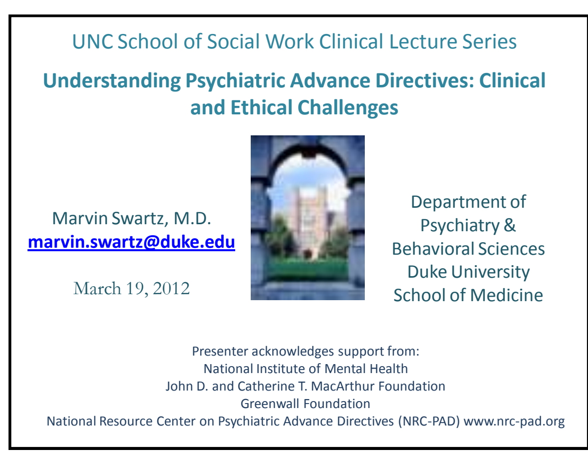


WHAT I WILL TALK ABOUT TODAY

- **Psychiatric Advance Directives (PADs)—what PADs are about, and how I got interested in studying them**
- **Where PADs "came from"**
- **Development of research evidence on PADs**
  - stakeholder landscape
  - prevalence and correlates
  - barriers to completion and use
  - intervention development
  - short-term and long-term outcomes
- **Why PADs are ethically challenging**

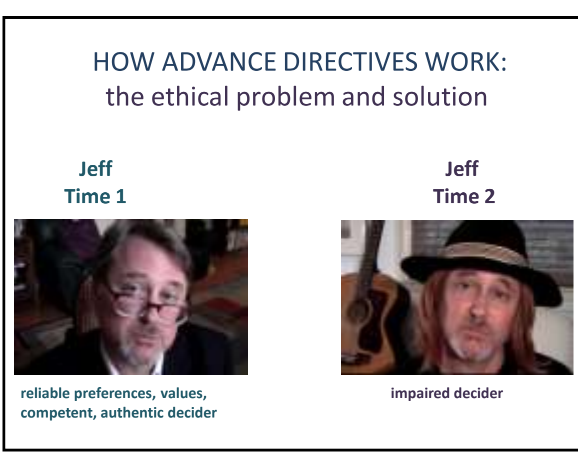
What are psychiatric advance directives?

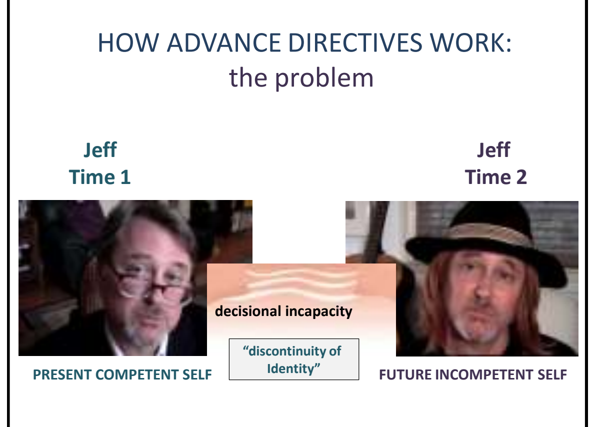
- **Psychiatric advance directives (PADs) are legal instruments that allow competent persons to document their decisions and preferences regarding future mental health treatment (Instructional Directive)**

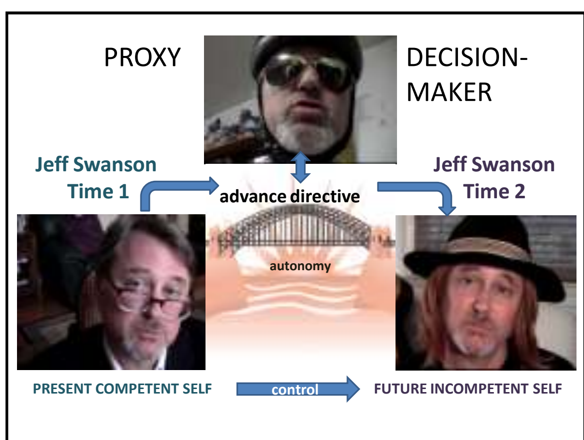
and/or

- **Designate a surrogate decision-maker in the event they lose capacity to make reliable treatment decisions during an acute episode of psychiatric illness.**

