

“How Research Evidence Informs Foster Youth Medication Policies”

An American Youth Policy Forum Panel Discussion

Friday, November 20, 2015

Background

Throughout the country, state agencies are developing new policies focused on the use of medications prescribed for emotional and behavioral problems (hereafter, “psychotropic medications”) by children in foster care. A federal government mandate that all child welfare agencies develop plans to review and manage the use of evidence in behavioral health services has spurred many state child welfare agencies to examine the ways in which research evidence can inform decisions about policies and practices related to the use of psychotropic medications by children in foster care. This forum focused on existing and developing research on the use of medications to address emotional and behavioral health, as well as model efforts from the state of New Jersey to incorporate this research to ensure that youth in its foster care system achieve positive life outcomes.

The panelists for the session included:

- Laurel Leslie, MD, MPH, Vice President of Research, American Board of Pediatrics
- Thomas Mackie, PhD, MPH, Assistant Professor, Rutgers School of Public Health
- Dr. Christopher Bellonci, MD, Associate Professor, Tufts University School of Medicine
- Debra Lancaster, Director of the Office of Strategic Development, New Jersey Department of Children and Families

AYPF Senior Director Loretta Goodwin opened the session by noting that emotional and behavioral needs are a crucial component of child development, but knowledge of available research varies amongst relevant child welfare professionals. She stressed, "The goal of all of this work is to improve the health and life outcomes of all children in care."

Presentations

Laurel Leslie’s presentation focused on the following question: Is there evidence that we should be concerned about children in foster care and the use of psychotropic medications?

Dr. Leslie began her remarks with relevant background information on the history of child welfare, the mental health needs of children in foster care, the use of psychotropic medications among children in foster care, and how research has come to play a role in informing the use of such medications among this vulnerable subpopulation of American children. She clarified that psychotropic medications are those used to address emotional and behavioral problems, and that research evidence in this context refers to any sort of empirical findings about the use and impacts of these medications derived from systematic research methods and analyses.

The U.S. Congress has mandated the collection of more information via the Fostering Connections to Success and Increasing Adoptions Act of 2008, the Child and Family Services Improvement and Innovation Act, and the Because Minds Matter Summit (a convening of representatives from Medicaid, mental health, and child welfare). Although the nation started talking about child abuse with the Mary Ellen McCormack case in 1874, it was not until federal legislation in 1997 that child welfare was mandated to address overall child well-being as well as safety and permanence. It is within the past two decades that we have begun to ask questions and investigate the impact of medications on the well-being of children in foster care.

According to epidemiological research, when compared to the overall community, children in foster care have higher rates of emotional and behavioral disorders and toxic stress (1-25% vs. 50 -80%). This is not surprising given their histories of abuse and neglect, exposure to domestic violence, poverty, and in-utero/environmental drug exposure.

Evidence on foster care placements and child welfare outcomes suggest these problems do affect these children's trajectories. Twenty percent of placement changes are related to behavior problems, and youth who have such problems are more likely to experience multiple placements and to remain in foster care 18 months after entry. A survey of Medicaid system costs found that children in foster care make up a disproportionate share of Medicaid costs – they account for only three percent of program enrollment, but represent 15 percent of behavioral service use and 29 percent of behavioral service costs. Children in foster care also have higher usage rates of psychotropic medications than children covered by Medicaid overall. It is also more common for them to be taking multiple drugs. Nearly 50 percent take two or more prescribed medications, making them twice as likely to be in this category as the TANF (Temporary Assistance for Needy Families) segment of the Medicaid population.

These children have mental health needs and there is a robust evidence base on the safety and efficacy of some psychotropic medications. However, clinical trials of their use in children with complex trauma histories and of multiple medication combinations are limited. For the children in the foster care system, this means that use of medications may reflect appropriate use, overuse, misuse, or underuse. Qualitative research evidence provides greater insight into the spectrum of experiences of children in foster care with medications. Youth on one end report that their prescription medications have improved their lives while those on the other end often report negative side effects, such as interference with schoolwork and reduced energy levels.

