Central East (HHS Region 3)
MHTTC Mental Health Technology Transfer Center Network
Funded by Substance Abuse and Mental Health Services Administration

Medication Self-Management Among Young Adults Transitioning from the Foster Care System

Kathleen M West, DrPH
Advocates for Human Potential, Inc.

June 4, 2020

The Danya Institute
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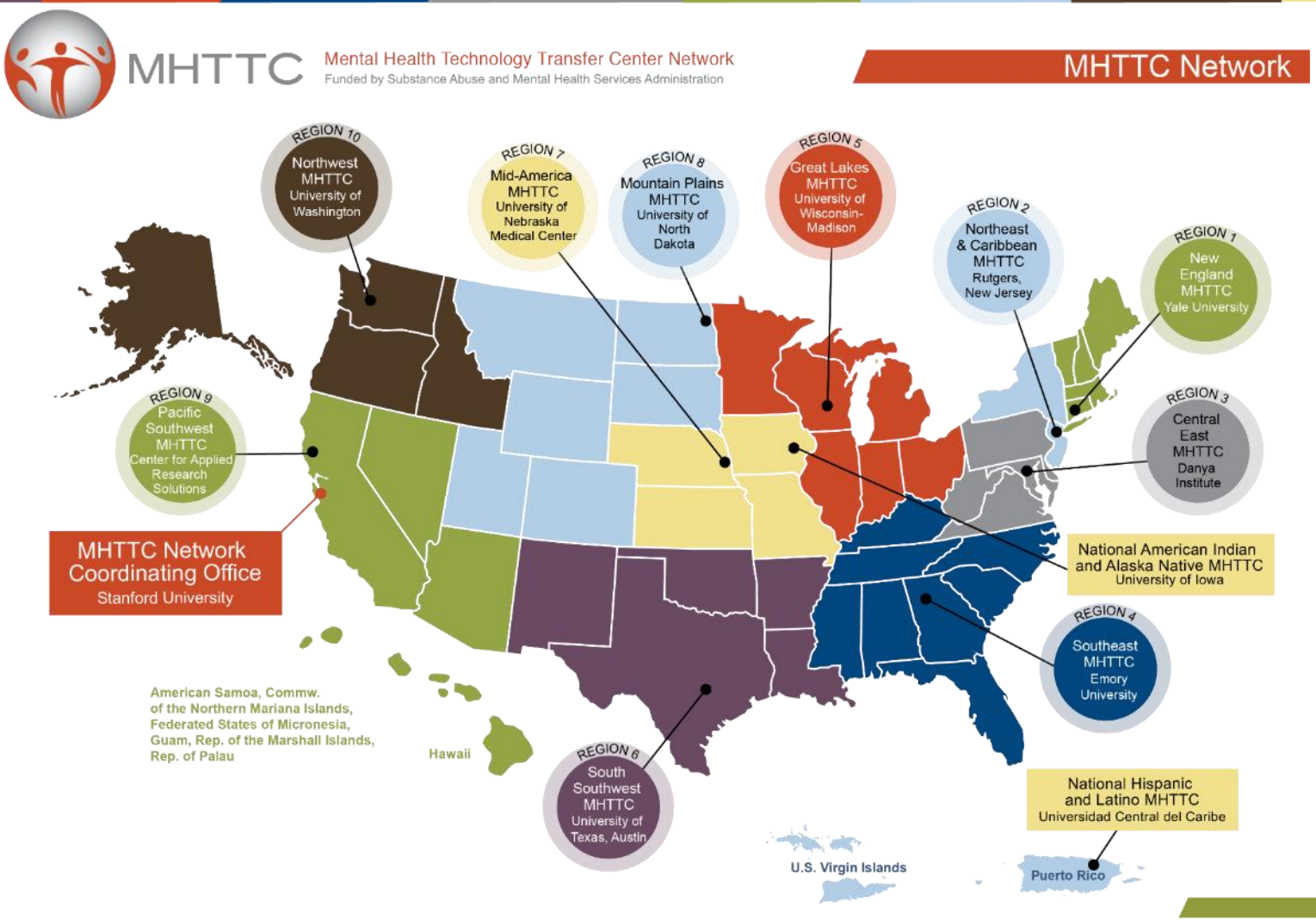
MHTTC Network



MHTTC Purpose

The MHTTC Network vision is to unify science, education and service to transform lives through evidence-based and promising treatment and recovery practices in a recovery-oriented system of care.

Central East MHTTC Goals

Funded by SAMHSA to:

- Accelerate the adoption and implementation of mental health related evidence-based practices
- Heighten the awareness, knowledge, and skills of the behavioral health workforce
- Foster alliances among culturally diverse practitioners, researchers, policy makers, family members, and consumers
- Ensure the availability and delivery of publicly available, free of charge, training and technical assistance

Central East Region

HHS REGION 3

Delaware

District of Columbia

Maryland

Pennsylvania

Virginia

West Virginia

The series . . .

MHTTC Webinar Series:

Improving Services for Transition Aged and Young Emerging Adults

April 9 - 1:00 PM to 2:00 PM

Young Adult Peer Mentoring

Recording available

June 4 - 11:00 AM to 12:00 Noon

Medication Self-Management Among Young Emerging Adults Transitioning from the Foster Care System

