

FAMILY SURVIVAL HANDBOOK

Reaching Mental Health Recovery Together

TOOLS
FOR AND BY
FAMILIES

A joint collaboration between:

Family Institute for Education, Practice & Research

Mental Health Resources

National Alliance on Mental Illness of New York State (NAMI-NYS)

New York State Office of Mental Health

January 5, 2010

Endorsements:

"This Family Survival Handbook is an important tool ...to aid families in providing a most comprehensive care and treatment available. I thoroughly endorse this Family Survival Handbook as an important tool for the mental health and wellness of the people of New York"

Michael F. Hogan, PhD, Commissioner
New York State Office of Mental Health

"This Handbook assists patients, families and others concerned in demystifying this complex issue and offering a wide repertoire of assists... it is an invaluable tool...I am sure it will be seen as an outstanding help in making the exposure to this very considerable stress from psychiatric disorders more manageable."

Herbert Pardes, MD, President and Chief Executive Officer
New York-Presbyterian

"The Handbook is truly a well-written document with the potential to help many, many families and individuals in navigating the mental health system."

John B. Allen, Special Assistant to the Commissioner
New York State Office of Mental Health

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About this handbook

The *Family Survival Handbook* is a collection of practical, useful information contributed by over 65 family caregivers from New York City and State who have learned from experience how to navigate the public mental health system in New York State. Intended for use by families when a loved one is first diagnosed, admitted to a hospital, and after his/her discharge, this handbook's purpose is to provide information and resources while guiding users with informative tips designed to enable them to:

- Access educational materials;*
- Build a support network;
- Advocate for their loved one;
- Become meaningfully involved with their loved one's treatment team,
- Participate in the development of meaningful, recovery-oriented Treatment and Discharge Plans;
- Become informed about the spectrum of services their loved one might need,*
- Enable them to both request these services and access them themselves, as necessary*

With its companion pamphlets, *When Families Join the Mental Health Care Team Everyone Benefits!*, and how-to guide, *Understanding HIPAA, NYS Mental Hygiene Law and the Confidentiality of Mental Health Treatment and Information in New York State*, this Handbook will provide you with essential tools to help you better understand the many aspects of the mental health system so you can effectively support your loved one while he or she navigates the mental health system. Whether he or she is experiencing a "first break" (i.e., first episode of psychosis or first admission to a psychiatric ward) or a relapse, these materials will arm you with information about laws, policies, professional guidelines and resources to make your involvement in your loved one's recovery dynamic and effective. Because this Handbook is focused on a team approach to recovery, we encourage sharing all or part of it with your family member, as well as with the providers that are caring for your loved one.


HOW DOES IT WORK?

The Family Survival Handbook is organized into two sections. Part One highlights information you may need to quickly access, such as how to obtain your loved one's consent to have his/her treatment information disclosed to you, or how to apply for supplement-

tal income or insurance benefits. Part Two includes resources and reading lists, as well as tools such as the *Hospital Checklist* and *Management Log Sheets* to help you record important information, and capture and organize documents, in one easy-to-locate place. Part two also includes a list of resources. We encourage you to make use of the *Handbook* during all meetings and telephone calls with mental health professionals, and use the Pamphlet and How-to guide as a basis for your advocacy efforts.

The Handbook uses the following logos to make it easy to find the information you need:

R The **Resource Logo** identifies where you can find additional information about a particular topic, such as contact information, links and/or websites. This information is located in the "Resource" section in the back of the Handbook. Resource pages start at pg. 37.

 The **Toolbox Logo** alerts the user that the referenced worksheet can be found in the "Tools You Can Use" section in the back of the handbook. These tools include:

- **The Hospital Checklist:** this is a worksheet you can use to store all pertinent information regarding your loved one and his/her treatment. It is critically important to have this information readily available when your loved one is hospitalized. The Checklist provides space where you can record information including your loved one's contact information, the names/ contact information of mental health professionals who have been involved in providing care to him/her, diagnoses, status of government benefits, treatment goals, medication lists and discharge planning. This Checklist is located at the back of the Handbook in the "Tools You Can Use" section, will arm you with the facts you need to intelligently and effectively represent your loved one if he or she is hospitalized, and ensure the hospital has the critical information it needs to provide quality care.*
- **Management Log Sheets:** These forms can serve as your "working papers" where you can record a

chronological list of people with whom you speak with respect to your loved one's care, noting what was said and what determinations were made, both in and out of the hospital setting. These sheets are located at the back of the Handbook in the *Tools You Can Use* section, will help you record information that may be difficult to recall or gather at a later time. Information documented on these sheets can form the foundation for future dialogues, inform the decisions made by future treatment teams, and serve as a record if ever you need to file a complaint. If you need help in completing these forms, we recommend that you ask a hospital social worker or case manager to assist you.

Pamphlet and How-to guide on inside flap and are also available on the NYS OMH and NAMI NYS web sites:

It's not possible to advocate for your rights if you don't know what they are. The materials below, which are available in the side flap of the *Handbook*, not only apprise you as to what your rights are, but can serve as powerful tools for your advocacy efforts:

- *When Families Join the Mental Health Care Team Everyone Benefits!*
- *Understanding HIPAA, NYS Mental Hygiene Law and the Confidentiality of Mental Health Treatment and Information in New York State*

Introduction:

Your loved ones in the hospital.

Now what?

FINDING OUT YOUR LOVED ONE has a mental illness may be the toughest experience of your life. Few families are prepared or equipped to handle the traumatic and demanding responsibility suddenly thrust upon them. You are in an unfamiliar world with no compass to guide you. Yet, you must immediately become an advocate as you find information, locate services, navigate the mental health system, and manage the emotional, social and financial consequences of mental illness that affects everyone involved. How will you cope?

Here's the good news. Never before have we known so much about mental illnesses and how to enable people living with the diseases to live, work, learn and participate fully in the community. Long-term studies have consistently shown that over half of people diagnosed with major mental illness go on to a significant or complete recovery. The new field of neuroscience is proving that the brain can regenerate to a greater degree than was previously thought possible. Significant advances in research are providing a wider range of medications and psychosocial treatments that offer tools for self- and peer- help. Meanwhile, the mental health system is beginning to accept the truth that recovery is possible, particularly with support from peers, family and community. For the first time, optimal well-being or "wellness," not just absence or reduction of symptoms, is the goal of mental illness treatment.

Despite gains made in recent years, challenges remain. Although research and everyday experience has shown recovery occurs best when treatment professionals, the family and the patient work together, much of the information needed by consumers and families is still not easily accessible. This means families not only have to learn what information they need, but they must also work hard to get it and understand how to use it.

Successful families learn how to advocate, which means to "plead the cause" to "argue, defend, recommend." In order to stand up for what your loved one deserves, you must know. You must know the laws that govern their, and your, rights, and you must be persistent and vigilant to ensure that facilities comply with them. To some degree, the services you get will be the ones you fight for and insist on.

In this time of economic hardship, families have to fill the gap left from diminishing services. Families must be resilient and self reliant—we need to help ourselves and our loved one as never before.

We know we are throwing a lot of ideas and possibly unfamiliar language at you all at once. First-timers may want to initially focus on the *Hospital Care/Paying For it All/Discharge Planning* sections located in the front of the *Handbook*. Our goal, however, is to provide a reference to enable you to become familiar with the entire spectrum of what you'll potentially have to deal with. There is a huge amount of help for you in the mental health system, but it's up to you to find it and use it. This *Handbook* can empower you to ask informed questions, track the professionals' progress, have the tools to take over when necessary and even be ten steps ahead of the game! We hope, with this *Handbook* reference, questions will be answered for you in a way that they haven't been for families in the past.

NOTE: We use the term "Loved One," "Consumer," "Patient" and "Peer" interchangeably.

FAMILY EXPERIENCE OF MENTAL ILLNESS

WHEN MENTAL ILLNESS STRIKES, it is a family affair. Regardless of who carries the symptoms, the event is a catastrophic one that affects all family members. Therefore, the entire family needs to be involved. The ill family member must be supported and stabilized. Well family members need assurance that they are not to blame for their loved one's circumstance and that the situation is not hopeless.

Most often, when a loved one has been hospitalized, he or she is experiencing symptoms and may display behaviors that can make them seem unrecognizable—even to family members who have known the person all of his/her life. Educating yourself about the nature of mental illness will give you a window into your loved

one's struggle and help you understand that their illness is not their identity.

A mental illness can rob your loved one of strengths, coping skills and cognitive abilities—which are the basic mental skills we use to think and learn. In fact, depending on their diagnosis, your loved one may not realize he or she is sick, displaying a common symptom called *Anosognosia* or “lack of insight.”

**LACK OF INSIGHT:
THERE'S NOTHING WRONG WITH ME!**

Your loved one may not realize he is ill. Instead, he may actually believe his delusions and hallucinations are real. The term used by neurologists is “anosognosia,” which comes from the Greek word for disease (nosos) and knowledge (gnosis), literally meaning, “to not know a disease.”

Here's what we know about anosognosia:

- It is not denial, but a symptom of illness.
- It is caused by damage to specific parts of the brain, most likely the frontal and parts of the parietal lobe.
- It affects approximately 50% of individuals with schizophrenia and 40% of individuals with bipolar disorder.
- Individuals can be partially aware or fluctuate, being more aware when they are in remission and less aware when they relapse.
- It is the single largest reason why individuals with schizophrenia and bipolar disorders do not take their medications.
- Medications can improve awareness in some patients.

Severe lack of awareness is part of the disorder. Psychologist Xavier Amador, who has studied this phenomenon, counsels to “externalize the illness by Listening, Empathizing, Agreeing and finding Partnership (the LEAP approach). LEAP is a way of connecting and getting out of the battle... to find a common ground to allow an ill person to find his own reasons for being adherent. You can't use logic and expect insight when someone is delusional—the brain dysfunction is the enemy, not the patient.

**GETTING SUPPORT:
OTHER FAMILIES ARE THE BEST SUPPORT**

Some people have one episode of mental illness and then get on with their lives with little or no impairment. For others, these disorders of the brain can be lifelong illnesses, with a level of disability ranging from modest to severe.

The process and outcome of mental illness can cause family members to cycle through feelings of hope and despair. While it is a normal part of the family recovery process, shifts in feelings can be extreme, painful and confusing.

One of the most useful sources of support for families is... other families!. Families can experience one or more of the following stresses when coping with mental illness in the family: financial, interpersonal, marital, social, emotional, physical and/or spiritual. Sharing experiences and feelings in family support groups can reduce tension and help identify solutions that others with similar experiences have found useful.

And don't wait! Experienced caregivers say joining a good support group as early as possible is critical. Over time, you must learn to create a balanced life for yourself and other well family members, even as you care for the family member who is ill.

NAMI's signature **Family-to-Family Program** is a free twelve-week course offered by National Alliance on Mental Illness affiliates or chapters all over the country. Call them at NAMI-NYS at (518) 462-2000 or 800-950-3228 to locate the one nearest you.

SUPPORT GROUPS

The time to join a support group is right now. Here's what they can offer:

- Emotional support
- A break from isolation
- An outlet for from the range of emotional stresses named above
- How-to information
- A chance to compare notes on local services*
- Ability to draw on the experience of others*
- Opportunity to work through the “Stages of Grief”, including denial, anger, bargaining, and acceptance.

HOSPITAL CARE

IN THE CASE of an airplane crash landing, adult passengers are instructed to first put the oxygen mask on their own faces and then help their children with theirs. Likewise, when mental illness hits, families will be in the best position to help an ill family member if they make sure they take care of themselves and other members of the family.

The dictionary defines rehabilitation in this way: “To restore to a state of physical and mental health through treatment and training.” For families, rehabilitation is about acquiring information and education, working through feelings and reaching acceptance, while learning ways to help the family rebuild.

Rehabilitation is a process that begins in the hospital and continues after your loved one’s discharge. A rehabilitation program includes many components (see “Rehabilitation” on page 17). Several activities that should take place *while your loved one is hospitalized and immediately after his/her discharge*:

1. The patient and his/her family should receive timely education about the illness and the importance of staying on medications.
2. The family should immediately become involved with the patient’s Treatment Team, as authorized by the patient.
3. The patient, and family members as appropriate, should attend programs and post-discharge meetings to monitor the patient’s illness, watch for early signs of relapse, and obtain support and information.

The extent and depth to which you are involved with your loved one’s treatment could affect the course of his or her illness. One main goal of this section is to show you what you should expect to be entitled to, and how to get what you deserve.

CONFIDENTIALITY—GETTING CONSENT

In general, an adult competent patient must give permission to the hospital before a family member can be provided with information about the patient’s case. The Federal Health Insurance Portability and Accountability Act (HIPAA) and New York State Mental Hygiene Law which protect the confidentiality of patient information are unfortunately misunderstood, and sometimes even misused, to create an artificial barrier to family involvement in a loved one’s treatment.

Under HIPAA, persons have the right to “agree or object” to disclosures to family members or persons involved in their care. Similarly, New York State’s Mental Hygiene Law state that patient “consent” must be given before disclosures to family members can be made., but the actual form the “consent” must take is not specified. Therefore, as a general rule, an adult patient must give permission before families can be provided with information about them, and the fact that this permission has been obtained should always be documented.

INFORMATION NEEDS OF FAMILIES

- While your loved one is in the hospital, make sure you find out the following information:
- What is the patient’s psychiatric diagnosis (for example, schizophrenia), and what does it mean?
- What is the patient’s treatment plan for the psychiatric disability?
- What are some ideas and strategies on how to prevent a relapse?
- How can symptoms be identified?
- What resources and supports are available?
- What are some sources of personal stress and how can they be addressed?
- What is the family recovery process?
- What family/patient self-help/ advocacy groups are available?
- What are the legal issues to be aware of , e.g., patient rights, trusts and commitment laws?

Record the specifics in the Hospital Checklist pgs. 25-34, and the Management Log Sheets (pg 35.)

FIRST THINGS FIRST - TRY TO GET CONSENT!

Confidentiality rules reflect the fact that health and mental health information is sensitive. These rules are designed to protect the privacy of the person to whom the information pertains. As a general rule, competent adult patients (age 18 years of age and older) have the right to choose with whom their medical information is shared.

In order to allow the hospital to share confidential information with family members, your loved one should sign a "consent form." Although consent can be made verbally (and should be documented in his or her clinical record), if something is not in writing, it is harder to prove it exists. Having a signed consent form in hand will increase your ability to fully participate in confidential aspects of your loved one's treatment and discharge planning.

