Catalyst
TREATMENT ADVOCACY CENTER www.psychlaws.org

Spring/Summer 2005: Family advocates

Hope for overwhelmed family caregivers

Assisted outpatient treatment significantly reduces caregiver strain

by TAC Executive Director Mary T. Zdanowicz, Esq.

This issue of *Catalyst* focuses on the families and friends who support loved ones with severe mental illnesses. Over the last year, the critical public role that families can play in improving treatment has been quite visible. Two Michigan state senators, who know severe mental illnesses firsthand through their brothers' experiences, forged a successful bipartisan campaign to improve their state's AOT law. A state senator in Maine, spurred by his family's experiences, has launched a long-term effort to improve that state's archaic treatment law. And Acting New Jersey Governor Richard Codey, whose wife courageously publicized her struggle with mental illness, made reform of the mental health system a cornerstone of his administration. "There are some who have said that mental health is my personal agenda," he said in part. "But this isn't my agenda, it's everyone's agenda ... Individuals with mental illness are our brothers and our sisters ... our mothers and our fathers. They are our sons and daughters ... our neighbors and colleagues. And, yes, our husbands and our wives. And they all deserve better."

It is no coincidence that legislators with personal experience recognize the necessity of a measure scientifically proven to both reduce caregiver stress and help those who deserve better - assisted outpatient treatment.

In that same state-of-the-state address in January 2005, Gov. Codey also recognized the critical private role that so many families take on, noting "50 percent of adults with severe mental illness live at home with their aging parents."

Although we all recognize that providing support for a loved one brings many rewards, caregiving responsibilities also generate significant stress. A myriad of studies document the effects of caregiving for adults with severe mental illnesses. Each day at the Treatment Advocacy Center, families contact us with heartbreaking stories about the stress of coping with a loved one who is refusing treatment. Aging parents find themselves still struggling to provide a psychotic adult child with even the basic necessities.

Continued on page 2

INSIDE ...

FAMILIES AT RISK

by TAC President E. Fuller Torrey, M.D.

Family members who care for those with untreated severe mental illnesses face tremendous burdens. One study of relatives of individuals with a severe mental illness showed that more than one-third had to give up leisure time, becoming isolated and often prevented from having company of their own. A fifth of the relatives had to give up their own occupation. And a 2005 study found that compared to a control group, family members of patients with bipolar disorder and major depression had mental health care expenses that were about three times what they would have been in the absence of these diseases.

Families also face the very real risk of violence. A 1997 study focusing on the prevalence of abuse faced by families of individuals with a mental illness found that 32 percent of relatives had been struck on at least one or two occasions. Verbal abuse, threats, and temper outbursts were reported by more than 50 percent of the relatives. The American Psychiatric Association notes that "Family members are most at risk of a violent act committed by a

Continued on page 3

AOT reduces caregiver strain

Continued from page 1

One recently published study provides a ray of hope for families. As part of the largest randomized control study of assisted outpatient treatment (AOT), known as the Duke study, researchers measured the effect of AOT on caregiver strain.[1]

The study involved caregivers of individuals with severe mental illnesses who were awaiting discharge from involuntary hospitalization and met these criteria for AOT: lack of capacity to survive in the community with available supports, a clinical history indicating a need for treatment to prevent deterioration that would predictably result in dangerousness, and an inability to make informed decisions to seek or comply voluntarily with recommended treatment. A caregiver was defined as a family or nonfamily member primarily responsible for providing care (assistance with daily living, transportation, treatment management, housing, emotional support).

The study results indicate that extended outpatient commitment over the course of a year *significantly* reduces caregiver strain.

The level of strain was measured over a year for caregivers of individuals who had sustained AOT (at least 180 days) compared with those who had brief periods of AOT or no AOT. The study results indicate that extended outpatient commitment over the course of a year *significantly* reduces caregiver strain. Not surprisingly, improved treatment adherence also reduced caregiver strain. However, the study showed that AOT operates as an independent factor from treatment adherence in reducing stress. That is, the researchers concluded that "extended outpatient commitment contributes significantly to reduced caregiver strain, over and above its effect on treatment adherence."

Family and friends are an important resource in providing care and support for individuals with severe mental illnesses. As a matter of public policy, it is imperative that families receive the support that they need. Assisted outpatient treatment is an evidence-based means of reducing caregiver strain. But it is also a proven means of improving consumer outcomes and quality of life.

After all, isn't that what caregivers really want?

1 April Groff, et al., August 2004, "Caregiving for Persons With Mental Illness: The Impact of Outpatient Commitment on Caregiving Strain," *192 No. 8 Journal of Nervous & Mental Disease*

Catalyst

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About TAC

The Treatment Advocacy Center (TAC) is a national nonprofit organization dedicated to eliminating legal and clinical barriers to timely and humane treatment for millions of Americans with severe brain disorders who are not receiving appropriate medical care.

Since 1998, the Treatment Advocacy Center has served as a catalyst to achieve proper balance in judicial and legislative decisions that affect the lives of people with serious brain disorders. TAC works on the national, state, and local levels to decrease homelessness, incarceration, suicide, victimization, violence and other devastating consequences caused by lack of treatment.

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Spring/Summer 2005

Family members at risk of violence are not alone

Continued from page 1

mentally ill person … [Another study] found that among those who had attacked people prior to their admission [to a psychiatric hospital], 65 percent ... had attacked a family member."

I became aware of this problem in the early 1960s, when my sister with schizophrenia, untreated at the time, violently attacked my mother. In the early 1980s, I began collecting data on the problem, which the mental health community seemed to be ignoring. I remember the 1984 case of Emily Cannon, a teacher in Charlotte, who wrote a letter to local mental health officials and county commissioners pleading for treatment for her son with schizophrenia. Four days later, she was killed by her son. As Don Richardson was being installed as President of NAMI in 1986, his son with schizophrenia tried to kill his mother. By 1991, the magnitude of the problem became clear when NAMI released a survey of over 1,400 members; in the preceding year, 11 percent of the severely mentally ill NAMI family members had physically harmed another person.

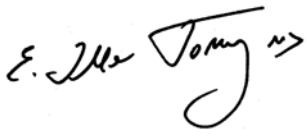
According to the MacArthur Violence Risk Assessment Study, "the people at highest risk are family members and friends who are in their homes or in the patient's home." Studies attempting to quantify how often family members are the victims of violent acts committed by individuals with severe psychiatric disorders have reported from half to three-quarters.

Mental health organizations have been reluctant to speak out about the risk to families. They have decried the problem of stigma, but failed to note that it is the violent acts by severely mentally ill persons - not the reporting of them - that are the major cause of stigma.

Individuals with severe psychiatric disorders are not more dangerous than the general population - IF they are being treated. Without treatment, some commit acts of violence because of their delusions and hallucinations. And, in the majority of cases, the victims of the violence are family members.

An important reason why I founded the Treatment Advocacy Center was to address the issue of violence against family members and others. It is a sad commentary on today's treatment system that thousands of families live in fear of a mentally ill family member because he or she is not being treated. I am very proud that TAC is addressing this problem by helping make treatment more accessible before crisis occurs.

Families and their ill loved ones deserve better treatment laws so these dangerous situations can be averted. And they deserve to be able to advocate without guilt for the health and safety not only of the one they love, but for themselves as well.



What to do if someone with a severe mental illness becomes assaultive

- **Don't underestimate the risk.** People who are acutely psychotic, especially if also delusional and abusing alcohol or street drugs, are capable of extreme violence and are not predictable.
- **Discuss the situation** with the person's case manager, social worker, and/or psychiatrist. Make sure they are aware of the person's threatening or assaultive behavior. If possible, put your concerns in writing to them: Written notification is much more difficult to ignore.
- **Safe-proof your house or apartment.** Have a room to which you can retreat if needed; it should have a secure lock and a telephone. Do not allow firearms in the house.
- **Clearly spell out the consequences** for the person if he or she becomes assaultive (e.g., no longer being able to live at home). Be prepared to carry out these consequences.
- **Minimize alcohol or street drug use** in whatever ways are possible. Substance abuse is often a trigger for assaultive behavior.
- **If threatened** by someone with manic-depressive illness (bipolar disorder), remain calm, keep conversation to a minimum, and exit the situation. If threatened by someone with schizophrenia, stay calm, remain physically distant (give the person lots of space), do not look directly into his/her eyes, sympathize, try to find something on which you can both agree.
- **Do not allow yourself to become trapped**; remain physically between the person and an open door.
- **Do not hesitate to call the police.**

Adapted from *Surviving Manic Depression: A Manual on Bipolar Disorder for Patients, Families, and Providers* (E. Fuller Torrey, M.D. and Michael B. Knable, D.O., Basic Books, January 2002) and *Surviving Schizophrenia: A Manual for Families, Consumers and Providers* (E. Fuller Torrey, M.D., Quill, May 2001).

