a mobile, on-site, face-to-face, therapeutic response to a youth experiencing a behavioral health crisis for the purpose of identifying, assessing, treating, and stabilizing the situation and reducing immediate risk of danger to the youth or others consistent with the youth’s risk management/safety plan, if any. Family Partners are among the staff working in this program to support youth and their families.

- **Adult Mobile Crisis Intervention:** ESP services will be offered in individuals’ homes and elsewhere in the community on a mobile basis. This service will be provided to any community-based location, including private homes, from 7 a.m. to 8 p.m. Outside of those hours, Adult Mobile Crisis Intervention services shall be provided by all ESPs in residential programs and hospital EDs. Additionally, some ESPs may choose to mobilize to other locations during these hours, and some will keep their community-based locations open during these hours (see below) as another alternative site.

- **ESP Community-Based Location:** Each ESP will operate at least one location in the catchment area where its services will also be available. These locations will be open a minimum of 12 hours per day on weekdays and eight hours per day on weekends. Some of these sites will be open 24 hours per day. Peer Specialist services are incorporated into the ESPs’ community-based locations.

- **Adult Community Crisis Stabilization (CCS):** ESPs operate CCS programs that provide staff-secure, safe, and structured crisis treatment services in a community-based program, which serves as a less restrictive and voluntary alternative to inpatient care. This program serves ages 18 and older.

### **Population Served**

ESP services are available to individuals of all ages who are uninsured as well as those covered by the following public payers:

- MassHealth plans (PCC Plan/MBHP, MassHealth-contracted Managed Care Entities, and MassHealth fee-for-service);
- DMH only; Medicare; and Medicare/Medicaid.
- Many ESPs are also contracted with various commercial insurance companies to provide similar services.



**Call the Statewide Emergency Services Program (ESP) Toll Free 1-877-382-1609 and enter your zip code to get the toll free phone number for your local ESP provider. Don't dial 911 first if you are a client of DMH or have MassHealth; contact the ESP that serves your area.**

## **FINANCIAL AND LEGAL CONSIDERATIONS**

### **Federal Programs: SSI, SSDI, Medicaid, Medicare**

Both SSI (Supplemental Security Income) and SSDI (Social Security Disability Insurance) are designed to provide monthly income to people with severe, long-lasting disability that would preclude self-supporting work. SSI is based upon need; information about living costs and resources must be supplied to qualify. SSI may also be available for a child in residential treatment. SSDI eligibility is based upon both disability (same medical requirements as SSI) and work history, including age.

You may apply by telephone, 800-772-1213, (TTY 800-325-0778) 7 a.m. to 7 p.m. Monday-Friday, by mail or in person at your local Social Security Administration Office. Since benefits are retroactive to the first application, if approved, early application and persistent follow-up are advantageous. It is recommended that you make a copy of anything mailed to these agencies and that they be sent "Return Receipt Requested" at the Post Office.

If benefits are denied, the ruling may be appealed by requesting:

- a reconsideration;
- a hearing before an administrative law judge;
- a review of the decision by the Appeals Council; or
- civil action in federal district court

You have 60 days to appeal between each level of ruling. Consult an attorney if you need to appeal. Start with the local legal aid in your community which can be located at [www.masslegalservices.org/perl/services.cgi](http://www.masslegalservices.org/perl/services.cgi) to see if you're eligible for sliding scale or free services. If you're not eligible for their services, request a referral to an attorney who specializes in Federal and State benefit programs.

SSI payments may go directly to the claimant or to a representative payee if the person disabled by mental illness cannot manage funds; benefits will begin immediately after disability and eligibility is established. SSI recipients in Massachusetts automatically receive Medicaid (MassHealth) simultaneously. SSDI payments can start the sixth month after established onset of disability. After two years on SSDI, the disabled person will automatically receive Medicare benefits. Social Security programs allow a disabled person to earn limited amounts each month and keep limited savings while benefits continue, and a variety of work incentives are available for those attempting return or entry to work.

To learn more about benefits and eligibility you should obtain publications from the Social Security Administration (SSA) and inquire further about your particular situation. Be sure to check on continued eligibility periodically, especially upon confinement in a mental hospital or state institution. The official Social Security website is [www.ssa.gov](http://www.ssa.gov).

## **STATE AND LOCAL ASSISTANCE AND PROGRAMS**

**Medicaid in Massachusetts is called MassHealth.** MassHealth offers a broad range of health-care services, including mental health care and prescription drug coverage, by paying



for part or all of a MassHealth member's health insurance, or paying medical providers for services given to MassHealth members.

If you meet one of the following descriptions and you are otherwise eligible, including your income, you may be eligible for MassHealth:

- You are a parent living with your children under age 19; or
- You are an adult caretaker relative living with children under age 19 who is related to you; or
- You are under age 19, whether or not you live with your family; or
- You are pregnant, with or without children; or
- You have been out of work for a long time; or
- You have been designated as disabled (this includes individuals with mental illness);
- You are an adult who work for a qualified employer; or
- You are HIV positive.

