Children's Mental Health Task Force
Report and Recommendations – September 30, 2014

Task Force Membership

Qualifications	*Appointee*
Senate Chair, Committee on Children (serves as co-chair)	Sen. Dante Bartolomeo
House Chair, Committee on Children (serves as co-chair)	Rep. Diana Urban
Senate Ranking Member, Committee on Children	Sen. Art Linares
House Ranking Member, Committee on Children	Rep. Whit Betts
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General statutes, appointed by the Senate Ranking Member, Committee on Children	Tina Fox Dugdale, RDN
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Overview

The following report represents the product of the Children's Mental Health Task Force after eleven months of work with the first meeting on October 16, 2013 and the final meeting on September 17, 2014.

The task force was established pursuant to Public Act 13-178, An Act Concerning The Mental, Emotional and Behavioral Health of Youths, with the following charge:

(1) Study the effects of nutrition, genetics, complementary and alternative treatments, and psychotropic drugs on the mental, emotional and behavioral health of children;

(2) gather and maintain current information regarding said effects; and

(3) advise the General Assembly and Governor concerning the coordination and administration of state programs that may address the impact of said effects on the mental, emotional and behavioral health of children using a results-based accountability framework.

With that mission in mind, the task force created four focus groups – Nutrition, Genetics, Complementary and Alternative Treatments, and Psychotropic Medication. Along with meeting in their respective focus groups, each of the focus groups made a presentation to the entire membership and submitted their findings and recommendations to the task force for consideration in the final report. The Nutrition, Genetics, Complementary and Alternative Treatments, and Psychotropic Medication focus groups' findings and recommendations can be found in their entirety in the Appendix of this report.

In order to make the work of the task force more manageable, the members selected three medical conditions to center their focus groups' attention on – Attention Deficit Hyperactivity Disorder (ADHD), Mood Disorders and Behavioral Conduct Disorders. The four focus groups then considered how their topic related to each of the medical conditions.

PA 13-178 states that the task force shall submit a report on its findings and recommendations to the Commissioner of Children and Families and the joint standing committee of the General Assembly having cognizance of matters relating to children, in accordance with the provisions of section 11-4a of the general statutes, not later than September 30, 2014.

All task force materials (including agendas, handouts, PowerPoints) can be found on the task force's website: www.cga.ct.gov/kid/MHTF

Findings and Recommendations

In light of the statutory charge of advising the General Assembly and the Governor using a Results Based Accountability (RBA) framework, the recommendations and findings section of this report has been designed with that framework in mind. Results based accountability is a methodology designed by Mark Friedman that has been embraced by the State of Connecticut for many years. This methodology uses data to drive thinking and actions to improve both program performance and the overall quality of life for Connecticut residents.

When using RBA one begins with the desired outcome, designing a "results statement" that reflects that outcome. From there areas of focus or "domains" are developed and eventually indicators are selected that represent measurable progress in each domain and the results statement as a whole. For the purposes of its charge, the Children's Mental Health Task Force developed the following results statement:

"All children in Connecticut have support and appropriate treatment for optimal well-being"

The three domains correlate with the previously mentioned three conditions used by the four focus groups of the task force to focus their work; Attention Deficit Hyperactivity Disorder (ADHD), Mood Disorders, and Behavioral Conduct Disorders. A full report card with indicators and population level data was not developed by this task force owing to the fact that such an endeavor is deeply time consuming and was not part of their legislative charge. However, while the findings and recommendations put forth by the focus groups are included in the appendices of this report, selected findings and recommendations have been pulled into the report to illustrate recommended action going forward in an RBA format.

One recommendation that found support in both the Nutrition and the Complementary and Alternative Treatments focus groups was increased access to vitamin and mineral supplements. This recommendation lends itself perfectly to the RBA format. Under all three domains, the indicator - pregnant women and children who have access to vitamin and mineral supplements - could be measured. Using household income as a proxy measure for individuals who currently have access, increase in access through the recommendation of making these supplements reimbursable through Medicaid could be charted and the correlation between increased access and increased mental well-being could be examined.

Another recommendation out of the Nutrition focus group, increased provisions of physical activity in schools, is also ideal for use with RBA. Physical activity is linked to improved brain function and lower rates of depression. The amount of physical activity provided by schools becomes the indicator. As the amount of physical activity provided by schools is increased, a correlation (or lack thereof) with an increase in mental well-being would demonstrate the usefulness of such programs and future policy decisions can be made accordingly.

The Psychotropic Medication focus group found itself at a different place in the RBA framework. Their research into the use of medications for the treatment of mental health issues

turned up a number of issues with data on medication use. Data sets on the number of individuals receiving a specific medication, what combinations of medications are being prescribed and by whom all proved very difficult to obtain. Access to medication, its use and side effects are all indicators that would potentially be useful in an RBA approach to children's mental well-being in Connecticut. However, no indicator is useful if the data to populate it is inaccessible. The focus group determined that, while much of this data is being collected, it is very hard to get access for the purposes of analysis.

Not all of the focus group categories lend themselves to the RBA format. The Genetics focus group in particular deals with a topic not easily measured. The overall recommendation of the Children's Mental Health Task Force in terms of genetics is for Connecticut to increase its efforts to support, both through funding and policy, studies of the links between genes and mental well-being. As whole-genome sequencing and gene co-expression analysis are undertaken more extensively and with more detail, we are rapidly approaching a time when we will have answers to our questions regarding the links between genetic and mental well-being. However, without a confirmed causal link between genetics and the three general domains of ADHD, Mood Disorders, and Behavioral Conduct Disorders, the design of measurable indicators to demonstrate whether specific programs or interventions have any effect on these links is problematic.

Based on this methodology, the following recommendations are highlighted for use with an RBA framework to achieve the results statement, "All children in Connecticut have support and appropriate treatment for optimal well-being".

- Reimbursement of vitamins and minerals for Medicaid patients
- Increase the amount of physical activity provided by schools
- Address food insecurity by increasing access to community gardens and fully utilizing money available from USDA for programs like summer meals and school breakfasts
- Reevaluate contracts between state agencies and data collection/ analysis providers to ensure simple and timely access by the State of Connecticut to its own data
- Increase support for studies of the link between genetics and mental well-being at Connecticut Universities and research sites.

Addressing the issue of Children's Mental Well-being in Connecticut is a monumental task and will surely not be accomplished through a single yearlong task force. Collaborative efforts by state agencies and private organizations must continue in order for the results statement developed by this task force to be realized. Therefore, in addition to the reported recommendations, this task force found that state agencies should move forward in contacting the Committee on Children with efforts they feel would allow them to contribute most to the larger effort of bringing support and appropriate treatment to all of Connecticut's children.

