

Antipsychotic Medication Oversight for Children in Foster Care: Perspectives from Foster Caregivers

"...it was kind of **DAUNTING**...I felt pressured, like I almost didn't have a choice whatsoever."
– Former Foster Care Youth



"I am an **advocate**, there is no reason, ever, a child in care is not seeing a counselor. Plain and simple. I don't care what we have to do."
– Foster Caregiver

Foster Caregivers play an important role in supporting and advocating for children and youth with mental health difficulties in their care. Caregivers, with the right tools and information, have the ability to advocate for collaborative systems of care for children and youth taking antipsychotic medications.

Rutgers University PCORI Foster Care Research Project

Goals of This Project

What is PCOR?

“Patient-Centered Outcomes Research (PCOR) helps people and their Caregivers communicate about research evidence and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options.”

Patient-Centered Outcomes Research Institute (PCORI)

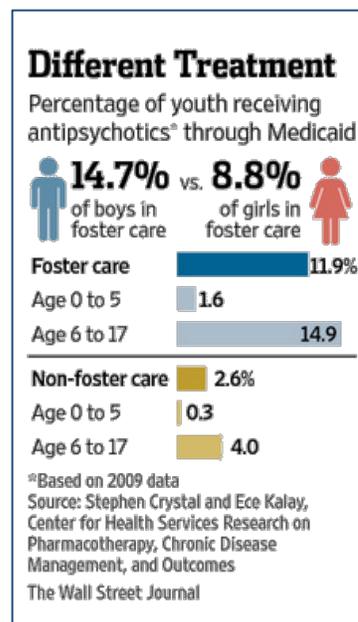
Children and youth in foster care are more likely to be prescribed antipsychotic medications (APs) compared to children and youth who are not in foster care¹. In response, states have put oversight systems in place to monitor prescribing APs to children and youth in foster care. Systems vary from state to state, and sometimes even within states. This research project aimed to better understand state AP oversight systems for children and youth in foster care from the point of view of important stakeholders.

An important part of this project was speaking directly to young adults with lived experience, their Caregivers, and other stakeholders who have a direct connection to children and youth in care taking APs.

Four innovative states partnered with the Rutgers research team for this project: Ohio, Texas, Washington, and Wisconsin. State policy leaders are very interested in better understanding the impact of medication monitoring systems.

The National Foster Parent Association Public/Academic Partnership: Speaking with Caregivers

The partnership between the Rutgers research team and the National Foster Parent Association (NFPA) was essential to the success of the project and was critical to keeping the research centered on patients and families. NFPA provided a connection to its national network and shared the caregiver recruitment flyers through social media and email newsletters. Members of the Rutgers team attended the NFPA Annual Conference to personally connect with Caregivers. Through these personal and social media connections, interested foster Caregivers were recruited from the four project states.



¹ Vanderwerker L, Olfson M, Gerhard T, Akincigil A, Crystal S. Foster Care, Externalizing Disorders, and Antipsychotic Use. *Psychiatric Services* 65(10), 2014. E-pub in advance of print, October 1, 2014. doi: 10.1176/appi.ps.201300455.

Why Talk to Foster Caregivers?

In an effort to improve mental health treatment for children and youth in foster care², the Rutgers research team talked to patients and families about how state antipsychotic (AP) medication treatment policies affect them.

CAREGIVER PARTICIPANTS AT-A-GLANCE

- **20** Caregivers participated from **4 states** (OH, TX, WA, WI)
- **Most** participants have been Caregivers for over 8 years.
- **All** Caregivers have cared for foster children with mental health difficulties.
- **Half** of participants **currently** care for children and youth on APs.
- **Half** have **recently** cared for children and youth on APs.

Interviews

Participating foster Caregivers shared their experiences and perspectives of the antipsychotic oversight systems in their state during a phone interview. Caregivers responded to a fictional story about a foster youth, a psychiatrist, and a foster caregiver navigating the process of making decisions about antipsychotic medication. All participating foster Caregivers had experience caring for foster youth prescribed antipsychotic medication. This research brief will focus on the findings from the phone interviews with Caregivers, particularly in relation to medical informed consent and shared decision making during treatment planning.



