

# **Guide for Psychotropic Medications for Youth in Foster Care**

## **How to make informed decisions for your child**

### **Your Voice Your Choice**

#### **Voicing your opinion for making healthy choices**

Youth in Foster care have number of challenges to face including dealing with memories of past trauma from physical, emotional, sexual abuse, neglect, chaotic upbringing, placement disruptions, losses, witnessing violence and multiple changes. This may lead to complex array of emotional reactions which can at times become overwhelming and may even lead to symptoms indicative of Depression, Anxiety, and Post-traumatic Stress Disorder or mimic other psychiatric diagnosis. Trauma may impact their ability to regulate their emotions, trust others, form further relations, respond appropriately to stressors and cope with any further perceived stress and life changes. Literature points out that acting out, tuning out or not sleeping may be their body's way of protecting against potential threats. Their behavior simply put may be reflection of their traumatic experiences.

What worked then may not be applicable no more but youth need healthy interactions and support to help learn new healthy behaviors to cope with daily stressors and uncertainties of foster care. Research shows that the teen brain can be rewired over time to learn new responses. They need to feel safe, cared for, have sense of belonging, healthy social interactions, and be part of healthy activities to help develop resilience to deal with past and ongoing trauma and stressors. They may be feeling alone, or damaged. Focusing on their strengths and listening and supporting helps them regain trust and strength to pull themselves together to heal.

This guide will help foster parents walk through some of steps to make choice as to what may be healthy form of treatment and interventions to seek out for youth in care especially reflecting upon use of psychotropic medications and therapy.

This guide is for information only and doesn't take place of professional medical advice. It is to provide you information on options to help deal with emotional, cognitive and behavioral problems youth may encounter and how to make informed decisions on some of available interventions.

#### **What are options when youth exhibit emotional and behavioral problems?**

- Psychosocial interventions or alternatives to medications
- Psychotropic Medications

#### **What are Psychotropic Medications?**

Medications aimed at changing mood, behavior and cognition and helping address emotional and behavior problems by working on neurotransmitters in brain. These include medications to treat Anxiety, Depression, Bipolar Disorder, Sleep disturbance, Attention Deficit Hyperactivity Disorder, Psychotic disorders and other conditions. They may be used long term in conditions such as Schizophrenia or short term to help deal with some acute symptoms such as sleep issues.

While psychotropic medications may be indicated and needed in some instances but considering the underlying trauma and complexity of this population that should rarely be the only treatment and should not take place of therapy that can help enhance the ability to cope with stressors and better regulate emotions for children in care. It been noted that many youth in foster care who may need therapy don't get it. Remember medication if considered should be used in combination with therapy and other psychosocial interventions.

On other hand most children in care don't need psychotropic medications and they slowly heal with structure and stable and nurturing environment. Also psychotropic medications if used should be prescribed after comprehensive assessment and should be only one part of comprehensive treatment plan.

## **What are Psychosocial Interventions?**

Psychosocial interventions are aimed at changing core behavior by psychological and environmental interventions that have long term benefits and longer lasting effects.

### **Counseling or Therapy**

Sometimes it is not enough talking to family, friends and other adults and youth may need trained therapist who can listen and give expert advice on how to deal with emotions and behaviors. Therapy especially trauma informed care helps explore root cause of child's behavior and emotions. It may include helping replace negative thoughts with good ones, help understand why youth feel and act certain ways, reframe trauma so it is considered one part of many life experiences, reduce their vulnerability to revictimization by teaching healthy boundaries, help focus on strengths, learn healthy coping skills to manage emotions and behavior before it escalates and help youth explore their identity and goals. Experts advise therapy should be considered before or at the same time as psychotropic medications.

### **Other Psychosocial interventions**

Youth may benefit from lifestyle changes to help heal which may include

- Meditation to help relax, calm mind and reduce the effect of stress.
- Exercise which releases feel good chemicals called endorphins in body that boost mood naturally, help feel calmer and reduce stress.
- Changes in food such as to eat regular balanced meals.
- Sleep hygiene to improve sleep which helps with mood regulation, energy and focus.
- Journaling, drawing, painting or other art work which helps express thoughts.
- Fun filled family activities and joining sports, clubs, volunteer activities that can help build social skills, teach to be team player and follow rules.
- Faith and cultural activities to develop healthy social interactions to help rebuild trust, to help feel part of community and strengthen sense of identity.
- Mentoring to provide positive role models.
- Interventions in school such as IEP/504 Plan, shadow, etc.
- Joining support group for youth with similar issues such as LGBT groups.

