



YOU ARE NOT ALONE

Finding Help for People with Mental Illness and Their Families

When people are diagnosed with serious mental illnesses such as schizophrenia or bipolar disorder, finding effective medical and psychiatric care is the first priority. But once such treatment begins, they and their families soon discover that the illness affects many aspects of their lives, and they need more than medical help.

This section describes the kind of non-medical services that promote recovery and are available in many communities for people with severe and persistent mental illnesses and their families.

No single, coordinated system of services currently exists across the United States. When someone has been diagnosed with a serious mental illness, and if the individual is severely disabled, the person's family often assists in managing the person's comprehensive care. Although the service system is often fragmented, support groups of other families and people living with mental illnesses (often called consumers) who have faced the same challenges exist in every state. Never worry alone.

If you or someone you love has received a diagnosis of a serious mental illness, the information in this booklet can help you find and evaluate the services in your community, find others who are asking the same questions you are, and perhaps join those across the country who are working to create more coordinated and comprehensive services for people living with mental illnesses in every community.

Evan describes his recovery this way: "It took a while and waiting through the treatment failures was discouraging, but I feel good now, and I know how to stay feeling good."

How can people living with serious mental illnesses lead satisfying lives?

With the advent of newer medications and improved understanding of the need for adequate housing and transportation, meaningful daily activities, and support from friends and family, we know recovery is possible.

People living with mental illness are people like many you know:

Evan, diagnosed with bipolar disorder after graduation from college, had a rough five or six years of it before he found the right combination of medication, sleep, diet, and exercise. He now owns his own business, which has grown from one to 12 employees in the past few years. "It took a while, and waiting through the treatment failures was discouraging," he remembers, "but I feel good now, and I know how to stay feeling good".

Justine, who experienced a crushing depression after her first baby was born, was very concerned that she was never going to feel well again. "Depression makes you feel like you'll never get better," she says, "but finding a good doctor, the right medication, going to my support group, and the love of my family saw me through".

Mark was diagnosed with schizophrenia early in his college career. His illness forced him to quit school, and he had a very difficult time adjusting to taking medication. After reading everything he could find about his illness, speaking with others who really listen to him, Mark has come to accept that he has an illness. "I take medication now, and I'm learning to cope with the side effects. I have hope again, " he says.

Recovery - A Journey

Although recovery may not mean returning to exactly the same life they knew before they became ill, with effective medication and a wide range of services tailored to their needs, most people who live with serious mental illnesses can significantly reduce the impact of their illness and find a satisfying measure of achievement and independence.

A key concept is to develop expertise in strategies to manage the illness process. NAMI's consumer education and support programs offer support to individuals from people who have been there - which help provide mentoring and teaching as people go forth to live and learn with their illnesses.

Another key concept is to have family and consumer involvement in every aspect of the service system. These represent opportunities to join others in supporting NAMI's efforts to improve the system of care for people living with

mental illness. This advocacy includes efforts to insist on a responsive system that supports recovery.

What kinds of services help individuals who live with mental illnesses live successfully in their communities and how do these services support their families?

For years, communities around the country have been experimenting to find the best ways to help people who are diagnosed with serious mental illnesses live balanced, healthy, meaningful lives in their community. Because mental illness affects so many aspects of life, people who live with them may need a wide safety net of services, such as help with social skills, personal care, employment, housing, finances, mutual support, education, and medical treatment.

Ideally, such services are well coordinated and assist with recovery and wellness. The most effective community service programs build on individual strengths, provide a sense of belonging, emphasize the possibility of work and personal growth, and are driven by the particular needs and preferences of each person.

Although a number of model programs have emerged in many parts of the country, non-medical services for people living with mental illnesses are often fragmented and difficult for families and consumers to find and use. In some cases, a family member still may find it necessary to take responsibility for managing and coordinating the care of a relative who has a severe mental illness.

Keeping a record of what works and what does not is important, as the fragmented care system frequently cannot integrate all the information needed for decision-making. That is best done by the individual and the family, who will know what helps and hurts for that particular person.

