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.

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.

Consumers' use of advance directives can—and should—complement and enrich the clinical process and strengthen treatment relationships between consumers and providers.

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.

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* e*nforceable* 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.

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.

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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Analysis of State Laws

WHAT ARE ADVANCE DIRECTIVES?

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.

Every state has enacted some form of statute providing a mechanism for clearly and formally expressing health care choices in such a written directive. While federal law does not require such statutes, Congress noted their importance in the Patient Self-Determination Act.[1] This law requires that any service provider participating in the Medicaid or Medicare programs must inform patients about the state's law concerning advance directives.

There are two principal types of advance directives: an instructional directive and a proxy directive.

- An *instructional directive* sets out in written form the person's desires about treatment. Many people are familiar with "living wills" used in end-of-life situations, and most states that recognize them require that the instructions be followed by health care providers.
- A p*roxy directive* , also known as a durable power of attorney or health care proxy, may include specific instructions but also appoints an agent, or attorney-in-fact, to act in place of the individual when the individual is not capable of making or expressing health care decisions. A proxy directive is usually not triggered until the person is determined, ordinarily by his or her treating physician, to be incapacitated. When that happens, the directive goes into effect, and the agent then is empowered to act in place of the incapacitated individual.

In most states, if the written proxy directive includes instructions to the agent, the agent must follow those instructions. If the directive does not include instructions, the agent may be required to employ a substituted judgment test or to act in what the agent determines to be the individual's best interest. Health care providers are usually required by the state's law to follow the instructions of an agent acting pursuant to an advance health care directive.

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Most state laws include a list of elements that must be in an advance directive, and many include suggested forms. In most cases, written directives may be followed even when precise formalities are not followed. A New York state case, *In re Rosa M.*,[2] upheld an advance directive by a patient refusing treatment with electroconvulsive therapy even though the written directive did not comply with the statutory form.

Most of the state advance directive statutes expressly or by implication apply to mental health care. A dozen or more states, however, have also enacted advance directive statutes that apply specifically and solely to at least some kinds of mental health treatment.

ADVANCE DIRECTIVES IN SELECTED STATES

A dozen or more states have enacted advance directive statutes that apply specifically and solely to at least some kinds of mental health treatment.

A review of every state law was beyond the scope of this project. We therefore focused on the laws in four target jurisdictions: New York, North Carolina, Nebraska and Washington D.C.[3] (Of these, only North Carolina has a state law specifically for advance decisionmaking for mental health care.) In this section we also include discussion about Vermont and Washington state laws, where recent legislative activity particular to psychiatric advance directives has occurred.

Relatively few judicial opinions address the legality and enforceability of psychiatric advance directives *per se*, but several legal issues have emerged as key considerations for determining whether consumers in a particular jurisdiction can utilize advance directives for mental health decisions in a meaningful way. When reviewing a state law, we focused on the following questions:

- Does the law address only advance directives for mental health care, or does it cover other health care decisions?
- What conditions trigger an advance directive when it is used for mental health care decisions? (When does it spring into effect?)
- Does the law provide for any limits on a provider's obligation to follow mental health treatment decisions made in an directive or made by an agent appointed as a health care power of attorney? Included in this issue are connections between the laws governing advance directives in a jurisdiction and the laws related to emergency detention and involuntary commitment (outpatient or inpatient).
- What, if any, limits are placed on the authority that a mental health consumer can assign to an agent through an advance directive?
- What consequences, if any, flow from a provider's failure to honor or comply with decisions expressed in an advance directive?
- How can advance directives be revoked or changed?
- If the law is specific to psychiatric advance directives, how do its provisions (particularly those described above) relate to the jurisdiction's more general advance directives laws?

NEW YORK

New York's law on "Health Care Agents and Proxies"[4] covers all types of health care decisionmaking. Under the New York scheme, an individual has the power to appoint a health care agent to make decisions when the attending physician determines that the person is unable to make health care treatment decisions. If the inability to make decisions is based on mental illness, "the attending physician . . . must consult, for the purpose of confirming the determination, with a qualified psychiatrist" and record the determination in the medical record.[5]

New York does not have a specific law allowing an individual to provide instructions about treatment and express attitudes and wishes about health care, as one would in a living will. The health care proxy law does state, however, that a proxy "may include the principal's wishes or instructions about health care decisions, and limitations upon the agent's authority."[6]

Importantly, the New York law gives continuing precedence to a principal's decisions, even when an attending physician has determined that the individual lacks capacity to make health care decisions. If the principal "objects to the determination of incapacity or to a health care decision made by an agent, the principal's objection or decision shall prevail unless the principal is determined by a court of competent jurisdiction to lack capacity to make health care decisions."[7]

Generally, health care proxies in New York are valid until canceled by the principal. The principal has the option, however, of specifying a particular expiration date or expiration-triggering event.[8]

The New York law allows for revocation of a health care proxy as long as the principal is competent.[9] Accordingly, even when the individual's *capacity* is questionable, the individual may revoke the health care proxy unless a court of law determines that he or she is incompetent to make the decision to revoke. A principal may revoke an advance directive by "notifying the agent or a health care provider orally or in writing or by any other act evidencing a specific intent to revoke the proxy."[10] Execution of a subsequent health care proxy will also revoke an earlier proxy.[11]

Interest in PADs appears to have increased in New York following the November 1999 enactment of the state's Involuntary Outpatient Commitment (IOC) Act.[12] The state legislature found that "the voluntary use of such [health care] proxies should be encouraged so as to minimize the need for involuntary mental health treatment." The law mandates that a court shall take into account any directions included in a health care proxy in determining what will be in a written treatment plan for involuntary outpatient treatment.[13]

The effect of including health care proxies (in effect, PADs) in the legislation is potentially positive. Right after enacting the IOC law, the New York legislature appropriated funds to train consumers and mental health treatment providers about advance directives and their im-

An important feature of the New York law is the way it gives continuing precedence to a principal's decisions, even when an attending physician has determined that the individual lacks capacity to make health care decisions.

plications for mental health care decisionmaking. The funds were distributed through the state's Office of Mental Health. Two private organizations were originally funded to develop and implement training programs. The Resource Center, a peer-run agency, implemented an advance directives training project for consumers, survivors and ex-patients across the state until January 2002,[14] while the New York Association of Psychiatric Rehabilitation Services (NYAPRS) trains community mental health professionals about advance directives. Both groups developed valuable training materials and strategies.[15]

Some advocates and consumers in the state were cautiously optimistic that the attention on advance directives by way of New York's IOC law would promote widespread use of PADs, which could, in turn, work to vitiate the need for IOC itself. Advance directives, if widely utilized, may also be helpful for documenting consumers' desires for services that are not offered or available in the state.