Times stated in Eastern Daylight Time

Today's Presenter

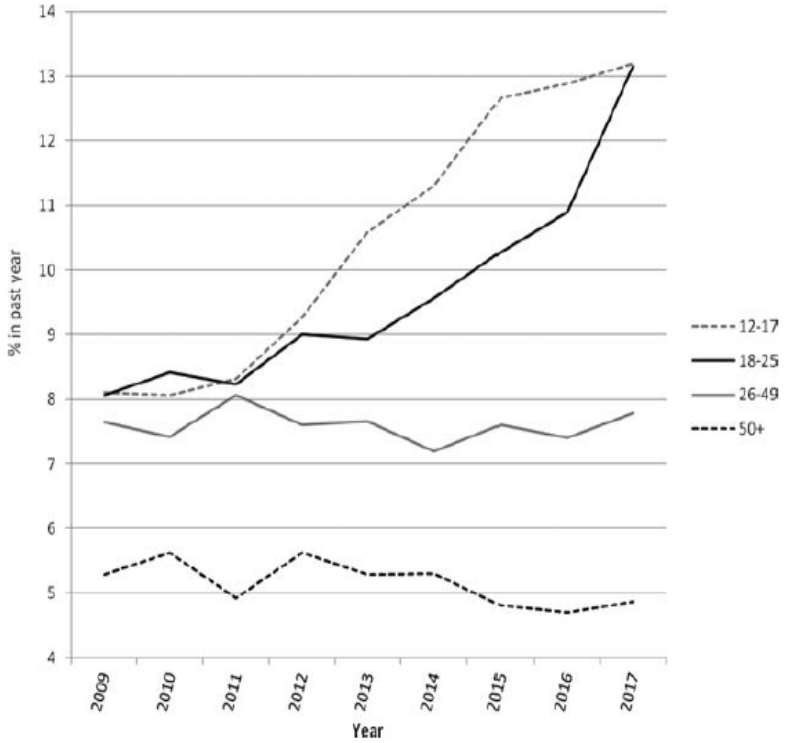
Kathleen West, DrPH

Senior Program Manager
Advocates for Human Potential

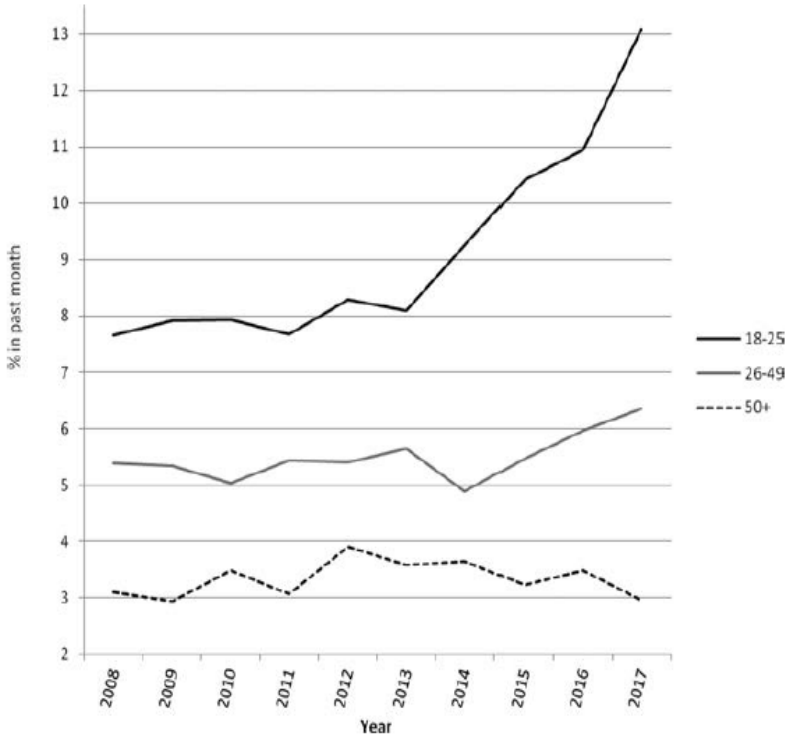
Learning Objectives

- Describe why youth in foster care may be prescribed psychotropic medications at higher rates than children in the general population
- Explain historic concerns about psychotropic medication use among youth in foster care that led to current best practice standards
- Identify frequently prescribed psychotropic medications, neurobiological effects, and common side effects
- Explain best and promising practices, including the “Shared Decision-Making” (SDM) model, that can support successful medication self-management among TAY leaving the foster system

Trends in Mood Disorder Indicators in General Population



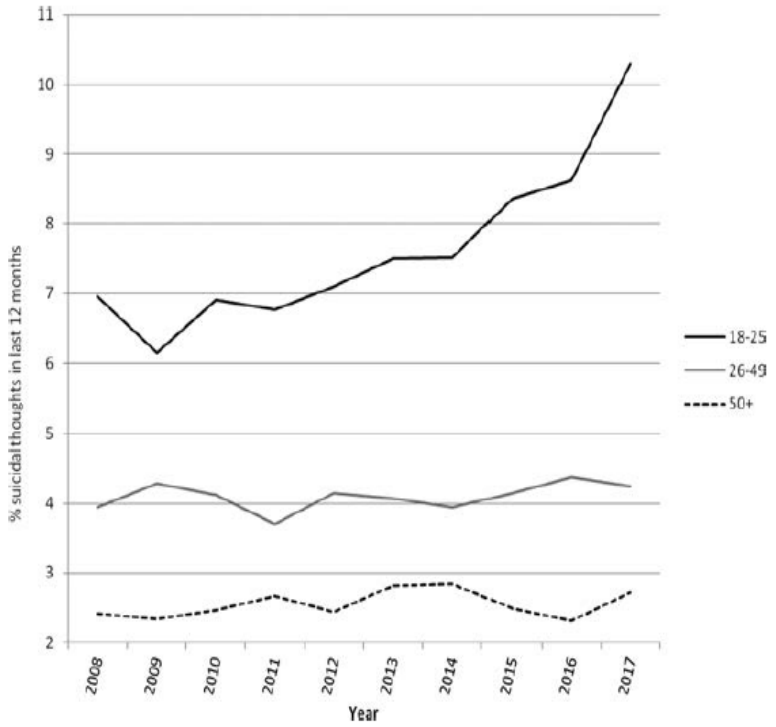
"Major depressive episode in past 12 months", by age group, 2009–2017



"Serious psychological distress in last month" by age group, 2008–2017

Journal of Abnormal Psychology (2019)

Trends in General Population & Foster Youth Suicide-Related Outcomes



"Have had at least one suicide-related outcome (thoughts, plans, or attempts) in last year" by age group, 2008–2017

FOSTER YOUTH FINDINGS

- A 2019 meta-analysis of multiple types of childhood maltreatment, with and without foster care placement, found a 2-3x increased risk for suicide attempts, as well as suicidal ideation.

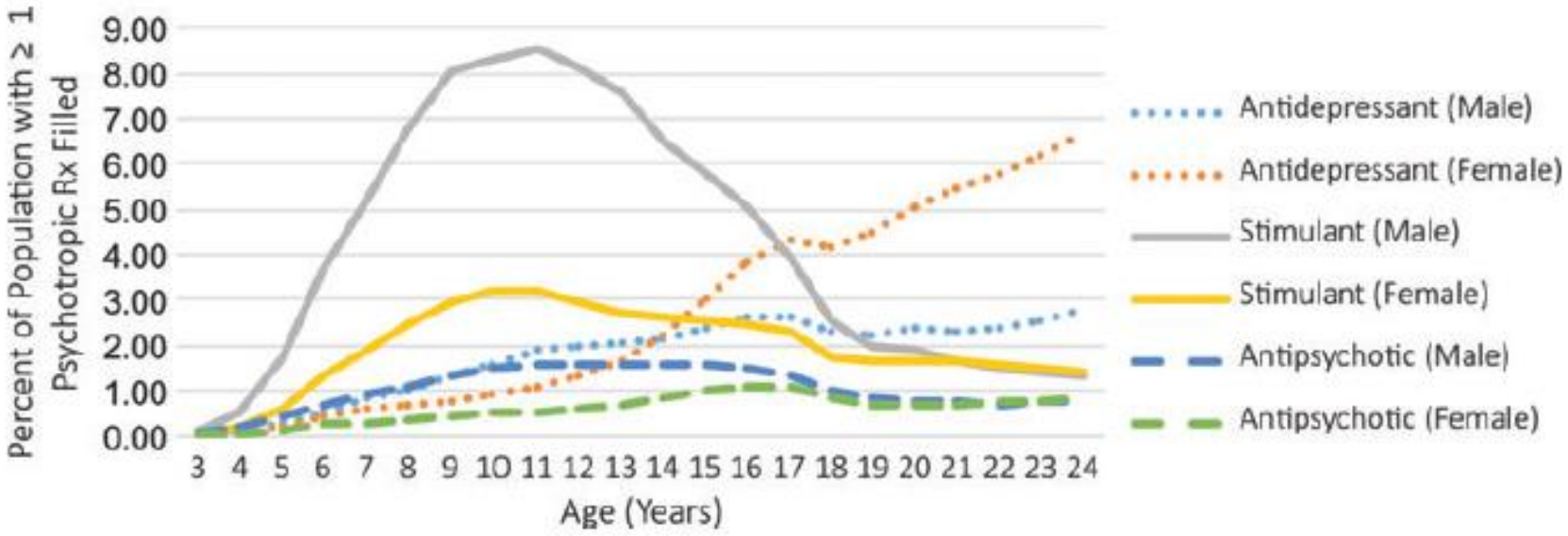
  Psychological Medicine (2019)