What is Medical Informed Consent?

Informed consent is legally required when any health professional recommends treatment to anyone. This includes providing information about the risks and benefits of treatment options.

When we discuss the informed consent process, we are referring to the process by which child welfare agencies – or others – legally act “in place of the parent” when a child is removed from their biological family. Because of this, the child welfare agency must either provide consent or designate someone to consent to medical treatments for youth in foster care. When minor youth are included in the decision making it is referred to as the Assent process.

² When referring to children and youth in foster care we are describing children in the foster care system who are from the ages 1-17. For the remainder of this brief we will refer to children and youth in foster care as youth.

Informed Consent and Shared Decision Making

Although informed consent is required for any AP prescription, the informed process varies from state to state. Often, foster Caregivers do not have the legal authority to provide consent for medication for youth in their care. Caregiver participants described their experience with their state's informed consent process and how it could be improved. Caregivers told us that informed consent should involve **shared decision making**. Caregiver participants emphasized the importance of having a team-based approach to shared decision making. Everyone that is involved in caring for foster youths' mental health treatment can contribute. Caregivers often spoke about informed consent and shared decision making as aspects of the same process.

- **Informed consent** is a legal requirement.
- **Shared decision making** is a tool to meet that legal requirement by involving Caregivers and youth in the discussion about treatment options.

What is Shared Decision Making?

Shared decision making is a collaborative process. The intention of shared decision making is for everyone involved in treatment planning – including caregivers and youth – to actively and openly discuss all treatment decisions, including the risks and benefits of potential treatments, and come together to decide on the best course of action.

Guiding Questions

The Rutgers research team sought to answer these guiding questions:

- Has the informed consent process affected how foster Caregivers provide care for foster children and youth? How?
- What factors promoted or interfered with the informed consent process?
- How do Caregivers work with other stakeholders to engage foster youth in the informed consent process?

Findings: What are the Themes?

Caregivers talked honestly and openly about their experiences with the informed consent process. They shared their perspectives on the best ways to implement and navigate informed consent for foster youth who are prescribed APs. Common themes emerged across all four states. These themes addressed the Caregivers' belief that informed consent is necessary, recognized concerns about the challenges of implementation, and repeatedly stressed the importance of engaging foster parents, youth and, when possible, biological parents to support collaborative treatment planning.



Caregiver Priorities

Caregivers told us how they prioritize a team-based approach to informed consent and shared decision making. Caregivers see this approach as a way to promote communication among stakeholders involved in a youth's care, which should lead to safe decisions.

"I think the biggest concern is getting someone to listen...I think more than anything, foster parents wanna know that there's someone out there that says okay, I see how heavy this is and I'm on your team... Whatever means necessary to get this child the help they need, we're here with you. We see it, we understand it and we're with you."

Team-Based Approach

Caregivers are concerned that an informed consent process that is not team-based can cause problems. They suggested that all medical and social information be available when making an important mental health decision. When the responsibility is left to one person, that one person may have limited information about the youth.

Caregivers gave examples of people involved who may lack all the knowledge needed when making important decisions. This can include a child welfare caseworker who does not attend appointments, a care manager who does not personally know the youth or their situation, or a prescriber who does not listen carefully to Caregivers or youths' opinions. Such an approach can also leave Caregivers and youth feeling like their opinions are being overlooked.

A team-based approach improves collaboration through open communication of the treatment risks and benefits between all the people involved in a youth's treatment. Caregivers expressed the importance of clear and respectful communication among team members in being essential to ensure a high standard of care. Caregivers expressed a desire for clear communication throughout the treatment process to make certain everyone is working towards the same goals. It is important for Caregivers and youth to understand all parts of the AP prescribing process, particularly the risks associated with treatment. This understanding allows Caregivers to be more actively involved in the process, even if they cannot legally provide consent.

"I think a team approach is absolutely the way to go, especially for foster care. I mean when you have your own children you have you, you have your husband, and your doctor and, I mean, that's sort of your team and when it comes to children who are in foster care it needs to be foster caregiver, caseworker, the doctor. It needs to be all the people whose job it is to care for that child. So I think a team approach is probably the best way."

