Children's Rights

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Public Facing Advocacy Writing

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I was a zombie, Jimmy said. I was on seven psychotropic medications when I was 14 years old. I couldnt eat. I had chest pain. Jimmy knew even at that age he didnt need all the medications he was being prescribed. He needed a home and healing for the trauma he had experienced before and during his time in foster care. As he told me, Kids in foster care dont need all these drugs. What they need is time. And nobody gives that to them. Jimmy tried to voice his objection to the drugs he was being prescribed, but his foster parents told him that if he wanted to stay under their roof, he would have to take the pills. He didnt want to be homeless, so he took the drugs. And felt like a zombie. He didnt think he had a choice. Years later, Jimmy overheard a supportive adult tell someone, Does he see a psychiatrist? No, he doesnt. Jimmy doesnt need the drugs. Something awoke in Jimmy that day. He gave me a gift, he explained. I had never heard anyone say no before. It had never occurred to me I could say no.

Jimmys story is not unique. Every day, thousands of children in foster care are administered powerful psychotropic medications. The federal government has coined this phrase with respect to the use of psychotropic medications for children in foster caretoo much, too many, too youngacknowledging a variety of ways in which the lack of oversight of psychotropic medications harms children. On any given day, up to 33 percent of children in out-of-home care may be administered a psychotropic medication, as compared to only about 6 percent of children in the general population. This large class of pharmaceuticals includes antipsychotics, stimulants, amphetamines, antidepressants, and other drugs known to cause adverse effects, including weight gain, tics, suicidal thoughts, and diabetes.

While these drugs do offer benefits to children who need them, most are not Food and Drug Administration (FDA) approved for use with children and are instead prescribed off label. Many are surprised to learn that once a drug is FDA approved, physicians may legally prescribe it for*any*indication and even in populations for which the drug was not originally intended. Given the ethical challenges surrounding clinical drug trials in children, off-label prescribing of psychotropic and other medications is prevalent in the pediatric community. Even more problematic, these medications are often administered to children not to treat a properly diagnosed mental health condition, but rather as a form of chemical restraint to control problematic behaviors resulting from trauma.

Although the federal government has taken steps to regulate some of the riskiest medications, including adding black box labels to certain medications, and continues to issue guidance to human services agencies regarding the oversight of psychotropic medications for youth in state custody, it has not significantly limited the ability of physicians to prescribe them to children.

Given the known risks, professionals in the health care and child welfare communities widely agree that psychotropic drugs should never be administered without a rigorous informed consent process that considers all the risks and benefits, involving physicians and caregivers. Often overlooked is the role of informed*assent*, defined as a 3-part process that includes the youth understanding (to the best of his/her developmental abilities) treatment options, the youth voluntarily choosing to undergo treatment options, and the youth communicating this choice.

Professional and governmental organizations alike acknowledge that involving youth in decisions about their health care, including the use of psychotropic medications, is essential. Federal guidelines on the Oversight of Psychotropic Medication for Children in Foster Care reference the need for written policies to contain provisions for . . . informed and shared decision-making (consent and assent). Many, though not all, state agencies have followed suit, including adding a reference to obtaining youth assent in their policies. For example, psychotropic medication oversight policies in Texas state that except in the case of an emergency, informed consent should be obtained from the appropriate party(s)*and*assent from the child or adolescent before beginning psychotropic medication.

And yet, in many states, a childs right to a voice in their own treatment is not ensured, even when state agency policies*do*provide youth with a specific set of rights. Many youth in foster care, like Jimmy, dont know that they have a right to be involved in their health care decisions. Others report that providers all too often do not even ask youth what they need or what they believe would most benefit their emotional and mental wellbeing. Another challenge is that these rights vary from state to state, creating confusion among youth-serving professionals. In recent years, advocates have begun to sound alarm bells regarding the failure of state agencies to safely oversee the administration of psychotropic medications and engage youth in their own health care decisions.

