



# What Families Need Providers to Know

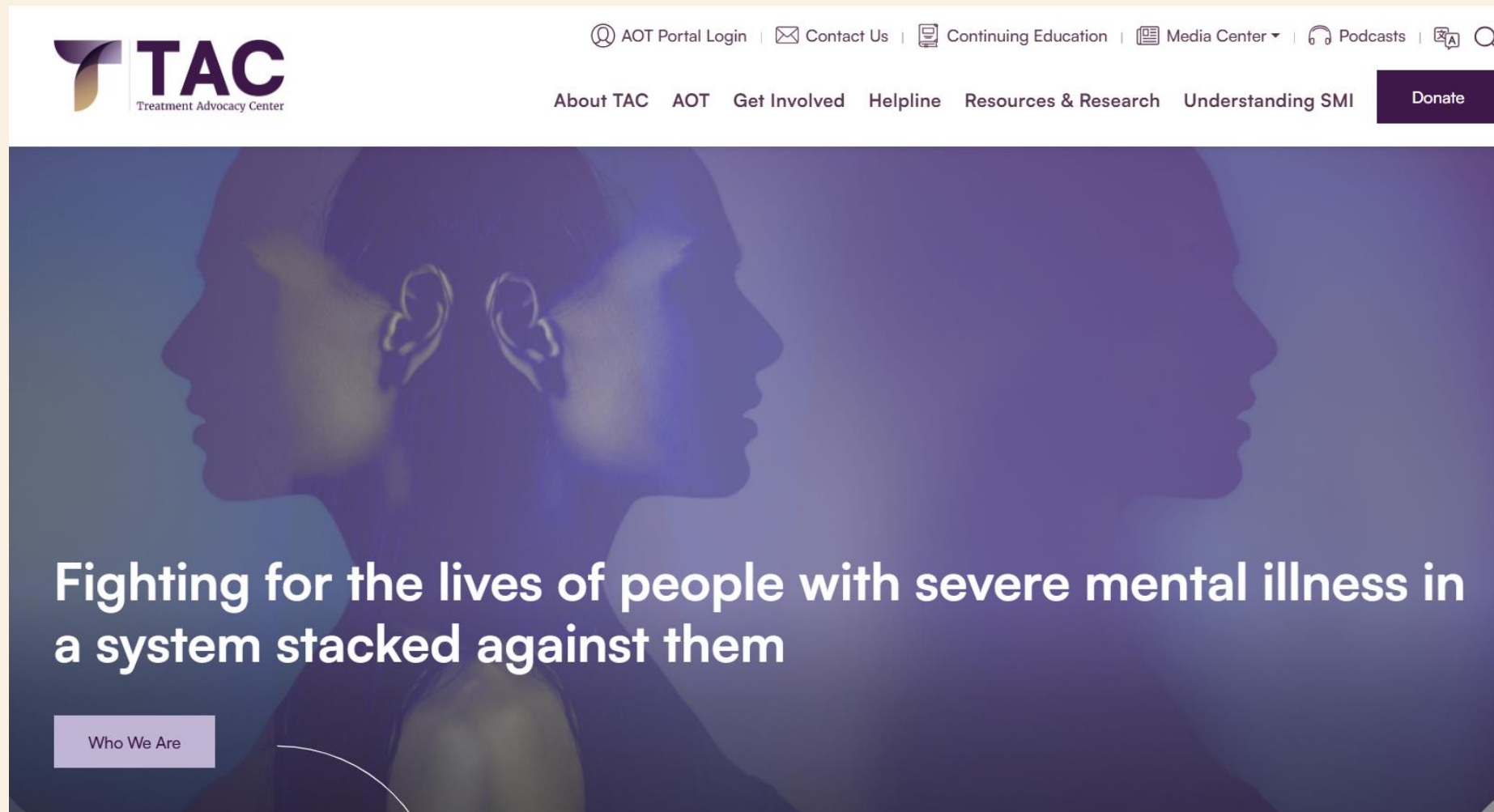
## Importance of Family Engagement

Texas Judicial Summit  
November 21, 2024

Jerri Clark  
Resource and Advocacy Manager



Calvin Clark  
1995-2019



At TAC:

We believe in the right to treatment for those with SMI...

...in a system poorly built to serve their needs.



