

# Advance Directives with Instructions for Mental Health Care

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## Contributors

- This presentation is the result of collaboration between:  
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[www.virginiaadvancedirectives.org](http://www.virginiaadvancedirectives.org)

## Presentation Overview

- Advance Directives and advance care planning
  - Why every adult should have an Advance Directive
  - History and Research
  - Implementation in Virginia
- Parts of an Advance Directive
  - What does Virginia require to make a valid Advance Directive
  - What are the main parts of an Advance Directive
- Roles for individuals, consumers, peers, advocates, family members
  - Raising awareness
  - Facilitation



## Advance Directives and Advance Care Planning

- Why every adult should have an Advance Directive

### Question: What if...

- You **needed** health care (including mental health care) and you were **not able** to make informed decisions about your care?
- **Someone** will make decisions for you when you can't make them for yourself.
- How can **you** control who that someone will be, and what decisions they will make?

### Answer: Make an Advance Directive

- A legal document that lets you direct your *future* health care, if you become unable to make informed decisions
- Three variations of an Advance Directive:
  - Appoint an agent to make decisions for you
    - or -
  - Give instructions regarding your care
    - or -
  - Do both – appoint an agent and give instructions

## Advance Directives: Other Terms You Might Hear

- Related to and/or called
  - Living will
  - Psychiatric advance directive (PAD)
  - Health care power of attorney
  - Health care proxy
- Historically related to living will
- Appointing an agent is same idea as giving power of attorney
- BUT some important details to know about how ADs with instructions for mental health are different in Virginia

## Fran's Story



- Fran has a serious mental illness
- She takes medication and goes to treatment, and usually she does fine
- Sometimes Fran has a crisis and needs to go to a hospital for help getting stabilized
- Fran knows how she feels and acts when she is building toward a crisis, so she asked her husband to look for those signs
- But, when Fran has a crisis, she loses those insights and refuses to go to the hospital
- Consider how her story might change if she has been separated from her husband for many years...or if she and her husband are common-law spouses...?

## Ted's Story



- Ted made a general medical Advance Directive and named his wife as his agent
- When Ted made his Advance Directive, he didn't have a history of mental illness, so he didn't give his wife power to make decisions about his mental health care
- Ted develops dementia and his symptoms include confusion and upset that would be best treated by some time in a psychiatric hospital
- But, his wife has limited power as his agent and cannot authorize his admission to a psychiatric hospital
- Consider how Ted's story might change if he is in a same-sex partnership

## Jill's Story



- Jill is a widow who just retired, and she is re-writing her will so her adult children know her wishes
- Jill also wants to plan for her end-of-life health care, should she develop a terminal condition
- Of her four children, two agree with what Jill wants regarding end-of-life care
- But, two of her children do not agree, so Jill needs a way to set out her wishes so that they will be followed

## Origins of Advance Directives

- “Living will” laws direct end-of-life care
- Patient Self-Determination Act of 1990 – a federal law, focused on *medical* health care planning
- Psychiatric Advance Directives (PADs)
  - Developed in the 1990s
  - Capitalize on **benefits of advance planning**:
    - Exert more control over own mental health treatment
    - Avoid involuntary treatment
    - In line with recovery, person-centered care, and shared decision making
    - Allow for family involvement in treatment decision making

## Virginia Law

- AD for mental health care in Virginia
  - The **Commission on Mental Health Law Reform** established in 2006
    - Thorough review of Virginia laws and practices relating to persons with mental illness
- Virginia enacted revised legislation in 2009
  - Virginia allows mental health and medical treatment planning to be covered in one Advance Directive health care form

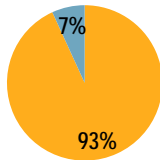
Separate PAD	Integrated AD
Keeping mental health info separate avoids stigma by providers	Integrating = commitment to overcoming stigma & addressing needs of the whole person
Still have the option to attach a PAD to their general Advance Directive	Integrated forms allow for coordination across treatment providers (e.g., avoiding drug interactions)

## Are We Interested in ADs in Virginia?

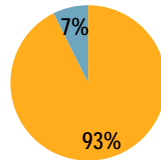
- Stakeholder survey in 2010 in anticipation of legislative changes
  - Knowledge of and attitudes about ADs from:
    - Mental health service users,
    - Family members,
    - Administrators of hospitals,
    - CSBs, and
    - Advocates.
- All respondents held favorable views of advance directives with instructions for mental health care

(Wilder, Swanson et al., 2012)

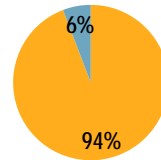
## Are We Interested in ADs in Virginia?