- Parenting classes that can help you learn behavior intervention techniques to better manage their behavior.

Ask the child's caseworker how you can access some of above resources. The doctor and or therapist can also help guide what other interventions may be beneficial.

## **Concerns about psychotropic medications**

Studies have shown a steady rise in the use of psychotropic medication to address children's emotional and behavioral problems over the last decade and there is evidence to point that the use of psychotropic medications is higher in the foster care population than in general population and that there is some inappropriate use for youth in care.

## **Factors contributing to use and misuse of Psychotropic medications**

- Legitimate need
- Lack of access or utilization of nonpharmacological interventions such as therapy and psychosocial supports
- Lack of proper assessment leading to misdiagnosis
- Limited access to Child behavioral specialists
- Misaligned financial incentives
- Aggressive pharmaceutical marketing
- Limited knowledge among child welfare workers and caregivers
- Lack of oversight as to Psychotropic medications

## **What are some of the concerns voiced by experts about psychotropic medications?**

- Use of newer medications over FDA approved for child's age. Many psychotropic medications have not been well tested with children and youth.
- Use despite lack of evidence for off-label use.
- Misdiagnosis including over and under.
- Medication use not consistent with diagnosis or symptoms.
- Lack of use of Evidence-base therapies such as Trauma Focused Cognitive Behavior Therapy, Cognitive Behavior Therapy, Dialectical Behavior Therapy, Parent Child Interaction Therapy, etc. Many not getting these therapies despite durable effects later vs none such effects for medications.
- When prescribers are not informed of medications youth are taking or have taken before they may prescribe medications that have unintended interactions or use medications that failed in past or had bad reactions.
- Primary care physician or nurse practitioner going beyond their comfort zone and prescribing for more complex diagnosis such as Bipolar or Psychotic disorders.

- Overuse of medications for purpose of chemical restraint.

Psychotropic medications can have some good benefits but can also cause side effects and some of these side effects can be harmful. Considering their risks the decision to take these medications should be made after thorough assessment and weighing of their risks benefits, looking at youth and family preferences and other options. These medications don't address some of causes of trauma and what is triggering some of emotions and behaviors which require trauma informed mental health services.

## **Side Effects**

Side effects are unwanted effects that may occur with medications that vary from medication to medication and person to person. Side effects may or may not go away and you have to see if it is worth putting up with these effects or is it time to change or come of these medications to try alternatives to medications. Some of side effects that can occur with psychotropic medications include:

- Headache
- Decrease or increase in appetite
- Sleep too much or too little
- Dry mouth
- Constipation, Nausea, Vomiting and stomach upset
- Sexual dysfunction
- Activation with restlessness, irritability and insomnia
- Fatigue or tiredness
- Inability to focus
- Increase in anxiety, low mood and mood swings

Some of Serious or concerning Side Effects may include

- Increase or decrease in Heart rate and elevated or low Blood pressure
- Diabetes or elevations in blood sugar
- Shaking and tremors
- Hallucination and delusions
- Confusion, disorientation and dizziness
- Tardive Dyskinesia and Extrapyrarnidal side effects
- Neuroleptic Malignant syndrome
- Serotonin Syndrome or serotonin toxicity
- Slowing of growth or significant weight gain

- Effect on Liver, Kidney, Thyroid, heart, brain, etc.

## **When you may need to seek a professional for emotional and behavioral issues?**

Below are some of signs to look for though you need to see how frequent, persistent, unexplained and serious these are and whether these may be amenable to changes in environment and talking to youth and caseworker:

- Child has unexplained fears, appears sad a lot, and often reacts overly.
- Sudden unexplained or recurrent mood changes, nervousness, irritability and tearfulness.
- Somatic complaints such as stomach upset or Headaches.
- Weight loss or gain, changes in sleep quantity or quality.
- Decline in functioning at school or job.
- Youth engaging in risky or dangerous behaviors such as fire setting, running away, cruelty to animals and inappropriate sexual activity.
- Drug or alcohol use.
- Relationship issues such as getting in fights with people, gang activity, lack of friends or isolating.

You may need to talk to the doctor or mental health professional immediately if the child expresses thoughts of hurting self or others or engages in harm to self and others, hears voices or sees things or engages in activities that pose serious risk to his health.

If youth have above symptoms and you feel youth need help you may talk to your caseworker, advocate, Guardian or child's doctor about seeing mental health specialist.