On the inside flap you'll find *Understanding HIPAA, NYS Mental Hygiene Law and the Confidentiality of Mental Health Treatment and Information in New York State* this is also available on the NYS OMH website. For the first time, this "how-to" guide addresses many issues around when and how family can work with the mental health team, whether or not with patient consent. In plain English, with lots of examples applicable for consumers, family and providers, this exhaustive look includes such subjects as:

- What is the difference between NY State Mental Hygiene Law and HIPAA?
- What are the rules that govern disclosure of clinical records?
- How can family provide important information, even without the patient's consent?
- Why is confidentiality an important principle in health care; what is the Hippocratic Oath?*

A complete guide to the Confidentiality of Mental Health Treatment and Information is provided in the inside Flap:

—*Understanding HIPAA, NYS Mental Hygiene Law and the Confidentiality of Mental Health Treatment and Information in New York State*

PARTICIPATING WITHOUT CONSENT

If the patient will not give consent to a family member voluntarily, here's what you need to know:

1. General information (such as mental health informational materials or information about community resources) **is not** confidential and can be tremendously helpful to family members.
2. Staff may discuss a range of subjects in a general fashion, provided they do not reveal specific information about the patient, such as the available programs offered by the hospital, or general procedural information, such as how privileges can be obtained. .

TREATMENT TEAM

The term "treatment team" usually refers to those employees of a facility who are responsible for the direct care of a patient (doctors, case managers, psychiatric nurses etc.). Sometimes, the treatment team can be expanded to include outside specialists such as vocational rehabilitation providers. However, the patient usually must grant

permission for them to be on the team and have access to confidential treatment information.

FAMILY MEMBERS AS PARTNERS WITH THE TREATMENT TEAM

Family members are often called upon to play a significant role in the support of their ill family member. Because family members can have insight that is incredibly valuable to the treatment team, such as family health history, the history of a loved one's illness, the patient's current

TIP: Although professionals might not be able to talk to you if your loved one has refused to sign a consent form, there is no reason why they shouldn't listen to you, directly or by phone, fax or email (please note some facilities may require that communications that include patient identifying information be made in a secure fashion to protect patient privacy) . Also, staff may share information provided by the family to the patients, such as messages of support, unless the doctor does not allow it


strengths and deficits, what was the level of his/her functioning before the onset of the illness, and/or knowledge of their loved one's use/abuse of alcohol or illegal substances, they are an important resource. Family involvement and collaboration with the treatment team should be actively encouraged and supported whenever appropriate.

Unfortunately, some facilities may not encourage family involvement with the treatment team, even though organizations such as the American Psychiatric Association recognize in their guidelines the considerable benefits to treatment of doing so: "A guiding principle is that the patient's family members should be involved and engaged in a collaborative treatment process to the greatest extent possible." (*American Psychiatric Association, Practice Guidelines for the Treatment of Patients with Schizophrenia, second ed., 2004, pp. 70, 106.*)

Furthermore, with respect to facilities operated by the New York State Office of Mental Health, Section 29.13 of the Mental Hygiene Law requires the development of a written treatment plan. The treatment plan outlines treatment goals, what programs or therapies will be undertaken to achieve these goals, and a timetable for assessing progress. Under this law, parents of minors in OMH operated facilities must be involved in the development of a treatment plan, (unless the minor is over 16 years of age and objects to such participation, and a clinician determines it is not clinically appropriate to involve them). If an adult patient in an Office of Mental Health operated facility requests that a family member be involved in the development of his/her treatment plan, that person *must* be included in its development.

Other accrediting organizations, such as The Joint Commission, have stated that "patients and, when appropriate, their families [must be] informed about the outcomes of care, treatment and services." (*The Joint Commission, Comprehensive Accreditation Manual for Hospitals (CAMH), 2006, §RI.2.90, second ed., 2004*)

TIPS FOR WORKING WITH TREATMENT TEAM MEMBERS

- Act professionally - be calm, polite and persistent.
- Respect others' time - be prepared for meetings, and don't be late.
- Prepare for meetings by writing down the points you want to cover (to be submitted at the meeting, as necessary). Be concise but thorough in your communications.
- Record information on the *Hospital Checklist* and *Management Log Sheets* (pgs 25-35) 

All of these references, as well as others, are included in the pamphlet, *When Families Join the Mental Health Care Team Everyone Benefits!* (see inside flap). We encourage you to become familiar with the information in this pamphlet and feel free to share it with your loved one's providers of care!


ROLES AND RESPONSIBILITIES: ACHIEVING TREATMENT PLAN GOALS

The contributions that should be expected of mental health professionals, family members, and the patient, as they partner together to develop and achieve the goals of the treatment plan, follow below:

Mental Health Professionals (the following assumes any necessary consents have been obtained)

1. Encourage and include families in discharge and treatment planning.
2. Seek information from families about the history, background and day-to-day progress of their relative's illness.
3. Inform families of shifts in treatment strategies and changes in medication.
4. Give timely reports on the patient's progress.
5. Consult with and inform families about possibilities for improving their relative's condition.
6. Establish open channels for family complaints and grievances.
7. Validate the family's early warning signs of relapse.
8. Remain in close contact during crises to offer concrete advice and assistance.

Family members

1. Provide the treatment team with details, preferably written, of the history of your loved one's illness (e.g., how it started, warning signs and family mental illness and/or addiction history) Keep it updated and be ready to give out copies to any new professional involved.
2. Cooperate with mental health professionals.
3. Maintain the Hospital Checklist and Management Log 
4. Keep a journal.
5. Become educated about mental illness.

6. Become familiar with the laws and professional guidelines surrounding mental health practices and family involvement (see pamphlet on inside flap, *“When Families Join the Mental Health Care Team Everyone Benefits!”* and *Understanding HIPAA, NYS Mental Hygiene Law and the Confidentiality of Mental Health Treatment and Information in New York State*).
7. Become informed about mental illness and the mental health system so you know what to ask for and how to ask for it.
8. Advocate for, and support, your loved one.

Patients

Patients have a personal responsibility for their own self-care and journeys to recovery. Taking steps toward their goals requires great courage. Patients must strive to understand and give meaning to their experiences and identify coping strategies and healing processes to promote their own wellness. Their job is to manage their symptoms or their symptoms will manage them.

TREATMENT PLAN

The Treatment Plan outlines treatment goals along with programs and/or therapies that will enable the patient to achieve his or her goals. In addition to a timetable for tracking progress, the treatment plan should address at least these six elements:

1. Role of family and professional staff
2. Pertinent information related to mental illness
3. The facility’s programs and services , as well as others offered locally and by the state
4. Names and telephone numbers of key staff and administrators
5. Names of Mental Hygiene Legal Service attorneys
6. Hotline numbers and regularly scheduled hours when families may make telephone contact or meet with specific staff

Chances are, after your loved one is discharged from the hospital, you’ll be called upon to provide some sort of assistance, such as providing housing or transportation. You should be consulted first. **If you are unable to provide a service, and the patient is a competent adult, you are under no obligation to do so—you can refuse for any reason. This includes the right *not* to accept the loved one back into your home.**

CULTURAL ISSUES AND SUPPORT

As you partner with the treatment team, you must make sure the treatment plan is realistic, effective and supportive of your loved one’s goals. One factor often overlooked by both family members and mental health professionals alike is the role culture plays in the family experience of mental illness.

When we talk about culture, what we mean is a set of beliefs, behaviors, norms, values, and language shared by people grouped together because of common ties based upon race, ethnicity, faith, gender, age, sexual orientation, etc. Because culture impacts the way people interact with one another, it is important to recognize that a person’s culture shapes the way they perceive and experience mental illness. A family’s culture could influence whether and when they seek help, what type of help they seek, what coping styles and supports they have, and what treatments might work. Mental health professionals are not only affected by their personal culture, but also by the culture of the medical field, which relies heavily on science and open communication for diagnosis.

When the provider’s cultural background differs from that of the patient and/or family (especially if there is a language barrier), the lack of knowledge about the patient/family’s culture can create impediments to effective treatment, including misunderstandings that can result in a wrong diagnosis. Although most providers want to work sensitively and effectively within various cultural contexts, it may be easier to find written information in non-English languages, than to find professionals skilled at delivering treatment that is sensitive, relevant and culturally competent.

In addition, after a patient has been discharged, some families have difficulty finding support groups with which they are comfortable. These are some problems family members have reported experiencing when trying to integrate themselves into mainstream support groups:

- Lack of aggressive and innovative outreach to families outside of mainstream culture.
- Structure and leadership styles may not reflect different cultures’ preferred styles.*
- Support group leadership and membership may lack comfort with issues of diversity or may simply lack knowledge or information.
- Social activities sponsored by groups may not be familiar, appealing or comfortable.
- Programs may be held in settings outside of neighborhood communities or in places where people feel uncomfortable.
- Lack of people from cultural group may cause families to feel alienated, isolated or uncomfortable.

In order to receive appropriate treatment and find a support model for your loved one and family member that is consistent with your cultural style and strengths, be prepared to reach out, bridge knowledge gaps, make connections and educate others about your culture.

Cultural differences to consider:

- Communication and presentation styles
- Verbal expression: open, self-disclosing, or closed?
- Eye contact
- Distance in personal space
- Problem-solving and decision-making
- Familial or gender role expectations and responsibilities
- Religious or spiritual beliefs and practices

What works?

- A. Find a mainstream program that already exists.
- B. Consider a “family network” approach. As opposed to building a group of unrelated individuals, this approach builds upon a large family network that shares kinship ties or membership in key community institutions, such as a church or well-regarded neighborhood community center. Family network approaches can make use of collective problem-solving and conflict resolution, which is common in many cultures.
- C. Join or create an ethnically or culturally specific psycho-educational group where all members are from the same cultural group.

R See “**CULTURAL ISSUES AND SUPPORT**” in the resource section. (p. 40)

HOW TO GET HOSPITAL RECORDS

Your loved one has the right to request access to his or her hospital records. If the hospital is required to comply with HIPAA, it will give the patient a Notice of Privacy Practices, which should provide information on how to request this access. Usually, this is done by dropping off a written request at the “Records” window, signed by the patient, before he or she is discharged. Although the hospital has the right to charge a reasonable fee for copying a record (unless the patient does not have the ability to pay) most often, they are provided without cost. It’s important to have these records, which document information that was used to make decisions about the patient, as a basis for building a recovery history.

WHAT TO DO IF YOU ARE DISSATISFIED WITH YOUR LOVED ONE’S CARE

Locate the most appropriate staff member to address your issue. If you cannot reach that person by phone, write a letter and deliver it by fax or email. The Mental Hygiene Legal Services (MHLS) should be available to assist patients and their families with complaints and are often located on or near the grounds of State operated psychiatric hospitals (note that MHLS is part of the Office of Court Administration and is not part of, nor does it legally represent, the hospital). Within the hospital itself, the following personnel or departments can handle complaints: Director of the Hospital, Office of Patient Relations, or Risk Management (Quality Assurance). A hospital’s Board of Visitors is empowered to inquire into the workings of the hospital and make recommendations. You can also contact the Office of Mental Health Customer Relations/General Information line at 1-800-597-8481 for guidance. Use the Management Log Sheets, included in this Handbook, to document the relevant facts and dates, and to substantiate your complaint

R See “**COMPLAINTS**” (p. 38) and “**LEGAL ISSUES**” (p. 45)

PEER BRIDGERS: COMPLEMENTARY SERVICES TO SUPPORT RECOVERY

As a complement to mental health services, Peer Specialists, who have taken additional training to qualify them as "Bridgers," can not only assist with discharge, but can also assist with community integration, resource linking, attainment of independent living, gainful employment, and other services needed to complete the journey to recovery. "Bridger" services are currently available in 6 counties (Albany, Ulster, Broome, Queens, Suffolk and Westchester). It is recommended that Bridgers be contacted early in the process to provide support in the hospital as the consumer explores or approaches discharge. For more information: www.nyaprs.org

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PAYING FOR IT ALL

INTRODUCTION TO SOCIAL SECURITY DISABILITY INSURANCE AND SUPPLEMENTAL SECURITY INCOME

THERE ARE TWO U.S. government disability programs in the Social Security Administration that may help. One is *Social Security Disability Insurance (SSDI)*, an insurance program. The other is *Supplemental Security Income (SSI)*, an income based program.

If mental illness is preventing your family member from working, obtaining income and health coverage to pay for hospital care is essential. The patient may file for SSI and/or SSDI, as well as Medicaid or Medicare coverage. Here's what you need to know about these programs:

- A person may receive both SSDI and SSI.
- Both programs have the same standard of disability for adults. The impairment must be severe enough to prevent the person from performing any substantial gainful activity to obtain SSDI.
- A person earning more than \$980 per month—the figure for 2009—is presumed to be performing substantial gainful activity, and is ineligible.
- SSI recipients automatically qualify for *Medicaid* in New York State, if a person gets as little as \$1 in SSI benefits
- Former SSI recipients can still maintain Medicaid if otherwise eligible.

Once a disability claim is filed at the district office, it will be sent to the Disability Determination Services (DDS) for evaluation of disability.

The process may be tedious; however, the effort is vital in both the short- and long-term to get coverage for crucial services, which might otherwise be unaffordable. (p 36 Benefits Eligibility, p. 44, "Health Insurance, p. 47 Social Services)

R See "BENEFITS ELIGIBILITY" (pg 37)

A SUBSTANTIAL SALARY DOESN'T HAVE TO JEOPARDIZE YOUR BENEFITS: MEDICAID BUY-IN PROGRAM FOR WORKING PEOPLE WITH DISABILITIES (MBI-WPD)

The *Medicaid Buy-In program* offers Medicaid health insurance coverage to people with disabilities who are working and earning more than the allowable limits for regular Medicaid. Your loved one can earn as much as \$55,188 per year without the risk of losing Medicaid. Through this program, your loved one will have the opportunity to return to the work life and aspirations he or she had prior to the onset of illness.

To qualify for the Medicaid Buy-In program for working people with disabilities, you must

- Be a resident of New York State;*
- Be at least 16 years of age (coverage up to 65 years of age);*
- Have a disability as defined by the Social Security Administration;*
- Be engaged in part- or full-time paid work*
- Have a gross income less than \$55,188 for an individual, \$73,884 for a disabled couple in 2009
- Have non-exempt resources that do not exceed \$13,800 for an individual, \$20,100 for a disabled couple in 2009.

If you apply, be prepared to submit proof of the following:

- **Disability** (if you are currently receiving a form of Social Security benefits for the disabled, that proof should be sufficient). Even if you don't receive benefits, you also qualify if you meet Social Security eligibility requirements as "disabled."
- **Medical:** Name, address and telephone number of physician.
- **Benefits:** Medicare Part A and B, private health insurance (if you have these benefits).
- **Income:** Social security, alimony, veteran's benefits, monetary support from family members.
- **Citizenship:** Birth certificate, U.S. Passport, Naturalization certificate with photo ID
- **Residency:** ID card, letter/lease/rent receipt with home address.
- **Resources:** Money in a bank, stocks, bonds, mutual funds, certificates of deposit, money market accounts, and 402k plans, trusts, cash value of life insurance.

