Behavioral Health is Essential To Health

Prevention Works

Treatment is Effective

People Recover
Psychiatric Advance Directives

Patricia M. Siebert
MMLA Minnesota Disability Law Center/MMLA, Federal Protection and Advocacy System for Minnesota

Marie Verna
Rutgers University Behavioral Health Care Behavioral Research and Training Institute
Through education, training, and resources the Recovery to Practice (RTP) program supports the expansion and integration of recovery-oriented behavioral health care delivered in multiple service settings.
RTP discipline-based curricula

http://www.samhsa.gov/recovery-to-practice
SAMHSA’s 10 Principles and 4 Dimensions of Recovery in Behavioral Health
Today’s Presenters

**Patricia M. Siebert**
MMLA Minnesota Disability Law Center/MMLA,
Federal Protection and Advocacy System for Minnesota

**Marie Verna**
Rutgers University Behavioral Health Care
Behavioral Research and Training Institute
Poll

On a scale of 1 (none) to 5 (very high), rate your EXPERIENCE WITH developing or implementing a Psychiatric Advance Directive (PAD).

1 none
2 a little
3 some
4 quite a bit
5 very high
The Evolution and Relevance of Psychiatric Advance Directives

Patricia M. Siebert
MMLA Minnesota Disability Law Center/MMLA, Federal Protection and Advocacy System for Minnesota
psiebert@mylegalaid.org
612-746-3734
Right to Personal Autonomy

“No right is held more sacred, or is more carefully guarded by the common law, then the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.”

Minnesota Supreme Court, 1976

“Right to Privacy”
“Right to Bodily Integrity”
“Right to Self-determination”
“Right to Informed Consent”
Legal developments in 1960’s through 1980’s began to more clearly articulate this right:

- 14th Amendment
- Competency & Choice
- Medical Power of Attorney
- Right to Refuse Medication
Jarvis v. Levine
418 N.W. 2d 139 (Minn. 1988)

• The MN Supreme Court acknowledged a fundamental right to personal autonomy/bodily integrity under federal and Minnesota constitutions.

• There is a legal presumption of competency. Commitment itself does not equal incompetency:

  “To deny mentally ill individuals the opportunity to exercise that right is to deprive them of basic human dignity by denying their personal autonomy”.

A person who is committed and legally competent has the right to make decisions about antipsychotic medications.
Psychiatric advance directives are anchored in this constitutional right.

Right to privacy/autonomy, while a fundamental right, is not absolute so in some matters may be balanced against legitimate government interests; for example, emergency medication.
People with disabilities who exercise greater self determination have a **better quality of life**: Better employment situations, less physical and sexual abuse, more successful community integration.

(Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003)

Advance directives support principles of recovery: person-driven; based on respect; and involving individual, family and community strengths and responsibilities.

(SAMHSA “10 Guiding Principles of Recovery”)
1990 Patient Self-determination Act added weight to the authority of PADs

- Medicaid/Medicare providers *must ask* if a person has a directive and note this in the medical record (including a copy of the directive if it is provided).

- Providers must summarize health care decision-making rights and facility’s policies about health care directives; *cannot require or prohibit* PAD.

- Must also *educate staff* and community about patient rights.
Why have an Psychiatric Advance Directive?

• Self-determination: PAD operationalizes an individual’s choices regarding treatment and services—a crisis prevention plan with teeth.

• Good vehicle to discuss planning and recovery with family, friends and providers.

• Gives providers who may not know you information which will help them provide you with good care.

• Opportunity to authorize in advance who can receive/release medical information.

• Can incorporate legal arrangements for care of children, finances, pets at a time of crisis.
Informed decision-making aka “informed consent”

- Understanding the psychiatric/medical condition
- Understanding the risks and benefits
- Understanding treatment options
- Understanding the possible consequences of agreeing or disagreeing with certain treatments
- Factoring in one’s values, beliefs, preferences
- Weighing these together.
- Making and communicating a reasoned decision, which is not *per se* a “best interest” decision
Role of providers in helping with informed decisions

Help individuals to understand condition, circumstances, treatment options, risks and benefits, and consequences—this is the ‘informed’ part.

Take a culturally holistic approach to the concept of community medical standards and the individual's understanding of their condition, not just whether person agrees with or accepts a given diagnosis.
Basic legal components of a PAD

**Instructions:** A legally recognized document with instructions (directives) on psychiatric/medical care, written in advance of the anticipated need: ‘Now, for later’.

**and/or:**

**Agent:** In most states a person may name a decision-making agent (‘health care power of attorney’, “proxy”) to carry out instructions. In some states the PAD is primarily the appointment of an agent.

**Executed:** The PAD is executed by an adult (age 18) with capacity to do so (usually legal presumption of capacity in law) in writing, signed and dated, usually two witnesses and/or notarized.
Different States; Different Requirements

Competency declaration? Does PAD statute require witness or other affirmation directed at competency, such as “the declarant understands the nature and significance of the declaration.”

Conflict of interest? In many states, a witness may not be the agent, and witness and agent may not be an employee of a current provider at the time of signing.