If you are eligible for MassHealth because of a disability (mental illness), you will have a choice of which plan you want: 1) one of four Managed Care Plans (MCOs) or the PCC plan (Primary Care Clinician). The rules for each MassHealth program are very complicated. You need to carefully review what mental health services are offered under each plan as they do differ.

If you think you are eligible, call MassHealth Customer Service at 1-888-665-9993 to request a Medical Benefit Request (MBR), which is the application. You can also download the form from the EOHHS website ([www.mass.gov/masshealth](http://www.mass.gov/masshealth)). Submit a completed MBR to (always keep a copy for your files):

MassHealth Enrollment Center  
Central Processing Unit  
P.O. Box 290794  
Charlestown, MA 02129-0214

It will take about 6 weeks to get a written response from MassHealth. It will take longer if you are seeking MassHealth because of your disability. If you don't already receive Social Security Disability Income (SSDI) or SSI, MassHealth will send you for a "disability determination" evaluation from a medical doctor and your application will take longer.

Effective July 1, 2009, new MassHealth Services for behavioral-health issues include mental health and substance abuse problems are available to children and youths under the age of 21 who are enrolled in MassHealth Standard and Commonwealth Care. In all services, parents and caregivers will play a strong and active role in deciding about treatment for their child.

If your child is not enrolled in MassHealth, but has a serious emotional disturbance, he or she may be eligible for Commonwealth Care; please call 800-497-4648. If your child is enrolled in MassHealth please call 1-800-495-0086.

The services that have gone into effect as of July 1 include:

**1. Intensive Care Coordination:** a care coordinator works with the family to create a care planning team for their child. Team members come up with an Individual care plan to address

the youth's needs and support the family and youth's goals. The plan guides the youth's care and helps organize any services the youth receives, even from other agencies.

**2. Family Partners:** Family partners are parents or caregivers of children with special needs themselves and help parents/caregivers to help their youth achieve their treatment goals.

**3. Mobile Crisis Intervention:** Mobile crisis intervention is called when a child is having a behavioral-health crisis. Teams are available 24/7 and go where your youth is located. They can help your family for up to 72 hours and can help secure other services.

**The Department of Transitional Assistance** (DTA formerly known as “Welfare”) serves one out of every twelve people in the Commonwealth - including working families, children, elders, and people with disabilities. Their services include food and nutritional assistance, cash assistance, employment supports, and emergency shelter.

**Transitional Aid to Families with Dependent Children** (TAFDC) is a state and federally funded program which provides cash assistance to families with children and pregnant women in the last 120 days of pregnancy, with little or no assets or income. It is operated under the federal Temporary Assistance for Needy Families (TANF) block grant and is described in the Commonwealth’s [TANF State Plan](#). Participants receive child care and transportation support associated with job assistance and can access a number of supportive referrals to substance abuse and mental health services, and domestic violence specialists.

As part of TAFDC, participants may be required to perform a work-related activity in order to receive benefits. DTA provides job assistance to TAFDC participants including job training, job search, and placements into jobs. Other key services include Access to Basic Education, English for Employment, Graduate Equivalency Diploma (GED) assistance, work readiness and skills training. It is especially important for clients to gain employment during their time on TAFDC as recipients are limited to 24 months of assistance in any continuous 60-month period. DTA offers many [job assistance programs](#) to provide clients with access to employment and training opportunities.

To be eligible for TAFDC, a recipient must:

- Meet certain requirements including:
  - Have at least one dependent child under 18 or 19 (including teen parents) OR
  - Pregnant women with no children (the child is expected to be born within 120 days of the application)
- Meet income and asset limits
- Be a U.S. citizen or a legal immigrant
- Live in Massachusetts

**The Emergency Aid to the Elderly, Disabled, and Children (EAEDC)** is a state funded program which provides cash assistance to those in need to stabilize their lives. To receive EAEDC, recipients must meet certain requirements including one or more of the following:

- Unable to work due to a physical or mental incapacity which has lasted or will last at least 60 days and meets the Department-established medical standards for disability;

- Over 65 years old and waiting for Supplemental Security Income (SSI) payments to begin;
- Caring for a child living in the home and not related to the individual;
  - Participating in a Massachusetts Rehabilitation Commission program; or
  - Required to be in the home to care for an incapacitated individual who would have to be institutionalized if someone does not provide the care in the home.
- Meet income and asset limits
- Be a U.S. citizen or a legal immigrant.

For more help applying for public assistance, call the Application Information Unit at 1-800-249-2007. There are Transitional Assistance offices located across the Commonwealth. To [locate the office](#) covering a city or town, call the Application Information Unit at 1-800-249-2007.