Where community services do offer social, vocational, housing, and other programs, they are making a significant difference in the lives of people with mental illnesses and their families. The Substance Abuse and Mental Health Services Administration (SAMSHA), the federal agency charged with monitoring mental health and substance abuse services, has identified a number of rehabilitation practices they consider to be "evidence-based" (www.samhsa.gov/SAMHSA_News/VolumeXI_2/article4.htm). These programs will be discussed along with other noteworthy models, in this section.

In general, comprehensive community services such as those described in this booklet are available to people with disability income or other public assistance, and the costs to individuals are covered by that income. In addition to

government funding, some programs also receive financial support from foundations, corporations, and individual donors.

While comprehensive services are expensive for governments and local communities to provide, the economic and social costs of frequent hospitalization - for individuals, families, and communities - are far greater. Society bears the expenses of poor service provision; hospitalization or the use of jails for petty crimes cost more economically and in terms of suffering than providing comprehensive services in the community. Where people are served by such community-based programs, they and their families are finding services and programs they need to manage their persistent and severe mental illnesses over the long term.

To find mental health services in your community, contact your state or county mental health department or local affiliate of the National Alliance on Mental Illness (NAMI), usually listed in the white pages of the telephone book, or contact NAMI National to find your local NAMI 800-950-NAMI (6264) or visit www.nami.org

If I or someone I love has a mental illness, what kinds of help might I look for in my community?

Financial Support - Paying for treatment and meeting basic living expenses can present major financial challenges for people with serious mental illnesses and their families. Some public money is available to help individuals and families meet these costs, but obtaining government benefits generally takes time and persistence. People coping with illnesses like schizophrenia and bipolar disorder often need help with the complicated process of applying for the money they're entitled to receive.

People who cannot work because of a serious mental illness may be entitled to disability payments from the Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), or General Public Assistance (GPA) programs. Money for medical treatment may be available through Medical or Medicare.

Be sure to find out if you are eligible for this kind of assistance. By themselves, few families and individuals can afford treatment for serious mental illness over an individual's lifetime. If you are eligible for support, you are entitled to receive it, and such income can bring a better quality of life to you and your family.

To learn about the financial support available in your state and community and how to apply for it, contact your local Social Security Administration (SSA) field office. The Social Security Administration should be listed in your telephone

directory's U.S. Government section. Your telephone book may also list local offices for Medical and Medicare.

Terms To Know

SSI (Supplemental Security Income) is a federal program to provide income to those who are aged, blind, or disabled. (Some states also contribute a small amount of money.) Eligibility is based on financial need and disability determination.

SSDI (Social Security Disability Insurance) is for disabled workers who have paid into the Social Security system through payroll deductions. Some disabled persons under age 22 may collect SSDI under a parent's account if the parent is retired, disabled, or deceased.

GPA (General Public Assistance) is available in some locations to those who are disabled and either ineligible or waiting for other assistance.

Medicare is a federal health insurance program for those over age 65 and disabled workers.

Medicaid is a state and federal health insurance program for those with low incomes. Eligibility varies from state to state.

Representative Payee is a family member, friend, or community advocate who receives a monthly SSI or SSDI check on behalf of the person diagnosed with a mental illness and helps him or her manage the money.

Questions to ask -

* What are the eligibility requirements for SSI, SSDI, and Medicaid, Medicare, or GPA disability income, and how do I apply.

* In my community, do the services and programs for people living with mental illnesses have financial and other eligibility requirements, and if so, what are they?

* If my request for benefits is denied, how do I appeal this ruling, and who can help me appeal?

Treatment, Crisis Intervention, and PACT

Many traditional services exist for people living with major mental illness. These may include medication visits with a psychiatrist (or in some cases a primary care M.D. or nurse), or interventions designed to prevent crisis, create housing, and promote recovery. Substance abuse services should be integrated

into the care system - NAMI believes this is essential, given the high rate of substance use disorders associated with mental illness, but it is not the reality everywhere. Many mental health centers are office-based, which works for some people. A movement towards more community-based and integrated care is occurring in some parts of the country.