Don't be overwhelmed. Medicaid customer service specialists can provide support and a "Tool Kit" to help guide you through the process. Missing application items may be submitted for up to ten days.

R See a **step-by-step guide to obtaining Medicaid-Buy-In** and a "Medicaid Buy-in At-A-Glance" sheet to share at the Medicaid Office to assure obtaining the service you need (pgs. 49-52 Appendix)

HOW TO GET FOOD STAMPS

Your loved one may qualify for Food Stamps to supplement his or her food budget (and you don't have to be destitute). You don't have to wait for a mental health provider to get it for you. You can take action yourself.

This federal Supplemental Nutrition Assistance Program (SNAP) program, run by state and local agencies, gives Food Stamps, in the form of a debit card for low-income households. How much you receive is based on your income.

See "FOOD STAMPS." for information of where to download applications and to find contact information for office locations where you can apply (p. 42)

GET A REDUCED FARE CARD

Those on Medicare who have serious mental illness or receive Supplemental Security Income (SSI) can get "Reduced Fare" NYC Metro Card and enjoy half-fare. You don't have to wait for a mental health provider to get it for you. You can take action yourself. (p. 46.)

DISCHARGE PLANNING: IMPORTANT CROSSROADS

BY LAW, hospitals must develop a written treatment plan for every patient. An important component of the treatment plan is the discharge plan, as it acts as a guide for treatment and identifies which services and supports will be offered to help your loved one recover.

As with the treatment plan, with the patient's consent, family members should be involved in the development of the discharge plan—especially since family caregivers will be directly affected by these decisions.

With respect to NYS Office of Mental Health operated psychiatric centers, Mental Hygiene Law §29.15 (f) (reference “*When Families Join the Mental Health Care Team Everyone Benefits!* Pamphlet inside flap) says that the discharge plan must be a written one, prepared in consultation with someone authorized to represent the patient, and must at least address the following:

1. Statement of patient's need, if any, for supervision, medication, aftercare services, and assistance in finding employment following discharge;
2. Housing recommendations and a list of available services ;
3. List of organizations, facilities, and individuals who will provide services in accordance with identified patient needs
4. Notification of appropriate school district and special education for patients under 21
5. Evaluation of patient's need and potential eligibility for public benefits.

ASSISTED OUTPATIENT TREATMENT (AOT): A WAY TO DEAL WITH RISK

An Assisted Outpatient Treatment or an AOT designation is a court-ordered treatment plan designed to help seriously mentally ill individuals who are “at risk” to themselves or others to comply with treatment. The order will require a person to accept the treatment that the court determines is necessary, and will require the local county director to provide such treatment.

An AOT treatment plan can detail a range of services that a person might need: medical, educational, vocational and supervision of living arrangements, to name a few. A patient with an AOT designation is assigned to a case manager, who assists the person in following the

plan. Because the county director is required to furnish the treatment, AOT status usually gives the person top priority for services from their local mental health system.

Once a person is under an AOT court order, it is expected that he or she will comply with it. If a doctor determines that the person has not complied with some aspects of the order, and also determines that he/she may need involuntary admission to a hospital, the doctor can recommend to the county director that the person be transported to a hospital and held for up to 72 hours to determine if inpatient care and treatment are necessary. If the person has refused to take prescribed medication, or has failed a test designed to determine either medication compliance or alcohol or drug use, that refusal or failure may be considered by the doctor in making this decision. Any decision to hold the person for more than 72 hours must be in accordance with the legal procedures for involuntary admission.

The process to obtain an AOT order begins with a petition to a civil court. An investigation will follow to determine if the patient meets the criteria. The court must be satisfied that AOT is the least restrictive alternative be-

QUALIFYING FOR AOT

To qualify for AOT designation, a patient must:

- Be at least 18 years of age and have a mental illness;
- Be unlikely to survive in the community without supervision, based on a clinical determination;
- Have a history of non-compliance with treatment for mental illness that has been a significant factor in his or her being in a hospital, prison or jail within the preceding three years, or which has resulted in one or more acts, attempts, or threats of serious violent behavior toward self or others within the preceding four years
- Be unlikely to voluntarily accept the treatment recommended in the treatment plan
- Need AOT to avoid a relapse or deterioration that would likely result in serious harm to self or others
- Be likely to benefit from AOT.

fore granting an AOT order. If a less restrictive treatment or program exists that could effectively address the person's mental health needs, the court will not grant the petition for an AOT order.

The director of the hospital can make an AOT petition or arrange for it to be done through the local county, so it's easiest and best to ask for it while the patient is in the hospital.

R See "AOT" to find information for contacting your local county AOT Coordinator (p. 37) and/or area Family Liaison (p. 54); for resources on New York State's Kendra's Law, the law from which AOT was derived. (p. 45)

EMERGENCY PLANNING

No recovery plan can be complete if it avoids planning for the next possible crisis. Crisis planning allows patients the opportunity to express preferences for their care in case of an emergency.

The crisis plan can be an effective tool in engagement, and sets the stage for consumer choice and recovery. When consumer engagement is an issue, the crisis plan can be used as an effective tool for dialogue between the clinician and the consumer. Crisis plans are typically updated during an annual review process or when the life circumstances of the consumer change.

There are three types of plans to prepare for or prevent a crisis. They include:

1. Crisis plans
2. Wellness Recovery Action Plan (WRAP)
3. Psychiatric Advance directives

Crisis Plans

A crisis plan document can be part of a patient's treatment plan. Initially, a patient's crisis plan may have only one item such as, "this is how I know when I need help" or "this is who to call when I need help." The basic elements of the Crisis plan can include any of the following, and can be expanded to include anything else that the patient feels is important to address in this document :

1. Signs that I am not feeling well
2. Signs that I need help from others
3. Who to call when I need help (My support team)
4. Who not to call when I need help
5. My medications are
6. I take medication to
7. My doctor or provider is

8. This is what usually works when I need help
9. Please make sure someone on my support team takes care to

Wellness Recovery Action Plan (WRAP)

The Wellness Recovery Action Plan (WRAP) is a self-management and recovery system developed by persons living successfully with mental illness. The program teaches people in recovery to develop activities for everyday well-being, track triggering events and early warning signs, prepare personal responses for when they are feeling badly, and create a plan for supports to care for themselves to decrease the severity and frequency of symptoms and improve the quality of their lives. WRAP comes in many forms: seminars, "WRAP groups," books, DVDs and online classes

R See "WRAP" in the resource section. (p. 48)

Psychiatric Advance Directives

Psychiatric Advance Directives are another group of tools that are useful to have in place before a relapse or other psychiatric emergency occurs. These legal forms are prepared when a person is competent and provide instructions about health care to be followed if a person is determined to be incapable of making decisions regarding her/his physical or mental health treatment.

There are several types of Advance Directives:

Durable Power of Attorney - A legal document that allows an individual to designate a person (usually a trusted family member or friend) to manage his or her financial affairs if he/she becomes unable to do so/t . Before the NYS Health Care Proxy law was enacted, durable powers of attorney could be used to delegate health care decision making powers, but that is no longer true. Now that the Health Care Proxy law is in place, durable powers of attorney cannot be used to assign authority to make health care decisions, unless it was signed prior to July 1, 1990 (which is when the Health Care Proxy law went into effect).

Health Care Proxy - A legal document that allows an individual to designate a person (usually a trusted family member or friend) to make health care decisions if he/she becomes unable to do so. The designated person is known as the "health care agent." The Health Care Proxy can give the health care agent the authority to make decisions about both mental and physical health care.

These decisions can include the provision of care as well as the withholding of consent to treatment. The agent's authority to make health care decisions begins when an attending physician has determined that the individual lacks the capacity to make these decisions.

Declaration for Mental Health Treatment - A document or statement that includes patient preferences regarding medication, hospitalization and electroconvulsive therapy (ECT), for example.

Living Will - A document that specifies your loved one's wishes regarding health care treatment if he or she becomes incapacitated. Although a living will is not restricted in terms of what types of health care matters it should address, they frequently are used to set forth a person's wishes with respect to end-of-life treatment. There is no specific law that addresses living wills, but courts have upheld them as valid documents that express a person's wishes and instructions if they are presented in a "clear and convincing" manner. Often, a living will is a document that a health care agent will use to guide his or her decision-making under a Health Care Proxy.

Do not Resuscitate (DNR) Order - A legal document that provides a person's advance instructions relating to the withholding or withdrawal of cardiopulmonary resuscitation (CPR)



See "ADVANCE DIRECTIVES" to find sample Advance Directive for Mental and Physical Care forms (p. 37)

FAMILY CONTRACT

If your loved one will return home after a mental health hospitalization, having a clear set of rules and expectations can reduce stress and act as a guide for starting over.

Many families have found it best to create and agree upon a set of "House Rules." These rules can form the basis of a family contract, which makes clear what each party pledges to do and includes specific consequences for breaking the contract.

The optimal place to draw up the family contract is in the hospital, where staff can take part in the negotiations. A family contract document is signed by all parties and can become part of the treatment plan.

At home, family members can follow-up on how the contract is working in periodic family meetings.

These meetings can also provide an opportunity to make new agreements and/or adjustments to the contract as necessary or desired.



Find a sample "FAMILY CONTRACT" in the "Tools you can use" section (p. 36)

HOUSING

Housing is often viewed as the most essential element to help patients to start building a life for themselves and to further the process of recovery. Preferences for housing and services should have been specified as part of your loved one's Discharge Plan.

The first housing placement can often be in *Level II supportive housing*. This is transitional, service-enriched housing. In Level II supportive housing, residents often live with a roommate and receive both rehabilitative and case management services. Housing costs are deducted from the individual's benefits check. The goal of supportive housing is to help individuals transition to more independent "*supported*" housing once the necessary independent living skills are gained. In supported housing, the tenant signs a lease or sub-lease, and is liable for rent amounting to no more than one-third of their income. Services may be used as needed.

Because of lack of availability of immediate housing, patients often return to their family's home while filing housing applications, which can take several months or even years, depending on clinical needs and preferences. It benefits the consumer and/or family member to educate themselves about the steps in the housing application and referral process, stay in close contact with his/her case managers or housing coordinators, (who often have large caseloads), and assist wherever possible. Remember—the required application, psychosocial and medical forms expire after six months, so be sure to keep all three up-to-date.

In New York City, the supportive housing application and referral process is as follows:

Work with the case manager to complete and submit the required Supportive Housing HRA 2010E application, which must be filed and submitted electronically to the Department of Human Resources Administration (HRA) by a staff person.

The HRA 2010E requires that all applicants submit these three documents:

1. A current psychiatric evaluation from a psychiatrist or Psychiatric Nurse Practitioner (Completed within the last 6 months)

2. A psychosocial assessment, which is usually completed by the case manager or a social worker (completed within the last 6 months)
3. Current TB test results (administered within the last 12 months).

If HRA approves the application—and the eligibility determination process usually takes between one and three business days—the case manager starts making referrals to specific housing programs in New York City. Family members and consumers also have the right to conduct placement providing they coordinate closely with the mental health professionals.

Decide whether or not to utilize the Single Point of Access (SPOA) Housing Program administered by the Center for Urban Community Services (CUCS) for the New York State Office of Mental Health. Since it guarantees three housing referrals in New York City, it is recommended for the City. If you elect to use their services, SPOA staff can access a centralized database containing detailed information on all mental health housing programs in New York City and provide referrals to clinically appropriate housing programs based on the needs and preferences of the applicant. Applicants are guaranteed three face-to-face interview at any housing program in New York City that they are referred to by SPOA.

****HINT** - Family members can help by tracking all supporting documents, making sure they are received by the case manager, who will submit them electronically to the Human Resources Administration with the final application.

TYPES OF HOUSING

FOR NEW YORK STATE AND IN SOME INSTANCES CITY

State-Operated Community Residences (SOCR's). These transitional residences are typically located on the grounds of State Psychiatric Centers.

Private Proprietary Homes for Adults (also known as Adult Homes) These residences are licensed by the New York State Department of Health.

Family Type Homes for Adults are private homes in the New York State communities where one or more persons living with mental illness may pay for room and board. The level of supervision varies. Also, these residences may be licensed by the local department of social services or may be unlicensed.

Section 8 rental voucher program Federal Housing & Urban Development (HUD) offers affordable housing choices for low-income households by allowing families to choose privately owned rental housing. This privately owned rental housing can be accessed through the HUD program providing Section 8 rental vouchers for low-income individuals on a limited basis through the local housing authority or certain non-profit organizations. Call your local Public Housing Authority and/or local Department of Mental Health to check out the availability of Section 8 vouchers in your locality. **Unfortunately, HUD opens their lists periodically and with unpredictability, it is sometimes a difficult system to navigate.**

R See HUD Section 8 Housing Program on p. 45 for contact information.

Supported housing and Supported Single Room Occupancy (SROs) are the only permanent housing models funded or licensed by the state. These housing programs are targeted to individuals living with mental illnesses who are capable of living more independently. A rent subsidy and mental health support services are provided through nonprofit housing agencies. Supported housing may be apartments scattered throughout the community or may be a single site residence. Supported SROs are single-site buildings.

APPLICATIONS OUTSIDE OF NYC

Application procedures vary by county. In most up-state counties, the application for state licensed and supportive housing options must be made by referral through the local Single Point of Access or SPOA. (As mentioned, In New York City, use of the SPOA Housing Program is optional). Check with your local Department of Mental Health to find out who is the administrator of the SPOA program in your community, and find out how to obtain a supportive housing application.

R See “HOUSING” for a detailed descriptions of licensed and supported housing options and listings of mental health housing programs with their related vacancy and wait list information.

GETTING WELL, STAYING WELL

REHABILITATION

UNTIL RECENTLY, a diagnosis of mental illness meant the end of one's hopes and prospects. There was little vision that people with mental illnesses could return to school, work or otherwise lead productive lives. Today, the long-term focus of mental illness is recovery. Many leaders in psychiatric rehabilitation rightly assert that recovery from mental illness is possible and claim that much of the chronic nature of mental illness is due to failures of services and not necessarily due to the nature of the illness itself.

An ideal rehabilitation program builds in assistance at each step of recovery. It also assumes the family will be part of a team that will help rebuild a loved one's skills and confidence, and provides the family with education and support as well.


Below is a list of what an innovative rehabilitation program might include.