## **HEALTHCARE INFORMATION AND DECISIONS**

### **Health Insurance Portability and Accountability Act of 1996 (“HIPAA”)**

The Health and Human Services Office for Civil Rights Web site ([www.hhs.gov/ocr/hipaa](http://www.hhs.gov/ocr/hipaa)) offers a variety of resources to help people understand HIPAA and how to file a complaint if your rights under HIPAA have been violated. The rules are complex and like any rules can have unintended consequences. They were not meant to discourage doctor-family communication, but only to give patients some control over their medical information.

Doctors are well within their rights to encourage patients to give consent for sharing information with family members, and they need to explain why it's important. Collaboration is needed when families are deeply involved in their loved ones' care. Research has shown that when family members are involved, patients with serious mental illness stay better longer and have fewer relapses. The patient and therapist together can specify what information can and cannot be shared.

Parents who are financially supporting a child over the age of 21 may decide the conditions under which they will continue their support and pay for treatment. They may decide that one of those conditions is that they have some basic information from the patient and therapist about how they can help. We are not suggesting that the family should get access to their child's full records, but only information on how to help and what to expect.

Most hospitals and clinics have their own HIPAA release forms. A person can sign a release so family members can have access to medical records and speak to the medical team.

Professionals often cite HIPAA when refusing to talk with Family Care Givers about their ill family member. There is nothing in the HIPAA laws that prevent professionals from listening to family caregivers.

### **Health Care Proxy**

If the ill person is willing, family members may wish to ask him or her to execute (1) a health care proxy and (2) a document authorizing a health care provider to disclose protected health information. You can obtain a form from this state website:

<http://www.massmed.org/AM/Template.cfm?Section=Search&TEMPLATE=/CM/ContentDisplay.cfm&CONTENTID=2570> or by contacting an attorney.

The use of a health care proxy in Massachusetts would allow a competent adult to authorize another person to make health care decisions on the individual's behalf. However, the health care proxy would not take effect until a doctor decides that the individual is incapable of making health care decisions. People who want to use a health care proxy or a written authorization may want to pursue these matters further with specific health care providers and/or a legal advisor.

Even if a health care provider is not able to communicate with a family member, family members and other caregivers should supply the health care provider with whatever written health information they would like to share. Letters, faxes or e-mails are preferable to telephone messages. If time is of the essence, a telephone message should be confirmed with some kind of written documentation. Keep copies of all letters, emails, faxes, etc.

### **GUARDIANSHIP AND CONSERVATORSHIP**

A guardian is a person appointed by the court to handle both the personal and financial affairs of another person or "ward," that is incapable of handling his or her affairs due to mental illness or other disability.

A conservator handles only the ward's financial affairs, leaving the ward to make personal decisions.

After age 18, all Massachusetts residents are legally considered to be adults able to make their own decisions, even if they are bad ones. Only through court action can anyone legally be appointed guardian or conservator. Since controlling someone else's right to make decisions is a serious step, all alternatives should be carefully considered:

- Can the mentally disabled person get by with the advice from family and friends?
- Can the mentally disabled person be taught improved living and decision-making skills?
- Can financial assistance such as direct deposit, special bank accounts, trusts, durable power of attorney or representative payee for benefits checks be set up on a temporary or long-term basis?
- Does the mentally disabled person have enough income to require conservatorship?

Guardianship could be limited to certain areas of decision-making such as medical treatment. The use of guardianship or conservatorship could undermine the already damaged confidence and self-esteem of a person confronting mental illness and cause more harm than good by hindering recovery or beneficial effects of treatment. Most alternatives to guardianship or conservatorship can be adjusted or reversed as an individual's needs and abilities change, but only the courts can turn off or alter guardianship and conservatorship.

The Mental Health Legal Advisors Committee has a detailed guide titled "*An Explanation in Simple Terms of Guardianship, Conservatorship, and Other Options*", (updated December 2007) which is available for purchase from its website [http://www.mhlac.org/Order\\_Publications.htm](http://www.mhlac.org/Order_Publications.htm).

### **WILLS AND ESTATE PLANNING**

Family members play an important role in helping relatives who are disabled by mental illness, but many are concerned about what will happen when they are no longer able to do so or are no longer alive.

Wills and estate lawyers can help families plan estates and trusts for disabled beneficiaries in ways that will prevent invasion of estates and trusts for "cost of care" reimbursement and supplement but not interfere with services and entitlements provided by the federal and state government, such as housing, case management, SSI, SSDI, Medicaid (MassHealth) and Medicare.

Trustees must file tax forms annually and must keep abreast of new laws as they might affect the operation of the trust. Remember: Money willed directly to a disabled person could cause cancellation or suspension of all of the person's financial (entitlement) support programs until the money is spent down to an established threshold.

