

# Child Welfare: Oversight of Psychotropic Medication for Children in Foster Care

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July 28, 2015

**Congressional Research Service** 

7-5700 www.crs.gov R43466

## Summary

Children in foster care are children that the state has removed from their homes and placed in another setting designed to provide round-the-clock care (e.g., foster family home, group home, child care institution). The large majority of children enter foster care because of neglect or abuse at the hands of their parents. Maltreatment by a caregiver is often traumatic for children, and may lead to children having challenges regulating their emotions and interpreting cues and communication from others, among other problem behaviors. Children in foster care are more likely to have mental health care needs than children generally.

Children in foster care who have mental health needs may receive psychosocial services such as individual or group counseling and case management to improve their health. Alternatively, or in addition, a medical professional may prescribe psychotropic medications. These are prescribed drugs that affect the brain chemicals related to mood and behavior. They are used to treat a variety of mental health conditions including attention disorders, depression, anxiety, conduct disorders, and others. While psychotropic medication alone is not necessarily advised, children in foster care may more readily receive psychotropics to treat their mental health needs due to the complexity of their symptoms and the lack of appropriate screening and assessment and/or the limited availability of health care professionals trained to provide effective therapies (e.g., cognitive behavioral therapy).

Between 16% and 33% of children in out-of-home care may be using psychotropic medication on any given day, although the rate of use varies significantly based on certain factors, including the child's age, placement setting, and length of involvement with the child welfare agency. Among children generally, about 6% are taking psychotropic medications (at some point during a given year). Some of the difference in prevalence of use may be explained by the higher levels of mental health risk factors among children in foster care.

The use of psychotropics by children in foster care has come under increased scrutiny by policymakers and stakeholders in the child welfare field. Little research has been conducted to show whether psychotropics are effective and safe for children who need mental health services. Despite these concerns, some children may benefit from specific psychotropic medication for managing mental and behavioral symptoms associated with their exposure to traumatic events. The President's FY2016 budget proposes a five-year initiative to reduce reliance on psychotropic medications for children in foster care by encouraging the use of evidence-based screening, assessment, and treatment of trauma and mental health disorders. Congress has also taken a strong interest in oversight of prescription medications used by children in care, addressing the issue in oversight hearings and other fact-finding forums. Further, federal law (Title IV-B, Subpart 1 of the Social Security Act) requires states to describe their oversight of prescription medications for children in foster care, including specific protocols used with regard to psychotropic medication.

The Congressional Research Service (CRS) reviewed state plans submitted to HHS in 2012 that described state protocols in five areas identified by HHS as important to monitoring and appropriate use of psychotropic medication. States' responses were wide ranging, and oversight efforts are nascent in some states and fairly robust in others. With regard to screening for mental health need and planning treatment: Mental health evaluations appear to be available for children generally who are entering care, though some states limit this kind of evaluation to children of a minimum age (e.g., age three or older). States most frequently indicated that evaluations are

conducted, within 30 days of removal from the home, by a primary care physician or a mental health professional such as a psychiatrist. With regard to consent and assent for the use of psychotropic medications by children in care, and methods for ongoing communication between stakeholders involved in the child's health care: Over half of states that responded reported that a parent or legal guardian is involved in providing consent. With regard to effective medication monitoring at both the client and agency level: States reported that monitoring at the child (i.e., client) level is primarily focused on determining how the medication is affecting the child and may be carried out by a foster caregiver, caseworker, and or clinician. Agency monitoring, which tracks use of psychotropics at a system level, may be conducted by the child welfare agency, an overall health program for children in foster care, or special committees or review boards.

The findings from the state plans suggest policy issues that may be relevant to Congress as it considers the next steps in oversight of psychotropic use among children in foster care. These issues include possible broader use of medical homes and electronic health records to improve oversight of psychotropic medications, the role of Medicaid in improving screenings and services for children in care with mental health needs, the involvement of youth in choosing their mental health care, and the extent to which states should report to HHS on their oversight policies.

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## Introduction

Children in foster care are more likely to have mental health care needs than children generally. They are also more likely than other children to receive psychotropic medications, which are prescribed drugs that affect the brain chemicals related to mood and behavior. Psychotropic medications are used to treat a variety of mental health conditions including attention disorders, depression, anxiety, conduct disorders, and others. On the one hand, prescription of psychotropic medication for foster children may be appropriate, given their mental health needs. Still, the evidence on the safety and efficacy of psychotropics in children is limited. Congress has taken a strong interest in how states are monitoring and regulating use of these medications. Federal child welfare law requires states to have a plan for overseeing prescription drug use among children in foster care, including the use of psychotropic medications.

This report first provides background on the mental health needs of children in foster care, and the prevalence of psychotropic medication use among these children. The next section of the report discusses congressional oversight of psychotropic medication, and recent efforts taken by the U.S. Department of Health and Human Services (HHS) to provide assistance to states in ensuring appropriate use of psychotropic medications for children in care and to fund an initiative that would encourage states to implement evidence-based psychosocial interventions as an alternative to prescribing psychotropic medications. Following this is a discussion of current federal requirements concerning state monitoring of the use of these medications for foster children. The final section of the report includes a review by the Congressional Research Service (CRS) of plans submitted by states to HHS that address oversight of psychotropic and other prescription medications. The report concludes with a brief discussion of policy implications in light of the findings from the CRS review.

## **Children in Foster Care**

Children in foster care are children that the state has removed from their homes and placed in another setting that is designed to provide round-the-clock care (e.g., foster family home, group home, child care institution). Placement in foster care means that a judge has determined that the child's removal from his or her home was necessary because the home was "contrary to the welfare" of the child and, accordingly, the judge has given responsibility for the child's "care and placement" to the state child welfare agency. Most children enter foster care because of neglect or abuse experienced at the hands of their parents, although a child's behavior problem may also be a factor in foster care placement. This is especially true for children entering care at an older age. Foster care is intended to be a temporary placement until a child can be reunited with his or

<sup>&</sup>lt;sup>1</sup> Psychotropic drug classes include those for attention deficit hyperactivity disorder (ADHD), antianxiety, antidepressants, antipsychotics, hypnotics, and mood stabilizers. For further information, see Table 1 of U.S. Government Accountability Office (GAO), Foster Children: HHS Guidance Could Help States Improve Oversight of Psychotropic Prescriptions, GAO-12-201, December 2011, http://gao.gov/products/GAO-12-201. (Hereinafter, GAO, Foster Children: HHS Guidance Could Help States Improve Oversight of Psychotropic Prescriptions.)

<sup>&</sup>lt;sup>2</sup> A small percentage of children nationwide enter foster care via "voluntary placement agreements." In these situations a parent or guardian signs over certain care and placement responsibility to the state child welfare agency and, after six months, a judge may be asked to determine if this placement continues to be in the "best interest" of the child.

<sup>&</sup>lt;sup>3</sup> "Neglect" was associated with removal and entry to foster care of close to two-thirds (65%) of children entering care at age 12 or younger and 36% of those entering at ages 13 through 17. By contrast, a "child's behavior problem" was (continued...)

her parent(s), or when this is not possible, until a permanent placement with relatives, an adopted family, or a legal guardian can be found. While working to find them permanent homes, states must attend to the safety and well-being of children in foster care, including their physical and mental health.

