Introduction and Summary

In December 1998, the Bazelon Center for Mental Health Law launched a three-year project[1] to explore the legal enforceability of advance directives for psychiatric care and promote their use as a tool to assist consumers of mental health care in making choices prior to a mental health crisis. The Bazelon Center had already developed a model form for creating such an advance directive and had published it on the Center's website.[2] Through this project, Bazelon focused on several jurisdictions across the country to assess the utility of advance directives generally and our tool in particular.

We approached the project with questions:

- Are mental health consumers interested in advance directives?
- Could advance directives empower consumers and help them realize more self-determination in their mental health care?
- How might the existence of an advance directive affect the therapeutic relationship between a mental health consumer and treatment providers?
- Could the use of advance directives help consumers avoid, or obviate the need for, forced treatment or involuntary commitment?
- What legal issues regarding psychiatric advance directives are being raised and litigated?[3]
- Assuming that psychiatric advance directives are valuable tools for consumers, what is the best way to implement a program to promote their use and ensure that they are honored?

At the outset, the Bazelon Center began tracking efforts to enact state laws on advance directives for psychiatric care (PADs). In 1998, nine states had special statutes covering PADs with varying degrees of specificity. At the end of our review, at least 14 states had such laws, and more were considering them.[4] We focused on four states—New York, North Carolina, Nebraska and the District of Columbia—of which only one, North Carolina, has such a specialized law.[1]

During the project's first year, Bazelon convened consumer/survivor groups to survey their opinions about and their experiences with PADs. J. Rock Johnson, a lawyer and experienced consumer activist, worked with the Bazelon Center on this and other aspects of the project.[5]

An advance directive is a written document, made pursuant to legal requirements defined by state law, in which an individual specifies in advance choices about health care treatment in the event that he or she becomes incapable of exercising or communicating such treatment choices in the future.

In year two, we set out to explore what mental health providers know about psychiatric advance directives and gather their opinions about clinical, ethical, legal and practical issues presented by consumers' use of these tools.[6]

Throughout the study, we had many discussions with legal and other advocates with experience promoting the use of PADs in different jurisdictions. Our recommendations for advance directives and for implementation and promotion strategies that will best serve consumers are informed by all these aspects of our exploration.

SUMMARY OF FINDINGS

> *It was really a good, self-empowering thing for me to be able to at least know that my thoughts, my coherent thoughts were gathered and collected and somebody might read them and understand me a little bit better before they would try to diagnose me or say what my problem is. That's all.*

At the project's end, we continue to see great promise for enhancing consumer self-determination through the use of psychiatric advance directives (PADs). These instruments can never remove all the uncertainties—or potential terrors—of mental health crisis. Advance planning, however, may help many consumers avoid traumatic experiences and potential disputes about hospitalization or other interventions and may lead to more palatable, respectful and effective options.

Nebraska, New York, North Carolina and the District of Columbia presented significant differences in knowledge about, stakeholder interest in, and political and legal support for PADs. The four states' laws on advance decisionmaking in the mental health context varied considerably.

We concluded that consumers' use of advance directives can—and should—complement and enrich the clinical process and strengthen treatment relationships between consumers and providers. The process of learning about the right to advance decisionmaking, gathering information, making treatment decisions, choosing an agent and executing a legal document—and all the other steps a consumer must take to create an advance directive—can be empowering to a consumer.

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To realize the potential of advance directives, everyone who plays a significant role in the process, including the consumer, providers and potential agents, needs education about the many rights, obligations and responsibilities that are triggered by advance directives. Consumers expressed interest in using PADs but had many questions about them. Providers appear more supportive of PADs if they understand and embrace both the *legal* nature of these documents and *clinical aspects* of advance planning. Accordingly, we make recommendations for

promoting the use of advance directives with education, training and peer resources (see “Lessons and Recommendations”). We believe there is potential for strong returns from such investments, in the more efficient and effective use of clinical resources, the avoidance of some treatment disputes, and stronger therapeutic partnerships.

Across the country, we saw a trend in enactment of special legislation for PADs, apart from the advance directives laws that each state has for other health care decisions. At first glance, this appears promising for consumers, as generating more attention to the issue and support for psychiatric advance directives. Yet our review suggests that caution is in order. A consumer’s advance decisions about mental health treatment should not be *less enforceable* than a consumer’s advance decisions about other health care. We urge as the guiding principle for state law and policy that psychiatric advance directives operate in exactly the same way as any other advance directive, subject, if at all, only to narrowly drawn and legitimate emergency situations.

As for what will, in the end, be legally enforceable in an advance directive for mental health, the courts have spoken on only a few legal issues. One federal court has held that the right to refuse treatment in a non-emergency situation cannot be trumped by the state, and that limiting the legal effect of a psychiatric advance directive, as compared to a general advance directive, violates the Americans with Disabilities Act.[7] Mental health advocates will continue to track this area.

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NOTES

1 Application of the following criteria informed our choice of states:

- ◆ the development of the law regarding PADs in the state;
- ◆ the extent of work done by consumer advocates in the state and their successes and failures;
- ◆ the extent of continuing advocacy resources dedicated to PADs and allocation of these resources to facilitate collaboration with Bazelon Center efforts and avoid duplication of effort;
- ◆ past and existing collaborations among the various stakeholders regarding PADs; and
- ◆ political receptivity in the state to the use of PADs.

2 The Bazelon Center template and instructions for its use can be found at http://www.bazelon.org/advdir.html.

3 When we first contemplated the project, we assumed that tracking litigation in this area — and possibly co-counseling some cases — would be a primary focus. But we found that the movement to utilize advance directives for psychiatric care was not generating much litigation. While there are a few important cases and decisions, which we discuss in this document, litigation was, in the end, a secondary aspect of the project.

4 States that have advance directives laws that apply specifically and only to mental health decisions, include: Alaska, Hawaii, Idaho, Illinois, Maine, Minnesota, North Carolina, Oklahoma, Oregon, South Dakota, Texas, Utah and Wyoming.

5 Among the strengths J. Rock brought to the project were her experience of serving on the boards of directors of NAMI and of Nebraska Advocacy Services (the Nebraska protection and advocacy system) and extensive experience working to promote psychiatric advance directives in a number of national consumer organizations in which she is active.

6 Our study and survey of consumer and provider views was not conducted in a scientific manner. Other researchers have and are reviewing this subject. See, e.g., Srebnik, Debra S. and LaFond, J.Q., "Advance Directives for Mental Health Treatment," 50 *Psychiatric Services* 919 (1999) (surveying information and suggesting future research.).

7 *Hargrave v. State of Vermont*, No. 2:99-CV-128 (D. Vt. Oct. 11, 2001), federal appeal to Second Circuit filed February 2002.

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