Families may need an organization to act in their place ensuring that the disabled family member receives government entitlement benefits and the best possible quality of care from the mental health system, whether the member is in the community or in the hospital. Here is where a PLAN type organization could help. PLAN-sponsored support services can be put in place while families are still alive and responsible, to supplement and reassure continuity of caring. Go to [www.nami.org](http://www.nami.org) and click on Special Needs Estate Planning for more information. You should also consult an attorney that specializes in Medicaid and Special Needs Trusts as well as other Estate Planning and Income Tax areas.

### **STRAYING, MISSING OR HOMELESS**

Some people who are mentally ill may feel a need to escape from their environment. Many families have had their mentally ill relatives missing for various lengths of time. Sometimes the ill person may call a family member or friend periodically or let him/herself be found in a hospital, shelter or jail. Some may vanish completely, however, possibly eluding much-needed treatment. As soon as you are certain your ill relative is missing, you should call the local police, requesting that the person be placed on the Police Missing Persons' List nationwide.

Pamphlets describing what to do when a person is missing and what to do when he or she is found are available at the NAMI Mass office, 800-370-9085 or on-line at [www.nami.org](http://www.nami.org) under Find Support you'll see Missing Persons. There is also information about what to do if one's family member has to deal with the criminal justice system.

### **NAMI MASS EDUCATION AND SUPPORT PROGRAMS:**

**FAMILY-TO-FAMILY** ("F2F") Education Program is a free course for caregivers of individuals affected with a serious brain disorder, i.e. mental illness. F2F is taught by trained family member volunteers in 12 weekly sessions of 2 ½ hours (usually on a week night). Class size is limited to about 20. Participants must be pre-interviewed by the co-teachers prior to the course. All instruction and course materials are free for class participants. The program is funded, in part, by the Massachusetts Department of Mental Health.

The Family-to-Family curriculum utilizes a variety of teaching techniques and includes a broad range of topics:

- Information about Bipolar Disorder, Major Depression, Schizophrenia, Borderline Personality Disorder, Panic Disorder and Obsessive Compulsive Disorder (OCD)
- Coping skills, handling crisis and relapse;
- Listening and communication techniques;
- Problem solving and limit setting;
- Understanding the actual experience of people suffering from mental illness;
- Self-care; learning how to recognize normal emotional reactions among families;
- Basic information about medications and their side-effects;
- Information about connecting with appropriate community services and community supports;
- Advocacy, getting better services, fighting discrimination and stigma; and more!

For more information about the Family-to-Family course please contact the Family Education & Support Programs Coordinator, at 800-370-9085 [info@namimass.org](mailto:info@namimass.org)

**FAMILY SUPPORT GROUPS FOR CAREGIVERS:** There are a number of free support groups around the state that can provide understanding, comfort, hope and help for family members and friends and other caregivers. It is always a good idea to call the contact person before attending the first meeting because meeting dates, times, and locations may change. To find the one closest to your area contact your local affiliate, go to [www.namimass.org](http://www.namimass.org) and click on Affiliate and Support Groups listings, call the NAMI Mass office at 800-370-9085 or email [info@namimass.org](mailto:info@namimass.org)

**NAMI Basics** is an education program for parents and other caregivers of children and adolescents living with mental illnesses. The NAMI Basics course is taught by trained teachers who are the parent or other caregivers of individuals who developed the symptoms of mental illness prior to the age of 13 years. The course consists of six classes, each lasting for 2 ½ hours. Classes may be offered weekly for six consecutive weeks, or may be offered twice per week for three weeks to accommodate hectic schedules. All instruction materials are FREE to participants.

NAMI is pleased to announce the publication of a recent research study on the NAMI Basics Education Program in the Journal of Child and Family Studies. The study was conducted in collaboration with NAMI Mississippi and NAMI Tennessee between 2008 and 2010 and found that NAMI Basics produces “significant improvement” for families in communication and coping skills. For more information about the Family-to-Family course please contact the Director of Children and Adolescent Programs, at 800-370-9085 [info@namimass.org](mailto:info@namimass.org).

**IN OUR OWN VOICE (IOOV a program also funded, in part by DMH)** is a free presentation given by trained speakers living with a mental illness, about their journey with their disease. The hour-long talk is appropriate for family members, friends, professionals, lay audiences and other people living with mental illness. It includes a videotape, personal testimony, and audience discussion. The presentation enriches the audience’s understanding of how people with serious disorders cope with the reality of their illnesses while recovering and reclaiming productive lives.

- Two trained speakers do the presentations together.
- Presenters receive a stipend for the presentations.



IOOV presentations are given to consumer groups, students, law enforcement officials, educators, providers, faith community members, politicians, professionals, inmates, and interested civic groups. All presentations are offered free of charge.

