Mental Health America

Psychiatric Advance Directives
Issue Summary

OVERVIEW

Through advocacy efforts over the past 30 years, laws about the care and treatment of people with mental illness have improved and have increasingly recognized the value and expertise of the person who is receiving the services in determining what works best. Unfortunately, during those times in which a person is determined to be unable to make decisions or to provide informed consent, judges, family members, friends and providers must frequently make decisions for the person in crisis.

In addition, providers or judges often make those decisions without knowledge of the individual's past experiences or treatment preferences. Even when their preferences are known, consumers of mental health services have often found that their treatment requests are disregarded during a psychiatric crisis, and that the treatments or interventions imposed upon them are not helpful and even harmful.

Unfortunately, many mental health systems in the United States are under-funded, fragmented, and often coercive. People seeking help frequently cannot obtain services in a timely manner or are only offered choices that fail to meet their needs. With their needs unmet, many people experience psychiatric crises. Some advocates believe that an expansion of forced treatment is the answer to these problems; others advocate that underutilized alternatives, such as psychiatric advance directives, can help to prevent or mitigate these kinds of crisis situations. It should be noted, however, that even the best pre-crisis planning and psychiatric advance directives cannot compensate for an overall shortage of voluntary community-based services and options.

There are a number of complex overarching issues relating to the creation and implementation of psychiatric advance directives. Understanding these issues can provide significant benefits to individuals with mental health needs, their families and the treatment system. This document provides background information on psychiatric advance directives, outlines the major issues surrounding their use, and offers suggestions for strategies and additional resources that advocates can use to implement successful psychiatric advance directives programs in their local communities.

This document is not intended to offer legal advice. State laws on this matter vary greatly, making it difficult to make broad generalizations. Therefore, it is crucial that stakeholders gain a working knowledge of their existing state laws on this topic. The purpose of this document is to educate advocates, consumers, family members, providers

and policymakers about advance directives and to suggest that they be considered as a viable option to promote individual autonomy, enhance communication, protect individuals from unwanted or harmful treatment, and to help in preventing crises.

BENEFITS OF ADVANCE DIRECTIVES

Advance directives are legal documents that tell others what an individual's treatment preferences or service needs are. They are *directions* for others to follow, that are made in *advance* of an illness or injury.

Advance directives can exist in both the physical health and mental health contexts. The majority of states with advance directive statutes expressly or by implication apply them to mental health. Some states have passed specific psychiatric advance directive laws.

Psychiatric advance directives offer several benefits. Correctly implemented and executed, they can:

- Promote individual autonomy and empowerment in the recovery from mental illness;
- Enhance communication between individuals and their families, friends, healthcare providers and other professionals;
- Protect individuals from receiving ineffective, unwanted, or possibly harmful treatment; and
- Help in preventing crises and the resulting use of involuntary treatment or safety interventions such as restraint or seclusion.

In addition, treatment preferences and instructions contained within a psychiatric advance directive can be very useful information for a provider or other professional at times other than during an acute psychiatric crisis.

TYPES OF ADVANCE DIRECTIVES

There are two basic types of advance directives:

1. **Instruction Directive –** a written document that describes what treatments and services an individual does or does not want, if and when he or she has been determined unable to make his or her own decisions.

   Specific aspects of treatment or services for which a person may wish to express preferences include, but are not limited to:

   - Options that help to avoid or minimize hospitalization;
   - Activities that are comforting and helpful in reducing distress;
   - People who should be contacted during a time of crisis;
   - Activities or situations that may exacerbate symptoms;
   - Medications (and dosages) that are acceptable or not acceptable;

- Effective alternatives to and/or preferences regarding the use of restraint or seclusion as safety interventions; and
- Other medical interventions that might be considered during a time of severe crisis (e.g., electroconvulsive therapy, commonly known as ECT or "shock treatments").

State laws vary, but generally, as long as the individual's expressed wishes are not inconsistent with accepted medical practice, physicians and other professionals are expected to comply with the instructions of an advance directive.

2. **Agent-Driven Directive –** a written document that designates a surrogate decision-maker when an individual's authority to make his or her decisions has been suspended. The selected person is called an "agent." This type of advance directive may also be called a durable power of attorney, proxy or attorney-in-fact.

   The agent-driven directive allows an individual to determine whom they want to advocate for their stated interests. In selecting the agent to carry out the advance directive, the individual should take the following into consideration:

   - Does the person understand the role and responsibilities of being an agent?
   - Is that person able and willing to serve as the individual's representative during times of crisis?
   - Does the person understand how to navigate the mental health system?