"In my experience it's somewhat takes away from the doctor being on a different level in making decisions about families ... which can be intimidating to families... It's not this controlling decision-making approach by a doctor but rather, um, I might be the expert on this medicine as the doctor and you are the expert on your child. Together we are going to partner in making these decisions."

This team-based approach would include a conversation between Caregivers, the youth, other supportive allies, and the prescriber, to clarify:

- Pros and cons of a medication
- Potential side effects
- Alternative therapies

Caregivers strongly emphasized how important it is for both Caregivers and youth to understand any technical information about medication. This is part of a larger plan to:

- Work with foster youth to understand their symptoms
- Overcome the stigma associated with medication
- Get youth on board with a long term treatment plan that includes medication

"So I just think that we empower our families by making sure they have the information needed in order to make the best decisions for their children."

Optimal Mental Health Treatment: Balancing Risks and Benefits, Promoting Safety

Caregivers reflected on the role of informed consent in providing the best possible treatment for youth, and discussed the pros and cons of how time consuming the informed consent process can be. Caregiver participants view the informed consent process as a safety measure. Many Caregivers emphasized that the process "slowed down" decisions. This could be seen as beneficial as it allows extra time to consider alternative therapies, such as counseling, to replace or supplement the use of medication.



"It just gives you more time to absorb, gather, and understand."

"The disadvantages are not being able to get a hold of the proper people to get the consent signed because that causes a delay in getting the child medicated properly and getting help for the child."

Caregivers also pointed out that a drawn out informed consent process could become a barrier to treatment for youth who need medication, especially in an emergency. The informed consent process can be time consuming, and reach beyond a visit with a doctor. Relaying information to all members of a treatment team and completing necessary paperwork can take days or weeks. Caregivers told us about difficult experiences when they were not able to reach caseworkers in a timely

manner. Any delay in the process can prevent foster youth from receiving necessary medication quickly. Without necessary treatment, a youth's placement, schooling, social life, and mental health can be at risk. This negatively affects Caregivers and others involved in the youth's daily life, including teachers, friends, and other children living in the foster home.

"All the individuals that are involved with this child are probably going nuts because of the behavior, driving everyone quite crazy including herself so that's, that's the disadvantage, but there's really not much you can do about it. I mean there's just very little you can do except try some other therapies, you know, to calm her down and everything."

Caregivers are concerned about anyone involved in the treatment process who supports the use of medication as the *first step* for controlling difficult behaviors. A team-based approach to informed consent promotes foster children's protection by allowing multiple eyes to monitor treatment options and observe behavioral improvements. Caregivers suggested that it is very important to be open and candid with everyone who is working and caring for the child.

Caregivers emphasized that a successful informed consent process allows youth to have immediate access to acute and emergency mental health services. Caregivers told us that seeking psychiatric care for a youth should indicate that a youth has significant needs.

"It's kind of like a last resort when you put kids on those types of drugs. But if they have to be on them, you really want people to really analyze should we be doing this?"

"If I'm to a point that I'm seeking our psychiatric services it's because literally I see my child struggling and can't find that balance between dealing with crap and things that happened with them and also being able to function on a day-to-day basis."

Voice, Agency, and Expertise: Cornerstones of Shared Decision Making

In order to make the best decision, Caregivers spoke to us about how a medical consentor needs to understand the technicalities of treatment options, have adequate experience, and have the youth's best interests at heart. According to Caregivers, a medical consentor's knowledge must include medical knowledge, the child's current circumstances, and experience with the child welfare system. Caregivers and other stakeholders are necessary and important partners in the treatment process because of the knowledge they possess and the role they play in the care and life of the youth.

"So, first and foremost, these children are not our children. You know we are doing our best to care for them and protect them and you know give them everything they need, but you know, they are not our children. So we don't really have a right to make decisions this big alone."

"Every situation is different and every person has a different perspective and goal and you know it is kind of you need to get everybody that has the child's best interest at heart to make a decision."

Caregivers told us how each stakeholder brings their own expertise to the decision making process:

- Doctor → Medical expert
- Caseworker → System and policy expert
- Caregiver → Expert on day-to-day behavior of youth in their care
- Youth → Expert on themselves, their feelings, and side effects

Overall, Caregivers believe that it is helpful to have as many voices in the informed consent process as possible as long as this does not become a barrier to youth receiving treatment.

