

Center on Children and the Law



NATIONAL COUNCIL OF IUVENILE AND FAMILY COURT JUDGES

Involving Parents When Psychotropic Medications are Prescribed to Children in Foster Care

Case Studies

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Quick Overview

This alert highlights:

- The importance of involving parents when children in foster care are prescribed psychotropic medication.
- How to involve parents when their children are prescribed psychotropic medication.
- Common concerns related to medicating children in foster care that parents should be aware of.
- How judges can support parents and ensure they are involved in decisions about psychotropic medication use with their children.
- Key elements of informed parental consent to psychotropic medication use with children.
- Resources to learn more.

- ♦ A 14-year-old girl in foster care is on five medications for impulsive and acting-out behavior. On the rare occasion that she goes to school, her disruptive behavior causes her to be suspended. The girl hates her foster home and has run away several times. Her mother, who is successfully working on a treatment plan with the goal of reunifying with her child, was not informed of the need for medication and did not meet with the provider or give her consent. The mother asks her attorney why she was never asked about her family's medical history, which includes a long struggle with diabetes, and objects to the medications because her daughter is gaining weight rapidly.
- A six-year-old boy in foster care is prescribed an off-label psychotropic medication to treat symptoms of depression. The psychiatrist who ordered the drug conducted a 10-minute exam of the child and obtained information about the boy from his foster parents and caseworker. His parents, who were working with the child welfare agency to reunify with the boy after a neglect investigation, were not consulted about the boy's depression, and were not asked to consent to or informed about the medication.

You're the judge handling these cases. What stands out? What concerns you? Both cases highlight the common and controversial practice of prescribing psychotropic medications to treat mental and behavioral health issues among children in the child welfare system. Also common, but less recognized, is the practice of undervaluing the parent's role in decisions about psychotropic medication use with their children. How often is the parent told about medicines, asked for input, given the chance to consent or object to medications, and truly "heard" in decisions about psychotropic medication use with their child? In your oversight role, raising the issue and asking a few questions can ensure parents are valued participants in these decisions.

Why is it important to involve parents when children in foster care are prescribed psychotropic medication?

Involving parents in decisions about administering psychotropic medication to their children is critical because it:

 provides medical decision makers important information about the child's physical and mental health history, and behavioral health and medical treatments that have been tried in the past and their outcomes.

- values parents' role in medical decisions and giving consent to their child's medical treatment.
- helps parents feel engaged and invested in their child's health and well-being while in foster care.
- motivates parents to work on their case plans and address underlying issues so they can support their child's health and well-being.
- smooths the transition when the parent resumes care of the child when reunification is the permanency goal.

Despite these benefits, parents are often not included in decisions to prescribe psychotropic medications to their children. This can create several immediate and long-term risks for parents and children, including:

Parents:

- lack of understanding of the medication plan
- inability to share critical information, including family medical history, with the prescribing doctor
- inability to oversee and monitor the child's psychotropic medication regime
- inability to share religious and cultural views relating to psychotropic medication use
- inability to handle the psychotropic medication's side effects
- lack of investment in the child's mental health treatment
- challenges to family reunification

Children:

- lack of essential parental input, guidance, and support in key medical decisions that may have lifelong consequences for the child
- provider's lack of awareness of child's full medical and psychological history, including trauma
- increased likelihood of the child receiving psychotropic medication unnecessarily¹
- loss of the parent as a vigorous advocate for the child's interests
- increased sense that the parents are not committed to reunification because they are not involved in key parenting decisions relating to health

Policies and practices are evolving to better engage and involve parents, when appropriate, in decisions about psychotropic medication use with their children, but they are not consistent or uniform across jurisdictions. A review of five states' efforts to improve use of psychotropic medication among children in foster care identified greater attention to the perspectives of children and their families about the use of psychotropic medications as an area for further development.² As a judge handling child welfare court cases, your role includes ensuring parents are involved, their rights are protected, and their views about psychotropic medication use with their children are heard and honored.

How should parents be involved when their child is prescribed medication?

Parents should be involved in decisions about psychotropic medication use with their children. Exceptions exist if there is a medical emergency, the child is deemed old enough under state law to consent to psychotropic medication and to decline to have the parent involved, the parent is not competent to make decisions, or the parent is unavailable or declines involvement. These should be viewed as true exceptions so that parents' involvement is expected and encouraged.