   Agent responsibilities include being familiar with the individual's expressed wishes and working to ensure that the instructions expressed in the advance directive are followed. If the individual's wishes about a particular treatment have not been expressed, it is up to the agent to use a *substituted judgment* standard to estimate what the individual would have wanted if they currently had the capacity to make their own healthcare decisions. (Note: Some states may require agents to apply a *best interest* standard, in which the agent is expected to make decisions he or she thinks will best benefit the individual's needs.) Similar to following an individual's expressed wishes, the provider should also comply with the agent's interpretation of them.

Instruction directives and agent-driven directives may be two distinct documents, or they may also be combined into a single form. Variations in state laws may require that a particular format or language be used for the written document, that it may be required to be witnessed by one or more persons, or that it be signed in the presence of a notary public.

CONSUMER/SURVIVOR SUPPORT OF PSYCHIATRIC ADVANCE DIRECTIVES

The use of psychiatric advance directives has generated widespread support from consumers of mental health services and persons who identify themselves as survivors of psychiatry. In August 1999, the Force and Coercion platform plank of the first National Summit of Mental Health Consumers and Survivors developed its first consensus statement on psychiatric advance directives. The background paper framed the discussion on advance directives in this way:

> "...The movement is supportive of advance directives, which are a way to specify, in advance in writing, how people want to be treated if illness, including mental disability, makes them incapable, or deemed to be incapable, of making choices. ...Some people are concerned that advance directives can be misused as a way of decreasing a person's choice if they are entered into under coercive circumstances, if the wrong person is an agent for treatment decisions, or if the 'living will' is difficult to change. Therefore, it is important to make sure that safeguards are in place so that this is an individual's free and informed choice."

Follow-up dialogue sessions were held at the national *Alternatives* conference in August 2001, and a consensus statement is in the process of being developed. In general, there is cautious optimism that the use of psychiatric advance directives will be beneficial. Concerns continue to be raised about provider non-compliance and enforceability, the issue of revocability, and the potential for misuse and coercion. The dialogue sessions also identified the need for more education and training as well as a national committee/clearinghouse to track what is happening around the country. The final report of the Force and Coercion platform plank is pending, and contact information is included in the Additional Resources section.

VARIATIONS IN STATE LAW

As of 2002, every state in the United States has a statute allowing advance directives for general medical purposes, but these laws vary widely in how they have been written and implemented. States may choose to only allow instruction or agent-driven directives, may limit the advance directives to situations in which persons have a terminal illness, or may limit the duration of the advance directive. A small number of states specifically exclude mental health from their advance directives statutes, which can make it difficult, if not impossible, for people to create psychiatric advance directives.

During the last few years, a number of states have passed legislation specific to psychiatric advance directives because it was felt that the existing law did not address the specific treatment needs of people with mental illness. For example, in 2001, the Maryland legislature passed an advance directives bill that requires residential facilities to inform residents about advance directives and to help them develop these documents, if the individual so wishes. Similar legislation has been used to require training on advance directives for state employees. Supporters of advance directives differ on which

is the best approach to take — amending already existing advance directive law, or passing a new statute. Stakeholders must determine which strategy is best for them when they consider the scope of current law and the tenor of their state legislature.

Again, state statutes may vary, but in general a psychiatric advance directive, especially the assignment of an agent, officially goes into effect when a determination has been made that an individual lacks the capacity or competence to make decisions regarding treatment or services.

The terms "capacity" and "competence" are often used interchangeably, but generally "capacity" is a medical term representing a determination by one or more physicians, and "competence" is a legal term representing the findings of a court of law. Some state statutes vary with regard to the determination of a person's ability or inability to direct their own care, but usually a person is considered capable and competent unless a finding of incapacity or incompetence has been made.

The determination of capacity and/or competence is not necessary for the information on the instructional advance directive to be useful to a healthcare provider. Many inpatient psychiatric facilities are now conducting admissions assessments to better understand the individualized support and treatment needs of their clients.

REVOCABILITY – THE "ULYSSES CLAUSE"*

In most states, a document such as a will, "living will," or advance directive can be revoked by the person who wrote it whenever he or she so wishes. However, a person in crisis might want to revoke the same instructions in a psychiatric advance directive he or she wanted to apply during a psychiatric emergency.

Some individuals and organizations believe that a psychiatric advance directive is of little or no utility if it is not irrevocable. Furthermore, an increasing number of state laws require a determination of capacity to revoke an advance directive. However, the "worst-case" scenario of an individual revoking a psychiatric advance directive during a crisis is that the individual loses the benefits of the advance directive, which is no different than what currently exists for a person who has not crafted one.