Advocates corner

Preparing for crisis, fighting for treatment

Getting care for those in crisis, hospitalized, or incarcerated because of a severe mental illness

The Treatment Advocacy Center's mission is to eliminate barriers to treatment. Although our main focus is improving laws and policies to encourage early intervention and sustained treatment, we get enough calls and emails to know that many of our friends are fighting individual battles every day to secure treatment for someone they care about. Following are some strategies to consider before a crisis occurs and when the person is getting treatment. Throughout, there are tips for information you can RESEARCH, MATERIALS you should prepare or have on hand, and ADVOCACY you can do, all to secure safe passage or timely treatment for the person you love.

IMPORTANT NOTE: The types of available public psychiatric services, procedures for their access, and pertinent legal provisions, particularly those concerning assisted treatment, vary widely from state to state. All of the information in this article will not be applicable to each specific jurisdiction. As always, please consult appropriate mental health, advocacy, and/or legal resources to learn about the applicable service mechanisms, procedures, and laws for your state.

Preparing for crisis

The events necessary to trigger most treatment laws are among the most trying and stressful imaginable.

Although the language differs from state to state, many state laws, or interpretations of those laws, require someone to be in danger of physical harm to themself or others before being placed in treatment. Being forced to wait until someone is incapacitated by a severe mental illness and presents an imminent danger often leaves families and treatment providers waiting for an extreme crisis before they can act. As too many family members know, that is a situation full of worry and pressure.

When a crisis does arise, family members must react minute-by-minute to a deluge of circumstances. It is not a time for efficient thought or strategizing, which is why preparation is critical. Now is the time to do research, gather materials, and reach out to key people in case the situation deteriorates, even while working on other fronts to avoid a crisis.

RESEARCH: Gather information

Information is power. The more you know - about the law, the options, and the people you might work with in a crisis - the more effectively you will be able to navigate through the system if such a crisis occurs. To start, get the answers to some basic questions.

What is your state's commitment law? Know your state's standard for intervention and familiarize yourself with its provisions for commitments. The statutes for each state are in the Legal Resources section at www.psychlaws.org. Your state/local mental health departments should also have materials summarizing the standards. In the 45 jurisdictions that allow direct petitioning for commitments, the clerk at the local court should have copies of the petition form. Gather printed copies of the criteria for emergency evaluation and civil commitment.

What is the local landscape for treatment? One place to start is with your local chapter of NAMI (the National Alliance for the Mentally Ill). NAMI is a support and advocacy organization for people with psychiatric disorders and their families. Local chapters have biweekly or monthly support meetings; leaders are usually willing to advise on the local treatment system and procedures. Find your chapter via the national hotline at 1-800-950-NAMI (6264). Also call the courthouse and ask the clerk of the court about the procedures for filing an involuntary commitment petition in your county. Different jurisdictions have different procedures, so always call the county *where your loved one lives*, not the one where you live (if they are different).

Which screening facility or local emergency room performs emergency psychiatric evaluations? Find out which facility your loved one would likely be transported to in a crisis. Contact them and ask about the process when someone is brought in. What is involved in getting someone committed? And what, if any, resources do they have to help avert crises? (Few facilities have such programs, but it is worth asking.)

What is the process to initiate placement? The process to initiate placement of someone incapacitated by a psychiatric disorder varies from state to state. A law enforcement officer can take a person deemed to meet the state's "pick-up" standard to a psychiatric facility for an evaluation, although a few states require that the officer first receive authorization from a judge or magistrate. In some states, physicians or other medical personnel can temporarily prohibit the release of a voluntary inpatient or call for an emergency evaluation without prior court approval.

Many states also allow other individuals to directly petition a court to order an evaluation, sometimes defined as "any person," "interested persons," family members, or designated mental health department employees.

What is the duration of evaluation? Regardless of the manner in which evaluations arise, almost every state limits duration. Providers must usually decide within 72 hours either that the person continues to meet the placement criteria (so pursue a formal commitment) or that they should be released.

MATERIALS: Build a CARE kit

In a three-ring binder, file box, or other easily-transportable storage system, create a CARE kit (Critical Advocacy Resources for Emergencies). A CARE kit is a "ready-file" of materials that you can quickly share with treatment professionals in a crisis.

Psychiatric history summary. It is unlikely that treating professionals will have immediate access to, or time to review, the full medical records of someone brought in for an emergency evaluation. A one-page summary of psychiatric history can be very useful. (And may also be useful as evidence in commitment hearings.) Keep at least five copies of this important document in your CARE kit, so it can be easily and quickly shared with more than one person in a short span of time. Keep it current (update it regularly) and short (one page is best) but be sure it contains the most critical information, including the following.

- ❑ Full name
- ❑ Current age
- ❑ Psychiatric diagnosis
- ❑ Age at diagnosis
- ❑ Town or city of residence
- ❑ Current symptoms
- ❑ Current concerns (suicidal, homeless, missing, vulnerable, violent, abusing substances, other)
- ❑ Psychiatrist's name and number
- ❑ Local service provider's name and provider
- ❑ Dates of previous hospitalizations and locations
- ❑ Dates of previous arrests or jailings and charge(s)
- ❑ Current medication name(s)
- ❑ Past medication(s) that have helped
- ❑ Past medication(s) that have not helped
- ❑ Past history of symptomatic behaviors (e.g., running up huge debt, getting into car accidents, threatening family members, failing to care for basic needs)
- ❑ Full name, contact numbers, and address for emergency contact person

Recent picture and description. Keep a recent picture of your loved one, a list of vital statistics (such as height, age, weight, hair color), and any pertinent physical medical conditions (such as allergies or diabetes). Ideally, keep these in a format that allows them to be easily faxed or e-mailed to police and mental health agencies. Leave space to add a description of clothing last worn in case that information is needed.

List of emergency numbers. Create, and periodically update, a list of emergency numbers, including those listed in the checklist on this page.

Checklist: What is in your CARE kit?

- ❑ One-page psychiatric history summary
- ❑ Recent picture and description
- ❑ List of emergency numbers
- ❑ Copy of criteria for emergency evaluation
- ❑ Copy of criteria for civil commitment
- ❑ Petition form for emergency evaluation
- ❑ Petition form for civil commitment
- ❑ Medical release
- ❑ Advance directive

Copies of important criteria. Print out a copy of your state's criteria for emergency evaluations and for civil commitments (as mentioned in the "research" section). That way if anyone along the way contradicts or misunderstands the law, you have a copy of it in hand.

Petition forms. Get blank copies of involuntary commitment forms if your state permits this. Complete any nonincident-related information ahead of time. You may never have to use them, but at least you will have them ready.

Medical release (if applicable). If possible, have your loved one sign a release that allows you access to his or her medical information. If you have such a document, keep a copy in your CARE kit. (For more details on medical information and privacy laws, see the full story on page 12.)

CARE kit: List of emergency numbers

Keep a list of emergency numbers in your CARE kit, including the following. If you have made direct contact with any key people (like the CIT team coordinator), include their contact names and any cell phone or pager numbers.

- ❑ Psychiatrist
- ❑ Case manager
- ❑ ACT/PACT team
- ❑ Community mental health center
- ❑ Mobile crisis team
- ❑ Crisis intervention team (CIT)
- ❑ Police department
- ❑ Local hospital
- ❑ Local emergency room
- ❑ Court for civil commitment
- ❑ Mental health court
- ❑ Homeless shelter(s)
- ❑ Friends of your family member

HELPLINES:

- ❑ Suicide prevention hotline (1-800-SUICIDE)
- ❑ Local NAMI

Continued on page 6

Preparing for crisis, fighting for treatment

Continued from page 5

Advance directive (if applicable). Advance directives are legal documents that allow individuals with mental illnesses to dictate aspects of their care in case they become incapacitated by illness. These documents might include the designation of a person to make treatment decisions should the subject become incapacitated. The specific details of these legal documents vary widely from state to state. Most advance directives are immediately revocable, which is a significant limitation on the effectiveness of these instruments as that can allow individuals to nullify their previous treatment decisions even when suffering from impaired judgment. If your loved one has such a directive, keep a copy in the CARE kit.

ADVOCACY: Share information

Alert your local mental health crisis unit. These outreach workers typically conduct on site evaluations and often are empowered to initiate commitments. They are also likely to be called by law enforcement to assist in crises involving an individual with a psychiatric disorder.

Reach out to your crisis unit. Ask to speak to or meet with the supervisor or director. In that short meeting, in person or via phone, ask for information about the process involved in a commitment, and what would happen to your loved one if he/she arrived at the unit for an involuntary commitment. Get the appropriate contact information for your CARE kit and ask if you can or should provide some information about your loved one for their files. And ask for a tour of the facilities.

If you think a crisis is imminent, alert the unit that you suspect that your family member is on the verge of meeting commitment criteria. Fax over or drop off a copy of your one-page history form for their records. If your state is one of the 42 that offers assisted outpatient treatment (AOT), ask about the steps needed to ensure that AOT can be used on discharge. (See the sidebar on page 7 for more on this treatment mechanism.)

Alert your local law enforcement agency. Make your local law enforcement agency aware of the person's condition in case officers are called to initiate an emergency evaluation or respond to a disturbance. Eliminating the element of surprise can help reduce the risk of a call escalating into a crisis.