Prior to the child starting use of psychotropic medication, the parents' involvement should include:

Sharing information about the child's behavior and treatment history to guide the treatment plan. The parent may have unique information and insights about the child's behavior and past treatments that could inform the treatment approach and decision to

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use psychotropic medication. Limited medical health histories and multiple transitions while in foster care can result in gaps in the child's medical information that a parent may be able to help fill.³

Sharing cultural views and preferences about psychotropic medication use. A parent should always have an opportunity to discuss cultural factors and family preferences regarding psychotropic medication use. The prescribing doctor should routinely meet with the parent in person to obtain the family's medical and psychiatric history. The provider should respect the family's preferences and priorities regarding psychotropic medication use, discuss reasonable alternatives to medication treatments, and honor any reasonable objections by the parent to psychotropic medication use.⁴

Receiving detailed information about the psychotropic medication and alternative treatments. The parent should be given as much information about the psychotropic medication as possible, including the drug name, why it is needed, its benefits, and any side effects and risks. A review of current evidence and promising practices for systems-level strategies that promote best practice prescribing for psychiatric medications among youth sought input from families. Families stressed the need for comprehensive information on psychiatric medications in lay terms that families can easily understand. They asked that prescribing clinicians provide more information about reasonable, nonpharmacological alternatives to psychiatric medication treatment such as psychotherapy. They also wanted more information about alternative medication treatment options, including benefits, risks, and potential side effects.⁵ Providing comprehensive information to parents allows them to make informed decisions about their child's treatment with psychotropic medication and to share their wishes and any objections.

Consenting to psychotropic medication use. More jurisdictions are requiring the parent's informed consent to psychotropic medication use with a child unless exceptions exist⁶ (e.g., if there is a medical emergency, the child is deemed old enough under state law to consent to psychotropic medication on their own and to decline to have the parent involved, the parent is not competent to make decisions, or the parent is unavailable or declines involvement).

However, practices vary widely.⁷ Parents' authority to make medical decisions for children in foster care may be determined by statute or by the judge.⁸ Some states allow the state (caseworkers, child welfare agency administrators) and foster parents to make medical decisions for the child.⁹ Check your local requirements regarding obtaining the parent's informed consent for specific requirements. (See the sidebar for recommended information that should be included on an informed consent form.) All reasonable parent preferences should be honored.

Informed Consent—Key Information

The following information should be included on an informed consent form:

- 1. Patient's name and date of birth
- 2. Name of prescribing physician
- 3. Contact information for prescribing physician
- 4. Brand name of medication
- 5. Generic name of medication (if applicable)
- 6. An attached list of possible side effects, including the risks of failing to take the medication properly and/or stopping the medication without physician approval and supervision. When the medication is prescribed the prescribing physician should go over the risks with the patient and/or guardian
- 7. Statement describing the symptoms being treated and the expected benefits of the medication
- 8. A list of other therapies tried and/or tried and rejected and the reasons why
- 9. Estimated duration of medication
- 10. Dosage
- 11. Maximum dosage allowed by the FDA.
- 12. Frequency of dosage
- 13. Signature of physician
- 14. Signature of patient or guardian if patient is a minor or under a disability.
- 15. Likelihood of benefit
- 16. Pros and cons of all reasonable alternatives (Alternatives are reasonable treatments that might be effective although they might not be the first choice of the provider.)
- 17. Black box warning
- 18. Whether the medication is FDA approved for the child's age or indication or is being used off-label.

Reprinted and adapted from O'Leary, Kate. <u>"An Advocate's</u> <u>Guide to the Use of Psychotropic Medications in Children</u> <u>and Adolescents.</u>" *ABA Child Law Practice* 25(6), August 2006. Numbers 15-18 were added to the original list based on input from Dr. Martin Irwin, Clinical Professor, Child and Adolescent Psychiatry, NYU Grossman School of Medicine. Asking questions about the child's psychotropic medication. Ideally the parent will have the opportunity to meet with the doctor prescribing the psychotropic medication to learn about the proposed treatment plan with psychotropic medication and to ask questions.