During FY2013, some 641,000 children spent at least one day (24 hours) in foster care and 238,000 left the system, resulting in more than 402,000 of those children remaining in care on the last day of that fiscal year. Although there is variation at the state level, the national foster care caseload has generally been in decline for more than a decade. Across the nation, there were 122,000 fewer children in foster care on the last day of FY2013 as compared to the last day of FY2002 (when 524,000 were in care).4

## Mental Health Needs of Children in Foster Care

Children in foster care have higher mental health service needs than children generally.<sup>5</sup> The abuse or neglect children experience before entering foster care can have serious mental health outcomes. Maltreatment by a parent or other caregiver is stressful for children and may alter how their brains develop in ways that lead them to have more difficulty regulating their emotions and interpreting cues and communication from others. This negatively affects their socialization and may result in a tendency to violence or aggression towards others, among other problem behaviors.6

In a national survey conducted in 2008 and 2009, more than 4 in 10 (43%-46%) children (aged 18 months to 17 years) who were placed in a foster family home following an investigation of alleged child abuse and neglect in their families were found at risk of a behavioral or emotional problem and potentially in need of mental health services. Among children of that same age group who were placed in a foster care group home or institution, as many as 7 in 10 (61%-70%) were at such risk. These rates are much higher than those found in the general population. In separate

#### (...continued)

associated with removal of less than 3% of children entering care at age 12 or younger and close to 45% of those children entering care at age 13 through 17 years of age. Based on state data reported via the Adoption and Foster Care Analysis Reporting System (AFCARS) as of July 2014 and provided to CRS by the U.S. Department of Health and Human Services (HHS), Administration for Children and Families (ACF), Administration for Children, Youth and Families (ACYF), Children's Bureau. Each child could have one or more reasons associated with his or her removal from the home and entry to foster care. For more information, see U.S. House of Representatives, Committee on Ways and Means, 2014 Green Book, Chapter 11, "Child Welfare," "Additional Tables and Figures," Tables 11-7 and 11-7A.

<sup>&</sup>lt;sup>4</sup> HHS, ACF, ACYF, Children's Bureau, Trends in Foster Care and Adoption: FFY 2002-FFY 2013, based on AFCARS data reported by state as of July 21, 2014.

<sup>&</sup>lt;sup>5</sup> John Landsverk, Barbara Burns, Leyla Stambaugh, and Jennifer A. Rolls Reutz, Mental Health Care for Children and Adolescents in Foster Care: Review of Research Literature, prepared for Casey Family Programs, February 2006.

<sup>&</sup>lt;sup>6</sup> John Stirling Jr., and Lisa Amaya-Jackson, "Understanding the Behavioral and Emotional Consequences of Child Abuse," American Academy of Pediatrics Clinical Report, Pediatrics, vol. 122, no. 3, September 2008, pp. 667-673. Jun-Oing Liu, "Mental Health Service Access Among Children and Adolescents Involved with Child Welfare Services," Dissertation, University of Albany, State University of New York, 2011.

<sup>&</sup>lt;sup>7</sup> Heather Ringeisen et al., NSCAW II Baseline Report: Children's Services, Final Report, RTI International for HHS, ACF, Office of Planning, Research and Evaluation, November 2011, p. 33. This report shows risk at the lower end (43% or 61%, depending on placement setting) and is based on survey data collected 4 to 6 months after the investigation of child abuse and neglect that brought the child to the attention of the child welfare agency. (Hereinafter, Heather Ringeisen et al., NSCAW II Baseline Report: Children's Services.) Cecilia Casanueva et al., NSCAW II Wave 2 Report: Children's Services, Final Report, RTI International for HHS, ACF, Office of Planning, Research and (continued...)

surveys, about 7% to 11% of all children (in roughly the same age range) were identified as having emotional and behavioral problems.<sup>8</sup>

In recent years, children whose Medicaid eligibility is based on their "foster care" status<sup>9</sup> have been increasingly more likely to be given mental health diagnoses. <sup>10</sup> This is also true of children generally. <sup>11</sup> Such diagnoses include attention disorders, anxiety, autism, bipolar disorders, conduct disorders, depression, and schizophrenia. <sup>12</sup> Nearly all children who are in foster care are eligible for health care services funded via Medicaid (as discussed further in the next section). <sup>13</sup> From 2002 to 2007, the share of children whose Medicaid eligibility is based on their "foster care" status who were diagnosed with mental health disorders increased for most of these conditions. The most common diagnoses varied by age and older children were more likely to be given one of these diagnoses. In 2007, children ages 3 to 5 were most likely to have diagnoses of conduct disorder (7.4%) and attention disorders (6.7%); children ages 6 to 11 were most likely to be diagnosed with attention disorders (52.5%) and conduct disorders (26.8%); and children ages

#### (...continued)

Evaluation, July 2012, pp. 9-11. This report shows risk at the higher end of range (45% or 70% depending on placement setting) and is based on survey data collected regarding the same group of children circa 18 months after the investigation of child abuse and neglect that brought the child to the attention of the child welfare agency. (Hereinafter, Cecilia Casanueva et al., *NSCAW II Wave 2 Report: Children's Services.*) The risk of a behavioral/emotional problem was defined as scores in the clinical range on any of the following standardized measures: Internalizing, Externalizing or Total Problems scales of the Child Behavior Checklist, Youth Self Report (YSR), or the Teacher Report Form (TRF); the Child Depression Inventory (CDI), or the Post Traumatic Stress section Intrusive Experiences and Disassociation subscales of the Trauma Symptoms Checklist. These estimates are based on participants' perceptions of symptoms rather than direct clinical diagnoses.

<sup>&</sup>lt;sup>8</sup> Cecilia Casanueva et al., *NSCAW II Wave 2 Report: Children's Services*, pp. 9-11. Exact comparable data for the general population are not available. Estimates cited in this report are based on national surveys (conducted between 2001 and 2007) that used somewhat different measures for determining emotional and behavioral concerns among children ages 2 to 17 or ages 4 to 17.

<sup>&</sup>lt;sup>9</sup> For purposes of Medicaid eligibility "foster care" status extends to some (but not all) children in foster care, most children who are adopted from foster care, and certain children who have aged out of foster care. For further information, "Limitations on Understanding Medicaid Spending for Foster Care Children," in CRS Report R42378, *Child Welfare: Health Care Needs of Children in Foster Care and Related Federal Issues*, by Emilie Stoltzfus et al.

<sup>&</sup>lt;sup>10</sup> David Rubin et al., "Interstate Variation in Trends of Psychotropic Medication Use Among Medicaid-enrolled Children in Foster Care," *Child and Youth Services Review*, vol. 34, no. 8 (2012), p. 1492. (Hereinafter, David Rubin et al., "Interstate Variation in Trends of Psychotropic Medication Use Among Medicaid-enrolled Children in Foster Care.") This study counted a child as in foster care if, in a given year (FY2002-FY2007), the child had at least one month of Medicaid eligibility under the "foster care child" eligibility pathway.

<sup>&</sup>lt;sup>11</sup> Mark Olfson et al., "National Trends in the Mental Health Care of Children, Adolescents, and Adults by Office-Based Physicians," The *Journal of the American Medical Association*, vol. 71, no. 1, January 2014. (Hereinafter Mark Olfson et al., "National Trends in the Mental Health Care of Children, Adolescents, and Adults by Office-Based Physicians.")

<sup>&</sup>lt;sup>12</sup> The report does not define these or other mental conditions that have been studied. The American Psychiatric Association's Diagnostic and Statistical Manual (DSM) is the standard classification of mental disorders used by mental health professionals, and defines these terms. For further information, see American Psychiatric Association, "DSM," http://www.psychiatry.org/practice/dsm.

<sup>&</sup>lt;sup>13</sup> Medicaid is a means-tested program available primarily to children whose families meet certain income eligibility tests. Children in foster care may qualify for Medicaid through a federal eligibility pathway specifically for them. For further information, see CRS Report R42378, *Child Welfare: Health Care Needs of Children in Foster Care and Related Federal Issues*, by Emilie Stoltzfus et al., Child Welfare: Health Care Needs of Children in Foster Care and Related Federal Issues.

12 to 18 years old were most likely to be diagnosed with conduct disorders (67.3%) and depression (44.4%). 14

**Figure 1** (below) shows, for 2002 and 2007, rates of major mental health diagnoses by age group (6 to 11 years and 12 to 18 years) among children whose Medicaid eligibility is based on their "foster care" status. The figure indicates that these rates went up across all diagnoses for both age groups, except for depression among children ages 6 to 11 and schizophrenia among both age groups.