One integrated and evidence-based program is the Program of Assertive Community Treatment (PACT). PACT is an intensive, multidisciplinary team effort in local communities to help people living with persistent mental illnesses, including people with co-occurring substance abuse, stay out of the hospital or jail and maintain wellness. Instead of operating a center where people with mental illnesses gather and receive services, PACT professionals often meet their clients where the clients live. They are available for 24-hours-a-day, seven-day-a-week, at-home support at whatever level is needed, and for whatever problems need to be solved. Rather than referring consumers to fragmented services, the PACT staff directly provides psychiatric, rehabilitation, substance abuse, crisis intervention, peer support, and other support services.

PACT Programs are now statewide in most states and are growing substantially. In these places, PACT is significantly reducing hospital admissions, improving the quality of life, and providing opportunities for those it serves. To learn more about PACT, visit the NAMI Web Site www.nami.org/ACT

Many people living with serious mental illnesses need continuous, long-term support at some level to manage their medications and symptoms. It is crucial to know what strategies a person prefers to prevent crisis.

When a crisis requiring hospitalization occurs, the person requiring such care needs people who know him or her to coordinate care with hospital staff and to ensure continuity of services when he or she returns to the community. Psychiatric advanced directives are recognized in most states and assist with planning for managing a relapse before it occurs.

While outpatient psychiatric and medical treatment services vary widely across the country, the most effective programs work closely with their clients to help them work toward recovery. Given the fragmentation so common in American mental health care, and the power of their lived experience, the family and the consumer are frequently the holders of the best information for decision-making.

Terms to know

Crisis Intervention Services (CIS) provide emergency help to people in a psychiatric crisis. Depending on the severity of the crisis, services may include telephone support, home visits, crisis residence, transportation to and from the

hospital, and coordination with hospital staff in admission, discharge, and treatment.

Community Mental Health Centers (CMHCs) are local facilities offering outpatient treatment and emergency services for people with mental illnesses. These are often funded by state and federal government and may also provide services and information for families.

Case Management is a service, usually provided by public mental health centers, that coordinates treatment, services, and supports.

Advanced directive In some states, individuals will record, when they are well, their wishes for their care, to be honored when they are ill. This can be woven into a preventive approach to possible clinical problems.

Questions to ask

*What service programs will work closely with the doctors and hospitals in my community to monitor medications and help if there is a crisis?

* Who provides transportation to those who need crisis intervention?

* What integrated services (such as PACT) are available, and what are the admission criteria?

Housing

Like everyone else, people who live with mental illnesses deserve to live in places that are clean and safe, where they can be full members of the community and maintain a high standard of living. Depending on each person's medical and financial condition and the kinds of support services available, choices in housing arrangements vary.

Housing options range from fully supervised group homes, and board-and-care homes with meals and care provided on-site, to apartments, home ownership, and an array of housing options. Arrangements can include supervised apartments in which clients live independently, whether in the same complex or in supported housing scattered throughout the community.

Supported housing allows people who live with mental illness to choose where they want to live and offers flexible services and supports wherever they are. Service programs like the Fountain House clubhouse model and Programs of Assertive Community treatment (PACT) help consumers find housing in the community and help them apply for government housing subsidies. There is a national housing shortage for many, including people living with mental illnesses. That shortage drives much advocacy.

Terms to know

Group home/congregate living provides 24-hour supervision, medication monitoring, and staff to help carry out the activities of daily life.

Board-and-care homes offer daily meals, dispensation of medications, and minimal staff supervision.

Supervised apartments are generally several apartments within the same complex, supervised by a staff member who sometimes lives in the complex. The focus is on developing social skills and independence, and supervision varies from daily to weekly contact.

Supported housing allows individuals with mental illnesses to live wherever they choose within the community and receive whatever level of support they need to remain independent. Supports are flexibly arranged to meet the person's need.

Section 8 housing is federally subsidized housing for people with low income. The public housing authority in your community manages Section 8 subsidies. Those who qualify pay a percentage of their monthly adjusted income for housing. A section 8 subsidy can be for specifically designated apartment developments or for an apartment with another landlord who accepts Section 8.

