

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.

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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.

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.

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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.

“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.’”

“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.”

◆ **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.

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.

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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."

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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."

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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 an 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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