- A 2006 study of 464 12-17 year olds foster or former foster care youths had more past-year psychiatric symptoms, more conduct symptoms, and past-year substance use disorders than those never placed in foster care.

- They were also about 4x more likely to have attempted suicide in the preceding 12 months and 5x more likely to receive a drug dependence diagnosis in the same period.

  J Adoles Health (2006)

General Youth Population & Common Psychotropic Medication Prescriptions



Percentage of population with one or greater filled prescription for an antidepressant, stimulant, or antipsychotic

(n = 6,351,482; aged 3-24 year. 2008 data.)

Journal of Child and Adolescent Psychophamacolgy (2018)

Traumatic Experiences Higher among Children and Youth in Foster Care

- Roughly 50 – 67% of all youth in the general population have experienced at least one traumatic event prior to age 18
- Children and youth in foster care or therapeutic foster care (TFC), have trauma exposure rates of 90%+; almost 50% were exposed to 4 or more types of traumatic events in one study
- The 1998 Adverse Child Experiences (ACE) study demonstrated the lifelong consequences associated with traumatic exposures in minors

Journal of Child and Family Studies (2012)

Prenatal Alcohol & Drug Exposure: Increased Risk of Behavioral & Cognitive Difficulties Over Time

- FAS children frequently diagnosed and mis-diagnosed with ADHD, Conduct Disorder, Bipolar Disorder
- Co-morbid psychiatric conditions may be present
- Medications and behavioral interventions not always effective for FAS
- Alcohol-Related Neurodevelopmental Disorder (ARND) is a separate, less well-defined entity in which behavioral manifestations of FAS present, but no facial anomalies or growth retardation

Mental Health Diagnoses Prevalence in Juvenile Justice Youths

- Any DSM Disorder 69%
- Substance Use Disorder 50%
- Conduct Disorder 39%
- ADHD 18%
- Major Depressive Episode 18%
- Mood disorder (dysthymia) 14%
- Manic Episode 2%
- Psychosis 1%
- Plus learning disabilities, FAS-spectrum, trauma exposure, TBI, etc.

Archives of General Psychiatry (2002)

Key Federal Legislative & Programmatic Responses to Psychotropic Medication Concerns for Children in Foster Care

[SAMHSA Prescribing Guidance (2019)]

GAO Studies on Psychotropic Medication Use in Child Welfare

- **2011**: 5-state study with 2008 data found rates of 2.7-4.5X greater psychotropic drug prescriptions in foster children than nonfoster children on Medicaid; not necessarily inappropriate considering childrens' possibly greater mental health needs

- **2014:** Follow-up study showed that States needed Federal guidance to ensure Managed Care Organizations monitored psychotropic medications to children in foster care

- **2017:** 7-state study found wide variability among states with HHS encouraging states to implement voluntary measures to track medication use, other MH treatment, and child health outcomes.

GAO Highlights (2017)

Increased Mental Health Risk Factors in Juvenile Courts Populations

ACES Video (2015)

National Council of Juvenile and Family Court Judges Resolution

- NCJFCJ recognized that “parens patriae” in dependency and juvenile court cases extends to oversight of psychotropic medication prescribing practices for children under court jurisdiction

- Initiated movement toward Trauma Informed Courts and appropriate use of psychopharmaceutical treatment as an element of children and youth’s case plans

- Propelled further study of “disproportionality” vis a vis impact of psychotropic medication prescribing practices on non-white foster children

National Council of Juvenile and Family Court Judges (2013)

GAO Studies on Psychotropic Medication Use in Child Welfare

Themes

- GAO consistently recommended more Federal guidance to promote collaboration and address concerns, such as data sharing
- Foster children's' prescriptions had greater health risks, primarily due to polypharmacy and dosage
- Concomitant use of 5 or more psychotropic drugs, as well as higher doses than FDA-approved labels and off-label, increase risk of side effects without increased efficacy

Guiding Framework for use of Psychotropic Medications

Biopsychosocial Assessment & Treatment

- Assess biological consequences of maltreatment and other trauma, exposure to drugs/alcohol in utero, nutrition, and overall physical health status.
- Assess emotional and behavioral functioning, strengths and interests, beliefs and values, social skills, and personal goals.
- Consider youth's family, neighborhood, educational, and community context, recognizing social strengths and protective factors, as well as social risk factors.

American Academy of Child and Adolescent Psychiatry (2015)

Guiding Framework for use of Psychotropic Medications

Trauma Informed Care (TIC)

Traumatic experiences: maltreatment, poverty, bullying, community violence, disrupted attachments, and other losses

Recognizes prevalence and impact of trauma; **commits to minimize its effects** & **avoid additional traumatization**, including by human service and medical providers.

Core TIC Principles

Practices that ensure

- Safety
- Trustworthiness
- Collaboration
- Choice
- Empowerment

Guiding Framework for use of Psychotropic Medications

System of Care Principles

- Informed consent and Shared-Decision Making, consistent with youth-guided care
- Individualized care, must include evidence-based psychosocial interventions
- Collaborative, integrated care across systems and among providers
- Monitoring of medication, consistent with outcomes-oriented, data-driven care

American Academy of Child and Adolescent Psychiatry (2015)

What are Psychotropic Medications or Drugs?

- Medications that are administered for the purpose of affecting the central nervous system to treat psychiatric disorders or illnesses.
- They act on the brain and central nervous system and are capable of affecting the mind, emotions, and behavior, by “targeting” certain symptoms.
- They typically change the way chemicals in the brain called "neurotransmitters" send messages between brain cells through a synapse or crossing.