Reach out to the crisis intervention team (CIT) coordinator, if your community has CIT, or to the commander for your precinct/district. Or ask for an officer who has expressed interest in or knows about mental health issues. It is also often helpful to talk to the 911 supervisor (reach them through the general office number of course, not via 911 itself).

The message to convey is that your loved one has a severe mental illness that might make encounters difficult. Explain specifically, if you can, what happens when the person is symptomatic or delusional - for instance, that he hears voices and cannot easily follow verbal instructions so he may appear to be disregarding officer orders. Or that she has delusions that police officers are aliens and may be unreasonably afraid and unable to comply with commands.

If there is a particular officer or sheriff's deputy who patrols the area regularly, invite that officer and any local CIT officer to come by to meet your family member when they are well. This can help build some rapport and trust for all involved.

Finally, as with the mental health facility, do not wait for a full-blown crisis before calling law enforcement. If you anticipate an imminent crisis, alert them so they are not caught off guard.

Fighting for treatment

Those who are the most severely ill often cannot get the services that they need. If you face obstacles advocating for needed services for someone you care about, you may want to try some of the following strategies.

RESEARCH: Investigate options

What treatment options are available? A person seeking the best possible care for a person suffering from a severe mental illness must first research what treatment options are available. The best and most obvious place to turn is to the professionals presently managing the person's care, but that is only the beginning of a thorough investigation. The leaders and staff of local NAMI affiliates will not only be familiar with service options, but may offer a better "real world" assessment of what is available than employees of mental health departments, hospitals, or private community providers. Another basic resource is state or local mental health administrators.

What are the eligibility criteria? Most specialized services (such as PACT or ACT teams) are reserved for specific populations. Those advocating for a particular service must also learn the eligibility criteria for these programs.

Does your loved one meet the criteria? Don't assume the answer is "no." Ask for written policies governing eligibility. Use the person's treatment history (for example, repeat hospitalizations) to establish whether they are eligible for those services.

Never accept a first answer, and know what questions to ask. For example, does the community have intensive case managers,

intensive family support services, and residential support services? Visit the local mental health center or mental health service providers and request a tour.

What are the financial incentives to treatment? There is often a financial disincentive for providers to serve those who are most acutely ill - they may require intensive and expensive treatment. One way to counteract this is to document what it costs *not* to provide those services. For a person who is repeatedly hospitalized, multiply the cost per day by the total number of days. A state or county mental health administrator may appreciate that providing the needed community services or additional inpatient days to more fully stabilize the person's condition will be less expensive in the long run. Law enforcement may respond to the costs of repeated jailing someone.

MATERIALS: Maintain detailed records

For long term use, there are materials in addition to those in your CARE kit that will be useful in dealing with caregivers and providers, whether in an outreach team, outpatient clinic, inpatient facility, or a jail or prison.

Fully documented medical history. Remember that patients have the right to request copies of their own medical records, which can be compiled and saved for future use. Any information/records that can be gathered along the way should be saved in a central file, including the names, addresses, and phone numbers of all previous or current treatment providers. The basic one-page summary is still important to maintain and share - the full history supports more indepth advocacy.

Informal incidences journal. Keep a journal that regularly documents the person's illness, medications and reactions to or side effects of medications, and any significant/related symptoms or problems. Journal entries should concentrate on observable facts, and use action words. They should be descriptive (not "we had a fight" but "he picked up a heavy frying pan and waved it at my head"). Being able to provide specific dates and detailed descriptions of events is a substantial advantage for someone testifying in a treatment hearing or trying to convince a treating professional of the severity of a person's illness.

ADVOCACY: Fight for the best care

Whether the person is in an inpatient facility or needs psychiatric care in the community, it can be frustratingly difficult to obtain appropriate mental health services from often unresponsive mental health care systems. However, a persistent family member or friend can secure action from these bureaucracies.

Be an advocate first. Building relationships with a service provider and letting them see how much you care about your loved one is vital and demonstrates your value as a member of the treatment team. But don't get too cozy. It is more important to be an advocate than to be friends with service providers and mental health officials. Feel free to disagree with politeness and persistence when cooperation is not possible. It sometimes may even be necessary to go over someone's head.

Don't be stymied by medical privacy laws. Sometimes treatment providers raise concerns about breaching confidentiality as a reason not to talk to someone trying to help another

Continued on page 8

Assisted outpatient treatment

In most states, treatment interventions are no longer limited to inpatient hospitalization. Most jurisdictions now permit assisted outpatient treatment (AOT).

When appropriate, AOT fosters treatment compliance in the community through a court-ordered treatment plan. Not only does the court commit the patient to the treatment system, it commits the treatment system to the patient.

Broadly available. Only Connecticut, Maine, Maryland, Massachusetts, New Jersey, New Mexico, Nevada, and Tennessee still do not have AOT. If your family member lives in one of the other 42 states, AOT is available in some form.

Less restrictive. Many states allow the use of AOT under eligibility criteria less restrictive than those for inpatient hospitalization - oftentimes before someone becomes a danger to themself or others. Visit www.psychlaws.org to see the criteria for your state and situation.

Stunning results. AOT's usefulness for those who are too ill to make rational treatment decisions is well studied and documented. For instance, statistics from New York's Kendra's Law show that during AOT, 74 percent fewer participants experienced homelessness, 77 percent fewer experienced psychiatric hospitalization, 83 percent fewer experienced arrest, and 87 percent fewer experienced incarceration. AOT also vastly improved treatment compliance. (See the article on page 15 for more details on AOT's successes.)

What you can do. If your family member lives in a state that allows AOT, ask your local treatment facilities about procedures for using it. Some states that allow this intensive, mandated, and supervised treatment use it more frequently than others - if your local facility is not using it, find out why. Primary reasons for underuse include a lack of awareness of the law or a state standard that requires someone to be in immediate danger before they can be helped. Despite these and other barriers, advocacy of a determined family member can sometimes result in the use of AOT even in those states where the treatment mechanism is rarely used.

For more on AOT, visit www.psychlaws.org.

Preparing for crisis, fighting for treatment

Continued from page 7

person who is receiving or in need of treatment. Sometimes confidentiality is used inappropriately. Remember that listening is not against the law. Even if treatment providers cannot tell you about someone's condition or treatment, no privacy law prohibits them from *taking* information concerning a patient's condition and psychiatric history. In fact, some would argue that a mental health professional is negligent if they fail to gain as much information about the person's condition as possible. If nothing else, you may establish a relationship that could at some point be invaluable. (See page 12 for a detailed discussion of medical privacy laws and some tips on navigating them.)

Call the department of mental health. Call the county department of mental health and explain that you are having a "service delivery problem." Keep a record of who you talk to at the county level, and try to get *in writing* whatever information they give you. Make sure you write down exactly what they say. Note the dates of conversations and any actions promised. If you are still not getting a satisfactory answer, follow the same steps with the state department of mental health.

Work your way to the top. Jails, hospitals, and treatment facilities have established chains of command. Work your way up the chain until you get results. For example, the chain of command in an inpatient setting may start with a social worker. From there, contact a nurse, psychologist, or psychiatrist. Next, ask for a treatment team leader or section chief. If those attempts fail, contact the hospital administrator. Every county and state has its own methods for handling grievances, so you need to find out what these procedures are.

Most organizations have oversight from a Board of Directors or Trustees. The identity of board members is a matter of public record. Write them a short letter documenting the problems and lack of responsiveness. The board has a fiduciary responsibility to ensure that the organization's mission is met and will likely investigate and address your complaints. For publicly funded services, you can work your way up from the director of mental health services to the very top. We have seen well-documented cases get a Governor's attention - and results.

Keep track of everything. Get the name of everyone you talk to, and their supervisor. Document each attempted contact or conversation by email or fax, which will also politely make it known that you are creating a paper trail that can later be reviewed by supervisors or even in court. If you have to, send a certified letter or even a telegram to the commissioner of mental health in your state highlighting your concerns, detailing your conversations with other county and state staff, and requesting an immediate response. (Once a common way to deliver urgent messages, telegrams are rarely used today because there are faster means of delivering messages. Because they are less common, they definitely get people's attention.)

Hire an expert. If you can afford it, an expert can be a huge help. Different situations call for different experts. For instance, care providers may react more readily to second opinions from fellow treatment professionals while hospital and community service administers are often more responsive to contacts from attorneys. Getting help in a jail or correctional facility can be easier with the assistance of a correctional expert.

Get help from law enforcement. If the person you are trying to help has repeated contacts with law enforcement, you may be able to get a sheriff or police chief to intervene. Help them understand that getting treatment for your loved one is in everyone's best interest - not only would appropriate treatment benefit the person, it could help avert a tragedy and remove the burden on local law enforcement created by the person's symptomatic actions. A call from a sheriff or police chief can be very influential in prioritizing services for someone you care about.

Get the media interested. Television and newspaper reporters cannot cover every story they hear about. But if your situation is particularly egregious, heart wrenching, or representative of a systemic problem, your local media outlet might be interested. Find contact information on their website and focus on a reporter who is in your community, especially if they have covered mental illness or crime issues before. When you call, summarize your story in one sentence and keep your comments focused on one main issue (such as treatment, insight, or criminalization). Picture the headline that you want to see and make that your theme. ("Man jailed for tenth time in five years because the law can't help him: Mother demands answers.") If an article is printed that is useful to you, email, fax, and mail copies to those you are trying to influence. Don't forget to send copies - with a personal note - to your legislator and governor.

