With more than 200,000 members, NAMI is the nation's leading grassroots advocacy organization solely dedicated to improving the lives of persons with severe mental illnesses including schizophrenia, bipolar disorder, major depression, obsessive-compulsive disorder, and severe anxiety disorders.

NAMI's efforts focus on support for persons with serious brain disorders and for their families; advocacy for nondiscriminatory and equitable federal, state, and private-sector policies; research into the causes, symptoms, and treatment for brain disorders; and education to eliminate the pervasive stigma surrounding severe mental illness.

NAMI has more than 1,200 state and local affiliates in all 50 states, the District of Columbia, Puerto Rico, American Samoa, and Canada.

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In accordance with NAMI policy, acceptance of funds does not imply endorsement of any business practice or product.



The Nation's Voice on Mental Illness

NAMI Assertive Community Treatment Technical Assistance Center

> 2107 Wilson Blvd., Suite 300 Arlington, VA 22201-3042 PH: 1-866-229-6264

ACT@NAMI.org www.nami.org/about/pact.htm



888-999-6264 www.nami.org

# The PACT

**Advocacy Guide** 



How to advocate for programs of assertive community treatment, the evidence-based approach providing successful community treatment for people with difficult-to-treat mental illnesses.







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Advocate and plan for PACT

Implement PACT

Sustain PACT

## NAMI's PACT Across America advocacy campaign

The PACT Across America Campaign is an aggressive, national grassroots effort to educate people about the Program of Assertive Community Treatment (PACT). Thirty years of research already demonstrates that PACT is more effective than office-based traditional care for people with the most disabling psychiatric illnesses. It reduces hospitalization, homelessness, and criminal incarceration.

PACT is also known by other national and local names. NAMI uses Assertive Community Treatment (ACT) and Program of Assertive Community Treatment (PACT) interchangeably. In Wisconsin, ACT programs are called Community Support Programs (CSP). In Florida ACT programs are called FACT, Florida Assertive Community Treatment; in Rhode Island and Delaware ACT programs are called Mobile Treatment Teams (MTT).

Frustrated by the nation's continued failure to provide the effective treatment that researchers know works, NAMI decided to "take the bull by the horns" and promote the PACT model throughout the country.

NAMI's goal is to make PACT teams available to all who need them. The NAMI national office, NAMI state organizations, NAMI local affiliates, and individual NAMI members are all involved, advocating together to make PACT teams available nationwide. As PACT programs are replicated, NAMI urges adherence to the program model and current clinical practice guidelines specified in the NAMI publication, *The PACT Model of Community-Based Treatment for Persons with Severe and Persistent Mental Illnesses.* Please see page 14 to order a copy of the manual.

### How will NAMI achieve its goal?

Via the national NAMI office—

NAMI commissioned two developers of the PACT model, Deborah Allness, M.S.S.W., and William Knoedler, M.D., to put their knowledge into writing. They wrote The PACT Model of Community-Based Treatment for Persons with Severe and Persistent Mental Illnesses: A Manual for PACT Start-up. This first-of-a-kind manual provides detailed instructions for starting and operating a successful PACT program.



In PACT programs, treatment, rehabilitation, and community support services are each tailored to an individual's needs and preferences.

- PACT advocacy plenary presentations and workshops are planned for NAMI national al conventions and state NAMI meetings.
- At the federal level, NAMI seeks congressional action to require states to provide PACT programs through expanded funding and program targeting.
- NAMI is working with the federal government to encourage state Medicaid programs to routinely pay for PACT.
- NAMI is establishing, supporting, and coordinating expert PACT consultants to assist state and county governments, providers, and health plans to implement and oversee the PACT model.
- NAMI is providing support and training on PACT advocacy to grassroots NAMI leaders.
- With a grant from the federal Center for Mental Health Services (CMHS), NAMI established an ACT Technical Assistance Center to develop and disseminate information to consumers and family members, other advocates, and policy makers. CMHS recognizes assertive community treatment as an "exemplary practice."
- NAMI is making this PACT Advocacy Guide available to members and other advocates throughout the nation.