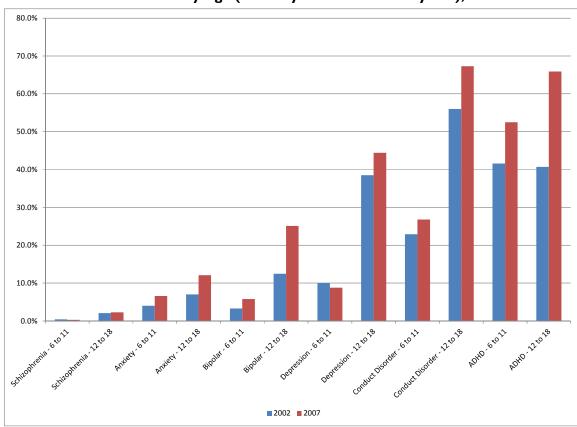


Figure I. Rates of Major Mental Health Diagnoses Among Medicaid-Enrolled Children in Foster Care by Age (6 to 11 years and 12 to 18 years), 2002 and 2007

**Source:** Figure prepared by the Congressional Research Service (CRS) based on data from David Rubin et al., "Interstate Variation in Trends of Psychotropic Medication Use Among Medicaid-enrolled Children in Foster Care," *Child and Youth Services Review*, Vol. 34, No. 8, 2012, p. 1492.

**Notes:** "ADHD" stands for attention deficit hyperactivity disorder." The report does not define ADHD or other health conditions that were studied. The American Psychiatric Association's Diagnostic and Statistical Manual (DSM) is the standard classification of mental disorders used by mental health professionals, and defines these terms. For further information, see American Psychiatric Association, "DSM," http://www.psychiatry.org/practice/dsm.

Nearly all children in foster care qualify for Medicaid through a designated pathway for this population or through other pathways. The study by Rubin et al., included children as in "foster care" if, in a given year

<sup>&</sup>lt;sup>14</sup> David Rubin et al., "Interstate Variation in Trends of Psychotropic Medication Use Among Medicaid-enrolled Children in Foster Care."

(FY2002 or FY2007), the child had at least one month of Medicaid eligibility under the "foster care child" eligibility pathway. For Medicaid reporting purposes, this includes some (but not all) children in foster care, many children who are adopted from foster care, and certain children who have aged out of foster care. For further information, see CRS Report R42378, Child Welfare: Health Care Needs of Children in Foster Care and Related Federal Issues.

#### Mental Health Services and Treatments for Children in Foster Care

National standards for mental health care developed by leading child welfare and pediatric organizations propose that all children should receive a mental health screening when placed into foster care, a subsequent comprehensive mental health assessment by a mental health professional within a month of being placed into care, and a coordinated approach to delivery of services to meet the children's ongoing mental health needs. Such diagnostic and treatment services should currently be available to children in foster care through Medicaid (Title XIX of the Social Security Act), which is a means-tested entitlement program administered by the federal government in partnership with the states. Under Medicaid, each state designs a plan for provision of medical assistance in its own state, including primary and acute medical services, as well as long-term care. The plan must be consistent with federal requirements and, if approved by HHS, entitles the state to federal reimbursement for a part of the cost of providing that medical assistance to each eligible individual in the state.

Most, if not all, children in foster care are eligible for Medicaid<sup>16</sup> and are generally entitled to the same set of "traditional" Medicaid state plan services available to other children enrolled in a given state's Medicaid program. Central among these benefits is a provision in the law requiring that children receive all medically necessary services authorized in federal statute through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. The EPSDT program covers health screenings and services, including assessments of each child's physical and mental health development; laboratory tests (including lead blood level assessment); appropriate immunizations; health education; and vision, dental, and hearing services. The screenings and services must be provided at regular intervals that meet "reasonable" medical or dental practice standards. Under EPSDT, states are required to provide treatment to meet children's identified health needs, including mental health needs. <sup>17</sup> Medicaid financing may be used to provide services to meet children's behavioral health needs, including case management or services provided by psychiatrists, psychologists, or clinical social workers. It may also be used to pay for prescription drugs. <sup>18</sup>

<sup>&</sup>lt;sup>15</sup> Ramesh Raghavan et al., "A Preliminary Analysis of the Receipt of Mental Health Services Consistent with National Standards Among Children in the Child Welfare System," *American Journal of Public Health*, vol. 100, no. 4 (April 2010).

<sup>&</sup>lt;sup>16</sup> CRS Report R42378, *Child Welfare: Health Care Needs of Children in Foster Care and Related Federal Issues*, by Emilie Stoltzfus et al.

<sup>&</sup>lt;sup>17</sup> HHS, ACF, ACYF, Children's Bureau, "Promoting Social and Emotional Well-Being for Children and Youth Receiving Child Welfare Services," Information Memorandum ACYF-CB-IM-12-04, April 17, 2012, http://www.acf.hhs.gov/sites/default/files/cb/im1204.pdf. (Hereinafter, HHS, ACF, ACYF, Children's Bureau, "Promoting Social and Emotional Well-Being for Children and Youth Receiving Child Welfare Services." April 2012). See also HHS, ACF, Centers for Medicare and Medicaid Services (CMS), Substance Abuse and Mental Health Services Administration (SAMHSA), "Dear State Director," July 11, 2013, http://medicaid.gov/Federal-Policy-Guidance/Downloads/SMD-13-07-11.pdf. (Hereinafter U.S. Department of Health and Human Services, ACF, CMS, and SAMHSA, "Dear State Director," July 2013.)

<sup>&</sup>lt;sup>18</sup> HHS, ACF, CMS, SAMHSA, "Dear State Director," July 2013.

In general, children who have mental health challenges may benefit from health care services that could include psychosocial treatment, such as counseling and case management from mental health professionals. There is a growing body of evidence on practices for responding to mental disorders in children through the use of psychosocial treatment. For example, certain psychosocial treatment interventions (i.e., behavioral and cognitive-behavioral therapy [CBT]; family-focused and group-based treatment; and treatments with multiple types of interventions) have been found to be moderately effective for children or parents of children with antisocial-related and disruptive behaviors. In addition, CBT—such as activities that include anger management, conflict resolution, and social skills training—has been found to be effective for children who experience trauma (defined as actual or threatened death or serious injury, or a threat to the physical integrity of self or others). 20

A medical professional may prescribe psychotropic medications to children in foster care when psychosocial treatment alone is not effective or when pharmaceutical or combination treatment has been demonstrated to be more effective than psychosocial treatment.<sup>21</sup> Nonetheless, psychotropics may still be prescribed without accompanying psychosocial therapies because medical professionals and other stakeholders may not have resources and support readily available to address the complex mental health needs of children in care.<sup>22</sup>

Analysis of data from a national survey of children who come into contact with child welfare agencies due to investigation of alleged child abuse or neglect found that children entering foster care were more likely to receive supports (i.e., mental health screening, a follow-up mental health assessment by a mental health professional, and referral to services) than were children with mental health needs who remained in their own homes following such an investigation. Even so, receipt of these services was not universal among those entering care. About 8 out of 10 children entering care received services consistent with at least one of the three services outlined by the national standards.<sup>23</sup>

Other studies have shown that children in foster care who need mental health services do not always receive them.<sup>24</sup> A national survey that collected data between 2008 and 2010 found that among children who had been in foster care for approximately 18 months or less, and who met clinical criteria for a mental health need, 3 out of 10 did not receive any specialty mental health

<sup>&</sup>lt;sup>19</sup> Christine M. Litschge, Michael G. Vaughn, Cynthia McCrea, "The Empirical Status of Treatments for Children and Youth with Conduct Problems: An Overview of Meta-Analytical Studies," *Research on Social Work Practice*, vol. 20, no. 1 (2010).