Working with a defense attorney

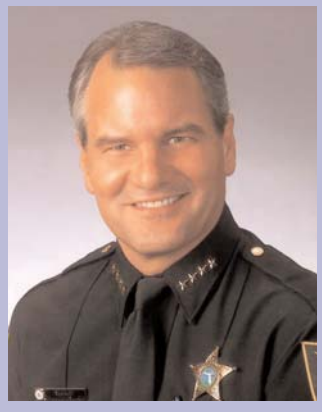
"The family may want a therapeutic result in the criminal case, and the defendant insists that he is not ill and opposes all treatment. In such a case, the defense attorney will not be an ally of the family. The family should nevertheless provide information to the defense attorney, including treatment histories and descriptions of symptomatic behavior of the defendant."

- from an article by Taylor Andrews in the *Catalyst* archives: http://www.psychlaws.org/JoinUs/CatalystArchive/CatalystV2N1.htm#tipsforfamilies (read the full article or browse other stories)

TAC announces advocacy award winners

Efforts of unlikely team result in new treatment law in Florida

Congratulations to Seminole County Sheriff Donald Eslinger, Linda Gregory of Jacksonville, and Alice Petree of Sanford, winners of the national Torrey Advocacy Commendation. The annual TAC award recognizes the courage and tenacity of those who selflessly advocate – despite criticism and opposition – for the right to treatment for those who are so severely disabled by severe mental illnesses that they do not recognize that they need treatment.



Sheriff Eslinger

Eslinger, Gregory, and Petree won this year's national Torrey Advocacy Commendation for their successful advocacy for a new mental illness treatment law in Florida.

TAC's board of directors voted unanimously to recognize all three advocates in an unusual move that paralleled an unusual advocacy partnership. "We are impressed by their heart-felt efforts over more than four years to get a more humane treatment law for Floridians with severe mental illnesses," said TAC board secretary Dr. Fred Frese. "We commend Sheriff Eslinger, Linda Gregory, and Alice Petree for their incredible dedication and effectiveness in spearheading a complex and critical reform of Florida's outdated treatment law."

"We commend [them for] spearheading a complex and critical reform of Florida's outdated treatment law."

- Fred Frese for the TAC board of directors

The Florida House of Representatives cited the TAC award in a resolution sponsored by Rep. David Simmons and Rep. Sandra Adams that recognizes these three advocates for "their successful advocacy in honor of Deputy Sheriff Gene Gregory and Alan Singletary and all people with severe mental illnesses who will benefit from their efforts."

The result of their work is Florida's new law, which took effect January 1, 2005, that allows assisted (court-ordered) outpatient treatment for people with severe mental illnesses, like schizophrenia and bipolar disorder, who have a history of noncompliance combined with either repeated Baker Act admissions or serious violence. Court-ordered outpatient treatment is a less restrictive, less expensive alternative for those who need intervention but do not require inpatient hospitalization. New statistics from New York, a state with a similar law, show that for those in the program, 74 percent fewer experienced homelessness, 77 percent fewer experienced psychiatric hospitalization, 83 percent fewer experienced arrest, and 87 percent fewer experienced incarceration. Individuals enrolled were also more likely to regularly participate in services and take prescribed medication.

On July 8, 1998, Deputy Sheriff Gene Gregory and Alan Singletary, a man with a history of severe mental illness, died in a 13-hour standoff. Seminole County Sheriff Eslinger vowed to not let their deaths be in vain, and created a Mental Health Task Force to advocate for reforms in mental health and substance abuse services and laws. With the unlikely team of Alice Petree, the sister of Alan Singletary, and Linda Gregory, the widow of Deputy Sheriff Gene Gregory, Sheriff Eslinger worked, through the task force and with other community groups and stakeholders, to increase awareness of the need for treatment of mental illnesses. With the leadership of the Florida Sheriffs' Association, the efforts of these advocates and the community network they helped to create resulted not only in reforming the Baker Act to allow for assisted outpatient treatment, but also in other beneficial programs for those with mental illnesses such as jail diversion, forensic treatment programs, mental health screening at a county correctional facility, funding for a detox receiving facility, a voluntary identification program, and law enforcement crisis intervention teams.

Linda Gregory

Alice Petree

About the award. The annual Torrey Advocacy Commendation is named for Treatment Advocacy Center president and founder Dr. E. Fuller Torrey, M.D., a nationally known and respected psychiatrist, researcher, and advocate whose unflagging resolve to remove barriers to treatment for people with severe mental illnesses sparked a national reform movement. Recipients make a substantial difference for their community through advocacy, awareness, research, or legislation in this field. To nominate someone for next year, visit our website at www.psychlaws.org.

Your voice

Life in one of the eight states of despair

With no option for AOT, New Jersey families are fighting for a better law

"My family has desperately attempted to get him help"

- excerpt of Joy Scoble's testimony before the Governor's Task Force on Mental Health, Jan. 19, 2005

My brother has recently been released [from prison] ... Since his release, he's moved from location to location because he has had fits of rage and the family member or friend, who has been so gracious as to support him, no longer feels comfortable having him live with them. Today, my brother is living on the streets ....

About 4 or 5 years ago, my brother attempted to attack my father ... [He] claimed that he was going to kill my father and when that was done, he was going to go back into the house and kill everyone else ... I do not hold this against my brother ... I know it was something that was triggered by his mental illness ....

For about 5 or 6 years now, my family has desperately attempted to get him help for his mental illness. My mom has pleaded to a judge at one point, to try and have him committed. This was unsuccessful because he's an "adult" who cannot be forced into help. For years, he's been thrown out of ... housing because he's been in fights with other residents ....

At one point, his doctor had put him on [medication] and when family had visited him, there was a significant change ... a few visits after that, he converted back to his depressive state. After questioning him about the medication, he explained that he didn't think it was working, so he decided to stop taking it ....

I've recently contacted my local city police station to inform them that my brother is living on the streets and that if he were to get into any trouble, I would prefer it if he was taken to a local hospital for evaluation ... When I explained that he's having fits of rage, [they] assured me that if they found him, they'd take him into a hospital. The next day, my mother called the police on my brother because he was trying to get into her house. The police officers showed up, and said they couldn't take him anywhere against his will.

This is why I've felt so helpless … I've been told I cannot get help for my brother until he attempts suicide. ... It's sad that society will not help others until extreme measures are taken.

"This is why I've felt so helpless … I've been told I cannot get help for my brother until he attempts suicide. "

Want to join the effort to change NJ law? Call us at 703 294 6001.

Gregory Katsnelson

"Gregory was not the only victim"

- excerpt of Cathy and Mark Katsnelson's testimony before the Governor's Task Force on Mental Health, Jan. 19, 2005

On October 17th, 2002, our then 11-year-old son, Gregory, completed his daily homework assignments and after getting permission to go out, jumped on his bike to go and find his friends ... [W]hen Gregory entered the bike path just feet away from our home, he had no idea of the danger he would encounter.

He was suddenly yanked from his bike and brutally murdered and his body left face down in the lake by 26-year-old Ronald Pituch ... We later learned that Gregory was not the only victim that day. Before taking our son's life, Ronald Pituch had savagely beaten his own mother to death with a bar bell because she had not gotten him a pack of cigarettes. He tied up his 5-year-old niece ... [and] assault[ed] an elderly woman passing by before ending his manic rampage with Gregory's murder.

... [Pituch] had been diagnosed with paranoid schizophrenia and was refusing treatment and medication for his illness. While his family reported signs of instability in the weeks prior to the violent spree, they were unsuccessful in getting the help from mental professionals that they were desperately seeking. The family was assured many times that he was not homicidal or suicidal although he had demonstrated violent behavior on several occasions, and, as is common among people with severe mental illness, he continued to deny his sickness ....

Yet, with the current laws in New Jersey, no one was able to do anything to prevent the tragedies ... New Jersey is one of only eight states ... where if a person with severe mental illness refuses treatment and medication to control their symptoms, families, caregivers, mental health professionals, and courts find that "their hands are tied." ....

Because of the limitations of the current law, two innocent people died that afternoon.

Your voice

Help and hope for families, providers, consumers

After 5 years of AOT, New Yorkers see vast improvements for the sickest

"We have witnessed many amazing turnarounds and successes"

- excerpt of Dr. Mary Barber's testimony at an April 8, 2005, public hearing in New York city on Kendra's Law. Dr. Barber is the medical director of the Ulster County Mental Health Department and AOT psychiatrist for Ulster County.

Ulster County Mental Health Department was initially skeptical about AOT. We felt ... court petitions would not really change the behavior of a patient truly resistant to treatment. We guessed ... that while a few extra case management resources might help some patients, court orders would not add much beyond that.