APPENDIX

A. Nutrition Focus Group Findings and Recommendations

B. Genetics Focus Group Findings and Recommendations

C. Psychotropic Medications Focus Group Findings and Recommendations

   a. American Academy of Child & Adolescent Psychiatry: "A Guide for Community Child Serving Agencies on Psychotropic Medications for Children and Adolescents", February 2012

D. Complementary and Alternative Treatments Focus Group Findings and Recommendations

APPENDIX A

NUTRITION FOCUS GROUP FINDINGS AND RECOMMENDATIONS

CT Children's Mental Health Task Force
Nutrition Sub-Committee
Recommendations to the Task Force for discussion
September 2014
Tina Fox Dugdale MS RDN RD CD-N. Member. Extension Educator UCONN.
Claire Dalidowitz MS RDN CD-N Clinical Pedi Nutrition Manager. CCMC

Quick Fixes:

-Reimburse complete vitamins w minerals for Medicaid patients

-Reimburse DHA supplementation for pregnant and non-breast-fed babies (Docosahexaenoic acid, is a type of fat abundant in the gray matter of the brain and in membranes of the photoreceptors of the eyes. Best source: mom's breast milk.). Also choline needs to be supplemented as most pregnant and breastfeeding moms are deficient and there is not adequate in most formulas (helps brain cells of fetus to develop properly; also functions like folic acid on neural tube development).

-Consider formula support for low income working families who do not qualify for WIC, or who are over WIC age and cannot afford Gastro-tube feeds.

-Continue to support breastfeeding as the perfect choice for newborn to year 1.

-Encourage schools provide PA before, during, and after school. Fill in mandated "gaps" as research continues to show connections to PA and lower rates of depression, better weight management, etc.

-Reimburse RD nutrition counseling under Medicaid funding. It's minimal and needs improvement. RDs are the food and nutrition experts, trained multiple years in the food and body sciences, and in behavior change theories.

Long Term:

-Address poverty in children. It's complicated. Paying families adequate wages with social programs built around education (budgeting, food resource management, health and wellness, prevention medicine) then we could perhaps decrease supplemental programs.

-Address food insecurity. Schools now engaging more and more in breakfast, lunch and suppers! Food insecurity is worse on the weekends, school holidays and summer. The first step is to utilize USDA monies allocated esp. for summer. CT towns leave money on the table in DC by not offering food in summer, and also by not engaging in the school breakfast program offered by the USDA.

-Address environment ie fund multiple community gardens (Knox Foundation model). Hartford has a partnership with the Mayor Segarra.

-Support pregnant and new moms. Perhaps a “pre” WIC nutrition assessment as soon as prenatal care starts. Brain cells are formed very early on in gestation, and many moms probably do not get on WIC prior to 2-3 months.

APPENDIX B

GENETICS FOCUS GROUP FINDINGS AND RECOMMENDATIONS

CHILDREN'S MENTAL HEALTH TASK FORCE
GENETICS FOCUS GROUP

Over the past ten months, the Task Force's Genetics Focus Group has gathered and exchanged reference materials relating to genetic contributions to the entire spectrum of mental disorders in children with particular attention to the three broad disorders/conditions selected for in-depth focus by the Task Force at its November 6, 2013 meeting – Attention Deficit Hyperactivity Disorder (ADHD), Mood Disorders and Conduct Disorders. We reviewed material in a standard child psychiatry test, Essentials of Lewis's Child and Adolescent Psychiatry by Yale Child Study Center professors Fred Volkmar and Andres Martin, published in 2011, current literature – in particular recent reviews – relating to the three highlighted disorders but also in other mental health disorders such as autism spectrum disorders and recent literature on advances in genetic testing including DNA microarrays, whole-exome and whole-genome sequencing. We considered both the genetics associated with specific diseases/disorders as well as the genetic and epigenetic associations with parental child raising and various environmental factors popularized under the rubric "Lifecourse Health Development". Dr. Genel also met with various experts at the Yale Child Study Center and Department of Pediatrics including Drs. Fred Volkmar, Joseph Woolston and Abha Gupta. Dr. Gupta provided a well-received "Overview of Genetics of Behavioral Disorders in Children" concentrating on her field of scientific interest, Autism Spectrum Disorders(ASD), at the Task Force's May 21, 2014 meeting.

With respect to the three specific disorders selected by the Task Force, it has been long recognized that there are strong familial associations although specific genetic etiologies in a traditional gene-clinical disorder model have for the most part been limited to specific disorders such as in Rett Syndrome and MECP2 mutations and Fragile X Syndrome and FMR1 mutations in ASD, as described by Dr. Gupta. Specific genes have been identified which convey increased risk in more well defined mental health disorders such as bipolar 1, but the clinical heterogeneity of the disorders selected by the Task Force, the host of mental health disorders in general and their clinical overlap make genetic cause and effect associations unreliable except in well-defined genetic disorders or in specific families. In all of these clinically defined disorders it is postulated that the genetic liability instead reflects the collective action/interaction of many genes of individual small effect rather than the effect of any specific genetic mutation/variation.

Among the three disorders selected, ADHD is one of the more common with an estimated 8-12% worldwide incidence and has one of the highest heritability, estimated to approach 75% in twin studies with significantly higher concordance in monozygotic than in dizygotic twin pairs (Goldman, Genel et al, 1998). While a number of specific genes have been reported, none meet a rigid significance threshold for genome-wide association. In addition there is frequent clinical overlap with affective/mood disorders, childhood conduct disorder, personality disorders and substance abuse. ADHD is particularly associated with conduct disorders (~50% of cases per Volkmar & Martin), anxiety disorders (~25-30%) and mood disorders, especially in older children. A overview editorial in a symposium issue of the American Journal of Medical

Genetics concludes that the advent of whole exome and whole genome sequencing "promise to provide further understanding of the likely genetic architecture of ADHD, how large these effects can possibly be, and the extent to which heterogeneity is inhibiting our capacity to understand ADHD at a neurobiological level". (Neale & Faraone, 2008)

Among the entities generally classified under the broad category of "mood disorders", depressive disorders and classic bipolar illness have very strong hereditary features, although distinct separation is often difficult in childhood and a precise diagnosis per standard criteria may be difficult (Volkmar & Martin). Much as in ADHD, depressive disorders have significant concordance of ~ 40-65% in twins, higher in identical twins. There are also strong environmental factors, including economic adversity, neglect & abuse, loss of a parent or primary caretaker. Classic bipolar illness is highly inheritable, estimated to account for 60-85% of variance in risk but the clinical diagnosis of mania, particularly in pre-adolescent children, is "complex and controversial" (Volkmar & Martin). A recent review concludes that "the validation of any genetic signal is likely confounded by genetic and phenotypic heterogeneities which are influenced by epistatic, epigenetic and gene-environment interactions" (Lee , Woon et al, 2011). Another review (Barnett & Smoller, 2009) states "it is now widely accepted that the genetic liability to bipolar disorder reflects the action of many genes of individually small effect", similar to ADHD.

Similarly there appears to be a strong hereditary component to the etiology of conduct disorders and the related category of oppositional defiant disorders, although with gathering evidence of significant interaction and modification by environmental factors, perhaps modified by epigenetic mechanisms. According to Volkmar & Martin, there is an estimated hereditable component of "about 50%" and "genetic factors can interact with environmental factors and…. appear weaker in children coming from supportive environments". A classic 2002 paper in Science (Caspi, McClay et al, 2002) found association with a functioning polymorphism in the gene encoding monamine oxidase A, a neurotransmitter-metabolizing enzyme. Maltreated children with high MAOA expression were less likely to develop antisocial behavior. Another study found a modest association of violent behavior and serotonin dysfunction mediated by genetic polymorphisms associated with serotonin transport (Retz, et al, 2004).