Most Common Psychotropic Medications for Children and Youth

Drug Class	Drug & Trade names	Treatment Purpose
Stimulant	Methylphenidate (Ritalin, Concerta, Methylin, +), Amphetamine (Adderall)	ADHD
Centrally acting alpha$_{2A}$-adrenergic receptor agonists	Guanfacine (Tenex, Intuniv) Clonidine (Catapres, Kapvav)	ADHD Anxiety, Hypertension
Serotonin-norepinephrine reuptake inhibitor (SNRI) *Antidepressants –"2nd or 3rd line treatment"*	Atomoxetine (Strattera) Duloxetine (Cymbalta) Venlafaxine (Effexor XR)	ADHD GAD (7+) Anxiety
Selective serotonin reuptake inhibitor (SSRI). *Antidepressants. "1st line treatment"*	Fluoxetine (Prozac) Fluvoxamine (Luvox) Sertraline (Zoloft) Escitalopram (Lexapro)	Anxiety, MDD (8+), OCD (7+) Anxiety,SAD, PTSD, OCD (8+) Anxiety, OCD (6+) MDD (12+)

Within the 4 drug classes, these medications have met FDA effectiveness, safety, dosing, and monitoring criteria for youth at specified ages.
All are available as generics.

Continuing Need for Efficacy Studies of Pediatric Psychotropic Drug Safety

Concerns:

- Stimulants' effects on children and youth growth patterns (changed endocrinologic assays)
- Requirements for medication monitoring and lab evaluations – especially of liver function - at least every three months are not consistently implemented
- FDA guidelines are for target purpose and intended population – not for prescribing practice
- Side effects are not insignificant, including sleep problems, weight gain, headache, dizziness, nausea, dry mouth, appetite issues, agitation. These may be especially disruptive to children and youths' self-esteem and development

Atypical Antipsychotics
Second Generation Antipsychotics (SGAs)

Table 1. Atypical Antipsychotics FDA-Approved for Pediatric Use

Drug (Brand)	Indication	Effective Dosage Range
Risperidone (Risperdal)	Schizophrenia (adolescents) Bipolar mania (children/adolescents) Irritability associated with autistic disorder	1-6 mg/day 0.5-6 mg/day 0.5-3 mg/day
Aripiprazole (Abilify)	Schizophrenia (adolescents) Bipolar mania (children/adolescents) Irritability associated with autistic disorder	2-30 mg/day 2-30 mg/day 2-15 mg/day
Olanzapine (Zyprexa)	Schizophrenia (adolescents) Bipolar mania/mixed (adolescents)	Start at 2.5-5 mg once daily, target 10 mg/day
Paliperidone (Invega)	Schizophrenia (adolescents)	Weight <51 kg: 3-6 mg/day Weight ≥51 kg: 3-12 mg/day
Quetiapine (Seroquel)	Schizophrenia (adolescents) Bipolar mania (children/adolescents)	400-800 mg/day 400-600 mg/day

U.S. Pharmacist (2015)

Atypical Antipsychotics ("Second Generation" SGA)

Olanzapine + Fluoxetine (Prozac) = **Symbyax**, used to treat depression in bipolar disorder

Olanzapine

Aripiprazole

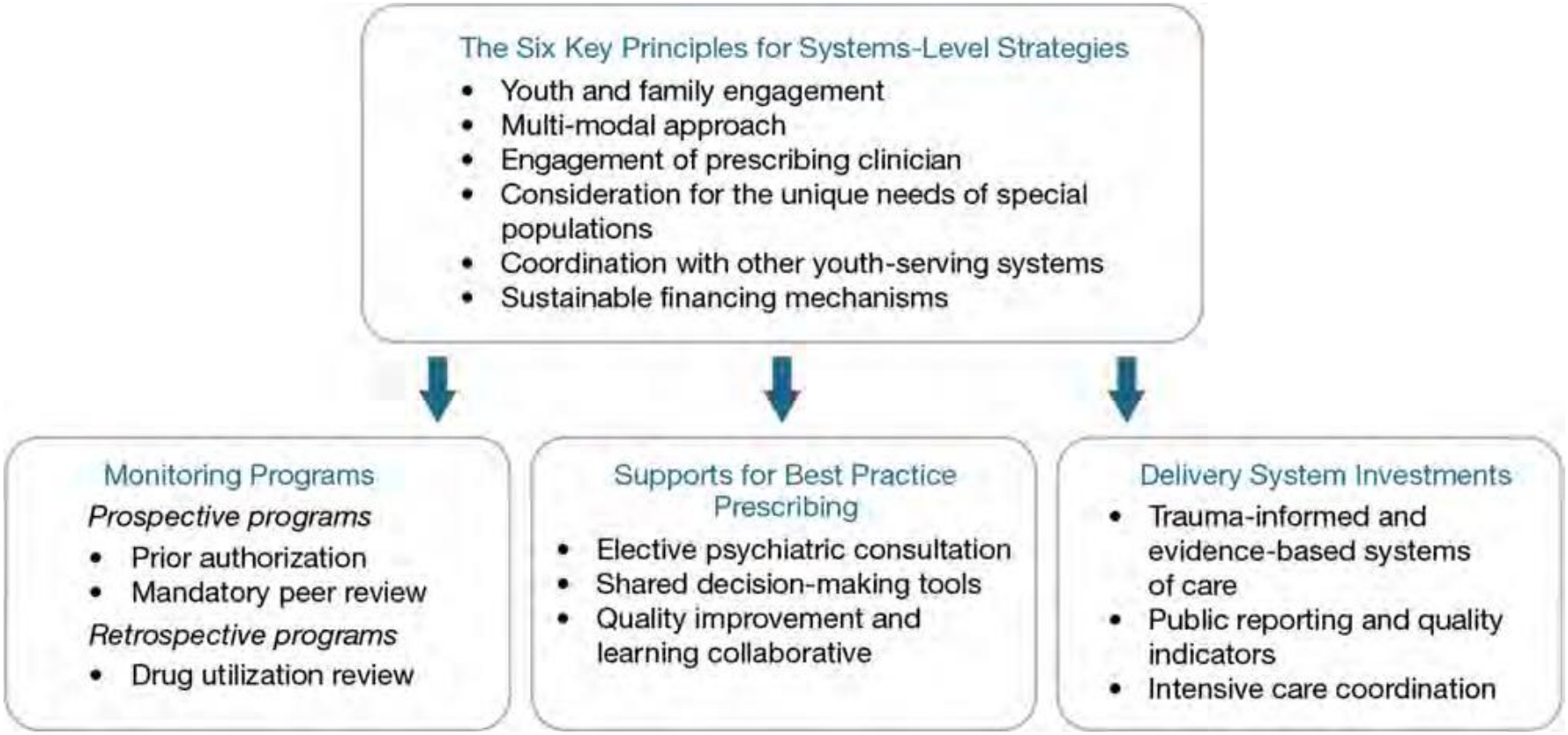
Atypical Antipsychotics (SGAs): Heads Up for Youth & Advocates

- SGAs carry a range of serious side effects – especially when concomitantly used with SSRI/SNRIs – which is more than half of youth patients.
- Risk of Type 2 diabetes increased dramatically based on dose and duration.
- Risk of morbid obesity with 2 SGA prescriptions was 5x, with higher rates for non-white, older youth.
- Risk of weight gain, high blood pressure, metabolic syndrome, and heart disease also increase.

