Tufts CTSI
Tufts Clinical and Translational Science Institute

Multi-State Study on Psychotropic Medication Oversight in Foster Care

September 2010

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STUDY REPORT

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"Estimated rates of psychotropic medication use for youth in foster care range from 13-52% compared to 4% in the general youth population."

Overview

What is this study about?

This study examined *state policies and practices regarding oversight of psychotropic medication use* (i.e., use of medication for the treatment of behavioral and mental health problems) for children and adolescents ages 2 to 21 years (hereafter "youth") in foster care.

Over the past decade, psychotropic medication use in youth has increased 2-3 fold[1] and polypharmacy (i.e., the use of more than one psychotropic medication at the same time) has increased 2.5-8 fold.[2] Estimated rates of psychotropic medication use for youth in foster care, however, are much higher (ranging from 13-52%)[3-8] than those for the general youth population (4%).[2] Recent research also has shown that there is a great deal of variation in rates of medication use for youth in foster care in different geographic communities.[9-11] There is therefore rising concern about the appropriate use (both over- and under-use) of psychotropic medications for youth in foster care.

This multi-state study aimed to: identify which states had policies or written guidelines regarding psychotropic medication oversight for youth in foster care; better understand the challenges states had encountered as they sought to address medication oversight, and determine what types of solutions states had implemented or were planning to implement.

How is this report organized?

In this report you will find:

- An overview of the *status of policies and guidelines for psychotropic medication oversight* across 47 U.S. states and the District of Columbia (hereafter "states") in 2009-2010; and
- Descriptions of *challenges* and innovative *solutions* implemented *by states*.

In the appendix to this report you will find:

- Descriptions of and links to *specific tools* developed by states and available online;
- Descriptions of and links to *websites* of interest;
- *Articles, professional organizations' policy/position statements,* and *guidelines*; and
- Information about *consulting services* on the use of psychotropic medication among youth in foster care.

Who might find this report helpful?

- *Child welfare agency administrators and staff*, including commissioners, quality assurance staff, foster care program directors, medical directors, mental health directors, and program staff.
- *State Medicaid and public mental health staff*, including directors, administrators, and others interested in medication oversight.
- *State leaders* such as governors, legislators, child advocacy directors, and their staff.
- *Pediatricians, family physicians, child and adolescent psychiatrists, mental health providers, and professional organization members and staff* who care for youth in foster care or who develop practice guidelines for youth in foster care.
- *Youth in foster care and foster care organization members*, including foster parent associations, foster youth advisory groups and membership organizations, and foster alumni organizations who advocate for improved outcomes for youth in foster care.

Relevance

Why is this study important and relevant to me?

Youth, especially those in foster care, are among the most vulnerable populations in our society. On a given day in 2008, approximately 463,000 U.S. youth resided in state governments' care.[12] Despite the many people who are typically involved in the lives of these youth (e.g., child welfare agency staff, birth and/or foster parents, primary care clinicians, mental health specialists, school personnel, judges, lawyers, guardians *ad litem*, Court-Appointed Special Advocates), youth involved with foster care often lack a single, clearly designated adult to monitor their health and mental health care.

"On a given day in 2008, approximately 463,000 U.S. youth resided in state governments' care."

Propelled by research documenting high rates of emotional and behavioral problems among youth in foster care, class action lawsuits, and state-generated quality improvement data, numerous child welfare agencies are investigating mechanisms to improve the quality of health and mental health services for youth in their care. However, little is known about the current approaches that states have implemented to provide psychotropic medication oversight. This study provides a summary of these approaches and may inform similar efforts for other vulnerable populations with high rates of medication use.

How does this study relate to Public Law (P.L.) 110-351?

In October of 2008, President Bush signed into law the *Fostering Connections to Success and Increasing Adoptions Act*, Public Law 110-351. This law requires state child welfare agencies and Medicaid to provide ongoing oversight and coordination of medical and mental health services, including psychotropic medications, for youth in foster care. Plans for oversight and coordination should:

- Promote collaborative efforts between child welfare agencies, Medicaid, pediatricians, and other experts to monitor and track medical and mental health;
- Include medical and mental health evaluations, both on entry into foster care and periodically while in foster care; and
- Provide continuity of care and oversight of medication use.

Definitions

We use the following terms in this report. Please refer to this alphabetized list for our working definitions of these terms.

Assent: A 3-part process that includes the youth understanding (to the best of his/her developmental abilities) treatment options, the youth voluntarily choosing to undergo treatment options, and the youth communicating this choice.

Decision-Maker: The individual designated by the state to provide informed consent.

Foster Care: The placement of a child into the temporary custody of the state child welfare system due to problems or challenges that are taking place within the home of the birth family. Definitions of "foster care" vary across state child welfare agencies.

Informed Consent: The process of the clinician providing information, including benefits and risks, to the youth and parent about all possible treatments, and the parent making an informed decision regarding which treatments are in the best interest of the child. Terminology and associated definitions for informed consent for youth in foster care vary; other terms include substitute judgment, informed permission, and medication decision-making.

Mental Health Evaluation: Screening and/or assessment for emotional and behavioral problems (hereafter "evaluation").

Outliers: Individual prescribers whose prescribing patterns fall outside of normal trends.

Psychotropic Medications: Medications used for treating behavioral and mental health problems.

Psychosocial Therapy: Non-medication therapies such as cognitive, behavioral, and family systems therapies. These therapies may be used with or without psychotropic medication.

Red Flags: Markers used in audits, case reviews, or databases located within child welfare, Medicaid, mental health, and managed care plans to identify cases in which available data suggest medication use may not be appropriate.

Stakeholders: Individuals involved in meeting the behavioral healthcare needs of youth in foster care at both the child and state level; this might include: youth, birth parents, foster parents, child welfare workers and administrators, guardians *ad litem*, pediatricians, psychiatrists, mental health administrators, Medicaid staff, Court-Appointed Special Advocates (CASAs), the courts, schools, juvenile justice, residential facilities, child welfare unions, and leaders in professional organizations, public agencies, and advocacy groups.