Requesting changes to a medication regime and reasonable alternatives to medication. The parent may observe changes in their child's behavior or concerning side effects related to the psychotropic medication. The parents should be able to discuss changes to a child's medication, including tapering and discontinuing the medication, or alternatives to medication with the treatment team.

What are some concerns related to medicating children in foster care that parents should be aware of?

Parents should be informed of common concerns and risks surrounding psychotropic medication use so they can contribute to decisions about their use with their children. Judges should ensure someone—the parent's caseworker, attorney, mental health professional helps educate and familiarize the parent about psychotropic medication use with children and common concerns.

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Parents should always be told the rationale for prescribing more than one medication, potential risks and side effects, drug interactions, and what reasonable nonpharmacological treatment options exist.

Treating a child with multiple psychotropic medications. Prescribing multiple drugs simultaneously is generally not supported. Unclear diagnoses can result in prescribing multiple medications to treat a variety of symptoms. Parents should always be told the rationale for prescribing more than one medication, potential risks and side effects, drug interactions, and what reasonable nonpharmacological treatment options exist.¹⁰

Prescribing psychotropic medication without using other treatment modalities. Prescribing psychotropic medications without using other therapies compromises healing and stabilization needed for healthy growth to occur.¹¹ Treating mental health issues and symptoms experienced by children and youth requires multiple treatment modalities in addition to medication or pharmacological treatments. Evidence-based behavioral treatments that are known to reduce symptoms, facilitate healing, and return a child to optimal functioning include behavioral therapy, cognitive behavioral therapy, play therapy, child parent psychotherapy and dialectical behavioral therapy.¹²

Medicating children under age six. Very young children are rapidly developing physically, neurologically, emotionally, and psychologically. This makes them more sensitive to psychotropic medications.¹³ Every effort should be made to treat very young children through behavioral interventions before psychotropic medications are tried.¹⁴ Despite growing use of psychotropic medications with this population, little evidence exists to support their use except in limited circumstances.¹⁵ Researchers advise constant monitoring of medications' impact on very young children's development by a doctor with specialized training with very young children.¹⁶ Use of antipsychotic medications is especially problematic because of their side effect profile. For these reasons, nonmedication therapeutic interventions are advised for very young children.17

Prescribing medication to treat side effects. A

child may experience a side effect from a medication. Instead of stopping the medication, a common practice is to add another medication. This can result in layering medications and "medication cocktails."¹⁸ If the first medication tried is causing side effects that require another medication, best practice is to consider a different medication that will treat the underlying condition without causing the side effects instead of adding a second medication.¹⁹

Prescribing off-label medications. Medications that are not approved by the Food and Drug Administration (FDA) are considered "off-label." FDA approval means a drug "has been found to be safe and effective for a particular diagnosis at a given dosage range for people of a particular age range as determined by evidence-based research."²⁰ A drug that lacks FDA approval may still be effective and safe but there may be little proof of safety and efficacy. An off-label drug should only be used after all other reasonable treatment approaches have been tried. Because of significant risks and side effects, off-label use of antipsychotic medication is especially problematic. When an off-label medication is recommended, the parent should be informed of the reasonable treatment approaches that were tried first and the outcomes, the rationale for prescribing an off-label medication, and any evidence in the medical community to support its use. Any objection by the parent to using an off-label medication should always be honored.

Failing to consistently monitor medication. The prescribing doctor should closely monitor the medication, especially in the early stages after it is first administered to a child. The doctor should monitor any side effects and related medical conditions. If bloodwork is required, the doctor must order the bloodwork and adjust the medication as needed based on the results. For example, a known side effect of lithium is elevated TSH, a thyroid hormone. Blood monitoring can reveal elevated TSH, which can be lowered if lithium use is stopped. However, if an abnormal blood test is ignored and a child is left on lithium, TSH levels will go back to normal in some children but remain elevated in others, leading to irreversible hypothyroidism.²¹ Diligent medication monitoring and adjusting the treatment plan as appropriate provide an important safeguard for children against long-term negative health issues.