Revocable? State statutes vary on whether a PAD ‘locks in’ and cannot be revoked when a person is adjudged incapacitated, or whether a person can revoke a PAD at any time.
Instructions commonly in PAD

When to treat/hospitalize

I authorize my agent to get me mental health help if I start to... order lots of stuff from TV ads... if I start hearing voices telling me to hurt myself...

Alternatives to hospitals

I want to go to a crisis bed but not a hospital if I am feeling self-destructive.

Preferences for care

Take me to X hospital, where I trust the staff.

Knowledge of medication effects

I will take this antipsychotic but have learned from past experience not to have a dosage over XYZ
Adverse actions

I do not want injections because I am afraid of shots but I am OK with pills.

Trauma concerns

Because of past sexual abuse, I cannot be put into restraints. This would worsen my condition. Do this instead...

Setting treatment parameters for providers and agents

I authorize my agent/provider to treat with anti-psychotics they decide on, but if I start exhibiting the following side effects, I want the medication reduced or stopped.

CAVEAT: A PAD is not a wish list.
It does not give a person more rights or services than they are reasonably and otherwise entitled to as a competent person.
Why have an agent?

To see that one’s instructions are carried out.

To work with care providers at a time when it is very hard for the person to do so.

An agent means a more flexible directive, able to adjust to unforeseen options or circumstances. For example, a new medication or a therapy the person did not anticipate in the directive.
Can a PAD Address Record Access?

A PAD can permit --or limit-- record review and consent to disclosure of medical records, and may have specific instructions regarding disclosure, through instructions or by the agent.

HIPAA and 45 CFR have specific considerations.

- HIPAA permits record disclosure where a person is incapacitated “consistent with prior expressed wishes known to the provider”. “Expressed wishes” can be written or oral. 45 CFR § 164.510 (a)(3)
- Note Psychotherapy note exception in 45 CFR § 164.524(a)
What about kids, pets and finances?

**Kids**
Designated temporary custodian document
- Designation of triggering events for transfer of custody
- Other parent must consent or be unable to consent due to unwillingness, absence in child’s life, termination etc.

**Finances**
Power of Attorney form

**Pets**
Make prior arrangements, with instructions, plan, and contacts placed in PAD.

*Attach these documents to PAD, with copies to designees.*
Can a person prepare a directive in the hospital or while under commitment?

- Generally, a person is assumed competent – even if committed.
- But, if under an involuntary medication order, a person has been found legally incompetent to make certain medication decisions.
- PAD *should not* be filled out when a person’s judgment is impaired.
- PAD *can* be filled out as part of a discharge plan if a person is doing well; has capacity to make informed decisions.
Where to keep a PAD

• If a person has an agent, it is essential that the agent have a copy.

• Some states have registries for directives, including PADs.

• Providers must keep a PAD document in the person’s medical record.

• Wallet cards or electronic options—flash drives, IPADs, smart phones.

• Some keep their PAD on the refrigerator so it is handy for emergency personnel.
Provider obligations: Implementing a PAD

Generally, provider obtains individual’s informed consent, unless agent is specifically authorized to consent or a person cannot consent.

PAD usually goes into effect when a person lacks the capacity to make informed decisions about care.

Provider must act in good faith per applicable standards of care; comply with the PAD to the fullest extent possible, consistent with reasonable medical practice, the availability of treatments requested, and applicable law.
PAD implementation: Does this person currently lack capacity? Are the instructions in the PAD within community medical standards?

Implementation involves clinical judgments, but a provider cannot ‘override’ or invalidate a directive; that is a legal judgment.

Assisting a person to understand the limits of community treatment standards and their options is an important aid to creating an effective PAD.
What if the providers refuse to go along with a PAD?

Provider must *in good faith* follow PAD that are within reasonable clinical practices/standards, and can be reasonably carried out.

A provider *acting in good faith* is generally not liable for refusing to follow a PAD.

In many states, consequences of this are limited, for example notify patient, document reasons in chart, and may transfer care.
What if a person refuses to go along with things they consented to in the directive?

An agent can be instructed in the PAD to work with providers to implement instructions and make other decisions as needed.

Treatment providers are obligated to follow a valid PAD, yet often defer to the courts because they are hesitant to enforce it.

Providers can file a petition for commitment and/or to administer medications, but a PAD may also have an effect on what the court decides,

The person may or may not be able to revoke PAD.
Legal Immunity

Agent acting in good faith reliance on directive instructions.

Provider relying on decisions made by an agent the provider believes is acting in good faith.

Provider relying on directive instructions in good faith and within standards of care is not subject to criminal prosecution, civil liability, or professional discipline.
Penalties

In many states, it is a misdemeanor to

• willfully concealing/canceling PAD
• withholding knowledge of a revocation
• falsifying a PAD
• coercing execution of a PAD
• requiring/prohibiting PAD as a condition of receiving services

It may be a felony if one of the above actions results in bodily harm to the person

Always check YOUR state’s law!
Duke University study on Psychiatric Advance Directives

• 66% of psychiatrists would honor a PAD, but thought they would be used to refuse treatment.
• 94% of PADs gave advance consent for at least one medication.
• 77% also rejected at least one medication.