# Who is here today?

- Judges
- Other court staff
- Law enforcement
- Lawmakers

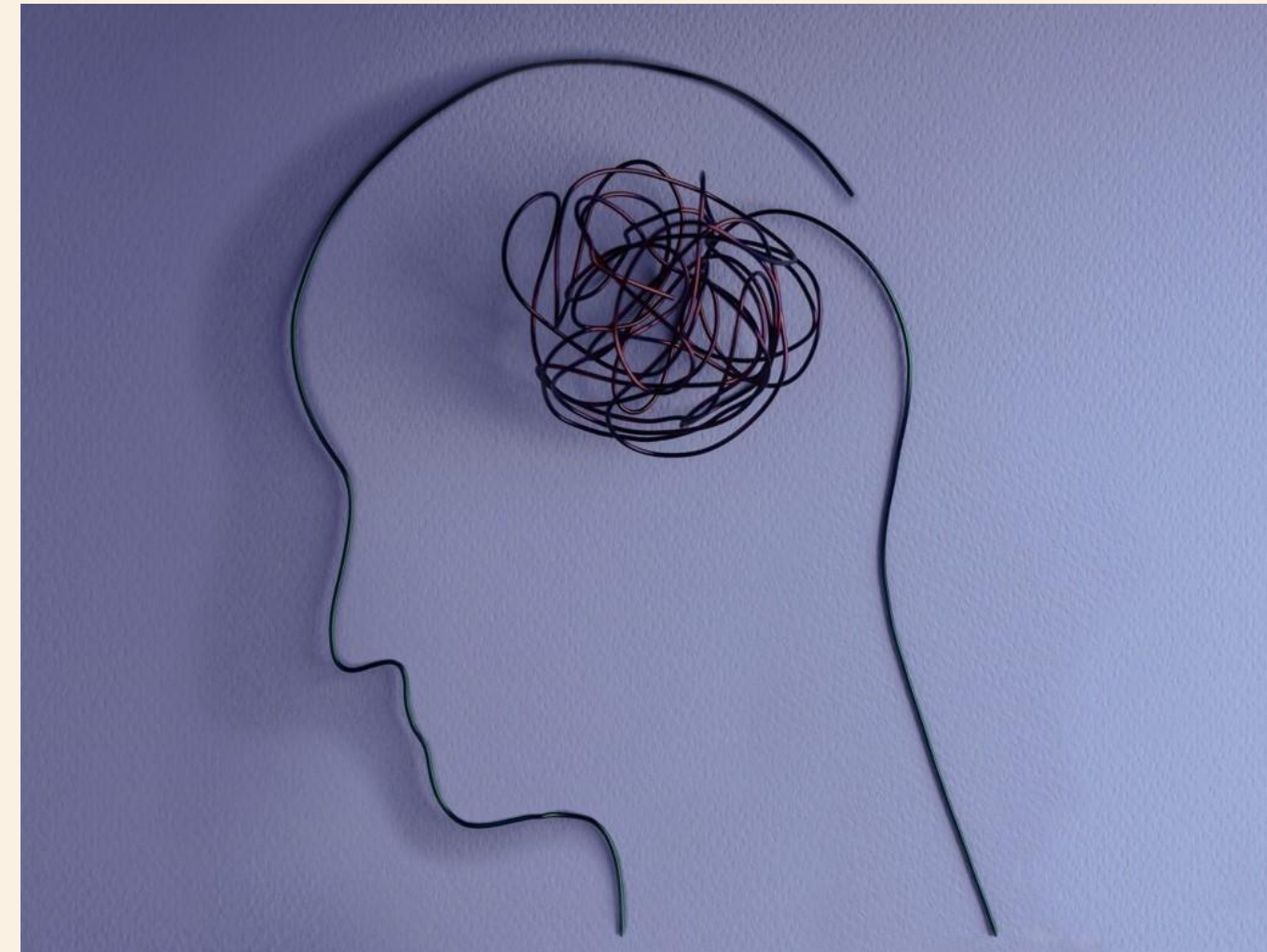
- Treatment providers
- Family members

- Others

# What is SMI?

## Severe Mental Illness

- Schizophrenia spectrum disorders
- Bipolar 1 disorder
- Severe depression
- Illnesses with psychotic elements



At least 25 percent of people with SMI have a co-occurring substance use disorder.

# Anosognosia

- Brain-based, neurological symptom.
- Not a willful denial of illness.
- Self-awareness is damaged.
- Makes it very difficult to motivate someone to participate in their own care planning.



