

Lessons and Recommendations

What can people interested in psychiatric advance directives learn from the investigations in Nebraska, North Carolina, New York and Washington D.C. and from our interviews and surveys of consumers, advocates and providers? This section summarizes the salient points for consumers, mental health advocates and state policymakers from this project and offers recommendations for promoting the use of PADs.

LESSONS FOR CONSUMERS WHO WANT TO USE PSYCHIATRIC ADVANCE DIRECTIVES

- Know your rights to informed consent to treatment, involuntary commitment, involuntary treatment.
- Seek help from peers and/or legal resources.
- Understand the consequences of decisions you may make in an advance directive.
- Know your responsibilities regarding advance directives; protect your document and distribute copies to key people.
- Know how to gather information. You need access to mental health providers and physical health care providers, too.
- Give serious consideration to appointing a proxy (in addition to or instead of advance instructions). Providers, especially physicians, may be less inclined to challenge decisions by a surrogate.
- Be careful what you wish for. Legislation or rules that distinguish advance directives for mental health care and advance directives for other types of health care must be reviewed carefully because you may end up with fewer rights

LESSONS FOR ADVOCATES

- ❑ Push for peer resources.
- ❑ Insist on an adequately funded training program for consumers, providers and agents (or potential agents).
- ❑ Advocate for a system to ensure that providers know when someone has executed a psychiatric advance directive.
- ❑ Make sure that the stakeholder expectations for advance directives are consistent with what a psychiatric advance directive can accomplish in the applicable jurisdiction.
- ❑ Recognize the opportunities for broad coalitions to support advance directives and push for inclusion of consumer, provider, family and other potential advocates. When possible, work together to educate rather than antagonize.
- ❑ Push for a system to gather data on the use of advance directives and on the effectiveness of training, and press for a consumer role on the evaluation team.

LESSONS FOR MENTAL HEALTH POLICYMAKERS

- ❑ Support consumers in creating advance directives and ensure that providers understand and respect them.
- ❑ Comply with legal obligations for informing consumers about their rights to develop advance directives—for mental health care decisions and other health care decisions.
- ❑ Understand the legal effect of an advance directive, including the legal obligations when emergency treatment interventions are implicated.
- ❑ Utilize advance directives as one component of an overall effort to strengthen consumer protections and improve clinical practice throughout the mental health system.
- ❑ Track the use of advance directives and use the information in program planning and quality improvement activities.
- ❑ Ensure that planning answers these questions:
 - ✓ Are consumers involved in all aspects of the program to promote advance directives?
 - ✓ Who can train consumers and providers and agents about how advance directives work?
 - ✓ How can we ensure that the right people know a consumer has an advance directive when it is needed, given that consumers move around systems so much, and providers may change?
 - ✓ How can consumers access support by peers or other advocates? How can they access legal assistance, if needed?
 - ✓ How will the system monitor the use of advance directives, evaluate training programs, etc.?

LESSONS FOR STATE LAWMAKERS

- ❑ Do not assume that an advance directives statute with a specific focus on mental health care decisionmaking is a necessary or preferred way to promote consumer self-determination through the use of psychiatric advance directives.
- ❑ Understand how such legislation may create confusion, restrict rights and even amount to illegal discrimination against individuals with mental illnesses.
- ❑ Apply the guiding principle that psychiatric advance directives should operate exactly the same way as any other advance directive.
- ❑ Make sure that nothing in an advance directive law will reduce the rights of individuals who are involuntarily committed.
- ❑ Understand what advance directives can and cannot do for consumers in your state.
- ❑ When the goal is to support and encourage consumers' use of psychiatric advance directives, ensure that consumers will be integrally involved in the development of legislative language, sample instruments, promotion plans and training materials. Ensure that what is developed will be relevant for their experiences and easy to use and understand.
- ❑ Be wary of wholesale adoption of another state's statutory scheme.
- ❑ Support a commitment of funding for the development and dissemination of materials about advance directives and education of consumers, their advocates and supporters, service providers and stakeholders in mental health delivery in the state.
- ❑ Support a commitment of funding for an evaluation plan that includes consumers and community members, to determine how advance directives are being used and respected.

The three-year project was funded by the Ittleson Foundation and directed by Bazelon Center staff attorney Ellen Harris. Funding for the production of this report and its distribution nationwide to public mental health systems, consumers and families, state protection and advocacy systems and other mental health advocates comes from the Targeted Technical Assistance Project of the National Association of State Mental Health Program Directors (NASMHPD) and the Division of State and Community Systems Development (Mental Health Block Grant) of the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. Additional funds for the project came from the general support provided to the Bazelon Center by the John D. and Catherine T. MacArthur Foundation, the Evenor Armington Fund and the Public Welfare Foundation.