Multiple system factors impact the use of medications. One example is a child's access to trained physicians who understand how to treat children who might not present with a full medical history. Also important is a clinician's knowledge and experience with trauma and their familiarity with non-pharmacological treatments. There often are challenges accessing high-quality non-pharmacological treatments that focus on the meaning of the behavior for the child and identifying other approaches. Finally, a child's outcomes can be shaped by a lack of coordination across sectors (e.g., Medicaid and mental health systems) and a lack of state oversight systems. Realistically, coordination is more difficult for this population due to the multiple adults and systems that enter and exit their lives. This includes

foster parents, social workers, physicians, Court Appointed Special Advocates (CASAs), judges, lawyers, and many others who may play a role in the lives of youth in foster care.

Tom Mackie's presentation focused on the following question: What evidence is available to inform state oversight of psychotropic medication use? Where is evidence lacking? How have states responded?

Various studies have examined state oversight of psychotropic medication use. Three publications were produced by the Government Accountability Office (GAO), suggesting a greater role for Health and Human Services in providing guidance to states in providing psychotropic medication oversight. Two additional studies were conducted in 2009 and 2011 by a team at Tufts Medical Center (TMC) funded by the Charles H. Hood and W.T. Grant Foundations), which relied on qualitative interviews with key informants in state public sector agencies, and document reviews of state policies, program descriptions, and technical reports.

TMC researchers found substantial state variations regarding oversight of psychotropic medications. Just under half the states had policies in place for mental health evaluations, just over half had an oversight policy for prescribing medications, and one quarter had no policies at all. Further examination revealed other differences:

- *Different Stages of Policy Development.* Some states were in the initial stage of prioritizing the issue of psychotropic medication oversight. Others were in the midst of assessing their state's status quo and planning for new policies. Further along were the states that had already implemented their policies or had gained enough experience to improve the quality of their policies.
- *Configuration of Mental Health and Medical Expertise.* Some states had medical directors within their Medicaid or child welfare agencies. Others had experts housed in partnering state agencies or had hired external consultants from places such as academic institutions.
- *Process Taxonomy.* States varied greatly in what is required for: (1) mandated mental health evaluations, (2) informed consent prior to being prescribed a psychotropic medication, and (3) monitoring psychotropic medication use once prescribed.
- *Timing of Medication Review.* Depending on the state, reviews can occur before the medication is dispensed or after.
- *Availability of Experts in Child-Level Monitoring.* Twenty percent of the monitoring mechanisms implemented by states did not routinely rely on licensed or credentialed professionals when monitoring optimal use of psychotropic medications.
- *Providers of Informed Consent.* State systems had varying rules for who can provide consent for medication. Potential individuals/entities included foster parents, biological parents, caseworkers, child welfare supervisors, judges, or the youth themselves.
- *Population-Level Monitoring.* Some states did population-level monitoring while others did not. For those that did, it could take various forms. For example, some monitored existing databases that may be used administratively or programmatically for Medicaid, child welfare, or state mental health programs. Another possibility is that the state could have been conducting

regular audits which involve selecting a random sample of cases to investigate via reviews of case records and/or interviews with key stakeholders.

- *Inter-Agency Collaborations.* Researchers sampled three states to learn about their inter-agency collaborations. All of the states engaged in at least two inter-agency collaborations for oversight efforts. Over half were meeting at least once a month. Collaborations allowed for exchanges of expertise, research evidence, and opportunities to leverage existing resources or jointly seek out new ones.

There were some general conclusions that emerged from the research. Despite some variations across states, some differences were appropriate, as they fit the unique needs of individual communities. Currently there is limited evidence on the effectiveness of existing state approaches. Such research is critical to evaluating intended and unintended outcomes.

Dr. Christopher Bellonci’s presentation focused on the following question: How are states using local evidence collaboratively to measure medication use?

Dr. Bellonci offered details about the Psychotropic Medication Quality Improvement Collaborative (PMQIC). Funded by the Annie E. Casey Foundation, it is a three-year initiative designed to develop best practices in psychotropic medication oversight and monitoring for children in foster care. Six states were selected to be in the collaborative and each developed individual goals and a series of common measures.