Via NAMI state organizations, local affiliates, and members—

What you can do to get PACT started in your community:

 Form PACT advocacy committees at both your local-affiliate and state-organization level. Coordinate your state and local efforts. The NAMI national office and the NAMI regional directors are available to assist your PACT advocacy committees.

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- Learn more about the model by reading the rest of this brochure. Get further information from the PACT section of NAMI's Web site, www.nami.org/about/PACT.htm, and from the PACT manual. You can order the PACT manual from the Web site.
- Document your family's need for PACT. Write down, or make a flowchart of, all the different places you, if you are a consumer, or your family member has lived and all the different agencies you have dealt with over the past five years. Would the comprehensive, "one stop shopping" PACT approach have helped you?
- Collect data on the community's need for PACT.
   Gather data and estimate the number of people with severe mental illnesses who may benefit from a PACT team, but are living with aging parents, are in hospitals, homeless shelters, or jails, or are living in other circumstances specific to your area.
- PACT advocacy committees can present workshops on the model with invited, knowledgeable speakers.
   The NAMI national office's ACT Technical Assistance Center can suggest speakers and connections to state NAMI offices that have successfully advocated for PACT.
- PACT advocacy committees should promote PACT with those who influence community-services decisions including:
  - > state mental health commissioners:
  - > state Medicaid directors:
  - > state legislators who oversee mental health services and mental health budgets;
  - > your own state legislators and city council members;
  - > mental health consumer organizations;
  - > other health advocacy organizations and coalitions;
  - > management of local community mental health and other provider agencies; and
  - executives and managers of managed care health plans that enroll people with severe mental illnesses, especially plans with—or seeking— Medicaid contracts.
  - PACT advocates should form a multi-organization PACT implementation work group made up of key decision makers, funders, and stakeholders to determine funding mechanisms, plan and oversee

implementation. Often the mental health authority will develop a request for proposals so that provider organizations can submit their proposals describing how they will provide PACT.

# How you can gain community support from groups who will benefit from better care for people with severe mental illnesses:

- Your PACT advocacy committee should meet with law enforcement agencies to explain how PACT can help them. Meet with:
  - local police departments and sheriffs and their state associations;
  - > local jail officials; and
  - > judges.
- Meet with landlords and their associations to explain how PACT helps people with severe mental illnesses to be good tenants.
- Meet with community associations and business groups to explain how you are working to initiate a proven, evidence based community-treatment program that succeeds with people with severe mental illnesses, including people who are homeless.
- Work with the media.
  - > Write letters to the editor about the value of PACT.
  - > Meet with editorial boards of newspapers.
  - > Invite reporters/other media to your meetings and share information with them about PACT.
- Participate in radio and television talk shows.
- As an individual NAMI member, ask your local NAMI affiliate or your NAMI state organization how you can work to make PACT available in your area. Your PACT advocacy should be coordinated, focused, and tailored to local and state conditions.

Visit the NAMI Website at www.nami.org/about/PACT.htm.

- "Assertive community treatment offered choices and helped me make better choices about places to live, medications, and employment."
- Joseph Phillipps, consumer, and community support program case manager

## Know the answers to frequently asked questions about PACT.

#### • What is PACT?

The Program of Assertive Community Treatment (PACT) is an effective, evidence-based, outreach-oriented, service-delivery model for people with severe and persistent mental illnesses. Using a 24-hours-a-day, seven-days-a-week, team approach, PACT delivers comprehensive community treatment, rehabilitation, and support services to consumers in their homes, at work, and in community settings.

- How many people does a PACT team serve? An urban team can serve up to 100 and a rural team up to 80 clients.
- Is PACT rehabilitation- and recovery-oriented? Absolutely! PACT is a rehabilitation model. From its beginning, before the words recovery and empowerment were used in the mental health field, PACT helped consumers regain control of their lives and move ahead with their plans. The PACT approach helps people live in regular housing, socialize in the community, and return to school or work. PACTs attention to basic needs (housing, medical care, income) enables consumers—even those with very severe disabilities—to regain stability, assess their goals, and take steps toward recovery.