1. Immediate "first break" education in the hospital about the illness and the importance of staying on medications.
2. Immediate inclusion of family by the treatment team.
3. Continued close collaboration between the consumer, treatment professionals and family member to monitor illness and watch for early signs of relapse.
4. Family Education program such as the NAMI Family-to-Family program for family members, referral to a NAMI support Group and supportive counseling for family members if necessary.
5. Extensive peer group education about mental illness
6. Peer support group—NAMI Connection program, Peer Bridger Program, and in NY, Peer2Peer .p 49
7. Supportive services while consumer is recovering and upon return to work or school.
8. Introduction to peer movement and opportunities to join in advocacy activities.

LIVING WITH A LOVED ONE RIGHT OUT OF THE HOSPITAL

Coming out of the hospital, people need time to recuperate. Not only do returning loved ones have to cope with the circumstances of a mental disorder and adjusting to strong psychiatric medication, but they can also need time to recover from the sheer trauma of commitment and hospitalization and the sedation caused during the stabilization process. They may, temporarily require many hours of sleep.

The following family guidelines (adapted from the Family Institute for Education, Practice and Research, University of Rochester Medical Center and NYS Office of Mental Health) are designed to aid the recovery process. They are designed with the biology of mental illness in mind. Use them as a guide to slow down sensory input for a person who may be coping with a psychotic illness and to help establish basic ground rules for living with and recovering from a mental illness.

1. **GO SLOW.** Recovery takes time. Rest is important. Things will get better in their own time.
2. **KEEP IT COOL.** Enthusiasm is normal, but keep it toned down. Disagreement is normal, but keep this toned down too. Avoid over-stimulating your loved one during this difficult time.
3. **KEEP IT WARM.** Family bonds are meaningful and important. Create an environment that is caring, supportive and loving.
4. **GIVE EACH OTHER SPACE.** Time out is important for everyone. Allow your loved one to withdraw when they need to, and learn to recognize the behaviors that signal this need.
5. **SET LIMITS.** Everyone needs to know what the rules are. A few good rules keep things clear. Establish house rules and consider a Family Contract . p. 36 
6. **IGNORE WHAT YOU CAN'T CHANGE.** Let some things slide but don't ignore threatening, violent or psychotic behavior.
7. **KEEP IT SIMPLE.** Say what you have to say clearly, calmly and positively.
8. **FOLLOW THE TREATMENT PLAN.**
9. **CARRY ON BUSINESS AS USUAL.** Reestablish family routines as quickly as possible.
10. **TAKE CARE OF YOURSELF.** It is difficult to care for someone else if you are not taking good care of yourself.

11. **HELP YOUR LOVED ONE AVOID STREET DRUGS & ALCOHOL.** They make symptoms worse, can cause relapse, prevent recovery and interfere with prescribed medications. If your relative uses alcohol or street drugs, encourage open dialogue about it with them and the treatment team in order to best optimize their recovery. Avoid caffeine too, as it can interfere with sleep.
12. **PICK UP ON EARLY WARNING SIGNS.** Develop a list of early warning signs that may indicate your relative is relapsing. Discuss any changes with your family member and their provider in order to head off a relapse.
13. **LOWER EXPECTATIONS, TEMPORARILY.** After an acute psychotic episode, an extended period of recovery is usually necessary. Compare this month to last month instead of last year or next year.

TIP - Don't forget your Family Contract!
(p 36)

Relapses can and must be avoided. One of the most important contributions a family can make is to be vigilant for early warning signs and report them to the doctor immediately. Injurious multiple relapses are unnecessary and must be avoided.

EARLY WARNING SIGNS OF RELAPSE

- Trouble Sleeping
- Feelings of tension or stress
- Anger, irritability or short-temperedness
- Difficulty concentrating
- Lack of energy
- Restlessness
- Loss of interest in previously enjoyed activities
- Fears people are talking about them
- Depression or sadness
- Withdrawn
- Discomfort around people
- Confusion or fear

DON'T FORGET PHYSICAL HEALTH

Individuals with a serious mental illness are two to three times more likely to have the risk factors for cardiovascular disease than the general population, and are increasingly being recognized as a high-risk population for diabetes. Factors include obesity, smoking, high blood pressure and high cholesterol, can be effectively treated

STICKING WITH MEDICATIONS

- 1) Keep a list of all medications, including over the counter medication and herbal supplements. Show this list to all doctors and your pharmacist.
- 2) Use one pharmacy, so they can detect drug interactions and call the doctor if any are detected.
- 3) Help your loved one follow the doctor's instructions for taking medications. However, advocate with the doctor to fit the medication schedule to your loved one's schedule.
- 4) Learn in advance how to manage a missed dose. Also, make sure the doctor explains under what circumstances he should stop taking a certain medication.
- 5) Help your loved one avoid alcohol and other street drugs. Changes in nicotine and caffeine consumption should be reported to all doctors since these changes can affect the way medications work.
- 6) Keep all appointments. Don't hesitate to ask questions (make a list ahead of time). Tell the doctor about any health problems or side effects or if your loved one is pregnant, planning to get pregnant or nursing.
- 7) Make sure the psychiatrist knows what the medical doctor is doing (whether prescribing a medication or recommending an operation or medical procedure) and vice versa.
- 8) Safely store medications in a cool, dry place away from children and pets.
- 9) Link your loved one's medication schedule to daily routines, like eating breakfast or brushing teeth.
- 10) Encourage patience. Remember, many side effects diminish in a few weeks. It may take a few weeks before he begins to feel better, too.
- 11) Help monitor any metabolic changes. Make sure the medical doctor keeps track of his weight and blood pressure and periodically tests for cholesterol problems and diabetes.

through good medical care, beginning with proper screening and monitoring. If a medication causes dramatic weight gain or blood pressure rise, an alternative medication should be considered before the condition advances. Observing good nutrition and getting regular exercise are essential for general health and to combat the effects of pharmaceuticals.

R

See “WELLNESS SELF MANAGEMENT” to find information on a tool kit created by the New York State Office of Mental Health to help consumers to improve and maintain their health p 48.

EDUCATION AND SUPPORT PROGRAMS

Since the founding of the National Alliance for Mental Illness (NAMI) in 1979, families living with serious and persistent mental illness have been looking after each other and providing a range of support groups, courses and educational events.

Recovery-centered rehabilitation programs and peer support services can reduce the number of psychiatric hospitalizations and relapses, so consumers and families need to use and, if necessary, create these community-based resources...

R

Find contact information for all programs listed below under “EDUCATION” (p. 41) OR “SUPPORT” (pg. 47)

PROGRAMS FOR FAMILY MEMBERS

As soon as possible get a crash course in dealing with mental illness during and out of the hospital. Here’s a starter:

NAMI Family-to-Family (F2F) is the most comprehensive family education course about mental illness. This free 12-week education course is taught by family members of those suffering from severe mental illness. F2F provides practical information on the biology of mental illness, medications and research, crisis management, communications skills, problem solving, self-care, advocacy and recovery. Based on the trauma model, participants work through the stages of grief (shock, anger, grief to, acceptance). F2F participant report greater understanding of mental illness, which leads to better coping skills, less worrying and feeling newly empowered to advocate for better treatment and services for their loved ones. (P. 59)

NAMI Support Groups - Contact your local NAMI affiliate to learn which groups are offered or call NAMI-New York State to identify your local affiliate. (p. 47) Referrals to the mobile crisis teams are made by calling 1-800-543-3638 (LIFENET)

JOINT FAMILY AND CONSUMER PROGRAMS

Behavioral Therapy (BT) - These privately or insurance paid for sessions between a clinician and a consumer and/or his or her family provide education and information, which can last a few sessions or a couple of years. BT typically emphasizes illness education and symptom management, practical problem solving, relapse prevention, family support and assistance to navigate the mental health system.

Consumer-Centered Family Consultation and referral linkage - Family Consultation is an outreach program in which a family consultant from an agency serving the patient visits the family after discharge from the hospital. During sessions (one to three, typically), concerns are discussed followed by an exploration of potential solutions and a plan for addressing them. Family Consultation is also a gateway service for the full Spectrum of Family Services offered by the Family Institute for Education, Practice & Research. (p. 41)

Multi-family Psychoeducation (“Multifamily Groups” or MFG) - These treatment programs bring together a group of six families, including the patient, for engagement, education and problem solving. Twice a month (for nine months to two years), program participants create a supportive community and practice a specific method of problem solving to help their loved ones obtain stability and prepare to re-enter the community at large. It has Evidence-based status from NIMH’s PORT study as proving to reduce relapse rates by half in the first year. Family Institute for Education, Practice & Research (p. 41)

FOR CONSUMERS

NAMI's Peer-to-Peer, 518-462-2000 or 800-950-3328 (P2P) For people with mental illness who want to establish and maintain their wellness and recovery. The program provides a binder of materials, including an advance directive; a "relapse prevention plan"; and mindfulness exercises to help focus and calm thinking; and survival skills for working with providers and the general public. Limited to New York State. p. 39.

NAMI Connection is a weekly recovery support group for people living with mental illness to learn from each others' experiences, share coping strategies, and offer encouragement and understanding. If you Google NAMI Connection it will bring up a map showing where in almost fifty states the group is available.

Peer Bridger project, sponsored by the New York Association of Psychiatric Rehabilitation Services (www.nyaprs.org) helps individuals being discharged from New York State Psychiatric Centers in six counties, ease transition into community life. (p. 39)

The Wellness Recovery Action Plan (WRAP) is a structured, self-monitoring system to identify uncomfortable and distressing signs and symptoms and, through planned responses, to reduce, modify or eliminate them. WRAP includes plans for others when symptoms prevent good decision-making, self-care and self-safety. WRAP Plans are individual. A daily self-monitoring journal helps organize behavior and actions to manage mental illness. (p. 48)

Founder Mary Ellen Copeland has provided for New Yorkers the contents of the plan and a 45-minute training session on this nationally acclaimed self-help tool if they visit www.nycnetworkofcare.org and search "WRAP." (p. 43)

Wellness Self-Management - Developed by the NYS Office of Mental Health, the Wellness Self-Management program consists of 57 lessons that are presented to groups of consumers in both inpatient and outpatient settings. The three major subjects covered are recovery, mental health wellness and relapse prevention, and healthy living. (p. 48)

COGNITIVE REHABILITATION

A majority of people suffering a psychotic episode lose "Executive Functioning" skills such as recall, categorizing and organizing information, solving problems and solving problems. Such cognitive problems pose major obstacles to employment.

Research shows that these problems can be reduced through cognitive rehabilitation combined with vocational rehabilitation, which, in turn, improves self-esteem and decreases depression.

Effective programs include using software for computerized remediation at one's own pace or "errorless teaching," which breaks down complex tasks into small component steps. For example, Alice Medalia, Ph.D. Director of Neuropsychology at Montefiore Medical Center, has developed a computer games for use with groups of eight patients. Clients who have used this Edmark software have found it fun and have increased their attention span and retention.

R See "COGNITIVE REHABILITATION" (p. 44)

NUTRIENT APPROACH TO MENTAL ILLNESS: COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) - AN EVOLVING OPTION

Research starting in the 1970's with Nobel prize winners Linus Pauling and his colleagues, laid a scientific basis to show that mental health problems including depression, bipolar disorder, schizophrenia, ADHD, learning disorders and obsessive-compulsive disorders often have a common cause: insufficient nutrients in the brain. They call this approach "orthomolecular" meaning "the right molecule" to bring about a state of health by balancing the concentration of natural substances normally present in the human body: vitamins, minerals, amino acids, trace elements and hormones." They have introduced a protocol of megavitamin and mineral supplements in recommended dosages, which many have benefitted from (www.orthomed.org).

EMPowerplus, a formulation from a Canadian EM-Powerplus, a formulation from a Canadian company called Truehope, was developed out of animal husbandry initiatives. EMPowerplus is receiving attention from mainstream neuropsychologists and many users with a range of brain disorders. The company's website offers information about scientific and case studies (www.truehope.com). Truehope believes that the nutrients can correct deficiencies that affect brain, organ function and nerve growth. Ex-

periments with rats which were fed the nutrients appear to show brain regeneration and growth of the neuron dendrite endings to address cognitive deficits. Regimens require taking nutrients three to four times a day, optimally under a doctor's supervision and with substantial support from Truehope's support team. This modality has not received mainstream acceptance for a number of reasons relating to lack of ability to patent formulations and lack of widespread and low cost availability.

(Inclusion of this information in no way constitutes any recommendation or endorsement for not taking medications; this information is offered for consideration as a possible aid to wellness for interested, well-informed, motivated and disciplined individuals)

EMPLOYMENT

The two magic ingredients for building a life are housing and a job.

Your loved one is entitled to assistance in addressing his or her employment needs. Section 29.15 (g) of the NYS Mental Hygiene Law provides that written discharge plans "shall include a statement of patient's need...for aftercare services and assistance in finding employment..." (Refer *When Families Join the Mental Health Care Team Everyone Benefits!*)

The main approaches for helping seriously mentally ill persons obtain employment are Pre-vocational Training (PT) and Supported Employment (SE). SE includes rapid job search, integrated vocational and clinical services and employment assistance. The goal is to rapidly acquire competitive jobs in integrated community settings, working along-side non-disabled workers, and to provide ongoing supports to facilitate success on the job. This contrasts with traditional vocational services that use extensive pre-employment training.

Pre-Vocational Training

The key principle of Pre-vocational Training is that a period of preparation is necessary before an individual enters competitive or open employment. One way your loved one can obtain this type of preparation is by joining a "Clubhouse" that offers a pre-vocational training approach. This approach also sets the standard for an international network.

A "Clubhouse" is a restorative community organized by and for persons with mental illness. It serves as a collegial place for consumers to pursue a range of activities, including seeking and obtaining housing, employment, and friendships. The first Clubhouse, Fountain House in New York City, was started in 1948 by con-

sumers who coined the word "clubhouse" to communicate a place of membership and belonging. Since then, Fountain House has served as the model for other clubhouses internationally. (see p. 38)

Clubhouse participants are called "members" because the focus is on the person's strengths not their illness. Employment opportunities are provided as a right of membership into the Clubhouse. Members transition to paid employment, while staff members assist in job placement, job retention and on the job training. Meaningful work in a Clubhouse may lead to transitional, supported or independent employment at local businesses.

Transitional Employment (TE) is a well-respected strategy for facilitating the vocational adjustment of men and women with serious mental illness in the community. The Clubhouse manages several job sites within the community that allows members a job coach for the duration of the six to eight months. While members are working at this job site, they are paid the prevailing wage.

Clubhouses usually train workers at the work site, and provide back-up for the employee when necessary. A TE position helps increase self-esteem, develops interpersonal and vocational skills, and develops a work history for future job applications.