[Today] we feel much differently about AOT ... Intensive case management and oversight by the AOT coordinator benefit patients on enhanced (voluntary) services. However, it must be emphasized that for some patients adding services is not enough and a court order is necessary. We have done 90 AOT investigations. Of these, 47 people received enhanced services and 15, or 32 percent, have gone on to require an AOT petition from the court. So, for many people, voluntary services are enough, but for a significant minority, court is an important addition. We currently have 23 people on enhanced services and 8 active petitions, so even mandated services do not need to be continued forever. The most common reason for choosing to not renew a petition has been improvement by the patient to the point that they could go on to participate voluntarily in treatment.

We measured hospital and jail days over a three-year period for patients prior to AOT petition and after AOT petition. We found a reduction of over 3,500 hospital days and over 1,000 jail days with petitions. When we separated out the time before a person was placed on petition and compared the period when they received no special services to the period when they received enhanced services, there was only a slight reduction in hospital and jail days. In other words, some individuals needed a court order to be able to remain in the community...

We have witnessed many amazing turn-arounds and successes for people on petitions .... It is clear to us from our experience that AOT petitions have saved patients from more restrictive institutional settings, have saved our communities money, and have most likely kept our communities safer by avoiding the incidents that lead to jail and hospital stays.... The AOT Law essentially says that counties now have ultimate responsibility over their most high-risk, high-need people.

"It is the only thing that has worked for my son"

- excerpt of one mother's testimony at an April 8, 2005, public hearing in New York city on Kendra's Law.

I am a [professional] with over 30 years of experience in the field of mental health ... I am also the mother of an adult son who has been under court ordered treatment in New York City through the AOT program for over three years ... [Troy*] has ... schizoaffective disorder ... He also suffers from anosognosia, the inability to understand that he is ill.

Troy struggles to understand what has happened to him over the years that he has been ill ... Troy has been hospitalized more than a dozen times ... [and] is unable to see that when he stops taking his medication he becomes psychotic and within a matter of days ... becomes so ill that he has to be rehospitalized.

What Troy *has* been able to understand, however, is that when he is in the Assisted Outpatient Treatment Program and under a court order, if he violates it ... he will be rehospitalized. Somehow, this has gotten through to him. Troy takes his AOT program and its court order very seriously. It is the only thing that has worked with my son and has made him compliant with his prescribed medications. With this program my son has had fewer hospitalizations. Without this program, and the mandate it represents, my son would be a danger to himself and others ...

I have been nothing short of amazed at the quality of the caring concern with which my son has been treated ... Troy called a meeting of the AOT team to talk about his treatment plan and see if he could be released early ... The whole AOT team attended ... Despite my son's difficulties articulating and organizing his wishes, [the team] related to Troy with respect and a caring concern ...

On another occasion when my son had to be hospitalized for an extended period of time and a question arose as to whether the halfway house that had been housing him was going to allow him to come back, Troy's AOT counselor ... was immediately on the case. He made clear to the representative from the halfway house that this was an ill-considered move and that their department would fight tool and nail to have him reinstated at that facility ... the halfway house reversed their decision ...

AOT ... is the only hope my son, and others like him, have.

**not his real name*

Families and privacy laws

Understanding and navigating the HIPPA privacy rule

Releasing health information to families of people with severe mental illnesses

by Laura Levit

Family members are frequently called on to provide care for a loved one with a mental illness.[1] To function in this capacity, family members need to understand what kind of information they can get regarding their relative's diagnosis, treatment plan, medications, etc. The following article describes the law - and outlines some creative legal ways to get needed information.

Knowing the law may help family members convince mental health care providers to share vital information about their relatives.

Both consumers and mental health care providers interpret confidentiality laws conservatively, according to a 2003 study.[2] This means mental health providers often do not share information with relatives because they think sharing violates confidentiality laws. This also means that family members often do not ask for information, because they do not think they have the right to be informed. Knowing the law may help family members convince providers to share vital information about their relatives.

What is HIPAA and why is it important?

The Health Insurance Portability and Accountability Act of 1996 (HIPPA) created a national standard for the protection of certain types of health care information. The U.S. Department of Health and Human Services then issued a "Privacy Rule" to implement the requirements of HIPAA. The Privacy Rule limits the circumstances in which individually identifiable health information can be used and disclosed by health care insurers, providers, and clearinghouses. The Privacy Rule refers to this type of information as "protected health information (PHI)."[3]

The Privacy Rule limits the use and disclosure of PHI by "covered entities." It does not affect other organizations or individuals. Covered entities can use and disclose PHI with no restriction only for treatment, payment, and health care operations. All other uses and disclosures must be authorized by the individual or be authorized under a section of the Privacy Rule.

Covered entities include:

Health plans. These are individual and group plans that provide for the cost of medical care, like insurers, HMOs, Medicare, Medicaid, and employer-sponsored group health plans.

Health care providers. All health care providers that use electronic technology in connection with a standard transaction are covered entities. Almost all health care providers meet this requirement.

Health care clearinghouses.[4] These are entities that process PHI received from other covered entities.

NOTE: An overview of the Privacy Rule is available online at: http://www.hhs.gov/ocr/privacysummary.pdf

Disclosure to the individual

An individual has the right to review and obtain a copy of his/her PHI. Covered entities must provide PHI to the individual who is the subject of the medical record.[5]

How it can help. If a family can convince their relative to request a copy of his/her medical records and share it with them, they will be informed of their relative's condition and treatment.

Restrictions. There are a few exceptions to this rule. An individual does *not* have the right to review or obtain psychotherapy notes, information compiled for legal proceedings, or medical records from correctional centers.[6] A health care professional can deny an individual access to their own records if they believe access could cause harm to the individual or another.[7] Also, some state laws limit the rights of mentally ill individuals to act on their own behalf.[8] In some states, a mentally ill individual may not be given free access to his/her PHI.

Disclosure to a personal representative

A personal representative is someone legally authorized to make health care decisions on behalf of another individual.[9] A personal representative can be the health power of attorney or guardian

NOTES:

1 National Alliance for the Mentally Ill. (April 8, 2001). NAMI letter to the Honorable Tommy G. Thompson regarding the final privacy rule.

2 Marshall, Tina & Solomon, Phyllis. (2003). Professionals' responsibilities in releasing information to families of adults with mental illness. *Psychiatric Services, vol. 54:12, 1626*.

3 45 C.F.R. § 160.103 (2003).

4 U.S. Department of Health and Human Services. (Visited July 28, 2004). Summary of the HIPAA Privacy Rule, at 2-3, http://www.hhs.gov/ocr/privacysummary.pdf .

5 45 C.F.R. 164.524 (2003).

6 Id.

Getting information under the constraints of HIPPA

Continued from page 12

for the person with a mental illness. Health care providers are required to treat personal representatives the same as they treat the patient.[10] This means that personal representatives are entitled to full access to the individual's medical records.

How it can help. A family member as the health power of attorney or guardian for the relative with a mental illness can access the individual's medical records and speak with the individual's doctors. State law, not the Privacy Rule, controls who can be a personal representative to make health care decisions on behalf of the individual.

Restrictions. An exception is when the treating physician suspects the personal representative of abusing or neglecting the person with a mental illness. When this occurs, the health care provider does not have to share information with the personal representative. Disclosure is also limited when a personal representative only has authority to act on behalf of the person in limited or specific health care decisions. In this situation, the personal representative only has access to the PHI that is relevant to their area of authority.[11] Also, a covered entity may refuse to share PHI with a personal representative if the person with mental illness objects to the disclosure and the disclosure is permitted but not required under the Privacy Rule.[12] Conversely, entities must make disclosures to personal representatives that are required under the Privacy Rule, even if the individual objects.[13]

Do not be intimidated when someone says "HIPPA." It does not always preclude families from getting information about a loved one's treatment.

Disclosure to a minor's parent/guardian

In most situations, parents/guardians are considered the personal representatives of their minor children (children under 18 years of age).[14] This means that parents/guardians can access medical records on behalf of their children. Even in situations where a parent/guardian does not consent to their minor child's treatment due to an emergency, a health care provider is able to discuss all health related information with the parent/guardian.

How it can help. Parents/guardians have almost complete access to their child's PHI. Not only does this section permit parents/guardians to see their children's medical records, it also authorizes doctors and health care providers to discuss the treatment of a minor with his/her parent/guardian. This can only be used while a person with mental illness is a minor. It does not authorize a child's PHI to be shared with other family members.

Restrictions. In several situations, parents/guardians are not considered personal representatives of their minor children: Where a state law does not require the consent of the parent/guardian before the minor can receive a health care service, when a court or law authorizes someone other than the parent/guardian to make treatment decisions for the minor, or where the parent/guardian agrees to a confidential relationship between the minor and treating health care provider.[15] In all these situations, the parent/guardian does not control the minor's health care decisions, or the minor's PHI.

Formal authorization

A covered entity must obtain the written permission of the person with mental illness for any use or disclosure of PHI that is not for treatment, payment, or health care operations, or otherwise authorized by the rule.[16] This written permission constitutes the authorization for disclosure. The authorization must be written in specific terms. It must state what information is to be used or disclosed, specify the person disclosing and receiving the information, specify the purpose of the disclosure, and have an expiration date.[17] The individual making the authorization must be told that he/she can revoke it at any time.[18]

How it can help. Families of persons with mental illness can get specific information about their relative if the relative is willing to give authorization.