Questions to ask

- * What kinds of housing are available in my community for people living with mental illnesses?
- * What does such housing cost, how does one apply for it, and who supports those who live in it?
- * Is there a waiting list for housing, and if so, how do I get on it?

Supported employment offers support for individuals to learn real work skills at a real job of their choosing. The model is growing in popularity nationally.

Employment

For people who live with mental illness, having meaningful work is a vital step toward wellness. Volunteering can be an important interim step. Vocational services help individuals recover their ability to find and keep a job. Programs

offering a range of social, vocational, housing, and other services often provide work on site for members, as well as transitional-employment programs to support them as they re-enter the mainstream work force.

Typically, rehabilitation staff provide placement, training, supervision, and backup for members in mainstream jobs. Supported employment offers support for individuals to learn real work skills at a real job of their choosing. The model is growing in popularity nationally, but major deficits in the availability of this model exist across the nation.

Another rehabilitation model is the clubhouse model, begun in New York City over 50 years ago, that has spawned hundreds of similar programs across the country. New York's Fountain House, the first clubhouse of its kind, is a social and vocational center serving hundreds of members with serious mental illnesses.

Every day, clubhouse members work in partnership with Fountain House staff to operate a kitchen, administrative offices, housekeeping services, and programs in education, research, financial management, and employment opportunities. A transitional-employment program helps members learn job skills.

Fountain House staff work closely with local hospitals and psychiatrists to coordinate members' medical treatment and assist when a crisis occurs. However, they deliberately maintain a non-clinical atmosphere at the clubhouse itself.

Terms to know

Transitional employment places people with mental illnesses in temporary paying jobs in the workplace. Often, two people share an entry-level position in order to develop the discipline to begin to have work as part of their lives. An agency staff member helps with training and emotional support and fills in during absences. The emphasis is on building skills and positive work experience for as long as it takes to achieve maximum independence.

Supported employment places people in competitive jobs in the community. This model helps them learn job skills and adjust to the work environment. The idea is to give people real support and skills for a job they are currently doing.

Questions to ask

- * How do the service programs in my community train and support people living with mental illnesses to re-enter the workplace?
- * How many jobs do they make available to their clients and members?

* What is the best match of employment options for me or my family member?

* If I receive benefits, what are the rules about my ability to make money without impacting my insurance (e.g., Medicaid, Medicare, or other) or cash benefits?

Personal and Social Needs

A serious mental illness may interfere with the ability of individuals to care for themselves and maintain comfortable and satisfying relationships with others. Many community programs offer social and recreational activities to reduce the isolation, loneliness, and internalized prejudice that so often accompany mental illnesses. Consumer-run drop-in centers provide a warm atmosphere of welcome and acceptance. Consumers can gather whenever they wish, and may develop positive long-term relationships. Peer-driven services are growing across the country, as the recognition that “if you have been there, you understand best” is becoming part of the culture of service provision.

NAMI offers a series of resources to attend to these concerns, including Peer-to-Peer, a program designed to help individuals with mental illnesses learn coping strategies.

Terms to know

Clubhouse programs like Fountain House offer mutual support in a caring, community setting. Members have a strong sense of ownership and know that they are needed to make the clubhouse function.

Psychosocial rehabilitation programs are often available through community Mental Health Centers and hospitals, while some operate independently. These programs provide a variety of services that may include vocational training, social and recreational programs, and personal support for independent-living.

Drop-in centers are places where people with mental illness can go for support and socialization. They are staffed by consumers and some also offer jobs training.

Peer support is a model that emphasizes the importance of learning from someone who has walked the path of living with an illness.

Questions to ask

* Is help with personal support, shopping, and housekeeping available if it is needed?

* What organized social and recreational activities are available for people living with mental illnesses?

* To what extent are people with mental illnesses involved in organizing and providing these services and programs?

Managing Money

To achieve independence, people who live with mental illnesses need skills to manage their own money and make their own decisions about spending and saving. In some programs, participants learn to create a budget, pay rent and other bills, and manage a checking account. Some also offer banking and small-loan programs.

Questions to ask

* Do the service programs in my community provide help with banking and managing money?