<sup>&</sup>lt;sup>20</sup> Holly R. Wethington et al., "The Effectiveness of Interventions to Reduce Psychological Harm from Traumatic Events Among Children and Adolescents: A Systematic Review," *American Journal of Preventative Medicine*, vol. 35, no. 3 (2008).

<sup>&</sup>lt;sup>21</sup> Leyla F. Stambaugh et al., *Psychotropic Medication Use by Children in Child Welfare*, HHS, ACF, Office of Planning, Research, and Evaluation (OPRE), National Survey of Child and Adolescent Well-Being II Report. No. 17, 2012, http://www.acf.hhs.gov/programs/opre/resource/nscaw-no-17-psychotropic-medication-use-by-children-in-child-welfare. (Hereinafter Leyla F. Stambaugh et al., *Psychotropic Medication Use by Children in Child Welfare*.)

<sup>&</sup>lt;sup>22</sup> The Children's Hospital of Philadelphia, "New PolicyLab Research Expands Understanding of Psychoactive Medication Use Among Children in Foster Care," press release, April 30, 2012, http://www.chop.edu/news/psychoactive-drug-use-among-children-in-foster-care.html.

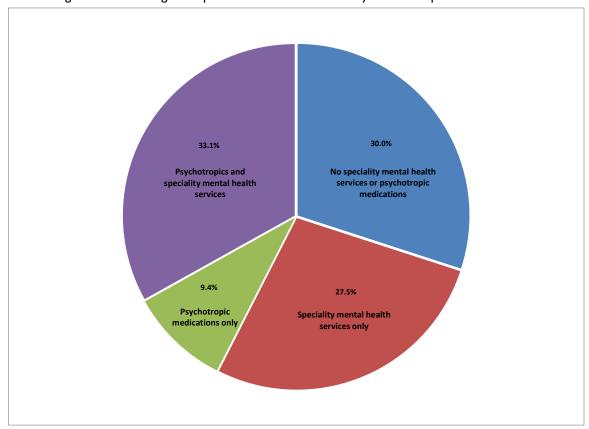
<sup>&</sup>lt;sup>23</sup> Leyla F. Stambaugh et al., Psychotropic Medication Use by Children in Child Welfare.

<sup>&</sup>lt;sup>24</sup> Barbara J. Burns et al., "Mental Health Needs and Access to Mental Health Services by Youths Involved with Child Welfare: A National Survey," *Journal of the American Academy of Child and Adolescent Psychiatry*, vol. 43, no. 8, 2004, pp. 960-970; Laurel K. Leslie et al., "Relationship Between Entry Into Child Welfare and Mental Health Service Use," *Psychiatric Services*, vol. 56, no. 8 (August 2005), p. 985.

services (e.g., counseling or residential or outpatient treatments) or psychotropics, and another 9% received psychotropics without any such services. <sup>25</sup> (See **Figure 2**.)

Figure 2. Share of Children in Foster Care (Ages 16 Months to 19 Years Old Who Met Clinical Criteria for a Mental Health Need) and Their Use of Psychotropics and Specialty Mental Health Services





**Source:** Figure prepared by the Congressional Research Service (CRS) based on data from Leyla F. Stambaugh et al., *Psychotropic Medication Use by Children in Child Welfare*, U.S. Department of Health and Human Services, Administration for Children and Families, Office of Planning, Research, and Evaluation, National Survey of Child and Adolescent Well-Being Report, No. 17, 2012.

**Notes:** These data are based on a subset of the overall sample of children in the survey who were involved in child welfare. Interviews were conducted with caregivers approximately 18 months after the investigation of child abuse or neglect that brought the child to the attention of the child welfare agency. Foster care refers to a foster family home, a formal kinship placement, and a group home or residential program. In a formal kinship care living arrangement, the caregiver receives some financial support for being a foster parent. A group home or residential program refers to a congregate care setting. Specialty mental health services can include services such as seeing a private mental health professional or family doctor mental health service, in-home counseling or

<sup>&</sup>lt;sup>25</sup> Leyla F. Stambaugh et al., *Psychotropic Medication Use by Children in Child Welfare*. Specialty mental health services include an outpatient drug or alcohol clinic, mental health or community health center, private mental health professional, in-home counseling or crisis services, treatment for emotional and substance abuse problems, therapeutic nursery, psychiatric unit in hospital, detox or inpatient unit, hospital medical inpatient unit, residential treatment center or group home, hospital emergency room for emotional and substance abuse problems, family doctor mental health service, and school-based mental health service.

crisis services, mental health or community health centers, outpatient drug or alcohol clinics, or a psychiatric unit in a hospital, among other services.

# **Use of Psychotropic Drugs by Children in Foster Care**

Between 16% and 33% of children in out-of-home care may be using psychotropic medication on any given day, although the rate of use varies significantly based on certain factors, including the child's age, placement setting, and length of involvement with the child welfare agency. Rates of psychotropic medication use among children in foster care far exceed the rates among children generally, which is about 6%. Children whose Medicaid eligibility is based on their foster care status have been found to receive psychotropic medication at three to nine times the rate of all other children served by Medicaid, and at a level that is somewhat comparable to (but still higher than) older children (ages 13 to 18) with a diagnosed mental disorder or neurodevelopmental disorder. At the same time, research based on a national study of the use of outpatient mental health services found that children living in non-relative foster family homes were no more likely than those living in their own homes to be prescribed psychotropic medication. (Importantly, this study does not include children in foster care group settings or residential treatment facilities, who tend to have higher rates of psychotropic use.)

### Variations by State and Over Time

Rates of psychotropic medication use among children involved with the child welfare system, including those in foster care, vary by state and over time. Research from the early 2000s found great variation in prescription of psychotropic medication for children involved with the child welfare system, including those in foster care. Closer analysis of the differences across states led the researchers to conclude that differences in risk for mental health services was not the primary factor leading to variation, suggesting the importance of state practices in prescribing psychotropic medication.<sup>31</sup>

<sup>&</sup>lt;sup>26</sup> Based on data from NSCAW II as received from the U.S. Department of Health and Human Services, Administration for Children and Families, Office of Planning Research and Evaluation (OPRE), January 2014. For more information, see **Annendix A** 

<sup>&</sup>lt;sup>27</sup> Leyla F. Stambaugh et al., *Psychotropic Medication Use by Children in Child Welfare*, p. 3. This prevalence is based on data from National Health Interview Survey, fielded in 2005 and 2006, and which looked at use of psychotropic drugs among children (ages 4 to 17 years) who were prescribed psychotropic drugs in the last 12 months.

<sup>&</sup>lt;sup>28</sup> Ibid. See also GAO, Foster Children: HHS Guidance Could Help States Improve Oversight of Psychotropic Prescriptions.

<sup>&</sup>lt;sup>29</sup> Kathleen R. Merikangas, et.al., "Medication Use in US Youth with Mental Disorders," *JAMA Pediatrics*, v. 167, no. 2 (2013), p. 141-148. This prevalence is based on national survey of general population of adolescents in the United States (National Comorbidity Survey Adolescent Supplement).

<sup>&</sup>lt;sup>30</sup> Lynn A. Warner, Na Kyoung Song, and Kathleen J. Pottick, "Outpatient Psychotropic Medication Use in the U.S.: A Comparison Based on Foster Care Status," *Journal of Child and Family Studies*, December 10, 2013, vol. 23, no. 4, pp. 652-665. The study is the Client/Patient Sample Survey, carried out by HHS, Substance Abuse and Mental Health Services Administration (SAMHSA) and the Centers for Medicare and Medicaid (CMS). Outpatient mental health services include those provided by a private practice mental health professional, outpatient clinic, general medical program or physician, hospital emergency room, outpatient substance abuse treatment program, and other outpatient programs.

<sup>&</sup>lt;sup>31</sup> Ramesh Ragavan, et al., "Interstate Variation in Psychotropic Medication Use Among Children in the Child Welfare (continued...)