Caregivers' Voice: The Youth's Advocate

Many Caregivers told us that their opinions were not heard or valued in the informed consent process. Caregivers have a variety of perspectives on who should legally be responsible to provide informed consent. Some Caregivers did not want the responsibility, while others advocated for a more central role in the process. Ultimately, regardless of who is the legal consentor, Caregivers want to be fully involved in the shared decision making process. Caregivers often consider advocacy an essential part of their role and told us how they will go to great lengths

"My first instinct is when you don't have that one person guaranteed looking out for your best interests, like the majority of children in biological home paths, you need extra eyes. You need extra people making sure that you are not just getting prescribed things..."

to access appropriate treatment for youth in their care. However, Caregivers struggle with feeling scrutinized by the child welfare system. Caregivers want their voice to be heard and respected, and support a team-based approach to shared decision making. Caregivers emphasized that they, unlike a prescriber or caseworker, are living with the youth, and they are monitoring how treatment progresses on a day-to-day basis. Any decisions about treatment or delays in the process may result in consequences only the Caregiver would have to handle.

"If you have [a Caregiver] who's been doing this five, ten years ...and has had lots of kids...you need to take their decision seriously. Or what they're telling you seriously because they've seen it before, and they have something to make good sound judgments."



Youth Voice: Consent and Assent

Caregivers see youth as a valuable member of the team because youth know themselves better than anyone else does and because young people have a right to be involved in decisions regarding their own healthcare.

However, Caregivers pointed out that their mental health challenges might prevent youth from

making healthy decisions.

Although Caregivers did not advocate for youth to have the final decision in the informed consent process, Caregivers recognized the importance of including youth in the communication and decision-making process because a successful informed consent process relies on the youth's cooperation and their assent to treatment. Team-based, shared decision making provides a method to foster youth involvement.

"...recognizing that the parent and the young lady know themselves the best versus the doctor knowing them the best and making decisions for a child he might see for 20 minutes every other month. It puts value on their experience and allows them to then advocate for themselves."

What is Assent?

Often minor youth in foster care are not able to legally consent for their own treatment, but their voice can still be considered in the shared decision making process. When minor youth provide their **assent**, they communicate their agreement with a recommended treatment, regardless of who provides the legal consent.

"There shouldn't be a problem with sitting down and talking to her like she's an adult...How my psychiatrist explained it...is that it is like baking a cake...and I thought it was a pretty good analogy because she said if we don't have the right ingredients then the cake isn't going to turn out right and if YOU are missing an ingredient then for sure it is not going to turn out right."

Voice of Biological Parents

Caregivers insisted that if reunification with biological parents is a goal, biological parents need to be part of the shared decision making process. However, Caregivers acknowledged that situations can differ dramatically between families and obstacles can be created by involving the biological parents. However, biological parents engaged in the treatment process may provide a unique and important perspective on their child. Depending on the relationship between the biological parent and their child, the biological parent could have the ability to help their child accept their treatment.

"I would be very upset if somebody else is making that decision to put my kids on medication. So I think it should be the parent ultimate decision to switch and change [a] kid's medication."

"So I guess in a perfect scenario it would be great if it would be bio family, social worker and foster family, but, in the real world that we've lived in bio families are not always easy to find."

How can Caregivers can use these findings?

Foster Caregivers can use these research findings, along with their first-hand experiences caring for youth receiving mental health treatment, to advocate for the children they care for as well as system improvement.



Caregivers Can Advocate for System Change

Individual Level Advocacy: In the Clinical Encounter

- Ask health care providers how the voices of Caregivers and Youth will be involved in treatment decision making.
- Bring an ally to the appointment, for example a CASA volunteer who is working with the young person in out of home placement.
- Ask clinicians to give examples of treatment risks and benefits in ordinary language that is easily understood by youth and their families.
- Ask for psychosocial supports before medication is tried. Bring ideas for referrals.
- Suggest a “team-based” approach to treatment planning. Have a list of who you and the youth feel are the important members of the team.