## **Mental Health Assessment and treatment**

Child's doctor may screen and assess by asking lot of questions, do physical exam and order some laboratory tests to assess for any medical problems contributing to how child feels or acts. He may help provide explanation for your concerns, explore possible diagnosis, recommend possible treatment options including getting help in school, talking to counselor to learn ways to cope with feelings and behaviors or recommend medications. On other hand he may decide to watch, reassure, or send child to a mental health specialist for a full evaluation and or further treatment.

Trauma screen and assessment by trained professional may help understand what the youth been through and guide towards effective treatment available to help heal from trauma.

Talk to caseworker who may help guide resources in community that specialize in working with kids in care with history of trauma or address their unique needs. Talk to school to find out if they child has any school related issues or learning disability that can be addressed in school, find out if biological parents have any family history likely to increase risk of certain diagnosis and gather information from previous treatment to help better coordinate ongoing assessment and care.

You can also reach out to Health insurance carrier case manager or nurse to seek assistance in needed services and referral resources.

## **What is your role in Care when your child sees the Doctor or Mental Health Specialist such as psychiatrist or therapist?**

Make every effort to be part of their treatment by making to their appointments to support and understand their treatment and make healthy choices. This is especially important if psychotropic medication is being prescribed for the doctor needs to know information to recommend best treatment options and you need to ask the right questions to help make the best decision before child gets prescribed any psychotropic medications.

Provide any information you have from caseworkers, caregivers, and youth to the mental health specialist that may help in proper assessment and selection of appropriate treatment. This may include:

- Presenting concerns and noted change in emotions and behavior. Where do these behaviors occur?
- Past medical, mental health and trauma history including treatment with any medications and therapies, response to such treatment and any reactions or side effects to medications.
- Biological family's health history if available as some of health problems are hereditary or there is risk of child having diagnosis that their parent or blood relatives may have had.
- Triggers or stressors child is experiencing including issues at school, peer issues or change in peer group, substance use and problems at work. Is the youth being bullied? Any issues related to visits or calls from family, court dates, and change in permanency planning or legal status.
- Reason/s for out of home placement.
- Placement history including number of placements.
- Any school interventions such as IEP or individualized education plan, and any concerns teachers have behaviorally about the child. Is child struggling to pay attention at school or have difficulties with certain subjects suggesting learning disability?
- Child's strengths and hobbies that can be used as coping skills.
- What has worked or didn't work? How consistent are these interventions?

Bring any records you may have on child including their psychological, educational evaluations or medical and mental health records.

## **Additional information to share with doctors and therapists during follow up**

- Do youth take medications as prescribed?
- Do they have any changes in their mood or behavior since last therapy session?
- Have they had any change in mood, anxiety, sleep, energy level or concentration since start of medication or dose change?
- Any physical symptoms such as headaches, stomach upset, nausea, change in weight, rash or other side effects since start of medication or dose change?

## **Rights related to health care decisions and medications**

Knowing your rights can help

### **Informed consent**

Informed consent is the process by which permission is provided for treatment after the provider has given information in words you can understand on risks and benefits of

- Proposed treatment
- Alternatives to treatment including therapy
- No treatment.

### **What to expect from Provider:**

Comprehensive assessment before prescribing treatment. This is accomplished by

- Listening to youth
- Listening to foster parent or person accompanying the child, and
- Collecting collateral information such as review of past records

Share the

- Results of assessment, diagnosis and recommendations
- Plan of care for child that includes available treatment options
- Going over informed consent before prescribing treatment

## **Questions to consider and take to appointment when seeing the Doctor**

Since psychotropic medications can have some serious side effects and there are alternatives to medications, don't hesitate to ask lot of questions of the doctors and mental health specialists to help you understand and decide if it is appropriate and worth taking these medications.

- What is the role of trauma in child's symptoms?
- Could child's symptoms be related to some triggers, stress or learning issues?
- Are there things that can be done in place or with medications such as therapy?
- How to know if the treatment (Medication or therapy) is working? What change in behavior, mood and thinking to expect to see?
- How long before I see the improvement?
- What is the medication being prescribed for and what is the diagnosis?
- What is available research on what works for youth and what is known about proposed medications helpfulness for what it is being prescribed for?
- Possible side effects of proposed medications and what to do if child experiences these side effects? Are any side effects worrisome and how soon should the provider be contacted for

these? Can these side effects be prevented? How long side effects last? Will medication cause sedation, weight gain or weight loss?

