

Advance Directives in Health Care: New Opportunities for Empowerment

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Outline

- Brief review of innovations in law governing health care decision-making over last 30 years
- Why advance directives are an important component of mental health law reform

I. Legal Background

Two Traditional Legal Models for Decision-making after Incapacity

- Making decisions while competent through exercise of “precedent autonomy”
 - Wills to govern disposition of property after death
 - Contracts and trusts to govern personal care or disposition of assets while alive
- Surrogate decision-making on behalf of incapacitated person who made no prior arrangements
 - Guardianship – with judicial oversight
 - Decisions to be made in person’s best interests

Innovations in healthcare decisions #1

(“extending precedent autonomy”)

- Durable “powers of attorney” (departure from traditional “agency model” in financial affairs) – VA statute in 1954
- “Living will” statutes to resolve end-of-life treatment dilemmas (Virginia did this in 1983)
- Note evolution of modern health care decisions acts: (1) proxy directives (designating health care agent) and (2) instructional directives
- Autonomy-driven model is elegant solution to the growing challenge of deciding when to stop
- It has powerful moral force and helps move decisions back to the bedside rather than the courtroom
- Propelled by Congress in Patient Self-Determination Act in 1990 after *Cruzan*

Innovations in health care decisions #2 (“default surrogates”)

- **The problem** – most people don’t have ADs
- Traditional practices (medical decision-making and family consent without guardianship) lacked strong legal foundation and were often ethically problematic
- Guardianship is costly and cumbersome

Innovation in health care decisions

#2 (“default surrogates”)

- **The answer:** statutory default list of surrogates, together with substituted judgment/best interests instruction (Virginia did this in 1992)
- Although this ratified longstanding practice, it represented a profoundly important legal change – even more so than ADs
- It strongly embraces medical capacity determination and family decision-making as alternative to guardianship or direct judicial decision-making when the patient has provided no direction
- Note parallel history of surrogate decision-making for people with intellectual disabilities and severe and chronic mental illness under DMHMRSAS/DBHDS Human Rights Regulations (in 1983)

Have Advance Directives been a “Failure”?

- Note that most people still don't execute advance directives. Why?
- In what contexts would people be more likely to want to use advance directives?

Advance Directives in Mental Health Care

- 24 states have separate statutes for psychiatric advance directives (“PADs”)
- Based on recommendations of Task Force on Empowerment and Self-Determination, Commission on Mental Health Law Reform opposed stand-alone “PAD” statute in favor of integrating advance planning for mental health crises into the HCDA
- Commission appointed Task Force to draft HCDA amendments to facilitate instructional directives for all health care, not only life-prolonging treatment, including (but not limited to) mental health crises

II. Why Advance Directives are a Key Element of Mental Health Law Reform

- Commission on Mental Health Law Reform established by Chief Justice of Virginia in summer of 2006 in response to widespread and growing dissatisfaction with the operation of the civil commitment process and with increasing involvement of persons with mental illness in the justice system

How will we measure success of mental health law reform?

- Unfortunately, mental health law seems to attract attention only when something bad happens. And bad events often lead to pressure for more coercion and more stigma.
- But the surest path to protecting public health and safety is not more coercion and less privacy for people with mental health problems, but rather facilitating access to services, creating conditions that will lead to deeper and more enduring engagement of people with mental health needs in the services system, making urgent care accessible when needed, and establishing alternatives to hospitalization.
- In the long run, the best indicator of success of mental health system reforms is fewer TDOs and commitments, not more TDOs and commitments.

Empowerment and Recovery

- A key element of reform is to create a services system that draws people who need services into the system because it helps them regain control over their lives and is responsive to their needs and desires
- Increasing empowerment and self-determination can promote engagement and trust, reduce crises and, even in crisis, reduce the need for coercion
- Advance directives provide a legal foundation for empowerment based on the recovery model of mental health services

What is the Evidence?

- Research on psychiatric advance directives (“PADS”) has been spearheaded by MacArthur Research Network on Mandated Community Treatment, with additional grant support from NIMH
- Duke Research Team headed by Jeffrey Swanson, Ph.D. and Marvin Swartz, M.D.

Design of core study: “Effectively Implementing PADs” (R01 MH63949 and MacArthur Network)

- Enrolled sample of 469 patients with serious mental illness from 2 county outpatient mental health centers and 1 regional state psychiatric hospital in North Carolina
- Random assignment:
 - 1. Experimental group: Facilitated Psychiatric Advance Directive (F-PAD) (n=239)
 - 2. Control group: receive written information about PADs and referral to existing resources (n=230)
- Structured interview assessments at baseline, 1 month, 6 months, 12 months, 24 months; record reviews

Summary of key findings

- Large latent demand but low completion of psychiatric advance directives among public mental health consumers in the USA
- Structured facilitation (F-PAD) can overcome most of the barriers: Most consumers offered facilitation complete legal PADs.
- Completed facilitated PADs tend to contain useful information and are consistent with clinical practice standards

Summary of key findings (cont.)

- Even though PADs are designed legally to direct treatment during incapacitating crises, they can have an indirect benefit of improving engagement in outpatient treatment process.
- PADs can help prevent crises and reduce use of coercion when crises occur.
- Bottom line: Good evidence of effectiveness but they are not being used

Opportunity in Virginia

- Virginia offers opportunity to put this strategy to work
- Commission's 3-year process of deliberation, drafting and enactment cleared obstacles and sources of misunderstanding that otherwise impede implementation
- Genuine enthusiasm among all stakeholders, including public and private providers, consumers and families.
- Troops are ready for direction
- Commission provides collaborative infrastructure and authority for coordinated implementation
- Recession clears the field for implementing empowerment strategy (nothing else is possible; may be antidote to demoralization)
- Research opportunity to measure effectiveness of a system-wide policy innovation

Rapid-Response Funding

- Collaborative research by UVA and Duke funded by:
 - RWJ Foundation Public Health Law Research Program
 - MacArthur Research Network on Mandated Community Treatment
- Implementation funding from Bazelon Center for Mental Health Law through Department of Behavioral Health and Developmental Services

Implementation Strategy

- Three “vanguard sites”
- Three channels of outreach and facilitation in each site
 - CSBs: incorporate AD facilitation into usual care
 - Consumer-directed peer facilitation
 - Web-assisted facilitation
- Coordinated by Commission, stakeholder leadership, and research team through training, development of forms, and continuing guidance

Research Strategy

- Measure effects of implementation in all sites on completion of ADs
- Measure effects of completing ADs on clinical course in all sites through aggregated data (capturing benefit of electronic health records flagging people with and without ADs)
- Client-centered clinical study of effects of facilitation in one site for 150 clients in context of usual care, with interviews within 2 weeks of AD completion and 6 months later

How will we measure success in mental health law reform?

- Reduce involuntary emergency detentions (statewide and in each locality)
- Promote voluntary alternatives to hospitalization (statewide and in each locality)
- Promote voluntary hospitalization when hospitalization is indicated (statewide and in each locality)
- ****Increase the number of people with mental health needs who have advance directives (statewide and in each locality)

Let's Get Started