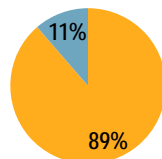
ADs will give people with SMI more control over their lives



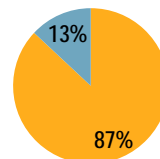
ADs will lead to better understanding of treatment desires in crisis and outpatient settings



ADs will lead to improved quality of life for individuals



ADs will improve relationships between providers & consumers



ADs will increase providers listening to consumers

## Are We Interested in ADs in Virginia?

- Excellent support for ADs, but variable knowledge about them and different perceptions of barriers
- Administrators and clinicians tended to worry about time to complete and complexity
  - No one to appoint as agent
    - 79% of clinicians vs. 24% of consumers
  - Consumers will not see ADs as relevant
    - 83% of clinicians vs. 10% of consumers
- So, we are interested, but maybe a bit unclear on how routine use of ADs might play out

## ADs are Useful for Treatment

- All ADs were rated as including useful instructions
  - In agreement with clinical practice standards
- No one used an AD to reject all treatment
- Everyone authorized hospitalization or feasible alternative
- When reasons for medication refusal given, doctors more likely to honor that choice

(Srebnik et al., 2005; Swanson et al., 2006; Wilder et al., 2007)

## Benefits to Individuals

- Increased sense of control → increased sense of well-being
- Improved working alliance with providers
- Improved feeling of having treatment needs met
- Increased likelihood of receiving medication requested → increased likelihood of staying on medication, reducing symptoms

(Srebnik & LaFond, 1999; Swanson et al., 2006)

## Benefits to Individuals

- Having an AD with instructions for mental health care reduces the incidents of coercive intervention
  - Police transport, involuntary commitment, seclusion & restraints, involuntary medications
- People with ADs were **HALF** as likely to experience coercive interventions compared to people without ADs
  - Over a 2 year period

(Swanson et al., 2008)

## So, Everyone Has an AD, Right?

- Demand
  - 66-77% of people say they would like to complete an AD with instructions for mental health care
- Use
  - Only 4-13% of people have completed an AD
- Virginia has committed itself to making ADs part of routine care
  - How can we increase use, if “being on the books” and education are not enough?

(Swanson et al., 2006)

## Facilitated Advance Directives

- Facilitation increases completion almost 30 fold
  - 3% of “control group” completed an AD
  - 84% of consumers who met with facilitator completed an AD
- 80% completion rate achieved in another study with peer-led education and software program
- Facilitated ADs are of higher quality
  - Feasible instructions
  - Meet legal requirements

(Elbogen et al., 2007; Srebnik et al., 2005; Swanson et al., 2006)

## Additional Benefits of Facilitation

- Facilitation improved working alliance and increased perception of having treatment needs met
- Facilitation improved decision making capacity
  - Helps people think through their reasons for decisions
- Understanding of ADs is related to increased sense of autonomy
  - And it helps people remember they have an AD during crisis

(Elbogen et al., 2007; Swanson et al., 2006)

## What's the Point of All This?

### ...ADs are Recovery Tools!

- Like other crisis planning, ADs provide a place to record your own thoughts about your treatment
- ADs shield your voice with **legal status**
- ADs promote **self-determination** and **autonomy**
- The process of completing ADs is **empowering**
- Completing an AD can improve **communication** with providers and agents
- ADs can serve as an informational **bridge** between providers



## Overview of Advance Directives Components

- The main parts of an AD

## What Health Care Can be Covered?

- Any or all of these types of health care:
  - Medical health care
    - E.g., medications, surgery, admission/discharge to hospital
  - Mental health care
    - E.g., psychiatric medications, psychiatric hospitalization
  - End-of-life care
    - E.g., respirator, feeding tube, medication to relieve pain