(Health Care Power of Attorney)







Key features of PADs

- Two legal types of PAD instruments; in many states can be used separately or together
  - instructional: advance consent/refusal
  - procedural: authorize proxy decision-maker
- PADs are device for advance communication
  - treatment decisions (consent/refusal)
  - preferences and values to guide future decisions
  - emergency information
  - portable "psychiatric resume"
- Limited waiver of confidentiality
- Ulysses contract or "self-commitment"

An agreement relinquishing the right to change one's mind can be called a "Ulysses contract."

On his 10-year voyage back to Ithaca from the Trojan War, Ulysses was warned by Circe to take precautions if he wanted to hear the Sirens' transfixing song, or there would be "no sailing home for him, no wife rising to meet him, /no happy children beaming up at their father's face."

Ulysses accordingly ordered his men to stop their ears with beeswax and bind him firmly to the mast and instructed them that if he gestured to be set free, they should stick to the original agreement and bind him tighter still.

Where did PADs come from?

– Medical advance directives and benchmarks in federal law

- Supreme Court decision in 1990 *Cruzan v. Director, Missouri Department of Health*
  - Required "clear and convincing evidence" of a patient's wishes in order to withdraw life-sustaining medical treatment
  - Defined need for written documentation as evidence of incapacitated patients' treatment preferences
- Patient Self-Determination Act 1991
  - Required hospitals receiving federal funds to ask patients if they had an advance directive on admission, and to have a policy for implementing advance directives

Why did people want psychiatric advance directives?

Lifetime prevalence of **coercive crisis interventions** among public-sector psychiatric outpatients in NC

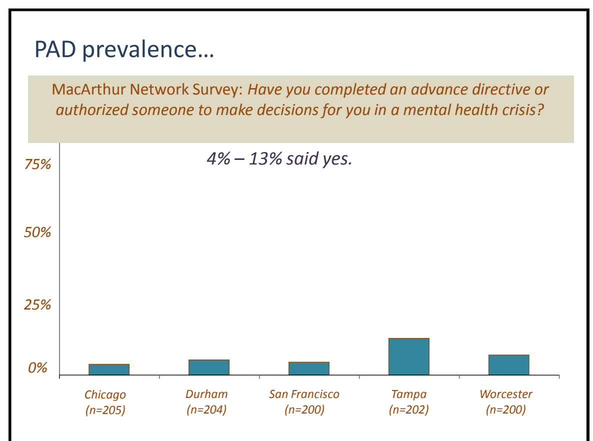
Type of intervention	Percent
Police transport to treatment	67.78
Placed in handcuffs	41.84
Involuntary commitment	61.09
Seclusion on locked unit	49.79
Physical restraints used	37.66
Forced medications	33.89
Any coercive crisis intervention	82.43

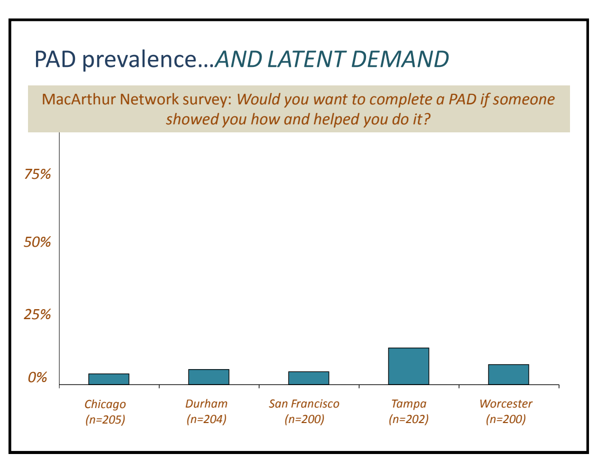
Where did PADs really come from?