#### • What does PACT cost?

The staff for a PACT team costs approximately \$10,000 to \$15,000 per client per year. Medication and housing are additional costs that must be considered. Even adding a figure of \$500 per month (\$6,000 a year) for medications, PACT's costs are just \$16,000 to \$21,000 a year. In many communities, the cost for high-quality PACT treatment will be less than the cost of inappropriately putting a mentally ill person in the county jail. Costs for a year in a residential treatment facility approach \$50,000, and state hospital costs are usually more than \$100,000 a year.

#### • Does Medicaid pay for PACT?

Yes. In states with successful PACT programs, the state department of mental health and the state Medicaid agency work together to establish a Medicaid payment rate for PACT, such as a per-day or per-month dollar amount covering all PACT services.



PACT is positive, person-centered, and practical

#### Where should the money for more PACT teams come from ?

If your state is downsizing or closing state hospitals or staffed facilities, PACT teams should be funded with the money saved to serve people leaving facilities and other people with severe disabilities who are living on their own or with relatives and need comprehensive care.

If your state or county is already using managed care, savings resulting from these programs

may be available and should be "reinvested" in PACT teams and other community programs.

If your state or county is downsizing or closing psychiatric hospitals prepare for community treatment by developing PACT teams. With the fewer and much shorter hospital stays typical today, community alternatives to hospitalization are essential

• When state budgets are tight, PACT makes good financial sense. Especially when state budgets are tight, it makes good sense to use proven, cost effective treatments. The PACT model has an impressive, 30-year track record of achieving good outcomes for individuals and at the same time saving money.

#### But we must avoid "robbing Peter to pay Paul."

Most people with severe mental illnesses will not be served by PACT teams. With increasingly effective medications for these severe brain disorders, many people don't need the comprehensive level of services provided by assertive community treatment teams. There are many effective psychiatric and psycho-social rehabilitation approaches, such as clubhouse programs certified by the International Center for Clubhouse Development, that serve people with schizophrenia and other severe disorders. NAMI wants the funding for effective rehabilitation programs—valued, and often started, by NAMI members—to continue so those served by these programs can enjoy stable, satisfying lives. PACT can make a critical difference to consumers who are among those most disabled and vulnerable.

## What else do you need to know about the PACT model?

The progress made during inpatient treatment by people with the most severe and persistent mental illnesses is too often lost when they leave the hospital. To avoid repeated returns to hospitals or other residential treatment facilities, many people with severe and persistent mental illnesses need more individual help and support in the community

than traditional community services provide.

Too many times the usual office-based mental health system fails people who need help with basic, everyday activities like caring for themselves, taking their medication, establishing social relationships, and finding and keeping a job and a place to live. With enough of the right kind of individual help, people with even the most severe mental illnesses can make significant strides toward recovery. The intensive support is the heart of the PACT program.



PACT is a costeffective solution to the challenge of serving people with the most severe disorders in natural community settings.

## Who PACT serves, and how it works.

The founders of PACT organized the way services are delivered to help people with the most chronic mental illnesses

(schizophrenia, bipolar disorder, and other illnesses that cause pronounced disability) to live in the community. Staff provides a 24-hour-a-day, seven-days-a week, multidisciplinary approach to deliver comprehensive care to people where they live, work or go to school, and spend their leisure time.

The PACT program successfully treats and rehabilitates people other models often fail to serve, including

- people who don't keep office appointments;
- people with both severe psychiatric and substance abuse disorders;
- people with intractable psychotic and affective symptoms;
- people with socially disruptive behavior who are at high risk for arrest and inappropriate incarceration;
- people who are high users of emergency and inpatient hospital services; and
- people who cannot meet their own basic needs and are living in substandard housing situations or who are homeless.