TAC provides [two videos](#), one with Texas sources.

# Case of concern

Mental Health Court denial:

“He does not agree with his diagnosis, and he does not wish to take medication.”

Errors in SMI understanding:

“He is in denial and has no insight regarding his mental health and needed treatment.”


- Rejected by ACT: “too ill.”
- Dismissed by crisis: “not violent enough.”
- Evicted: “disruptive, destructive.”

Man, 31, with schizoaffective disorder who has fallen through the cracks.

Where is the help in this system?





 **By Ellen Barry**  
Ellen Barry spent many hours interviewing Andrey and his family and reviewed hundreds of pages of medical and court records for this article.

Published Jan. 28, 2024 Updated Jan. 29, 2024

# Family knew

Parents knew he was motivated to complete MH Court to clean up his life, despite his inability to see his illness.

They understood their son's symptom of anosognosia.

Their insights were ignored.





# What families request

Please consider the human elements of the difficult work that you do.

Note that the system offers very little help or reasons for hope.

Please consider families as your allies, unless there is an obvious and known reason to disregard them.

# What family means

Parents  
Siblings  
Spouses  
Adult children  
Partners  
Significant others  
Close friends



Family may be by origin  
or by choice!

# What families need providers to know

1

Family wisdom

2

Data support

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HIPAA facts

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How to start

# Providers asked

Judge Elinor Stormer of Ohio and Dr. Daniel Garza of New York wanted to know what families had to say about AOT for their loved ones with SMI.



Our venue: AOT Symposium in San Antonio, October 2022.

# Families answered

- What do families offer?
- What do families need?
- How to include us?
- Our ideas for improvements?
- What's our role?



Emergent theme:  
We want to help but are often  
cut out and pushed away.

# FOCUS GROUP

# WHAT DO FAMILIES WANT OUT OF AOT?

SOMETIMES, YOU HAVE TO STEP AWAY FOR YOURSELF

WE TAKE a LOT OF ABUSE.  
FAMILIES are HELPERS!

WE HAVE THE DATA

BROKEN RELATIONSHIPS/ FAMILY DISFUNCTION are SYMPTOMS of the MENTAL ILLNESS

FAMILIES KNOW MOST ABOUT SCHIZOPHRENIA

AUTHENTIC AN PARTNER IN CARE

AS A FAMILY MEMBER, I WANT to BE a CHEERLEADER.

BEING a GOOD NOTE TAKER

EVERY HUMAN BEING DESERVES DIGNITY

HAVING FLUID EXPECTATIONS

I NEED to STAY a PARENT

WE ARE DOING THE BEST THAT WE CAN.

THERE is HOPE for HAPPINESS

YOU CAN DO IT!

I AM AN EXPERT in BEING a LOVED ONE.

COMMUNICATE EARLIER

TRAINING TO BE THE POINT OF CONTACT

SOMETIMES, WE NEED TO MAKE DIFFICULT CHOICES TO PROTECT OUR FAMILIES.

IT IS NOT OUR FAULT

EVERY MOMENT MATTERS

A RELIABLE ACCOUNT of SYMPTOMS

GIVE ME A CHANCE to LIVE the LIFE I DESERVE

I'M THE ONE WHO KNOWS  
• IF MEDICATIONS ARE WORKING  
• IF THERE are SIDE EFFECTS

I SHOULDN'T HAVE TO PROVIDE CARE.

NOT THEIR THERAPIST

NOT THEIR NURSE

CULTURALLY APPROPRIATE RESOURCES & CARE

EDUCATION

TIME WITH LOVED ONE

RESPECT MY FAMILY MEMBER!

COLLABORATION  
WE NEED MORE ACCOUNTABILITY  
REMOVE BLAME

ACKNOWLEDGEMENT

SUPPORT FAMILIES in BEING ABLE TO LEAVE WORK

FAMILIES LIKE OURS

REUNIFICATION

SHATTERING SILENCE & SHAME



2022 National AOT Symposium and Learning Collaborative  
October 13th-14th, 2022

GRAPHIC RECORDING BY ERICA BOTA *for* Drawing Change

# Key takeaways



Our wisdom is hard won, but we can affirm why data is accurate when showing improved outcomes with our involvement.

