An Advocate’s Guide to the Use of Psychotropic Medications in Children and Adolescents

by Kate O’Leary

“‘It is no use saying, ‘We are doing our best.’ You have got to succeed in doing what is necessary.’”

—Sir Winston Churchill

Introduction

At the end of 2005, 523,062 children were in foster care. There is no nationwide data on how many of these children have been diagnosed with a mental illness that requires treatment with psychotropic medications. Estimates range from 10% to 66%. It is no longer enough to say, “we are doing our best under difficult circumstances with limited funding and time.” It is time for us to do what is necessary to ensure psychotropic medication is being used properly and only when necessary. To achieve this goal, we must, as a community of advocates, begin to educate ourselves.

This article provides advocates with a basic understanding of the use of psychotropic medications in children and adolescents. It also provides concrete guidelines and solutions to ensure that when and if a child is prescribed psychotropic medications, the medications are used properly and the child is given every opportunity to process any trauma that is contributing to the child’s need to be placed on medication. Depending on individual circumstances, it may be possible to address issues of trauma through conventional therapies before resorting to psychotropic medications. However, there may be times that a child needs to be immediately prescribed medication. It is imperative at this point, that the child also have access to therapies that will allow him/her to address the underlying issues that have led to the need for medication. The intended audience includes guardians ad litem, court appointed special advocates (CASAs), attorneys representing children, probation officers, and judges and administrative hearing officers. Since the intent of this article is to provide a brief overview of issues relating to the use of psychotropic medications, an index with a list of resources is available at the end of the article for anyone interested in further study.

1. What are psychotropic medications and what disorders do they treat?

Psychotropic medication: Any medication capable of affecting the mind, emotions, and behavior, also called a psychodynamic medication. From the Greek psycho-, the mind + trop, a turning = (capable of) turning the mind.¹ The seven most common psychotic disorders are: schizophrenia, bipolar disorder, depression, psychotic depression,² attention deficit/hyperactivity disorder, anxiety, obsessive compulsive disorder and panic disorder. There are currently 62 psychotropic medications that are commonly prescribed to treat these disorders.³

2. Why should you care about psychotropic medications prescribed to children in foster care?

The number of children in the United States prescribed medications to treat depression, attention-deficit/hyperactivity disorder (ADHD) or other behavioral conditions nearly tripled between 1986 and 1996.⁴ Most of these medications have not been approved by the FDA to treat

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mental health disorders in children and adolescents. This practice is known as off-label use. The problem with off-label use is that the prescribed medications have not been systematically studied for safety and efficacy. Yet the medications are still prescribed without any firm knowledge of long-term side effects.

Children who are before the court on dependency and/or delinquency issues and are placed on psychotropic medications are more likely to miss dosages, have significant time lapses in obtaining prescriptions, and not be monitored for medication compliance, outcomes, and side effects. There are many reasons for this including but not limited to: a) parents selling their child’s medication; b) a parent’s own drug use and/or mental illness that prevents them from monitoring their child’s medication compliance; c) change in placements, and d) lack of medical insurance. As advocates for children, it is our responsibility to ensure children who are placed on psychotropic medications truly need them. Once it is determined that a child should be prescribed psychotropic medications it is imperative that the medications are taken as prescribed, without lapses.

Failure to take these medications as prescribed can result in significant problems including: a) increased resistance to the medication resulting in the need to increase dosage; b) re-emergence of symptoms the medication is prescribed to manage; and c) a drop in the child’s belief that the medication prescribed can help the child lead a normal life. Advocates need to have an honest and open dialogue with their clients and/or their caregivers to ensure they understand why the child is taking the medication, the importance of taking the medication as prescribed, and the importance of letting someone know of side effects that are severe enough to stop taking the medication.

3. Should the drugs be used in conjunction with other therapies?
Absolutely. Remember, at all times, that psychotropic medications affect the brain and behaviors. These medications have the ability to change who we are and while there are times that medications allow a child to have what society deems a more “normal” existence, few studies document the long-term effects of psychotropic drug use on developing brains. All advocates must be aware that children today are in uncharted territory. It is still unknown whether the use of psychotropic drugs in children and adolescents will impact how these children function as adults. The questions that need to be asked and ANSWERED include:

1. Will taking these drugs during childhood predispose the child to abuse substances as an adult?
2. What, if any, impact will these drugs have on later reproductive health?
3. Will a child placed on psychotropic medication be more likely to be placed on psychotropic medications as an adult?
4. Will a child placed on psychotropic medication learn to rely on medication as a solution for all problems?