There is increasing evidence for modification of genetic and biologic physiology and neurobiology by environmental mechanisms, perhaps through epigenetic mechanisms. An excellent review of "The Lifelong Effects of Childhood Adversity and Toxic Stress" from the American Academy of Pediatrics summarizes the ecology of childhood developmental outcomes and life course trajectories in an "ecobiodevelopmental framework" (Shonkoff, Garner et al, 2012). Much of this is modeled on the Lifecourse Health Development Model championed by Neal Halfon and collaborators (Halfon, Larson et al, 2013). For example, a recent study published only this year in the Proceedings of the National Academy of Sciences (PNAS) demonstrated correlation between stressful home environments and decreased length of chromosome endings(telomeres) that is moderated by genetic variation in brain serotonin and dopamine(Mitchell, Hobcraft et al, 2014).

In summary, while there is increasing evidence linking genetic influences on various mental health disorders affecting children, with the exception of some well-defined genetic disorders,

these associations are varied and intermixed with environmental associations, some of which have yet to be defined and fully characterized and likely involve a complex interplay of nature and nurture.

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September, 2014

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APPENDIX C

PSYCHOTROPIC MEDICATIONS FOCUS GROUP FINDINGS AND RECOMMENDATIONS

Psychotropic Medication Focus Group Recommendations

1) Studying psychotropic medication use in children/adolescents was difficult because the data were largely unavailable and very difficult to obtain - improvements in data access for stronger data analysis opportunities must be be made. We need to be able to not only know how many individuals are receiving any particular medication of interest, but we should also be able to understand what combinations are being used as well as the total # of medications per child/adolescent. Lastly, we need to be able to understand who is prescribing the medications and if the patient has a single provider, or multiple providers.

2) Future efforts should look to use the attached AACAP document as a resource.

3) DCF's Psychotropic Medication Advisory Committee should be the vehicle for all the medication tasks outlined in the Task Force's mission, and that monetary and personnel support be granted to PMAC to assist in data collection and data analysis.

(see attached AACAP, A Guide for Community Child Serving Agencies on Psychotropic Medications for Children and Adolescents)

AMERICAN ACADEMY OF CHILD & ADOLESCENT PSYCHIATRY

WWW.AACAP.ORG

A Guide for Community Child Serving Agencies on Psychotropic Medications for Children and Adolescents

February 2012

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The American Academy of Child and Adolescent Psychiatry is the leading national professional medical association dedicated to treating and improving the quality of life for children, adolescents, and families affected by these disorders. Composed of over 7,500 child and adolescent psychiatrists and other interested physicians, our members actively research, evaluate, diagnose, and treat psychiatric disorders and pride themselves on giving direction to and responding quickly to new developments in addressing the health care needs of children and their families.

**The content of this publication does not necessarily reflect the views, opinions or policies of the Center for Mental Health Services, the Substance Abuse and Mental Health Services Administration or the Department of Health and Human Services.

INTRODUCTION

This document, developed by the American Academy of Child and Adolescent Psychiatry (AACAP), provides information to service providers in community-based systems of care, and families, regarding the role of psychotropic medications in a youth's treatment plan. It will give guidance to service providers on what to look for in the youth and how best to collaborate with psychotropic medication prescribers before, during, and after a course of treatment with a psychotropic medication.

In preparation for developing this document, child serving agency providers from across the country from child welfare, education, juvenile justice, substance abuse and developmental disabilities were asked what questions they, and youth and families they work with, have about the use of psychotropic medications for children in community-based systems of care. These questions lead each section in which they are answered. The information in this document is a compilation of AACAP policy, including policy statements, Practice Parameters, practice modules and medication guides (see references). The document addresses the following areas:

- The Context for Prescribing Psychotropic Medications
- Phases in Treatment
- Issues in Prescribing
- Considerations for Child Serving Agencies
- Sources of Information about Psychotropic Medications
- References
- Addendum: Internet Resources about Psychotropic Medications for Families

Psychotropic medicines are taken for the purpose of improving the emotional and behavioral health of a child or adolescent diagnosed with a mental health condition.[1] There is evidence that psychotropic medications are both over and underprescribed for children and adolescents. Overall, the use of psychotropic medications in children and adolescents has been increasing over the past 20 years, as evidence to support effectiveness when used appropriately has increased. Prescribing psychotropic medications for children and adolescents requires a competent prescriber, optimally a child and adolescent psychiatrist, with training and qualifications in the use of these medications in this age group.

Psychotropic medications are only one component of a comprehensive biopsychosocial treatment plan that must include other components in addition to medication. A comprehensive treatment plan requires a collaborative, team effort. The term biopsychosocial recognizes the three domains that impact a youth's emotional and behavioral well-being that must be considered in creating a comprehensive treatment or service plan:

- "Bio" refers to biological, including physical health and genetic factors. Psychotropic medications affect biological factors by altering the levels of chemicals in the brain that help to regulate the activity of neurons (brain cells) that determine emotions and behavior.

- "Psycho" refers to psychological factors in the youth that contribute to emotional and behavioral functioning including feelings and thoughts, including goals and understanding of self and the youth's environment.
- "Social" refers to the environmental factors that influence a youth's functioning, such as family circumstances and relationships and other resources in the community, including those provided by child serving agencies as well as natural supports. Evaluation of history of trauma and disrupted attachments is particularly important to obtain within the social domain. Natural supports are people such as other family members, friends, including peers of the youth and members of the community such as members of the family's faith community.

Professionals in child serving agencies can best support the treatment of youth with a mental illness by ensuring access to a comprehensive diagnostic assessment including biopsychosocial formulation conducted by a qualified licensed mental health professional in collaboration with the youth and the family. Discussions and use of psychotropic medication should recognize and address an individual's and family's cultural beliefs. A comprehensive assessment will include options for support and treatment that extend beyond just prescribing medications.[2,3]

THE CONTEXT FOR PRESCRIBING PSYCHOTROPIC MEDICATIONS

Prescribing psychotropic medication is greatly influenced by the context in which the prescribing occurs. Individuals create desired change, not medication. Medication removes physiologically-based obstacles to change, enabling the individual's own efforts to be more effective. Even with medication, clinical disorders may remain difficult to treat.

Frequently Asked Questions

- *How can professionals in child serving agencies best support the treatment of youth with a mental health disorder?*
- *The first line of treatment for a child often seems to be medication. How can we look at other options besides psychotropic medications?*
- *Should a child be on medications if they are difficult to manage, or are there times a difficult to manage child should not be on a medications?*
- *If a child goes on a medicine, will they be on it forever?*
- *What is the training and expertise of the child psychiatrist? What can they help us with?*

Many youth benefit from psychotropic medications used as part of a comprehensive treatment plan. Treatment with psychotropic medications allows these youth to remain in their homes and schools and make best use of community treatment interventions and natural supports. Medication may be overprescribed when there is insufficient attention paid to other supports and services that may benefit the youth. Medications may also be underprescribed if a youth has not had access to any mental health assessment and/or families are unable to follow-up with mental health treatment, including medications. Medications may also be overprescribed or underprescribed when prescribers have not had sufficient training in use of psychotropic medications in youth but are practicing in an underserved area where access to prescribers with expertise in treating youth with psychopharmacology, such as child and adolescent psychiatrists, is extremely limited and there is pressure to prescribe because of very challenging or dangerous behaviors in the youth. Active pursuit of alternative interventions to medications are especially important when there are serious side effects that can occur, such as weight gain or movement disorders, especially when medicine is prescribed over an extended period of time.