Written Policy/Guideline: Policy refers to state legislation, court rules, inter- and intra-agency policy, or administrative directives. Guideline refers to written procedures that constitute formal procedure or protocol for the child welfare agency.

Methods

How was this study conducted?

Phone surveys were conducted with key informants in state child welfare and affiliated agencies between March 2009 and January 2010. Respondents included medical or mental health directors, foster care administrators, and other agency staff who were knowledgeable about psychotropic medication oversight, or some component of it, for youth in foster care. In states with inter-agency linkages, surveys were conducted with multiple key informants from the same state. The survey inquired about current policies and guidelines in place, challenges unique to child welfare, and innovative programmatic and policy solutions.

In addition, existing state policies and guidelines, either available on public websites or provided by key informants, were reviewed. For analyses, quantitative methods were used to examine descriptive and numerical data. Qualitative data were reviewed to identify themes.

Findings

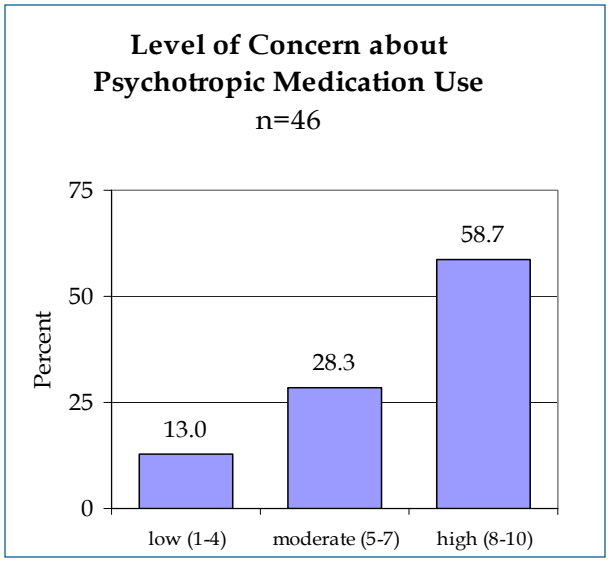
Forty-seven of the 50 U.S. states and the District of Columbia participated in this study.

During the study period (March 2009 – January 2010), states were in various stages of developing policies, guidelines, and programs pertaining to psychotropic medication management and oversight for youth in foster care.

How important was the issue of psychotropic medication use to states?

On a scale of 1-10, with 10 being high, almost 60% of respondents rated psychotropic medication use in the 8-10 range.

These ratings indicate that oversight of psychotropic medication use was a high concern within these respondents' state child welfare agencies.



What did states say about psychotropic medication use?

The majority of respondents reported an increasing trend in the use of psychotropic medications among youth in foster care, specifically:

- Increased use of antipsychotics, antidepressants, and ADHD medications;
- Increased polypharmacy;
- Increased medication use among young children; and
- Increased reliance on PRN medications (i.e., medications administered "as needed") and "blanket authorizations" in residential facilities.

Some respondents felt that this *increase* partially reflected demand by foster parents, schools, and other stakeholders. Others felt that reimbursement and time pressures in the healthcare system encouraged medication use. A few respondents indicated a *decrease in medication use* in their state and thought that these changes reflected policy and practices implemented over the last several years.

Many respondents understood that medication plays an important role in addressing mental health problems. However, respondents were concerned that medications were being used to manage problems that might respond as well, or better, to psychosocial treatments.

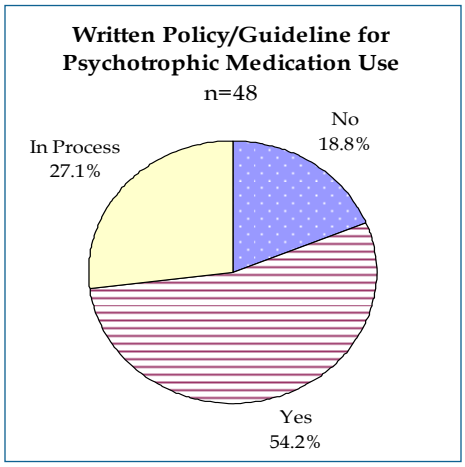
"[There is] pressure from foster parents to decrease behavioral issues in order to keep children in foster homes."

"Teachers will say that a child cannot return to school unless his/her behavior is controlled."

"The medical community wants to prescribe meds because Medicaid will pay for them…"

How many states had a written policy or guideline for the use of psychotropic medications?

- 26 states (~ 54%) had a written policy/guideline regarding psychotropic medication use;
- 13 states (~ 27%) were currently developing a policy/guideline; and
- 9 states (~ 19%) had no policy/guideline regarding psychotropic medication use.



Written policies/guidelines were housed within the child welfare agency in most cases. In two states, however, respondents indicated that their child welfare agency followed written policies/guidelines housed in other state agencies, specifically the Department of Health and the Medicaid office.

Policies/guidelines had been in place for 1-25 years at the time of the interviews.

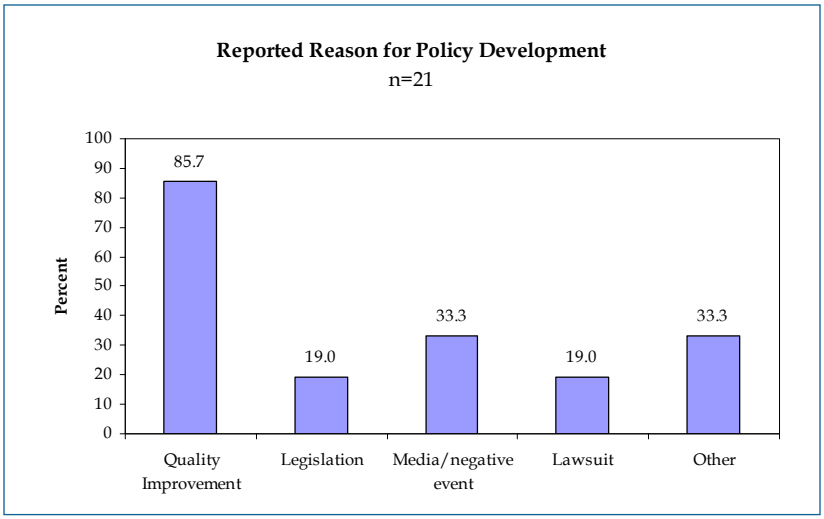
How did policies/guidelines differ?