As a society, we may not be able to answer these questions for de-
medication error/omission guidelines (View the policies at http://www.state.tn.us/youth/policies/index.htm).

✓ Practice standards
Eight standards related to use of psychotropic medication for children in state custody have been added to the state child welfare agency practice standards. These standards outline specific agency expectations when a child has been prescribed psychotropic medication. (View these standards at http://www.state.tn.us/youth/providers/ProvidersForms/DCS_PracticeModel11.24.03.pdf)

✓ Centers for Excellence
A state partnership with three academic medical centers across the state provides expert guidance to agency workers and providers for diagnosing and treating medical and mental health disorders. Two additional medical centers will soon be added to provide full state coverage. The centers’ functions include: case consultation and triage, training and education, case coordination, case review, provider monitoring, psychiatric and psychological evaluations, psychiatric medication management, and screenings for Early and Periodic Screening, Diagnosis and Treatment. An especially valuable role is providing an outside perspective, which is helpful when there are conflicting views in a case or a need for a second opinion.

✓ Web-based medication tracking tool.
A web-based application was developed to track psychotropic medication use by all children in state custody. This tool permits data to be gathered and analyzed in a variety of formats. For example, data can be gathered to show how many children in state custody are taking more than one psychotropic medication, and how many have appropriate informed consent. Medical monitoring “red flags” will be built into the system so that staff will be alerted to issues that require attention and close monitoring. The system will permit much greater oversight over use of psychotropic medications by children in the child welfare system.

cades. As advocates, we need to be aware that these questions exist and do all within our power to ensure that children who need to be placed on psychotropic medications have as many opportunities to work on the underlying issues that are affecting their behavior. At a minimum, all children on psychotropic medications should be involved in some type of counseling with a qualified and caring therapist. Often a child may need to change therapists a few times to be able to develop a positive and therapeutically beneficial relationship. A good therapist will not be insulted by this and should be willing to provide feedback on the child’s needs and even suggest other members in the therapeutic community who may be able to provide the type of therapeutic relationship that will allow the child to succeed. There are a number of ways to find qualified therapists:

- Ask caseworkers who are well respected and are involved in all aspects of their client’s treatment and life goals.
- Determine who does the majority of evaluations for children who come from middle and upper class homes. Call this person and ask him/her to devote some time to children who are in foster care.
- Ask colleagues for referrals.

Children who are nonverbal due to age or other incapacity should also have the opportunity to engage in therapy, including play therapy, art therapy, and music therapy. It is the advocate’s job to determine what programs are offered in his/her community and then advocate on behalf of the child and make sure the child receives what he/she needs. Not all of these therapies are covered by Medicare. As a result, the legal custodian may be reluctant to pay for alternative therapies. Advocates should be creative. Try going to local colleges and universities and seeing if there are programs that can meet the needs of these children. Work with nonprofit agencies to develop and implement programs that will meet the needs of the children and families in the community. Be willing to think outside of the box.

Last, placement must be addressed. If a child is not in a placement where he/she is going to get his/her medication as prescribed, no amount of therapy, medication and/or intervention is going to remedy the problem. If a child is in a placement where he/she receives medication as prescribed but is not encouraged, supported, and safe, the medication alone is not going to remedy the problem. If a child’s home environment is not supportive and nurturing and is harmful to the child’s emotional development and/or health, a petition to remove the child from the home may need to be filed. If a child is in state or court custody, an advocate needs to make sure the placement is appropriate. Ask the following questions:

1. Is the child in the least restrictive placement possible?

2. If the child is in a foster home, what type of training have the foster parents received? How many other children are in the home? What are the ages of the other children in the home? Is the child getting the attention he/she needs to address any and all issues of trauma? What type of long-term commitment are the foster parents willing to make?

3. If a child is in a shelter or group home, what type of training has
Resources

If you want more information on psychotropic drugs, and children and adolescents, the following resources are a good place to turn.

- National Center for Mental Health and Juvenile Justice
  www.ncmhjj.com
  866/963-6455

- United States Department of Health and Human Services Substance Abuse and Mental Health Services Administration
  www.mentalhealth.samhsa.gov/child/childhealth/asp
  800/789-2647

- National Mental Health Association
  www.nmha.org
  703/684-7722

- Federation of Families for Children’s Mental Health Issues
  www.ffchm.org
  240/403-1901

- National Institute of Mental Health
  www.nimh.nih.gov/HealthInformation/childmenu.cfm
  866/615-6464

- Mental Health – A Report of the Surgeon General
  www.surgeongeneral.gov/library/mentalhealth/home.html
  Warning: This report is close to 600 pages long, but it is very informative.