## Required Elements to be Valid in Virginia

- For an AD to be legally valid in Virginia, it needs:
  - To be signed by the person making it
  - To be signed by two adults who witness the person's signature
- In Virginia, an AD does **NOT** need:
  - To be on a particular form
  - To be notarized
  - To be written by an attorney
- Photocopies of the original are valid for use by health care providers

## Capacity to Make an Advance Directive

- For the Advance Directive to be valid, the person making the AD must have **capacity**
  - That is, she must be capable of making decisions for herself at the time she makes the AD
- Under Virginia law, every adult is **presumed** to have capacity
  - Unless there is a legal finding of incapacity

## Option for Setting Out Wishes

- Only appoint an agent
  - or-
- Only give instructions
  - or-
- Both appoint an agent and give instructions

## Appointing a Health Care Agent

- An **agent** is a person you trust who will advocate on your behalf and carry out your wishes
- Any competent adult can be your agent
  - But best to pick someone who knows your values and preferences regarding health care and is willing to follow your instructions
- Your agent has the **duty** to follow your instructions and preferences
  - (or make decisions in your best interest if your preferences are unknown)

## Appointing a Health Care Agent

- Part of being an agent is having powers to act on behalf of you
- The powers given to an agent are the powers that you usually have when making health care decisions
  - The agent temporarily get those powers so the powers can be used for you while you are unable to use them yourself
- You can limit and tailor the powers to what you are comfortable with
  - For example, you might allow mental health care but not allow participation in research

## The Power to Authorize Treatment Over Your Objection (“Ulysses Clause”)

- Why give this power?
  - There may be times that a person objects to treatment that he would want if he was not in crisis (recall “Fran”)
  - E.g., Confusion or delirium due to head injury, medical condition, or side-effect



- Extra protections around giving this power to agent
  - Physician or licensed clinical psychologist signature

## Giving Instructions

- You can give instructions about the health care you agree to and the health care you refuse
- Your agent must follow your instructions
- Your doctor must follow your instructions
  - UNLESS she finds it illegal, unethical, medically inappropriate
  - BUT she cannot treat you in a manner that goes against your instructions without separate legal authority
    - Emergencies to prevent harm; court-ordered treatment

## Giving Information and Preferences

- **Information:** Important background information to know, like allergies or devices
- **Preferences:** Important details about what the person prefers and values – to provide guidance to agent/doctors
- **Instructions:** Specific directions that the agent and doctors must honor in most cases, including refusals

## How is an Advance Directive Activated?

- A finding of incapacity by your attending physician
  - In-person examination
  - “incapable of making an informed decision regarding your care”
- **PLUS** a finding of incapacity by a second physician or psychologist who is not currently treating you
- The doctor must tell you their finding and put their finding in writing in your record
- Note: Psychiatric commitment does not automatically result in a finding of incapacity

## How is an Advance Directive De-Activated?

- As soon as any doctor examines you and finds you are able to make informed decisions again
  - → You are put back in charge of making decisions
  - This finding must be put in writing by the doctor
- Your AD is “de-activated” and is no longer used to make decisions about your health care

## If You Do Not Have an Advance Directive...

- There are other laws and regulations that direct who should make decisions about your care:
  - Health Care Decisions Act
    - Guardian, Spouse, Adult child, Parent, Adult sibling, other relative, “next friend”
  - Authorized Representative
    - In programs regulated by DBHDS
  - Guardianship – a last resort



## Roles for Individuals, Consumers, Peers, Advocates, Family Members

- Raising awareness and use of Advance Directives

### Raising Awareness and Creating Demand

- Survey after survey shows a “latent” demand for ADs
  - But ADs are still generally not widely discussed
  - Also, misunderstandings to overcome
- Peer-run groups are vital wellsprings for promoting adoption of new, useful tools
  - Evidence in Virginia
- Peer-run groups are also key collaborators for cross-systems adoption
  - Education to consumers and providers

## Facilitation

- Peer facilitation may be the most desirable strategy
- Unauthorized practice of law
  - Virginia Bar Association opinion
  - Exception for health care providers
- Providing general education and referrals
- Coming Soon: Certification Training for Facilitators

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