Despite the positive potential, the New York connection between advance directives and IOC might undermine the potential for consumer empowerment if the concept is presented in a coercive context or the tools are used inappropriately. For example, the health care agent or proxy should enter the picture only when the principal is incapable of making his or her own decisions and should not be drawn into treatment decisions at other times.

Prior to passage of the IOC Act, advance directives had faced only one court test in New York, and to date no other published decisions exist on the issue. In the 1999 case, *Matter of Rosa M,*[16] a court refused to order electroconvulsive therapy (ECT) for an incompetent woman who had previously written a statement ("I am withdrawing my consent to electroconvulsive therapy and am refusing any more treatments with this procedure."), even though the statement did not comply with statutory standards.

Advance Directives for Youth

During the Bazelon Center's three-year project, we were contacted by several parents about the use of advance directives for youth. We've learned in some cases families have informally adapted the Bazelon Center's advance directive template for use by youth as a statement of treatment preferences. While individuals who have not reached the age of majority cannot make legally binding advance directives, we have heard from the field in these instances that the young person's experience of considering the treatment options and completing the form was very positive, consistent with many comments we have gotten from adult consumers.

We suspect that interest in advance directive-style documents may be increasing among youth and their advocates. At least one jurisdiction, New York, has taken hold of this interest in a thoughtful way. The Bureau of Children and Families in the state's Office of Mental Health (OMH) began a consumer-driven project in January 2000 to utilize the concepts behind advance directives for youth, who may not be able to execute a legally binding PAD but might nevertheless benefit from a tool to help them explore treatment options and make their preferences and ideas known in advance of a crisis. OMH developed two tools for youth. First is "My Prime Directive Journal," a booklet of probes with space for teenagers and other youth to express such things as "I fell my best/worst when:"; "The real me is: "; "Someday I'd like to:" and "Ten years from now, I'd like my like to be or not to be:". The second part is "My Prime Directive," a document modeled on an advance directive form and designed to facilitate communication between youth and professionals about their experiences with treatment, the services they are receiving and what they believe they need from the mental health system. The document can also be shared, at the consumer's direction, with parents or others who could appreciate insight into the young person's goals for recovery. Other jurisdictions may look to this as a model. *See* www.omh.state.ny.us/omhweb/omhq/q0601/onev0601.html.

NORTH CAROLINA

North Carolina has a law that deals specifically with psychiatric advance directives, known as "Advance Instructions for Mental Health Treatment" or AIMHT, N.C.[17] This law was first enacted in January 1998, then amended later that year, as an addition to the state's general Health Care Power of Attorney Act (HCPOA).[18] Unfortunately, consumers do not seem to have benefitted from the AIMHT. As one local observer explained to us, North Carolina had an "inadequate law, incompetent advocacy resources and a nonexistent education and dissemination plan." This combination may have dashed hopes for more consumer self-determination in that state, but can serve as useful information for other jurisdictions hoping to promote the use of advance directives.

The original AIMHT statute apparently pleased none of the stakeholders—consumers, medical professionals, legal professionals. Negotiations among consumers, providers and the bar (particularly trusts and estates attorneys) throughout most of 1998 led to compromise legislative amendments, effective in October 1998. However, the law remains seriously flawed.

One of the more significant problems is a list of conditions under which a mental health provider is permitted to override an advance instruction document. The list is so broad that it is unlikely that a physician or other mental health provider will ever feel compelled to honor an advance instruction if he or she is not otherwise inclined to do so. The statute lists four conditions that allow the attending physician "or other mental health treatment provider" to disregard all or any part of an advance directive. These conditions include:

- The AI is not consistent with generally accepted community practice standards of treatment to benefit the principal.
- The AI is not consistent with the availability of the treatments requested.
- Compliance, in the opinion of the attending physician or other mental health provider, is not consistent with appropriate treatment in case of an emergency endangering life or health.

These conditions weaken the law in several respects. The meaning of "not consistent with the availability" is not defined in the statute and is ambiguous. Conceivably, the phrase could refer to economic or geographic availability or inadequate numbers of trained staff. Further, the statute does not obligate providers to seek an acceptable treatment substitute if they do not follow the advance instructions. Additionally, "mental health provider" is not defined, which means the statute may be read to give override authority to individuals who are not qualified to make such medical determinations. Furthermore, while an exception for emergency treatment is not unique to North Carolina's statutory scheme, this exception is not narrowly tailored to allow for only what is necessary to avert serious harm.

As for revocation, the AIMHT law originally included a two-year

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expiration of the advance instruction, which was not suspended by a principal's incapacity. The revised statute, in effect, removes the expiration clause, and allows for revocation by the principal as long as he or she is not incapacitated. Since an AI instrument is triggered upon incapacitation, once activated, it cannot be revoked while in use.

In addition to problems with the NC advance instruction law itself, its provisions do not work easily with other state laws. The general HCPOA[19] provides that a health care power of attorney may incorporate or be combined with an advance instruction for mental health treatment, but doing that may not be so easy. Under the general statute, if an advance instruction exists, the health care agent's decisions about mental health treatment shall be consistent with any statements the principal has expressed in the AI. If no advance instruction exists, the agent's decisions are to be consistent with what the agent believes in good faith to be the manner in which the principal would act if the principal did not lack sufficient understanding or capacity to make or communicate health care decisions. The form included in the general HCPOA statute, however, applies one standard of care for an agent's decisions about physical health care ("use due care to act in the principal's best interests and in accordance with this document") and another standard for making decisions about mental health care ("health care agent will act according to how the health care agent believes you would act if you were making the decision").[20]

The statute does have positive features, among them the requirement of documentation for noncompliance. The attending physician or "other mental health care provider" must promptly notify the principal if he or she will not honor the preferences in an advance directive.

Some legal professionals in the state also believe that the general HCPOA statutory form, as it existed, would have been stronger and could have been used more easily in connection with an AI had the AIMHT been incorporated into it by reference. The form that was used prior to the 1998 amendments was general and did not include references to specific illnesses. Reportedly, many attorneys prefer the earlier version, and they continue to advise their clients to use it.

Despite its shortcomings, the statute has positive features. Among these is the requirement of documentation for noncompliance. The attending physician or "other mental health care provider" must promptly notify the principal if he or she will not honor the preferences in an advance directive. Also, the provider must document in the medical record both the notification and the reason for not complying. Such documentation may be useful for analyzing the effectiveness of advance directives. At present, however, it has limited use because usage of advance instructions is not being tracked in North Carolina.

