



Evidence-Based Policymaking Is an Iterative Process: A Case Study of Antipsychotic Use among Children in the Foster Care System

Johanna Butler, Jennifer Reck, and Maureen Hensley-Quinn

Executive Summary

State policymakers must sometimes take action even when relevant, credible evidence identifying the best policy approach may not be available, such as during a recent, emerging crisis impacting the health of children, adults and families. This brief explores successful state responses to dramatic increases in antipsychotic prescription rates in Medicaid-enrolled children, including children in foster care. In August 2018, the National Academy for State Health Policy (NASHP) convened researchers and a cross-agency group of officials with expertise in financing and operating Children's Health Insurance Program (CHIP) and Medicaid programs, children's health, and health policy and pharmacy research. Participants from multiple states discussed state strategies to ensure the appropriate use of antipsychotic drugs in youth in foster care. Strategies discussed and shared in this brief include payment reforms, delivery system innovations, and quality supports for clinical care. Other areas for improvement include increasing monitoring rates for side effects, advancing psychosocial and trauma-informed care, enhancing patient engagement, and improving data collection and use.



New evidence from a forthcoming Patient Centered Outcomes Institute-funded [comparative effectiveness study](#) at Rutgers University may help state officials understand the impact of various oversight approaches to antipsychotic prescribing in children in foster care. The study provides quantitative analysis about the relationship between different oversight policies, the rate of antipsychotic use in foster children and their health outcomes, as well as qualitative findings from various stakeholders' perspective. The forthcoming findings represent important evidence state officials can use to refine their own policy approaches. Results are expected in 2019.

State officials value and [use evidence](#) to make policy but relevant, credible evidence is not always available when decisions need to be made, particularly when responding to a new development or emerging crisis impacting the health of adults, children and families. Policymakers must often take initial action using incomplete information, while continuing to seek out research to hone their policies and practices as it becomes available.

When state policymakers became aware of the growing use of antipsychotic drugs in children, including higher rates among youth in the foster care, many took action.¹ Policymakers implemented various oversight policies to ensure antipsychotics were used appropriately, especially given their risk of serious side effects that require metabolic monitoring.² In the absence of evidence defining the comparative effectiveness of different policy approaches, many states used existing policy levers and feedback from stakeholders to design policies recognizing

the multifaceted, interdisciplinary issue involved in addressing antipsychotic use in foster children. Emerging evidence from a [comparative effectiveness study supported](#) by the Patient Centered Outcomes Institute (PCORI) will provide states with first-of-its-kind evidence exploring how different state policies impact the number of foster children receiving antipsychotics, as well as their health outcomes. This study will provide unique data previously unavailable to states that will inform continued efforts to refine policy approaches to antipsychotic use in foster children.

The National Academy for State Health Policy (NASHP) convened a cross-agency group of officials representing multiple states to discuss strategies used to ensure the appropriate use of antipsychotic prescription drugs in youth in foster care. The topic serves as an example of how states develop policy about a complicated issue while under pressure -- given the impact on a particularly vulnerable population -- by using available information. It is also an example of the inherently iterative relationship between research and state policymaking, because as new information becomes available, officials can usually make changes or adapt policy to incorporate emerging evidence. This brief shares themes from this discussion, which include the identification of policy levers states use as payers of health services, to add or create oversight of antipsychotic use with the goal of achieving improved outcomes. Officials also raised remaining questions that research can help answer to improve related policy and better serve children.

Antipsychotic Use in Children and Youth

Thirteen to twenty percent of US children -- nearly one in five -- have a mental, emotional, or behavioral disorder in a given year.³ Research indicates that youth served by state foster care systems have experienced trauma to a greater extent than the general population, which could include abuse, neglect and exposure to violence.⁴ Studies suggest up to 80 percent of foster youth enter the system with a significant mental health need. The uncertainty in foster care may exacerbate childhood trauma and adversity underlying existing mental health issues.⁵ Children with emotional and behavioral disorders are more likely to be expelled from preschool, require special education and health care services, become involved in the juvenile justice system, and become chronically ill and unemployed as adults.⁶ Therefore, there is a strong incentive to appropriately address mental and behavioral health issues in youth. Although the Food and Drug Administration (FDA) approves the use of antipsychotic drugs in youth, given their sometime serious side effects, as well as the need to effectively monitor children for the development of side effects, it is important to balance the risks and benefits of their use. Children in foster care are at higher risk of traumatic experiences and have often dealt with adverse life experiences at an earlier age, so increased use of antipsychotics in foster youth should not be taken as a de facto sign of their misuse. In some cases, antipsychotics may be an appropriate treatment, especially for high-risk youth.