Science Digest (2016)

American Academy of Child and Adolescent Psychiatry (2017)

Strategies to Promote Antipsychotic Medication Oversight & Best Practice Prescribing for Youth



SAMHSA Prescribing Guidance (2019)

Shared Decision Making (SDM) in Mental Health

- Tool that provides “support for best practice prescribing”
- SDM Process
  - Recognition that a decision needs to be made;
  - Identification of partners in the process as equals;
  - Statement of the options as equal;
  - Exploration of understanding and expectations;
  - Identifying preferences;
  - Negotiating options/concordance;
  - Sharing the decision; and
  - Arranging follow-up to evaluate decision-making outcomes.
- Steps do not all have to be taken at one time; may not all be conducted in the presence of both parties.
- Decision aids (DAs) can be used by consumers on their own or with peer assistance. DAs can help the foster TAY identify treatment options and explore their preferences prior to meeting with their mental health provider.

SAMHSA Shared Decision-Making (2011)

SDM VALUE ADDED

Evidence of the value includes:

- "Clients who believe they are actively involved in treatment decisions generally have better outcomes, whereas having a low sense of control over decisions is associated with less behavioral involvement in care, poorer self-rated health, and increased illness burden".*

- The use of decision aids appears to increase the utilization of underused services and decreases the utilization of overused services.**

*Community Mental Health Journal (2006)

**Canadian Medical Association Journal (2007)

Promising Practices for Engaging TAY in Self-Care with Medication Management

No population-level studies have been done to examine effectiveness of SDM tools that support psychopharmacologic treatment decisions among youth and caregivers.

However . . .

Promising practices include:

- Providing youth with risk/benefit information and planning tools for early identification of any side effects
- Engaging special populations with peer support
- Using social media & technology to increase uptake of decision aids, in keeping with SDM model

SDM Implementation Challenges

Participants at an SDM meeting identified **some barriers**:

- "Culture of silence" among youth surrounding the use of psychiatric medication due to stigma, shame, confusion.
- "Caretaking" of providers by youth who withhold information about medication's side effects, do not ask questions, nor seek change in treatment out of fear of loss of care and upsetting providers.
- Lack of youth knowledge about medication options—including the option to have treatment without medication—and acceptance of side effects as unavoidable.

SAMHSA Shared Decision-Making (2011)

SDM Implementation Challenges

- Rejection of authority and increased autonomy to act freely by youth
- Misaligned treatment goals and paternalism by providers, plus lack of psychoeducation throughout course of treatment
- *"There's an enormous taboo against those of us using psychiatric medications discussing them with one another. Many patients don't believe they have a right to mention side effects to their providers; they think they just have to live with them."*

SAMHSA Shared Decision-Making (2011)

What We Know about Youth Transitions to Medication Self Management

- Using 2012 California data, it was found that the overall rate of psychotropic medication use dropped from age 17 to age 19. Among youth with at least one behavioral health problem, rates of psychotropic medication use also declined over time.
- Decreases in psychotropic medication use between 17 and 19 years were found in youth with diagnoses of: mania, alcohol use disorder, and Substance Use Disorder.
- Behavioral health status and youths' living arrangements were associated with the likelihood of psychotropic medication use at age 17, whereas only behavioral health status was associated with the likelihood of psychotropic medication use at age 19.
- Most youth reported either a positive or neutral view of the relative benefits of using medications; those in relative foster homes were less likely than those in non-relative foster homes to report negative views of their medications.

Child and Adolescent Social Work Journal (2019)

What We Know . . . cont.d

- Foster Youth (n=727 17 y/o), especially those with past sexual or physical abuse, had high rates of mental health use; 20% felt unprepared to manage their mental health.
- Youth who identified as 100% heterosexual used counseling less than others.
- Successful treatment engagement models may be adapted and must be implemented before youth transition out of care.

Journal of Adolescent Health (2020)

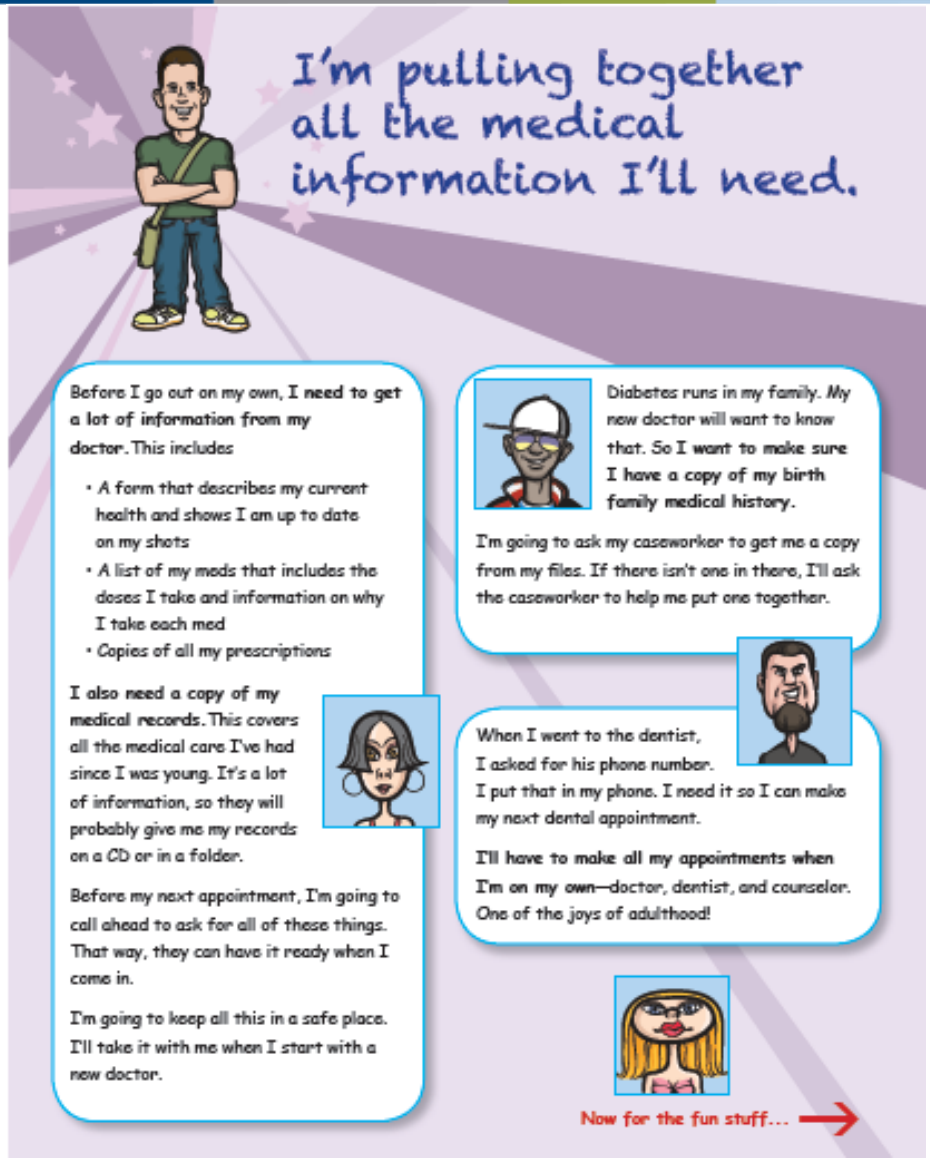
Child and Adolescent Social Work Journal (2020)