Most state policies/guidelines addressed *all* psychotropic medications, but a handful of policies/guidelines addressed only *some* medications. Roughly half of state policies/guidelines addressed only youth of a *specific age* (e.g., young children) or youth in a *specific placement type* (e.g., residential treatment facility).

What motivated states to develop a policy/guideline around psychotropic medications?

Respondents reported various reasons for policy development. The majority of states had developed a policy/guideline specifically to improve the quality of existing programs. Quality improvement efforts were driven by state-generated data as well as by results from Child and Family Services Reviews through the Administration for Children and Families. Some respondents reported that a change in leadership prompted quality improvement efforts. Some respondents commented that legislation, negative events (which often generated media attention), or class action lawsuits motivated policy/guideline responses.

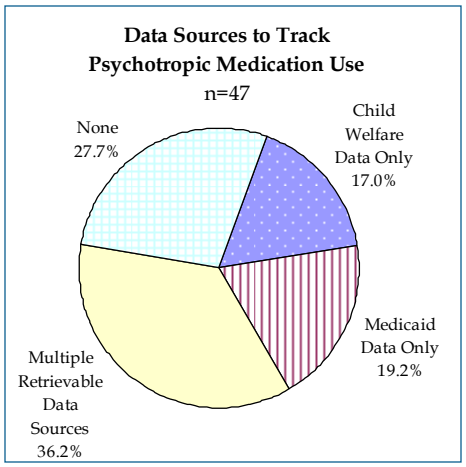
The approximately one-third of respondents who selected "other" noted that policy development was prompted by an increased focus on the role of youth, foster parents, and child welfare staff.



Note multiple responses were permitted for each state so percents do not sum to 100.

What data sources were states using to track psychotropic medication use?

States that were tracking psychotropic medication use were drawing from a variety of data sources. Some states did not have access to a database and relied on individual case reviews or audits. Other states used their *Statewide Automated Child Welfare Information System* (SACWIS). Several states had a specialized unit that had the authority to decide whether a child began medications and that tracked the benefits and side effects of medications. These units usually kept a *separate database*. Other states were using data from *Medicaid, mental health, or managed care plans*. Some databases provided real-time information, whereas others provided data at periodic intervals or on a case-by-case basis.



Several states had developed or were in the process of developing mechanisms by which to *merge* data from both Medicaid and child welfare. In general, respondents felt that developing information technology systems that could "talk" to each other was of high importance.

What specialized staff positions, within child welfare, did states have that might provide expertise in psychotropic medication use?

Some states had administrative positions such as Medical Directors, Mental Health Directors, and specialized mental health staff that may provide expertise to assist with implementing an oversight system for psychotropic medication use.

States had the following specialized staff positions within child welfare:

- 16 (34%) states had a *Medical Director*;
- 24 (51.1%) states had a *Mental Health Director*; and
- 32 (68.1%) states had *specialized mental health staff*.

States with specialized mental health staff positions employed psychiatric nurses, public health nurses, clinical social workers, and other specialized professionals to provide expertise in this area.

"DCFS brought me over from behavioral health to look comprehensively at the mental health services provided to youth in child welfare, not just medications."

"Every DCF area office has both a nurse and a mental health specialist…caseworkers can contact these individuals for guidance about psychotropic meds."

What "red flags" were states using to identify problems with safety and quality of care?

Of the 48 states that participated in this study, 25 (53.2%) states used at least one of the "red flag" markers that were asked about in the interview (see Table 1 below). These markers were used in audits, case reviews, or data print-outs from databases located within child welfare, Medicaid, mental health, and managed care plans.

In addition to the "red flag" markers that were asked about in the interview, 6 (12.8%) states used other "red flags." These included the use of any PRN medications or the use of PRN medications two or more times in one week, and side effects such as weight gain or loss.

These "red flags" served multiple purposes, including: prompting case reviews; ordering lab work when indicated for specific medications; initiating the prior authorization process from Medicaid for select medications; conducting internal quality assurance initiatives; and identifying "outliers" (i.e., individual prescribers whose prescribing patterns fall outside of normal trends).

Table 1. "Red Flag" Markers

"Red Flag"	# (%) of states that endorsed
Use of psychotropic medications in young children (states varied in cutoff from 3-6 years of age)	22 (46.8%)
Polypharmacy before monopharmacy (i.e., the use of multiple medications before the use of a single medication)	10 (21.3%)
Use of multiple psychotropic medications simultaneously (states varied in cutoff from 3-5 medications)	18 (38.3%)
Use of multiple medications within the same class for longer than 30 days, including: 2-3 or more antidepressants; 2 or more antipsychotics; 2 or more stimulants (not including long-acting and short-acting stimulants); or 3 or more mood stabilizers	18 (38.3%)
Dosage exceeds current maximum recommendations (e.g., manufacturer, professional, federal, or internal state guidelines developed by state-convened panels)	14 (29.8%)
Medications not consistent with current recommendations (e.g., professional or internal state guidelines developed by state-convened panels)	14 (29.8%)
Use of newer, non-approved medications over FDA-approved medications	8 (17.0%)
Primary care doctor prescribing for a disorder other than Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder, Adjustment Reaction, or Depression	8 (17.0%)
Antipsychotic medication use for longer than 2 years (if not diagnosed with Bipolar Disorder, Psychosis, or Schizophrenia)	8 (17.0%)
No documentation of discussion of risks and benefits of medication	10 (21.3%)

What did states identify as the components of a psychotropic medication oversight system?

Respondents identified a number of components essential to developing psychotropic medication oversight for youth in foster care. These can be grouped into 10 primary components, as listed below in Table 2.