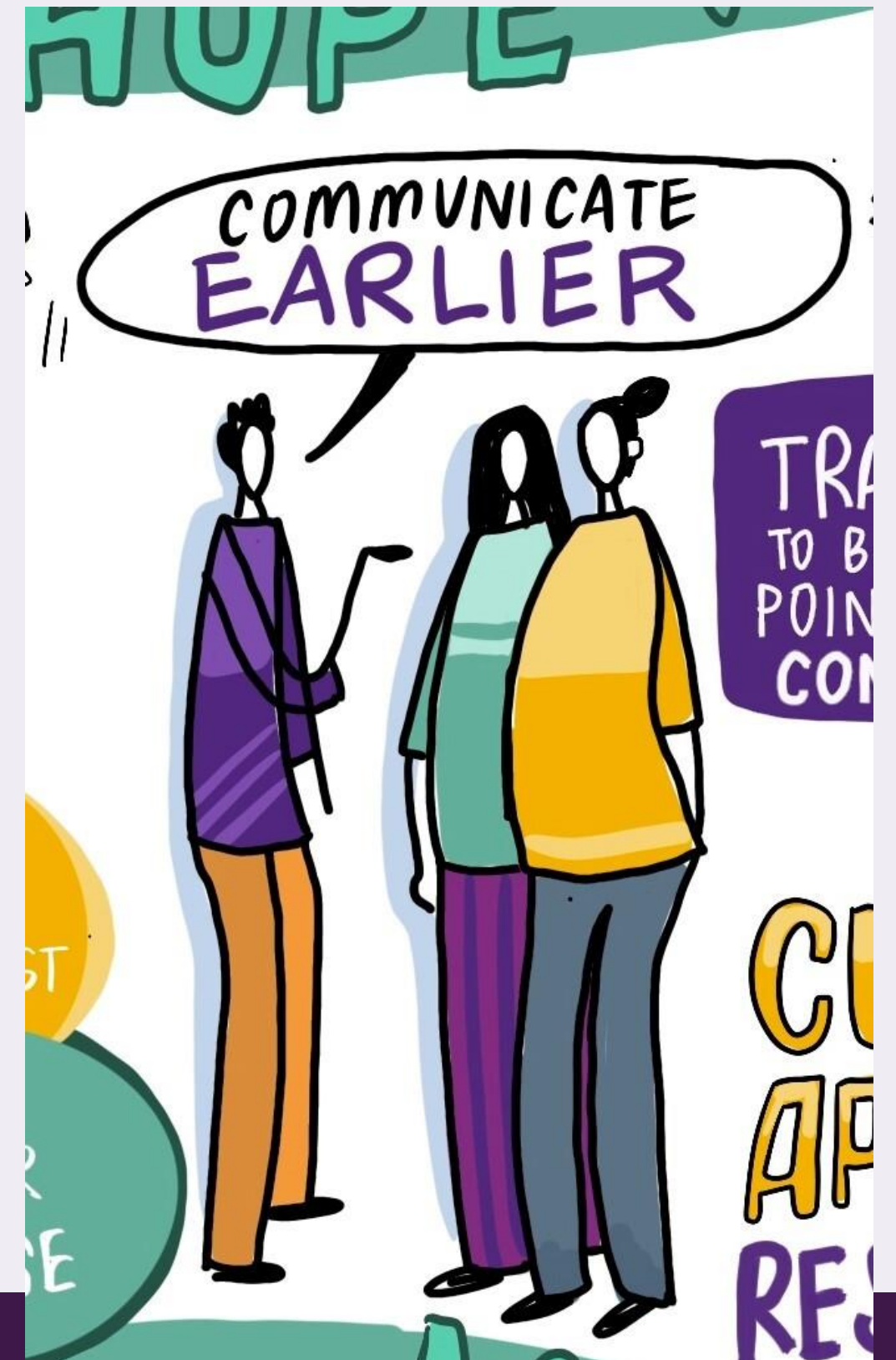
These diseases are not our fault.

We want to collaborate, especially when sharing history.

# Stop the crisis cycle

Families want to partner with the system to prevent a crisis, not watch and wait for a crisis to finally force the system to respond.

We are the ones most invested, so we keep our eyes and ears wide open.





# We've been hurt

Families want you to remember: Not all mental illnesses are caused by trauma, but they often bring trauma.

“Mental Illness didn't run in our family; it strolled in and took its time, with all of us.”