* What are the criteria to identify a person who cannot manage his or her money adequately?

Education

Returning to school to acquire basic skills or technical training or to work toward a high school or college degree can help people regain confidence, follow personal interests, and acquire skills and credentials for pursuing a career. In some communities, supported education programs help people diagnosed with mental illnesses enroll in school, apply for scholarships, schedule classes, and buy books and supplies. Staff also provide support to help people learn to adjust to a school atmosphere.

For example, Boston University has created a continuing education programs especially for young adults with a history of psychiatric disability. When students in the program complete four semesters of coursework, they can take other courses at the university or move into jobs. An active alumni program continues to support students after they graduate. Similar programs are increasingly available at local community colleges.

The NAMI Program *In Our Own Voice* is designed to create consumer educators and leaders. These individuals offer first-hand experience and lessons derived from their coping strategies. AS consumers develop and drive the service system, it will improve the quality and design of the services available. Information about *In Our Own Voice* is available at www.nami.org/IOOV.

Questions to ask

- * What education programs are available in my community to help people living with mental illnesses pursue their degrees?
- * What cognitive (thinking) issues occur with my illness, and how might I get the tutoring supports to best make accommodations for it?

In Conclusion

Serious mental illnesses affect virtually every aspect of life and present many challenges to individuals and their families. People who struggle with these disorders need community support and continuity of care to move toward maximum recovery.

Support groups of other individuals and families coping with severe mental illnesses exist in your state. These groups are affiliated with NAMI, and their members can help you learn more about finding the help you need where you live. NAMI's signature education program is called Family-to-Family; it is found in hundreds of communities, and thousands of people across the country have taken the 12-week course.

You are not alone – NAMI members across the country welcome you to a national network of caring, support, and advocacy for all who live with serious mental illnesses and their families.

- Written by Ken Duckworth, M.D.

What is NAMI?

The National Alliance on Mental Illness (NAMI) is the nation's largest grassroots mental health organization dedicated to improving the lives of persons living with serious mental illness and their families. Founded in 1979, NAMI has become the nation's voice on mental illness, a national organization including NAMI organizations and affiliates in every state and in over 1,100 local communities across the country who join together to meet the NAMI mission through advocacy, research, support, and education. Members of NAMI are families, friends, and people living with mental illnesses such as major depression, schizophrenia, bipolar disorder, obsessive-compulsive disorder (OCD), panic disorder, post-traumatic stress disorder (PTSD), and borderline personality disorder.

To learn more about your local affiliate:

Call your local NAMI San Diego office at:

NAMI San Diego Helpline

619-543-1434 or 800-523-1434
information@namisd.org

4480 30th Street
San Diego, CA. 92116

Contact your state NAMI office:

NAMI California – www.namicalifornia.org

Write to: NAMI – Colonial Place Three

2107 Wilson Boulevard, Suite 300
Arlington, VA. 22201-3042

Contact the NAMI Information Helpline at 1(800) 950-NAMI (6264) or

Visit NAMI's website at www.nami.org

Many NAMI affiliates offer programs designed to assist individuals and families affected by mental illness.

Peer-to-Peer is a NAMI learning program taught by a team of three trained "mentors" who are personally experienced at living well with mental illness. Participants come away from the course with many resources, including a "relapse prevention plan" and survival skills for working with providers and the general public.

Family-to-Family, another NAMI education program, is a free 12-week course for family caregivers of individuals with severe mental illnesses. The course is taught by trained family members and focuses on schizophrenia, bipolar disorder (manic depression), clinical depression, panic disorder, borderline personality disorder, post-traumatic stress disorder (PTSD), and obsessive-compulsive disorder (OCD). The course discusses the clinical treatment of these illnesses and teaches the knowledge and skills that family members need to cope more effectively. All instruction and course materials are free for class participants.

In Our Own Voice is a NAMI program in which trained consumers give a recovery and education presentation for other consumers, family members, friends, professionals, and lay audiences. Brief, yet comprehensive-including video, personal testimony and discussion-it enriches the audience's understanding of how people cope with the reality of their illnesses while recovering and reclaiming productive lives.