

ELIMINATING BARRIERS

Tips for Advocates on Busting Through

It is extremely frustrating when you're trying to help someone and the system is unresponsive. Here are some tips for getting action from a slow-moving or unresponsive bureaucracy.

OBSTACLE: Unresponsive system SOLUTION? Be tenacious.

Be an advocate first, a friend second. Building relationships with service providers and letting them see how much you care about your loved one is vital to advocating and demonstrates your value as part of the treatment team. But don't get too cozy. It is more important to be an advocate than to be friends. Sometimes, cooperation is not possible. Feel free to disagree and to be respectfully assertive.

Document document document! Keep a record of all communications. Log the date and time of each attempted contact and the name and role of any individual you reach - whether by telephone, email, fax, mail. Take notes during your conversations and keep them with the log. Print out any correspondence and keep it with the log, too.

Go over heads to decision makers who can help. Jails, hospitals, treatment facilities – each has an established chain of command. Regardless of which system your loved one is in, ask questions until you know the chain of command and who occupies each link. Then work your way up until you get results. Write the agency's board members, trustees or directors – whoever has ultimate oversight – a short letter documenting the problems and lack of responsiveness. If you're dealing with a public agency, work your way up to state governor if you don't get results.

Use delivery systems that make a statement. When writing, use overnight delivery, a registered letter, or another out-of-the-ordinary means of delivery. Set your message apart from others.

Hire an expert. If you can afford one, an expert can be a huge help. Different situations call for different experts. A health care provider may be more responsive to an attorney than to a family member. Getting help in a jail or correctional facility can be easier with the assistance of a correctional expert.

Involve law enforcement in your personal advocacy. 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. Explain that getting treatment for your loved one is in everyone's best interest and could help avert a tragedy. A call from a sheriff or police chief can be very influential in prioritizing services for someone you care about.

OBSTACLE: No services for your loved one SOLUTION? Look into new places.

Get the media interested. If your situation is particularly egregious, heart-wrenching or representative of a systematic problem, your local media outlet might do a story. Find contact information on the outlet's website, identify a reporter who covers your community or who has reported on mental illness or crime issues before, then call or email. Many news organizations have online "Submit an idea" areas on their websites, often under "Contact us." Summarize your story in one sentence and keep your comments focused on one issue (e.g., treatment, criminalization, etc.). It may help to think of the headline that best states your theme (e.g., "Man jailed for tenth time in five years because the law can't help him: Mother demands answers") and phrase your comments with that in mind.

Know what services are available in your community. Your local NAMI affiliate is a good place to start, but specialized services are often a well-kept secret. Don't stop with NAMI. Contact your state or local mental health administrator. Research what is funded by the



state budget in your local area. Visit the mental health center or local mental health service providers and request a tour. Don't accept the first answer you get.

Document the costs of not providing services. Because people with the most severe mental illnesses often require intensive treatment that is expensive, providers may try to avoid providing outpatient services in order to save money. One way to counteract this tactic is to show what it costs *not* to provide those services. For example, multiply the cost per day of hospitalization by the total number of days your loved one has been hospitalized over a period of time. A state or county mental health administrator may be persuaded by the argument that providing the needed community services will be less expensive in the long run.

**OBSTACLE: Confidentiality issues
SOLUTION? Understand the law.**

Sometimes concerns about breaching confidentiality laws are raised by treatment providers as a reason not to talk to a third party. Here are some important things to remember about confidentiality.

Providers can listen even if they can't talk. When you reach a provider who needs information, start by saying, "I know you can't give me information, but you can hear the information I have" before they have a chance to tell you they can't talk to you.

Don't be intimidated when someone says "HIPAA." HIPAA stands for the "Health Insurance Portability and Accountability Act of 1996" and is designed to create a national standard for certain types of health care information. HIPAA is often used as an excuse to withhold health information, but it does *not* absolutely preclude families from obtaining medical information.

- A patient has a right to request copies of their medical records. At a time when your loved one is not in crisis, encourage them to request their own records and give them to you for safekeeping. Copies of past treatment records can be invaluable if a future crisis occurs.
- If you have a power of attorney or guardianship, you are considered a personal representative and are entitled to full access to the

patient's medical records. You will have to show your authorization papers so keep a copy handy.

- Health care providers cannot withhold information if the patient has authorized release of it. If possible, have your loved one sign a release to have on file with your local hospital in case of emergency. If hospitalization occurs without a release on file, ask your loved one to sign a release.

If a provider withholds information from you because there's no release, insist that they at least ask your loved one if they are willing to sign an authorization.

- Even if no release has been signed, the provider can discuss treatment if the patient is present for the discussion and has an opportunity to "agree to object" to the disclosure. This discussion can take place by telephone as well as in person. Request to speak to the provider with your loved one present.
- There is also a "best interest" rule that applies when a patient is incapacitated, in an emergency situation, or not available. In those cases, a provider may disclose information determined to be in the "best interest" of the individual. Argue that it is in your loved one's "best interest" for the provider to talk to you.
- 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. The jail can sometimes get medical information you cannot. Insist that they do.

At least 21 states have their own laws governing confidentiality. To learn about your state's law, consult web sites like

www.cdc.gov/privacyrule/privacy-links.htm

OR

www.healthprivacy.org/info-url_nocat2304/info-url_nocat_search.htm