Table 2. Components of an Oversight System

1	Recognition in child welfare agencies that psychotropic medication use is a systems problem that needs to be addressed
2	Collaboration among youth-serving organizations and stakeholders
3	Access to up-to-date guidelines on clinical practices
4	Mechanisms for identifying who needs psychotropic medication
5	Informed decision-making/consent and appropriate medication monitoring for individual youth in foster care
6	Involvement of biological parents and youth in ongoing clinical decision-making
7	Oversight program for monitoring population trends
8	Presence of a feasible and employable policy/guideline
9	Fiscal, human, and technological resources
10	National approach and resources for psychotropic medication oversight

The following pages provide descriptions of the *challenges* and *solutions* that respondents identified for each component.

For information on specific solutions that states have implemented, or for additional tools and resources, please see the Study Appendix.

1 Recognition in child welfare agencies that psychotropic medication use is a systems problem that needs to be addressed

STATES IDENTIFIED THE FOLLOWING CHALLENGE:

Some respondents reported that psychotropic medication use among youth in foster care had not been identified as a problem in their state. Other respondents thought that their agency had identified medication use as a problem but had *not yet defined it as a "systems" issue* requiring a programmatic response. Others felt that the issue suffered from lack of recognition due to *limited data* at the local, state, and national level about psychotropic medication use among youth in foster care.

Some thought the lack of recognition reflected a *debate over who "owns" the problem of psychotropic medication oversight for youth in foster care*. Some state respondents felt that the *child welfare system and courts,* which function as a "parent" for the child, must play a more specific role in medication oversight. However, even states that had put resources into training or who had hired staff with mental health expertise found that *these staff did not always have sufficient authority to question a doctor's medication recommendations*.

Other respondents commented that assuring appropriate psychotropic medication use was in large part the responsibility of the prescribing clinician, and that solutions should focus on reimbursement, training, and oversight mechanisms in *the medical and mental health sectors*.

"This issue has never been looked at on an organized basis. It has always been left up to the individual case workers."

"We are in the stage of identifying the problem – not everyone agrees that it is a problem!"

STATES HAD IMPLEMENTED THE FOLLOWING SOLUTIONS:

- *Obtained and employed available local, state, and national data on differences in prescribing rates* among the child welfare population, the Medicaid population, and the general youth population to highlight concerns about practice trends.
- Commissioned a *report regarding medication use* among youth in foster care.
- *Identified stakeholders within the child welfare system* committed to improving mental health care for youth in foster care.
- Recognized that this was a multi-system issue and *developed collaborative efforts with other state agencies* (e.g., mental health, Medicaid, mental retardation/developmental delay, education, juvenile justice).
- Employed *newsletters* or other mechanisms to keep the issue of psychotropic medication use visible among child welfare staff and administrators.

2 Collaboration among youth-serving organizations and stakeholders

STATES IDENTIFIED THE FOLLOWING CHALLENGE:

Most respondents voiced the critical importance of *bringing together all involved stakeholders* to develop a shared vision about the need for psychotropic medication oversight and to collaborate to implement that vision.

Many respondents commented on the *lack of collaboration* across state agencies, professionals, and organizations working with youth in foster care and how this hindered efforts to improve mental health care for these youth. Some respondents noted that their states had neglected to include all stakeholders and found that this limited their success in developing a feasible, sustainable plan for medication oversight.

"No one agency can do it all – it must be a collaboration between social services, mental health, public health, and Medicaid."

"Typically, we don't work together."

"The whole issue is under discussion now because the policy was not followed and we didn't have doctors involved in these meetings – that was a big mistake…now everyone is on the same page and this is too important an issue not to get right."

STATES HAD IMPLEMENTED THE FOLLOWING SOLUTIONS:

- *Identified stakeholders* committed to improving mental health care for youth in foster care. (See Definitions on page 3 of this report.)
- Established a *child-serving advisory group or board,* comprised of identified stakeholders at the local or state level, to examine psychotropic medication oversight.
- Identified a *publicly-visible champion for youth in foster care* – either internal or external to government agencies.
- *Developed a policy and/or standards of practice* regarding psychotropic medication use *in collaboration with other stakeholder groups.*
- *Provided education and training* about psychotropic medication use and about issues unique to youth in foster care for key stakeholder groups at the local and state level.
- Developed *Memorandums of Understanding* or *Agreement* (MOU or MOA) regarding continuity of care, child presumptive eligibility for Medicaid, shared staff, data sharing, etc.
- Developed a *coaching/mentoring program* in which retired child welfare staff worked with new staff to support them in dealing with complex mental health issues.

3 Access to up-to-date guidelines on clinical practices

STATES IDENTIFIED THE FOLLOWING CHALLENGE:

Respondents recognized the benefit of medication use for some emotional and behavioral problems but wanted *access to up-to-date guidelines about psychotropic medication use among youth in child welfare.* Respondents felt that this information was needed across stakeholder groups including youth, caregivers, child welfare workers and administrators, prescribers, and other youth-serving organizations (e.g., schools, residential facilities).

Respondents also wanted information about *psychosocial therapies* for youth in foster care. In particular, respondents felt that behavioral issues for youth in foster care might reflect a number of *situational factors* (e.g., past history of trauma, placement change, poor fit between child and caregiver) that needed to be addressed. Respondents reported that these situational factors led to challenges in ensuring that treatment provided to youth matched the youth's behavioral health needs.

"Most children who are on meds are also receiving therapy, however the therapy may not be all that specific…we are not looking at other interventions enough."

"We have seen differences in a child's behavior by the care provider. How do we get this help to the caregiver to train/teach them behavior modification techniques without meds?"

"[We] need guidelines to determine whether medications are needed, and if so, for how long."

STATES HAD IMPLEMENTED THE FOLLOWING SOLUTIONS:

- Found *reliable, up-to-date* sources of information about clinical care, both for psychosocial (non-medication) and psychopharmacologic (medication) treatments, for youth in foster care.
- Partnered with professional organizations to provide *clear guidance to prescribers* about standards of care using American Academy of Child and Adolescent Psychiatry (AACAP) guidelines/practice parameters and other resources. (See Study Appendix for a list of guidelines and policy/position statements.)
- Partnered with Medicaid or mental health to provide *feedback to "outliers."*
- Hired staff or co-located Medicaid or mental health staff with *mental health expertise* within the child welfare system.
- Developed *tele-psychiatry programs* to address shortages of specialists in rural areas.
- *Consulted with pediatric and mental health experts* interested in youth in foster care outside the child welfare system. These experts might include clinicians at a local community public health department or mental health agency, or researchers at an academic medical center with interests in youth in foster care, public mental health, psychotropic medications, psychosocial interventions for behavior problems, or healthcare economics.
- Developed a referral network of *primary care and mental health clinicians with expertise in foster care.*
- Established *placement specialists* in child welfare to work with foster parents around behaviors that result in placement changes.