A separate study of Medicaid claims data from 2002 to 2007 showed variation among psychotropic medication use among children whose eligibility for Medicaid was based on their "foster care" status.<sup>32</sup> The study found an initial increase in the use of psychotropic medications followed by some decline in most states. However, across this same time frame the study found an increase in the use of antipsychotic medications—which are a subset of psychotropic drugs generally used to treat schizophrenia and sometimes bipolar disorder—among children whose Medicaid eligibility was based on their "foster care" status. Specifically, it found that 45 states experienced a relative increase in the use of these medications from 2002 to 2007, two states experienced a relative decrease, and one state experienced no change over the period. In 2007, the annual rate of antipsychotic medication use among children in foster care ranged from 2.8% to 21.7% in each state.<sup>33</sup>

# Findings from the Second National Survey of Child and Adolescent Well-Being (NSCAW)

This section uses data primarily from the second National Survey on Child and Adolescent Well-Being (NSCAW II) to provide a more detailed discussion of psychotropic medication use among children in foster care.

NSCAW II examined the outcomes of a national sample of 5,872 children who came into contact with the child welfare system through an investigation of child abuse or neglect in their homes, including the extent to which these children were prescribed psychotropic medications.<sup>34</sup> The survey captured the experiences of children in this sample who remained in their homes following the investigation (including those children who stayed with their biological or adoptive parents and those who lived informally with relatives) and those who were removed from their homes and placed in foster care (including children who were placed in a non-relative foster family home, those placed formally with kin, and those who went to live in a group home or a residential program). At the time of the initial NSCAW II Survey, 4 to 6 months after the initial investigation (in 2008-2009), these children's ages ranged from 2 months to 17.5 years. At the time of the 18-month follow-up (in 2009-2011), they were 16 months to 19 years; and at the 36-month follow-up (2011-2012), they were ages 34 months to 20 years old.<sup>35</sup> Children in the sample were not

System," Child Maltreatment, vol. 15, no. 2, pp. 121-131.

<sup>(...</sup>continued)

<sup>&</sup>lt;sup>32</sup> For purposes of Medicaid eligibility "foster care" status extends to some (but not all) children in foster care, most children who are adopted from foster care, and certain children who have aged out of foster care. For further information, "Limitations on Understanding Medicaid Spending for Foster Care Children," in CRS Report R42378, *Child Welfare: Health Care Needs of Children in Foster Care and Related Federal Issues*, by Emilie Stoltzfus et al.

<sup>&</sup>lt;sup>33</sup> David Rubin et al., "Interstate Variation in Trends of Psychotropic Medication Use Among Medicaid-enrolled Children in Foster Care." This included 47 states and the District of Columbia. See also Julie M. Zito et al., "Psychotropic Medication Patterns Among Youth in Foster Care," *Pediatrics*, vol. 121, no. 1 (July 2008), pp. e157-e163 (hereinafter Julie M. Zito et al., "Psychotropic Medication Patterns Among Youth in Foster Care"); and GAO, *Foster Children: HS Guidance Could Help States Improve Oversight of Psychotropic Prescriptions*.

<sup>&</sup>lt;sup>34</sup> Congress authorized and funded this longitudinal research in Section 429 of the Social Security Act. NSCAW I, which included five waves of data collection, was conducted between 1999 and 2007. NSCAW II, which included three waves of data collection, was conducted between 2008 and 2012. Congress last provided NSCAW funding for FY2011.

<sup>&</sup>lt;sup>35</sup> NSCAW II data in this report are based on four sources (1) Heather Ringeisen et al., *NSCAW II Baseline Report: Children's Services* (for data based on four to six months after the investigation); (2) Cecilia Casanueva et al., *NSCAW II Wave 2 Report: Children's Services*, Exhibit 14, Final Report, RTI International for HHS, ACF, Office of Planning, Research and Evaluation, July 2012 (for data based on 18 months after the investigation); (3) correspondence with the (continued...)

necessarily in foster care for the entire 18- or 36-month period. They may have entered and reentered care, or they could have entered care after a subsequent investigation.

As discussed in the following sections, the NSCAW II data show that children living with their own parents following an investigation of child abuse or neglect were less likely to be using psychotropic medication than those living in foster care at that time. Among children who were in foster care, living in a congregate care and being school age forecast a greater chance that a child in foster care was taking psychotropic medications.<sup>36</sup>

### Living at Home vs. Living Out of Home

Among children in the NSCAW II study, there was not a statistically significant difference in the use of psychotropic medications among those who, at four to six months following the investigation, were placed in foster care (15.9%) and those who had remained in their homes (11.6%). However, at 18 months following the investigation, children in foster care were significantly more likely to be taking psychotropic medications than those who remained in their homes (23.1% vs. 10.9%). At the 36-month follow-up, more than one out of three children in care (32.8%) was taking psychotropics, compared to 12.9% of children who remained in their homes. (For more information, see **Appendix A**.)<sup>37</sup>

### **Placement Setting**

Among children placed in foster care, psychotropic medication use was significantly greater for those who lived in foster group homes or residential treatment programs than among those in foster family homes and formal kin care. Prevalence among children in group foster care settings was close to one-half (48.2%) for children who had been in care for six months or less after the initial investigation of child abuse or neglect. This is compared to 11.8% to 19.5% of children in the foster care settings.<sup>38</sup>

**Figure 3** shows the rate of psychotropic medication use by whether children lived out of home, or for children in foster care, all placement settings approximately 18 months after the initial investigation of child abuse or neglect.<sup>39</sup> As with the earlier wave (six months or less after the

<sup>(...</sup>continued)

U.S. Department of Health and Human Services, Administration for Children and Families, Office of Planning Research and Evaluation (OPRE), January 2014 (for data based on 4 to 6 months, 18 months, and 36 months after the investigation); and (4) Cecilia Casanueva et al., NSCAW II Wave 3 Report: Wave 3 Tables, Final Report, RTI International for HHS, ACF, Office of Planning, Research and Evaluation, June 2014 (hereinafter Cecilia Casanueva et al., NSCAW II Wave 3 Report: Wave 3 Tables.)

<sup>&</sup>lt;sup>36</sup> Some studies also show a higher rate of psychotropic use among males, compared to females. For example, the NSCAW II data indicate that a far greater percentage of males who had contact with child welfare services (including those who are not removed from the home and placed in foster care) were prescribed psychotropics (14.9% for males versus 8.5% for females) approximately 18 months following the investigation for abuse and neglect. Cecilia Casanueva et al., *NSCAW II Wave 2 Report: Children's Services*, p. 40. Similarly, data from NSCAW I showed somewhat similar results for males in foster care (19.6% versus 7.7%). Ramesh Raghavan et al., "Psychotropic Medication Use in a National Probability Sample of Children in the Child Welfare System," *Journal of Child and Adolescent Psychopharmacology, vol. 15, no. 1*, p. 97.

<sup>&</sup>lt;sup>37</sup> Based on correspondence with HHS, ACF, OPRE, January 2014.

<sup>&</sup>lt;sup>38</sup> Heather Ringeisen et al., NSCAW II Baseline Report: Children's Services, p. 45.