Ignoring a medication's risks in favor of its ben-

efits. Some medications are too risky or have detrimental side effects that outweigh their benefits. For example, some psychiatric medications cause drowsiness and withdrawn behavior. Some medications used to treat thought disorders can cause lifelong disorders such as smacking one's lips or other odd movements. Many antipsychotic medications and mood stabilizers are associated with excessive weight gain. A rarer side effect of antipsychotic medications is big breasts in boys and enlarged breasts and milk leakage in girls. The social consequences of these side effects can be devastating for a child as they can affect self-esteem, performance, and relationships. Alternative treatments should always be explored first.²²

Allowing long-term use with no attempt to taper.

Before deciding on long-term use, a two-to-threemonth trial of the medication should be attempted to determine safety and benefit for the individual child. Once a child's behavior and environment has stabilized for a period of 8-18 months, a strong consideration should be given to putting a plan in place to taper or discontinue the medication to see if the medicine is still needed or a lower dose can be administered.²³ **Abruptly stopping medication.** If a child has been on the medication for a long period, abruptly stopping the medication has risks and can cause new side effects. A plan to slowly discontinue a medication or decrease the dosage gradually should be followed with close monitoring by the prescribing doctor.²⁴

Overmedicating children of color. Some evidence shows children of color are medicated at increased rates compared to nonminority children. A report on antipsychotic medication best practice strategies²⁵ identified higher rates of antipsychotic medication use among children of color. It recommended: "[a]ttention should be provided to innovative approaches that respond to the unique needs and preferences of these communities as well as provide redress to the obstacles that youth and families from these communities face in receiving safe and effective antipsychotic medication (e.g., investments in culturally and linguistically appropriate treatment alternatives)."

What is my role?

Your role includes ensuring parents are informed and involved in decisions about psychotropic medication use with their children and their wishes and objections to medication are given strong preference in decision making. Steps you can take include:

Review the decision to prescribe psychotropic medication and the parent's role in it.

Questions to ask:

- Did the prescribing doctor conduct a full evaluation with the child and review all of the child's medical records? Did the evaluation include input from the parent about the child's and family's medical and behavioral health history?
- Did the prescribing doctor seek input from the child and the parent to gain a fuller understanding of the child's mental health and behavior to inform the treatment approach?
- Did the prescribing doctor explain the need for medication to the child and parent in language they could understand?
- Was the parent given reasonable treatment alternatives? Were the parent's wishes regarding treatment honored?
- Was there time for questions from the child and parent? Did the child and parent feel their questions were answered adequately?

Best Practices

American Academy of Child & Adolescent Psychiatry. <u>A Guide for Community Child Serving Agencies</u> <u>on Psychotropic Medications for Children and Adolescents</u>, February 2012.

Substance Abuse and Mental Health Services Administration, Office of Behavioral Health Equity and Office of Chief Medical Officer. <u>Guidance on</u> <u>Strategies to Promote Best Practice in Antipsychotic</u> <u>Prescribing for Children and Adolescents</u>, 2018, 17

Court Oversight

National Council of Juvenile and Family Court

Judges. <u>Resolution Regarding Judicial Oversight of</u> <u>Psychotropic Medications for Children under Court</u> <u>Jurisdiction</u>, July 3, 2013.

Solchany, Joanne. <u>Psychotropic Medication and</u> <u>Children in Foster Care: Tips for Advocates and</u> <u>Judges</u>, October 2011.

Informed Consent

Mackie, Thomas, Laurel K. Leslie & Erick Rojas. "<u>A</u> National Examination of Informed Consent Processes for Psychotropic Medication Use among Youth In Foster Care: A Typology of Approaches to Informed Consent and Implications for Policy and Practice." *Pediatrics*, August 2019, 144.

 Did the child and parent support the decision to use psychotropic medication? Were their views considered and weighed in the decision?

Ensure the parent has been informed and involved in decisions about psychotropic medication use.

NCJFCJ policy requires that the court "[e]nsures parents are fully involved and informed about the use of the medications and the reason for their use and have the ability to maintain the regimen or meaningfully decide, in consultation with medical professionals, whether and how to discontinue medications during reunification or upon return to their custody."²⁶

Questions to ask:

• Did the parent sit down with the prescribing psychiatrist? When and for how long? Sample state informed consent policies:

- Washington State Department of Children, Youth & Families. <u>Policies and Procedures:</u> <u>4541. Psychotropic Medication Management</u>
- Maryland Department of Human Resources, Social Services Administration SSA-15-08 Oversight and Monitoring of Psychotropic Medications
- Pennsylvania Office of Children & Families and the Courts requires completion of a <u>Case</u> <u>Manager Informed Consent form</u>, and <u>Court</u> <u>Summary – Psychotropic Medications</u>

Parents' Rights

"Psychiatric Medication and Foster Care Preserving the Parent's Voice." ABA 2021 Parent Representation Conference Virtual Convening, May 20, 2021. (Presentation by Dr. Martin Irwin, Clinical Professor, Child and Adolescent Psychiatry, NYU Grossman School of Medicine & Christine Bruno, JD, Center for Family Representation, NY).

