**Research Summary:** Ensuring that Youth in Out of Home Care are only Prescribed Psychotropic Medication when it is in their Best Interests.

**Background**

Psychotropic medications can be a helpful part of a comprehensive treatment approach to address mental health challenges in youth in foster care, but every year, tens of thousands of children and youth in foster care nationwide suffer damage to their health as a result of being unnecessarily prescribed multiple psychotropic medications. Based on existing research, we know that:

- One in four children in foster care between ages six and seventeen are administered at least one psychotropic drug.
- A significant number of children are given a combination of two, three, or four drugs at the same time.
- Monitoring of foster children administered psychotropic medications is infrequent and often fails to follow professional guidelines.
- Oftentimes these drugs are prescribed without clarity as to who is authorized to consent, and without procedures that protect youth in foster care.

Recent research suggests policies and practices that can help ensure youth in foster care are only prescribed psychotropic medications when in their best interest, yet policymakers and practitioners have limited knowledge of this research. Armed with effective policies regarding the administration of psychotropic medications, states can decrease instances of harm caused by these medications to the youth in their care. This memo will lay out the current research and research gaps on the potential harmful side effects of psychotropic medications, the most problematic prescribing practices we are seeing, and the most promising policies and practices states are using to ensure youth in foster care are only prescribed psychotropic medications when doing so is in a youth’s best interest.

**Risks vs Benefits**

The prescribing of psychotropic medications to children has increased in recent decades. In particular, prescriptions for antipsychotics – an especially dangerous class of psychotropic medications used to treat behavioral disorders like ADHD – have gone up substantially over the last twenty years.\(^1\) One national study found that approximately 1% of all youths under age 20 come out of doctors’ visits with a prescription for an antipsychotic medication, and that percentage is higher for publicly insured youth than those privately insured.\(^2\) Among publicly insured youth, all categories of psychotropic prescriptions to youth in foster care are far more prevalent than to youths not in care. A 2011 report released by the U.S. Government Accountability Office reported that youth in foster care are prescribed psychotropic medications at a 2.7 to 4.5 times higher rate than other children on Medicaid.\(^3\)

There is little clinical trial data to show the benefits for youth using psychotropic medications, particularly compared to data on use in adults. To be approved by the FDA, a drug must have sufficient clinical trial data to assess its benefits and its potential harms to people. These experiments typically test for short-term benefits to adults in treating specific medical conditions. The findings from these trials do not generally

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translate and apply to youth. There is very little information about long-term effects of psychotropic medication use in youth, which is particularly concerning because youth do not have the liver and kidney capacity that adults do to metabolize these medications. Some studies of psychotropic medication after they have been approved for the market show marked differences in benefits and harms between use in adults versus use in youth. Some antidepressant trials showed benefits to adults but only modest or questionable benefits for youth, with only fluoxetine (Prozac) showing a statistically significant benefit.

When a medication is prescribed to age groups, at dosages, or for treatment purposes outside those approved by the FDA, it is called “off-label” use. The benefits of off-label use are essentially unknown – there is not enough evidence to confirm benefits or harms. Most psychotropic medication prescriptions for youth in foster care are off-label uses of the medication. The FDA reports that 50–75% of prescriptions for psychotropic medications for youth are for off-label uses. Many times this happens because the youth receiving the prescription is younger than the age tested and approved by the FDA, or the dosage given is higher than that approved. It also frequently happens, though, because the medication is prescribed for the treatment of a condition different than the one it was tested for. One study found that only 9.2% of visits to a doctor regarding SSRIs (a type of antidepressant) were being used to treat an FDA-approved indication. Off-label use of antipsychotics in youth has increased substantially over the last twenty years. Many are prescribed for behavioral disorders like ADHD and disruptive disorders rather than the psychotic disorders they were tested and approved for, even though research shows that the use of such medications for behavioral disorders is neither recommended nor effective.

