





Psychiatric Advanced Directives: Youth & Young Adults Implementation Guide



The Youth MOVE National TA Center is a program of the Substance Abuse and Mental Health Services Administration (SAMHSA) under grant 1H79SM082658-01 and, U.S. Department of Health and Human Services (HHS). Interviews, policies, and opinions expressed are those of the authors and do not necessarily reflect those of SAMHSA or HHS.

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Introduction

Psychiatric Advance Directives, also known as PADs, are powerful tools that prioritize people having control of their mental health treatment decisions. In this implementation guide, we will explore what PADs are, why they matter, and how they can empower youth and young adults to protect their voice, choice and autonomy over their personal mental health treatment. This guide should be used by organizations to help youth & young adults understand and create their own PADs. The material included can potentially guide a youth, young adults, and youth peer providers on creating PADs.





PADs empower autonomy and help make sure that you receive the care you want, especially if you are in crisis and are unable to remember or communicate what your choices for care are. By completing a PAD, you can communicate your treatment preferences to medical providers, the hospital, law enforcement, and caregivers even if at that moment you are not able to communicate as well as you usually can. Planning ahead like this can help prevent unwanted or harmful treatment and ensure that your needs are met on your terms. Additionally, having a PAD offers you a doorway legal protection if you feel as though the wishes of your PAD are not honored to the best of the treatment team's ability during any involuntary mental health treatment.

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youthmovepeercenter.org

Across the country, recovery-oriented services and consumer run organizations, including youth and family- run organizations, are increasingly seen as vital supports within the mental health service array. Youth MOVE National's Consumer Peer Center was established in July 2020, with grant funding support from the Substance Abuse and Mental Health Services Administration. As a youth-run peer organization, YMN honors lived experience and recognizes the value of both traditional and non-traditional supports. We serve peers across the lifespan, their families, and providers of all ages, to grow the youth peer movement across the United States. As one of five funded Centers, we look forward to collaborating with our partners to improve and sustain the implementation of peer and recovery-oriented services and supports.

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copelandcenter.com

The Copeland Center for Wellness and Recovery is a peer-run organization that serves as the hub of an organic, grassroots movement of tens of thousands of individuals with lived experience of mental health challenges and hundreds of organizations in mental health systems using evidence-based peer support and self-help strategies for achieving personal and community-wide wellness and recovery. The Copeland Center is recognized as the world's preeminent organization advancing the knowledge, skills, and values of evidence-based peer recovery practices. The Copeland Center's Doors to Wellbeing Program is a SAMHSA-funded National Consumer Technical Assistance Center under grant 1H79SM082653-01 that focuses on peer support, peer-led education, and promotion of psychiatric advance directives.



https://www.onourownmd.org/s/

On Our Own of Maryland, Inc. (OOOMD) is a statewide peer-operated behavioral health advocacy and education organization which promotes equality, justice, autonomy, and choice about life decisions for individuals with mental health and substance use needs. On Our Own of Maryland, Inc. is a registered 501(c)(3) nonprofit organization; financial statements are available upon request.







WHAT ARE PSYCHIATRIC ADVANCED DIRECTIVES (PADS)?

A PAD is a legal document that outlines your preferences for future mental health treatment and/or assigns someone to make decisions for you during a crisis when you are unable to do so. While advance directives for health care have existed for years, PADs specifically focus on mental health care, addressing unique issues like medication and inpatient treatment preferences.

PADs are documents that allow you to self direct your care so that you have the best chance possible of having your treatment wishes followed. They are read by medical professionals, in a setting where you might be deemed incapacitated, incompetent and/or under an involuntary commitment.⁴

Incapacity¹

The state of lacking decision-making capacity. This is usually a temporary state that is determined by a physician or a psychologist upon examination of a patient. A person may experience incapacity if they are unconscious, delirious, intoxicated, psychotic, manic or catatonic, among other states.

Incompetence ¹

A legal determination based on whether a person has a long-standing lack of capacity or lack of ability to manage their own affairs. Incompetence is decided in a court hearing based on medical evidence. If a person is found to be incompetent, then a judge will appoint a legal guardian to make decisions for the person.

Guardianship

There are different types of guardianship, including guardian of the person and guardian of the estate. To reverse the legal finding of incompetence, a person must petition the court and provide medical evidence of competence.