Determining what rights the Constitution guarantees to foster youth related to psychotropic medication is an evolving area of law. Courts have repeatedly recognized that adultsin government custody have a significant liberty interest in avoiding nonconsensual or unnecessary administration of psychotropic medications. Others have recognized this right to bodily integrity in the youth context, concluding that youth in state care must be involved in their own health care decisions, such as being institutionalized for mental health treatment. In*Parham v. J.R.*, the Supreme Court found that the decision to institutionalize a child must include an interview with the child. In a 2018 decision in*M.B. v. Corsi*, a first-of-its-kind class action challenging the state of Missouris failure to safely oversee the administration of psychotropic medication to children in foster care, the Court followed these and other precedents to conclude that plaintiff children indeed possessed a strong liberty interest in not being unnecessarily administered psychotropic drugs. Though the Courts decision did not delineate exactly what this liberty interest would protect for youth in terms of involvement in their own care, plaintiff children

ultimately reached a settlement agreement with state officials confronting informed assent head-on and including a set of commitments designed to protect the bodily integrity of foster youth. The agreement also requires improvements in medical records, training for social workers and caregivers, secondary review of prescriptions, and defines a rigorous informed consent process involving adults who know the child best.

The rights guaranteed to Missouris foster children, which originate in the constitutional principles established by*Parham*and others, provide a roadmap for the minimum protections to which all children in foster care should be entitled. For example, Missouris policy manual includes the premise that bodily integrity is the principle that it is the right of each human being, including children, to autonomy and self-determination over their own body. To protect that bodily integrity, Missouri policy guarantees youth in foster care the following rights:

Following engagement with advocates such as the National Center for Youth Law, Californias state guidelines for psychotropic medication oversight now also go well beyond basic informed consent and oversight, describing expectations regarding treatment plans, non-pharmacological treatments, and principles governing medication safety and youth engagement. Californias system is distinct from the Missouri model and many others in one critical wayin California, judicial approval is required for the administration of a psychotropic medication to a child in foster care. That approval process is initiated by child welfare staff using a form (the JV-220), which contains information about the medication and the childs treatment plan. The form asks explicitly whether the youth has shared feelings about starting to take medication. California also has an optional form dedicated*solely*to seeking feedback from the youth (JV-218), which asks questions about the youths experience and allows them to share anything they would like the judge to know. While the judicial approval process adds an extra layer of oversight and opportunity for youth engagement that many youth advocates support, making the JV-218 a mandatory part of that process would serve the much-needed function of elevating the youth voice.

In light of the long-term physical and emotional impacts of psychotropic medication, more needs to be done to ensure other states follow in Missouri and Californias footsteps in protecting the basic right of youth to assent to the use of psychotropic medication as part of their treatment plan. We have already seen a decline in the number of children being administered psychotropic medications in both Missouri and California. But to be clear, the rights described above are just the beginning, not the end, of youth justice in this area.

There is no one-size-fits-all solution. It is a complex issue. But it would be a mistake for child-serving agencies to conclude that there isno solution and fail to listen to the voices of the youth in their care. Youth in foster care do have rights when it comes to taking psychotropic medications. They deserve to know their rights and to be empowered to exercise them. And we, as advocates, have the obligation to support and safeguard those rights.

> Foster Care: HHS Has Taken Steps to Support States Oversight of Psychotropic Medications, but Additional Assistance Could Further Collaboration
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> A Guide for Community Child Serving Agencies on Psychotropic Medications for Children and Adolescents
>
> Psychotropic Medication Utilization Parameters for Children and Youth in Texas Public Behavioral Health (6th Version)
>
> *M.B. v. Tidball*Settlement Agreement
>
> Missouri Department of Social Services Psychotropic Medication Settlement Reports
>
> California Guidelines for the Use of Psychotropic Medication with Children and Youth in Foster Care

Elizabeth Pitman Gretter, of counsel, joined Childrens Rights in 2011. Together with teams from Childrens Rights, the National Center for Youth Law, and others, she has served as counsel on numerous cases advocating for the rights of children in foster care, including those related to the oversight of psychotropic medication and the denial of mental health services.