Restrictions. Often this is not a practical choice, since the relative is not willing to give authorization. Also, since authorization under the Privacy Rule must be so specific, it does not provide a general and continuous way for family members to keep track of what is going on with their relative.

Continued on page 14

7 Id.

8 U.S. Department of Health and Human Services. Questions and answers. (last visited July 28, 2004).

9 U.S. Department of Health and Human Services, Summary of the HIPAA Privacy Rule, at 16, http://www.hhs.gov/ocr/privacysummary.pdf (last visited July 28, 2004).

10 45 C.F.R. 164.502(g) (2003).

11 OCR HIPAA Privacy Memo, Personal Representatives, Revised April 3, 2003, http://www.hhs.gov/ocr/hipaa/guidelines/personalrepresentatives.pdf.

12 Id.

13 Id.

14 Id at 3.

15 Id at 3-4.

16 45 C.F.R. 164.508 (2003).

17 Id.

18 45 C.F.R. 164.508(c) (2003).

19 45 C.F.R. 164.510(b)(2) (2003).

Understanding and navigating HIPPA

Continued from page 13

Opportunity to agree or object

There is also a less formal process for families to obtain information. A covered entity can provide family members with information if the entity obtains informal permission from the person with the severe mental illness by either asking the person outright or by circumstances that clearly give the person the opportunity to agree or object to the disclosure.[19]

How it can help. As long as the individual is present and does not object, a provider may disclose information to the family.

Restrictions. This disclosure must be made according to the professional judgment of the covered entity - in most cases, the treating physician.[20] An individual's doctor may feel it is inappropriate to disclose information to the family in front of the patient. Disclosures of this type are permitted, but not required.

DID YOU KNOW? Jails and correctional facilities are exempt from some HIPAA provisions and can obtain medical information about an inmate for many purposes, including the provision of health care to such individual. This is important if a loved one is in jail and the jail is trying to get information from a prior health care provider.

Under the concept of "minimum necessary," providers must limit unnecessary or inappropriate access to an individual's PHI.[21] But this is not an absolute standard; entities can make their own assessment of what part of the PHI is reasonably necessary for a particular purpose.[22]

Best interest of the individual

Where an individual is incapacitated, in an emergency situation, or not present, providers may make disclosures determined to be in the best interest of the individual.[23]

How it can help. It is not clear from the Privacy Rule what qualifies as an emergency. However, one source suggests that Alzheimer's disease can constitute an emergency.[24] It seems likely that if Alzheimer's disease, which affects an individual's mental function, can be considered an emergency, mental illness could also qualify as an emergency in certain situations. This means that providers can give information to family members about a relative if it is in the best interest of the individual.

Restrictions. Because this disclosure type is limited by the professional judgment of the health care provider, family members cannot depend on getting information in this way.

The role of state law

Under the federal Privacy Rule, state laws are very important. HIPAA sets a national floor for the protection of patient's rights. States can then add to these rights, and make the rules governing the use and disclosure of PHI more stringent. Only those state laws that are contrary to the federal requirements are preempted.[25]

This means that the federal law takes precedence when state laws conflict. State laws that provide greater privacy protections or privacy rights, with regards to PHI, still apply.

Twenty-nine states do not have any statutory language guiding the release of medical information to families.[26] These states are bound by the rules described in HIPAA. However, there is a trend in health care facilities to identify a contact person for a patient during registration. Only that contact person is given information on the patient.[27] This is permissible since most informal disclosures are made based on the professional judgment of the licensed health care provider.

In the remaining 21 states, it is necessary to know the individual state law. Many states have more stringent release laws, which make it illegal to release information pursuant to either the "agree or object" or the "best interest" rule.

Useful websites

http://www.cdc.gov/privacyrule/privacy-links.htm: Links to each state's HIPAA site. Each state's site lists a contact person to whom questions can be addressed.

http://www.healthprivacy.org/info-url_nocat2304/info-url_nocat_search.htm. Overview of each state's privacy law.

20 U.S. Department of Health and Human Services. Questions and answers. (last visited July 28, 2004).

21 Id.

22 Id.

23 45 C.F.R. 164.510(b)(3) (2003).

24 HIPAAcomply, HIPAA FAQ's, http://www.hipaacomply.com/privacy_faq.htm (site sponsored by Beacon Partners) (last visited July 28, 2004).

25 45 C.F.R. 160.203 (2003).

26 Marshall, Tina and Solomon, Phyllis. Professionals' Responsibilities in Releasing Information to Families of Adults with Mental Illness. Psychiatric Services, vol. 54:12, p. 1622 (2003).

27 HIPAAcomply, HIPAA FAQ's, http://www.hipaacomply.com/privacy_faq.htm (site sponsored by Beacon Partners) (last visited July 28, 2004).

AOT's real-world results

Kendra's Law families and participants laud program

Report shows sharp reductions in hospitalizations, incarcerations, homelessness

Kendra's Law, New York's 5-year-old program for court-ordered community treatment for those with severe mental illnesses, is a remarkable success. During assisted outpatient treatment (AOT), 74 percent fewer participants experienced homelessness, 77 percent fewer experienced psychiatric hospitalization, 83 percent fewer experienced arrest, and 87 percent fewer experienced incarceration. Individuals in Kendra's Law were also more likely to regularly participate in services and take prescribed medication.

Without action by the state legislature, Kendra's Law will sunset June 30, 2005. Gov. George Pataki released a bill to make Kendra's Law permanent, noting "The results are clear, Kendra's Law works."

"Without AOT, my son would either be in jail or dead. "It alone has made a difference for him by helping him to stay on his meds."

"Thanks to Governor Pataki's leadership, AOT resulted in fundamental changes to New York's overall mental health system," said Sharon Carpinello, R.N., Ph.D., Commissioner of the New York State Office of Mental Health, whose office maintains data on the law. "We have seen improved access to mental health services, improved coordination of service planning, enhanced accountability, and improved collaboration between the mental health and court systems ... Individuals with mental illness who participate in AOT are able to make and maintain real gains in their recovery - the data tells us that, and so do the recipients."

With only about 747 initial orders placing individuals under Kendra's Law each year, Kendra's Law primarily helps the most ill. A full 97 percent had at least one psychiatric hospitalization in the 3 years before their court order. When compared with a similar population of mental health service recipients, those placed in AOT were twice as likely to have been homeless, 50 percent more likely to have had contact with the criminal justice system, and 58 percent more likely to have a co-occurring mental illness and substance abuse condition.

STUNNING RESULTS FOR PARTICIPANTS**

- **74% fewer experienced homelessness**
- **77% fewer experienced psychiatric hospitalization**
- **83% fewer experienced arrest, and**
- **87% fewer experienced incarceration.**

"Without AOT, my son would either be in jail or dead," said Susan* from New York City. "It alone has made a difference for him by helping him to stay on his meds."

"We were very dubious of Kendra's Law at the beginning," said Dr. Mary Barber, associate medical director of the Ulster County Mental Health Department. "We feel differently now ... We measured hospital and jail days over a three-year period for patients prior to ... and after AOT petition. We found a reduction of over 3,500 hospital days and over 1,000 jail days with petitions. When we separated out the time before a person was placed on petition and compared the period when they received no special services to the period when they received enhanced services, there was only a slight reduction in hospital and jail days. In other words, some individuals needed a court order to be able to remain in the community."

Among the report's other major findings:

A reduced length of hospitalization Hospitalization was reduced an average 56 percent from pre-AOT levels. Even after termination of the court order, the decline continued - in the first six months after the order ended, total days were reduced 73 percent from the pre-AOT total.

A decrease in harmful behaviors that averaged 44 percent: 55 percent fewer recipients engaged in suicide attempts or physical harm to self, 49 percent fewer abused alcohol, 48 percent fewer abused drugs, 47 percent fewer physically harmed others, 46 percent fewer damaged or destroyed property, and 43 percent fewer threatened physical harm to others.

Improved compliance. Individuals exhibiting good adherence to medication increased 51 percent; those exhibiting good service engagement more than doubled.

A positive effect on the therapeutic alliance. 87 percent of participants interviewed said they were confident in their case manager's ability to help them; 88 percent said they and their case manager agreed on what is important for them to work on.

Recipients endorsed the effect on their lives. After receiving treatment, 75 percent reported AOT helped them gain control over their lives, 81 percent said AOT helped them get and stay well, and 90 percent said AOT made them more likely to keep appointments and take medication.

**not her real name, interviewed by NAMI New York. **OMH's report is available at http://www.omh.state.ny.us/omhweb/Kendra_web/finalreport/.*

News roundup

MICHIGAN: Implementation of new law begins

Effective March 30, 2005, Kevin's Law allows judges to order outpatient treatment for people with untreated severe mental illnesses who meet specific criteria, including a recent history of hospitalizations, incarcerations, or behavior dangerous to themselves or others because of their illness. The package of four bills known as Kevin's Law was championed by Sens. Tom George (R, 20th District) and Virg Bernero (D, 23rd District) and signed by Gov. Jennifer Granholm in December. The progressive measure is named for Kevin Heisinger, who was beaten to death in a Kalamazoo bus station in August 2000 by Brian Williams, a man with untreated schizophrenia. Williams' illness caused him to cycle in and out of institutions and the criminal justice system for years. He was functional when in treatment, but his condition deteriorated when he stopped medication.