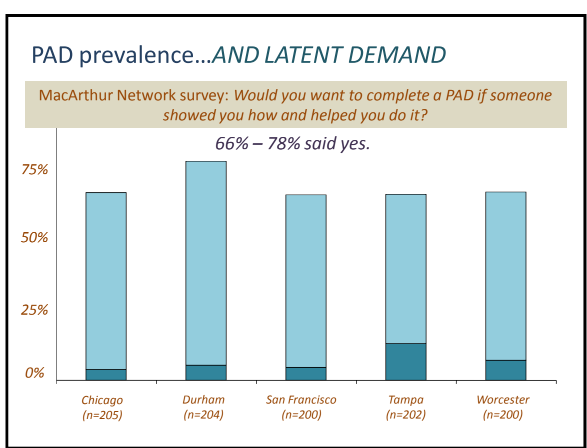
- Driving factors in the USA in the 1990s:
  - Concerns about widespread coercion and social control in mental health treatment; PADs were seen as an alternative to involuntary treatment.
  - New emphases on recovery, patient-centered care, and shared decision-making in mental health services.
  - Family involvement in treatment decision-making.
  - Mental health advocates adapted advance directives to the context of "episodic incapacity" around mental health crises.
  - Political collaboration: Protection & Advocacy attorneys, state-level NAMI members, mental health consumer advocacy organizations, academic bioethicists and legal experts came together to support PAD legislation in several states.

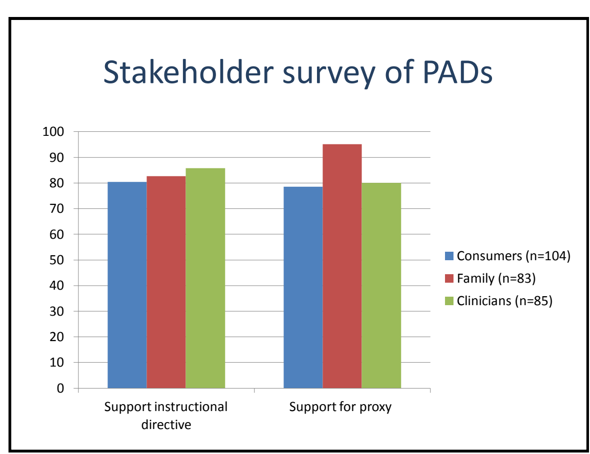
Increasing interest in PADs in the US: new laws in 26 states since 1991

Period	Number of states	States
1991-1995	5	Minnesota, Arizona, Maryland, Oregon, Maine
1996-2000	8	Illinois, Utah, North Carolina, South Dakota, Texas, Idaho, Michigan, Wyoming
2001-2005	10	Louisiana, Oklahoma, Kentucky, Ohio, Washington, Alaska, Hawaii, Indiana, Pennsylvania, New Jersey
2006-2011	3	New Mexico, Virginia, Montana









Research questions

- What are the barriers to PADs?
  - completion and use
  - different stakeholders, different perceived barriers
- Does structured PAD facilitation work for people with serious mental illness?
  - address, overcome barriers
  - result in completed, legally-valid PADs
- When consumers do complete PADs, what do these documents contain?
  - structure
  - clarity, feasibility of instructions
  - concordance with clinical practice standards

Research questions

- Do PADs work as intended?
  - Short-term outcomes: empowerment, working alliance, treatment satisfaction
  - Long term outcomes: prevention of crises and reduction of involuntary treatment and coercive crisis interventions

Why don't people complete psychiatric advance directives?

Consumers' perceived barriers to PADs
(N=469 participants)

- Don't understand enough about PADs.
- Hard to find someone or somewhere to get help to complete the PAD.
- Don't know what to say or write in the PAD.
- Don't have anyone I trust enough to make decisions for me.
- Don't have a doctor I trust.

85% percent endorsed at least one of barrier.
55% reported 3 or more of the barriers.