<sup>&</sup>lt;sup>39</sup> Cecilia Casanueva et al., NSCAW II Wave 2 Report: Children's Services, p. 40; and HHS, ACF, ACYF, AFCARS (continued...)

investigation), those in group settings were most likely to be prescribed psychotropics (67.4%), compared to less than a quarter of children in other foster care settings (15.9% to 23.8%), children who remained in their own homes (10.9%), and informal kin care (11.9%). This pattern held true 36 months after the investigation for child abuse and neglect (not shown in the figure). Just over half of children in group settings were taking psychotropics (52%). The rate of use was 16.5% to 36.1% among children in other types of foster care settings; 12.5% for children who remained in their own homes; and 16.5% for those who were in informal kin care.<sup>40</sup>

## **Concurrent Use of Psychotropic Medications**

**Figure 3** also displays the frequency with which children involved in the child welfare system were taking more than one psychotropic medication, by placement setting, approximately 18 months after the initial investigation. Compared to children in other placement settings, children in foster care group homes or residential settings were most likely to be taking more than one psychotropic medication. About half of foster children in group settings (48.6%) who were prescribed psychotropics were taking two or more drugs, whereas the rate of children in other child welfare settings taking two or more drugs was 5.7% to 14.6%. <sup>41</sup>

At 36 months following the initial investigation (not shown in the figure), about 4 of 10 children in group settings were taking two or more psychotropic medications, followed by children in foster care (18.2%), formal kin care (11.1%), informal kin care (8.8%), and those who remained in their own homes (7.2%). Children in group settings were significantly more likely to be using three or more psychotropic medications at 36 months following the investigation than children in all other settings.<sup>42</sup>

Report No. 21, July 2012. The NSCAW survey data include children in foster care at 18 or 36 months after the initial investigation that brought them to the attention of the child welfare agency. The median time that children remain in foster care is approximately 13 months, and the average stay is 22 months.

<sup>(...</sup>continued)

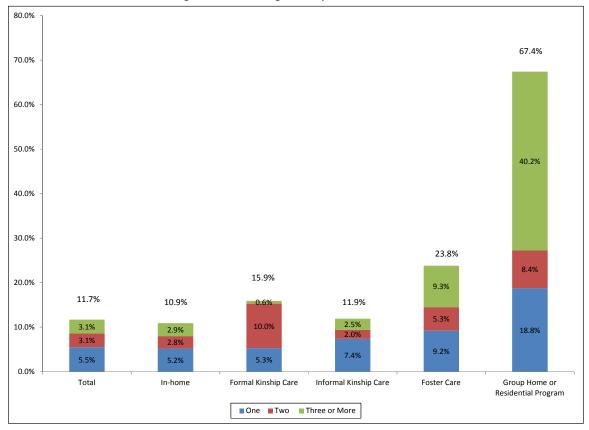
<sup>&</sup>lt;sup>40</sup> Cecilia Casanueva et al., NSCAW II Wave 3 Report: Wave 3 Tables.

<sup>&</sup>lt;sup>41</sup> Cecilia Casanueva et al., NSCAW II Wave 2 Report: Children's Services.

<sup>&</sup>lt;sup>42</sup> Cecilia Casanueva et al., NSCAW II Wave 3 Report: Wave 3 Tables.

Figure 3. Current Use of Psychotropic Medication by All Children Who Come Into Contact with Child Welfare Services, by Placement Type, and Number of Psychotropic Medications





**Source:** Figure prepared by the Congressional Research Service (CRS) based on data from Cecilia Casanueva et al., *NSCAW II Wave 2 Report: Children's Services*, Exhibit 14, Final Report, RTI International for U.S. Department of Health and Human Services, Administration for Children and Families, Office of Planning, Research and Evaluation, July 2012.

**Notes:** Interviews were conducted with caregivers approximately 18 months after the investigation of child abuse or neglect that brought the child to the attention of the child welfare agency. In-home refers to children who were not removed from the home of their parents following an investigation for abuse and neglect. Kinship care refers to living with a relative caregiver, such as a grandparent, aunt, uncle, or other relative. In a formal kinship care living arrangement, the relative caregiver receives some financial support for being a foster parent. Foster care refers to a nonrelative foster family home, and group home or residential program refers to a congregate care setting.

## Age of Children in Foster Care

In general, children in foster care were more likely to be using psychotropic medication if they were of elementary and secondary school age. **Figure 4** shows that at each wave (4 to 6 months after investigation, 18 month follow-up, and 36 month follow-up), youth ages 11 to 17 were most likely to be using psychotropics. This is followed by youth ages 6 to 10, youth ages 18 and older, and youth ages 1.5 to 5 years. Notably, the oldest youth, those ages 18 and older, were not as likely to be taking psychotropic medications as children ages 6 through 17.

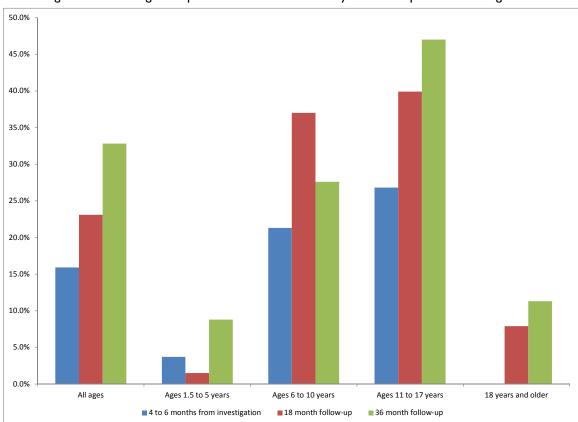


Figure 4. Current Use of Psychotropic Medication by All Children Who Come Into Contact with Child Welfare Services, by Age and Time From Initial Investigation

Percentage based on caregiver report at time of interview or youth self-report for those age 18 or older

**Source:** Figure prepared by the Congressional Research Service (CRS) based on data from Cecilia Casanueva et al., NSCAW II Wave 2 Report: Children's Services, Exhibit 14, Final Report, RTI International for U.S. Department of Health and Human Services, Administration for Children and Families, Office of Planning, Research and Evaluation, July 2012.

**Notes:** Children in the sample were not necessarily in foster care for the entire 18- or 36-month period. They may have entered and re-entered care during this time, or they could have entered care after a subsequent investigation. In-home refers to children who were not removed from the home of their parents following an investigation for abuse and neglect. Kinship care refers to living with a relative caregiver, such as a grandparent, aunt, uncle, or other relative. In a formal kinship care living arrangement, the relative caregiver receives some financial support for being a foster parent. Foster care refers to a nonrelative foster family home, and group home or residential program refers to a congregate care setting.

## Prescribing Patterns: "Too Many, Too Much, and Too Young"

The research literature has characterized patterns of prescribing psychotropic drugs to foster children as "too many, too much, and too young." "Too many" refers to children taking multiple

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<sup>&</sup>lt;sup>43</sup> HHS, ACF, ACYF, CB, "Oversight of Psychotropic Medication for Children in Foster Care; Title IV-B Health Care (continued...)

psychotropic medications at a time. An analysis of national Medicaid claims data from 2002 through 2007 found that polypharmacy—defined in the analysis as concurrent use of three or more psychotropic medication classes for at least 30 days during a one-year period—was fairly consistent over that period, at about 5.2% to 5.9%, annually, among all children whose eligibility for Medicaid was based on their "foster care" status. <sup>44</sup> Data from the NSCAW II study indicate that for children in foster care who were prescribed psychotropics, the average number of psychotropics per child was 1.9 on a given day. <sup>45</sup>

As discussed previously, **Figure 3** illustrates the percentage of children who were prescribed one, two, or three or more psychotropic medications. The difference between the shares of children in group or residential settings who are prescribed three or more psychotropics is statistically significant when compared to the other groups of children. Concerns have been raised about using certain classes of psychotropics, such as antipsychotics, concurrently. Antipsychotic polypharmacy (i.e., use of multiple antipsychotic medications) has not been well researched and has typically demonstrated "greater adverse effects with only marginal benefits."