Strassburger, Zach. <u>"Medical Decision making for</u> <u>Youth in the Foster Care System.</u>" John Marshall Law Review 49:4, Summer 2016.

- Was the parent given the opportunity to share cultural views and preferences about psychotropic medication use? Were they honored?
- If the parent objected to medication use, was the parent's objection reasonable? Was the objection honored?
- Does the parent understand the drug treatment regimen and how to administer the drug if needed (e.g., during visits, when reunification occurs)?
- Does the parent know about the drug's side effects and how to handle them?
- Does the parent know who is monitoring the child's psychotropic medication, how frequently monitoring occurs, and the process for adjusting or discontinuing a medication?
- Is someone regularly informing the parent of the

child's progress and any issues that arise?

• Does the parent have questions that haven't been addressed?

Ask if the parent's consent to psychotropic medication has been obtained. Informed consent is a best practice even when not required by law.

Questions to ask:

- What are my jurisdiction's requirements relating to obtaining a parent's informed consent to administer psychotropic medication to a child?
- Have the caseworker and/or treating doctor obtained the parent's consent when required?
- Is a court order needed to administer psychotropic medication to the child? Has an order been issued?
- Do exceptions to obtaining the parent's consent exist (emergency, child old enough to give consent/ decline parent's involvement, parent's competence, parental rights terminated, other reason)?
- Has the parent been informed of relevant exceptions to obtaining parental consent?

Ask if the parent has any concerns about psychotropic medication use with their child.

Areas to address:

- Understanding of the need for child to take psychotropic medication.
- Role in decisions about psychotropic medication use and opportunity to feel heard/share relevant information.
- Concerns about child's behavior or side effects while taking medications.
- Comfort with child's treatment regimen and ability to administer medication(s).
- Knowledge of long-term treatment plan for child and role of medication(s) in it.
- Conflicts with foster parents, caseworker, child, or others about the child's psychotropic medication use.
- Concerns about common concerns relating to psychotropic medications and children.

If the answers to these questions raise concerns about the parent's involvement in decisions and knowledge about psychotropic medication use, take steps to address those concerns. For example:

- Order the prescribing doctor to come to court to respond to questioning about the parent's involvement.
- Order the child welfare agency to set a meeting between the prescribing doctor and parent and participate in that meeting to ensure the parent has all necessary information.
- Ask the parent's attorney to advocate for the parent to be informed and involved in decisions related to the child's psychotropic medication treatment.

Engage in system reform to ensure parents are engaged in decisions involving psychotropic medication use.

Strategies:

- Join or create a multidisciplinary committee to establish clear expectations for parent involvement in child welfare cases involving psychotropic medication.
- Review your state's statute and child welfare and court policies relating to obtaining parental consent to psychotropic medication use with children in the child welfare system. Advocate reforming laws and policies to ensure they align and give parents an opportunity to consent or object to psychotropic medication use.
- Engage with mental health professionals who regularly prescribe psychotropic medication to children in your jurisdiction's child welfare system. Influence how they engage with and involve parents in treatment decisions.

A parent still wants to parent her child even when they are apart. Many children still look to their parents as their closest allies and advocates during their time in foster care. Mental health treatment that includes psychotropic medication is often complex. It may seem easier to proceed without involving the parent to avoid a potential roadblock or the time needed to bring the parent up to speed and actively involve him in decisions. Involving the parent adds an important perspective to decision making and gives the child a key ally during a challenging, often traumatic, period. Supporting the parent's active involvement in decision making promotes the child's successful treatment and permanency.

Endnotes

1. See Strassburger, Zach. <u>"Medical Decision making for Youth</u> <u>in the Foster Care System.</u>" John Marshall Law Review 49:4, Summer 2016, 1110 ("...children who have someone other than parents making their healthcare decisions are the most likely to be receiving these medications.")