PMQIC formed a data subgroup comprised of representatives from Child Welfare, Mental Health, and Medicaid for each of the six participating states (Illinois, New Jersey, New York, Oregon, Rhode Island, and Vermont). Since trauma can present as any number of psychiatric diagnoses, it was important to have trauma experts onboard to inform the work. Ultimately, the goal was to improve mental health outcomes for youth. In doing so, the group aimed to identify and agree upon common definitions and measures that each state could implement in addressing the inappropriate use of psychotropic medications.

PMQIC states adopted the following approaches:

- Developing and revising informed consent procedures.
- Developing a method for generating real-time medication utilization data. (If asked, many states are unable to automatically pull-up information on what medications are being taken by particular children in their care.)
- Developing a protocol for reviewing “red flags” or outlier prescribing practices based on factors such as age and dose.
- Developing oversight and monitoring processes appropriate for local needs and practice concerns.

They decided to define “psychotropic medications” as medications being used for an emotional and behavioral condition. This includes antipsychotics, stimulants, antidepressants, benzodiazepines, anti-anxiety medications, and mood stabilizers.

Some medications have pediatric dosage guidelines that are approved by the Food and Drug Administration. In the absence of such established pediatric dosage guidelines, the Texas Children's Medication Algorithm Project guidelines are used. If neither of those sources has set guidelines, the adult dosage standards are applied. For children, as many as 75 percent of prescriptions are off-label, meaning the medications were not tested in the pediatric population or they are used for non-approved indications. Beyond the concerns attached to an individual prescription, children may also be prescribed problematic medication combinations (i.e. polypharmacy).

The three-year PMQIC developed an ambitious number of common measures, gathering data on the percentage of children in foster care who were:

- On any psychotropic medication
- On specific classes of medication
- On more than 1 medication from the same class (co-pharmacy)
- On 2, 3, and 4+ psychotropic medications (polypharmacy)
- <6 years old on any psychotropic medication
- <6 years old on 2, 3, and 4+ psychotropic medications
- <6 years old on antipsychotics.

There were also qualitative measures used by the PMQIC. This includes evidence-based or promising interventions for sleep disorders and/or aggression. Also of interest is the development of an informed consent process or means of increasing compliance with existing processes.

Debra Lancaster's presentation focused on the following question: What has been one state's experience?

Ms. Lancaster works for the Department of Children and Families in New Jersey. The state began implementing policies regarding psychotropic medication oversight before the GAO reports were released in 2011 -2014.

According to Lancaster, "We ultimately agreed to develop policy rooted in evidence, to the extent there was evidence." The Department also made it a priority that the policy aligned with the agency's case practice model, child health plan, and child health values: access, continuity, child/family centered, quality, integration, and partnership. A central tenet in New Jersey's case practice model and approach to working with families is partnership. When a child is placed in foster care, the partnership with the family must continue and include the healthcare of the child. In New Jersey, non-routine medical care and decision making requires the consent of the biological parent in most cases. To help operationalize their child health values and approach to working with families, New Jersey invested in developing Child Health Units (CHUs) in each of their child welfare offices. CHUs are staffed with nurses who provide healthcare case management for each child and youth in foster care. Nurses partner and coordinate with community providers and families to ensure that children receive the care they need and that caregivers understand the individual healthcare needs of each child. Nurses visit with each child

regularly. Each nurse has a caseload of approximately 50 children. The cost of the \$30,000,000-dollar investment in CHUs is shared between State dollars and Federal Administrative Medicaid Claiming.

Rather than investing in “healthcare islands” or special sections of the healthcare system that only target young people in foster care, New Jersey delivers healthcare to children and youth in foster care by leveraging existing healthcare infrastructure and community resources. The CHUs are there to help ensure each child and youth has an established medical home and access to professionals and subspecialists in the community. Unless parental rights are terminated, most children return home—by having children and youth served by medical homes and professionals and subspecialists in the community, those transitioning out of foster care and back to their home can maintain continuity of care.