For the reasons described above, the North Carolina law is not a strong model for consumer rights, and even its limited potential seems to have been squandered. It is our understanding that shortly after the AIMHT law was passed in 1998, the local chapter of the National Alliance for the Mentally Ill (NAMI N.C.) and the North Carolina Mental Health Consumers Organization (NCMHCO) had conference workshops and presented information about the AIMHT. In contrast to what

has happened in New York, however, it appears that no one in the state ever developed a statewide strategy for continuing the education or promotion of advance directives, and no organization or group has taken on the responsibility for this type of activity. With no champion, opportunities for promoting the advance directives concept and possibly improving the law seem to have been lost.

WASHINGTON D.C.

Consumers and advocates in the District of Columbia have been very interested in promoting the use of advance directives for psychiatric care on a widespread scale since at least 1997. However, they faced a major hurdle: the public mental health system had announced its legal position that advance directives for psychiatric treatment—unlike those for other medical care— were unenforceable under District law.[21] As a result, providers in the public mental health system and consumers who relied on the system for services were told that psychiatric advance directives need not, and would not, be honored if presented at St. Elizabeths Hospital (the public psychiatric hospital), the city's emergency psychiatric response division or any of the community mental health centers in the public system.

In early 2000, however, following the federal court's appointment of a transitional receiver to run the public system,[22] this interpretation changed dramatically. The new public mental health authority, the D.C. Department of Mental Health, recognizes the legality of advance directives for mental health care decisions under D.C. law.

The current legal basis for psychiatric advance directives in D.C. is the Health Care Decisions Act of 1988 (HCDA)[23] and the Mental Health Service Delivery Reform Act of 2001, the law setting up a Department of Mental Health pursuant to federal court order. Accordingly, D.C. has a general law but specifically clarifies its applicability to mental health care decisions.

The Mental Health Consumers' Rights Protection Act of 2001[24] expressly recognizes that "[a]ll consumers may execute a durable power of attorney for health care in accordance with the 'Health Care Decisions Act of 1988'" and it strengthens the general HCPOA provisions as they apply to mental health decisions. The law states that a "durable power of attorney for health care may include a statement of the consumer's mental health treatment preferences, which shall be honored by his or her attorney-in-fact or by any substitute health care decision-maker in accordance with D.C. Code § 21-2210(b)."[25] Moreover, "[t]he consumer's treatment preferences shall be followed by the Department or other provider except for good cause as documented in the consumer's clinical records, and shall never be overridden for the convenience of the Department or other provider."[26]

The HCDA provides that "[a] competent adult may designate, in writing, an individual who shall be empowered to make health-care

At any time the principal has the capacity to make a durable power of attorney, he or she may revoke it.

decisions on behalf of the competent adult, if the competent adult becomes incapable, by reason of mental disability, of making or of communicating a choice regarding a particular health-care decision..."[27] An agent may have the authority "to grant, refuse or withdraw consent on behalf of the patient with respect to the provision of any health-care service, treatment or procedure,"[28] with the exception of psychosurgery, ECT and behavior modification programs.[29]

As to revocability, the Health Care Decisions Act provides that at any time the principal has the capacity to make a durable power of attorney, he or she may revoke it, and it includes a rebuttable presumption that a principal has the capacity to revoke the durable power of attorney.[30] In other words, it is presumed, absent other evidence, that a principal has the capacity to revoke when he or she takes steps to do so. It is not clear from the law exactly where the limit on revocability falls, but the statutory form states that a principal may take away the authority of an attorney in fact, "unless [the principal has] been adjudicated incompetent."[31]

The limited exceptions make it clear that the law does not allow for a wholesale override of an advance directive just because an individual is subject to involuntary commitment.

The basis of the new law is that no mental health services or supports shall be provided without a consumer's informed consent.[32] When a consumer's physician believes that the consumer is incapable of making a decision, the physician must seek a certification of incapacitation in accordance with the Health Care Decisions Act, which will activate an advance directive if such a document has been created by the consumer.[33]

Through the new mental health law, the District of Columbia has also addressed some of the concerns that providers and consumers have expressed about how advance directives relate to obligations and rights that arise during mental health emergencies or involuntary commitment proceedings. Generally, only the particular mental health services and supports to which the attorney-in-fact consents shall be provided to a consumer whose PAD has been activated. Limited exceptions to this rule apply during emergency situations. An "emergency" exists "when it is the written opinion of the attending physician that delay in obtaining the consent of the consumer, the attorney-in-fact, or a substitute health care decision-maker is likely to result in serious injury to the consumer or others, and mental health services and supports are delivered only to the extent necessary to terminate the emergency."[34] The law clearly does not allow for a wholesale override of an advance directive just because an individual is subject to involuntary commitment.

The new consumers' rights law also includes a section on the administration of medication, and it clarifies how the provisions in a psychiatric advance directive come into play when forced medication is proposed.[35] Here, again, the overarching principle is that medication may only be administered with the consumer's informed consent. If the consumer has been certified as incapacitated, his or her attorney-

in-fact or substitute health care decision-maker may consent to the administration of medication only in accordance with the consumer's treatment preferences, as expressed in a durable power of attorney or declaration of advance instructions for mental health treatment.[36] Except in an emergency, as discussed above, a provider may administer medication to an incapacitated individual without such informed consent *only* after following a prescribed administrative procedure, which includes a right to advocacy representation, a review of the medication recommendation by a neutral party (who may order no more than 30 days of involuntary administration of medication) and the right of appeal of the decision to an independent panel.[37]

During the review period of our study, neither the new legal position of the public mental health system nor the provisions about mental health care decisionmaking in the new consumer rights law led to an increase in the use of advance directives by consumers in the District of Columbia. Whether the system and local advocates will promote the use of these tools in a way similar to the New York approach or continue the *status quo* remains to be seen, given that the law is still new and many changes are underway to create a recovery-oriented mental health system in D.C. that can be operated without court oversight.[38]

NEBRASKA

For a number of years, the great majority of complaints received by Nebraska's protection and advocacy system, Nebraska Advocacy Services (NAS), focused on alleged inappropriate treatment. Advocates have interpreted the statistic as showing that large numbers of consumers believe they are either prevented from making their own health care decisions or afforded

The state of Maine has become a national leader in recognizing trauma and developing systematic responses to the needs of abuse survivors. The Maine Department of Behavior and Developmental Services (formerly the Maine Department of Mental Health, Mental Retardation and Substance Abuse Services) formed an Office of Trauma Service ("OTS") in 1995 to "increase awareness and knowledge of the prevalence and disabling impacts of interpersonal violence in the lives of children, adolescents and adults served by Maine's public health and human services systems, and to build capacity within the existing (mental health) system to deliver trauma-sensitive services which will assist these individuals in their recovery." Data from the state indicate that the large majority (as high as 70-80%) of mental health consumers in Maine's public mental health system have a history of sever abuse trauma.