“No one liked Haldol.” Dr. Eric Elbogen

• 75% listed side effects experienced on particular medications.
• 50% instructed staff on how to avoid seclusion and restraint.
• 88% named a hospital they would go to.
• 62% named hospitals they would refuse.
Relevance of PADs in legal proceedings

- Having a PAD (especially if combined with a medical healthcare directive) with an agent may be a less restrictive alternative, preventing a guardianship.

- The existence of a valid PAD could affect the outcome of a court’s decision about forced medication.

- A valid PAD consenting to hospitalization or other treatment may prevent civil commitment.

- If a state has a form of commitment that ‘enforces’ prior wishes of an individual, court may follow PAD instructions.
Important considerations if you help someone draft a PAD

• **A directive is not a wish list.**

• Make sure instructions consider insurance networks, physician privileges, etc. Talk with trusted providers about the viability of desired instructions.

• PAD can be an important part of an effective WRAP/relapse prevention/crisis intervention plan, including hospitalization and medication, and these documents should dovetail.

• An agent given flexibility can address contingencies not in the directive. Directives can also coordinate other aspects of incapacity—children, finances, etc.

• A PAD can help someone get the care they want at a time when they are not doing well.
But we’re not attorneys...

PAD is a legal document that does **not** require an attorney. The legal intention is to “do it yourself”.

Individuals should:

• Read the form over first, asking questions if they don’t understand how it works.
• Do their homework. Who would be a good agent? What does my doc recommend about meds? What hospitals are out of network? Should I talk it over with my family?
• Do at least a couple of drafts before finalizing.
• **Legalese is not needed!**
Liability issues if we help with PADs?

- Provide forms, information and basic help, but the person is the author and the one to make the required decisions.
- Don’t agree to be a person’s agent.
- Don’t pressure your choices/will on your clients: coercing execution is illegal, and if it’s not their choice -- it won’t work.
- It is important to remind an unrealistic client of the limits of a directive.
- You and other providers are not obligated to take actions beyond reasonable medical practices/standards.
PAD Take Aways

1. A directive is a self-determination tool to use to make informed decisions now about things that may happen in the future.

2. Consider combining a PAD with health care and end-of-life directives to cover the span of medical decision-making that might be needed.

3. A directive does not give a person more care than they are otherwise entitled to, so be realistic in the instructions in the directive.

4. Make sure those who need to know have a copy of the directive.

5. A directive needs to be updated regularly, especially when there are changes in one’s life!!!—new insurance, new providers, etc.
So, How Do PADs Play Out During Treatment?

Marie Verna, MPAP (C)
Rutgers University
Behavioral Health Care
732-235-9289
vernamd@ubhc.rutgers.edu
On a scale of 1 (none) to 5 (very high), rate your **COMFORT** with developing or implementing a Psychiatric Advance Directive (PAD).

1 - none
2 - a little
3 - some
4 - quite a bit
5 - very high
Hesitation from Practitioners

- Assumption that a PAD applies only in a crisis
- Liability
- Inability to find services requested
- Lack of practice using “shared decision-making”
- Need to read another document in addition to the chart
Hesitation from Families

• Assumption that a PAD applies only in a crisis

• Person will “change his (or her) mind”

• Provider won’t listen

• Lack of familiarity with “person-centered care”

• Lack of trust
Hesitation from people managing behavioral health issues

- Assumption that a PAD applies only in a crisis
- Fear of anything “legal”
- Sense of being overwhelmed
- Traumatic to think back to relapse or crisis
- Lack of trust in THEMSELVES
Preferences vs. Demands

"WHY?"
Preferences vs. Demands

- Medication
- Alternatives to hospitalization
- Hospital preferences
- ECT (refusal)
- Emergency response alternatives
Preferences vs. Demands

- Medications an individual would want in a crisis and which ones the individual would refuse
- Side effects an individual is not willing to tolerate
- Allergies to medication
Preferences vs. Demands

- Signs and symptoms of a mental health crisis
- Who should be informed, permitted to visit, participate in treatment meetings
- Who should be called to care for the pet, pay the rent
- Childcare
- Medical conditions
“Collateral”
Knowledge of self
Prevention and early intervention
Responsibility and control
More Than Legal

“Primum non nocere”
“First Do No Harm”

Hippocrates
Late 5th century, BC
Q & A Discussion
For more information on today’s topic review the RTP September 2016 Newsletter

http://www.samhsa.gov/recovery-to-practice
Do you want CEUs?

A certificate of participation in today’s webinar?

Continuing Education Hours from NAADAC:

• Complete the following quiz and a certificate will be provided to you at the end.

Certificate of Participation and Presentation Slides

• Click on “Download Materials” box
• Download certificate PDF and print
• Download presentation slides

A feedback form will automatically load at end of webinar.
Let us know what you think!
Visit the RTP website!
http://www.samhsa.gov/recovery-to-practice

• Learn more about recovery-oriented approaches to practice
• Receive quarterly RTP newsletter
• Access upcoming and archived webinars, events, and resources for recovery-oriented practice
• Check out the RTP discipline-based curricula and other resources

Email RTP at
RTP@AHPnet.com