PADS FOR YOUTH & YOUNG ADULTS

PADS can be considered a legal document for folks who are 18 years of age or older. If you have a legal guardian, they must sign it for it to be legally binding. However, youth under the age of 18 are encouraged to work with a supportive adult, a youth peer specialist, or another <u>natural support</u> to start thinking about crisis planning and developing a PAD. This will not only help you think through important elements of your care now, it will help you in the future if you wish to turn it into a legal document once you are 18. Using this approach, and including your parents or guardian as well as your providers, will support them in knowing your preferences, and you will have practiced using a crisis planning tool like this before you turn 18.







THE IMPORTANCE OF PADS

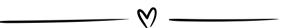
PERSONAL BENEFITS

- Support recovery and overall well being
- Help you prepare in advance of a crisis
- Give you an opportunity to track what is working and what is not working in your treatment
- Capture your voice and choice regarding your mental health treatment needs
- Be a tool for holistic advocacy, such as the dimensions of wellness (education, housing, employment, legal involvement, etc.)
- Improves access to treatment and care that is specialized for you
- Serve as a pathway of communication between yourself and an advocate for your choice to speak on your behalf if you cannot.
- Reduces coercive or forced interventions, creating a safer and more respectful experience for someone during a mental health crisis.



CARE TEAM BENEFITS

- Be viewed as a gift to eliminate the guessing game of which treatments work and which don't
- Give guidance on how to address crisis and treatment needs if a crisis occurs
- Offer an opportunity for communication between an individual and a supporter/care team



HEALTH SYSTEM BENEFITS

- Can coordination care regarding current treatment teams and medical history
- Collect data to find trends in treatment to support the system in seeing what's working & what isn't.
- Improve quality of care overall for individuals in services
- Increases cultural humility of services provided
- Reduce hospitalizations, criminal justice interactions and homelessness
- Offer a more cost-effective approach to services











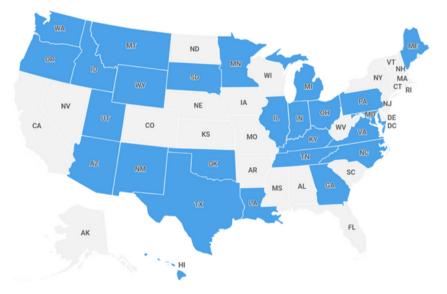
PAD LEGISLATION



The <u>Patient Self-Determination Act</u> guarantees your right to make decisions about future healthcare treatments without discrimination from any healthcare providers/organizations. This law ensures that facilities receiving Medicare or Medicaid reimbursements must inform patients about their right to have an advance directive.

<u>27 states</u> have laws allowing PADs, however under federal law, any facility receiving Medicare or Medicaid reimbursements is required to use advance directives. Individuals with physical and mental health conditions are covered under this mandate [2]. See if your state has a PADs law by

clicking on the map >>



Some states are starting to have conversations regarding age of consent laws and how they relate to PADs. An aspect of age of consent laws mean that there is an agreed upon age that a youth is able to consent to their mental health treatment. These laws can be very specific and can vary state-by-state. Some states are trying to lower the age of consent laws around PADs to be below 18, this would offer youth a stronger pathway to person-centered, pre-planned self directed treatment and autonomy over mental health care <u>here</u>.

"When I was 16 years old, in the state of Pennsylvania, my mother wanted me admitted to a psychiatric hospital. Since I was not a danger to myself or others as deemed by the hospital staff and because of age of consent laws, I had the right to refuse treatment. This was not what my mother wanted, but ultimately it was my choice, and my choice was honored by the hospital due to age of consent laws."

-Amey Dettmer (she.her)







TYPES OF PADS

Laws vary state to state on what can be included in a PAD. Some states will only allow one of the following parts, some allow both, and some allow either/or. If you live in a state that does not accept written instructions as a legal part of a PAD, you can still write out your wishes in a crisis plan, which is a non legally binding document.

Sometimes your wishes may not be legally honored, depending on which state you are in. Writing out your preferences might not be part of the legal document but can still support you and your supporters in knowing what you want and need. Having a crisis plan can be a great first step for thinking about what goes into your PAD. A crisis plan can be as thought out as you would like, and can apply to any crisis, whether you are receiving inpatient care, outpatient care, or just support from natural supports. See "Crisis Planning" on page 12 for things to consider.

1

Healthcare Power of Attorney/Agent Driven

This type of PAD designates a person of your choice who can make decisions regarding your treatment when you are unable to. The designated person should be someone you trust to advocate on behalf of your needs. All states allow some form of a power of attorney but the types of decisions a power of attorney can make vary state by state. It is important that your power of attorney knows what your needs are so they can best advocate for you.