It is always acceptable for a parent or legal custodian to seek a second opinion about their child's treatment plan, including medication use. There are a number of scenarios that may be indicative of the need for a second opinion. These scenarios include when there is concern about the advisability of initiating a trial of medication; when treatment with medicine has not resulted in improvement within two months of starting the medicine; any time a parent has concerns with the medications and talking with the prescriber about these concerns has not helped[4]; or when a youth is being treated with benzodiazepines or narcotics for more than a month. Parents should be encouraged to discuss their concerns with the primary prescriber first, before requesting the second opinion. The prescriber should not be upset by this and should help with obtaining and informing the second opinion.

Prescribing Basics

The benefit from the medicine must be evaluated against the potential unwanted side effects, both biological and psychosocial, when considering whether a medication should be prescribed.

Parents and guardians and the youth must be informed about the potential risks as well as the benefits when giving consent and assent for initiation of a trial of psychotropic medications.[3]

A child who is difficult to manage or has a mood disturbance may benefit from medication if there is scientific or clinical evidence that the medication is safe and effective for the specific diagnosis or behavioral indication. When youth are on psychotropic medications over extended periods of time, it is important periodically, especially when the child is doing better, to cautiously try to decrease the dose to the lowest effective amount. Youth generally should not be abruptly discontinued from taking psychotropic medications that they have been on for any extended period of time: their brains have become used to the medicine and may react adversely with sudden changes in blood level.[5]

Prescribers of psychotropic medications to youth must be licensed to prescribe and have knowledge about indications for prescribing the medication as well as potential benefits and risks associated with taking the medication.[3,6] Prescribers include physicians, advanced practice registered nurses, physician assistants, and in some states psychologists who are licensed to prescribe. Child and adolescent psychiatrists are the most trained providers to prescribe these medications. They have completed four years of medical school, three or four years of general (adult) psychiatry residency training, and two years of child and adolescent psychiatry residency training. Child and adolescent psychiatrists have extensive training in providing a comprehensive biopsychosocial assessment and have the most training and expertise among prescribers regarding the use of psychotropic medications.

PHASES IN TREATMENT WHEN MEDICATION IS PART OF THE PLAN[3]

First Concerns

When a youth is identified as having emotional or behavioral difficulties that are not responding to help offered by the youth's primary care provider (PCP), parents, school staff, or others in the community, the youth and family should consider a referral for a mental health evaluation. The youth's PCP should be helpful in identifying resources to provide this evaluation. Mental health evaluation should be provided by licensed mental health professionals. The mental health evaluation may include assessment for indications for a trial of a psychotropic medication. Indications for a trial of psychotropic medications must be identified by a qualified health care provider licensed to prescribe medications.

Child and Adolescent Mental Health Evaluation

A mental health evaluation that includes evaluation for medication treatment should identify the needs best addressed by medication as well as the needs best addressed by other psychosocial treatments. An evaluation also needs to identify medical and psychosocial factors that may interfere with an adequate and safe medication trial.

Frequently Asked Questions

- *Why don't prescribers assess the child or adolescent before drugs are administered?*
- *How should psychotropic medications be monitored?*
- *How can professionals and parents learn about interactions of psychotropic medications with other medications, for example allergy or asthma medications?*
- *If a parent agrees to medicine for their child, are they sending a message that it is okay to use (illicit) drugs?*

Interviews with the youth and family/caregivers are necessary. In order to understand the many possible reasons for the youth's symptoms, information should be gathered including the history of current symptoms and concerns, the youth's developmental, medical and mental health history, strengths and interests, the family's situation regarding supports and stressors, the youth's education status, and other community and environmental factors impacting the youth and family such as natural disasters. The records of previous medication and nonmedication treatment should be reviewed along with discussion with other professionals involved with the youth and family. A review of the youth's medical history is done with attention to medical conditions such as obesity or diabetes that could affect medication use. A pediatric examination and/or laboratory work may be necessary before starting a medication trial.

A plan for treatment of the youth's identified needs should include nonmedication interventions as well as medication, if appropriate, and must be developed with the youth and family based on the best available research evidence and the family's preferences.

Medication Trial

Informed consent and assent for the use of medication is necessary. This means that the prescriber provides feedback about the diagnosis and educates the youth and family regarding the youth's diagnosis and the proposed treatment and monitoring plan. The parents must be

informed and have a full understanding of the risks and benefits of any medications as well as options for alternative or complementary treatments before they give their consent to the prescriber for a medication trial.

While consent for a trial of medicine must be obtained from parents and guardians, it is also necessary for the youth to give assent. The youth needs to have a developmentally appropriate understanding of why the medication is being prescribed and its risks and benefits. If the youth refuses to start a trial of medicine, it is not advisable to try to force the youth to take medications unless the situation is an emergency and the safety of the child or others is under immediate threat.

All medications have side effects which can sometimes be serious. Deciding whether to take a medicine requires knowledge of both the likelihood of benefit as well as the risks of harm from taking a medication. Some medicines begin working right away while other medicines can take several weeks. To work best, the dose of medicines must be high enough, but without causing side effects that are worse than the benefit that may come from the medicine. Determining the best dose of a medicine requires review by the prescriber in consultation with the youth and family and others on the treatment team regarding the benefit and side effects at each dosing level.

Follow-up After a Trial Has Been Initiated

Follow-up, in person or by phone, after starting a medicine should ideally occur within two weeks and at least monthly until a youth's symptoms are improved and stable on the medication. Once stable, visits can be less frequent and may be scheduled based on the needs of the individual youth and family. Follow-up assessment should be augmented by input from providers involved with the child.[3] Lab tests including medication blood levels and other blood tests may be important for monitoring dosage and side effects.

As dosage of medicines are being increased or reduced, more frequent follow-up appointments may be necessary. Medicine dosages should not be changed by the parent without discussing with the prescriber because both increasing the dose, as well as sudden discontinuation, can cause harmful or even dangerous side effects.

If the youth is taking more than one psychotropic medication at a time, medicine dosages should be changed only one at a time. When possible, dosage changes should be made when the rest of the youth's life and routine are stable and not when there are changes in schedule such as the start of a new school year or when there are other major life changes going on such as a medical illness or a move.

If emotions or behavior in the youth change when the youth is taking a medicine, one should not assume that the change, either for better or worse, is necessarily due to the medicine or due to the medicine alone. Emotions and behavior can be greatly affected by other factors, including stress, changes in the environment, physical illness, and specific efforts by the youth, family and other

supports to improve functioning. Rating scales or logs documenting the frequency of symptoms and/or side effects are often helpful in monitoring response to medication.

Medication Tapering and Discontinuation

If the youth's behavior has been stabilized, and circumstances in his or her environment are also stable, a trial of medication reduction or discontinuation to determine if the medicine is still needed and/or could be given at a lower dose should be considered. Before deciding a medicine is not helpful, it is important to be sure that the trial has lasted long enough and at a high enough dosage to determine if it will work. This can take up to two months for some medicines such as antidepressants.

When a youth has been taking a medicine for a long period of time, the brain may have become used to it, and abrupt discontinuation can cause side effects that should not be mistaken to mean that the medicine is still needed. For this reason, a decrease in dosage or discontinuation must be conducted gradually. This does not mean that the youth is addicted to the medication but rather that the youth's brain has become used to the medication and that discontinuation must occur gradually so that the brain has time to adjust.