4 Mechanisms for identifying who needs psychotropic medication

STATES IDENTIFIED THE FOLLOWING CHALLENGE:

The majority of respondents commented on the importance of developing mechanisms to *screen and/or evaluate all youth* for mental health problems, as stated in guidelines developed by the American Academy of Child and Adolescent Psychiatry (AACAP), the American Academy of Pediatrics (AAP), and the Child Welfare League of America (CWLA). Evaluators varied by state and included child welfare workers, mental health counselors, pediatricians, family doctors, early intervention providers, or psychologists. States had different opinions about the degree of mental health expertise necessary for an evaluation. Some states screened for mental health problems and then conducted assessments only on youth identified through screening; others conducted a more thorough evaluation on all youth entering foster care. Screening and/or evaluation mechanisms for youth in foster care varied in the type of tools used. Some states specified tools to use; others left the content of the evaluation up to the evaluator.

Some respondents saw a particular need for evaluation for youth for whom a *residential placement* was being considered.

"All of our initiatives [must] make sure that meds flow from accurate screening and assessments."

"We want to require a full medical work-up for kids, especially those for whom psychotropic meds have been requested. [We] must rule out all underlying medical conditions – it is not enough to provide concomitant therapy."

STATES HAD IMPLEMENTED THE FOLLOWING SOLUTIONS:

- Screened for *emergent risk* of mental health issues *within 72 hours* of entry into foster care.
- Either *conducted a more thorough screening* (with subsequent evaluations for those youth with positive screens) or *completed a comprehensive mental health evaluation* within 30-60 days following entry into foster care.
- Recommended the use of a *standardized evaluation tool*. (See Study Appendix for a link to the California Evidence-Based Clearinghouse (CEBC) for child welfare, which maintains a list of tools on its website.)
- Performed *routine screenings and evaluations* at least *once per year*, as well as when *significant behavioral, environmental,* or other *major changes* occurred (e.g., placement change, court hearing, behavior change, transition out of care).
- *Based recommendations* on AACAP, AAP, and CWLA guidelines. (See Study Appendix for these guidelines.)

5 Informed decision-making/consent and appropriate medication monitoring for individual youth in foster care

STATES IDENTIFIED THE FOLLOWING CHALLENGE:

Informed consent in the usual patient-parent-clinician encounter involves the clinician providing information to the youth and parent about all possible treatments, including benefits and risks, and the parent making an informed decision regarding which treatments are in the best interest of the child.

For youth in foster care, this process is more complex because more than one person may play a part in the process (see Figure 1 below).

"How do you educate your staff about psychotropic medications? Our caseworkers are not nurses or medical professionals, so how do you gear training?"

"We need to have someone on the child welfare staff who could address medication issues."

Figure 1. Informed Decision-Making/Consent Roles

INFORM → **MAKE** → **AUTHORIZE** → **NOTIFY**

A decision-maker is *informed* about the mental health history (when available) of the youth, the presenting emotional or behavioral problem(s), and the treatment plan.

The decision-maker (or another party) then *makes* the decision to provide informed consent for the use of psychotropic medications.

In some states, a third party *authorized* the use of medications. A third party may be the court system, an expert panel internal or external to child welfare, or a state agency such as Medicaid.

Relevant stakeholders are *notified* of the decision to begin psychotropic medications. Notification can include: name of the medication(s); targeted symptoms; and risks, benefits, and side effects.

Monitoring an individual youth's response to medication and side effects also was seen as an important aspect in medication oversight. Most respondents questioned whether or not child welfare workers alone had the skills and authority to effectively challenge prescribers if they were concerned.

STATES HAD IMPLEMENTED THE FOLLOWING SOLUTIONS:

- *Facilitated ongoing communication*, through Child and Family Team Meetings and other venues, among youth, stakeholders who understand the youth's behavioral/emotional needs best, and people who are authorized decision-makers to assure that the treatment plan: was appropriate for the youth's needs; included psychosocial treatments; and built on the youth's strengths.
- *Clarified a system for informed decision-making/consent*, including assent of the older youth.
- Required *periodic reporting and review of benefits and side effects of medications* among relevant stakeholders about individual youth in foster care.
- Developed the capacity for a *second opinion* in complex cases (i.e., cases that repeatedly trigger "red flags," or cases in which the youth is not responding to standard treatment approaches).
- Chose various mechanisms for *determining decision-making authority*. Decision-makers ranged from foster parents to the courts (see Figure 2 on the following page).

Where did states locate decision-making authority in the informed consent process?

In two states, decision-making authority resided at the clinical encounter with the prescriber, foster parent, and youth participating in the process. In other states, this authority resided within the child welfare agency. This might include child welfare workers, supervisors or administrators, or units with mental health expertise within the child welfare system. Some states had contracted with an external agency to provide expert review of prescriber requests prior to obtaining informed consent and a prescription being filled. Two states relied on the court system to approve the use of some (e.g., antipsychotics) or all psychotropic medications.

States with expert units either internal or external to child welfare, or who used the court system, prioritized more systematic approaches for obtaining informed consent. The informed consent process was seen as one mechanism for *overseeing prescribing practices* at the individual child level by requiring consent through a third party, such as a child welfare administrator, specialized unit (either internal or external to child welfare), or the courts. Other states expressed concerns that a more centralized and systematic consent process would limit the ability to *personalize a child's mental health care* and had chosen to locate authority for informed consent closer to the clinical encounter.

Figure 2. Location of Authority for the Informed Consent Process

Where should *your agency* locate authority for informed consent?