Further, "too much" refers to the prescriptions for foster children in dosages that exceed recommendations. This is of particular concern because, as discussed above, studies on the safety and efficacy of these medications for children are limited. Finally, "too young" refers to concerns that very young children are prescribed psychotropics. The NSCAW II study found that 2.2% of children under the age of 6 in out-of-home care (foster care, formal kinship care, or group home and residential programs) were prescribed psychotropics. A 2011 GAO report examined the use of psychotropic drugs among foster children in five states, and found that in each of these states 0.3% to 2.1% of children under age 1 were prescribed psychotropics, compared to a lower rate (0.1% to 1.2%) of infants of the same age who were not in foster care. Health experts have raised concerns that there are no established mental health indications for the use of psychotropic drugs in infants, and that psychotropics use by infants can lead to serious health effects. A

# Weighing the Benefits of Psychotropics

Because children in foster care tend to have greater mental health service needs than other children, they may be more likely to benefit from psychotropic medications. Still, as mentioned previously, psychotropic medications may not be effective in treating the mental health needs of some individuals.

Children in care may more readily receive psychotropics due to the paucity of psychosocial services available. This could be due to a number of factors, including a shortage of mental health

Oversight & Coordination Plan," April 11, 2012. (Hereinafter HHS, ACF, ACYF, CB, "Oversight of Psychotropic Medication for Children in Foster Care; Title IV-B Health Care Oversight & Coordination Plan.")

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<sup>(...</sup>continued)

<sup>&</sup>lt;sup>44</sup> David Rubin et al., "Interstate Variation in Trends of Psychotropic Medication Use Among Medicaid-enrolled Children in Foster Care."

<sup>&</sup>lt;sup>45</sup> Leyla F. Stambaugh et al., Psychotropic Medication Use by Children in Child Welfare, p. 4.

<sup>&</sup>lt;sup>46</sup> Susan dosReis et al., "Antipsychotic Treatment Among Youth in Foster Care," *Pediatrics*, vol. 128, no. 6 (December 2011). (Hereinafter Susan dosReis et al., "Antipsychotic Treatment Among Youth in Foster Care.")

<sup>&</sup>lt;sup>47</sup> Cecilia Casanueva et al., NSCAW II Wave 2 Report: Children's Services, Exhibit 14.

<sup>&</sup>lt;sup>48</sup> GAO, Foster Children: HHS Guidance Could Help States Improve Oversight of Psychotropic Prescriptions, p. 15.

providers generally and of those who have clinical understanding of the complex trauma many children in foster care may have experienced and/or who specialize in therapies that have proven to be effective. While the rate of prescribing psychotropics has decreased in recent years, the use of certain classes of these drugs—namely antipsychotics, used for the off-label treatment of children who have bipolar disorders and schizophrenia, and used to treat certain other behavioral conditions—has steadily grown. As discussed previously, the share of children in foster care prescribed antipsychotic medication increased from 2002 to 2007, with an average change across states of 12.8% over this period. This increase could be due to a number of factors, including more research (albeit limited) on the efficacy of these medications in children and the role of pharmaceutical companies marketing drugs to prescribers and consumers. Further, children generally have increasingly been prescribed certain psychotropic medications in recent years.

The use of psychotropics by children in foster care has come under growing scrutiny by policymakers and stakeholders in the child welfare field. Although there is an expanding body of research on psychotropic use among children with mental health disorders, few studies show that they are safe and effective for this population. A review by the Department of Health and Human Services (HHS) of research on one class of psychotropics, antipsychotics, found that most studies had insufficient evidence to draw a conclusion about the safety of these drugs in addressing child mental health disorders generally—not just those occurring among foster youth. Further, little to no evidence was available for certain conditions such as disruptive behavior disorders, obsessive compulsive disorders, or eating disorders (i.e., anorexia nervosa). According to the analysis, the median study duration of eight weeks was insufficient to evaluate some long-term outcomes. The analysis also found that most of the studies had a high risk of bias because missing data were not handled and reported properly, study participants were not randomly assigned to the treatment groups, and/or the studies were funded by pharmaceutical companies that manufacture the psychotropic medication. Other research has shown that antipsychotics are associated with

<sup>&</sup>lt;sup>49</sup> Institute of Medicine of the National Academies, Committee on Crossing the Quality Chasm: Adaptation to Mental Health and Addictive Disorders, *Improving the Quality of Health Care for Mental and Substance-Use Conditions: Quality Chasm Series*, 2006; and Myrna M. Weissman et al., "National Survey of Psychotherapy Training in Psychiatry, Psychology, and Social Work," *Archives of General Psychiatry*, vol. 63 (2006).

<sup>&</sup>lt;sup>50</sup> The Food and Drug Administration (FDA) approves a drug for sale based on evidence of safety and effectiveness in its intended use, manufacturing requirements, and labeling. Despite the indications for use in the approved labeling, a licensed physician may—except in highly regulated circumstances—prescribe the approved drug without restriction. Prescription to an individual whose demographic or medical characteristics differ from those indicated in a drug's FDA-approved labeling is called off-label use and is accepted medical practice. Off-label use presents an evaluation problem to FDA safety reviewers. Using drugs in new ways for which researchers have not yet demonstrated safety and effectiveness can create problems that premarket studies did not address. Manufacturers rarely design studies to establish the safety and effectiveness of their drugs in off-label uses, and individuals and groups wanting to conduct such studies face difficulties finding funding. FDA's role in making sure a drug is safe and effective continues after the drug is approved and it appears on the market. FDA oversees surveillance, studies, labeling changes, and information dissemination, among other tasks, as long as the drug is sold. For further information, see CRS Report R41983, *How FDA Approves Drugs and Regulates Their Safety and Effectiveness*, by Susan Thaul.

<sup>&</sup>lt;sup>51</sup> GAO, Children's Mental Health, GAO-13-15, December 2012, http://www.gao.gov/products/gao-13-15, pp. 10-11.

<sup>&</sup>lt;sup>52</sup> Mark Olfson et al., "National Trends in the Mental Health Care of Children, Adolescents, and Adults by Office-Based Physicians."

<sup>&</sup>lt;sup>53</sup> HHS, Agency for Healthcare Research and Quality, Effective Health Care Program, *First- and Second-Generation Antipsychotics for Children and Young Adults*, Executive Summary, Comparative Effectiveness Review No. 39, February 12, 2012, http://www.effectivehealthcare.ahrq.gov/ehc/products/147/835/CER39\_Antipsychotics-Children-Young-Adults 20120221.pdf.

harmful health outcomes in some children, including high cholesterol levels, weight gain, and type-2 diabetes. 54

Despite these concerns, some children in foster care may benefit from psychotropic medication for managing symptoms and issues associated with mental health and behavior concerns stemming from their exposure to complex trauma, particularly if this treatment is coupled with psychosocial services. Stimulants for the treatment of attention deficit hyperactivity disorder (ADHD), a common childhood disorder, appear to be among the best researched of the antipsychotic classes. Multiple studies with research methodologies that used randomized control trials have found that some stimulants are very effective at reducing the core symptoms of ADHD, including hyperactivity, impulsivity, inattention, and aggression. State of the state

Further, children in foster care are more likely to have a mental health diagnosis than children generally, including children who are low income. A 2011 Government Accountability Office (GAO) report on psychotropic medication use by children in foster care cited statements from state officials and child psychiatrists that higher levels of psychotropic drug use may be appropriate to deal with the increased prevalence and greater severity of mental health conditions among this population. In addition, multiple foster care placements and inconsistent state oversight practices for managing their care may contribute to the likelihood that psychotropics are used to respond to the mental health needs of these children.<sup>57</sup>

## **Congressional Oversight**

Congress has taken a strong interest in oversight of prescription medications used by children in foster care. In 2005, the House Ways and Means Subcommittee on Human Resources held a hearing to examine the enrollment of children in foster care in clinical drug trials. The hearing followed media reports concerning use of foster children in clinical AIDS drug trials and addressed the extent to which states properly oversee prescription drug use by children in foster care. As part of the Child and Family Services Improvement Act of 2006 (P.L. 109-288), Congress required state child welfare agencies, as a condition of receiving certain child welfare funding, to describe how they actively consulted with physicians or other medical professionals in assessing the health and well-being of children in foster care and in determining appropriate medical treatment for them. 59

The issue of oversight of psychotropic medication use for children in foster care in particular was briefly discussed at a 2007 congressional hearing on health care oversight for children in foster care, and it was the sole topic of a 2008 hearing (both held by the Ways and Means Subcommittee

<sup>&</sup>lt;sup>54</sup> Leyla F. Stambaugh et al., *Psychotropic Medication Use by Children in Child Welfare*.