System Level Advocacy: Local, State, and Federal Government

Irene Clements, Executive Director of the National Foster Parent Association, shares her insight on how caregivers can advocate for the youth they care for. Caregiver efforts can be at the individual and policy change levels.

- **Start locally. Contact someone at the local or county level who makes decisions about child welfare.** Call or email your local district office and ask to speak with the person who works on child welfare policies. Irene says, “It’s everybody’s responsibility to advocate for what they believe in. Start where your comfort level is.” As you gain experience, you can expand your reach to state or federal government representatives.
- **Prepare your talking points ahead of time.** You may be speaking with a staff member, or leaving a message. You have to communicate your message clearly and quickly, so it helps to have points written down ahead of time. Irene says, “Be concise, and always follow up!” Keep messages short and to the point. You may have to send more than one email over the course of a few weeks.
- **Remember, you have unique experience that is valuable to the people making decisions about foster care.** Irene says, “Look at this as educating decision makers. Decision makers can’t know everything about every topic they are making decisions about. They look to other people to inform them. Who better to inform decision makers about foster care, and the needs of the kids, than the actual people who are welcoming those children into their families?”
- **Learn how the legislative process works in your state, and nationally.** To advocate at the state or national level, it’s important to understand how national laws and policies may affect changes in your state.

Are you or a family member:

- On an advisory board?
- Mentoring another Caregiver?
- Working with your state chapter?
 - National Foster Parent Association (NFPA)
 - National Alliance on Mental Illness (NAMI)
 - Youth MOVE National
 - Foster Care Alumni of America
 - Family Voices



Online Resources for Caregivers

Advocacy

Advocacy Resources: A Top Ten Insider's Guide to Legislative Advocacy

- <http://www.flhousing.org/wp-content/uploads/2012/12/A-Top-Ten-Insider%E2%80%99s-Guide-to-Legislative-Advocacy.pdf>

Child Welfare League of America: Tips for successful advocacy.

- <https://www.cwla.org/advocacy-tips/>

Legislative Handbook: A Guide to Being a Successful Advocate

<https://www.apse.org/wp-content/uploads/docs/Leg%20Handbook%203.30.10Vedited2.pdf>

Child Welfare

Child Welfare Gateway

- **Psychotropic Medication:** Research and Reports. Link to various research, reports, advocacy, and information on Psychotropic medication involving all children and children in the welfare system.
 - <https://www.childwelfare.gov/topics/systemwide/bhw/casework/medications/reports/>
- **Supporting Youth in Foster Care in Making Healthy Choices:** A Guide for Caregivers and Caseworkers on Trauma, Treatment, and Psychotropic Medications.
 - https://www.childwelfare.gov/pubPDFs/mhc_caregivers.pdf
- **Making Healthy Choices:** A Guide on Psychotropic Medication for Youth in Foster Care. Health and psychotropic medication information for youth in Foster Care.
 - <https://www.childwelfare.gov/pubPDFs/makinghealthychoices.pdf>
- **Parenting a Child Who has Experienced Trauma.** A fact Sheet for Families
 - <https://www.childwelfare.gov/pubPDFs/child-trauma.pdf>

National Foster Parent Association Homepage

- <https://nfpaonline.org/>

National Wraparound Initiative Homepage

- <https://nwi.pdx.edu/>

Youth MOVE National Homepage

- <https://www.youthmovenational.org/>



Mental Health

Mental Health.gov (U.S. Department of Health & Human Services)

- **Talk About Mental Health:** Information about mental health for children, parents/caregivers, family/friends, and how to start conversations in your community about mental health.
 - <https://www.mentalhealth.gov/talk>

Substance Abuse and Mental Health Service Administration (SAMHSA)

- **Homepage:**
 - <https://www.samhsa.gov/>
- **Community Conversation about Mental Health:** Information Brief
 - <https://store.samhsa.gov/shin/content//SMA13-4763/SMA13-4763.pdf>

U.S. National Library of Medicine & National Institutes of Health (NIH)

- **Medline plus:** An A-Z index of generic and brand name drugs. Information on side effects, dosage, and precautions for medications.
 - <https://medlineplus.gov/druginformation.html>

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