Structured facilitation of pads

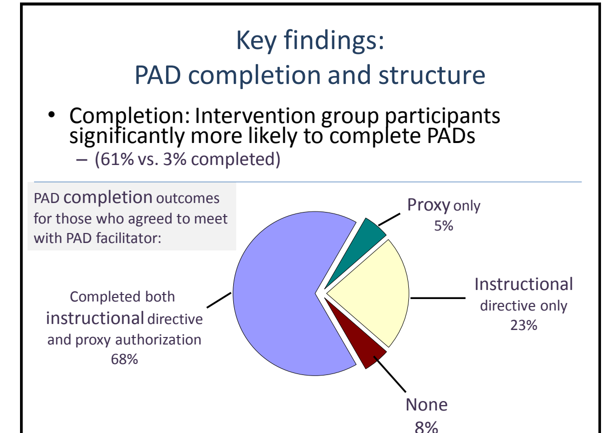
- Facilitated Psychiatric Advance Directive (FPAD) intervention developed at Duke
  - 60-90 minute session with trained facilitator
  - Guided, structured discussion of future treatment choices
  - Educate and assist consumer in completing legal advance instruction for mental health treatment and/or health care power of attorney
  - Witnesses, notarization, file in medical record, copy to proxy, store in electronic registry

Duke study: Effectively Implementing PADs (NIMH R01 and MacArthur Network funded)

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

Key findings: PAD completion and structure

- Completion: Intervention group participants significantly more likely to complete PADs
  - (61% vs. 3% completed)



PAD document content

- **Prescriptive and proscriptive function:** Almost all PADs included treatment requests as well as refusals, but no participant used a PAD to refuse all treatment.
- **Most PAD included specific, relevant information** about relapse factors, crisis symptoms, medication and hospitalization preferences, ECT, contact information and other instructions
- **Concordant with standard clinical care:** PAD instructions were systematically rated by psychiatrists, and mostly found to be feasible and consistent with clinical practice standards.

Do PADs work?

???

Outcome study findings

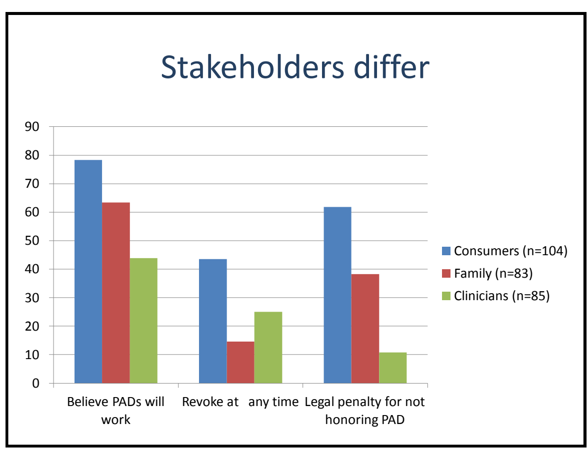
- Improved working alliance with case managers and clinicians
- Increased treatment satisfaction: *"As the result of services I received, I deal more effectively with daily problems…I am better able to control my life…I am getting along better with my family…I do better in school and/or work."*
- Higher utilization of outpatient services for medication management and crisis prevention
- Increased concordance between requested and prescribed meds.
- Fewer crisis episodes
- Reduced likelihood of coercive crisis interventions

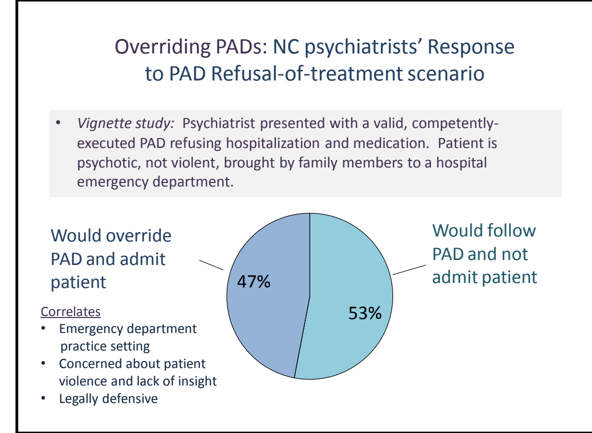
Problems with implementing PADs in usual care: Clinicians' perceived barriers to implementation