Sometimes when a youth is having a particularly challenging time, especially if requiring psychiatric hospitalization or acute residential treatment, a "medication washout" may be undertaken in which the youth is carefully taken off all medications to confirm what symptoms remain and to make sure the medications are not themselves causing any of the symptoms. The youth and family may need to be seen more frequently by the prescriber during the discontinuation phase to be sure symptoms do not return. After a youth has been discontinued from a psychotropic medication, it is important to have follow-up with the prescriber to confirm that gains have been sustained.

ISSUES IN PRESCRIBING

Factors a Provider Considers When Prescribing Medication

The prescriber evaluates and considers the scientific and clinical evidence supporting the indication of treatment. Mood disorders, anxiety disorders, psychosis, and attention-deficit/hyperactivity disorder (ADHD) are examples of disorders that have strong evidence supporting the use of medication.[3]

Food and Drug Administration Approval

The Food and Drug Administration (FDA) is responsible for the regulation of food and drug safety in the United States. FDA approval is a complicated and lengthy process. Generally, medication is granted FDA approval when it is found to be safe and effective for a particular diagnosis at a given dosage range for people of a particular age range as determined by evidence based research.[5]

Frequently Asked Questions

- *Have studies established that the use of psychotropic medications in pre-school children is safe and effective?*
- *Are all psychotropic medications approved by the FDA for adults also approved for youth?*
- *How do I know if a behavior is a result of a side effect from a medication?*
- *Can psychotropic medications make the child angry and more aggressive?*

When a medication is not FDA approved it is considered "off label". It is important to note that the absence of FDA approval also does not indicate that a medication is not effective and safe. Pharmaceutical companies may not choose to dedicate the necessary resources to seek FDA approval. Medication used in the treatment of youth with mental illnesses is often used "off-label", as is frequently the case in the medication treatment of pediatric physical illness. There are many medications approved for adults that are used off-label for youth. Off-label prescribing is very common, and the parent or guardian should ask the youth's provider about the supporting evidence and agreement among other doctors that the medication is effective and safe.[3,5] Such uses may include indications, dosages or age ranges which differ from those formally specified by the FDA. It is ethical, appropriate and consistent with general medical practice to prescribe medication off-label when clinically indicated. The prescriber or pharmacist can advise whether a specific medication is FDA-approved.

Some psychotropic medications have **FDA Black Box Warnings.** Medicines with black box warnings are still FDA approved, but their use requires particular attention and caution regarding potentially dangerous or life threatening side effects. Selective Serotonin Reuptake Inhibitors (SSRI's) carry a black box warning that they may cause suicidal ideation or behavior, although the most recent review of the evidence is not conclusive that SSRIs increase suicidal behavior. Families should work in consultation with their child's physician or other mental health professional to develop an emergency action plan, called a "safety plan". This is a planned set of actions for the family, youth and doctor to take if and when the youth has increased suicidal thinking. This should include access to a 24-hour hotline available to deal with crises. AACAP recommends that family members discuss this with the provider if they are uncertain about a black box warning.[7]

Preferred Drug Lists

In some states, Medicaid, like other insurance companies, has a list of medications that patients can obtain for free or at a reduced cost. These are called Preferred Drug Lists (PDL). PDLs serve to contain costs and seek to assure that prescribed medications are in line with typical prescribing practice. PDLs often use many generic medications that have a similar composition to the brand-name medications. This is comparable to cooking with a brand name product versus a grocery store brand that is often cheaper – that is, the ingredients are the same, but they occasionally "cook differently". Generic medications offer a viable alternative to a brand name medication at a potentially reduced cost. The use of generic medications should be discussed with the prescriber.

PDLs are often developed for adults and youth by insurance companies and other concerned parties to identify what medications cost the least and work the best. Medication options on most PDLs will be acceptable for many people. However, the doctor may decide to prescribe a medication that is not on the PDL (e.g., a youth has tried the approved medications and they have not worked, or the youth has side effects with the medications on the PDL). When the prescriber decides to prescribe a medication that is not on the PDL, he/she may have to obtain special permission (prior approval) for the youth to take it in order for the insurance company to pay for the medication.

Risk for Misuse of Medication

There are some medications that have the potential to be overused by youth, sold to others in the community, or taken in a way that was not prescribed. The prescriber should tell parents and guardians if the youth is taking one of these medicines and family members should feel free to ask.[4]

The prescriber may take into account the youth's past history (for example, a history of substance abuse) and environment when considering this possibility. The prescriber should also discuss how the medication is stored and dispensed to reduce the risk of medication misuse.[4] However, a history of substance abuse does not necessarily mean that a youth should not be prescribed a particular medicine. With appropriate monitoring, medication use can still be an important component of treatment. Youth, family members, and prescribers should share concerns and work together regarding concerns about substance abuse and prescribing of psychotropic medications. Severe substance abuse and chemical dependence in adolescence may be a chronic and relapsing disorder. Parents should ask what treatment services are available for continued or future treatment. If questions or doubts persist about either admission to a substance abuse treatment program or about a denial of treatment, a second opinion may be helpful.

Many parents express concern that if they agree to put their youth on psychotropic medication, there will be a risk of later substance abuse.[7] There is no scientific evidence to support this. In fact, there is evidence that children with ADHD who are prescribed stimulants are actually at lower risk of subsequent substance abuse, when compared to children with ADHD who are not prescribed stimulants.[8]

Side Effects

Side effects generally fall into three categories: minor (such as headaches), moderate (such as decreased appetite), or severe (such as obesity or seizures). After a medication trial is started, the prescriber should ask about any side effects, and the youth and family members should alert the prescriber if there are concerns about side effects.[4]

A common potential side effect of some psychotropic medications is a change in appetite and weight (e.g. stimulants, antipsychotics, and mood stabilizers). Whereas loss of appetite and weight loss due to stimulants tends to decrease over time and is clinically significant in only a small minority of youth, weight gain due to antipsychotic and mood stabilizer medications is very often significant and does not decrease significantly over time. It is important for the prescriber to monitor height/weight and monitor blood tests for medication side effects.[4] The prescriber should emphasize healthy eating habits and exercise as well. For youth who are overweight or obese, the prescriber should take into account medications and the side effect profile.[3] Prescribers should discuss options to reduce the risk of weight gain.

Youth can have side effects to psychotropic medications that result in a change in behavior. For example, restlessness can occur as a side effect of antipsychotics, and irritability can occur as a side effect of stimulant medications. If a youth, family member, or guardian is concerned about this possibility, it should be discussed with the prescriber.

Preference of Family Members and Youth

Cultural factors and family preferences are important considerations in making decisions about prescribing. The prescriber should discuss the opinions and beliefs about medication use with family members and youth. In addition, the prescriber considers scientific evidence and clinical experience with the safety and efficacy of the medication. The doctor or other prescriber should be respectful of the preferences and priorities of families and youth, while also sharing his/her expertise with the youth and family.

Families may be using or may decide to try complementary and alternative medicines (CAM). CAM is defined as any healing practice that does not fall within the realm of traditional Western medicine. It is important for parents to tell their child's prescriber about use of CAM to prevent possible interactions with prescribed medications (e.g. St. John's Wort). In addition, parents should inform the child's prescriber about using any over the counter medicines and dietary restrictions, such as casein and gluten-free diets, in order to avoid any adverse health effects. It is important for the prescriber, parents, and the youth to have an open discussion about how the prescribed medicine complements other supports and services identified in the treatment plan.