An absolute prohibition on an individual's right to revoke a psychiatric advance directive would be cause for many people to avoid signing this type of legal document. The

* The language crafted into a psychiatric advance directive that would make it irrevocable is sometimes referred to as the "Ulysses clause." In Homer's *Iliad*, seafaring mariners knew of the *Isole li Galli* in the Gulf of Sorrento where female Sirens sang with voices so seductive that no captain could resist steering towards them and crashing onto the rocks. However, Ulysses very much wanted to hear the voice of the Sirens, and he devised a plan to do so without jeopardizing the safety of his ship. He instructed his crew to plug their ears with beeswax and to follow a course he charted for them, a course that would take them near enough to the Sirens so he could hear them but not so close as to cause the ship's demise. He further ordered his crew to lash him to the mast and not to obey him until they reached a location out of range of the Sirens' voices.

limited availability and adequacy of training for individuals to serve as agents is another concern that complicates the concept of irrevocable psychiatric advance directives because not everyone has someone they completely trust, or who is sufficiently skilled at advocacy, to be their agent.

In order to promote the adoption and implementation of what has yet to become a widely used legal tool, many advocates believe the optimal middle ground is for each individual to retain the right to choose, in advance, whether or not his or her psychiatric advance directive can be revoked in the middle of a crisis. Another option some may wish to consider is for portions of the advance directive, such as the assignment of the agent, to be revocable without causing the revocation of the entire document.

POTENTIAL PROBLEMS AND LEGAL REMEDIES

As advocates work to increase the number of people utilizing advance directives, the major question confronting proponents is how to make it a viable instrument of protection and empowerment. Provider non-compliance is seen as a major barrier to the promotion and effectiveness of psychiatric advance directives. Medical professionals may see advance directives as an erosion of their decision-making authority, or, at a minimum, yet another bureaucratic step in the process of delivering services. Personal experiences and stories shared by consumers/survivors serve to highlight the significant problems encountered thus far when trying to ensure that providers comply with advance directives.

Currently, there are few legal requirements for providers to comply with an individual's advance directive; however, court decisions appear to favor recognition of the individual's expressed wishes and the authority of the agent. Additional litigation may be needed to ensure provider compliance with psychiatric advance directives until such practice becomes commonplace.

Although most of the advance directives statutes are not specific to mental health, case law suggests they are applicable unless stated otherwise. Important case decisions include, but are not limited to:

- *In re: Peter*, 529 A.2d 419 (NJ 1987), the court determined that a durable power of attorney for healthcare decisions should be honored even if New Jersey statute does not specifically authorize such powers.

- *In re: A.C.*, 573 A.2d 1235, 1250 (DC 1990), the court should give the most weight to a person's written or oral directives in order to protect a patient's right to choose his or her own treatment.

- *Matter of Rosa M.*, 155 Misc. 2d 103, 597 N.Y.S. 2d 544 (Supreme Court 1991), the court refused to order ECT for an incompetent woman with a previously written statement refusing treatment, even though the statement does not comply with statutory standards.

- *In re: Next Friend of R.R. v. State of Vermont et al.*, (VT 1999), the agent of an individual deemed to lack capacity was barred from participating in the duties granted to her through the individual's Durable Power of Attorney for Health Care. This case was settled with a judgment forcing the state to allow her to act in her friend's behalf.

- *Hargrave v. State of Vermont,* No. 2:99-CV-128 (D. VT 2001), involved a Vermont law that allowed doctors to go to court to nullify mental health provisions in a durable power of attorney/advance directive if the treatment choices made by the agent do not result in improvement of the declarant's condition. In October 2001, a federal Magistrate Judge ruled that this provision is discriminatory and violates the Americans with Disabilities Act.

SUCCESSFUL PROMOTION OF PSYCHIATRIC ADVANCE DIRECTIVES

Advocates have a number of options to promote the adoption and use of psychiatric advance directives. These options include but are not limited to:

- **Develop and Distribute Educational Training Material**. Mental Health Associations (MHAs) and other organizations can educate consumers of mental health services, providers, family members and legal professionals about the existence and value of psychiatric advance directives. States may need to offer special training for consumers, providers, agents and potential agents, family members and court officials about the usefulness of advance directives. In addition, individuals who create their own advance directives need to understand the importance of assuring that up-to-date copies are in the possession of those individuals (e.g., family members, friends, and providers) who will become involved if a crisis arises.

- **Facilitate Community Dialogues**. Interested parties will learn by coming together to discuss and better understand how psychiatric advance directives can help to prevent or shorten crisis situations. The Center for Mental Health Services (CMHS) offers free guides specifically on organizing interactive discussions on mental health issues among consumers, providers and family members.