Supported Employment (SE) is grounded in the principle that placement in competitive employment should occur as quickly as possible, followed by on-the-job support and training. In SE, a job is developed with a particular member in mind. After an adjustment period, the member remains on the job, receiving support when and as needed.

EMPLOYMENT: AGENCY SERVICES

Ticket to Work

Administered by the Federal Social Security Administration, the "Ticket to Work" is actually a cash voucher a person can take to any Employment Network or State Vocational Rehabilitation agency to obtain assistance in job training, preparing materials to use when seeking a job, locating employers, obtaining information about work incentives, and other assistance needed in order to reach employment goals. The program is available for people between the ages of 18 and 65 who receive Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits because they are disabled or blind. p. 42

There are a number of benefits to using the "Ticket to Work" program. For example, consumers can "test out" a job without losing their benefits and maintain ac-

cess to other Social Security Administration programs and work incentives as they transition into work. Here are the details:

1. If you have to stop working, you can easily regain your benefits (known as “expedited reinstatement of benefits”). Also, for an additional 36 months after completing the trial work period, benefits can be reinstated again if a consumer’s earnings fall below the “substantial” level and he or she continues to have a disabling impairment.
2. If you go back to work, you will NOT automatically lose your disability benefits. The Ticket to Work and special rules called “work incentives” allow you to keep your cash benefits and Medicare or Medicaid during a trial period while you test your ability to work. For the Social Security Disability Insurance (SSDI) program, there is a trial work period during which you can receive full benefits regardless of how much you earn, as long as you report your work activity and continue to have a disabling impairment.
3. Consumers will not receive a medical continuing disability review (CDR) while using the “Ticket.” p. 42

NYS Office of Vocational and Educational Services for Individuals with Disabilities (VESID)

Through the VESID program, Vocational Rehabilitation agencies furnish a wide variety of services, through special education and vocational rehabilitation programs, to help people with disabilities return to work, enter a new line of work, or to enter the workforce for the first time.

VESID coordinates services relating to vocational assessment, vocational counseling, training and placement, and job follow-up/ It works to ensure that both the individual and the employer are satisfied with the placement and will intervene if problems occur once an individual is placed in a job.

VESID participants have an Individual Plan for Employment (IPE), which details specific occupational goals and steps needed to achieve them. The IPE could include such things as vocational training at a trade school, a certificate program at a Continuing Education Department of a college, supportive employment, or a two or four-year degree. Ask VESID about the availability of cognitive rehabilitation if you think this service will improve your loved one’s chance of employment. p. 42

In New York City, Workforce 1 centers are located in every NYC borough. These centers have a Disability Navigator on staff. All NYC residents are eligible for this

program. In addition to placement assistance, they provide some limited training vouchers, access to a computer, printer, phone, and fax, and GED classes.(p. 51)

See “EMPLOYMENT” (pg. 41) for all employment and agency resources.

NOTE: The future looks rosier for vocational support due to a generous grant from Medicaid to the New York State Office of Mental Health. Coalitions and potential for multiple year funding could result in raising the currently low employment rate for those with mental illness.

R **Hint - CUNY and SUNY two- and four-year college has an office for students with disabilities that can be very helpful.**

EMPOWERMENT AND THE PEER MOVEMENT

The thriving and articulate consumer movement has spearheaded recovery as a right. This social movement for self-determination asserts that the consumer has primary control over decisions about his/her own care and advocates for “peer support specialists” to manage a range of services: Peer Drop in Centers, Peer Employment Supports and Peer Crisis Diversion, Bridger, Advocacy Services and now Peer health services. That those who experience illness are best equipped to provide these services is expressed in their slogan, “Nothing About Us Without Us.” They see peer services as an approach whose time has come, whether it be to promote recovery, empowerment and employment or to provide timely interventions to help people avoid crisis and improve their health and wellness.

Ten thousand consumers have clearly stated how to respect their choices in a 2006 White Paper, entitled, Infusing Recovery-Based Principles into Mental Health Service. At the heart are ten rules:

- (1) There must be informed choice;
- (2) Treatment must be recovery-focused;
- (3) Treatment must be person-centered;
- (4) First, do no harm;
- (5) There must be free access to records;
- (6) The system must be based on trust;
- (7) Treatment must have a focus on cultural values;
- (8) Treatment must be knowledge-based;
- (9) Treatment must be based on a partnership between consumer and provider; and
- (10) There must be access to services regardless of ability to pay (www.thewhitepaper.org)

RECOVERY

Official definitions include: “Mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of their choice while striving to achieve their full potential.”

This is much broader than the definition historically used in the mental health treatment system: compensating for, or accommodating, the impairment of a psychiatric disability.

Viewing recovery as remission or as a return to the way your loved one was before could damage recovery efforts. Being “in recovery” however, opens up the possibility to operate under a new set of parameters with growth potential as defined by the individual.

Recovery is not something you can do to or for your loved one. Your loved one must take responsibility for his or her own recovery. The family’s role is to share the powerful consumer sources in this Handbook to empower their loved one to design their own recovery goals and plan. (pgs 38-39).

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Tools You Can Use

HOSPITAL CHECKLIST

PATIENT INFORMATION:

PATIENT'S HOSPITAL ADDRESS: _____

PATIENT'S PHONE NUMBERS:

Hospital Ward Public Phones: _____
Front Desk numbers: _____
Home: _____
Cell: _____

VISITING HOURS & OTHER PERTINENT INFORMATION:

CURRENT AND PAST MEDICAL DIAGNOSES

Current diagnosis (if any) _____
Medication(s), if any _____
Primary care physician _____
Psychiatrist? _____
Dentist _____

PHYSICAL ISSUES

HISTORY OF MENTAL ILLNESS/BRAIN DISORDERS IN THE FAMILY

PROFESSIONAL CONTACT INFORMATION:

HOSPITAL CHECKLIST (continued)

Attending Psychiatrists (in charge of assigning medications)

#1 Name: _____ SHIFT from/to _____

Phone numbers: _____ cell: _____

Best times to call: _____

Contact days & hours: _____

Fax: _____ Email: _____

#2 Name: _____ SHIFT from/to _____

Phone numbers: _____ cell: _____

Best times to call: _____

Contact days & hours: _____

Fax: _____ Email: _____

Social worker (recommends resources: social services, housing, employment and does counseling)

Name: _____ SHIFT from/to _____

Phone numbers: _____ cell: _____

Best times to call: _____

Contact days & hours: _____

Fax: _____ Email: _____

Nurse Practitioner (advises on diagnosis and treatment)

Name: _____ SHIFT from/to _____

Phone numbers: _____ cell: _____

Best times to call: _____

Contact days & hours: _____

Fax: _____ Email: _____

HOSPITAL CHECKLIST (continued)

Caseworker/ Case Manager

(Guides and Directs, helps get benefits and access health, education and social services, counsel on diagnosis and treatment of illness. For more intense coverage: Intensive Case Manager)

Name: _____ SHIFT from/to _____

Phone numbers: _____ cell: _____

Best times to call: _____

Contact days & hours: _____

Fax: _____ Email: _____

Manager or Medical Director

(Physician who serves both clinical and management positions)

Name: _____ SHIFT from/to _____

Phone numbers: _____ cell: _____

Best times to call: _____

Contact days & hours: _____

Fax: _____ Email: _____

Religious Counselors

(traditional counseling with healing through scripture lessons)

Name: _____ SHIFT from/to _____

Phone numbers: _____ cell: _____

Best times to call: _____

Contact days & hours: _____

Fax: _____ Email: _____

Peer advocates counselors

(counsel for recovery by sharing their success working toward and achieving independence)

Name: _____ SHIFT from/to _____

Phone numbers: _____ cell: _____

Best times to call: _____

Contact days & hours: _____

Fax: _____ Email: _____

HOSPITAL CHECKLIST (continued)

WORKING DIAGNOSIS

A) upon admission _____

B) upon discharge _____

Basis of Working Diagnosis _____
(How was diagnosis arrived at?): _____

4. TREATMENT GOALS:

5. INITIAL MEDICATIONS

1) Name _____ Dosage/when to take _____
Benefits _____
Side Effects _____

Contact doctor (name(s)) if any: _____

2) Name _____ Dosage/when to take _____
Benefits _____
Side Effects _____

Contact doctor (name(s)) if any: _____

3) Name _____ Dosage/when to take _____
Benefits _____
Side Effects _____

Contact doctor (name(s)) if any: _____

4) Name _____ Dosage/when to take _____
Benefits _____
Side Effects _____

Contact doctor (name(s)) if any: _____

7. GOVERNMENT INSURANCE BENEFITS

A social worker or representative from the hospital's financial office should help you obtain appropriate financial assistance.

Insurance benefits representative(s) 1. _____
2. _____
3. _____

Patient qualifies for: _____
Benefit Application date _____
Date effective _____
Costs covered/other benefits: _____

Patient qualifies for: _____
Benefit Application date _____
Date effective _____
Costs covered/other benefits: _____

Patient qualifies for: _____
Benefit Application date _____
Date effective _____
Costs covered/other benefits: _____

SOCIAL SECURITY contact person(s):

Name _____ Phone number _____
Fax: _____ Email: _____

MEDICAID contact person(s):

Name _____ Phone number _____
Fax: _____ Email: _____

MEDICARE contact person(s):

Name _____ Phone number _____
Fax: _____ Email: _____

Other Pertinent Information:

DESCRIPTION OF PATIENT'S LEGAL STATUS

8. DISCHARGE PLANNING

(In the case of two diagnoses, e.g. substance abuse and mental illness, services must address both.)

A) CASE MANAGEMENT SERVICES

Assertive Community Treatment

Treatment Provider _____ Start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

Supportive Case Management

Treatment Provider _____ Start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

Intensive Case Management

Treatment Provider _____ Start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

B) MENTAL HEALTH TREATMENT

Outpatient treatment (individual or group)

Treatment Provider _____ Start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

Day Treatment Program

Treatment Provider _____ Start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

Psychiatrist/social/worker/therapist

Treatment Provider _____ Start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

C) OTHER COMMUNITY SUPPORTS

Self-Help Groups, AA, NA, MHA, NAMI, NYAPRS, Double Trouble (circle)

Provider _____ Start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

Psychosocial Club

Provider _____ Start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

Other program

Provider _____ Start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

Support Group

Provider _____ Start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

IPRT (Individual Psychiatric Rehabilitative Treatment)

Provider _____ Start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

Vocational Program

Provider _____ Start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

D) HOUSING: WHERE TO LIVE AFTER DISCHARGE

Community based Housing Provider _____ If yes, start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

E) FOR DUAL DIAGNOSIS

MICA (Mentally Ill Chemically Addicted) Program

Treatment Provider _____ Start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

Support Group

Treatment Provider _____ Start date _____

Contact information: Name _____

Phone _____ Cell Phone _____

Fax _____ E Mail _____

Tools You Can Use #2

MANAGEMENT LOG SHEET

(Use these log sheets to record all meetings, phone conversations, emails, letters, side effects in the hospital or at home.)

DATE _____

WHO ATTENDING _____

WHAT WAS DECIDED _____

SYMPTOMS _____

ACTION STEPS _____

Who Does What By When _____

SIDE-EFFECTS _____

CHANGES: Physical _____

CHANGES: Behavioral _____

Tools You Can Use #3

FAMILY CONTRACT SAMPLE

(adapt parenthetical parts for your individual situation) family member) agree to the following terms:

1. I will (make my home available during the transition while family member awaits supported housing placement)
2. I will (not enter _____'s room without knocking)
3. I will (provide _____ with meals and spending money in the amount of \$_____per week)
4. I will (help _____with transportation to appointments and services, and, when I am able to do so, other appropriate destinations)
5. Other _____ I, (consumer) agree to the following terms:
 1. I (agree to take my medications as prescribed from a credentialed psychiatrist, to keep the twice-a-month appointments with my case manager and to cooperate with treatment and planning goals).
 2. I (understand that getting the medication right is trial and error and that it's my responsibility to regularly report to the doctor to "get it right.")
 3. I (promise to report early warning signs like sleeplessness, anxiety and hearing voices).
 4. I (agree not to harm myself or others, and I will not threaten to harm others).
 5. I agree to do the following task: (list chores and when they are to be accomplished).
 6. I (will not expect monetary help from my family, other than the \$_____ weekly spending money.
 7. I (will be civil in my family's home and use stress and emotional regulation techniques).
 8. I (agree to commit to a plan toward getting full-time work: set up volunteer hours on a flexible basis while stabilizing and attend a skills-building program).
 9. Other _____

Family member

Signature

Date

Consumer

Signature

Date

Provider

Signature

Date

RESOURCES

ADVANCE DIRECTIVES

New York Association of Psychiatric Rehabilitation Services
518-436-0008 x19

www.nyaprs.org

Visit this website to download Planning for Your Mental and Physical Health Care and Treatment, which is a comprehensive set of Advance Directives forms and instructions, as well as a carrying card: http://www.nyaprs.org/Pages/View_Content_A.cfm?ContentID=39

AOT

New York State Office of Mental Health

http://www.omh.state.ny.us/omhweb/ken dra_web/ksummary.htm

BENEFITS ELIGIBILITY

Advocacy Counseling and Entitlement Services (ACES)
212-614-5552

Call to find out which benefits your loved one qualifies for.

Centers for Medicare and Medicaid Services
800-342-3009 (Medicaid)
877 472-8411 (NYC only)

<http://www.cms.hhs.gov/medicaideligibility/>

800-772-1213 (Medicare Basic Information Line for sign-up/eligibility)

<http://www.medicare.gov/Help/MET.asp>

NYC Human Resource Administration, Department of Social Services

718-472-8411, (TTY) 718-262-3566
or toll free 1-800-342-3009

<http://www.nyc.gov/html/hra/html/home/home.shtml>

New York State Office of Temporary and Disability Services
800-342-3009

<https://www.mybenefits.ny.gov/selfservice/>

The "My Benefits" home page is a quick and easy way for people in New York State to find answers to questions about New York State's programs and services, including eligibility for benefits.

New York Association of Psychiatric Rehabilitation Services (NYAPRS)

Social Security Disability Benefits

800-772-1213, (TTY) 800-325-0778

<http://www.ssa.gov/dibplan/dqualify.htm>

CHILDREN

American Academy of Child and Adolescent Psychiatry
202-966-7300

www.aacap.org

The site offers news alerts, fact sheets, legislative action, publications, research, and a directory of mental health organizations and doctor organized by regions.

Families Together in New York State

518-432-0333 or 888-326-8644

www.ftnys.org

Families Together is a non-profit, family-run organization that strives to establish a unified voice for children and youth with emotional, behavioral, and social challenges. Its mission is to ensure that every family has access to needed information, support, and services. Website features publications, guides and reports.