2. Center for Health Care Strategies. <u>"Improving the Use of Psychotropic Medication for Children in Foster Care: State Profiles,"</u> March 2018.

3. Substance Abuse and Mental Health Services Administration, Office of Behavioral Health Equity and Office of Chief Medical Officer. <u>Guidance on Strategies to Promote Best Practice in</u> <u>Antipsychotic Prescribing for Children and Adolescents</u>, 2018, 17.

4. American Academy of Child & Adolescent Psychiatry. <u>A</u> <u>Guide for Community Child Serving Agencies on Psychotropic</u> <u>Medications for Children and Adolescents</u>, February 2012.

5. Ibid. at 9.

6. E.g., Washington requires parental consent to administer psychotropic medication to a child in child welfare agency custody unless the child is age 13 or older and competent to give consent. See Washington State Department of Children, Youth & Families. Policies and Procedures: 4541. Psychotropic Medication Management, citing compliance with Chapter 71.34 RCW, Mental Health Services for Minors; Maryland requires informed consent to use of psychotropic medication from the child's parent or legal guardian. If the parent or legal guardian is unavailable or unwilling to give consent and the psychotropic medication is medically necessary, the local department of social services may file a motion with the court requesting consent to use of the psychotropic medication. See Maryland Department of Human Resources, Social Services Administration SSA-15-08 Oversight and Monitoring of Psychotropic Medications; The Pennsylvania Office of Children & Families and the Courts requires completion of a Case Manager Informed Consent form, and Court Summary-Psychotropic Medications to verify that parental consent to psychotropic medication use with a child has been obtained.

7. Mackie, Thomas, Laurel K. Leslie & Erick Rojas. "<u>A National</u> <u>Examination of Informed Consent Processes for Psychotropic</u> <u>Medication Use among Youth In Foster Care: A Typology of</u> <u>Approaches to Informed Consent and Implications for Policy</u> <u>and Practice</u>." *Pediatrics*, August 2019, 144; Strassburger, 2016, 1112-1118

8. Strassburger, 2016, 1120.

9. Ibid.

10. American Academy of Child & Adolescent Psychiatry, 2012, 14.

11. Solchany, Joanne. *Psychotropic Medication and Children in Foster Care: Tips for Advocates and Judges*, October 2011, 4.

12. Ibid., 7

13. Ibid., 16.

14. Irwin, Dr. Martin, Clinical Professor, Child and Adolescent Psychiatry, NYU Grossman School of Medicine. <u>"Psychiatric Medication and Foster Care Preserving the Parent's Voice</u>." ABA 2021 Parent Representation Conference Virtual Convening, May 20, 2021.

15. Some evidence supports use of psychotropic medication to treat Attention Deficit Hyperactivity Disorder (ADHD), symptoms, autism, and severe developmental disabilities in very young children. See American Academy of Child & Adolescent Psychiatry, 2012, 15.

 American Academy of Child & Adolescent Psychiatry, 2012, 15.

17. Solchany, 2011.

18. Irwin, 2021.

19. Irwin, Dr. Martin, Clinical Professor, Child and Adolescent Psychiatry, NYU Grossman School of Medicine. Phone conversation, October 15, 2021.

20. American Academy of Child & Adolescent Psychiatry, 2012, 11 (citing American Academy of Child and Adolescent Psychiatry. <u>Policy Statement: Prescribing Psychoactive</u> <u>Medication for Children and Adolescents</u>. Revised and Approved on September 20, 2001).

21. Irwin, 2021.

22. Ibid.; American Academy of Child & Adolescent Psychiatry, 2012, 13, Sochaney, 2011, 13.

23. American Academy of Child & Adolescent Psychiatry, 2012,10; Dr. Martin Irwin, Clinical Professor, Child and AdolescentPsychiatry, NYU Grossman School of Medicine.

24. Ibid.

25. American Academy of Child & Adolescent Psychiatry, 2012, 16.

26. National Council of Juvenile and Family Court Judges. <u>Resolution Regarding Judicial Oversight of Psychotropic</u> <u>Medications for Children under Court Jurisdiction</u>, July 3, 2013.

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