Consider the following questions when *determining your approach* for informed decision-making/consent:

- How close to the clinical encounter do you want the medication decision-making process to be?
- To what extent is it important that child welfare be engaged in the medication decision-making process?
- Would it be advantageous to vest authority for informed consent in an external agency for medication oversight?
- How important is it to your child welfare agency to have a systematic approach to informed consent?
- What other state agencies might have resources to assist in funding the informed decision-making process?
- How will you ensure that your system responds quickly to a youth's medication needs?
- How will you assure the necessary training and expertise for relevant stakeholders to make informed decisions around psychotropic medication use?

6 Involvement of biological parents and youth in ongoing clinical decision-making

STATES IDENTIFIED THE FOLLOWING CHALLENGE:

Respondents were concerned about the *lack of involvement of birth parents and/or guardians* in the informed consent process. Many expressed interest in implementing a family-centered approach, in part to help increase the involvement of birth parents and other key stakeholders.

Involvement of biological parents from the beginning is particularly important if family reunification is a goal. Parents and youth need to better understand the mental health issues experienced by youth in foster care and the role of medications in improving well-being.

In addition, many respondents identified the inability to adequately *train and educate youth* about psychotropic medications as a challenge. This was of particular concern for youth transitioning out of the foster care system.

"Keep families involved because they need to be willing to keep the care going after reunification. [We] need to keep in mind the long-run when dealing with these issues – not only where the child came from but also where he/she is going."

"[We need] to involve families and youth, when age-appropriate, in decisions about the child…we also need better training for youth about diagnoses and medications."

"When starting any med, the following info is to be provided to the child: name of the med, dosage, why it is being prescribed, side effects, risks, and consequences of not taking it – all in language that the child can understand."

STATES HAD IMPLEMENTED THE FOLLOWING SOLUTIONS:

- *Educated* all stakeholders about medications and about psychiatric diagnoses and treatment options.
- Provided *ongoing information to youth and families* about diagnoses, effective treatment options, and managing care throughout life.
- Developed a *transition plan* for youth aging out of foster care that specifically addressed *engaging the youth* in managing their own symptoms and treatments and *identifying who will prescribe medications* once out of care.
- *Developed a policy/guideline, advisory panel, and training guide* to engage youth in psychotropic medication oversight. States often included youth in the development and planning process for these tools.
- Established *parent consumer boards* to provide guidance to the agency on mental health issues around youth in foster care.
- *Hosted "brown bag" call-in sessions*, led by medical or mental health experts in child welfare, for foster parents, biological parents, and youth about mental health issues and treatments, including medications.

7 Oversight program for monitoring population trends

STATES IDENTIFIED THE FOLLOWING CHALLENGE:

Respondents described the need for *quality and timely data to track medication use at the child and population level in addition to the individual child level*. Some states used case reviews and audits; other states used autonomous and/or linked databases available from child welfare (e.g., SACWIS), Medicaid, mental health agencies, and managed care plans.

Most states struggled to get workers to enter data into their SACWIS systems because of time and responsibility demands. Some had staff dedicated to coordinating mental health care who entered these data.

Many states were interested in sharing data across public agencies. A major challenge was the lack of "cross-talk" between different public data sources (e.g., SACWIS, Medicaid, mental health, managed care).

"Our SACWIS system wasn't developed to collect some of this data but we have updated our system to do this. Now [we] have quality assurance to do case related review – are kids getting identified, assessed, served, and how can we do what we need to do with limited resources?"

"Our system could track the data if people would enter it."

"We want to cross-check with Medicaid but our systems speak different languages."

STATES HAD IMPLEMENTED THE FOLLOWING SOLUTIONS:

- *Developed a tracking system* using the best available data (e.g., SACWIS, Medicaid, mental health, managed care, audits) in order to get *accurate, timely data* on prescribing trends for youth in the child welfare system.
- *Developed a centralized system* within child welfare for informed consent. This helped eliminate delays and provided a database through which to track youth on medications.
- *Developed a performance improvement plan* around youth mental health issues as part of the federally mandated Child and Family Services Review process.
- *Contracted* with academic medical centers or other entities *to collect and analyze aggregate data* on a periodic basis, using state or grant funding.
- *Worked with other systems* to find staff to track medication use (e.g., public health nurses, Medicaid pharmacy staff).

8 Presence of a feasible and employable policy/guideline

STATES IDENTIFIED THE FOLLOWING CHALLENGE:

Some respondents from states that did not have a policy/guideline saw this as a *missed opportunity*. Others were concerned about policies that might be *too prescriptive* and not address an individual child and family's needs. Some respondents pointed out that having a policy/guideline in place did not equate with having a system of psychotropic medication oversight, as policies/guidelines often are *not implemented* in practice.

Among those states with significant regional differences, respondents commented that a "one size fits all" model cannot apply to policies/guidelines. Respondents identified needing help with developing policies that *incorporate enough flexibility* to work across different settings (e.g., rural versus urban, available mental health expertise versus no expertise, county- versus state-administered child welfare systems) yet provide some means of holding different geographic areas accountable for outcomes.

"[Our challenge is] developing a policy that maintains consistency with industry standards but allows flexibility for a person-centered approach."

"[There is] no real challenge to developing a policy – the challenge is compliance and getting one that will work."

STATES HAD IMPLEMENTED THE FOLLOWING SOLUTIONS:

- *Identified states or counties with policies* that were *applicable to similar settings* and *considered the advantages and disadvantages* of different options for addressing psychotropic medication oversight.
- *Crafted a policy/guideline that was sufficiently flexible* but required accountability at the local level.
- Undertook a *quality improvement project* to determine what was working and how to build on that, as well as what wasn't working and what could be done about it.
- Set up informal "*virtual networks*" with other child welfare administrators to share strategies and results.
- *Considered the role of legislation at the state level* in terms of assisting with implementation and accountability issues.
- Posted policy/guideline online *for all stakeholders to access*.
- Developed DVD *training tools* for stakeholders on medication oversight and on state policies/guidelines.
- Identified mechanisms to *use data for measuring outcomes* to drive changes in procedures and policies.
- Ensured *all components* of an oversight system were addressed in policy/guideline (see Conclusions and Figure 3 on pages 20-22).