OTS developed a "Personal Safety Form," very similar to an advance directive, as one tool to assist consumers and clinicians in collecting relevant information in a sensitive way that fosters clinical recovery. The form is a guide to gathering information that is to be incorporated into treatment planning for the individual. The Personal Safety Form is a key part of the clinical protocol that OTS has developed for the use of seclusion and restraint, aimed at ensuring that when it is necessary to utilize these interventions. It is done based on knowledge of what may constitute a re-traumatizing experience for the consumer and the consumer's own understanding of what helps him or her to de-escalate the crisis.

Among other information, the form asks the consumer to identify what things help when he or she is having a hard time and provides a long list of possibilities to spur thinking in this area (voluntary time out, punching a pillow, exercise, taking a shower, deep breathing, talking with a therapist, etc.). The form also asks about triggers that the consumer knows will cause a crisis to escalate, preferences for alternative interventions if he or she becomes in danger of hurting self or others, preferences in the gender of emergency staff, and information about medications. More information about the program is available through OTS and in their publications, including *In Their Own Words*, a 1997 report from trauma survivors and professions they trust about what hurts and what helps when during a crisis. *See* www.umaine.edu.sws.ots.

little influence by the mental health providers who are making those decisions for them.

Driven by these views, NAS has been interested in promoting advance directives for psychiatric care since at least 1994. During the mid-1990s, the organization's advisory council made it an agency priority to help build and support a consumer movement in the state. NAS viewed its advance directive work as a way to work toward enhanced consumer self-determination.

The availability of legal advice and counsel to consumers who want to execute advance directives appears to have been helpful in getting a promotion strategy off the ground.

Advocates pushed for advance directives on several fronts, first working unsuccessfully for passage of a "mental patients bill of rights" with a reference to advance directives. NAS retooled its efforts in 1997 to promote the use of advance directives among mental health consumers pursuant to existing state law on living wills and health care power-of-attorney documents. In 2000, NAS published "Health Care Power of Attorney: A Manual for Nebraska Advocates," a workbook for consumers and their advocates, and began to train individuals around the state about psychiatric advance directives and assist those who expressed an interest in executing such documents.

Nebraska's advance directive law is a general health care power of attorney law that does not specifically mention mental health care decisionmaking, but also does not exclude it.[39] Under the law, the authority of an attorney-in-fact commences upon a determination that the principal is incapable of making health care decisions.[40] The decision about capacity must be made in writing by the attending physician and any physician consulted with respect to the determination that the principal is incapable, who must document in the medical record the cause and nature of the principal's incapacity. [41] If a dispute arises as to whether the principal is incapable, a proceeding triggering a court determination may be initiated.[42] In certain situations, when a consumer is refusing certain treatments, the decision about incapacity must be made by a judge.

A power of attorney for health care in Nebraska may be revoked at any time by a principal who is competent, and in any manner by which the principal is able to communicate his or her intent to revoke.[43]

Nebraska advocates report that their materials have generated increasing interest in mental health advance directives. State advocates are prepared to defend the legality of advance decisionmaking for mental health care. They also have a plan to monitor or track the use of PADs. As in New York and the District of Columbia—but not North Carolina—the availability of legal advice and counsel to consumers who want to execute advance directives appears to have been helpful in getting a promotion strategy off the ground.

OTHER JURISDICTIONS AND KEY LEGAL ISSUES

◆ **Vermont:—**Permitting people who are not mentally ill to engage in advance planning through advance directive instruments on a wider basis than people with mental illnesses raises significant equity issues. A federal court, reviewing a Vermont law, addressed such an issue.

Vermont has two statutes that allow residents to create advance directives:. One allows for "durable powers of attorney for health care"[44] and the other permits creation of "terminal care documents," commonly referred to as "living wills."[45] Against this scheme, the state legislature enacted a new law, commonly referred to as "Act 114," which allows the state to ask a court to override an individual's advance directive if adherence to it does not result in "significant clinical improvement" within 45 days.[46] There is no comparable procedure allowing the state to seek vitiation of a durable power of attorney for health care of an individual who is not characterized as having a psychiatric disability.

Permitting people who are not mentally ill to engage in advance planning through advance directive instruments on a wider basis than people with mental illnesses raises significant equity issues. A federal court, reviewing a Vermont law, addressed such an issue.

A 1999 class action, *Hargrave v.. State of Vermont*, challenged the law as discriminatory under the Americans with Disabilities Act[47] and Section 504 of the Rehabilitation Act.[48] The lead plaintiff, a woman diagnosed with a mental illness and cancer, who had an advance directive in which she expressed preferences against certain treatments for her cancer and against psychiatric medication, was joined by the Vermont protection and advocacy system as plaintiff-intervenor.49 The state sought to forcibly medicate Ms. Hargrave with psychiatric medication, in a non-emergency situation, in direct contravention of the wishes expressed in her durable power of attorney. Plaintiffs argued that since the only advance directives that can be overridden are those regarding mental health treatment, the law discriminates against people with mental illness and violates the ADA.

In October 2001, a federal trial court ruled that this provision is discriminatory and violates Title II of the ADA, which provides that no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."[50] The court held that:

> Although every state has done so, no state is required by federal law to establish a mechanism whereby individuals can articulate prior health care directives to control their medical treatment in the event of a later incapacity. However, once a state creates the opportunity, it [cannot] prevent individuals from establishing the directives and having them accorded the deference inherent in the statute because of their disabilities.[51]

The court rejected the state's argument that Act 114 did not single out individuals with mental illnesses due solely to their illness, but due to the "dangerousness" caused by their illness.[52] Comparing the rights

of individuals facing physical illness, the court found that:

> [A] prior decision to forego medical intervention necessary to sustain life is permitted for the physically ill or disabled, even though at the time of incapacity, rejection of the treatment could be seen as posing a "danger to themselves." In fact, that is the very purpose behind legislation permitting individuals to execute prior health directives such as Vermont's DPOA. While there is no provision in Vermont law to compel an incompetent physically disabled individual to undergo treatment in violation of a DPOA, *even if that treatment is needed to save the individual's life*, the State would have the Court declare that because a mentally ill individual at a particular point poses a danger to herself, her prior wishes to forgo medical treatment calculated to abate the danger can be ignored.[53]

This ruling has been appealed to the Second Circuit. Demonstrating the importance of the issue, 18 former state mental health commissioners and others, including the National Mental Health Association, the International Association of Psychosocial Rehabilitation Services and the American Association of People with Disabilities, filed an amicus brief in support of the right of individuals to inform caregivers of their treatment preferences through the execution of legally enforceable advance directives.