Researchers and state policymakers recognize that antipsychotic medication may be clinically-indicated for some children, but caution that a treatment plan and careful monitoring post-prescribing are necessary for safe use. Antipsychotics come with risks for children and adolescents, including cardiovascular issues, seizures, and cognitive dulling. Weight gain and other metabolic changes due to antipsychotic medication use can predispose children to diabetes.⁷ Prescribing guidelines therefore require doctors prescribing antipsychotics to children to monitor for metabolic changes. A [March 2018 PCORI Evidence Update](#) found that for children with diagnosed attention-deficit/hyperactivity disorder (ADHD) and/or impulse-control and conduct disorders, the benefits of antipsychotics may be modest and the harms may be significant with the possibility of affecting children throughout their lifetimes.

Youth in foster care may be prescribed multiple drugs to address comorbidities. Compounding the situation, there are multiple stakeholders, including different health care providers and specialists, educators, social workers, and biological and foster parents, who all want to ensure these children are receiving the best care possible, but may not be positioned to monitor all interventions. Health care decisions for foster youth involve many parties that change, sometimes on a continual basis, throughout the time children are in the foster system. As a result, there is fear that care decisions may be made to address individual symptoms or issues as they arise, without knowing the

child's full history. This sometimes results in a child taking multiple antipsychotic medications without proper medication management. State officials report that the lack of sufficient access to mental and behavioral health care services and the growing number of children entering into the foster care because of the opioid epidemic compounds the problem. While states have made strides in this area, researchers and state policymakers acknowledge the existing need for continued improvement and additional evidence to inform policy development to optimize care for foster youth.

State Strategies and Policy Levers

States have a variety of policy levers to respond quickly to emerging challenges. In 2008, one such challenge was the rising prescription rate of antipsychotics for youth in the foster system, which prompted questions nationally about potential overuse and what states needed to do to ensure children's safety. At the time, there was little to no evidence-based research available to help guide states in addressing this issue.

Therefore, officials used their own policy expertise and experiences to inform and, over time, adapt or add to their approach to addressing this issue. For instance, a state's primary lever is financial as a payer of health services, which can be used to incentivize care delivery transformation. Another policy lever states can use is increasing regulation and oversight. With decades of experience using these tools, states can employ them quickly in times when research into the comparative effectiveness of various policy approaches may not be available to inform decisions. The following are examples of policy changes states implemented to ensure the clinically appropriate prescribing and monitoring of antipsychotics in children.

Payment Reforms

Prior authorization: This requirement that a payer approves a service or drug before it is prescribed for an individual is an important tool states can use to immediately respond to issues related to prescriptions, such as high-cost or potentially harmful medication. Most states now use prior authorization as a form of care coordination to ensure additional caution when a youth in foster care is prescribed an antipsychotic. Thirty-one states have implemented age-restricted prior authorization policies, which require medical professionals to obtain preapproval from state Medicaid agencies to prescribe antipsychotics to children younger than a certain age as a condition for coverage for drugs.

Episode of care for antipsychotic prescribing: There is a growing interest among state policymakers in payment reforms like episodes of care (or bundled payments) to reimburse providers for all of the care a patient receives for a specific treatment or illness, condition or medical event. The episode of care payment model establishes an expected cost along with quality metrics for a medical event. The expected cost is paid to a provider who is responsible for managing a patient's care for that medical event within quality parameters. When the cost and quality of the episode is better than predicted, the provider may keep shared savings. However, if the cost is greater than expected, or if quality metrics are not achieved, the provider could be a risk for the additional costs of caring for the patient.