9 Fiscal, human, and technological resources

STATES IDENTIFIED THE FOLLOWING CHALLENGE:

Respondents described the impact of *limited fiscal, human, and technological resources* on the development, implementation, and maintenance of an oversight system. Limited fiscal resources for child-serving organizations at both the state and national level were noted.

Recent *budget cuts* were frequently cited as curtailing plans to address psychotropic medication oversight in the child welfare system. *Human resources* (e.g., overworked staff, high turnover, young age, and limited training and experience of many child welfare workers) were also cited as barriers. Additionally, a *lack of data and trained personnel to enter and analyze data* were noted as barriers.

Contrastingly, some states commented that limited resources had *galvanized state or county agencies* to collaborate.

A *lack of resources* was frequently voiced as a concern in states with regional differences. For example, respondents from states with large rural areas noted that there was often little to no availability of mental health services, particularly specialists in pediatric mental health care, in rural regions. In some county-administered systems, a state may develop a policy or practice guidelines but counties may not have the resources to implement the change.

"We need resources for the management and tracking required at both the state and county level."

"We are having severe budget problems and are down to about 50% of our regular staff levels."

"We have had continued conversations but it is all driven by what the legislature is willing to fund."

Respondents commented that *development of a system* requires:

- Time to bring diverse stakeholders together and create possible solutions;
- Data regarding state and national trends;
- Information regarding possible options for addressing psychotropic medication use; and
- Creative use of existing and/or accessible *fiscal, human, and technological resources*.

STATES HAD IMPLEMENTED THE FOLLOWING SOLUTIONS:

- Partnered with Medicaid or mental health to *pool funds* or develop *braided funding* (i.e., process by which multiple stakeholders contribute a portion of money toward shared outcomes).
- *Partnered with academic medical centers* for research or demonstration project funds.
- *Applied for foundation grants* to develop "promising practices."
- *Developed mechanisms for engaging* child welfare staff and additional stakeholders in appropriately using the oversight system developed.

10 National approach and resources for psychotropic medication oversight

STATES IDENTIFIED THE FOLLOWING CHALLENGE:

Respondents called for the formation of a national consensus on psychotropic medication use in the child welfare population. Specifically, states inquired: *"where are we now, and in what direction do we need to head?"*

Respondents wanted to see this issue *prioritized at the national level.*

Respondents identified the need to gather information about what other state child welfare agencies were doing and to *disseminate these "best practices" at a national level*. Respondents felt that models should not only address psychotropic medication oversight systems but should also address more holistic approaches for improving the emotional and behavioral health of youth in foster care.

Besides information, respondents wanted *practical assistance* with implementing practices in their agency settings.

"What would be the national message about meds?"

"What are state child welfare agencies doing to look at other means of treatment other than resorting to psychotropic meds? What other 'best practices' are being used before meds?"

"Sharing information with other states [about] what is truly effective [would be helpful]."

"[We] need to have resources that/who could guide [us], especially with technical assistance."

STATES *RECOMMENDED* THE FOLLOWING SOLUTIONS:

- *Establish a national advisory group or board* with representative stakeholders to address the quality of mental health care for youth in foster care.
- *Implement a national system* for identifying promising practices and evaluating their impact on child well-being.
- *Promote research on best practices* for providing psychotropic medication oversight in foster care.

Conclusions

This study examined state policies and practices regarding oversight of psychotropic medication use for youth in foster care. This report provided descriptions of the challenges that states were facing, and of the innovative solutions that states had implemented. The appendix to this study contains descriptions of some of these novel solutions and provides direct links to these online tools. In addition, the appendix offers websites, articles, policy/position statements, and guidelines that may be useful as states determine their course of action in response to P.L. 110-351.

It is important to keep in mind that the issues around safe and appropriate use of psychotropic medications for youth in foster care echo similar concerns at a national level. As a society, we push for "quick fixes." The reimbursement structure of our health care system offers incentives for brief medication visits instead of comprehensive, collaborative, and interdisciplinary mental health treatment approaches. Despite research that suggests comprehensive treatment approaches are more effective in treating many mental health problems commonly seen in youth, the reimbursement structure of our health care system tends to impede this treatment strategy. The American health care system continues to struggle in its attempt to balance the benefits of maintaining the prescriber's professional autonomy with the provision of external oversight. Similar issues are being debated for other populations with high rates of medication use, such as youth in the juvenile justice system, children of recently deployed armed service members, and the elderly. Efforts to develop mechanisms for psychotropic medication consent and oversight among youth in foster care should both be informed by and contribute to these national, state, and local discussions.

"We are a state in transition. We need to do this interview again in 6 months because everything will be different."

As several respondents pointed out, state policies/guidelines and practices are rapidly changing in response to P.L. 110-351 and other pressures. How states respond, what leads to successful implementation, and whether or not these solutions improve outcomes for youth in foster care need to be addressed as we move forward in elevating the quality of care for these vulnerable youth. While this report captures states' policies/guidelines and practices from March 2009 – January 2010, this landscape is rapidly evolving. Ongoing dissemination of state initiatives and collaboration between state agencies will be critical in the coming years.

State child welfare agencies requested guidance on how to conceptualize a system for quality and safe mental health services for youth in foster care. No published research, to our knowledge, provides estimates of the comparative effectiveness of oversight systems for appropriate mental health services for youth in foster care. However, respondents indicated that a child-level perspective helped in efforts to conceptualize the components of this type of system.

Figure 3, located on page 22, provides a summary of the components of an oversight system, from both a child-level perspective and a population perspective, as articulated by respondents in this study.