Families USA

www.familiesusa.org

A comprehensive clearinghouse for children's issues.

CRISIS

Mobile Crisis Teams.
800-543-3638 (LIFENET)

Are a team of mental health professionals (nurses, social workers, psychiatrists, mental health technicians, addiction specialists, peer counselors and sometimes police). responding to persons in the community, usually at home. Their 23 New York Citywide teams serve anyone experiencing or at risk of, a psychological crisis and requiring mental health intervention.

COGNITIVE REHABILITATION

NYS Office of Vocational and Educational Services for Individuals with Disabilities (VESID)

<http://www.vesid.nysed.gov/>

Offers access to a full range of services that may be needed by persons with disabilities through their lives, including special education, cognitive rehabilitation, vocational rehabilitation and independent living programs. Visit the website for contact information for the district office in your county.

Lieber Recovery and Rehabilitation Services

Columbia University Medical Center Eastside

16 East 60th Street, Suite 400, New York, New York 10022

212-326-8441

Offers the NEAR method (Neuropsychological Educational Approach to Rehabilitation), which provides specific neurocognitive exercises to improve attention, planning, memory, and other cognitive skills. Computer-based exercises and group exercises teach cognitive awareness and cognitive skills and improve self-esteem and intrinsic motivation. Private pay.

New York State Office of Mental Health

www.omh.state.ny.us

From the website, search "Dealing with Cognitive Dysfunction" to download a handbook on the cognitive remediation authored by Alice Medalia

COMPLAINTS (ALSO SEE "LEGAL SERVICES")

NYS Commission

on **Quality of Care**

800-624-4143 (Voice/TTY/Spanish)

<http://www.cqcapd.state.ny.us/>

For problems concerning inpatient and outpatient treatment

NYS Office of Mental Health

main hotline

1-800-597-8481

in Spanish 1 800 210-6456

NYS Office of Mental Health

Family Liaisons

518-474-4888

Assists families in advocating for loved one in hospital or clinic settings)

NYS Office of Recipient Affairs

518-473-6579

Peer advocates assist consumers with problems with treatment and/or getting services)

CONSUMER SUPPORT AND SELF HELP

Center for Independence of the Disabled, NY

212-674-2300

212-674-5619 TTY (Manhattan)

646-442-1520

718-886-0427 TTY (Queens)

<http://www.cidny.org>

This not-for-profit is part of the Independent Living Centers movement. Its goal is to ensure full integration, independence and equal opportunity for all people with disabilities by removing barriers to the social, economic, cultural and civic life of the community. CIDNY's offices in Manhattan and Queens provide benefits counseling, direct services (e.g. housing assistance,

transition services for youth with disabilities, employment-related assistance, healthcare access, peer support groups), information and referrals, and recreational activities.

Depression and Bipolar Support Alliance

www.dbsalliance.org

Dedicated to educating about depression and bipolar disorder, fostering self-help, eliminating discrimination and improving access to treatment.

Community Friends

scohen@JBFCs.org

212 632-4611

This program, run by the Jewish Board of Family and Children's Services, has trained volunteers contact ill members to break any sense of isolation by offering them simple get together such as a walk in the park or a coffee at Starbucks progressing to more stimulating outings that take advantage of the endless free opportunities of the City.

Fountain House

www.fountainhouse.org

582-0340

A "Clubhouse" restorative community organized by and for the mentally ill. With some staff, it's basically consumer run. Its members pursue a range of activities in a beautiful and warm clubhouse, as well as provide opportunities to obtain housing, a job and friendships. The first Clubhouse, Fountain House in New York City, was started in 1948 by a group of consumers, sitting on the steps of New York's 42nd Street Public Library discussing what kind of place they would like to "hang out" in. Founding this first one, they coined the word "clubhouse" for their "members," defining it as a place of membership and belonging... Since then, Fountain House' model sets rigorous standards for a network of Clubhouses internationally.

Friendship Network

www.friendshipnetwork.org

Serving the five boroughs of New York City (Queens, Bronx, Manhattan, Staten Island, Brooklyn); Long Island (Nassau and Suffolk County); Westchester County and Northern New Jersey, the Friendship Network is a not-for-profit organization that introduces single men and women recovering from mental illness to one another. Sponsored by NAMI Queens-Nassau.

Mental Health Empowerment Project

800-643-7462

(for list of consumer self-help groups)

Mental Health Recovery

802-254-2092

www.mentalhealthrecovery.com

www.copelandcenter.com

Mary Ellen Copeland has written several books and developed a variety of programs for helping people in the recovery process, including Wellness Recovery Action Plan (WRAP), a program that teaches self-help monitoring skills for handling particularly the ups and downs of Bi-Polar Disorder. Websites offers helpful information, a free newsletter, and a list of publications and workshops that can be purchased.

NAMI's Peer-to-Peer

518-462-2000 or 800-950—3328(P2P)

For people with mental illness who want to establish and maintain their wellness and recovery. The program provides a binder of materials, including an advance directive; a "relapse prevention plan"; and mindfulness exercises to help focus and calm thinking; and survival skills for working with providers and the general public. Limited to New York State.

NAMI Connection

Google NAMI Connection for a map showing where (in almost all fifty states) the groups are.

It is a weekly recovery support group for people living with mental illness to learn from each others' experiences, share coping strategies, and offer encouragement and understanding.

Mental Health Association of New York State

518-434-0439

<http://www.mhany.org>

This hundred-year organization provides programs, resources, education and referrals. All other national chapters are known as "Mental Health America"

National Mental Health Consumers Clearinghouse

www.mhselfhelp.org

News, publications, resources, training materials, technical assistance and a directory of consumer-driven services.

New York City Voices

www.nycvoices.org

A peer journal for mental health advocacy, New York City Voices is an excellent publication written by consumers for consumers and the New York community.

New York Association for Psychiatric Rehabilitation

(518) 436-0008, www.nyaprs.org

The premier consumer organization is a statewide coalition of people who use and/or provide recovery-oriented community based services. Dedicated to improving services and social conditions for people with psychiatric it sponsors a comprehensive listserv, provides training and lobbying and sponsors the Peer Bridger project (see below). Their listserv is one of the most comprehensive tracking of policy and legislative issues currently available (call above number to be placed on it).

New York State

Office of Mental Health, Bureau of Recipient Affairs

(518) 473-6579

Staffed by consumers, OCA offers advocacy trainings, technical assistance and peer support, as well as quarterly "advisory committee meetings.

Peer Bridger Project

518-436-0008

Tanyas@nyaprs.org,

<http://www.nyaprs.org/Index.cfm>

The NYAPRS Peer Bridger Project has helped individuals being discharged from New York State Psychiatric Centers in six counties (Albany, Ulster, Broome, Queens, Suffolk and Westchester) to ease the transition into community life and to significantly decrease their need for readmission.

Recovery x-Change

<http://www.recoveryxchange.org/about.html>

The Recovery x-Change is a wellness management training partnership of peer specialists and providers partnering with providers to create, design and customize recovery focused trainings for an integrated approach necessary for recovery.

CRIMINAL JUSTICE

NAMI-NYS Criminal Justice

Advocacy program

260 Washington Avenue

Albany, NY 12210

518-462-2000 or 1-800-950-3228

<http://naminy.org/criminaljustice.html>

Helps families navigate their loved one through the criminal justice system and advocate for jail diversion initiatives.

New York State Office of Mental Health (OMH) Bureau of Forensic Services and Criminal Procedures
518-474-7219

<http://www.omh.state.ny.us/omhweb/forensic/BFS.htm>

Responsible for services provided to persons with mental illness as mandated via Criminal Procedure Law or Corrections Law.

Reentry Resource Center - New York

<http://www.reentry.net/ny/>

Reentry Net/NY is the first ever support network and information clearinghouse on prison and jail reentry, and the collateral consequences of criminal proceedings on individuals and families in New York State.

Urban Justice NYC
646-602-5600

www.urbanjustice.org

- The Urban Justice Center serves New York City's most vulnerable residents through a combination of direct legal service, systemic advocacy, community education and political organizing.

CRISIS INTERVENTION

LIFENET Mobile Crisis Intervention team
800 543-3638

CULTURAL ISSUES AND SUPPORT

NAMI Multicultural Action Center (MAC)

Online resources include fact sheets, manuals, and other informational materials about mental health issues specific to traditionally underserved communities: African American, American Indian Alaska

Native, Asian American Pacific Islander, Latino and GLBT. Resources are available in Spanish, Chinese, Italian, and Portuguese. Website: Go to www.NAMI.org. From the home page, choose the "Find Support" drop down menu and select "Multicultural Action Center."

New York State Office of Mental Health's Bureau of Cultural Competence
518-474-4144

Furthers multicultural interests and activities

Office of Minority Health
240-453-2882

www.health.state.ny.us/nydoh/omh Mission is to improve the health of racial and ethnic minorities through communication, and customized services and practical approaches to problems and issues

MEDICATION (FINANCIAL) ASSISTANCE

PhRMA Patient Assistance Programs
www.phrma.org

Find patient assistance programs for which you may qualify.

The Medicine Program
www.themedicineprogram.com

An organization established by volunteers to help obtain prescription medications free of charge for those who cannot afford them.

Rx Assist
www.rxassist.org

This searchable database locates patient assistance programs by company, brand name, generic name and drug class. It includes eligibility and application instructions.

Together Rx
<http://www.togetherrxaccess.com/Tx/jsp/apply.jsp>

A free prescription-savings card for eligible residents of the United States and Puerto Rico who have no prescription drug coverage.

EPIC
http://www.health.state.ny.us/health_care/epic/

EPIC is a New York State program that helps seniors pay for their prescription drugs. Most enrollees have Medicare Part D or other drug coverage, and use EPIC to lower their drug costs even more by helping them pay the deductibles and co-payments required by their other drug plan. EPIC also helps members pay for Medicare Part D premiums.

Medicare Part D
800-633-4227, TTY: 1-877-486-2048

<http://www.medicare.gov/pdphome.asp>

Medicare prescription drug coverage is insurance that covers both brand-name and generic prescription drugs at participating pharmacies in your area for anyone with Medicare, regardless of income and resources, health status, or current prescription expenses.

DUAL DIAGNOSIS

Office of Alcoholism and Substance Abuse Services (OASAS)
518-473-3460 or 212-399-8404

<http://www.oasas.state.ny.us/>

National Association for the Dually Diagnosed
1-800-331-5362

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

Provides educational services, training materials, advocacy and some referrals. This not-for-profit's mission is to address the

mental health needs of persons with developmental disabilities.

EATING DISORDERS

National Eating Disorders Association (NEDA)
800-931-2237

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

Dedicated to providing education, resources and support to those affected by eating disorders.

American Anorexia/Bulimia Association
212-575-6200

Support groups, information and referrals

EDUCATION

Family Institute for Education, Practice and Research (FIEPR)
585-224-1324

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

Offers Consumer-Centered Family Consultation and referral linkage. With consumer consent, their Family Consultation provides one-to-three session meetings post hospital with a mental health provider to discuss concerns, explore solutions and a plan for addressing them. It is also a gateway service for FIEPR's full Spectrum of Family Services. . Contact: Anne Smith, annem_smith@urmc.rochester.edu.

Mental Illness Education Project (MIEP)
800-343-5540

www.miepvideos.org

Seeks to improve understanding of mental illness through the production of videotapes for people with psychiatric disorders, their families, mental health practitioners, administrators, educators and the general public.

National Alliance on Mental Illness - New York State (NAMI-NYS)

518-462-2000 or 800-950-3228

www.naminys.org

Offers comprehensive education and training programs for patients and families including the 12-week Family-to-Family program. Visit the website at <http://naminys.org/educationandtraining.html>, contact your local NAMI chapter (you can find affiliate listings on our website) or call NAMI-NYS to find details about education course offerings near you. They sponsor an annual conference presenting speakers leaders in the field of mental health, workshops and an opportunity to network statewide.

National Alliance on Mental Illness of New York City Metro (NAMI-NYC Metro)

212-684-3264

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

One of the largest affiliates of the National Alliance on Mental Illness, this grassroots organization provides support, education and advocacy for families and consumers of all ethnic and socio-economic backgrounds who live with mental illness. Their twenty support groups address the needs of those suffering from schizophrenia, bipolar Disorder, with family and children dealing with mental illness, even providing pet therapy. The only advocacy group us held the first-Friday-of-the-month. The Media & Advocacy Group (MAG) provides advocacy information, skill-building, networking and a monthly speaker from the field. NAMI-NYC Metro's Helpline is available Monday through Friday, noon to 7PM Mon - Thurs, noon to 6PM Fridays (212) 684-3264. (pgs 47, 58)

NYS Office of Mental Health (NYSOMH), Bureau of Family & Recipient Affairs
518-473-6579

The quarterly meeting, of their Commissioner's Committee for Families, is an opportunity for families and providers to learn

about NYSOMH's latest activities, network with their colleagues, and become a focus group for OMH's internal projects as well as ones they generate. Call to obtain a Wellness Self Management "Toolkit" or to join their listserv: listserv.omh.stte.ny.us.

EMPLOYMENT

The Center for Rehabilitation and Recovery
212-742-1600

www.coalitionny.org

The center has created a comprehensive workbook listing of 115 NYC mental health programs supporting employment. It also offers information on how to work without letting a salary interfere with receiving benefits as well as how to choose and employment program. The workbook is downloadable from their website.

Employer Assistance & Recruiting Network (EARN)

<http://www.earnworks.com>

This free service connects employers looking for quality employees with skilled job candidates. Federal and private employers, employment service providers, and job seekers can sign-up through the website, and either post openings or locate job opportunities in their local region.

Equal Employment Opportunity Commission (EEOC)

800-669-4000 or (TTY) 800-669-6820

<http://www.eeoc.gov/>

The EEOC is responsible for the enforcement of the Americans With Disabilities Act (ADA). In addition to mental illness issues in the workplace, this site also deals with a variety of other topics related to discrimination, including reporting procedures to file a complaint. Other interesting topics include Best Practices for the Employment of People with Disabilities in State Government and Information for Small Businesses in Complying with the Americans with Disabilities Act.

Reaching Mental Health Recovery Together

Job Accommodation Network (JAN).

1-800-526-7234 (V/TTY)

<http://www.jan.wvu.edu/>

This free consulting service of the Office of Disability Employment Policy through the U.S. Department of Labor is designed to increase the employability of people with disabilities by: 1) providing individualized worksite accommodations solutions; 2) providing technical assistance regarding the Americans with Disabilities Act and other disability related legislation; and 3) educating callers about self-employment options.