This preventable tragedy spurred Sen. George, a practicing doctor and then state representative, and Sen. Bernero, a consistent champion of those afflicted by mental illness, to introduce Kevin's Law. "Kevin's Law will make our communities safer and at the same time provide compassionate, earlier care for people who seriously need it," said Sen. George. "Until today, families had to wait until their loved ones made a threat or actually hurt someone before they could get help, and then the only option was inpatient care. Now people can be helped earlier, and on an outpatient basis. If the treatment is successful, the person never needs to reach a crisis point and hospitalization may be altogether averted."

"I wish when I had been homeless and severely mentally ill … someone had mandated to me I either take medication in the community or I would have to go to a hospital. I believe I would have taken the medication and not endured the great dangers of being vulnerable and exposed on the streets."

- Valerie Fox, NJ consumer

NEW JERSEY: Task force recommends AOT

The Governor's Task Force on Mental Health has recommended adopting assisted outpatient treatment, which they call involuntary outpatient commitment (IOC). New Jersey is one of only eight states without such a law. Current law makes hospitalization the only option when a person with a severe mental illness is in crisis and refuses treatment. The proposal would allow court-ordered outpatient treatment, making New Jersey's outpatient services available to those who are too ill to seek or accept services voluntarily.

"The Task Force concluded that any comprehensive reform of a mental health system requires that the needs of the people with the most severe and persistent mental illnesses be addressed," said Task Force Chair Bob Davison. "Our careful deliberations and extensive research led us to conclude that for those who are too ill to access mental health services, IOC strikes the appropriate balance of an individual's well being and their constitutional liberties."

"There are too many people with serious mental illness whom we have not been helping, and Kevin's Law can change that. We are worried about people who are homeless and living under a bridge, who would never choose that lifestyle if their brain disorder was being treated. They merit our intervention."

- Mark Reinstein, President and CEO of the Mental Health Association in Michigan and a member of the Governor's Mental Health Commission

Acting Gov. Richard Codey and Sen. Gerald Cardinale introduced a bill last year, with the unprecedented support of 37 other Senate cosponsors, to establish a progressive AOT program for the state. Groups like the New Jersey State Association of Chiefs of Police and the New Jersey Psychiatric Association are among those who support bringing AOT to New Jersey. The Task Force recommendation paves the way for much needed reform of New Jersey's outdated civil commitment law. (Call us to get involved: 702 294 6001.)

WEST VIRGINIA: Pilot program becomes law

On May 2, 2005 Governor Manchin signed SB 191 into law, creating a pilot AOT program in four to six judicial circuits, under the direction of the Secretary of the Department of Health and Human Resources and the Supreme Court of Appeals. SB 191 also allows for the emergency hospitalization of individuals prior to a probable cause hearing – a practice common in almost all other states.

Memorials and Tributes

Our deepest appreciation to the people and organizations who sent in memorials and tributes since our last issue of *Catalyst*. We are grateful that you chose to support the Treatment Advocacy Center's mission in memory or in honor of someone very special to you. Your generous contributions allow us to continue our mission.

– The board and staff of the Treatment Advocacy Center

Nora Jill and Joan Adelman/Cummings, Glen Ellyn, IL	In honor of a courageous son and friend
Amgen Foundation, Thousand Oaks, CA	In memory of Mary J. Fazio, mother of Denise Fazio
Anonymous, Boston, MA	In honor of Terry and Nelson Goguen
Jerry and Aedene Arthur, Palmer, AK	In honor of Tara Arthur and in memory of Beth and Aaron Arthur
Agnes Atkins, Fond du Lac, WI	In memory of Mary J. Ayres
Margaret Atkins, Morgantown, WV	In honor of a sibling
Richard Avery, Denver, CO	In memory of David Teets
Larry and Mary Bacon, Grand Lake, CO	In honor of Mary Zdanowicz and Rosanna Esposito for work on Florida's Baker Act
Mary Barber, Newburgh, NY	In memory of Howard Telson, MD
Thomas and Marcia Barnes, Williamsville, NY	In honor of Gregory Barnes
Kathleen and Robert Barry/Burnett, Berkeley, CA	From the Tara Fund in Memoriam, Jack Atkinson 1969-1998
Michael Bit-Alkhas, Belleville, NJ	In honor of the mentally ill
Richard and Linda Berglund, Brooklyn Park, MN	In honor of Kris Berglund
The Bergman Family, Closter, NJ	In memory of The Lentino Family
Hollis and Marilyn Booth, Inverness, FL	In honor of Evelyn Till, volunteer extraordinaire @ NEFSH - state hospital in MacClenny, FL
Kathleen Borge, Silver Spring, MD	In honor of Kristina Borge
Walter and Mary Born, Aberdeen, NJ	In honor of Karen A. Born
Helen Brown, Gahanna, OH	In honor of E. Fuller Torrey
Robert and Evelyn Burton, Potomac, MD	In honor of Rosanna Esposito
Gerald Caprio, Verona, NJ	In honor of Mary Z.
A.J. and Jane Carlson, Westlake, OH	In memory of Christopher Carlson
James and Iva Chambers, Roanoke, VA	In honor of E. Fuller Torrey, MD
Richard Cleva, Washington, DC	In memory of Henry Cleva
Susan Cleva, Bellevue, WA	In memory of Martha Tarutis
Susan Cleva, Bellevue, WA	In memory of Henry Cleva
Susan Cleva, Bellevue, WA	In honor of Dr. Torrey and Mary Z
Susan Cleva, Bellevue, WA	In memory of Henry Cleva
Melinda Cohen, Dove Canyon, CA	In honor of my son Jordan Y. Molina
Steven and Denise Cohn, Silver Spring, MD	In memory of Harold Freedman
Carolyn Colliver, Lexington, KY	In memory of Scott Lee Helt
David, Lynda, Tag, and Lizzie, Eutaw, AL	In memory of Edmond Ray Carp
Rachel Diaz, Miami, FL	In honor of all families
Marna Dickson, Dana Point, CA	In honor of Kelly Miller
John and Janice DeLoof, Fullerton, CA	In memory of Bradley J. DeLoof
Jean Ellis, San Antonio, TX	In honor of Club House Organization
Ken and Marilyn Fischer, Sheridan, WY	In honor of Cathy M. Fischer
Alice Fitzcharles, Media, PA	In honor of TAC board of directors
Karen Frank, Albuquerque, NM	In honor of W.D. Frank
Harold and Joyce Friedman, Lake Worth, FL	In honor of Joyce H. Friedman
Anthony and Judith Gaess, Montvale, NJ	In memory of Kimberly Rose Gaess
David and Lorraine Gaulke, Crosslake, MN	In memory of Scott Hardman
William Gesch, Lilburn, GA	In memory of Patrick Coffer
Tom and Sandy Giger, St. Jacob, IL	In honor of our sons
Billie and Wilma Gilfillan, Winston-Salem, NC	In honor of E. Fuller Torrey
Sharon Gilpin, Chesapeake, VA	In honor of Deborah Gay Gilpin
Doris Goewey, Austin, TX	In memory of Chris Goewey

"Thank you for all you do. I think your organization has benefited the mentally ill more than any other organization I know."

- Katherine Porovich, Chair, NAMI-Lake County, California

"I am so proud to be a part of TAC. The work you do is invaluable."