Barriers to Follow-Up and Medication Adherence

Families with multiple stressors may find follow-up difficult due to conflicting demands and/or logistical difficulties (e.g. transportation, work/school conflicts). Difficulty with follow-up and adherence should not be assumed to be "resistance" or some other lack of motivation for treatment by the youth and family. Lack of adequate informed consent or assent can also present a barrier in adequate follow-up as well as cultural differences regarding perception of psychiatric

treatment.[1] It is important for providers to understand the specific reasons why a youth and family may be having difficulty with follow-up and adherence.

Transition Age Youth

Young adults over the age of 18 years are legally able to consent for themselves regarding any treatment recommendations, including psychotropic medication. Because young adulthood is a critical age of onset for many serious and persistent mental illnesses, these young adults may need additional support in making informed decisions on their own.

Polypharmacy

Polypharmacy is the prescribing of more than one psychotropic medication at the same time. There are a number of circumstances when polypharmacy occurs in youth. For some youth, an optimal medication regimen does involve multiple medications. For example, in a youth with more than one psychiatric diagnosis, the use of more than one medication may be needed. In some cases, a second or third medication can be used to "augment" or enhance the first medication. In a few cases, there is evidence supporting the use of more than one psychotropic medication in specific circumstances, such as "treatment-resistant" conditions (e.g. clonidine to augment the effect of a stimulant or atomoxatine in the treatment of ADHD).[3]

There are nonoptimal circumstances that result in polypharmacy, circumstances that reflect fractured care or nonevidence-based prescribing. For example, when a youth has had multiple providers, new providers less familiar with the youth may be uncomfortable discontinuing a particular medicine. Some prescribers may start two or more medications simultaneously. This practice is not generally recommended; there is little to no support in the literature for initiating more than one medication at the same time because it can be difficult to know which medicine is helping or causing side effects. At other times, a lack of diagnostic clarity can result in adding multiple medications in an attempt to treat difficult symptoms.

It can be difficult for parents and guardians to tell if polypharmacy is optimal or nonoptimal for a particular youth. Whenever multiple medications are used, there should be a rationale provided to the family or guardian as to why each is prescribed. The prescriber should always assess the risk of interactions between the medications, and assess any side effects of the combination of medications. Caregivers should be aware that the use of more than one medication can result in increased side effects and risks, but may also at times help improve outcomes for a youth.. The use of polypharmacy may be helpful to support treatment, but should not just be a response based on the failure of an initial medicine to be helpful. Before additional medications are prescribed, a careful review of other treatment options that may be helpful to the youth, in close involvement with the youth, the youth's family, and the treatment team is necessary. Child and adolescent psychiatrists are uniquely positioned to provide both psychotropic advice as well as expertise on other treatment options within the child-serving systems.

Medications in Children Under Five Years of Age

Young children are often more sensitive to medication side effects as compared to older youth. Any consideration of such medication in a child or infant below the age of five should be very carefully evaluated by a clinician with special training and experience with this very young age group.[5] The developmental considerations for prescribing psychopharmacological treatment to preschool children should be reviewed.[9] Given that there is a limited evidence base for efficacy of psychotropic medications in young children, medications should be used conservatively in this group. Developmental interventions (e.g., speech therapy or occupational therapy) and psychosocial interventions (e.g. parent-child therapies) should be prioritized.[1,5] Antipsychotic medications should be used with extreme care in young children because of their potential for serious side effects. Very limited evidence exists for use of antipsychotic medications in young children. Evidence-based indications are limited primarily to use in autistic children and children with severe developmental disabilities who have serious aggression that has not been responsive to psychosocial treatment interventions. There is no evidence establishing benefit of mood stabilizer medications such as valproic acid and carbamazepine for behavioral symptoms in young children.

Importantly, there are circumstances when psychotropic medications for children under the age of five can be very helpful in the context of a complete treatment plan. There is evidence to support the use of psychotropic medications in young children in specific circumstances (e.g., stimulants for ADHD after behavioral treatments have been tried). In preschool children carefully diagnosed to have ADHD, stimulants have been found to be helpful in treating their ADHD symptoms. However, side effects including changes in mood with mood liability and irritability are more common in young children than in older children.

Workforce Considerations

The lack of an adequate workforce trained to treat youth with mental illnesses is a barrier to appropriate treatment. Too few medical professionals are trained to prescribe psychotropic medications, increasing the need for concern. Child and adolescent psychiatrists are among the few medical professionals with training and qualifications in the use of these medications in this age group. Consultation/collaboration programs between child and adolescent psychiatrists and primary care physicians and pediatricians have been established throughout the country to help alleviate the workforce demand and assist primary care physicians and pediatricians with the development of treatment plans and medication management. The use of telepsychiatry is another option to assist with workforce demands.

Considerations for Community-Based Child Serving Systems

There are some considerations regarding psychotropic medications and involvement of prescribers that each child serving system can help promote:

1. the use of psychotropic medications within a comprehensive biopsychosocial treatment/care plan, based firmly on the broad framework of system of care values and principles.[1-4,10,11]
2. the development of policies and monitoring systems regarding patient safety and the appropriate use of psychotropic medications in children and youth.[1,5]
3. the responsiveness of prescribers to questions regarding the role of psychotropic medications in the overall treatment plan.

Frequently Asked Questions

- *As a juvenile probation officer how can I work together with the child psychiatrist?*
- *What should we (child serving system professional staff) say when parents ask questions about psychotropic medications?*
- *Who gives consent regarding medication use when a youth is in state custody?*

When psychotropic medications are part of a youth's treatment plan, it is essential that the prescriber of these medications participate actively with the treatment team. Treatment planning should include discussions by the whole team about the assessment of target symptoms, behaviors, function, and potential benefits and adverse effects of treatment options. The prescriber should be expected to advise on the efficacy of medications and interactions between pharmacotherapy and other treatment modalities and strengths-based activities. Pharmacotherapy in systems of care should focus on helping the youth function more effectively in the home and community, as well as addressing symptom relief. When psychotropic medication is indicated there should be informed guardian consent and youth assent with consistent medication monitoring protocols and procedures.[4,6] This will allow for all parties to have a clear understanding of why medication is being used and the plan for follow-up.

Child and adolescent psychiatrists, having greatest expertise on the use of psychotropic medications, should promote clinical standards for effective pharmacological therapy, including the use of evidence-based systematic assessment and symptom-rating tools and the use of evidence-based pharmacological interventions. They should become actively involved in quality assurance and development of policies regarding pharmacological decision making, practices, and therapies. Child and adolescent psychiatrists, have a responsibility to participate in the development of policies related to the use of these medicines within child serving systems. Child and adolescent psychiatrists and other prescribers should also promote and implement training in psychopharmacotherapy for nonmedical mental health professionals and staff so as to better support the practice of psychopharmacotherapy and eliminate the stigma about the use of psychotropic medications.[1] As noted previously, child and adolescent psychiatrists can provide expert consultation and input on the broader biopsychosocial formulation and treatment planning for youth within the child serving systems, beyond input limited to psychopharmacological treatment options.