Lancaster noted key factors associated with the development of New Jersey’s Psychotropic Medication Policy (issued in January of 2010). It was informed by the American Academy of Child and Adolescent Psychiatry (AACAP), the American Academy of Pediatrics (AAP), and the Child Welfare League of America (CWLA) guidelines as well as practices in other states. Internal workgroups were key for multiple reasons, including helping to reduce staff concerns about adding more complexity to their workload. The drafted policy was consistent with DCF values and the case practice model. A Commissioner’s Advisory Group on Psychotropic Medication was created to advise and guide the Department in policy development, implementation and monitoring. DCF presented the policy to several key stakeholder groups, including prescribers. While a handful of prescribers were initially unnerved by the policy and the active role of the CHUs and caseworkers, most valued the Department’s interest in partnering to improve the treatment and care of children and youth in foster care.

The key components of the final policy include:

- Psychiatric evaluation
- Authorized prescribers
- Treatment plans (must include non-pharmacological interventions but more research on these methods would be useful)
- Informed consent (working with the young person and family)
- Medication guidelines
- Safety monitoring guidelines
- Prescribing parameters

Ultimately, approaches will vary by state according to their local needs, starting points, and available resources.

New Jersey had certain resources that helped with implementation. For example, all children in foster care are enrolled in the N.J. Medicaid program. Although atypical, the state has a children’s behavioral health system (reaching children beyond those in foster care). New Jersey has a Child Health Unit that 1) develops healthcare plans specific to each child’s health needs, 2) coordinates healthcare services to ensure access to healthcare and timely follow-up, and 3) facilitates effective communication amongst

relevant parties (Child Welfare, Child Health Program, birth families, children). Finally, DCF has a full-time Chief Child/Adolescent Psychiatrist and several other clinical team members. (Many other states have part-time medical directors who are not always the most qualified people for the job.)

Lancaster then provided some additional information about DCF's Child/Adolescent Psychiatrists. They are available for consultation when questions or concerns arise. Typically, certain children are referred to them, including those who are 1) prescribed off-label medications, 2) prescribed three or more psychotropic medications, 3) diagnosed with a complicated medical illness. The psychiatrists respond to requests for consultation with a conference call or a treatment team meeting.

Finally, Ms. Lancaster discussed New Jersey's tracking system. The Children's Health Unit maintains basic information for every child prescribed a psychotropic drug—demographic data, medication details, diagnosis, prescriber listing, most recent treatment plan, and other information. The unit compiles and analyzes this data on a quarterly basis to establish trends. Special attention is paid to at-risk cohorts (i.e., under six years old, prescribed four or more psychotropic medications).

Audience Q&A

Question 1 was focused on the role of lawyers and the legal system. It was suggested that lawyers might be good individuals to provide informed consent since they may have longer relationships with a child than other actors. The questioner was also interested in the panel's thoughts on judicial oversight for prescription questions.

The panelists answered the question with some examples from the states. In Texas the process requires judges to select a medical decider as soon as a child enters care. Massachusetts requires a 24-page affidavit that includes the information that the court needs to make the medical decision but only for the use of antipsychotic medications. California also invests authority in judges. However, some of the panelists suggested that such decisions should rest with individuals other than judges who are closer to the clinical treatment of the child. When developing decider policies, states should have an understanding of the advantages and disadvantages of each option and be prepared to deal with the disadvantages.

Question 2 focused on coordination, suggesting that it can be difficult when privacy protections inhibit the sharing of child and family information.

The panelists reiterated the importance and value of cross-system collaborations and partnerships. In New Jersey, these challenges are a part of an ongoing learning process. The state has developed some creative ways of working around some of the issues but is still unable to freely share all useful information.

Question 3 focused on models for letting biological parents make the decisions, noting that this is the policy in Washington, D.C. (along with judicial override authority).

The panel indicated that this is the most prevalent policy in the United States. In reality, most parents do not make the decisions due to their own personal challenges or lack of involvement. Therefore, child

welfare staff typically make the decisions in the absence of being able to contact the biological parents. New Jersey has nurses and extra caseworkers assigned to children—they help to facilitate decision-making by biological parents. Nurses are initially reluctant to spend more time working with parents. However, most parents will show up if engaged in the right ways.

Question 4 reflected an interest in the appropriate metrics for judging policy success.

According to Dr. Bellonci, “The most important outcomes are the ones you would want for your own child.” You would not want your own child to be homeless or out-of-school so those are the kinds of metrics we should be most concerned about. Unfortunately, we do not have many metrics that go beyond current prescription rates. This is something we have to work on.