There are many potentially serious adverse effects associated with the use of psychotropic medications for youth. For example, ADHD medications like Adderall, Ritalin, and Concerta have been associated with side effects such as sleeplessness, loss of appetite, tics, agitation, hallucinations, liver problems, and suicidal thoughts. Antidepressants are associated with adverse side effects including agitation, sleeplessness or drowsiness, and suicidal thoughts. Antipsychotics are a particularly dangerous class of psychotropic medication that can potentially cause life-threatening conditions due to cardiovascular and

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metabolic effects and central nervous system depression.\textsuperscript{15} A December 2018 study was the first published study to report significantly increased risk compared to the control group of sudden unexplained death among youth newly starting an antipsychotic at a high dosage.\textsuperscript{16} Other known side effects of antipsychotics include sometimes-irreversible movement disorders (e.g. muscle spasms and contractions, tremor, jerky movements, rigidity, restlessness), type II diabetes, seizures, high cholesterol, kidney and liver damage, weight gain, and breast enlargement.\textsuperscript{17} One study showed substantial weight gain of 10-19 pounds in a 12 week period for the group of 4-19-year-olds.\textsuperscript{18} Weight gain increases the risk of type II diabetes, which in turn increases the risk of death from cardiovascular or other causes.\textsuperscript{19} Chronic diseases like diabetes or irreversible movement disorders reduce psychological well-being and quality of life because the youth must deal with chronic disease or potentially debilitating symptoms.\textsuperscript{20} Another study showed that new antipsychotic users were three times more likely than a comparison group of users of other psychotropic medications to be diagnosed with type II diabetes within a year of starting their antipsychotic.\textsuperscript{21} Data suggests that these adverse effects of antipsychotics are more common in youth than in adults.\textsuperscript{22}

The lack of evidence that the benefits outweigh the harms has created concern for experts in child and adolescent psychiatry and federal agencies studying the use of psychotropic medications in youth.\textsuperscript{23}

**Dangerous Practices**

While even the proper administration of psychotropic medications to youth carries risks of adverse effects, research has identified several highly problematic and, unfortunately, widespread practices and patterns that dangerously increase these risks. Addressing and minimizing these practices will go a long way in reducing the risks youth in foster care taking psychotropic medications face.

**Polypharmacy**

The use of more than one psychotropic medication, called polypharmacy, rose dramatically in the 1990s, and has continued to increase since then.24 A national sample of youth visits to physician offices showed the rate of combined antidepressant and stimulant use increased from 4% in 1994 to 29% in 1997.25 Like general prescribing of psychotropic medications, polypharmacy is more common in the foster care population than the general population.26 Some research indicates that of youth in foster care prescribed antipsychotic medication, up to 41.3% are receiving drugs from three or more different classes, and as many as 72% are receiving drugs from two or more classes.27

Polypharmacy increases the risk of harmful side effects and dangerous drug interactions.28 Research has shown that medication combinations at any age increase the risk of adverse effects, while there is little evidence regarding the benefits.29 Youth under the age of 10 are substantially more at risk for adverse effects than older youth.30 There is clear evidence that increasing the number of medications and off-label use in youth increases the risk and likelihood of adverse drug reactions, and these continue to increase the longer the youth is on the medications.31 For example, one study showed increased risk of developing type II diabetes mellitus in type II diabetes youth using both an antipsychotic and antidepressant, which grew as youths continued to take the antidepressant.32

Prescriptions to very young children

Experts are concerned about the increase in psychotropic medications being prescribed to very young children.33 While there is little data to support psychotropic medication use in youth in general, it is especially rare for a clinical trial to involve youth below the age of 7.34 Community practice patterns show psychotropic medications are being prescribed to children as young as 2.35 One study of psychotropic medication use in a group of youth born in 2007 and in Medicaid since birth found that 10% had been prescribed a psychotropic medication by the age of 8.36

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24 Safer, Zito Concomitant Psychotropic Medications for Youth 2003.
Lack of Monitoring through Lab Tests

Psychotropic medications can pose risks to youth, but they can also be a helpful tool in managing youth health when properly prescribed and monitored. The main question in determining whether a particular youth should be taking a particular medication is whether the benefits outweigh the harms. If they do, it could be appropriate to prescribe that medication. If the harms outweigh the benefits though, the medication should not be prescribed. The answer to this question can change over time. For certain types of psychotropic medications, particularly antipsychotics, periodic laboratory testing is a vital part of having the information needed in continuing to weigh the balance between benefits and harms.