- **Coordinate Legal and Legislative Work with Other Agencies**. As stated earlier, the implementation of advance directives is often subject to differing state laws. Some states have passed laws that impede an individual's ability to use advance directives for mental health purposes. An opportunity exists for advocates to foster collaboration with federally-funded state protection and advocacy (P&A) agencies and legal aid organizations that are well-versed in the laws of their respective states. Organizations seeking to promote advance directives can partner with P&As to benefit from their expertise in the law as well as to tap into the funding they receive to advocate on behalf of people with disabilities. State P&A systems also have the statutory authority to

protect and advocate for clients in inpatient settings. Therefore, they have a vested interest in the promotion and use of advance directives.

- **Seek Funding for Pilot Programs**. Resources are needed to conduct trainings and promote the implementation of psychiatric advance directives. Both public and private funding can be used to support psychiatric advance directives programs. Legislators, public health agencies and private foundations can be sources of funding for programs such as these.

- **Explore the Establishment of Registries of Advance Directives**. Although confidentiality issues may be a concern and some individuals may not wish to participate, many individuals feel that centralized registries of psychiatric advance directives can provide the benefit of coordinating services among a variety of provider agencies.

- **Promote Research into Best Practices**. Despite their potential for reducing crisis situations and hospital stays, outcomes data on the implementation and benefits of psychiatric advance directives remains sparse. As the number of individuals who have psychiatric advance directives increases, information pertaining to the use of advance directives will increase our knowledge and understanding of the best practices regarding the implementation of advance directives and will provide a basis for expanding funding for these instruments.

CONCLUSION

Psychiatric advance directives offer an approach to personal empowerment and crisis prevention that has not been widely used. Although psychiatric advance directives cannot solve the basic problems of mental health systems that are under-funded, fragmented, and often coercive, they do offer an opportunity for consumers of mental health services to express their preferences for treatment and services during psychiatric crises. The successful use of psychiatric advance directives will require the intentional participation of consumers of mental health services, family members, healthcare providers and other professionals. Such collaboration can be facilitated through community dialogues, training and public education. Effectively implemented, psychiatric advance directives offer many benefits for persons diagnosed with mental illnesses, their friends and families, and the healthcare, social service and legal professions that serve them.

ADDITIONAL RESOURCES

- **Mental Health America (MHA)** – MHA has developed a website of resources for organizations and individuals to use in promoting the successful implementation of psychiatric advance directives in their local communities. Please visit www.myplanmylife.com.

- **National Resource Center on Psychiatric Advance Directives**-This site offers practical advice for consumers and professionals, relevant research, and state-specific laws and forms for psychiatric advanced directives. Visit www.nrc-pad.org.

- **National Mental Health Consumers' Self-Help Clearinghouse** – For more information about the consensus statement on psychiatric advance directives developed at the 1999 National Summit of Mental Health Consumers and Survivors, and the follow-up dialogue session at *Alternatives 2001*, see www.mhselfhelp.org//rforce.html or call the Clearinghouse at 800-553-4539.

- **Judge David L. Bazelon Center for Mental Health Law** – The Bazelon Center has developed an online Psychiatric Advance Directive that is extremely comprehensive but not state-specific. Contact: www.bazelon.org/advdir.html, or 202-467-5730.

- **National Disability and Rights Network** – Many state protection and advocacy (P&A) programs are in the process of developing advance directives training initiatives. NDRN maintains a listing of all the federally-funded P&A programs across the country at www.protectionandadvocacy.com. Their phone number in Washington, DC is 202-408-9514.

- ***Participatory Dialogues: A Guide to Organizing Interactive Discussions on Mental Health Issues among Consumers, Providers, and Family Members*** – U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, Publication SMA 00-3472, available through the Knowledge Exchange Network at 800-789-2647 or www.mentalhealth.org.

- **Mental Health America in Hawaii –** Through a three-year grant award from the Hawaii Community Foundation, MHA in Hawaii engaged and collaborated with consumers, mental health professionals and service providers, and legal experts to develop ways to facilitate the refinement and use of psychiatric advance directives in Hawaii. Their ultimate goal is to pass psychiatric advance directives legislation in Hawaii and implement it effectively throughout the state. Contact: Paula Heim, MHA in Hawaii, 808-521-1846, info@mentalhealth-hi.org.

- **Advance Directive Training Project** – Over 15,000 advance directives have been completed in this consumer-directed program in New York State. The program uses a very "user-friendly" booklet format. Contact: Resource Center, Inc., Albany NY, 518-463-9242, www.peer-resource.org.

- **Wellness Recovery Action Program (WRAP)** – Although not a formal legal advance directive instrument, the pre-crisis planning steps outlined in the WRAP program can lead to the development of a legal advance directive.

Contact: Mary Ellen Copeland, West Dummerston, VT, 802-254-2092, www.mentalhealthrecovery.org.