Special considerations

As child serving systems work with many youth and families, special situations can occur that affect the processes related to psychotropic usage. For example, for youth with more complex mental health needs resulting in more severe functional impairment, such as those suffering from the effects of trauma and/or disrupted attachments, there is a need to seek additional resources beyond treatment with psychotropic medications. These additional resources are best identified and coordinated by a youth and family team, utilizing "wraparound" service planning. This is a community-based approach to provide comprehensive, integrated services through inter-professional collaboration and collaboration with families. This planning process involves the youth and family and results in a unique set of strength-based and culturally-based community services and natural supports individualized for that youth and family that complement medications to support the best functioning of the youth.[13]

There are a host of child serving systems in the U.S. including primary health care, education, mental health, child welfare, juvenile justice, early childhood services, developmental disabilities and substance abuse treatment services system. There are specific issues related to use of psychotropic medications and coordination of care in each system.

Primary Health Care System

Approximately 75% of youth with psychiatric disorders are seen for initial assessment in their primary care provider's office. As a result, primary care providers (PCP's) represent the front line in the effort to identify, diagnose and treat psychiatric disturbances in youth.[14] PCPs include pediatricians, family medicine physicians, advanced practice registered nurses, and physician assistants. PCPs often treat psychiatric disorders in children and youth with psychotropic medications. When needed, PCPs can seek consultation with a child and adolescent psychiatrist to address issues related to the usage of psychotropic medications while continuing to treat the child or youth themselves. At other times the family and PCP may decide that a referral to a child and adolescent psychiatrist to take over psychotropic medication management is indicated. In all these scenarios, there should be active collaboration and coordination between the PCP and all mental health providers, and other child serving systems such as schools, child welfare, the juvenile justice system, and other critical arenas in the life of youth. The child and adolescent psychiatrist can fill the dual role of the medical specialist devoted to the diagnosis and treatment of mental disorders and as a bridge to community-based mental health and child serving systems.[15]

Education System

Many medications are given at home before a child goes to school. However, some children and youth need to receive medication during the school day. Schools typically have a policy for medication administration and this policy should be understood by all parties. All parties need to be sensitive to the stigma that the child or youth may have regarding taking medicine at school and explore ways to minimize this stigma. Child and adolescent psychiatrists are trained to consult with school personnel on individual case consultation and medication administration/management.

Mental Health System
Public mental health systems are responsible for addressing children and youth with severely impairing and chronic mental health disorders; those without access to services because of poverty or other constraints; and those who are involved in other public sector systems such as child welfare, juvenile justice, special education, and developmental disabilities, among others.[16] Child and adolescent psychiatrists have broad training in multiple areas of development and developmental psychopathology and their biopsychosocial knowledge can be used most effectively as an integral part of the ongoing assessment and treatment process.[1] Pharmacological management may be provided by the child and adolescent psychiatrist.

Child Welfare System
The child welfare system, mandated by the federal government, involves services and supports to ensure the safety, permanency, and well-being of children, and to strengthen families.[17] Studies indicate that 60-85% of the children being served by the child welfare system meet criteria for a psychiatric diagnosis.[18] In many states there is a disproportionate number of children in foster care who receive psychotropic medication. To assure the use of appropriate standards of care in treatment, in 2011 the federal government has mandated states to develop and implement consent, authorization, and monitoring procedures for the use of psychotropic medications for children in state custody.[12] Child and adolescent psychiatrists should be a part of developing and implementing these systems. AACAP has developed guidelines to assist states with developing these systems.[12]

If the child or youth is placed in state custody, as a result of their involvement in the child welfare system there are multiple issues regarding psychotropic usage to consider: "Unlike mentally ill children from intact families, these children often have no consistent interested party to provide informed consent for their treatment, to coordinate treatment planning and clinical care, or to provide longitudinal oversight of their treatment. The state has a duty to perform this protective role for children in state custody. However, the state must also take care not to reduce access to needed and appropriate services."[12]

Juvenile Justice System
Youth involved with the juvenile justice system have an increased incidence of mental and substance-related disorders compared to other youths.[19] Studies show that as many as 75% of juvenile offenders have one or more diagnosable psychiatric disorders.[20] Juvenile justice staff members should be aware of this issue and help coordinate referral for these youth to receive evaluations for these disorders, as needed. Child and adolescent psychiatrists can provide training to professionals in the juvenile justice system regarding monitoring for mental health conditions and consideration of benefits and risks of psychotropic medications in the care of youth in juvenile justice facilities.

Early Childhood Services System
Pediatricians, family medicine physicians, and other prescribing providers (APRN, PA) are most often the first contact for young children, and their families for health care and when there are suspected developmental delays, emotional, and/or behavioral problems. Child and adolescent

psychiatrists may be consulted in the process as needed by the members of the primary health care team. There are multiple components in the early childhood services system including Early Intervention, Special Education services, Head Start, primary health care, child care, family court, developmental therapy services, and mental health services. Navigating the service system for young children can be a complex task, as often the elements of the service array for younger children are administered by several state agencies. In addition, the administrative structure for many of these services may vary from state to state.[21] Therefore, it is important for parents/guardians to have guidance while working with these multiple systems and agencies. If psychotropic medications are also recommended there needs to be a clear reasoning and diagnosis and target symptoms identified, and the provision of frequent monitoring by the prescribing provider.[5] For further discussion of the issues regarding the use of psychotropic medications in young children please see the section on Issues in Prescribing.

Developmental Disabilities System

Youth with developmental disabilities may have higher rates of comorbid medical illnesses that may impact prescribing psychotropic medications. Medical illnesses in youth with developmental disabilities may present first as a change in behavior. These youth may have higher risk of medication side effects and a limited ability to bring these side effects to the attention of providers. Due to higher risk for accidental injury, these youth should have a careful assessment of safety risk at beginning of treatment and regularly during treatment.[22] Many genetic disorders have specific behavioral presentations that will require psychiatric treatment. These youth may benefit from the involvement of multiple service agencies such as occupational therapy, physical therapy, speech therapy, and special education services. These services should be actively considered in addition to or instead of medications for youth with developmental disabilties.[1] The prescribing provider who works with the child/youth and family needs to be aware of the many service transitions in the system (some required and others due to system issues) and should advocate for continuity of care throughout childhood and adolescence for the child's many services, including medication management. Furthermore, coordination of care between the multiple agencies and providers is essential, including the potential for multiple medical and developmental therapy providers.[22]

Substance Abuse Treatment Services System

Substance use disorders in youth are associated with psychosocial and academic impairment.[23] Many studies have noted the high rates of co-occurring mental health disorders with youth who have substance use disorders. When recommending psychotropic medication as part of the treatment plan the prescribing provider should recognize the potential for adverse effects when combining the use of substances and prescribed psychotropic medications, the potential for abuse of prescription medications, and the potential for diversion of medications for abuse by other people (e.g. peers of the youth). Nevertheless, the presence of substance abuse should not automatically preclude the use of psychotropic medication to treat a psychiatric disorder that is responsive to such medication. The prescriber should first obtain information about the nature and severity of the substance abuse, so that psychotropic medication can be given safely and substance abuse treatment can be initiated.

SOURCES FOR INFORMATION ABOUT MEDICATIONS

Importance of Information About Psychotropic Medications for Youth, Families, and Their Service Providers

Youth and families and the professionals working with them need to have an understanding of the medication options that are recommended. Having the correct information allows youth and families to make an **informed decision** about whether they should agree to take a medication. It is helpful when parents and families and the professionals working with them do their own research to complement information they receive from the provider. Youth, their families, and the professionals working with them should not be afraid to ask the prescriber about questions they have regarding the information they have obtained.