As mentioned above, antipsychotics create a risk of cardiometabolic adverse effects. Proper lab monitoring can reduce the risk by catching abnormal levels in a timely way, so the medication can be switched or stopped before the youth suffers greater or more permanent adverse effects. For example, the American Diabetes Association has collaborated with the American Psychiatric Association to create a protocol for testing glucose and lipid levels of antipsychotic users to monitor and minimize the risks of users developing diabetes.37 One study of screening rates of children starting antipsychotics from combined data from Medicaid programs in three states showed they were woefully inadequate: only 31.6% of the youth had glucose screening and a paltry 13.4% had lipid testing done.38

Poor Record Keeping

Youth in foster care are also put at risk by disorganized and ineffective record-keeping practices. A streamlined medical record that is kept up-to-date and reliably follows a foster child from placement to placement allows healthcare providers to make informed decisions based on a complete medical history, including a history of any adverse reactions a patient may have experienced in the past. It also ensures that care providers in a new placement have up-to-date information about the medications that an incoming youth in foster care should be taking, and prescriptions that need to be filled. Without such systems in place, children in foster care – a highly mobile population – are at risk. Unfortunately, child welfare systems frequently lack reliable medical record keeping policies and procedures, leaving children vulnerable to problems such as lapses in their medications, incorrect dosages, and even being re-prescribed medications that have previously caused adverse and even life-threatening reactions.

Possible Solutions

Fortunately, states are deploying an array of promising policies and practices to ensure that youth in foster care are only prescribed psychotropic medications when doing so is in a youth’s best interest. These include robust informed consent and assent policies, the use of reliable medical record-keeping systems, effective monitoring and oversight policies to catch dangerous outlier prescriptions, and adherence to adherence to best practice guidelines, both for the prescription of psychotropic medication to youth and the dissemination of relevant information.

Informed Consent and Assent

Informed consent involves appointing a specified person who is authorized to consent to the administration of psychotropic medications to a youth in foster care and ensuring that the consenter has the information needed to make an informed decision when deciding whether to grant or deny consent for that drug. An effective informed consent policy helps prevent youth from starting unnecessary medications in the first place, and avoids the more difficult process of taking them off an inappropriately prescribed medication.

Making an informed decision requires that the consenter have adequate knowledge and understanding of a range of information, including the youth’s medical history, the condition being treated, the intended benefits and possible harms of the medication in question, and whether alternate non-pharmacological treatments have been tried and whether they were successful. Consent must be sought and received before a youth starts taking the medication, and the consenter should have access to the prescribing healthcare provider and the opportunity to ask any questions before making an informed consent decision.

To support consenters, states should offer periodic intensive trainings on psychiatric conditions and psychotropic medications for caseworkers, parents, foster parents, and other stakeholders. Consenters should also have the opportunity to consult with a child and adolescent psychiatrist when they have questions, and to initiate a peer review of a concerning prescription by another clinician.

Best practice also mandates that the prescriber seek informed assent to any psychotropic medication from the child patient. As developmentally appropriate, the youth assenter should also receive accessible information about the youth’s medical history, the condition being treated, the intended benefits and possible harms of the medication in question, and possible alternate non-pharmacological treatments.

In order for its informed consent policy to be effective, a state should track when informed consent has and has not been sought and given in advance of psychotropic medication administration and create consequences for when it has not. The use of standardized consent forms to be included in the child’s case file is useful for this purpose.

Medical Records

As discussed above, a key component needed to successfully monitor and oversee psychotropic medications use in youth in foster care is an adequate medical record keeping system. This is particularly important because youth in foster care are frequently moved around between placements, assigned different caseworkers, and experience other situations that break continuity of care. Having a centralized, up-to-date records system is often the only way a youth’s medical data will follow them rather than get lost in the shuffle. Without an effective system for collecting and maintaining medical information, the usefulness of any other policies and practices will be seriously hobbled.