- What to do if a dose of medication is missed?
- What are risks of using medication with drugs or alcohol? Some medications when taken with alcohol can be sedating and hence be risky if driving, swimming or engaging in other activities requiring alertness.
- Any activities to avoid on medications?
- How long treatment or medication will be continued?
- How much and how often to take medication/s?
- Will taking at school be barrier? Can it be dosed to avoid having to take at school?
- Does the medication need be taken with or without food?
- Does the medication require blood work before and after starting it to monitor its side effects?
- Does child need monitoring of Blood pressure and heart rate on this medication?
- What are other precautions such as not taking this medication with other medications or over the counter products or herbs?
- How should the medicine be stored?
- Is this medication addictive or hard to get off once started and can it be abused?
- What to do if the child refuses to take the medication?
- When to follow up with the provider and what would be the frequency of follow up?

Follow up varies depending on number of factors but generally with new medication follow up may be needed in 2-4 weeks. When child is doing well the average follow up on medication may be every 3 months. The child may need to be seen sooner than scheduled follow up if the child is having side effects to medications, not responding or partially responding to medication or therapy, and child is worsening or has new concerning change in emotions and behaviors. The doctor or his nurse may provide advice over phone in between if there are any concerns about medication/s.

If you disagree with diagnosis or assessment ask the provider how he came to that diagnosis or assessment and what are your options such as second opinion. Ask the provider how you get the second opinion.

If you are worried about type or number of medications prescribed you may talk to child's doctor, caseworker or child's guardian.

Consider young person's and his or her family's preferences and concerns in choice for treatment.

Remember the pharmacy gives you medication information that can be valuable resource for looking up information on medication.

## **What would you need to know about therapy?**

Therapy is an important part of treatment and if your child is in therapy it is important to monitor child's progress in therapy and support youth in practicing skills learned in therapy. Let the child know that you are there to support them in therapy. You may observe and ask youth

- If they are being open and honest in therapy?



- If they feel the therapist understands them?
- If therapy is helpful and they feel it is helping them change?
- If they are learning any skills in therapy to help deal with their emotions and behaviors?
- Has there been any change in their emotions, thinking or behaviors since they been in therapy?
- Are they given any homework assignments in therapy that they need to practice?
- If they would like you to be part of therapy and in what ways?

If you feel the medication or therapy is not working well or having ill effects, you may consider having a meeting with the doctor, therapist and or child's caseworker to express your concerns and explore if there needs to be change in medication and or change in form of therapy. Your child may need different form of therapy or different therapist due to their specific needs or therapeutic style of therapist.

## **Engage and empower youth in their assessment and treatment**

Let the child express their concerns with the doctor and therapist. Help them voice how they feel about different treatment options and if these treatments are helping or making them feel worse or doing nothing. Use language they understand about their medications, diagnosis, etc. Help them feel cared and listened. If they are partners in their health decisions they are more likely to own the treatment and succeed with that treatment.

They may fear to take medication due to stigma, side effects, how medications may affect their goal to get a job or go to military and others finding out that they take medications. Engaging them and having these questions answered by their doctor helps ward some of these concerns to avoid barriers to their treatment.

## **Confidentiality**

Youth in care may have trust issues which may affect their willingness to open up in treatment if they are not sure how information they disclose would be shared further. Let youth know when information is about to be shared and with whom to help them feel comfortable and willing to share in future. Their doctor or counselor may respect their privacy and share only general information about their treatment rather give details as to everything the child said. This is so the child feels comfortable sharing freely with them. However as required by law the medical providers are required to report if child discloses abuse that need be reported, or makes a serious threat of harm to self and others.

For youth at or above age of majority (when they are considered an adult due to age criteria by state or other criteria outlined in state law) they must consent in writing to sharing of all health information except when there is risk of harm to self or others. If the child opposes sharing of information talk to him as to reasons for that. They need to feel comfortable that information they share would not be used against them.

## **Who provides consent?**

For youth at or above age of majority (when they are considered an adult due to age criteria by state or other criteria outlined in state law) may consent or give permission to their treatment with few exceptions. The health care provider also has to determine if the youth has capacity to consent based on

their ability to understand the proposed health care service and appreciate the nature and consequences of it. For minor youth the biological family may need be involved in consent process especially if there is no Termination of parental rights and there are no safety concerns with biological family. Please look at Court order for clarity as to who may be able to provide consent to treatment including routine and major medical care. Youth 16 and less may provide assent (agreement). If you have questions about consent ask your caseworker.