A study by Ohio's Medicaid agency on antipsychotic medications in children led to the creation of an episode of care value-based payment model for ADHD. The ADHD episode is triggered by a professional visit with an ADHD primary diagnosis code or with a secondary diagnosis of ADHD and a primary diagnosis of a related trigger code, such as impulse control disorder. The [ADHD episode](#) begins on the day of the triggering claim and lasts 179 days (called the "episode window"). Although ADHD is chronic in nature, the 180-day window aims to capture services associated with ADHD and compare provider performance. The episode model is designed to address care and services directly related to the diagnosis and treatment of ADHD. Services could include hospitalizations, outpatient care, and professional claims with a primary diagnosis for ADHD, or pharmacy claims with eligible and therapeutic codes.

Episode of care payments are intended to incentivize doctors to provide high-quality, evidence-based care to patients. In this case, an episode of care may or may not reduce the number of prescribed antipsychotic medications, but it may include a quality metric to encourage doctors to perform the required monitoring for metabolic side effects in youth using antipsychotics to address ADHD.

Delivery System Innovations

Telehealth consults: Many states are looking to telehealth, the use of telecommunications to connect patients to providers (or providers to providers), who may be a significant distance apart, to bridge access gaps and provide care for critical subpopulations. States are using telehealth to expand access to mental health services for children and youth. Telehealth is also used to provide primary care providers, who may be the first access point of care, with greater mental health expertise from psychiatrists and other mental health professionals. There is a severe shortage of child and adolescent psychiatrists across the country.⁸ As a result of this shortage, state officials report that primary care physicians, who are more accessible, frequently prescribe antipsychotics to children and adolescents, though they lack the expertise in child psychiatry as a specialist. In response, states are piloting telehealth programs to address this workforce shortage. Telehealth consultations allow states to enable better integration of primary care and mental health specialists. For example, Wyoming offers the Partnership Access Line (PAL), which allows primary care doctors to connect with available child psychiatrists over the phone for immediate consultation. PAL, funded by the Wyoming Department of Health, is available to any provider caring for patients in Wyoming. Providers treating patients covered by Medicaid, the Children's Health Insurance Program (CHIP), and private insurers can all use PAL. State officials noted that doctors like the availability of the call line and that it is a relatively low-cost program.

Specialized managed care: A few states, including Florida, Georgia, and Texas, enroll children in foster care into their own Medicaid managed care organizations (MCOs), which are separate from the health plans offered to most Medicaid-covered families. The specialized MCOs are designed to include more comprehensive services that focus on specific needs of foster youth, including robust mental health care. The [Texas STAR Health](#) program is particularly notable for its care of foster youth and safe prescribing standards. While the STAR Health program includes a variety of components, its focus on care coordination allows Texas to provide more robust care than under a fee-for-service system. Texas' MCO, Super HealthPlan, has also built in an automatic review of antipsychotic prescribing for children under age four, or in cases of polypharmacy, the use of two or more medications in the same drug class, or five or more antipsychotics concurrently. States using specialized managed care programs may be able to incorporate evidence-based research into new contracts during the re-bidding process.

Supporting Standards of Care

Prescribing parameters and guidelines: Many states are using prescribing parameters to promote evidence-based practices. Antipsychotic prescribing guidelines recommend limiting the number and dosage of antipsychotics and using metabolic monitoring before and during use. In the Texas managed care model, [prescribing parameters](#) are enforced through peer review when a doctor prescribes medication outside of the guidelines. The utilization standards create safeguards, alerting the state if a foster child is prescribed two medicines from the same class of drugs, or four or more psychotropic medications from any class to be taken at the same time. Texas' STAR Health program conducts ongoing Psychotropic Medication Utilization Reviews of children in foster care whose medication regimens fall outside of the parameters.