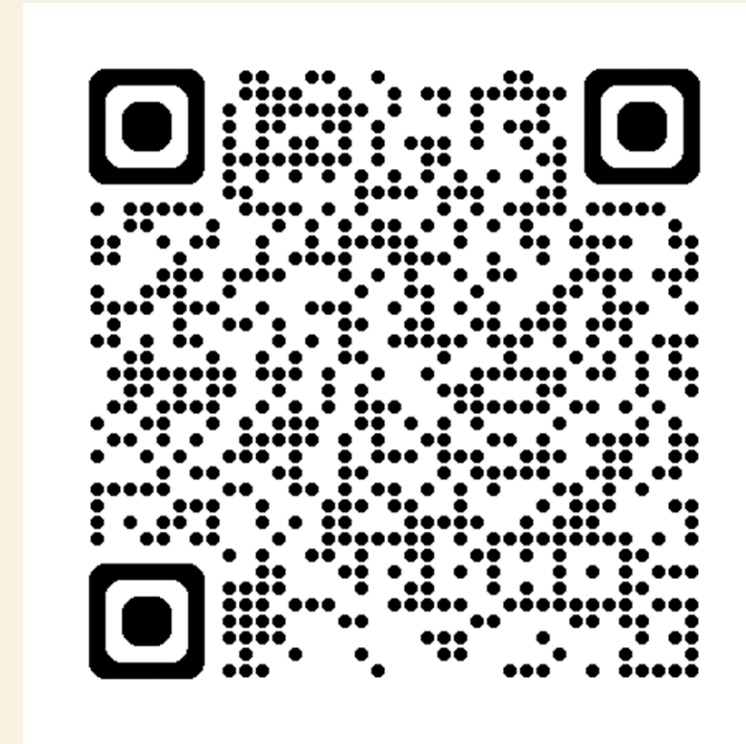
# Honor diversity

Please remember that all people deserve respect and to have their individualized needs well served.