Developmentally Appropriate Engagement of Transitional Age Youth

- Recognize that TAY are a discrete developmental cohort- not adolescents, not adults
- Offer coordinated, continuous access to MH care to support successful transition to adulthood
- Address and provide advocacy around systemic factors of insurance, access to service facilities, age of majority and state law constraints
- Encourage the individual and collective youth voice to plan and implement effective treatment

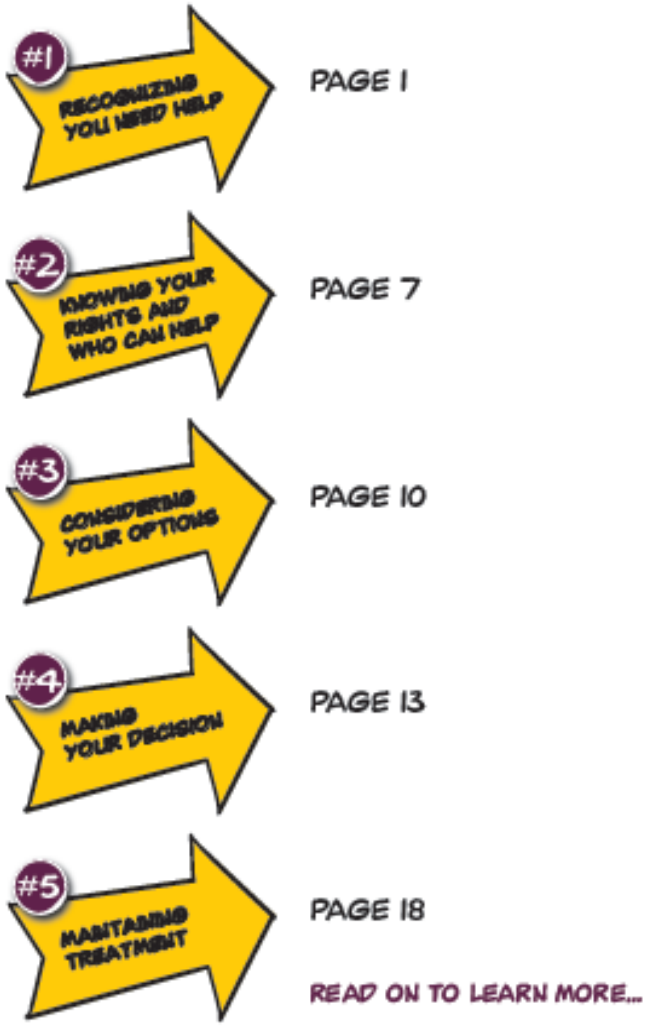
Journal of the American Academy of Child and Adolescent Psychiatry (2018)

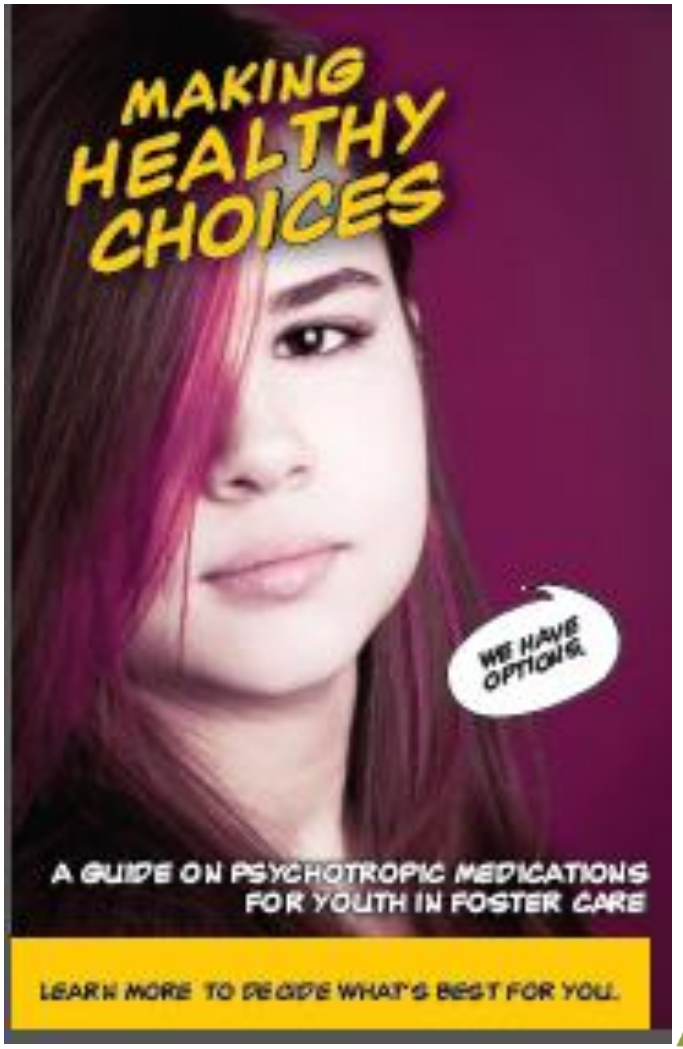
Excerpt from AAP "Aging Out" Handout



[American Academy of Pediatrics (2014)]