Please contact the In Our Own Voice Statewide Coordinator, at 800-370-9085 or [helpline@namimass.org](mailto:helpline@namimass.org) if you would like to participate in the program or if you would like to arrange for speakers to come to your group.

**NAMI CONNECTION RECOVERY SUPPORT GROUPS:** The NAMI Connection recovery support group, for adults living with mental illness, provides a place that offers respect, understanding, encouragement, and hope.

The support groups are run by people living with mental illness themselves. Each group meets weekly for 90 minutes, is confidential, free of charge, and is open to anyone with a mental illness, regardless of diagnosis.

To find the support group closest to your area, contact your local affiliate, go to the NAMI Mass website ([www.namimass.org](http://www.namimass.org)) and click on NAMI Connection Recovery Support Groups call the NAMI Mass office at 800-370-9085 or email [helpline@namimass.org](mailto:helpline@namimass.org).

### **LEGISLATIVE ADVOCACY:**

Legislative advocacy engages the NAMI membership, the community, public and private entities, and members of the legislature in supporting or opposing legislation that impacts the well being of mentally ill persons. To get involved contact your local affiliate or call the NAMI Mass office at 800-370-9085. NAMI Mass is the ***State's Voice on Mental Illness***.

### **LEGISLATIVE PRIORITIES for NAMI MASS:**

**Restore Funding to the Department of Mental Health:** We must increase community-based services for individuals with serious psychiatric conditions whose lives depend upon residential, community support services and, at times, acute services. The lack of available DMH services severely impacts the care of individuals with mental illness, gravely affecting families and communities. Governor Deval Patrick has, in fact, stated that "Increasing access to mental health treatment and support for children and adults" is one of his core principles for Health and Human Services. The FY 2009 budget of \$685 million was cut by \$33.5 million last October. A total of 2,600 individuals with severe mental illness lost all DMH day services, while 3,600 people experienced a reduction in their DMH services. A one-time infusion of trust funds, \$24.2 million, lessened the impact on services this year, but the trust funds will not be available in the FY 2010 DMH budget. DMH's proposed FY 2010 budget, starting July 1, 2009, includes a massive cut of roughly \$50 million from the original FY 2009 appropriation of \$685 million. Fifty million dollars is essentially **four times** the amount of cuts this year. The result will be a catastrophic dismantling of services.

**Preserve Access to Appropriate Medications** Mental health patients often do not experience similar therapeutic effects from similar medications. Therefore, all anti-psychotics, anti-depressants and anti-convulsants used in the treatment of mental illness must be made available to optimize successful treatment. Restricting access to mental health medications and medical treatments, especially those for acute illness, can easily require more costly inpatient treatments and emergency services in the long run.

**Promote Housing for People with Mental Illness:** Safe and affordable housing for the mentally ill is crucial for recovery. State hospitals were originally intended to serve the mentally ill, and with the advent of more cost effective, humane, community-based services, it is now possible to consolidate hospitals and save valuable tax dollars. Housing for the mentally ill must be established when state surplus land use legislation is passed.

**Encourage Jail Diversion and Coordinated Re-Entry Services From the Criminal Justice System.** Incarceration of the mentally ill is detrimental to both the individual who does not receive proper treatment and taxpayers who must pay the cost of unjust imprisonment. Jail diversion has been shown to be an effective way to provide appropriate treatment for the mentally ill and ensure a safer community.

**Establish a Comprehensive Children's Mental Health Service System:** About 1 in 10 children in the U.S. suffers from a mental illness severe enough to cause impairment. Research shows that reaching children with mental illnesses early with appropriate treatment significantly improves their long-term prognosis. Conversely, the failure to provide treatment has tragic consequences. Families know all too well that the system is failing children and adolescents with mental illnesses. NAMI Mass must focus attention on systems reform and to help and support families so that no child or family is left behind as the state works to be in compliance with *Rosie D. v. Romney*.

### **NAMIWalks**

Every year in May, NAMI Mass hosts the "Walk for the Mind of America."

Join the thousands of concerned citizens in Massachusetts to raise money and awareness about our state's need for a world-class treatment and recovery system for people with mental illness. Won't you join us? NAMI Mass depends on generous volunteers to raise funds and awareness at our Walk.

Affiliates keep a 45% share of the walk revenues they earn, and they spend the money locally on efforts such as funding wellness programs, purchasing recreational equipment, paying for varied clubhouse expenditures and conducting educational and support programs, including absorbing the transportation costs of the volunteer facilitators at support and education group meetings

To date, the Children's Challenging Behavior and our advocacy programs are largely funded by Walk money. With the money raised by the sponsors, teams and individuals walkers, we continue to expand our education and support groups, improve our informational and referral services, advocate for the rights of those with mental illness and their loved ones and advance public policy which will improve the mental health system.