Officials participating in NASHP's discussions reported a positive impact from imposing prescribing guidelines with a range of enforcement options -- some are mandatory while others are voluntary. For example, Wisconsin developed a [prescribing guidelines memo](#) for Medicaid prescribers without the enforcement mechanisms contained in Texas' managed care program, yet Wisconsin experienced a near 40 percent reduction in antipsychotic prescribing for children from 2013 to 2016, following dissemination of the

guidelines in 2012. Maine also developed [voluntary guidelines for prescribing antipsychotics in children](#), which it disseminated to primary care practice sites as part of the [Maine Independent Clinical Information Service](#). Prescribing guidelines offer states an opportunity to update and add recommendations as research evolves.

Quality measures: In addition to state-based policy levers, there are national evidence-based quality measures in place for antipsychotic prescribing that can also support standards of care. As part of the Pediatric Quality Measures Program, the Agency for Healthcare Research and Quality (AHRQ) and its partners developed [seven measures](#) assessing the safe and judicious use of antipsychotic medications in children and adolescents. Three of those measures became part of the [National Committee for Quality Assurance \(NCQA\) Healthcare Effectiveness Data and Information Set \(HEDIS\)](#) reporting in 2015. They emphasize “thinking before prescribing” and the importance of monitoring when prescribing. The measures assess performance on factors such as: metabolic monitoring, concurrent use of multiple antipsychotic medications, and use of first line psychosocial care. The National HEDIS Behavioral Health Measurement Set is often incorporated into state Medicaid pediatric quality measurement improvement efforts as the [Center for Medicare & Medicaid Services \(CMS\)](#) has adopted the following metrics:

- Follow-Up Care for Children Prescribed Attention-Deficit/Hyperactivity Disorder (ADHD) Medication
- Follow-Up After Hospitalization for Mental Illness: Ages 6–17
- Use of First-Line Psychosocial Care for Children and Adolescents on Antipsychotics
- Use of Multiple Concurrent Antipsychotics in Children and Adolescents

State Medicaid programs can also integrate the quality measures (CMS Core Set and HEDIS) into their managed care organization contracts to advance quality improvement.

Areas of Concern for Future Improvement

While states have successfully used policy levers like payment reform and delivery system innovation, to improve psychotropic medication prescribing, there are areas of concern that must still be addressed. Emerging research and new policies could increase monitoring rates, advance psychosocial care, enhance patient engagement, and improve data collection and use. Standard quality metrics currently exist to track improvement rates for metabolic management and first line psychosocial care, and are currently deployed in both MCO contracts and pediatric quality of care efforts.

Monitoring for side effects: Metabolic monitoring is an important best practice for safe prescribing as it tracks potentially dangerous weight and hormonal changes, potential side effects from antipsychotic medication use. Metabolic monitoring requires lab testing to measure baseline factors such as blood pressure, glucose, and cholesterol before prescribing and during medication use. Despite the importance of monitoring for these developments in children taking antipsychotics and the existence guidelines, the practice of monitoring continues to happen at very low rates, even when providers are aware of the guideline. A 2017 survey of child psychiatrists asked providers about the monitoring recommendation. Of 1,300 respondents, 95 percent had heard of the guidelines requiring monitoring, 85 percent agreed with them, but less than 20 percent implemented and adhered to the guidelines.⁹ State policymakers and researchers agree that they must continue to identify barriers to monitoring and find approaches to increase monitoring. More education efforts could be targeted at specific populations, such as physicians in nonacademic practices and physicians who have been out of training longer, as they have been shown to adhere to guidelines at lower rates. Other obstacles may include the absence of reminders indicating when a child is due for monitoring and both a guardian’s and child’s knowledge and attitude toward monitoring. Child psychiatrists report that guardians may forget to obtain laboratory tests or be resistant to testing.

Psychosocial care: State health officials, patients and families, and researchers emphasize the need to increase

use of psychosocial care before and while prescribing antipsychotics to foster children. Although estimates vary, a substantial number of children in foster care prescribed psychotropic medications do not receive identifiable behavioral health services, such as talk therapy, in addition to medication.¹⁰ Other foster youth may receive medication and behavioral health services, but could benefit from more comprehensive mental health services. State policymakers participating in the NASHP discussion reported a lack of clear evidence around how to effectively implement supportive mental health services for children who have suffered trauma and need antipsychotic medications.