New York State Department of Labor and Workforce New York

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

The New York State Department of Labor and Workforce New York sponsors Career Zone, which offers careers explorations and helps match interests, skills and abilities of job-seekers to job openings.

Vocational and Educational Services for Individuals with Disabilities (VESID)

518-474-1711, 800 222-jobs or 5626)

VESID, New York State's vocational rehabilitation system, offers both transitional and supportive employment opportunities. VESID coordinates services relating to vocational assessment, vocational counseling, training and placement, and job follow-up. VESID ensures that both the individual and the employer are satisfied with the placement and VESID will intervene if problems occur once an individual is placed in a job. VESID is also a vendor in the Ticket to Work Program administered by the Social Security Administration.

Partnership for Workplace Mental Health

703-907-8561 or 703-907-8673

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

This site offers educational materials and a forum to explore mental health issues for employers and employees, including

the publications Mental HealthWorks and A Mentally Healthy Workforce: It's Good for Business.

Ticket to Work

866-968-7842 or (TTD) 866-833-2967

www. <http://www.yourtickettowork.com/>

A federal program administered by the Social Security Administration, the Ticket to Work is a coupon you can take to any provider to gain vocational rehabilitation, training, job referrals, and other ongoing support and services to reach employment goals.

NYS Office of Vocational and Educational Services for Individuals with Disabilities (VESID)

<http://www.vesid.nysed.gov/>

Offers access to a full range of services that may be needed by persons with disabilities through their lives, including special education, cognitive rehabilitation, vocational rehabilitation and independent living programs. Visit the website for contact information for the district office in your county.

Workforce One Centers (NYC Only)

954-677-5555

<http://www.wf1broward.com/>

Located in every NYC borough, have a Disability Navigator on staff. All NYC residents are eligible. In addition to placement assistance they provide some limited training vouchers, access to a computer, printer, phone, and fax, and GED classes.

FOOD STAMPS

NYC Human Resource Administration, Department of Social Services

718 472-8411, (TTY) 718-262-3566 or 800-342-3009

<http://www.nyc.gov/html/hra/html/directory/food.shtml>

Visit the website to download application as well as locate addresses and information for 19 centers throughout the city open from 8:30AM to 5PM Monday through Friday. (see p. 14)

New York State Office of Temporary Disability Assistance

1-800-342-3009 and press "1" for Food Stamps

<http://www.otda.state.ny.us/main/food-stamps/>

FUTURE CARE PLANNING FOR SPECIAL NEEDS TRUSTS

Future Care Planning Clearinghouse

800-652-2090

Information on wills, trusts, guardianship and some referrals. A Special Needs Trust (SNT) needs to be set up in the case of an inheritance to a) protect consumer from loss of benefits and b) to keep the inheritance intact to provide for supplemental needs.

HEALTH, GENERAL

Healthfinder

www.healthfinder.gov

This web site can help locate selected online publications, clearinghouses, databases, and support and self-help groups as well as government agencies and not-for-profit organizations.

MedicineNet

www.medicinenet.com

Produced by a network of doctors, this site includes news and perspectives, treatment updates, health facts, a medical dictionary and an index of commonly used medications.

HEALTH - MENTAL (GENERAL)

Center for Mental Health Services
www.mentalhealth.org

A Substance Abuse and Mental Health Services Administration (SAMHSA) site that promotes education of mental illness on a large scale. It includes mental illness statistics regarding mental as well as news and a searchable database. They offer excellent ongoing gratis educational materials to subscribers to their listserv.

Family Institute for Education, Practice and Research
www.nysfamilyinstitute.org

Provides statewide training, technical assistance and supervision to mental health providers in the design, implementation, and evaluation of research-based family interventions for individuals with severe mental illness and their families. It's Consumer-Centered Family Consultation is a gateway service for the full Spectrum of Family Services. . For more information, contact: Anne Smith by phone or send an email to annem_smith@urmc.rochester.edu. (p. 25)

Mental Health America
www.nmha.org

Formerly the National Mental Health Association. News, legislative alerts, free publications, extensive resources, links and more. Their website is very easy to navigate.

Mental Health Association in New York State
518-434-0439
www.mhanys.org

Mental Health Resources
www.mentalhealthed.org
mhresources@nyc.rr.com

Family run, Mental Health Resources educates families about how to exercise their rights, navigate the mental health system,

get services and partner with their loved one to build an independent life—securing treatment, employment, housing and more.

National Alliance on Mental Illness
www.nami.org

The National Alliance on Mental Illness (NAMI) is a nonprofit, grassroots, self-help, support and advocacy organization of consumers, families, and friends of people with severe mental illnesses. Founded in 1979, NAMI has more than 210,000 members who seek equitable services for people with severe mental illnesses.

National Alliance on Mental Illness of New York State
518-462-2000 or 800-950-3228

www.naminys.org

The National Alliance on Mental Illness of New York State (NAMI-NYS) is a grassroots education, advocacy and support organization of persons with mental illness and their families in 56 affiliates statewide. The website features a variety of information and resources, including this handbook.

National Alliance on Mental Illness of New York City Metro
212-684-3264

http://www.naminycmetro.org/

The National Alliance on Mental Illness of New York City Metro, Inc. is one of the largest affiliates of the National Alliance on Mental Illness. This grassroots organization provides support, education and advocacy for families and individuals of all ethnic and socio-economic backgrounds who live with mental illness.

Network of Care for Behavioral Health
http://newyorkcity.ny.networkofcare.org/mh/home/

A highly interactive, one-stop site to access information on NYC services.

New York City Division of Mental Hygiene
212-219-5003
http://www.nyc.gov/html/doh/html/dmh/dmh.shtml

Division Of Consumer Services, offers the consumer services in a wide range of recovery-oriented programs.

New York State Office of Mental Health
518-474-2568 or 800-597-8481
http://www.omh.state.ny.us/
44 Holland Avenue
Albany, New York 12229

New York State Office of Mental Health. This New York State agency is authorized by law to operate 25 psychiatric hospitals and oversees 2500 local non-profit and government providers of mental health services statewide (including inpatient and outpatient, emergency, community support, residential and family care programs).

National Institute of Mental Health (NIMH)
www.nimh.nih.gov

Authority on mental health research. Visit this website to learn about mental illnesses, research and treatment.

GOVERNMENT

Mental Health Links to Federal Web Sites
http://mentalhealth.samhsa.gov

National Institute of Mental Health
www.nimh.nih.gov

This web site provides information on basic and clinical research activities.

New York City Services
www.nyc.gov

New York City Services provides the public with access to information about New York City agencies and services

New York State Government
<http://www.state.ny.us/>

New York State Governor
www.state.ny.us/governor

New York State Senate
www.nysenate.gov

New York State Senate features information on the activities of the state senate as well as the location of your senators offices.

New York State Assembly
www.assembly.state.ny.us

This web site allows you to contact your district Assembly representative by e-mail.

New York State Office of Mental Health
www.omh.state.ny.us

Social Security Online
www.ssa.gov

Answers to your FAQ's, news, a special section on understanding social security and much more. Information in English and Spanish.

HEALTH INSURANCE (private)

Health Insurance Hotline
 800-333-4114

NYS Insurance Department
 800-342-3355

NYS Attorney General Health Care Bureau
 800-692-4422

HEALTH INSURANCE (public)

Medicaid: New York State Medicaid Hotline
 800-342-3009

Medicare: Basic Information Line for sign-up/eligibility: 800-772-1213

Medicare Hotline
 800-MEDICARE (pgs. 13, 41)

Children's Health Insurance Program

<http://www.cms.hhs.gov/LowCostHealthInsFamChild/>

Previously known as the State Children's Health Insurance Program (SCHIP), this state and federal partnership targets uninsured children and pregnant women in families with incomes too high to qualify for most state Medicaid programs, but often too low to afford private coverage.

Child Health Plus
 800-300-8181 /718-630-0126

http://www.healthplus-ny.org/en/119_ENG_HTML.html

Child Health Plus/Health Plus provides a child or teenager with free or affordable health coverage depending on their household income.

Family Health Plus
<http://www.health.state.ny.us/nysdoh/fhplus/>

Family Health Plus is a public health insurance program for adults who are aged 19 to 64 who have income or resources too high to qualify for Medicaid. Family Health Plus is available to single adults, couples without children, and parents who are residents of New York State and are

United States citizens or fall under one of many immigration categories.

Family Health Plus provides comprehensive coverage, including prevention, primary care, hospitalization, prescriptions and other services. There are minimal co-payments for some Family Health Plus services, which are provided through participating managed care plans.

Healthy New York
<http://www.ins.state.ny.us/website2/hny/english/hny.htm>

An extremely basic State health insurance plan that does not include mental health coverage.

HELPLINES

New York City Department of Mental Health
 1-800-LIFENET
 (24 hours, professional staff)

NAMI-New York City Metro Helpline
 212-684-3264
 (open noon to 7PM Mon - Thurs, Friday noon to 6PM)

HOUSING

Association for Community Living (ACL)
 518-426-3635
www.aclnys.org

ACL is a statewide membership organization of not-for-profit agencies that provide housing and rehabilitation services to more than 20,000 people diagnosed with serious and persistent mental illness. This website offers detailed descriptions of licensed and supported housing options as well as resources, links, discussion forums and a shortcut to the Office of Mental Health residential program finder.

Center for Independence of the Disabled, NY

212-674-2300
212-674-5619 TTY (Manhattan)

646-442-1520
718-886-0427 TTY (Queens)

<http://www.cidny.org>

This not-for-profit is part of the Independent Living Centers movement. Its goal is to ensure full integration, independence and equal opportunity for all people with disabilities by removing barriers to the social, economic, cultural and civic life of the community. CIDNY's offices in Manhattan and Queens provide benefits counseling, direct services (e.g. housing assistance, transition services for youth with disabilities, employment-related assistance, healthcare access, peer support groups), information and referrals, and recreational activities.

Center for Urban Community Services (CUCS)

212-801-3300

www.cucs.org

Since 1987, CUCS' Housing Resource Center has provided information and access to housing for homeless people with psychiatric disabilities and other special needs. CUCS administers the Single Point of Access service. (SPOA). One-stop shopping for New York City residents to work with consultants in a housing outreach campaign.

Community Access Inc.

212-780-1400

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

Community Access, Inc. (CA) helps hundreds of people with psychiatric disabilities make the transition from hospitals and shelters to independent living. CA's primary mission is to identify needs and create solutions for homeless people with psychiatric disabilities. Our programs include housing, support services, counseling, education and employment opportunities. Community Access believes that all people can lead productive, self-

sufficient, dignified lives, and we are dedicated to providing the resources needed to achieve that goal.

Corporation for Supported Housing
212-986-2966

Advocacy, information and referrals and housing services

New York State Department of Health

<http://www.health.state.ny.us/>

Find a statewide listing of adult homes, including a list of homes on the State's 'Do Not Refer' List: http://www.health.state.ny.us/facilities/adult_care/memorandum.htm

NYS Office of Mental Health Single Point of Access

Moira Tashjian,
Director of Housing Re-Design
(518) 402-5233

coctmwt@omh.state.ny.us

US Department of Housing and Urban Development also known as the "Section 8 Housing Program"

(212) 306-3322

<http://www.hud.gov/progdsc/voucher.cfm>

Find information and eligibility requirements for the federal government's Housing Choice Voucher program, which enables very low-income families, the elderly, and the disabled to afford decent, safe, and sanitary housing in the private market. -Under the Section 8 Program, the public housing authority (PHA) generally pays a supplement to the landlord. Although currently HUD is not accepting new applications and it only extending expiring commitments it does periodically open the vouchers.

JAILS AND PRISONS

New York State Department of Correctional Services

<http://www.docs.state.ny.us/faclist.html>

This website provides an alphabetical listing of all correctional facilities within New York State, including the phone number, mailing address, security level, and links to MapQuest.

KENDRA'S LAW (Assisted Outpatient Treatment, AOT)

New York State Office of Mental Health

http://www.omh.state.ny.us/omhweb/Kendra_web/Khome.htm

New York State law provides for court-ordered assisted outpatient treatment (AOT) for certain people with mental illness that, in view of their treatment history and circumstances, are unlikely to survive safely in the community without supervision. Visit the above OMH website to find links to further information concerning Kendra's Law and Assisted Outpatient Treatment.

LEGAL SERVICES

Bazon Center for Mental Health Law

www.bazon.org

Focuses on legal issues pertaining to mental illness and developmental disabilities, including involuntary admissions and advance psychiatric directives.

Disability Advocates

<http://www.disability-advocates.org/>

Legal Aid Society of Northeastern New York

800-462-2922

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

Covers Albany, NY area, but can give other regional numbers

Legal Referral Service (Sponsored by the NYS Bar Association)
800-342-3661

Mental Hygiene Legal Services
Provides legal representation for inpatients, for those referred for Assisted Outpatient Treatment, and for outpatients with mental illness and developmental disabilities if they are in a certified community residence)

Bronx/Manhattan: 212-779-1734

Duchess, Kings, Nassau, Orange, Putnam, Queens, Richmond, Rockland, Suffolk and Westchester counties: 516-746-4545.

Allegheny, Cattaraugus, Cayuga, Chautauqua, Erie, Genesee, Herkimer, Jefferson, Lewis, Livingston, Monroe, Niagara, Oneida, Onondaga, Ontario, Orleans, Oswego, Seneca, Steuben, Wayne, Wyoming and Yates counties: 716-530-3050.

All other counties: 518-474-4453

New York Lawyers for the Public Interest
<http://www.nympi.org/>

Advocates on behalf of disabled groups. Offers fact sheets about employment discrimination.

Protection and Advocacy for Individuals with Mental Illness (PAIMI)
800-624-4143

Urban Justice Center
<http://www.urbanjustice.org/>

The Urban Justice Center serves New York City's most vulnerable residents through a combination of direct legal service, systemic advocacy, community education and political organizing.

MEDICAID

New York State Medicaid Hotline:
800-342-3009

MEDICARE

Basic Information Line for sign-up/eligibility
800-772-1213

Medicare Hotline
800-MEDICARE (pgs 13, 41)

REDUCED FARE CARD

1. Go to: www.mta.info
Put in "Reduced Fare Card" in the search box on the left
2. Double click on the link top of the Google list "Reduced Fare Card"
3. Print "Application and Condition." Ask a physician or other licensed health provider "certifier" to fill out the "Certification" sheet and return it with the application and a passport photo to: 130 Livingston Street, Brooklyn NY 11201-9625

For Metro Card Customer Service (212) 638-7622

If you don't have a computer you can call for the application at (718) 243-4999. It takes six to eight weeks to process.