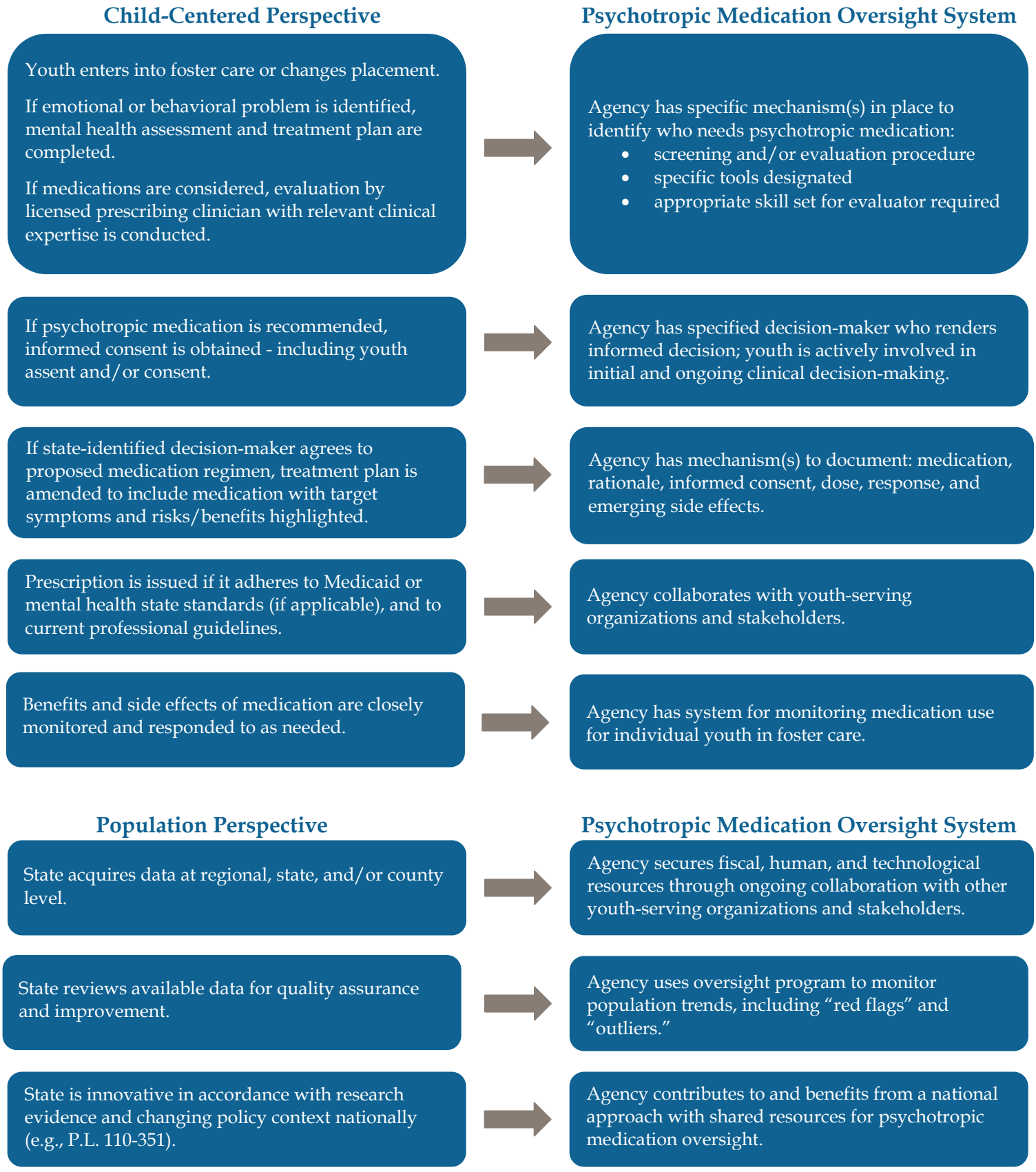
Despite the challenges described by respondents, many had identified novel, creative solutions to address improving both the safety and quality of psychotropic medication use among youth in foster care.

As authors of this report, we celebrate their achievements and encourage greater attention to a national agenda that respects states' uniqueness and that actively promotes improved care for some of our most vulnerable youth.

As states establish or improve their existing systems, stakeholders will benefit from reflecting on the following *key questions:*

- What internal capacity do you currently have in place with regard to mental health expertise, including psychotropic medication oversight?
- What other stakeholder groups, external to child welfare, that have available human, fiscal, or technological resources, could you partner with to improve the quality and safety of mental health care services for youth in foster care?
- What leadership, internal and external to child welfare, is available to champion mental health care for youth in foster care?
- What characteristics of your state are important to consider in developing a system for psychotropic medication oversight (e.g., rural communities, state- versus county-administered)?
- How will you address the components of an oversight system, as depicted in Figure 3 on the following page, in your state?
- What capacity exists, internal and external to child welfare, to train relevant stakeholders on important issues related to psychotropic medication use in foster care and on any new system you establish?
- What information systems are available and/or necessary to support the ongoing coordination and monitoring required for providing psychotropic medication oversight within the system?
- What is your state's plan for successful implementation?
- How will your state collect reliable data to demonstrate that the system has achieved improved outcomes?
- How will this system work to improve mental health treatment capacity more broadly, including preventative measures and appropriate psychosocial and pharmacological treatments, for youth in foster care?

Figure 3. Components of a Child Welfare Psychotropic Medication Oversight System



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Acknowledgements

We gratefully thank all the state child welfare administrators and their colleagues who participated in this study.

We also would like to thank the following individuals for their expert advice regarding the conceptual framework for and presentation of this report: Gail Garinger, JD, The Child Advocate, Commonwealth of Massachusetts Office of the Child Advocate; Elizabeth Armstrong, BSN, JD, Deputy Director, Commonwealth of Massachusetts Office of the Child Advocate; Gordon Harper, MD, Medical Director, Child and Adolescent Services, Commonwealth of Massachusetts Department of Mental Health; Russell Livingston, MD, Medical Director for Psychiatry, Commonwealth of Massachusetts Department of Children and Families; and Mary Lutz, RN, MPH, Director of Medical Services, Commonwealth of Massachusetts Department of Children and Families.

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Funding for this study was provided by the Charles H. Hood Foundation and by the Child and Adolescent Services Research Center. The production of this report was funded by the William T. Grant Foundation and by the Tufts Clinical and Translational Science Institute (supported by grant number UL1RR025752 from the National Center for Research Resources). The content of this report is solely the responsibility of the authors and does not necessarily represent the official views of the National Center for Research Resources, the National Institutes of Health, or other funding agencies.

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