Advancing comprehensive mental health services requires expanding the evidence base and addressing other barriers, such as reimbursement challenges. Providers often lack appropriate billing codes to charge for comprehensive mental health services. Some payers prohibit reimbursement for same-day or two-generation services -- strategies that could allow children and parents to be served together. Fee-for-service reimbursement practices may limit primary care visits to 10 to 15 minutes, which makes it difficult to administer screening tools, discuss the patient's history of trauma, and offer appropriate referrals. Critical referrals to specialists do not always occur when needed.¹¹

State officials said they understood that screening for trauma is the first step in addressing it. Oklahoma and Texas have taken specific steps to make mental health services for foster children more comprehensive by first expanding screening for trauma. Oklahoma is using a US Department of Health and Human Services demonstration grant to educate child welfare officials on trauma-informed care and train caseworkers to screen for trauma and collect longitudinal data. The program will help identify which children should be referred for more thorough mental health assessments. In Texas, when a child enters the foster care system, they must go through a comprehensive trauma-informed behavioral health assessment within 30 days. Texas added parent-child interaction therapy to the program in 2016 and is considering adding parent-child psychotropic therapy to the STAR Health program. Adding new services can be a cost driver, so evidence that either provides support for or against such interventions can help states' identify the appropriate action.

Enhance patient engagement: Providing health care for foster youth creates particular obstacles for shared decision-making and informed consent. Any sensitive medical decision, such as the decision to initiate the use of an antipsychotic, requires collaboration and shared understanding among foster parents, social workers, biological parents, and medical professionals. In some states, foster youth are also appointed special advocates by the court in order to determine the best interests of the child. Making medical decisions requires constant education of all parties involved. As foster children age, it is also important that they are engaged in their own treatment. State policymakers and researchers are interested in ensuring adolescents are involved in their health care decisions and are prepared to make their own medical decisions about whether to take antipsychotic medication as adults.

In the Texas foster care system, anyone who makes medical decisions for a child in the custody of the Texas Department of Family and Protective Services must go through [medical consent training](#). The training is for foster parents, case managers, relatives and kinship caregivers, or youth who make their own medical decisions. The training specifically covers behavioral health, psychotropic medications, and trauma informed care.

The Texas training also differentiates between medical consent and informed consent — a difference that policymakers and researchers agree is important for all patients, but particularly those who are prescribed antipsychotics. Medical consent means making a decision about whether to agree or not agree to a medical test, procedure, or a prescription while informed consent means having complete information (risks, side effects, etc.) before making a decision. The training outlines how to make an informed decision and specifically how to make an informed decision about psychotropic medication. As foster youth age and become adults, they must go through informed consent training before age 18, and if they are taking psychotropic medication there is an additional training that provides information specifically about these medications.

Improve data collection and use: State policymakers emphasize the difficulties associated with research and data collection on emerging health policy issues such as antipsychotic prescribing for Medicaid-enrolled foster children. In some states, it is difficult to identify children in the foster system in their Medicaid data sets, making it challenging to study specific youth in the foster program and monitor their health outcomes. State policymakers are working to use existing data sets across government agencies and divisions. For example, the Minnesota Department of Human Services has multiple data-generating, social services under one agency. Combining the multiple data sets and analyzing them has proved illuminating on a number of health policy issues. By linking data from different programs, Minnesota is able to gain a broader, more person-centered perspective on the needs and resources of Medicaid enrollees. For example, data from Medicaid and behavioral health systems illuminates the physical and mental well-being of participants, while data from cash assistance and housing programs provides detailed information about participants' access to financial and other resources. Washington State also uses internal data to enhance policymaking through an integrated client database that allows for analysis within and between the Department of Social and Health Services' programs. Washington uses the integrated data to compile research reports, such as an [October 2018 report](#) highlighting the relationship between childhood adversities and increased health care costs. The report used data from youth enrolled in Medicaid and looked at their behavioral health care costs in 2015. States strive to not only look for external research, such as patient-centered outcomes research for evidence-based policymaking, but also to look inwards at their own data sources to enhance their own evidence base.