2

Instructional

This type of PAD captures your written or verbal wishes for what types of treatment preferences you have for medication, hospitals, releases of information, specifics on what works for you in supporting your mental health, medical and mental health history, types of therapy preferences and more.

*Note: The titles describing the different types of PAD vary state by state.







WHAT IS INCLUDED IN A PAD?

- → Snapshot of your medical history. This can include allergies, chronic health conditions, and current medications
- → List of medications that have worked or haven't worked in the past (& medication preferences)
- → Emergency contacts and the healthcare providers you currently see
- → List of preferred hospitals/treatment settings, and those you wish to avoid
- → Important factors on treatment options: Are you willing to try drug trials or experiential studies or would you prefer to avoid these things?
- → Ways to reduce or avoid emergency treatments. Include things that calm or escalate a situation.
- → Spiritual wishes and considerations that would help during any time in treatment
- → Cultural considerations that would be important for a treatment team to know

It is preferable to attach a reason to your preferences in your PAD, as it gives the treatment team a more understandable view of why you have the needs you do. Some examples are:

My first choice in a hospital is; because I have had previous positive experiences with the treatment teams there. I would like to avoid hospital because of a past
traumatic experience there and returning would reactivate the traumatic event for me.
As an African American, having a hairbrush and hygiene products that are for my body and hair type will make a significant difference in my ability to be receptive to the treatment available to me.
I am not interested in being restrained in anyway, as that will prompt past memories of my exual abuse history and trauma. A better way to respond to me is to offer me a padded room to be in if I am deemed unsafe.

I do not want to take _____ medication, as I have experienced past side effects that have made me have thoughts of suicide.







I am requesting to not be put in a padded room, as this elevates my anger and in the past has made me not able to respond to treatment.

Listening to religious music and reading scripture helps me with feelings of hopelessness.

As a Native Indigenous person, I need the treatment team to understand that plant medicine and ceremonial purification is part of my cultural beliefs. I would benefit from connecting with other Indigenous people during my hospitalization.

Again, PAD laws and forms for PADs vary in each state. Some are very open-ended and some are very specific. You can find state specific information on PAD forms, laws, and other information at the <u>National Resource Center on Psychiatric Advance Directives</u>.

TIPS FOR WRITING YOUR PADS

BARRIER

The Process ~

Knowing what you want to express,
how to word it, and the steps needed
to make it "official"

SUGGESTION

Find out if your state requires a specific form, notary, healthcare agent and witnesses. Patient advocates, disability rights legal groups and PAD workshops can be great resources. Once you're finished, hand out copies to your support system. This can include loved ones, healthcare providers and local hospitals.







BARRIER

SUGGESTION

Not having someone you can trust to appoint as your agent/POA.
*some states do not require a healthcare agent to complete a PAD

If you do not have a supporter that you trust now, you can work on that. If your state allows, start with an instructional PAD until you can identify the POA/agent that is the right person to support you.

Always make sure that you are speaking with supporters on whether or not they are interested in being your designated agent.

Matthew Federici CEO of the Copeland Center, who developed a simple way to think about how you can support PADs called ASAR >>

What is ASAR?

ASAR is an acronym to help guide systems to prepare for implementation of the use of PADs. it tells us (1) what to expect from other people supporting you, (2) how you can be a supporter for others, and (3) the provider/organizer policy.³

ASK

Within 30 days of services: "Do you have or have you ever heard of a PAD?" Mark a person's response in medical records. If a person has a PAD, Ask for copies of the plan, supporter and agent contact information to keep on record.

SUPPORT

If a person does not have a PAD, ask; "Would you like to learn more or develop one?" If the person says "**not now**", ask again in 30, 60, 90 days.

If the person says **yes**, refer them to a trained PAD's facilitator.

ADVOCATE

Ensure copies, supporters and agents are accessible and are coordinated throughout services. Review and follow the plan when needed. Support the patient advocate to have a copy. Connect to legal aid support if needed.

REVISE

After a crisis, episodes or events related to the plan discuss how it went and if the individual learned anything new or about things that they want to change. Support them if needed in revising their plan based on what they learned.