For more information visit [www.nami.org/namiwalks/ma](http://www.nami.org/namiwalks/ma) or contact the NAMI Mass office at 800-370-9085.

Membership	
Individual/Family Membership	\$35
Low Income Membership	\$3

You can mail a check made payable to NAMI Mass and mail it to: NAMI Mass  
400 West Cummings Park, Suite 6650  
Woburn, MA 01801

You may also join online at [www.nami.org](http://www.nami.org)

You may also donate online at [www.namimass.org](http://www.namimass.org)

Tax deductible donations are welcome. NAMI Mass is a 501(c)(3) nonprofit organization.

### Local NAMI Affiliates

NAMI Berkshire County	413-443-1666
NAMI Cambridge/Middlesex	617-984-0527
NAMI Cape Ann	978-281-1557
NAMI Cape Cod & the Islands	508-778-4277
NAMI Central MA	508-368-3562
NAMI Central Middlesex	781-982-3318
NAMI Coastal	781-878-4400
NAMI Greater Boston Consumer Advocacy Network (CAN)	617-305-9975
NAMI Greater Fall River	508-678-2584
NAMI Greater Framingham	508-875-1544
NAMI Greater Lowell	978-677-0618
NAMI Greater North Shore	877-221-6264
NAMI Latino Metro Boston	857-234-9688
NAMI Newton/Wellesley	617-244-9833
NAMI North Central MA	978-772-4243
NAMI Northeast Essex County	978-462-2471
NAMI Plymouth	781-829-7215
NAMI South Norfolk	508-668-2941
NAMI South Shore	617-773-7440
NAMI Western MA	413-786-9139

### Some Common Acronyms

National Alliance on Mental Illness	NAMI
Dept. of Mental Health	DMH
Dept. of Children & Family Services	DCF (formerly DSS)
Dept. of Social Services	DSS (now DCF)
Dept. of Developmental Disabilities	DDD (formerly DMR)
Dept. of Mental Retardation	DMR (now DDD)
Diagnostic & Statistical Manual of Mental Disorders, 4th Edition (1994)	DSM-IV
Severe and Persistent Mental Illness	SPMI
Post Traumatic Stress Disorder	PTSD
Obsessive Compulsive Disorder	OCD
Attention Deficit Hyperactivity Disorder	ADHD
Cognitive Behavioral Therapy	CBT
Dialectic Behavioral Therapy	DBT
Electroconvulsive Therapy (ECT)	ECT
Licensed Social Worker	LICSW
Community Mental Health Center	CMHC
Community Based Flexible Supports	CBFS
Emergency Service Programs	ESP

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## Appendix A – Useful Resources

Note: Many more resources are located on the NAMI Mass website ([www.namimass.org/](http://www.namimass.org/) click on How to Find Help and then on the Comprehensive Resource List) or you can contact the NAMI Mass office at 800-370-9085 or your local affiliate

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### **SAMARITANS: 1-877-870-4673 (statewide) - not a crisis line**

**Massachusetts Warmlines:** The Warmline is a call in service that provides the community with a place to turn if they need someone to talk to. The Warmline Staff are Mental Health Consumers. All staff have received the training and education needed to provide Warmline services to the community. All calls are kept confidential. What you say is kept between you and the Warmline staff. The only exception is when the call is considered a crisis. In this case the call will be referred to the crisis service.

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- **Edinburg Center warmline:** Mon-Fri 5-10 pm, Sat & Sun 1-10 pm, 781-862-3000, 781-860-0570, or 1-800-243-5836 (For the 24 hr crisis line call 1-800-540-5806, (TTY) 1-800-498-4850)
- **South Shore:** Mon-Fri & Sun, 617-689-1050, 617-689-1051 (For the 24 hr crisis line call 1-800-528-4890 or 617-774-6036)
- **CASTLE: SU-F, 7-11 pm, 617-610-7907, 617-243-3977 (this is not a crisis line)**
- **SMOC:** 508-879-2250 x 131 (this is not a crisis line)
- **MetroBoston Recovery Learning Community**  
Peers can request regular check-ins  
Toll-free number: 877-733-7563 (877-PEER LNE)  
Hrs of operation: every Mon., Thurs. & Sat., 4-8 p.m.  
Email: [adwyer@metrobostonrlc.org](mailto:adwyer@metrobostonrlc.org)

There are more warmlines listed on our website under How to Find Help, on the Comprehensive Resource List ([www.namimass.org/helpline/inforefer3.htm](http://www.namimass.org/helpline/inforefer3.htm))

<b>NAMI</b>
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**NAMI Mass helpline**

Phone: 800-370-9085 Mon.-Fri. 9am – 5pm

Email: [info@namimass.org](mailto:info@namimass.org) anytime

Website: [www.namimass.org](http://www.namimass.org) check out our frequently asked questions (FAQ) page