- American Academy of Child and Adolescent Psychiatry
  www.aacap.org
  202/966-7300

- Child Welfare Information Gateway
  www.childwelfare.gov
  Offers bibliography of written materials addressing psychotropic medication use in the child welfare system.

If a child is in a residential facility, ask:

- What type of education and training has the staff received?8
- How long is the child expected to stay in this treatment facility?9
- Have there been any problems with licensing in the past 24 months? If yes, have these issues been resolved and what steps are being taken to prevent further problems?9
- Does the program have a reputation for success or is it known as a facility that warehouses children?9
- What is the policy on using restraints?9
- How are the children grouped—by age, gender, IQ, mental health diagnosis, or a combination of the four?9
- What is the staff retention rate?9
- Who is going to be the primary case manager for the child? How do you get in touch with this person?10
- How often are the children seen by a qualified psychiatrist for medication management and evaluation?9
- What is the facility’s treatment modality? Cognitive behavior, group process, solution focus, or strength-based brief therapy?9

4. What about informed consent? Currently, each state has its own policies and procedures regarding informed consent. Some organizations believe informed consent can hinder obtaining psychotropic medications for children in custody.12 However, the potentially serious consequences of using psychotropic medication, along with a lack of empirical research identifying the long-term effects of psychotropic medication use in children, mean that no child should be placed on any type of psychotropic medications without first obtaining informed consent by a knowledgeable and competent adult.

States have independent authority to determine who can consent to mental health treatment for children in care. Identified parties include: parents, the courts, a guardian ad litem, a social worker, and on occasion foster parents. Any person identified to provide the informed consent needed for mental health treatment, including the agreement to administer psychotropic medication, should receive training in the areas of medication management, potential side effects, common psychotropic medications and their use, along with state/local laws and policies that regulate medication use and requirements for informed consent. Most state mental health departments have drafted forms for providing informed consent.13

While each state has its own form that is used to obtain informed consent, it is important that the following information is included on the 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 risk 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.


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.

5. Questions that should be asked by attorneys, guardians ad litem, CASAs, and judges.

The following questions should be asked by all parties who are responsible for the care and safety of a child before the court when there is a request to place the child on psychotropic medication.

1. Who is requesting that the child be placed on medication?

2. What is the reasoning for the request?

3. How long has the requesting party known the child?

4. Does the requesting party have any specialized knowledge in child development?

Once these four questions have been answered and it is determined that there is a possibility that a child may need to be placed on medication, the court and/or other authorized person should have the child formally evaluated. A child should not be placed on any psychotropic medications until a full evaluation has been completed. For best practice, the evaluation should include a full physical, including blood work, a psychological, including a social history and I.Q. tests, and a full psychiatric examination.

The following questions should be asked at the end of the evaluation and before the child is placed on any medication:

1. Who performed the formal evaluations?

2. What is the evaluator’s experience and education?

3. How many medication evaluations has the evaluator performed?

4. How long did the evaluator spend with the child?

5. What and/or whom did the evaluator rely on for a complete and accurate history of the child’s life, including health history, trauma history, and other events that have impacted a child’s life. Remember a child who has been the victim of violence and/or trauma is likely to act out; your responsibility is to make sure normal response to trauma is not used to label a child as mentally ill and in need of psychotropic medications.

6. What percentage of children has the evaluator put on medication? If the evaluator is prescribing medication for many children, it may be prudent to have another evaluation performed.

7. What is the recommendation for medication, including type of medication, dosage, and number of times a day?

8. What symptoms are the medications intended to treat?

9. What are the potential side effects?

10. Possible side effects can include but are not limited to the following:

- Allergic reaction (difficulty breathing, swelling of lips/tongue, rash or fever).

- Change in level of alertness (excess sleepiness, insomnia or confusion).

- Eating problems (nausea, vomiting, weight gain or loss).

- Change in heart pattern (constipation, diarrhea).

- Change in heartbeat (slow, fast, and irregular) or blood pressure (high or low).

- Fainting or dizziness, especially with change in position such as upon standing.

- Abnormal posture, movement, or gait.

- Yellowing of eyes or skin.

- Unusual bruising or bleeding.\(^\text{14}\)

11. How will the side effects be treated?

12. Who is going to be responsible for disbursing the medication? If a child is living in a home with a parent who has a history of substance abuse and/or suffers from mental health issues, you may want to determine if the medication can be administered by an outside provider, possibly school personnel or an in-home provider. Additionally, many
communities have volunteer home health care providers who may be willing to go into a home and administer medication. The medication will not achieve the desired effect if it is not administered as prescribed.