When child comes into foster care the court usually gives SCDSS permission to obtain routine health care for the child. This usually includes regular checkups by the doctor, sick visits, immunizations or shots, routine dental treatment, talking with the counselor to include some but not all. The court may in some circumstances give SCDSS permission for major medical treatment as well. Depending on the complexity of major medical treatment or procedures the SCDSS policy may spell out who specifically may provide consent for major treatments such as surgeries, anesthesia or other procedures. Please consult with child's case worker for clarification on extent of consent for children under DSS custody.

If the parent or guardian with right to consent can't be located or refuses to sign the necessary treatment, it may be necessary for a judge to decide whether or not the child will receive the treatment.

Consent for treatment may not be needed if the doctor believes it is true medical emergency and waiting to get the treatment would risk the health or life of the child.

## **Health Passport and keeping up with child's health information**

Caseworkers are to update the Health Passport and give a copy of Health Passport to foster parents who then are responsible to keep the Health Passport up-to-date while the child is in their care. This update in health passport is to be shared with caseworkers so they can update the copy of passport in their records.

This information in passport may include list of medications and any over the counter products the child is on including name, dose, frequency, date prescribed, any refills and dates child may run out of refills, name of prescribing physician and child's experience with the medication including any side effects or reactions.

Please also include all medical and counseling appointments including names of providers, dates seen, recommended follow up appointments, results of evaluation including any psychological, psychiatric evaluations to help understand current diagnosis and treatment recommendations.

## **Medication Safety**

- Keep all medications in safe locked location.
- Make sure medication is given as instructed by the physician.
- Do not share child's medications with anyone else as that may lead to serious unintended side effects for some and may even be abused.
- Consult the physician before stopping or starting any new medications. Some medications if stopped suddenly can lead to uncomfortable withdrawals and harmful effects so always talk to the child's doctor in this regard. Some of these medications may have to be decreased slowly over weeks to avoid these effects. The doctor would advise how to safely come off medications and if that is in child's best interest.

- The doctor may recommend other medications or treatment options if current medications are not working and or leading to unwanted side effects. Remember not all medications work for everyone and not all lead to side effects.
- If child starts feeling better on medication that may not necessarily mean he/she no longer need that medication.
- Ask youth if they are experiencing side effects and observe child for any change in behavior.
- Youth should be administered medications by caregiver.
- Closely monitor to make sure youth are taking medications especially if you suspect they are not taking it. This may mean you may have to do mouth check after they swallow medication.

## **Who to contact for help?**

Remember you are not alone. Following are resources to reach out to:

- Child's doctor (pediatrician or psychiatrist) if you have any concerns as to side effects from medications and or response to medications.
- Select Health 24-hour Nurse Help Line (1-800-304-5436, [www.selecthealthofsc.com](http://www.selecthealthofsc.com)) that is toll free and you can call for foster children under Select Health. The nurse can help you decide if you should call your doctor or go to hospital when your child is sick or give health advice.
- Child's caseworker who can advise and guide to resources.
- Child's caseworker can also reach out to Regional Clinical Specialist who can consult Child Psychiatrist on team if you are concerned as to child's psychotropic medications and would like to have formal review. This may be indicated if the child is prescribed too many psychotropic medications (5 or more), child is on too much dose of medication or child is too young (5 or younger) and prescribed psychotropic medications especially an antipsychotic.
- The pharmacist can be another valuable resource as to side effects or potential interactions with medications.
- Child's guardian ad Litem or court ordered special advocate can assist advocate the best interest of the child.
- Child's therapist.
- Birth parents/family members if involved in child's medical care may also be resource.

## Resources for foster parents and other caregivers on psychotropic medication and Mental Health Diagnosis

<https://www.childwelfare.gov/pubs/mhc-caregivers/>



Supporting Youth in Foster Care in Making Healthy Choices: A Guide for Caregivers and Caseworkers on Trauma, Treatment, and Psychotropic Medications

<https://www.childwelfare.gov/pubs/makinghealthychoices/>



Making Healthy Choices: A Guide on Psychotropic Medications for Youth in Foster Care

[http://www.aacap.org/AACAP/Families\\_and\\_Youth/Facts\\_for\\_Families/FFF-Guide/FFF-Guide-Table-of-Contents.aspx](http://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/FFF-Guide/FFF-Guide-Table-of-Contents.aspx)

This site has valuable information in common childhood diagnosis as well following resources:

Psychiatric Medication For Children And Adolescents Part I- How Medications Are Used

Psychiatric Medication For Children And Adolescents Part II- Types Of Medications

Psychotherapies For Children And Adolescents