LEGAL PROTECTION FOR PADS

If you feel that your PAD has not been honored, or your needs were ignored, there are rights protection agencies such as the <u>National Disability Rights Network</u>. Additionally, each state has a designated protection and advocacy agency that would be able to speak with you about your rights. You can find state specific information and support through state Disability Rights Networks, as well as Legal Aid Organizations.

GETTING READY FOR YOUR PADS ~ CRISIS PLANNING

A crisis plan can be as thought out as you would like, and can apply to any crisis, whether you are receiving inpatient care, outpatient care, or just support from natural supports.

THINGS TO CONSIDER...

- If the police or a crisis team is called, this is what will help me.
- Include details about what you are like when you are well and what you are like when you are feeling unwell. ex: talkative/quiet, pessimistic/optimistic. Situations and triggers that could lead to a crisis.
- Make sure supporters included in your crisis plan know to share this plan with a crisis team, or law
 enforcement if that level of support is called into the situation. Ensuring that probation/parole
 officers are informed of any hospitalization so there are no negative legal repercussions as a result of
 the crisis. *Note- law enforcement involvement could be dangerous in certain situations.
- Preparing in advance for household needs; such as making sure bills are paid, plants and pets are taken care of.
- Options that you would want for support in the community, such as mental health alternatives like peer-run respite centers.
- A list of medications, current doctors and treatment teams
- A list of things that you find helpful and supportive during a time of crisis
- A list of things that may make the crisis worse for you.

YOUTH & YOUNG ADULT THINGS TO CONSIDER...

- Have phone numbers of friends/supporters written down somewhere, especially if you plan to go into a hospital setting. Being able to maintain communication with natural supports may be something that is very helpful during a time of crisis or hospitalization.
- Make a request list of what a family member could bring you if you are hospitalized to make things better. (games, books, hygiene products, food, etc.) Have youth friendly printable self-care/wellness planning worksheets available to you
- Think ahead about education/college/future life plans so a crisis does not entirely disrupt theses areas of your life
- Give ourselves grace in this process, thinking about these things may be the first time we are self-directing and navigating health decisions in our life- it is okay to take our time and not know the answer.
- Every time of crisis in our lives is an opportunity to learn and grow. Even in a crisis, there is hope.







CONCLUSION

Psychiatric Advance Directives (PADs) are valuable tools that allow youth and young adults to take charge of their mental health treatment decisions. By completing a PAD, you can make sure your choices are respected even during times of crisis. Youth and young adults can empower themselves with knowledge and action. They can protect their autonomy and support their own recovery, resilience, and/or wellness. Remember, individuals should have the right to make decisions about your mental health care, and PADs help their own exercise that right.

ADDITIONAL RESOURCES

- SAMHSA- A Practical Guide to Psychiatric Advance Directiveshttps://www.samhsa.gov/sites/default/files/practical-guide-psychiatric-advance-directives.pdf
- NRC-PAD youtube series https://www.youtube.com/playlist?list=PLqC-klqOiwn3R9wCVQJ3uzQV2WR_S4XiH
- Psychiatric Advance Directives for Youth and Young Adults Webinar: https://conta.cc/3ozHFPy
- National Resources Center on Psychiatric Advance Directives: https://nrc-pad.org/
- Mental Health America Psychiatric Advance Directives: Taking Charge of Your Care: https://mhanational.org/psychiatric-advance-directives-taking-charge-your-care



- National Alliance on Mental Illness Psychiatric Advance Directives: https://www.nami.org/Advocacy/Policy-Priorities/Responding-to-Crises/Psychiatric-Advance-Directives
- https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2793222
- https://tucollaborative.org/wp-content/uploads/2023/08/Advanced-Self-Advocacy-Plan-A-Guidebook.pdf
- Painted brain video, PAD stories from peers https://www.youtube.com/watch?v=q-KaPrC0jls
- https://copelandcenter.com/doors-wellbeing/psychiatric-advance-directives

If you would like to request technical assistance and consultation from Youth MOVE National, you can submit your request <u>HERE!</u>

REFERENCES

- ¹ https://www.samhsa.gov/sites/default/files/practical-guide-psychiatric-advance-directives.pdf
- https://www.samhsa.gov/certified-community-behavioral-health-clinics/section-223/governanceoversight/directives-behavioral-health
- 3 Peer Supported Advanced Directive Implementation 2021, M. Federici M.S. Copeland Center for Wellness & Recovery.
- ⁴ https://www.samhsa.gov/sites/default/files/practical-guide-psychiatric-advance-directives.pdf