One question raised is whether an advance directive may be used to accomplish a "voluntary admission" to an inpatient facility, where the agent follows written instructions over the principal's contemporaneous objection to admission.

◆ **Washington—**One aspect of debate in Washington state highlights a concern that is likely to resurface in that state and elsewhere: that promising aspects of advance decision-making for mental health—helping consumers get treatments they have found helpful and avoid forced hospitalization and negative or harmful interventions—are potentially subverted when the focus is on getting signers to agree to treatment and commitment and, in effect, to weaken or evade involuntary treatment laws.

Washington state has a generic durable power of attorney for health care statute that does not specifically mention mental health decisions, but allows a principal to authorize an agent to give informed consent for health care decisions on the principal's behalf.[54] While consumers have executed mental health advance directives pursuant to existing law, proposals for a new and separate mental health advance directives statute have been debated recently in the state. Concerns with the existing law relate to a perceived lack of clarity regarding how it interacts with state guardianship laws and questions regarding the enforceability of mental health care directives.[55] In its 2002 session, the state legislature considered proposals for an advance directives statute that would apply specifically and exclusively to mental health treatment, but none passed.[56]

As various legislative proposals have been considered in Washington, one question raised is whether an advance directive may be used to accomplish a "voluntary admission" to an inpatient facility, where the agent follows written instructions over the principal's contemporaneous objection to admission.[57] New York and some other jurisdictions limit an agent's power to authorize voluntary admission to a psychiatric facility, even if made pursuant to an advance directive. This issue will likely receive continued attention in Washington and other states.

CONCLUSION

Making decisions about health care in the event of future incapacity can be empowering to anyone. Advance planning may be even more important, but also more complex, in the mental health context, where insistence on particular, unwanted options has been the experience for many.

The Bazelon Center's three-year exploration into the legal and practical issues that are raised by psychiatric advance directives allowed us to look closely at how these tools have been used in four states and to have many conversations with consumers, providers and advocates about the subject.

Advance planning may be even more important, but also more complex, in the mental health context, where consumers face the possibility of losing the capacity to make or communicate treatment decisions and where insistence on particular, unwanted options has been the experience for many.

NOTES

1 42 U.S.C. §§ 1395cc(f) & 1396a(w)(1994).

2 597 N.Y.S.2d 544 (Sup. Ct 1991).

3 An excellent reference for a more global review of state laws affecting advance directives for mental health care is in Robert D. Fleischner, "Advance Directive for Mental Health Care: An Analysis of State Statutes (1998) (prepared for Advocacy, Training and Technical Assistance Center for the National Association of Protection and Advocacy Systems). This document can be accessed through the Bazelon Center's website, via www.bazelon.org/advdir.html.

4 N.Y. Pub. Health L. 2980, *et. seq.*

5 See § 2983(1)(b).

6 § 2981(5)(b). The courts in New York have honored living wills when such documents have established a person's wishes by "clear and convincing proof." *See Matter of Storar* and *Matter of Eichner v. Dillon* , 52 N.Y.2d 363 (1981). That is, it must be shown that the person who has become incapacitated had previously given clear and specific instructions regarding a certain type of medical care or procedure. New Yorkers who create both types of documents – health care proxy and living will – can thus have instructions for the health care agent that will guide his or her decisions. It is possible, however, that general instructions about refusing treatment, even if written down, may not be effective if they do not meet the "clear and convincing proof" test.

7 §2983(5). See also §2989(2): "Nothing in this article creates, expands, diminishes, impairs or supersedes any authority that a principal may have under law to make or express decisions, wishes or instructions regarding health care, including decisions about life sustaining treatment, whether or not expressed in a health care proxy."

8 § 2981(5)(c).

9 § 2985.

10 *Id.* at § 2985(a).

11 § 2985(c).

12 Mental Hygiene Law §§ 9.60 as added by Chapter 408 of the Laws of 1999, commonly known as "Kendra's Law."

13 N.Y. Cons. Laws, Mental Hygiene Law §§ 9.60(c)(8).

14 It is our understanding that no group is currently providing consumer training on advance directives in the state.

15 See "Advance Directives for Mental and Physical Health Care in New York State," by Disability Advocates, Inc. (revised 2/2000), at http://www.cqc.ny.us/advdi.htm.

16155 Misc. 2d 103, 597 N.Y.S. 2d 544 (Sup. Ct. 1991).

17 Gen. Stat. at Chapter 122C-71, *et seq.*

18 N.C. Gen. Stat. at Ch. 32A, Article 3, 32A-15, *et seq.*

19 N.C. Gen. Stat. at Ch. 32A, Article 3, 32A-15, *et seq.*

20 See N.C. Gen. Stat. § 32A-25.

21 The City's attorneys argued that even though the Health Care Decisions Act (HCDA) does not defined "health care," it governs medical but not psychiatric decisions. In at least one trial court decision, however, a judge specifically found that nothing in the language of the HCDA implies that health care is limited to treatment for physical conditions or excludes treatment for psychiatric conditions. *See In re Gibson*, No. 97-FM-1425.

22 The District of Columbia's mental health system has been under federal court order since the 1970s, pursuant to the lawsuit now known as *Dixon v. Williams*. The first Receiver was appointed to run the system in November 1997. He was replaced by a "Transitional Receiver" after systemic problems continued, pursuant to a new agreement between the parties.

23 D.C. Code Ann. §§ 21-2201 *et seq.* (1998)

24 Title II, Section 101, *et seq.*

25 See § 106(a).

26 *Id.*

27 § 21-2205(a)

28 § 21-2210(a)

29 § 21-2211

30 *Id.* at § 21-2208.

31 § 21-2207.

32 (§ 107(a))

33 *Id.* at § 107(b)-(c).

34 *Id. at* § 107(c)(3)(A).

35 *Id.* at § 108.

36 §108(b).

37 When the consumer's refusal to consent to medication is made on the basis of a "valid religious objection" such objection may not be overridden without a specific court order. § 108(d).