Evidence-Informed State Policymaking

At times when policymakers must move forward with time-sensitive policy decisions in the absence of conclusive evidence, they may consider “implementation with evidence development.” Policymakers can generate their own evidence by including program evaluation as a critical component of implementation or coverage. Implementation with evidence development allows a promising strategy to move forward while officials continue to collect and monitor data to answer questions.

In addition to the implementation with evidence development approach, some state Medicaid and public health agencies engage state universities or local foundations to assist with research to seek assistance in evidence development. Oklahoma received permission from CMS to use a small portion of their CHIP administrative dollars through the [Health Services Initiatives](#) option to conduct a study on its antipsychotic use among foster youth. Oklahoma researchers analyzed quantitative Medicaid prescription data to understand the landscape of antipsychotic use in foster children in their state. Researchers also conducted focus groups with stakeholders, including department of health services workers, inpatient and outpatient providers, foster families, and legal professionals to identify the challenges in serving foster youth. They found consensus among stakeholders that prescribing guidelines are not clear. Oklahoma Medicaid is now using the study to design new strategies to disseminate best practices and prescribing guidelines. Not all states, however, are able to afford the type of research that Oklahoma conducted, so external sources of evidence remain key.

New evidence from a [forthcoming comparative effectiveness study](#) promises to help states understand the impact of various oversight approaches to antipsychotic use in foster children. A PCORI-funded study at Rutgers University examines the comparative effectiveness of state oversight systems in four states — Ohio, Texas, Washington, and Wisconsin. The Rutgers study will provide quantitative analysis of state Medicaid administrative data (2008-2017) in order to understand how policy timelines align with prescribing trends. Multiple stakeholder perspectives on state monitoring systems are also explored, including views of patients, families, prescribers, child welfare case workers, and young adult alumni of foster care. The researchers partnered with YouthMOVE National to speak with foster care alumni to develop feasible data collection strategies and recruit young people with lived experience. The Rutgers study will provide important evidence states can use to understand the comparative effectiveness of state policies in order to further refine their own.

Conclusion

Many states are responding to high prescribing rates of antipsychotic medications for foster youth with traditional policy levers, such as payment reforms, delivery system innovations, and supporting standards of care. These tools are often used by states to immediately respond to pressing policy issues. However, policymaking is an iterative process, so as new evidence becomes available, states strive to incorporate it into future action. For example, researchers and policymakers agree that there is a gap in evidence illustrating how states can better incentivize monitoring metabolic side effects, advance psychosocial care, enhance patient engagement, and improve data collection and use. States, such as Oklahoma, have conducted research to better understand antipsychotic prescribing. Additionally, the anticipated PCORI-funded comparative effectiveness study promises to provide states with important information to optimize policy responses to this issue and inform future efforts.

Endnotes

1. In 2005, 8.73% of foster children were prescribed antipsychotics. The number rose to 9.26% in 2008. In comparison, the prescription rate for privately insured children remained below 1% throughout the same period, and the rate for Medicaid-insured children outside of foster care peaked in 2008 to 1.86%. [Crystal, Stephen, Thomas Mackie, Miriam C. Fenton, Shahla Amin, and Sheree Neese-Todd. "Rapid Growth Of Antipsychotic Prescriptions For Children Who Are Publicly Insured Has Ceased, But Concerns Remain." *Health Affairs* 35, no. 6 (June 2016).]
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Acknowledgements:

The authors wish to thank the state officials from the Patient Centered Outcomes Research Work Group – Michelle Miller, Leslie Levine, Gary Franklin, Anya Wallack, Jane Beyer, Jennifer Johnson, Robert Walker, Leah Hole-Marshall, Ellie Garrett, Dena Stoner, Cathy Caldwell, Norman Thurston. They would also like to thank Robyn Liu of Oregon Health Sciences University, Sheree Neese-Todd of Rutgers University and Tammy Lambert and Shellie Keast of University of Oklahoma College of Pharmacy. Additional thanks goes to Greg Martin of the Patient Centered Outcomes Research Institute. This work was supported through a Patient-Centered Outcomes Research Institute Program Award (6231-CHPD).

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