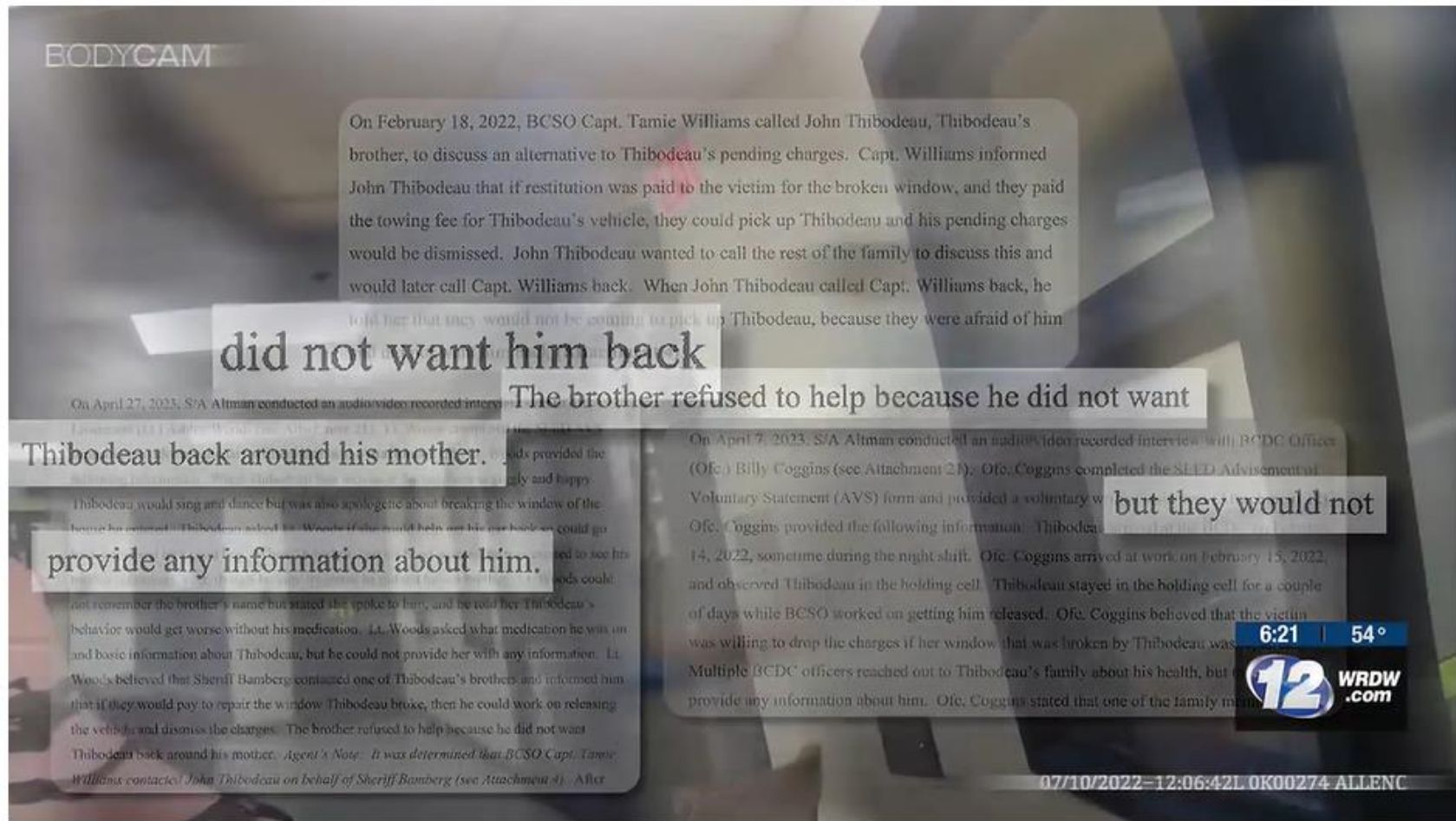


# Summary handout

Click the QR code to access a [two-page summary](#) of TAC's key findings about what families most want providers to know.



The handout is useful for all stakeholders.



By [Meredith Anderson](#), [Saint Julian Cox](#) and [Estelle Parsley](#)  
Published: Feb. 8, 2024 at 3:13 PM PST

# Tragic example

After a man with SMI died from neglect in a South Carolina jail, agents stated that family did not want him back, refused to help or ***wouldn't provide information.***

Family are clear in news reports that they were never contacted.

# Myth: Families are already broken

Data make clear that most people with SMI caught in the system want loved ones involved.

A New York study of 179 inpatients in 2019 found that only 14 individuals did not want family involved in their care planning. That's 92 percent who wanted it!

“Involving family in the care of inpatients with serious mental illness is known to be beneficial.”

- APA

# Strange story, common theme

While the medical examiner's office said the dead man's family declined to identify the body before cremation, his family said they were never asked.

The New York Times

***Ashes Were Given to His Family. But He Wasn't Dead.***

Tyler Chase, 22, was living in transitional housing in Portland, Ore., when the authorities misidentified a body as his and cremated it.

 By [Livia Albeck-Ripka](#)

Feb. 7, 2024

Tyler's mom: "I had ashes of someone's child, and they didn't know that their loved one was dead...They just treat them like they're no one."

# Habit: Don't bother with families

Barriers related to professional culture, organization, and lack of leadership are fixable!

“The uptake of family involvement in health care services for patients with psychotic disorders is poor, despite a clear evidence base.”

- BMC Health Services Research

“Knowledge-practice gap” results in “patients and relatives being deprived of highly recommended treatment and support.”

# Clinical data

“The role of the family and improvement in treatment maintenance, adherence, and outcome for schizophrenia”

24 of 27 patients who had supportive families improved; Only nine of 23 without family support showed improvement.

Journal of Clinical  
Psychopharmacology,  
31(1), 82-85, 2011



# Hospital data

In 2019, researchers from New York State Psychiatric Institute and Columbia University examined family involvement by analyzing inpatient medical records from two major urban community hospitals.

Finding: Family involvement during inpatient care significantly impacts:

1. The creation of a comprehensive patient discharge plan.
2. The prompt continuation of treatment in an outpatient setting.



# HIPAA is workable

FAQ 2087: Does HIPAA allow a health care provider to communicate with a patient's family, friends, or other persons who are involved in the patient's care?

“Yes. In recognition of the integral role that family and friends play in a patient's health care, the HIPAA Privacy Rule allows these routine — and often critical — communications between health care providers and these persons.”



U.S. Dept. of Health & Human Services  
**Guidance Portal**

# HIPAA protects families, too

Providers may withhold some information from clients to protect family relationships.

“An individual’s access may be denied if the protected health information was obtained from someone other than a health care provider under a promise of confidentiality and the access requested would be reasonably likely to reveal the source of information.”