The data a state collects is important. The AACAP Best Principles Guidelines recommends for individual youths’ medical records that states keep ongoing records of “diagnoses, height and weight, allergies, medical history, ongoing medical problem list, psychotropic medications, and adverse medication reactions” and that these records should be “easily available to treating clinicians 24 hours a day.”

Creating a centralized record-keeping system like this generally requires different government agencies to share amongst themselves the disparate pieces of information captured by each. Usually this information is protected and confidential. As states design these centralized records systems, they should create systems and protocols to facilitate the data sharing necessary to maintain up-to-date records and keep children safe.

**Monitoring and Oversight**

Effective monitoring and oversight programs can catch dangerous prescribing practices both prospectively and retrospectively, helping to prevent harms to youth caused by unnecessary psychotropic medication prescribing. The Administration for Children and Families published guidance in 2012 on “Promoting the Safe, Appropriate, and Effective Use of Psychotropic Medication for Children in Foster Care” that sought to require states to develop monitoring and oversight systems to assure safety in psychotropic medication use in youth in foster care. Examples of such systems include restrictions at the pharmacy that would prevent outlier prescriptions from being filled without approval by a peer reviewer; a secondary review system that flags potentially dangerous prescriptions and drug combinations after the fact and refers them for peer review; and outreach and education programs targeting providers identified as consistently prescribing outside best practice guidelines.

**Additional Best Practices and Guidelines**

Best practices for prescription of psychotropic medications to youth are incorporated into the Healthcare Effectiveness Data and Information Set (HEDIS) performance measures, and include:

- Psychosocial treatment (i.e., therapy) before or at least concurrent with the use of any antipsychotic
- Regular monitoring of blood glucose and lipids (because of the increased risk for type II diabetes); and
- Avoidance of multiple concurrent prescriptions for antipsychotics.

More generally, the American Academy of Child and Adolescent Psychiatry (AACAP) has published Best Principle Guidelines to create a roadmap for states wanting to create or improve their systems overseeing psychotropic medication administration to youth in foster care. Their recommendations include that “[s]tate child welfare agencies, the juvenile court, or other state or county agencies empowered by law to consent for treatment with psychotropic medications, in consultation with child and adolescent psychiatrists, should establish policies and procedures to guide the psychotropic medication management of youth in state custody.” Such policies and procedures should include:

- A consultation program administered by child and adolescent psychiatrists; and
- A website to provide ready access for clinicians, foster parents, and other caregivers to pertinent policies and procedures, psychoeducational materials, consent forms, adverse effect rating forms, reports on prescription patterns, and links to helpful, accurate, and ethical websites about child and adolescent psychiatric diagnoses and psychotropic medications."

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40 U.S. Dep’t of Health and Human Servs., Admin. for Children, Youth and Families, Promoting the Safe, Appropriate, and Effective Use of Psychotropic Medication for Children in Foster Care (2012)
Finally, ongoing assessment of the efficacy of the various strategies employed, including tracking of relevant data, is integral to successful reform efforts.

**Recommendations**

Following current research and best practices, states can develop policies and practices regarding the administration of psychotropic medications to youth in foster care that could seriously ameliorate the risk of harm from these potent medications. Implementing the following recommendations will make these systems more effective:

- Implement a robust informed consent and informed assent policy that ensures consenters and youth have the information they need and access to consult a child and adolescent psychiatrist to make a truly informed decision;
- Create a centralized, up-to-date, accessible medical records system;
- Implement monitoring and oversight systems that will flag dangerous outlier prescribing practices for peer review both prospectively and retrospectively, and will seek to curb such practices moving forward;
- Promote safe prescribing practices, including by ensuring the availability of concurrent psychosocial services and closely tracking required bloodwork monitoring;
- Provide ready access to pertinent information for clinicians, foster parents, and other caregivers;
- Collect, track, and analyze relevant data to evaluate the efficacy of the various initiatives implemented.