- Judith Perlman, Illinois

Memorials and tributes

Nelson and Theresa Goguen, Ashby, MA	In honor of Dr. Torrey
Nelson and Theresa Goguen, Ashby, MA	In memory of Donna M. Laura
Jean Gotchall, Waynesburg, OH	In memory of Glenn E. Gotchall, Stark County NAMI - Canton, OH
Linda Gregory, Jacksonville, FL	In memory of Deputy Eugene Gregory
Linda Gregory, Jacksonville, FL	In honor of and with thanks to Sheriff Don Eslinger
Linda Gregory, Jacksonville, FL	In honor of and with thanks to Florida Legislators for passage of Baker Act Reform
Claire Griffin-Francell, Dunwoody, GA	In honor of Edward G. Francell Jr.
Janice Hagan, Ocala, FL	In honor of Jay A. Wilson
Custis Haynes, Nevada City, CA	In honor of Clara, Marjorie, Martha, Stacia, and Jonathan
Claire Hedgcock, Fruitland Park, FL	In memory of Martha Jean Rank
Allen Herbert, Ruston, LA	In memory of Clay Huckaby
Norb and Beth Hoffman, Green Bay, WI	In honor of Kim and Tom Hoffman
Norb and Beth Hoffman, Green Bay, WI	In honor of Tom and Kim Hoffman
Anne Hudson, Grosse Pointe, MI	In memory of Ellen Rouse
June and John Husted Travis, Lincoln, CA	In memory of Todd E. Husted
Stewart Hutt, Woodbridge, NJ	In honor of Debra Hutt
Irish Invitational, Newton Square, PA	In memory of Richard J. O'Brien Jr.
Carla Jacobs, Tustin, CA	In honor of Veda Stanley's birthday
D.J. Jaffe, New York, NY	In honor of a speedy recovery for Dr. Torrey and in memory of Charles Ballister
D.J. Jaffe, New York, NY	In memory of Howard Telson
D.J. Jaffe, New York, NY	In honor of Rosanna Esposito
Laura Hawley Jarvis, Ridge, MD	In memory of Susan Marie Dovel - died 2/25/99
Olive Jones, Atlantic Beach, FL	In memory of Wyly Jones
Merry Kelley, Hiawatha, IA	In memory of Bonnie R. Picard
David and Jean Kelly, East Providence, RI	In honor of those who suffer from mental illness.
William and Marianne Kernan, Pinehurst, NC	In honor of TAC
William and Marianne Kernan, Pinehurst, NC	In honor of those continuing to work on behalf of the seriously ill
Ted and Martha Kitada, Alta, CA	In honor of Ted Jr.
Janet Lane, Mt. Airy, MD	In honor of Nancy and Paul Merola
Anne Lange, Norfolk, NE	In honor of Thor, Tyrone, Joanna, and Theresa
Dallas and Susan Lee, Titusville, FL	In memory of Isabel Hayden
Neal and Naomi Lonky, Yorba Linda, CA	In honor of Jeffrey Hoblin
Kenneth Marcus, New Haven, CT	In memory of Albert Solnit, MD
Michael and Marcia Mathes, Orlando, FL	In memory of Eugene Gregory
Michael and Marcia Mathes, Orlando, FL	In memory of Alan Singletary
Terry McCue, Red Bank, NJ	In memory of Joan T. McCue
Paul and Nancy Merola, Austin, TX	In honor of Todd C. Merola
Cynthia Montano, Old Bridge, NJ	In honor of Elizabeth Montano
Rosemarie Moretz, Allentown, PA	In memory of M/M Stephen Moretz
Erin Moriarty, Long Beach, CA	In memory of Robert McGhee
Tex and Jane Moser, Springfield, MA	In honor of David Moser
Solomon Moshkevich, New York, NY	In honor of Dr. Torrey's dedication to the field of psychiatry and his understanding that improving the economics of treatment raises the quality of care
Keith Mundt, Riverside, CA	In memory of Winifred E. Mundt - Mom
Wesley and Rita Murray, Whittier, CA	In honor of Carla Jacobs, Randall Hagar, and Chuck Sosebee
NAMI Collin County, Plano, TX	In memory of Don Schaper
Vini and Gladys Nielson/Herreid, Seattle, WA	In honor of Natalie Johnson
Cathy O'Connor, Charlestown, MA	In memory of John B. O'Connor
Janet Olson, Versailles, KY	In memory of Sandra Olson
Alfred and Charlene Ortwein, Lewes, DE	In memory of Sharra Taylor Hurd
Marjory Osborn, Crystal Bay, NV	In honor of David Osborn
Loretta Ostmann, Silver Spring, MD	In honor of Mary Zdanowicz
Cheryl Pachinger, Newark, CA	In honor of Jeffrey Pachinger
John and Bonnie Plesko, Pontiac, IL	In honor of Kim McGraw
Katherine Porovich, Clearlake Oaks, CA	In honor of David Hoover
Jose and Eulogia Rios, Los Angeles, CA	In memory of Ronald Reagan
Norman Ritterling, Napoleon, OH	In honor of Orv, Elaine, and Scott Ritterling

"It is truly a pleasure to send [a donation] to ... your organization, in light of the real contribution you and your staff make. I'm impressed by the dedication and effectiveness."

- Richard J. Madigan, Massachusetts

"I'm very grateful for your dedication and hard work in improving the lives of people that are essentially disenfranchised and that are in need of so much help."

- Arthur J. Tobinick, California

Memorials and tributes

Catherine Rossiter, Vestal, NY	In honor of Thomas Hachett and in memory of all who have and do suffer
Marsha Ryle, Emeryville, CA	In memory of Margaret Bonnet
Glory Sandberg, Wilmington, DE	In memory of Sharra Taylor Hurd
Elise Sanford, Athens, OH	In memory of Dr. Edward R. Sanford
James and Judy Schmidt/Hutchins, Ossineke, MI	In honor of NAMI of NE Michigan
Louise Schnur, Auburn, CA	In memory of Jack Jones
Steven and Margaret Sharfstein, Baltimore, MD	In honor of Mary Z.
Hilary Silver, Stockton, CA	In honor of Aram Silver
Ingrid Silvian, Columbus, OH	In honor of Debbie Gleeson
Marge Simeone, Natick, MA	In honor of Paul Simeone
Norma Slattery, Berryville, VA	In honor of Aric Slattery
Caren Staley-Warren, Federal Way, WA	In honor of the mentally ill
Caren Staley-Warren, Federal Way, WA	In memory of Domenico Vomenici Jr.
Herbert and Anne Stiles, Blackstone, VA	In honor of TAC's persistence and success
Jesse Stinson, Birmingham, AL	In honor of Dr. E. Fuller Torrey
Al and Dorothy Supino, Ramsey, NJ	In honor of A.J. S.
Vic and Linda Taggart, Seattle, WA	In honor of Alicia Taggart
Dick and Judy Taylor, Wilmington, DE	In memory of Sharra Taylor Hurd
Rose May Thibeaux, Lafayette, LA	In memory of John Thibeaux, my husband, a dedicated mental health advocate.
Donald and Judith Turnbaugh, Palm Harbor, FL	In honor of Danny Moschelli
Joanne Varrichio, Brookhaven, NY	In memory of Florence and Edward King
Mary Wade, Princeton, WV	In honor of Kenneth R. Wade Jr.
Jeanne Walter, Sumner, WA	In memory of Jan Geary
George and Mary Weber, Tucson, AZ	In memory of Saleem Shaw
Joel and Diane Wier, Columbia, SC	In honor of Judge Amy W. McCulloch
Donald and Elisabeth Wilcox, Tempe, AZ	In honor of daughter, Debbie
Barbara Williams, Poland, OH	In honor of Robert N. Williams
Henry Winters, Seattle, WA	In honor of Mary Winters
Sarah Woelfel, Elburn, IL	In honor of Floyd Taylor
Susan Wuhrman, Bellevue, WA	In honor of NAMI - Eastside IOOV team
Pat York, Griffin, GA	In memory of Brandon Gish
Connie Yetter, Cinnaminson, NJ	In memory of Barbara Yetter
Kenneth and Donna Yocom, Brookings, SD	In honor of Dave and Doug Yocom

"We are SO grateful to TAC, its founders, supporters and staff. It is the constant ray of hope, along with medical research, that keeps family members emotionally sustained and optimistic about the future. No other organization has been so effective at improving the lives of persons suffering from mental illness."

- Alice Fitzcharles, Media, PA

"Out of the Shadow": A new film about a family's struggle

This very personal documentary chronicles the filmmaker's mother, Millie, and her family through Millie's battle with schizophrenia and her subsequent trials within the system. Millie was just 25 with two small children when she was first plagued by the symptoms of schizophrenia. As mental chaos overwhelmed their mother, Susan and her sister Tina struggled to cope with her. For years, the family's ignorance and shame kept Millie's behavior shrouded in a veil of secrecy. Now, after 20 years of transience and inadequate care, Millie finally has a chance to reclaim her life.

A story of madness and dignity, shame and love, this intimate film illuminates a national plight through a family's struggle and helps dispel stigmas and misconceptions surrounding this illness.

How to get the film: "Out of the Shadow" has been playing at festivals worldwide and is scheduled to air on PBS stations beginning February 2006. Find out about educational guides and get purchasing information online at www.outoftheshadow.com or via phone at 310 636 0116. Distributed through Vine Street Pictures.

Catalyst

Treatment Advocacy Center

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"Until we find the causes and definitive treatments for schizophrenia and bipolar disorder, we have an obligation to those who are suffering to try to improve their lives. Except for biological chance, any one of us might today be there, living on the streets or in jail. TAC is the only organization willing to take on this fight, and I am very proud to be part of it."

- E. Fuller Torrey, M.D.

Why support the Treatment Advocacy Center? We get results. Since TAC opened its doors in 1998, treatment laws in 17 states have been improved. Today, we continue the fight toward sustained and effective treatment for individuals touched by severe mental illnesses. In doing so, we are constantly connecting experts, the media, and legislators, serving as the hub for ideas on the policies and practices that are working - and the ones that are not.

Most importantly, you can trust that what we say reflects the best interest of our community, because unlike many advocacy groups, TAC does not accept funding from pharmaceutical companies or entities involved in the sale, marketing, or distribution of such products. This also means, however, that our success hinges on support from generous donors like you. Every donation, large or small, makes a difference.

I want to help the Treatment Advocacy Center with a gift of $ _____

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Thank you for your generous support.

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The Treatment Advocacy Center is a nonprofit 501(c)(3) organization. Gifts are tax-deductible to the extent allowed by law. TAC does not accept funding from pharmaceutical companies.

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