13. How is the medication going to be monitored to determine if it is having the desired effect? (i.e., self reports, caregiver observations, blood work, etc.)

14. What is going to be done to ensure the medication is used as a therapeutic tool and not a way to mask the underlying issues that may be the real reason the child is acting out and behaving in ways that require medication?

Once you have received satisfactory answers to these questions and the professionals involved agree that a child needs to be placed on a psychotropic medication, it is important to set a formal review date to ensure that the medication is being properly monitored. A judge should set a 90-day deadline for a report to be filed by a local agency that has legal custody of a child who has been placed on psychotropic medications.

A guardian ad litem should ask for and receive a monthly report from a local agency detailing the child’s behavior and any side effects that are being reported that may be linked to the medication. Attorneys and CASA workers should follow the guidelines set out for guardians ad litem. Probation officers should get signed releases and speak to the child’s doctor on a monthly basis as part of the child’s supervision and probation services.

All parties who are responsible for the care and safety of a child before the court should ask the following questions when the child is currently taking prescribed psychotropic medications.15

1. When did the child start taking the medication?
2. What led the child to be placed on the medication?
3. Who performed the evaluation?
4. What was the evaluator’s experience?
5. When was the last time the child was evaluated?
6. How has the child’s behavior changed?
7. What other therapies are being used in conjunction with medication?
8. How long does the current treating physician believe the child will need to stay on the medication?
9. Has the child experienced any side effects? If yes, how are they being handled?
10. Is the parent/caregiver receiving Supplemental Security Income (SSI) due to the child’s mental health disorder? If yes, how is the money being spent?
11. Is the child getting ready to age out of the system? If yes, what safeguards have been put in place to ensure the child will still have adequate access to medication and/or treatment?16

Conclusion

The reality is that many of the children in the child welfare system who are before the court will suffer from some type of mental health issue due to past trauma, in utero exposure to drugs and alcohol, and genetic predisposition. On occasion, the use of psychotropic drugs may help a child lead a more “normal” life. However, there are risk factors involved with the use of psychotropic medications. Some of these risk factors are known while others may not come to light for decades.

As an advocate, you have a responsibility to make sure that any and all decisions to place a child on a psychotropic medication are decisions that are made with full and accurate information, including knowledge of a child’s history. Additionally, as an advocate you have a responsibility to ensure that once a child is placed on a psychotropic medication that the medication is properly managed and that all parties continue to monitor and re-evaluate regularly the benefits and risks of the medication.

Last, remember that psychotropic medications are not a panacea. A child needs the opportunity to engage in conventional therapies, including talk therapy, art therapy, and music therapy. Psychotropic medications can help manage behaviors and allow a child the opportunity to move forward. But medications should never be a first choice and they should always be closely monitored. For children in foster care, this is the responsibility and the duty of an advocate. Often due to parental absence or inability, coupled with high caseloads and limited resources, it is only going to be facilitated by courts and advocates.

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Endnotes

2. Psychotic depression is depression that can include hallucinations and psychotic episodes.
3. MH Today (http://www.mental-health-today.com)
5. National Institute of Mental Health. Medications, 2002. This booklet describes and lists mental disorders and medications for
6. These questions are basic and not all encompassing. Each child is unique and advocates should expand on these basic questions when necessary.

7. While a for-profit placement may be suitable and appropriate, there are times when the bottom line may become more important than the child’s well-being. Alternatively, while one would hope a nonprofit would always place the child’s well-being at the forefront, this may not always be true. All parties involved in the case in the role of advocate for the child should make at least one unannounced visit to the group home or shelter every three months.

8. You want a minimum of a college degree in a relevant field for all staff directly involved in a child’s therapy.

9. Remember, there are differences in degrees of mental health issues. A child who is exhibiting signs of depression should not necessarily be placed in a facility that also houses children who have full-blown psychosis.

10. You should ask the case manager to keep you informed and to call you immediately if the child has had to be restrained, has gotten into a physical altercation with another resident and/or staff, or the placement has disrupted.

11. These therapies can be used alone or in conjunction with one another. The goal is to determine what type of therapy is being used and is likely to address your client’s needs.


13. These forms can be found on the internet by doing a basic search for “psychotropic medication and informed consent.”


15. These questions should be asked when a child has been placed on medication prior to your initial involvement in the case.

16. Often when children age out of the system they lose their health insurance and stability. There MUST be a plan in place that will allow these children to continue to receive their medication. An abrupt stop in medication can have extremely detrimental results for the child and possibly the community.