PACT teams are coordinated combinations of psychiatrists, nurses, social workers, substance abuse treatment specialists, vocational rehabilitation counselors, and, increasingly, peer counselors. The team does not wait until a person comes to the office. The majority of services are delivered where consumers live, work, and spend their leisure time, not in the program office. The team uses a positive, persistent, practical approach offering

- direct provision or coordination of all medical care, both psychiatric and general health care
- help in managing symptoms of the illness
- immediate crisis response
- up to date, careful use of medications
- supportive therapy
- practical on-site support in coping with life's day-to-day demands including
  - > help obtaining financial entitlements and housing
  - > assistance with housing tasks so a person can live in regular housing alone or with a roommate
  - > help with learning how to socialize
  - > treatment for clients with coexisting substance abuse
  - > employment service and job placement
  - > assistance with legal issues
  - > support, education, and skill-teaching for family members

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PACT team staff members serve both as specialists and as interchangeable generalists assisting the client in meeting his or her own goals. Team members accommodate individual life circumstances—as people change over time—and respect the preferences of each client. If needed, team members will meet a client throughout the day and evening, in a restaurant, at their apartment, or at a parent's home.

The result? Greater strides toward recovery and a better quality of life, fewer dropouts, fewer rehospitalizations, diversion from jails, and more support for families.

## Why PACT is different from traditional services.

Consumers in PACT programs receive all services from the PACT team, not from multiple, loosely linked mental health, substance abuse, housing, and rehabilitation agencies. The PACT team meets a client's many individual—and 'round-the-clock—needs by providing a full range of psychiatric medical care, substance abuse treatment, social, and rehabilitation services. The PACT team provides nearly all services. Whether a client needs help remembering to take medication (for a mental illness or diabetes or high blood pressure), going to the dentist, dealing with a problem at work, finding a roommate, managing money, grocery shopping, doing the laundry, or handling anger and despair, a PACT team member is there.

The research-based U.S. Surgeon General's Mental Health Report says, "Across the Nation, certain mental health services are in consistently short supply. These include assertive community treatment, an intensive approach to treating people with serious mental illnesses. All too frequently, these effective programs are simply unavailable in communities. It is essential to expand the supply of effective, evidence based services throughout the Nation."

Mental Health: A Report of the Surgeon General.
 U.S. Dept of Health and Human Services, 1999.



In PACT programs, psychiatric treatment, substance abuse treatment, rehabilitation, housing and community support services are each tailored to an individual's needs and preferences.

## Why PACT is a "one stop shopping" approach.

Unlike traditional community services, PACT teams

- have 10 12 full time equivalent (FTE) staff plus the psychiatrist and administrative assistant in an urban/suburban area and 5 8 staff plus the psychiatrist and administrative assistant on a team in a rural/frontier area. An urban/suburban team serves up to 100 clients, while a rural/frontier team serves up to 80 clients.
- have at least 16 hours a week of a psychiatrist's time for every 50 clients. In an environment where homelessness and alcohol and drug abuse are common, a full-time psychiatrist is desirable.
- treat both psychiatric and substance abuse disorders at the same time
- take services to the client rather than requiring clients to come to the office
- provide team case management—the person with a mental illness is a client of the team, not of an individual staff member—so continuity is maintained when staff leave the team
- help clients who have children strengthen their parenting skills
- coordinate provision of psychiatric care with general medical care and dental care
- continue to see a client who is in a hospital or jail, which often facilitates an earlier return to the community

- employ a psychiatrist who is a full team member (participating in treatment planning and teaching staff how to carry out treatment), not a consultant to the team
- lessen the family's responsibility for providing and coordinating care so a PACT client and his or her family can relate more easily as family members

## Is there a history of success?

Yes, 30 years of documented success. PACT is the only community mental health program with an extensive research base. Findings from ongoing National Institute of Mental Health (NIMH) research comparing PACT clients with persons whose primary treatment site was the hospital indicate the program's success.

- PACT clients spend much less time in hospitals and more time in independent living, spend less time unemployed, earn more from competitive employment, have more positive social relationships, enjoy greater satisfaction with life, and have fewer symptoms of severe mental illness.
- In one study, only 18 percent of PACT clients were hospitalized the first year compared with 89 percent of the non-PACT treatment group. For those PACT clients who were rehospitalized, stays were significantly shorter than stays of the non-PACT group.
- PACT clients spent more time in the community, but the impact on family and community residents was no greater.
- The PACT model has shown an economic advantage over institutional care. In a Veterans' Administration study over 2 years PACT costs were \$33,296 less per consumer than standard care.