38 In 1999 and early 2000, under the first receiver's tenure, a format for non-binding documents, entitled Consumer Statement of Treatment Preferences (CSTP), was developed and promoted to a limited degree as a substitute for a legally enforceable advance directive. The CSTP was to be used in treatment planning in the public hospital and throughout the publicly funded community system. While these documents did not meet consumers' desires for legally enforceable advance directives—and reportedly were never widely embraced by consumers or providers—some of the work that the small office of Consumer and Family Affairs did on that project could be of use in advance directive training. Other consumers have been trained to develop Wellness Recovery Action Plans developed by Mary Ellen Copeland under the "WRAP" program used in other jurisdictions, and this peer-run training may also be a launching pad for widespread promotion of advance directives.

39 See Neb. Rev. Stat. § 30-3401 *et seq.* (1992). "Health care" is defined as "any treatment, procedure, or intervention to diagnose, cure, care for, or treat the effects of disease, injury, and degenerative conditions." Neb. Rev. Stat. § 30-3402(4). "Health care decision" includes "consent, refusal of consent, or withdrawal of consent to health care. *Id.* at § 30-3402(5).

40 *Id.* at . §30-3411.

41 *Id.* at § 30-3412.

42 See *id.* at § 30-3415.

43 *Id.* at § 30-3420(1).

44 14 V.S.A. §3451 *et seq.*

45 18 V.S.A. § 5251 *et* seq.

46 18 V.S.A. §7624 *et seq.*

47 42 U.S.C. § 12132.

48 29 U.S.C. § 794

49 A class was certified consisting of "individuals within the state of Vermont who have been or in the future will be diagnosed as having a mental illness and who either have or will execute a durable power of attorney for health care or have been or in the future will be deterred from executing such an advance directive for health care as a result of Act 114."

50 *Hargrave v. State of Vermont*, No. 2:99-CV-128 (D. Vt. Oct. 11, 2001), federal appeal to Second Circuit filed February 2002. This decision can be found on the Bazelon Center's website.

51 *Id.* at 22-23.

52 *Id.* at 24

53 *Id.* at 25-26 (emphasis in original).

54 Wash. Rev. Code 11.94.010(3).

55 It is our understanding that initial legislative proposals for a PAD statute in Washington were a response, at least in part, to concerns of some about legal

limitations of involuntary hospitalization and treatment

56 All of this activity is taking place while a five-year project to study PADs has been underway in the state. Under the direction of Debra Srebnik, Ph.D. of the University of Washington, the project recruited participants from at least two sites in the state to execute PADs and has begun tracking whether and how those PADs are used/honored during mental health crises. As the project began its third year in April 2002, some of the experiences indicated that additional training within crisis and hospital systems was needed to ensure that working mechanisms were in place for providers to know who has a PAD and to access them at a time of crises. The ultimate findings of the study may well inform future legislative proposals in Washington and other jurisdictions looking at mental health advance directives.

57 At least one Washington proposal in 2002 would have permitted a 72-hour inpatient hold of an individual who executed an advance directive but later wanted to revoke provisions related to inpatient hospitalization, if the revocation was expressed when the individual lacked the capacity required to revoke the directive. The involuntary admission over the contemporaneous objection of the individual could be accomplished without the due process protections of existing involuntary commitment procedures.

The three-year project was funded by the Ittleson Foundation. 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.

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.

Consumers and Providers Speak Out

FINDINGS FROM CONSUMERS

I was concerned about what [would] happen if I ended up in the hospital and they would put me on some awful drug that would really screw me up because they didn't know any better so I thought I should have it written down what treatment I did or didn't want.

• • •

I feel if the provider took the time to look at [my advance directive] they could say 'ok, let's put her in a room and lay her down and let her listen to music' and certain other things I have written [about] alternative treatments for me. I wish—I hope—that would be looked at before they do the traditional shot of isolation.

Consumers expressed a number of key points in their comments to us about advance directives:[1]

◆ **The development and use of psychiatric advance directives can be empowering for consumers in many ways.**

The documents, and the process of developing them, can inform a consumer's own understanding of how the psychiatric illness affects him or her—for example, what are the triggers and early warning signs of impending psychiatric deterioration, what types of interventions can help avoid a crisis or relapse, and what interventions are especially harmful, hurtful or counterproductive. Before executing a PAD, a consumer must become comfortable enough with treatment choices to memorialize them. Exploring treatment options and the process of gathering (and coming to understand) the information a consumer needs to make informed decisions can be an empowering experience.

"I had been in the hospital a couple of times and had been coerced into several treatments, including shock treatments, and I wanted it made very clear that this was not an option. I felt safer. I felt I was advocating for myself. It took away some of the 'if.'"

It was very thought-provoking. You really had to think about what is good for you and you had to relive some of the past to remember what wasn't good for you. I found it empowering; you could stand up for yourself.

• • •

It is a hard thing to do because it does bring up trauma, it does bring up past events. And it is hard, for me it was a hard thing to do. I'm glad it is over.

◆ **This process of completing a psychiatric advance directive can improve communication between providers and consumers and in some situations can strengthen treatment alliances.**

Psychiatric advance directives can enhance a consumer's ability to communicate to providers preferences about how they want to be treated in the event of a psychiatric crisis. The process may also improve communication with family.

"When I learned about (a mental health advance directives project), I was excited at the prospect of being able to let my loved ones know what I would want them to decide if I were ever declared incompetent. It seemed a natural for the way I have developed my treatment. They, in turn, are more comfortable, knowing what I would want done, so they don't have to agonize over certain decisions."

I've never really had a true dialogue as far as how we're told our treatment plan is something that we are participants in.... But once an advance directive was in place and I put it in their hands, every time we looked at the treatment plan afterwards it absolutely was more of an open dialogue, a give-and-take. I actually believe this will work for me with my therapist vs. them telling me 'we believe this is what you are going to need to get what you say you want.' They became more receptive to what I had to say, once they knew I had the AD or that I was developing an AD.

• • •

My expectation is that they would believe I was of sound mind when I completed it [and that] as much as they are able to just follow it. I know which medicines I do well on, I know which ones I don't do good on. I know what will calm me down vs. getting me naked and giving me an extreme dose of medicine.... There are better things that work for me than to use extreme tactics, that help me gain some self-control back if I may have gone out of control.

◆ **Peer support and peer education are key components to the promotion of psychiatric advance directives.**

The process of putting together an advance directive can be difficult, particularly if it requires a consumer to closely examine experiences during past periods of instability in his or her illness (traumatic events, for example, such as forced treatment), or when it requires making difficult decisions (about agents, contact people, treatment options, etc.) that may cause interpersonal strife. Well-trained peer advocates can be invaluable throughout this process.

I reviewed my Wellness Recovery Action Plan..., being...painstakingly honest with myself about what really works for me. I just had people help me put things down and word things correctly. I'm bad with words and putting my thoughts in the right words, so X and other people at the Independent Living Project made sure that my thinking came out in the right words.