Frequently Asked Questions

- *How can professionals in the child serving systems, parents, and youth get sufficient, accurate information about the medications that have been prescribed so that they understand the benefits and safety risks?*
- *How do professionals, parents, and youth obtain an updated drug list and their generic equivalents?*

Searching for this information can be time consuming and difficult if one does not know where or how to look. In this modern day, a vast abundance of information is at our finger tips. Unfortunately, there is so much information out there that it can be hard to interpret the quality and reliability of everything that is available.

Types of Information Available

Two classic sources of information are **printed materials** and **experts**. Books and journals can provide valuable resources, but are becoming harder to obtain in their printed form due to advances in technology. Many professionals will be able to provide additional information on medications. These include your doctor, your pharmacist, and other medical professionals.

In recent times, the **Internet** has become the primary source of information. If the Internet is used it is important to understand and consider the source of the information in order to decide what is accurate and useful and what is not.

Direct Marketing (.com)

Advertisements by the drug companies and promotional materials that may be handed out by your provider are types of direct marketing. In addition, there is also a vast amount of information on their websites. This information can be very useful for factual data related to medications. This includes dosing guidelines, how and when to take the medication, side effects, and contraindications (reasons the medication should not be taken).

However, there are limitations with this type of resource. They are only allowed to discuss FDA indications. These materials are only available for branded medication (not generics). They will present positive information, but do not have to present unfavorable studies, results, or outcomes from research.

Medically Oriented Commercial Websites (.com)
These sites will include information on illnesses in addition to medications. They are designed to be very user friendly. It is important to remember that these websites are driven by advertising and/or have a subscription fees. Examples include www.drugs.com and www.webmd.com.

Government Resources (.gov)
Government websites provide accurate information without advertising. Examples include www.nlm.nih.gov, www.nimh.nih.gov, or www.samhsa.gov

Professional Organizations (.org)
Many professional organizations have websites designed for the public. They will include information that will help provide an overview to the illness and provide information on treatment. They may also include information related to guidelines for treatment, handouts for families, information on current research, and contacts for support groups.

The content on these sites are usually created and written by experts in the field. These organizations are not for profit agencies and the websites will not contain advertising. Examples include www.aacap.org, www.psych.org, www.aap.org, and www.parentsmedguide.org.

Consumer Support/Advocacy Groups (.org)
These agencies are created by consumers and advocacy organizations to serve a specific population. They are helpful for finding links to resources as well as basic information. Many of these sites also have discussion groups where you can pose questions to other consumers. Examples include www.ffcmh.org, www.autismspeaks.org, www.adaa.org, www.chadd.org, and www.nami.org.

Other Sources of Information
The package insert that comes with every medication includes prescribing information that can be very useful, but overwhelming to look at. In addition to the prescriber, the pharmacist filling the prescription can be very helpful in explaining the package insert and in answering questions about the medication, including side effects and any concerns about interactions with other medications or dietary considerations.

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INTERNET RESOURCES FOR PSYCHOTROPIC MEDICATIONS FOR FAMILIES

Government Resources: These websites provide reliable information without advertising.

- National Institute of Mental Health - www.nimh.nih.gov
- National Library of Medicine - www.nlm.nih.gov websites will provide
- Substance Abuse and Mental Health Services Administration - www.samhsa.gov
- World Health Organization - www.who.int/mental_health/en/

Professional Organizations: These websites represent not for profit organizations designed to serve members. They also have sections dedicated to the clients they serve.

- American Academy of Child and Adolescent Psychiatry – Resources available by the organization include Facts for Families, Policy Statements, and Resource Centers - www.aacap.org
- American Psychiatric Association - www.psych.org
- American Academy of Pediatrics - www.aap.org

Consumer Advocacy Groups: These websites represent not for profit organizations designed to serve a particular type of consumer.

- General websites for parents and children
  - National Alliance on Mental Illness - www.nami.org
  - Parents Medication Guide - www.parentsmedguide.org
  - The Annenberg Foundation Trust at Sunnylands Adolescent Mental Health Initiative - www.copecaredeal.org
- Specialty websites for specific disorders
  - Anxiety Disorders Association of America - www.adaa.org
  - Autism and Asperger Syndrome Resources
    - www.autismspeaks.org
    - www.feat.org
    - www.autismsource.org
    - www.aspergersyndrome.org
  - The Balanced Mind Foundation - www.thebalancedmind.org
  - Children and Adults with Attention-Deficit/Hyperactivity Disorder - www.chadd.org
  - Depression and Bipolar Disorder Alliance - www.dbsalliance.org
  - National Association of Anorexia Nervosa and Associated Disorders - www.anad.org
  - Obsessive Compulsive Disorder Foundation - www.ocfoundation.org
  - Tourette Syndrome Association - www.tsa-usa.org

APPENDIX D

COMPLEMENTARY AND ALTERNATIVE TREATMENTS FOCUS GROUP FINDINGS AND RECOMMENDATIONS

Gracelyn Guyol

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To: **CT Children's Mental Health Task Force**

From: **CMH Task Force CAM and Integrative Sub-Committee**

Goal: **Introduce holistic, evidence-based, effective, affordable methods for treating:**
ADHD (6.8% prevalence)
Behavior/conduct disorders (3.5%)
Mood disorders of depression, anxiety, & bipolar (3.0%)

Folders with information on holistic methods	**Treating**
1. Brain Balance Centers, Robert Melillo, Neurologist, Dyslexia, Professor, Functional Neurology Researcher	ADHD, Autism, Tourette's
2. Nutrient Therapy, William J. Walsh, PhD, Director, Behavior Walsh Research Institute	ADHD, Mood and Disorders
3. Neurofeedback, Mary Jo Sabo, PhD, LMHC, BCIA, AIBT Anxiety Biofeedback Consultants, In-School & Private Programs Disabilities	ADHD, Depression, OCD, Dev.
4. Fast ForWord Language Programs, Michael M. Merzenich, PhD, Brain Plasticity Researcher, Co-Founder, Scientific Learning	ADHD, Special Ed, At Risk Students
5. Cerebral Electrotherapy Stimulation (CES), Charles Fisher, President and Co-Founder, Fisher Wallace Laboratories	Depression, Anxiety, Insomnia, Chronic Pain
6. Bipolar Nutrient Supplements: EMPowerplus & Equilib, or Customized protocols by Anne Procyk, ND, Third Stone Health	Bipolar Disorder
7. Emotional Freedom Technique (EFT), Jane Percy, BA, CIH, ChT, Director, Riverlight Wellness	Anxiety, Trauma, PTSD
8. ACACD Auriculotherapy (Ear Nerve Stimulation); with Amino	Addiction Recovery

	Acid Therapy SynaptaGenX developed by Kenneth Blum, PhD	
9.	Homeopathy Medicine, created by Christian Frederich Samuel Hahnemann, of Neissen, Germany, circa 1790	All Mental Disorders
10.	Holistic Treatment of Psychiatric Crises & Violence, Mania Psychiatrists Peter R. Breggin, MD, and Michael B. Schachter, MD, CNS	Violence, Aggression,