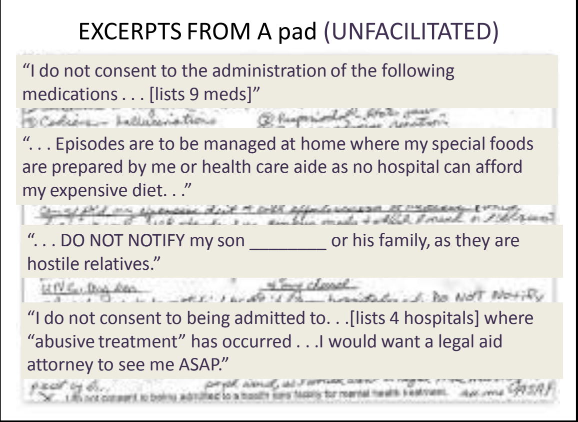
– Perceived operational barriers
  - lack of communication and coordination across service sectors
  - lack of access to the document in a crisis

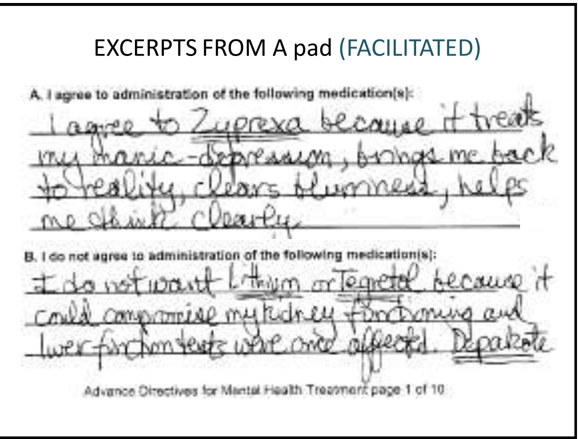
– Perceived clinical barriers
  - inappropriate treatment requests
  - consumers' desire to change their mind about treatment during crises
  - concerns with consumers' competency to complete document

– Legal defensiveness
  - Psychiatrist: "Would I rather be sued by a patient because I didn't follow their advance directive, or by somebody else because I did?"









A. I agree to administration of the following medication(s):

I agree to Zyprexa because it treats my manic-depression, brings me back to reality, clears flumness, helps me think clearly.

B. I do not agree to administration of the following medication(s):

I do not want Lithium or Tegretol because it could compromise my kidney functioning and liver function tests were once affected. Depakote

Advance Directives for Mental Health Treatment page 1 of 10

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 these 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 determine treatment during incapacitating crises, they can have an indirect benefit of improving engagement in outpatient treatment process.
- PADs can help prevent crises as well as reduce the use of coercion when crises occur.
- Need for system-wide implementation efforts. As yet, PADs remain a promising idea with little implementation in usual care.

NORTH CAROLINA DEPARTMENT OF THE SECRETARY OF STATE
ADVANCE HEALTH CARE DIRECTIVE REGISTRY

Welcome to the North Carolina Advance Health Care Directive Registry! We are pleased to offer this service of registering your Advance Health Care Directives online for easy accessibility

Internet: www.sosnc.com

NORTH CAROLINA DEPARTMENT OF THE SECRETARY OF STATE
ADVANCE HEALTH CARE DIRECTIVE REGISTRY

Standard Forms:

- **Registration Form**
- **Health Care Power of Attorney Form**
- **Advance Instruction for Mental health Treatment**
- **Revocation Form**

NORTH CAROLINA DEPARTMENT OF THE SECRETARY OF STATE
ADVANCE HEALTH CARE DIRECTIVE REGISTRY

Steps to register:

- **Print a registration sheet from the website**
- **Fill in the required information.**
- **Witness (2) and notarize forms.**
- **For each directive you wish to register with the North Carolina Secretary of State, please attach a $10.00 fee.**
- **Submit one (1) cover sheet for each directive to be filed.**
- **Mail to:**
  North Carolina Secretary of State
  Attention of Advance Health Care Directive Registry,
  Post Office Box 29622,
  Raleigh, North Carolina 27626-0622.