For those outside the five boroughs a good start to locate where to get a Half Fare card would be your local County Transit Authority of the Department of transportation. (p. 14)

RESEARCH

National Alliance for Research on Schizophrenia and Depression (NARSAD)
800-829-8289 or 516-829-0091
www.narsad.org

A private, not-for-profit organization that raises funds for scientific research into the causes, cures, treatments and prevention of brain disorders such as schizophrenia and depression.

National Institute of Mental Health (NIMH)
www.nimh.nih.gov

Engages in research on the causes and treatment of mental disorders. Its website provides educational materials and an extensive list of free publications on psychiatric disorders, including a comprehensive listing of helpful resources.

Nathan Kline Institute for Psychiatric Research (NKI)
<http://www.rfmh.org/nki/index.cfm>

Focuses on patient-oriented research programs emphasizing the causes, diagnosis, treatment, prevention, and care of severe and long-term mental disorders, also basic research on physiological and biochemical aspects of mental disease.

New York State Psychiatric Institute
<http://www.nyspi.org/research.html>

Research on a wealth of subjects ranging from basic neurobiology to clinical, epidemiological, child psychiatry and services-related studies. Conducts ongoing clinical trials in disorders ranging from depression to schizophrenia to borderline personality disorder.

SOCIAL SECURITY
800-772-1213
<http://www.ssa.gov/>

SOCIAL SERVICES

NYC Human Resource Administration, Department of Social Services
718 472-8411, (TTY) 718-262-3566 or 800-342-3009

<http://www.nyc.gov/html/hra/html/directory/directory.shtml>

Visit the website to download application as well as locate addresses and information for 19 centers throughout the city. They administer Medicaid. Open from 8:30AM to 5PM Monday through Friday.

Community Service Society
www.cssny.org
212-254-8900

160 years of providing services for three million low income New Yorkers in such areas as improving literacy, assisting children and families of the incarcerated and help in navigating the health care system

NYS Department of Social Services
518-474-2121 or 518-463-4829

General information on eligibility requirements, local phone numbers/locations, how to get HEAP, food stamps, emergency shelter, etc.

SUPPORT GROUPS

NYC Depressive & Manic Depressive Group (DMDG)
(917) 445-2399

A support group for persons with mood disorders, depression and bipolar disorder as well as their family members and friends

National Alliance on Mental Illness - New York State
518-462-2000 or 800-950-3228
www.naminy.org

NAMI-NYS lists local affiliates of the National Alliance for the Mentally Ill in New York State. Call or visit the website to find a support group in your area.

National Alliance on Mental Illness of New York City Metro (NAMI-NYC Metro)
212-684-3264

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

One of the largest affiliates of the National Alliance on Mental Illness, this grassroots organization, it provides support, education and advocacy for families and consumers of all ethnic and socio-economic backgrounds who live with mental illness. Their twenty support groups address the needs of those suffering from schizophrenia, bipolar disorder, for family and children dealing with mental illness as examples. The only group dedicated to advocacy is held the first-Friday-of-the-month Media & Advocacy Group (MAG). It provides advocacy information, skill-building, networking and a monthly speaker from the field. NAMI-NYC Metro's Helpline is available Monday through Friday, noon to 7PM and Friday from noon to 6PM 5PM (212) 684-3264.

NYS OMH Bureau of Family Affairs
(518) 473-6579

NYS OMH Commissioner's Committee for Families
Offers a listserv and quarterly advisory meetings to learn about OMH's activities, an opportunity to network with other statewide family groups and to learn how to improve the system through informed and focused advocacy.

PEER SUPPORT

The Alliance Empowerment Coalition
800 654-7227

The Alliance Peer Support Center
315 732-5377

Dreamweavers Peer Support
315 542-3427

The Empowerment Center
(914) 576-7022

Hands Across Long Island
631 234-1925

Howie the Harp Advocacy Center
212 865-0775

Mental Health Empowerment Project
1-800-MHEPinc

NAMI Peer-to-Peer:
www.naminycmetro.org

NAMI Connection
www.nami.org

Peer Bridger project
www.nyaprs.org

P.E.O.P.L.E s., Inc.
845 452-2728

Step by Step
315 394-0597

Treatment & Research Advancements National Association for Personality Disorder (TARA),
www.tara4bpd.org
888-4-TARA APD

A national association devoted to personality disorders, has pioneered raising public awareness about this least understood mental illness. TARA's hotline, workshops, educational seminars, symposia, teen groups, advocacy and referral service, provide all-round support to families and sufferers

Family Support:

Family-to-Family program. Contact your local NAMI chapter (you can find affiliate listings on our website) or call NAMI-NYS at 518-462-2000 or 800-950-3228 to find an education course near you.

SUICIDE HOTLINES AND PREVENTION**American Foundation for Suicide Prevention**

Toll-free: 1-888-333 AFSP (2377)
Phone: 212-363-3500
Fax: 212-363-6237
Email: inquiry@afsp.org
Website: www.afsp.org

Covenant House
1-800-999-9999**Deaf Hotline**
1-800-799-4889**LivingWorks Offices**

Phone: 910-867-8822
Fax: 910-867-8832
Email: usa@livingworks.net
Website: www.livingworks.net

National Hope Line
1-800-SUICIDE (784-2433)
1-800-273-TALK (8255)**New York State Office of Mental Health (S.P.E.A.K. Suicide Prevention kit)**
1-800 597-8481**Suicide Prevention Action Network USA (SPAN USA)**

Phone: 202-449-3600
Fax: 202-449-3601
Email: Info@spanusa.org

The Trevor Project Gay Hotline
1-800-850-8078**WELLNESS SELF MANAGEMENT****New York State Office of Mental Health**

http://www.omh.state.ny.us/omhweb/ebp/adult_wellness.htm

Wellness self-management program offers tools, in the form of workbooks to structure a path to recovery: to assist managing stress, to provide education on the symptoms of a diagnosis and to offer skills overcome barriers to pursue personal goals.

WRAP**Copeland Center**

802-254-2092 or 866-IDOWRAP

www.mentalhealthrecovery.com

To find a WRAP group in your community, send an email to info@mentalhealthrecovery.com specifying where you live.

APPENDIX

MEDICAID BUY-IN

Note: Share *At-A-Glance Medicaid Buy-In* attached with the Medicaid office to assure you get the service you need)

FAMILIES TAKE NOTE:
YOUR LOVED ONE CAN EARN AS MUCH AS
\$55,188 PER YEAR (2009-2010) AND NOT LOSE
THEIR ACCESS TO HEALTH BENEFITS. TO THE RESCUE:

Medicaid Buy-In Program for Working People with Disabilities (MBI-WPD)

The Medicaid Buy-In program offers Medicaid coverage to people with disabilities who are working, and earning more than the allowable limits for regular Medicaid, the opportunity to retain their health care coverage through Medicaid. This program allows working people with disabilities to earn more income without the risk of losing vital health care coverage.

To qualify for the Medicaid Buy-In program for Working People with Disabilities, you must

- Be a resident of New York State;
- Be at least 16 years of age (coverage up to 65 years of age);
- Have a disability as defined by the Social Security Administration;
- Be engaged in paid work (includes part-time and full-time work
- Have a gross income that may be as high as \$55,188 for an individual, \$73,884 for a disabled couple
- Have non-exempt resources that do not exceed \$13,800 for an individual, \$20,100 for a disabled couple in 2009.

To Apply:

1. Be prepared to submit proof of disability (if you are currently receiving a form of Social Security benefits for the disabled that proof should be sufficient). Even if you don't receive benefits, you also qualify for MBI-WBD if you meet Social Security eligibility requirements as "disabled."
2. In NYC contact your local NYS_ State Medicaid office and fill out their LDSS-2021 form. Don't be overwhelmed. A customer service specialist is there to provide support and a "Tool Kit" to take you through the process. Since the LDSS-2021 is a Medicaid common application, identify it as "MBI-WPD" with a bold black marker on the upper right, corner, date it and make a copy.

**To help the staff person be clear about which program you're referring to, you may want to attach the two-page "At a Glance" sheet found on p. 51. Also, bring it with you to your appointment.

For the rest of NYS contact your local Dept. of Social Services/Medicaid office and Neighborhood Legal Services (see below).

Make sure you take to your appointment proof of the following:

- a) Medical: Physicians' name, address and telephone number.
- b) Benefits: Medicare Part A and B, private health insurance (if you have these benefits).
- c) Proof of income: social security, alimony, veteran's benefits, \$ support from family members et al.
- d) Citizenship: birth certificate, U.S. Passport, Naturalization certificate with photo ID.
- e) Residency home address: ID card, letter/lease/rent receipt with home address etc.

- f) Resources: money in a bank, stocks, bonds, mutual funds CDs, money market accts, 402k plans, trusts, cash value of life insurance. If anything is missing you have ten days provide it to the processing can go ahead.

MEDICAID BUY-IN OFFICES ETC.

New York City

Bronx Medicaid Offices: Bronx Lebanon Hospital, Lincoln Hospital, North Central Bronx Hospital, Jacobi Hospital, And Morrisania

Brooklyn Medicaid Offices: Boerum Hill, Coney Island, Kings County Hospital, East New York, Woodhull Hospital

Manhattan Medicaid Offices: Bellevue Hospital, Chinatown, Metropolitan Hospital, Columbia Presbyterian Hospital, and Harlem Hospital

Queens Medicaid Office: Elmhurst Hospital, Rockaway, Jamaica

Staten Island Medicaid Office: Staten Island

To determine where you should apply and get answers to additional questions concerning MBI-WPD and Work Incentives programs statewide call:

Neighborhood Legal Services

Work Incentives Hotline

888) 224-3272

www.nls.org

(Share with the Medicaid office to assure get the service you need)

At-A-Glance: Medicaid Buy-In

Who is Covered?

- 1.) **Basic Coverage Group:** Workers who are at least 16 but under age of 65, who meet the SSI definition of disability.
- 2.) **Medical Improvement Group:** Workers who received coverage in the Basic Coverage Group and, on a continuing disability review, lost eligibility for that group as a direct and specific result of medical improvement but retain a severe medical impairment.

Basic Coverage Group: Who Is Eligible?

- Individuals who have certification of disability as defined by the Social Security Administration; and are at least 16 but not yet 65 years of age;
- Are engaged in paid work (includes part-time and full-time work);
- Have a gross income in 2009 that may be as high as \$55,188 for an individual, \$73,884 for a disabled couple;
- Have non-exempt resources that do not exceed \$13,800 for an individual, \$20,100 for a disabled couple.

Note: There is no substantial gainful activity rule (i.e., an individual can earn more than \$980 per month in 2009 and still be eligible for the buy-in).

Income Limits

- Individuals with countable income up to 250% of federal poverty levels (FPL) (i.e., gross wages as high as \$55,188 in a household of 1 for the year 2009).
- Monthly countable income for a household of one must be \$2,257 or less in 2009 (i.e., up to 250% of FPL). If monthly countable income is \$1,354 or less in 2009 (i.e., up to 150% of FPL), no premiums will be due.
- Individuals with income above 250% of FPL may not purchase Medicaid coverage.

Determining Countable Income will follow the same SSI budgeting rules as used in the regular Medicaid spend-down program.

Typical deductions from income:

- first \$20 of unearned income excluded; first \$65 (or \$85 if no unearned income), plus 50% of remaining earned income excluded; impairment related work expenses are a deduction from earned income; money set aside in an approved Plan for Achieving Self Support (PASS) can be excluded from unearned or earned income.

Example: An individual has \$3,885 in gross monthly wages and no other income. This individual will have \$1,900 in countable monthly income ($\$3,885 - 20 - 65 = 3,800 - 1,900 = \$1,900$).

Asset Limits

- \$13,800 is allowed in countable resources for an eligible individual and \$20,100 for an eligible couple.
- Countable resources include bank accounts, savings bonds, stocks, retirement accounts, and other liquid assets.
- Exempt resources include: a house, a vehicle, certain life insurance policies, a limited burial reserve, and several other items.

Premiums

- Old rule: No premium owed if countable income is below 150 percent of federal poverty level. If income between 150 and 250 percent of poverty level, premium calculated at 7.5 percent of countable earned plus 3 percent of countable unearned per month. Premiums were never collected under the old rule.

- New rule: No premium is owed if countable income is below 150 percent of the federal poverty level. If income is between 150 and 250 percent of the federal poverty level, premium will be \$25 per month for an eligible individual, \$50 per month for an eligible couple. As this is written, the State Department of Health still does not have a system in place to collect premiums.

Applying For the Medicaid Buy-In Program

An application for the Medicaid Buy-In Program for Working People with Disabilities must be made at the Local Department of Social Services or the Human Resources Agency in New York City.

Medical Improvement Group: Who Is Eligible?**Individuals who are**

- Members of the Basic Coverage Group, who lose eligibility for the Basic Coverage Group due to medical improvement but retain a severe medical impairment, and
- Are engaged in paid work (40 hours per month and earn at least the federal minimum wage)

Grace Periods Or What If I Lose My Job?

Change in Medical Condition: A grace period of up to six months will be allowed if, for medical reasons, the Medicaid Buy-In recipient is unable to continue working. Medical verification will be required.

Job Loss (through no fault of recipient): A grace period of up to six months will be allowed if, through no fault of the recipient, a job loss occurs (layoff, etc.). Verification will be required that the recipient is reasonably expected to return to work, or that the recipient is actively seeking new employment. If this is less than 250% of the FPL for 2009, this individual will be eligible for the Buy-in.

Plan for Achieving Self-Support (PASS) is a plan that allows a person to exclude income other than SSI so the money could be used for education, training or equipment that will help them to return to employment. The goal of a PASS is to help a person become self-sufficient and lessen their dependency on disability benefits. There are 2 cadre offices in NY Contact: NYC Pass Cadres at 800 551-9583 x4048 or x4045, or outside of the Metro NYC area, 800-510-5680 or 716-551-4640 x242, 246, 286.

CONTRIBUTORS

The Family Survival Handbook is a collaborative project between Family Institute for Education, Practice & Research, Mental Health Resources, National Alliance on Mental Illness of New York State and New York State Office of Mental Health.

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- Judith Carrington, initiator and primary writer President, Mental Health Resources

Let us hear how this Handbook works for you, what should be added or eliminated—it's a work in progress.

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OMH FAMILY LIAISONS

The Bureau of Family Affairs works directly with families, recipients and local and state mental health providers. This coordinated approach was developed to strengthen communications, linkages, policies and best practice standards to improve the quality of mental health care in New York State.

The Commissioner of the Office of Mental Health has designated Family Liaisons in each of these regions to assist family members and other advocates of individuals with psychiatric disabilities.

The names, addresses and telephone number of the five Family Liaisons and their staff are available on the OMH website at www.omh.state.ny.us or by calling:

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