**NAMI helpline**

Phone: 800-950-6264 Mon.-Fri. 11am – 4pm

Website: [www.nami.org/Content/ContentGroups/Helpline1](http://www.nami.org/Content/ContentGroups/Helpline1)

<b>Substance Abuse</b>
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Mass. Substance Abuse Information & Education

Phone: 800-327-5050

Website: [www.helpline-online.com/HelplineSearch.aspx?pl=helpline](http://www.helpline-online.com/HelplineSearch.aspx?pl=helpline)

Alcoholics Anonymous

Phone: 617-426-9444  
Website: [www.aaboston.org](http://www.aaboston.org)

Narcotics Anonymous  
Phone: 866-624-3578  
Website: [www.newenglandna.org](http://www.newenglandna.org)

Dual Recovery Anonymous  
Phone: 913-991-2703 (afternoons)  
Website: [www.draonline.org](http://www.draonline.org)

### **Grief Support Services**

Samaritans- SafePlace peer support groups, Survivor to Survivor Network, Befriending Services:  
Phone: 877-870-4673  
<http://www.samaritansofboston.org/survivor.html>

### **Housing**

Mass. Nonprofit Housing Association  
Phone: 617-367-9798  
Website: [www.masshousinginfo.org/mnpha/members](http://www.masshousinginfo.org/mnpha/members)

Mass. Housing Consumer Education Center  
Phone: 800-224-5124  
Website: [www.masshousinginfo.org/resources/index](http://www.masshousinginfo.org/resources/index)

Mass Access: The Accessible Housing Registry (CHAPA)  
Phone: 800-466-3111  
Website: [www.massaccesshousingregistry.org](http://www.massaccesshousingregistry.org)

Household Goods Recycling Ministry  
Phone: 978-635-1763  
Website: [www.hgrm.org/](http://www.hgrm.org/)

### **Health Insurance**

Health Care For All – helpline  
Phone: 800-272-4232  
Website: [www.hcfama.org](http://www.hcfama.org)

Medicare Advocacy Project  
Phone: 860-456-7790  
Website: [www.medicareadvocacy.org](http://www.medicareadvocacy.org)

Medicaid (MassHealth)  
Phone: 800-841-2900  
Website: [www.mass.gov/masshealth](http://www.mass.gov/masshealth)

### **Legal**

Mass. Legal Aid Services by County  
Website: [www.masslegalservices.org/perl/services.cgi](http://www.masslegalservices.org/perl/services.cgi)

Mass. Bar Association Referral  
Phone: 866-627-7577

American Bar Legal Referral Service  
Website: [www.abanet.org/legalservices/lris/directory/main.cfm?id=MA](http://www.abanet.org/legalservices/lris/directory/main.cfm?id=MA)

Mass. Housing Court (By County, Frequently Asked Questions)  
Website:  
[www.mass.gov/courts/courtsandjudges/courts/housingcourt/housingquestions.html#19](http://www.mass.gov/courts/courtsandjudges/courts/housingcourt/housingquestions.html#19)

Mass. Trial Court Law Libraries – Forms  
Website: [www.lawlib.state.ma.us/formsf-l.html](http://www.lawlib.state.ma.us/formsf-l.html)

### **Patient Assistance Programs**

NAMI list of pharmaceutical companies and other patient assistance programs  
Website:  
[http://www.nami.org/Content/ContentGroups/Helpline1/Prescription\\_Drug\\_Patient\\_Assistance\\_Programs.htm](http://www.nami.org/Content/ContentGroups/Helpline1/Prescription_Drug_Patient_Assistance_Programs.htm)

MassMedLine is a free, confidential service available to all Massachusetts residents who are seeking information regarding their medications. Whether you are having difficulties affording your medications or want to know what the side-effects are to your prescriptions, MassMedLine can help:  
Phone: 866-633-1617  
[http://www.massmedline.com/for\\_patients/index.html](http://www.massmedline.com/for_patients/index.html)

Extra help for Medicare (Part D) beneficiaries: help with lowered premiums and co-pays if you have limited income and resources, find out if you are eligible and apply online, in English and Spanish:  
<http://www.ssa.gov/prescriptionhelp/>

### **Food Stamps and Food Pantries**

Project Bread Food Source Hotline:  
Phone: 800-645-8333  
Website: [http://www.projectbread.org/site/PageServer?pagename=end\\_foodsourcehotline](http://www.projectbread.org/site/PageServer?pagename=end_foodsourcehotline)

### **Other Assistance Programs (Utility, Oil/Gas, etc)**

Mass. Association for Community Action Programs (MASSCAP),  
Phone: 617-357-6086  
Website: <http://www.masscap.org/agencies.html>

### **Public Transportation**

American Public Transportation Association – Mass Transits Links  
Website: [http://www.apta.com/links/state\\_local/ma.cfm](http://www.apta.com/links/state_local/ma.cfm)