NORTH CAROLINA DEPARTMENT OF THE SECRETARY OF STATE
ADVANCE HEALTH CARE DIRECTIVE REGISTRY

Next Steps:

- **Will receive a registration card and password**
- **Copies should be given to people who might need them**
- **Password will provide access to webs**
- **Revocation will remove forms**

Case Report

- JR is a 28 yr. old single WM with 8 yr. history of schizophrenia, with one prior hospitalization, now petitioned by his parents for exacerbation of psychosis.
- Had executed an Advance Directive (AD)1 yr. ago during an evangelical religious retreat, witnessed by a lay minister.
- Parents unsure whether advanced directive could be invoked, so proceeded to commitment with hope of revisiting issue of AD once patient was hospitalized.

History

- Functioning in community, holding a job with a technology company as a computer specialist for the past two years.
- Discontinued olanzapine several weeks ago due in part to excessive weight gain.
- Has become increasingly isolative, withdrawn and paranoid.
- Increased religious rituals such as praying constantly for several hours on his knees.
- Grandiose delusions that he is a messenger from God with prophetic powers.
- Refusing all but liquids. Refusing medications.
- Auditory hallucinations of two voices giving running commentary on his behaviors.
- One voice directed him to "scarify himself" and he cut his wrist and arms.
- Loss of insight concerning his illness.

Past Psychiatry History

- One prior involuntary hospitalization at initial onset of illness when 20 yrs. old and a sophomore in college.
- Found the experience dehumanizing and believes was a form of religious persecution.
- No history of violent or dangerous behaviors or prior suicide attempts or self injury.
- No history of substance abuse.
- Medication trials on prolixin (oral) and perphenazine.
- Developed extrapyramidal symptoms with prolixin (parkinsonian symptoms).
- Recently developed facial tic while on perphenazine, resolved with change to olanzapine.
- 40 lbs. weight gain over past six months on olanzapine.
- Has never had complete resolution of hyper-religious focus or hallucinations.
- Limited insight into illness, although one year ago executed an advance directive.

Past Medical History

Medications:

- Olanzapine 20 mg qhs for past 6 months.

Family History:

- Negative for mental illness, developmental disabilities or substance abuse.
- Parents with college education; father is a professor of economics at local university.

Social History:

- College graduate; also obtained master's degree in computer science.
- Had moved into his own apartment several weeks ago about the time he also began to discontinue his medication.

Advance Directive

Legally executed advance directive included the following:

- Requests no involuntary hospitalization.
- Requests treatment only with a Christian psychiatrist.
- Requests no forced medications.
- Requests no treatment with prolixin or perphenazine but would like treatment with chemically related drug if shown to be safe and effective in long-term clinical use.
- Selected his mother as a proxy decision-maker if determined to be incapable.

Informed Directives?

1) Did the patient create the PAD while capable?
2) Is the PAD informed by present knowledge of risks and benefits?
3) Is a schizophrenic patient, who never achieved full remission, capable of making an informed reasoned judgement?
4) Was the patient adequately educated about the pros and cons of treatment, and the likelihood that the treatment can be carried out?
5) Was the surrogate decision maker adequately involved in the preparation of the PAD?

Informed Directives?

6) Was the patient coerced during the preparation of the PAD?

7) Is it possible that since the PAD was legalized, the patient changed their mind for reasons unrelated to delusional beliefs?

Ethical Dilemmas

- What is the "authentic voice" of JR?
- What represents his true wishes?
- Is it ethical to force the wishes of a "prior self" on the "current self"? (Ulysses contract)
- When is it ethically appropriate to force treatment against the patient's wishes?

Is it feasible to carry out the PAD?

1) Can specific medication requests be honored?

2) Are the patient's requests in the patient's best interest medically?

3) Is there enough detailed instruction so that the patient's request can be honored?

4) Are there adequate financial and medical resources available so that the requests can be instituted?

5) Is the surrogate decision-maker available?

6) Is there evidence that the patient's preference for outpatient care has failed?

Will carrying out the treatment plan in light of PAD serve to foster patient cooperation or further damage the patient's trust in health care providers?

Ways To Improve Usefulness of PADS

- Patients should participate in the actual writing of the PAD, with their MD's guidance, tailored to the patient's specific situation.
- PADs should be updated regularly, especially after crisis periods.
- Family members should be involved as much as possible.
- Patients without family members should be assisted in finding suitable advocates/surrogate family member.