 In a landmark five-year NIMH-funded study by the Schizophrenia Patient Outcomes Research Team, scientists reviewed current scientific evidence documenting the most effective treatments for schizophrenia. Along with appropriate and careful use of antipsychotic medication, the study endorses the comprehensive approach of assertive community treatment as a treatment model of proven benefit to people with schizophrenia.

PACT's success is well documented. Extensive research by the National Institute of Mental Health confirms that the Program of Assertive Community Treatment's is clearly an evidence-based, exemplary model of care. PACT brings opportunities for recovery to people with severe psychiatric disorders who do not respond to traditional methods of community treatment.

The PACT model, now in its 30th year, has been researched in Madison, Wisconsin, where it originated, and at replication sites. It has consistently decreased the time persons with severe and persistent mental illnesses spend in hospitals and increased quality of life and independence.

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# PACT manual and other ACT Technical Assistance Center resources

**To order** *The PACT Model of Community-Based Treatment for Persons with Severe and Persistent Mental Illnesses: A Manual for PACT Start-Up* for \$19.95 please place your order on-line at *http://www.nami.org/namistore.html.* **To have a NAMI Resource Catalogue faxed or mailed to you, please call 1-888/780-4167.** The NAMI Resource Catalogue includes a description of the PACT Manual, and other items, and an order form.

Copies of this brochure are available by calling the NAMI ACT Technical Assistance Center at 1-866/229-6264.

## NAMI's Assertive Community Treatment (ACT) Technical Assistance Center

provides complete ACT assistance from introductory fact sheets, consultation on funding and planning an ACT initiative, on-site consultation and training for new ACT teams, through help sustaining your ACT teams over the long term.

## We will help you start ACT teams or strengthen existing ACT teams by providing:

- a Web site, http://www.nami.org/about/pact.htm with material in English and Spanish;
- consultation in English and Spanish via email at ACT@nami.org;
- information and consultation in English and Spanish via free telephone line, 1/866-229-6264;
- conference calls with local advocates to help you plan an ACT team in your community;
- · written mailed materials in English and Spanish;
- the comprehensive 350 page PACT Start-Up Manual on how to start an ACT team;
- presentations at conferences and meetings;
- TA Center staff and expert ACT consultants provide on-site help with: 1) Advocating and planning ACT;
   2) implementing ACT; and 3) sustaining ACT.

# Expert ACT consultants and TA Center staff provide telephone and on-site consultation tailored to your needs. Areas include:

#### Advocating and Planning for ACT

- forming and using a NAMI ACT **Advocacy Steering Committee**
- forming and using a key stakeholder, key decision-maker ACT implementation committee
- funding an ACT team using Medicaid and other funding sources
- including ACT as one of the service options for **jail diversion**
- writing an ACT request for proposals (RFP) and reviewing provider bids to select an agency that understands the model's values and structure.

#### **Implementing ACT**

- teaching team staff how to carryout treatment,
   rehabilitation, crisis resolution, and support services
   using ACT values and methods;
- consulting on team operations, assessment and treatment planning;
- adding more ACT teams when you already have pilot teams;
- strengthening current teams to meet the National PACT Standards;
- integrating consumer peer specialists as team staff;
- accessing affordable housing;
- forming the team's **stakeholder advisory group**;

#### **Sustaining ACT**

- developing the on-going consumer/family/community stakeholder advisory group to encourage model fidelity and adequate resources for the team;
- sustaining teams for years to come through methods including mental health authority certification, mentoring and monitoring, and on-going quality improvement.

Please call 1-866-229-6264 if interested in consultation.

"There is no question that the PACT model is essential for persons with severe and persistent mental illnesses to move forward with their lives and enjoy some aspects of living with more independence in the community. If people think PACT is expensive, compare it to the cost to warehouse people in institutions and, now more and more, in jails. What is the cost to the individual who goes without appropriate community treatment?"

## Nancy Abraham Mother, first president of AMI of Wisconsin



"PACT was the ultimate key to my functioning again. The help, support, and superb workers helped me deal with my problems while staying out of the hospital. I was not treated as an ill person, but as a human being who has suffered greatly from mental illness and who, most important, needed support and friendship."

### Dylan Abraham, consumer, PACT and emergency services support counselor Madison, Wisconsin