Targeted Foster Care Youth Resource on Psychotropic Medication Management

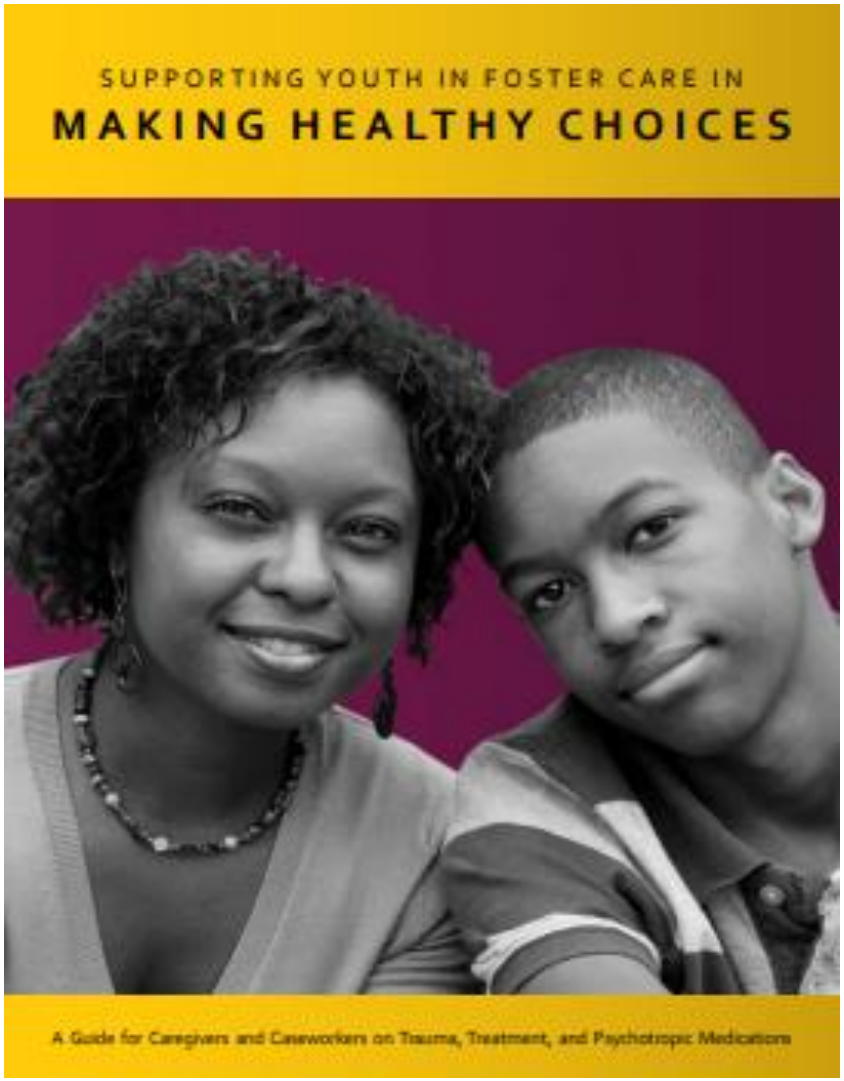




Central East (HHS Region 3) MHTTC

[Administration for Children and Families (2012)]

Supporting Youth Making Healthy Choices



[Administration on Children, Youth and Families Children's Bureau]

A message from youth around the country who participated in the Young Adults Training and Technical Assistance Network under the National Resource Center for Youth Development:

It is important for us to know that the adults in our lives care about us and are working together with us to act in our best interests. We need support and encouragement to understand the issues we are facing and to seek the help we need. But we also want to be heard and want to have a say in decisions being made. This guide will provide you with a lot of information, but here is what is most important to us:

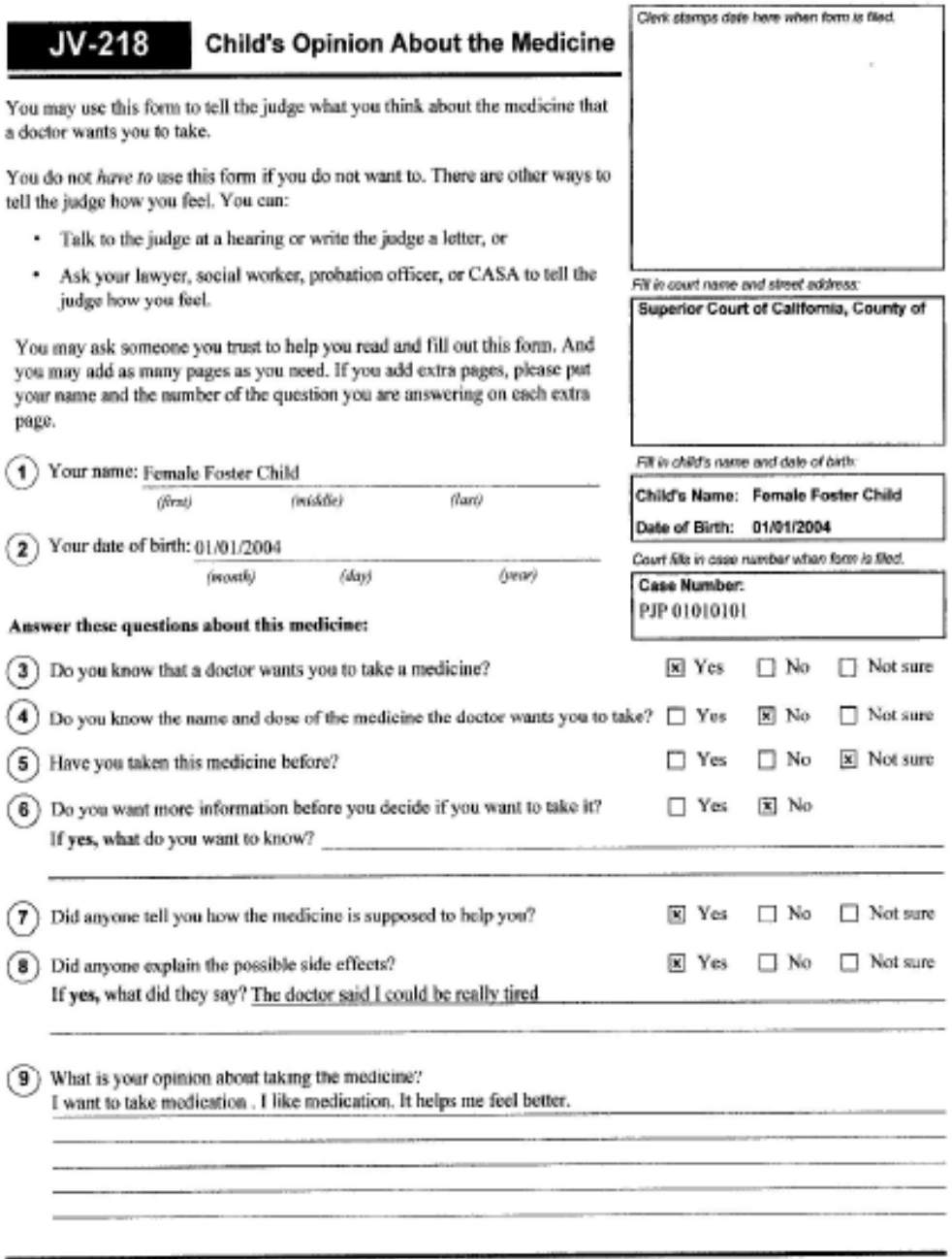
- Ask us what we think and want. If there is something we are not happy about, or we are doing something you might not advise (like dropping out of counseling), take time to understand why, rather than fighting against us.
- We don't always know what is best for us, but when our opinion is paired with those who have expertise in certain areas, the outcome will be better.
- Engage with us about our needs, but use language we can understand. Take time to explain things to us, like what certain medications do, what our diagnosis means, etc. Do it in a way that is not intimidating or stigmatizing.