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[Providers] tell people they need to get an advance directive, but that's it. They give them absolutely no information on how it can support them, how it can hinder them. People just hear words AD and unless a peer goes out and does some informational promotion they don't know what is going on.

Access to peer support may help address consumers' concerns that mental health providers may have interests that conflict with decisions the consumer might want to make in an advance directive. Well-trained peer advocates can also be very effective at educating providers and potential agents about advance directives.[2]

◆ **Finding a suitable agent is a primary concern for consumers who are putting together advance directives or contemplating the task.**

I think I was very lucky to have a brother who could act as my healthcare proxy but I don't think many other survivors are that lucky and I think more should be done to help people get other people in their lives so they can advocate for them when they might need it. Because I think that is what holds back a lot of people; they don't know who to trust or who to turn to about it. I think as a peer I want to make myself available to others because I know, left alone, I could get hurt or violated.

Consumers expressed an appreciation of the important role of an agent, and some expressed understandable anxiety about who in their life could take on this responsibility. Many consumers do not have strong family relationships, and will thus need to turn to friends or peers or other advocates in their lives.

[My designated agent is] the person that I live with, we've been together for 10 years and I've know him since I was 13 so I know this person very, very well. So I know this person would respect what I have there and would do everything possible to make my wishes come about, as much as possible because, you know, you have glitches here and there and you don't always get what you want.

◆ **Consumers expressed the view that many of their peers have no faith in the advance directive process. They want to know what expectations are most realistic, given the laws in their states.**

We were informed it was our right to create this document and if push came to shove it was something we could use in court. We may have a battle once we get to court if a doctor says 'the person is insane and we can't go by what they said on any type of document because these are sick people.' But it gave me a little confidence that maybe I'd get lucky and draw a judge who would say, "well, wait a minute, maybe the person does know a little bit about what helps them stay well. Let's pay attention to it."

• • •

I feel that most people feel having the health care proxy and having your wishes written out as well, so people could follow it, your proxy could follow it, as well as telling them, having them know you, it gives you are feeling of control. As far as if…there is….the theory of control. The application of control, who knows what is going to happen.

"…I know that, bottom line (having an advance directive) could be a false sense of security if you don't finish it or you don't have it in the right place. We've had people who couldn't find theirs when they needed it and so it was null, it didn't have any effect."

Consumers' interest in psychiatric advance directives is peppered with a high degree of skepticism about their enforceability. A telling reaction from one consumer who was presented with a sample advance directive, as reported to us, was "Great, another unenforceable right." Some consumers expressed concern about facing a negative reaction from (from treatment providers or others) if they execute such a document.

FINDINGS FROM PROVIDERS

Mental health providers in various professional disciplines in three different jurisdictions (New York, Nebraska and Washington D.C.) described what they knew about psychiatric advance directives and, even if they had never encountered such a document in their practice, what they thought of the concept.[3] As with the discussions with consumers, the investigation regarding provider views on PADs was by no means scientific, yet we believe it yielded important information.

"PAD is not necessarily adversarial, but could be helpful. (An example of someone for whom a PAD may be helpful is a consumer) who does not talk when at a low point of mental health, but who could make a plan in advance when she has judgment and willingness to express it."

What do we do about how to approach patients about what they want? This is the age of consumer pro-advocacy. Patients are not out of it. Sit down with the person and know what they want. You must know their history back and forth. Have time to do this. Get family involved. Let patients know you care what they want. Patient will usually follow the doctor's recommendation. In emergencies, make a judgement as a doctor; consider safety of patient, peers and staff. Sit with family, patient and entire team. 'Spread Liability' out by opening discussion with patient, team, family.

◆ **Providers who saw these tools as being part of a therapeutic strategy that makes their clinical efforts more meaningful and effective expressed the most positive views of PADs**.

A significant number of providers with whom we had contact expressed support for the use of advance directives even though they had never actually faced such a legal document in the mental health context. Some said they worked hard to elicit and honor consumers' preferences. One psychiatrist, for example, described how he used the underlying concept of an advance directive in his day-to-day practice:

I ask them things like, how bad has this gotten for you? What has happened? So I try to get functionally what's happened: losing job, assaulting someone, spending down the bank account, cheating on the wife, drinking alcohol, staying up all night. ... Once we get this kind of...bottoming out ... the low part of the cycle, then I try to elicit from them what are the earliest signs that they are going downhill, in terms of their functional status.... With some people it's like, if they're not taking a bath, or realizing that they're not ironing their clothes, or they're letting their daily chores go, they're sleeping late in the morning, they're not getting to sleep at night.... [Next] I ask them what can you do

that helps when those things start to occur?... And then the fourth part is, what will you do, or what do you want to do when you notice yourself slipping in, and your home remedies don't work, what are you going to do at that point?

Others clinicians were optimistic about the possibilities of PADs:

Impact on clinical relationship will be "only positive . . . . if some can feel she has a say and her ideas and concerns respected, it will only improve relationship."

• • •

For those people who have had involuntary hospitalizations may want it and find it useful [to plan for future] . .. But need to leave some "wiggle room" for physicians.

◆ **Some providers expressed negative views about the use of advance directives for mental health care decisions.**

Our investigation led us also to providers who did not readily see a place for advance directives in mental health care. At an extreme were a few clinicians who expressed adamant views that *no one* with a diagnosis of a serious mental illness could *ever* be competent to express treatment preferences in a legally binding advance directive. While such views were not the most common that we heard, they were strongly held among a few.[4]

If an advance directive is only made when a person is competent, how do you do one when you do not have a sound mind? I think that the only person who would need an advance directive is someone who might be involuntarily hospitalized. If they are voluntary, then they would be competent, so AD does not kick in.[5]

◆ **Providers in all disciplines need a great deal of basic education on PADs.**

Providers' understanding of advance directives and the legal obligations that flow from them, as well as the clinical role for these tools, varied considerably. Most with whom we spoke expressed a desire for information and training, especially training focused on potential clinical benefits. A number of providers suggested that consumer trainers could be valuable.

◆ **Providers prefer proxy directives over instructional documents and may be more supportive of them.**

Among the providers with whom we explored the concept of PADs, most seemed to readily conceive of a situation where the consumer creates a proxy directive, appointing a surrogate decisionmaker to act when the consumer is not capable of making or expressing decisions about mental health treatment. Some expressed the view that doctors

"Consumers who have used a relapse prevention plan to take control of recovery process would be good candidates to use PADs. . . .Would need for consumer to be willing to spend much time on process to make the decisions about options – learn about options, make decisions, feel good enough about those decisions to stick with them."

and others were more likely to follow a PAD if they could consult with someone about the consumer's written decisions.