<b>Children</b>
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Parent Professional Advocacy League

Phone: 866-815-8122

Website: [www.ppal.net](http://www.ppal.net)

Massachusetts Society for the Prevention of Cruelty to Children

Phone: 617-587-1500

Website: [http://www.mspcc.org/site/PageServer?pagename=progs\\_Overview](http://www.mspcc.org/site/PageServer?pagename=progs_Overview)

The Home for Little Wanderers

Phone: 888-HOME-321

Website: [http://www.thehome.org/site/PageServer?pagename=programs\\_about](http://www.thehome.org/site/PageServer?pagename=programs_about)

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### Hotlines/Helplines

Disabled Person's Protection Hotline, Adults (Ages 18-59) can report physical abuse or neglect by their caretakers: 617-727-6469 or 800-426-9009

**National Suicide Hotline: 1-800-273-8255**

<http://www.suicidepreventionlifeline.org/>

Center for Violence Prevention and Recovery, Services and Resources: Website:

[http://www.bidmc.harvard.edu/display.asp?node\\_id=9808](http://www.bidmc.harvard.edu/display.asp?node_id=9808)

Rape, Abuse & Incest National Network, Local Crisis Centers in Mass: 800-656-4673

Website: <http://centers.rainn.org/>

National Domestic Violence Hotline: 800-799-7233

Website: <http://www.ndvh.org/help/index.html>

Parents Stress Line: 800-632-8188

Baby Safe Haven:

Phone: 866-814-SAFE

Website: <http://www.babysafehaven.com/>

Child-At-Risk Hotline, report child abuse: 1-800-792-5200

### Veterans Resources

Dept. of Veterans Affairs **Hotline, Staffed 24/7** with Mental Health professionals who can refer callers to one of more than 120 VA crisis centers closest to them. **800-273-8255**. Spanish speaking line is 888-628-9454.

Veterans Outreach and Counseling in Massachusetts:

<http://www.sec.state.ma.us/cis/cisvet/vetoutr.htm>

VA New England Healthcare System:

<http://www.newengland.va.gov/>

Operation Healthy Reunions, information for troops and their families:

<http://www.nmha.org/reunions/>

Veterans Resources at the NAMI website:

[http://www.nami.org/Template.cfm?Section=Veterans\\_Resources&Template=/ContentManagement/ContentDisplay.cfm&ContentID=53587&Istid=879](http://www.nami.org/Template.cfm?Section=Veterans_Resources&Template=/ContentManagement/ContentDisplay.cfm&ContentID=53587&Istid=879)

### Recovery Learning Communities

Metro Boston Recovery Learning Community

Solomon Carter Fuller MHC Ground Floor

85 East Newton St., Boston, MA 02118

Phone: (617) 305-9976

Email: [info@bostonresourcecenter.org](mailto:info@bostonresourcecenter.org)  
Website: [www.metrobostonrlc.org](http://www.metrobostonrlc.org)

Metro Suburban Recovery Learning Community  
460 Quincy Ave., Quincy, MA 02169  
Phone: (617) 472-3237  
Toll-Free: (888) 752-5510  
Email: [info@metrosubrlc.org](mailto:info@metrosubrlc.org) '  
<http://metrosuburbanrlcblog.com/>

Central Mass Recovery Learning Community  
91 Stafford St., Worcester, MA 01603  
Phone: (508) 751-9600  
Email: [info@centralmassrlc.org](mailto:info@centralmassrlc.org)

Southeast Recovery Learning Community  
71 Main St., Suite 1100, Taunton, MA 02780  
Phone: (508) 880-8527  
Email: [ecampbell@comcounseling.org](mailto:ecampbell@comcounseling.org)

Northeast Recovery Learning Community  
NILP, 20 Ballard Rd., Lawrence, MA 01843  
Phone: (978) 687-4288 (V/TTY)  
Email: [ndonald@nilp.org](mailto:ndonald@nilp.org)  
Website: <http://www.nilp.org/RLC.html>

Western Mass Recovery Learning Community  
187 High St., Suite 303, Holyoke, MA 01040  
Phone: (413) 539-5941  
Toll-Free: (866) 641-2853  
Email: [info@westrnmassrlc.org](mailto:info@westrnmassrlc.org)  
Website: [www.westernmassrlc.org](http://www.westernmassrlc.org)



## NOTES

## **EASY REFERENCE**

Local NAMI Affiliate:

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Day, Time, Location of Support Groups in my area:

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Crisis Team:

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DMH Area Office:

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Local Hospital:

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Psychiatric Hospital:

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Outpatient Services:

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Day Treatment Center:

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Local Clubhouse:

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Vocational Services and Training:

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Children's Services:

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Social Security Office:

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Legal Resource:

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