TAY offer some suggestions about their needs and wishes

Promoting Decision Making Readiness for TAY: California Example

- **By age 14**
  - articulate what medications s/he is taking & how s/he feels about taking medication
- **By age 15**
  - identify a trusted adult with whom they can discuss their medical needs & share medical/mental health (MH) information
- **By age 16**
  - aware of when, how and any contra-indications to taking medications. Share job of filling prescriptions & taking on time with an adult
- **By age 17.5**
  - make medical & MH appointments, and refill prescriptions
- **By age 18**
  - understand job to make own MH decisions; maintain copies of records; schedule MH & medical appointments; know details about medication regimen & contact information for prescribers; work with treatment team to revise plan as needed & discuss range of alternatives.

Children's Law Center of California (2014)



JV-218 **Child's Opinion About the Medicine**

Clerk stamps date here when form is filed.

You may use this form to tell the judge what you think about the medicine that a doctor wants you to take.

You do not *have to* use this form if you do not want to. There are other ways to tell the judge how you feel. You can:

- Talk to the judge at a hearing or write the judge a letter, or
- Ask your lawyer, social worker, probation officer, or CASA to tell the judge how you feel.

You may ask someone you trust to help you read and fill out this form. And you may add as many pages as you need. If you add extra pages, please put your name and the number of the question you are answering on each extra page.

Fill in court name and street address:
Superior Court of California, County of

Fill in child's name and date of birth:
Child's Name: Female Foster Child
Date of Birth: 01/01/2004

Court fills in case number when form is filed.
Case Number:
PJP 01010101

1. Your name: Female Foster Child (first) (middle) (last)
2. Your date of birth: 01/01/2004 (month) (day) (year)

Answer these questions about this medicine:

3. Do you know that a doctor wants you to take a medicine? ☒ Yes ☐ No ☐ Not sure
4. Do you know the name and dose of the medicine the doctor wants you to take? ☐ Yes ☒ No ☐ Not sure
5. Have you taken this medicine before? ☐ Yes ☐ No ☒ Not sure
6. Do you want more information before you decide if you want to take it? ☐ Yes ☒ No
   If **yes,** what do you want to know?
7. Did anyone tell you how the medicine is supposed to help you? ☒ Yes ☐ No ☐ Not sure
8. Did anyone explain the possible side effects? ☒ Yes ☐ No ☐ Not sure
   If **yes,** what did they say? The doctor said I could be really tired
9. What is your opinion about taking the medicine?
   I want to take medication . I like medication. It helps me feel better.

Judicial Council of California, www.courts.ca.gov
New July 1, 2016, Optional Form
Welfare and Institutions Code, § 369.5
California Rules of Court, rule 5.640

Child's Opinion About the Medicine JV-218, Page 1 of 3

p. 1 JV -218 Child's Opinion About Medicine

[Judicial Council of California (2016)]

Child's name: Female Foster Child

Case Number: PJP 01010101

(10) Do you agree to take the medicine? ☐ Yes ☐ No ☐ Not sure
Explain your answer here, if you want to: Yes, I want to take medicine

Questions about you

(11) List any other treatment or therapy you are doing now:
☐ None ☒ Individual talk therapy ☐ Family therapy
☐ Group talk therapy ☒ Counseling at school ☐ Art or play therapy
☐ Cognitive Behavioral Therapy (CBT or practicing behaviors)
☐ Other *(list any other treatment here)*:

(12) What do you like to do for fun?
I like to play games like checkers and I like to make blankets

(13) What activities would you like to be involved in now?
I would like to play volleyball, dance, and be in Girl Scouts again.

(14) Say anything else about yourself or the medicine that you want the judge to know.
I still want to live here. This is my favorite place.

For a 17-Year Old Youth ONLY
*If you are **under** 17, skip to the next question.*

(15) When you turn 18,
a. Will you be able to keep the doctor you have now? ☐ Yes ☐ No ☐ Not sure
b. Will you know how to get this medicine if you want to keep taking it? ☐ Yes ☐ No ☐ Not sure

p. 2 JV -218 Child's Opinion About Medicine

[Judicial Council of California (2016)]

Case Number:
PJP 01010101

Child's name: Female Foster Child

For a child taking this medicine now
If you are NOT taking this medicine now, skip to the next question.

16 Do you have any side effects from the medicine? ☒ Yes ☐ No
If *Yes*, check below:
☐ Weight gain ☐ Weight loss ☒ Headache ☐ Constipation
☐ Problems sleeping ☐ Feeling very sleepy ☐ Nausea ☐ Feel dizzy
☐ Other *(list any other side effects here)*: Sometimes I get headaches. When I get angry, I get headaches.

17 I you have side effects, did you tell your doctor? ☐ Yes ☐ No
If *Yes*, your doctor's name: _____

18 Did someone help you with this form? ☐ Yes ☐ No
If *Yes*, who? ☒ my social worker ☐ my probation officer ☐ my caregiver ☐ my lawyer ☐ my CASA
☐ Other *(explain)*: _____

☐ Check here if you are going to add extra pages to this form. And say how many pages: _____

Date:

Female Foster Child
Type or print child's name

Child signs here

SW Special(SW asked and wrote child's responses)
Type or print name of other person who helped child fill out form

Helper signs here

New July 1, 2016 **Child's Opinion About the Medicine** JV-218, Page 3 of 3

p. 3 JV -218 Child's Opinion About Medicine

[Judicial Council of California (2016)]

Resources

American Academy of Pediatrics Healthy Foster Care America.

Tips for Working with Children & Teens in Foster Care

Health Form for Foster Care Youth & Children

Foster Care Friendly Tip Sheet for Health Care

AGING OUT HANDOUT

Making Healthy Choices - Psychotropic Medication Decision Making Guide

Shared Decision-Making in Mental Health Care: Practice, Research, and Future Directions. HHS Publication No. SMA-09-4371. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, 2010

California Guidelines for the Use of Psychotropic Medication with Children and Youth in Foster Care

Guidance on Strategies to Promote Best Practice in Antipsychotic Prescribing for Children and Adolescents. SAMHSA, 2019

Psychotropic Medication in Foster Care Version 1.0. Trainers' Guide. April 2017

Alameda County Transition-Age Youth and Shared Decision Making Tools

References

Substance Abuse and Mental Health Services Administration: Guidance on Strategies to Promote Best Practice in Anti- psychotic Prescribing for Children and Adolescents. HHS Publication No. PEP19-ANTIPSYCHOTIC-BP. Rockville, MD: SAMHSA. 2019

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Funding for this presentation was made possible by SAMHSA grant no. 3H79SM081785. The views expressed by speakers and moderators do not necessarily reflect the official policies of HHS; nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. Government.