Providers viewed proxy directives as more flexible. For example, several providers suggested that PADs would be most useful if the consumer has given his or her agent some leeway to assess treatment options that may not have been available when the PAD was written, and were therefore not considered by the consumer, but which might be consistent with the consumer's preferences and directions when the PAD is activated.

Providers did not think that an agent's role should be unchecked, however. They expressed concerns about possible conflicts of interest (financial, for example) or other conditions (health, for example) which may lead an agent to deviate from a consumer's wishes. As one doctor cautioned, "Do not give a blank check to any surrogate."

"We do not know (if an advance directive will be legally enforceable), but we need to have providers buy in and have it done collaboratively with a treatment team for the best chances of its being enforced or followed."

◆ **Providers want to know what role they should play either in promoting the use of advance directives or in educating consumers about their rights in this area**.

Providers expressed the desire for adequate information about PADS so that they can give consumers realistic expectations about how their advance directive will be considered and honored. While some providers believe that a PAD "must be created with a treatment provider or the provider will not follow it," others questioned whether they should actually help consumers draft advance directives.

"Maybe this [patient education on PADs] is not our role. The family physician, rather than psychiatrist might be in a better position to educate on this issue."

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Conflict [of interest] issues need to be reviewed. . . . what if I'm on the hospital staff. Maybe I should not work with people on an advance directive, because I might want to admit at any time, or I might want to unduly influence the surrogate to agree to admission in order to fill beds.

◆ **Many providers are concerned about how the existence of an advance directive will affect their legal or ethical responsibilities in emergency situations.**

Most providers who spoke with us seemed familiar with the involuntary treatment laws in their jurisdictions, but they questioned how the existence of a PAD might affect their legal and/or professional obligations in emergency situations or civil commitment proceedings.

"Example I see is someone with command hallucinations to slash a neck. Needs anti-psychotic meds. Advance directive says no meds by shot and consumer will not take meds by mouth. How do you resolve this conflict – treatment against will (to save life) vs. preference?"

◆ **Many providers are concerned about the possibility that a consumer may choose to refuse all treatments through an advance directive.**[6]

Intent in doing an AD would not be to refuse treatment and end up in full blown mania and harm someone, but that could happen. Some people now only get treatment if they are dangerous.

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What is the point of becoming an expert as a doctor? I am an expert in ECT. For practical purposes, this [PAD] will handcuff us as doctors in making fundamental treatment decisions.

◆ **Some providers express support for PADs, believing that they will be binding on the consumer who agrees to treatments when the directive is made, but later wants to refuse particular interventions.**

Providers wanted to have realistic expectations about the enforceability of psychiatric advance directives. Many of the answers to their questions depend upon state-specific revocation provisions and, in some cases, limitations on the types of decisions that may be made through an advance directive (see accompanying analysis of state laws).[7]

◆ **Providers expressed concern about their obligations for determining whether an individual has executed an advance directive.**

Providers asked about central registries for PADS and their own responsibility for determining whether a consumer has created such a document. Some providers expressed a concern about liability for not following a PAD that was not known to them.

Providers' Own Psychiatric Advance Directives

At the Department of Psychiatry of the University of Vienna, 101 psychiatric nurses and psychiatrists responded to a questionnaire about psychiatric advance directives ("psychiatric wills") and anonymously drafted advance directives for themselves concerning psychiatric treatment in the event of an acute psychosis. The report includes findings similar to those summarized here.[1]

The authors were encouraged that "a substantial proportion of mental health professionals is favorably included towards advanced directives as a method to increase patient choice and input into their treatment, even if it is involuntary. This study does not address the persistent problems associated with involuntary treatment, but offers insight into the promulgation of a promising alternative."

Only about half of those surveyed had known of advance directives, but about the same number viewed it to be an appropriate legal option. Knowledge about these tools among psychiatrists was significantly higher than among nursing staff.

The advance directives written by those surveyed responded to a narrative form seeking answers about what the person would not want in treatment, what he or she would want instead and why that was so. About 75% of the respondents made at least one statement about a method of treatment they would not want, primarily pharmacological interventions, while others expressed rejection of physical restraint and refusal to participate in research, among other areas of concern. The reasons for rejections or preferences most often related to side-effects and presumed efficacy of treatment methods, or what the subject termed "general human rights issues," such as dignity and self-responsibility. Of the 30 professionals who rejected neuroleptic medication, most frequently because of the side-effects, 26 requested some alternative medication or other treatment.

The participants were reportedly "thoughtful" in drafting their "wills," and gave lengthy written statements and explanations about their preferences. The researchers found that the wills included very specific statements about refusal or demand for certain treatment strategies, usually with "reference to past personal or observed experiences," but also with reference to arguments "for the positive impact of maintaining patients' rights and responsibilities also in a situation of compulsory treatment."

1 See Amering, Denk, Griengle, Sibitz, Stastny, *Psychiatric Wills of Mental Health Professionals: A Survey of Opinions Regarding Advanced Directives in Psychiatry,* Social Psychiatry and Psychiatric Epidemiology, 34:30-34 (1999).

NOTES

1 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.).

2 Being a peer educator or peer supporter also may be an attractive opportunity for consumers to work as advocates (with compensation) and gain the personal benefits of helping others.

3 Our informants included psychiatrists who had worked in a wide range of practice settings: public mental health systems and private practice, inpatient facilities and outpatient centers, office practices and less traditional and non-office-based practices in community locations (e.g., in the consumer's home, at shelters, on the streets). We also interviewed nursing and social work professionals, both those who work primarily with consumers in inpatient settings and others who work in outpatient and community support programs. Interviews were conducted by meeting with groups, through individual interviews (live and by telephone) and written surveys.

4 These views were sometimes based on a inaccurate understanding of the law.

5 The law generally holds that competence is presumed unless a court finds otherwise and that an individual may meet an involuntary commitment standard and nevertheless continue to have legal rights to make treatment decisions.

6 We believe this to be unlikely. Reports from consumers and PAD advocates around the country, many using the Bazelon Center template, have shown us that consumers are not using PADs to reject all treatments, but that they are thoughtfully completing the forms with their directions and preferences about specific medications, treatment approaches, treatment settings and providers.

7 For example, consent to voluntary hospitalization may not be possible through a PAD where the principal contemporaneously objects. Forced treatment laws, and the due process protections that flow with forced treatment proposals, will be triggered in most cases.

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