[45 CFR 164.524\(a\)\(2\)\(v\)](#)



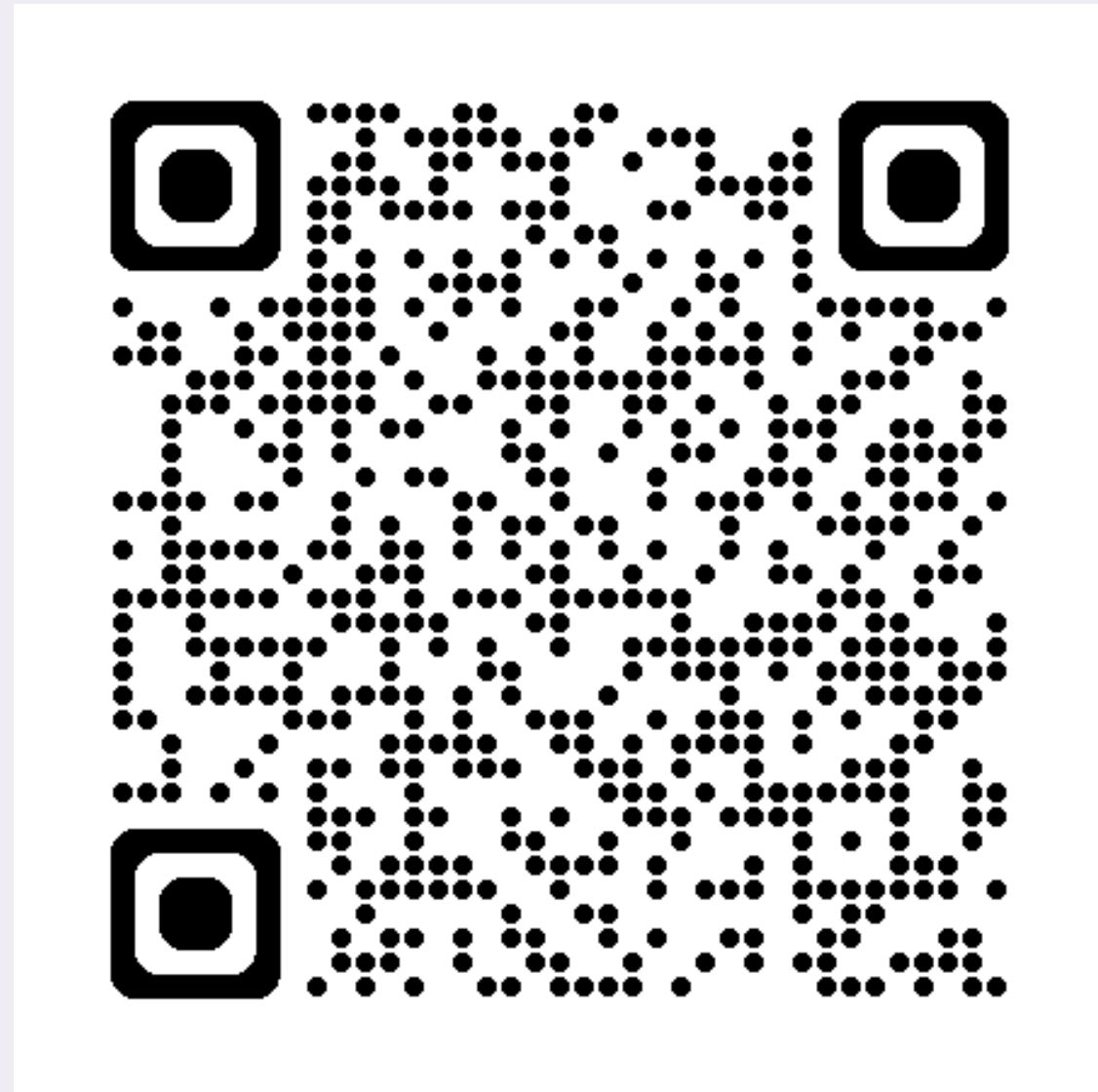
NATIONAL  
ARCHIVES

**Code of Federal Regulations**

A point in time eCFR system



**Title 45**



## More on HIPAA

Click the QR code to access a TAC website [article about HIPAA](#) to better understand what's allowed and what's been misunderstood.

# Please start now!



Ask for history.

Listen to our stories, and thank you for respecting our wisdom.

Don't give up: ask our loved ones about the people they care about.