<sup>&</sup>lt;sup>55</sup> JoAnne Solchany, "Psychotropic Medication and Children in Foster Care: Tips for Advocates and Judges," *Child Law Practice*, vol. 31, no. 2 (February 2010), pp. 17, 22-27; HHS, ACF, ACYF, CB, "Promoting Social and Emotional Well-Being for Children and Youth Receiving Child Welfare Services," April 2012.

<sup>&</sup>lt;sup>56</sup> Barbara J. Burns, Kimberly Hoagwood, and Patricia J. Mrazek, "Effective Treatment for Mental Disorders in Children and Adolescents," vol. 2, no. 4 (1999), pp. 212-213, 232-233.

<sup>&</sup>lt;sup>57</sup> GAO, Foster Children: HHS Guidance Could Help States Improve Oversight of Psychotropic Prescriptions.

<sup>&</sup>lt;sup>58</sup> U.S Congress, House Ways and Means Subcommittee on Human Resources, *Protection for Foster Children Enrolled in Clinical Trials*, May 18, 2005, 109<sup>th</sup> Cong., 1<sup>st</sup> Sess.

<sup>&</sup>lt;sup>59</sup> Section 6(c) of P.L. 109-288, which added this requirement to Section 422(b)(14) of the Social Security Act.

on Income Security and Family Support<sup>60</sup>). Subsequently, as part of the Fostering Connections to Success and Increasing Adoptions Act of 2008 (P.L. 110-351), Congress expanded on the requirement that states consult with medical professionals on the health and well-being of children in foster care. Specifically, states are required through their child welfare and Medicaid agencies, and in consultation with appropriate medical professionals, to develop a coordinated strategy and oversight plan to ensure access to health care, including mental health services for each child in foster care. The 2008 law directed states to ensure this coordinated strategy provided for oversight of drugs prescribed to children in foster care. In October 2011, the Child and Family Services Improvement and Innovation Act (P.L. 112-34) amended this provision to further stipulate that the coordinated strategy must include protocols for use of psychotropic medication for children in foster care.

In December 2011, the Senate Homeland Security and Governmental Affairs Subcommittee on Federal Financial Management, Government Information, Federal Services and International Security held an oversight hearing<sup>62</sup> that focused on the results and recommendations of the aforementioned study by the Government Accountability Office. GAO reviewed state policies and regulations for oversight of prescribing psychotropic medications in six states.<sup>63</sup> The study compared state policies against best practice guidelines for prescribing psychotropics for foster children and other vulnerable child populations. These best practice guidelines were developed by the American Academy of Child and Adolescent Psychiatry (AACAP) in consultation with the Substance Abuse and Mental Health Services Administration (SAMHSA) at HHS.<sup>64</sup> Overall, GAO found that each of the six state programs falls short of providing comprehensive oversight as defined by AACAP. For example, though all six states implemented some practices consistent with the guidelines for consent procedures, only one state (Texas) fully implemented these procedures.<sup>65</sup> According to the report, states that do not incorporate consent procedures similar to AACAP's guidelines may increase the likelihood that caregivers are not fully aware of the risks and benefits associated with the decision to use psychotropic medications.

Witnesses at the hearing spoke about the role of HHS and the state Medicaid programs in increasing cooperation and communication between the agencies and discussed how HHS could increase the guidance on best practices to assist states in preparing plans for psychotropic medication oversight. Further, a 12-year-old former foster youth described being given multiple

<sup>&</sup>lt;sup>60</sup> This subcommittee was previously, and is now, known as the Human Resources subcommittee.

<sup>&</sup>lt;sup>61</sup> U.S. Congress, House Ways and Means Subcommittee on Income Security and Family Support, *Health Care of Children in Foster Care*, July 19, 2002, 110<sup>th</sup> Cong., 1<sup>st</sup> Sess. and *Prescription Psychotropic Drug Use Among Children in Foster Care*, May 8, 2008, 110<sup>th</sup> Cong., 2<sup>nd</sup> Sess.

<sup>&</sup>lt;sup>62</sup> U.S. Congress, Senate Committee on Homeland Security and Governmental Affairs, Subcommittee on Federal Financial Management, Government Information, Federal Services, and International Security, *The Cost of Medicating America's Foster Children*, 112<sup>th</sup> Cong., 1<sup>st</sup> sess., December 2011, S. Hrg. 112–448.

<sup>&</sup>lt;sup>63</sup> GAO, Foster Children: HHS Guidance Could Help States Improve Oversight of Psychotropic Prescriptions, GAO-12-270T, December 1, 2011, http://www.gao.gov/products/GAO-12-270T.

<sup>&</sup>lt;sup>64</sup> American Academy of Child and Adolescent Psychiatry, AACAP Position Statement on Oversight of Psychotropic Medication Use for Children in State Custody: A Best Principles Guideline, no date, http://www.aacap.org/ App\_Themes/AACAP/docs/member\_resources/practice\_information/foster\_care/
FosterCare\_BestPrinciples\_FINAL.pdf. The AACAP guidelines are targeted for children in care and other settings.
These guidelines focus on screening and monitoring; continuity of care, effective case management, and longitudinal treatment planning; access to effective psychosocial, psychotherapeutic, and behavioral treatments, and when indicated, pharmacotherapy; consent by the authorized person or agency and assent from the youth; and effective medication management that identifies symptoms, monitors response to treatment, and screens for adverse effects.

<sup>&</sup>lt;sup>65</sup> These states are Florida, Maryland, Massachusetts, Michigan, Oregon, and Texas.

mental health diagnoses and side effects he experienced from multiple psychotropic medications that were prescribed to him while in foster care. He also testified that a therapist that he saw with his adoptive parents was most helpful to him.

Additionally, in April 2013 the Senate Finance Committee convened a roundtable discussion with Senate staff and child welfare stakeholders to address issues associated with the prescription of psychotropic medications for children in foster care and to highlight alternative strategies to effectively respond to trauma experienced by children and youth in foster care. At the roundtable, current and former foster youth shared their experiences with psychotropic medication and some noted that therapy ultimately helped them transition from psychotropic medications. The youths' stories sometimes highlighted the importance of an invested caregiver or other knowledgeable professional in ensuring that appropriate mental health treatment is identified and provided. Child welfare stakeholders discussed the prevalence of psychotropic medication use among subpopulations of youth; the role of the federal government in promoting alternatives to psychotropics; tools for determining whether youth should be prescribed medications; and the roles of schools, the mental health system, and foster parents in engaging with youth on whether psychotropic medications should be prescribed.

Finally, in May 2014 the House Ways and Means Subcommittee on Human Resources held a hearing on the use of psychotropic medications among children in foster care and the efforts of states and the federal government to ensure that such medications are used appropriately. Witnesses included the Associate Commissioner of HHS's Children's Bureau; GAO; a researcher who focuses on psychotropic medication use among children in care; and Dr. Phil McGraw, who has sought to bring greater awareness to the issue. 66

## **Recent Executive Branch Actions**

The Administration has proposed expanding funding for oversight of psychotropic medications as part of the FY2016 budget, which, as of the date of this report, has not been enacted. In addition, several federal agencies have worked both together and independently to help gain a better understanding of psychotropic medication use among children (especially children in foster care). As part of their efforts to promote interagency cooperation, they have publicized best practices and successful state strategies related to the oversight of psychotropic medication use for children and the development of alternative strategies for children with mental health needs.

# FY2016 Request: Demonstration to Address "Over-Prescription" of Psychotropic Medication for Children in Foster Care<sup>67</sup>

The President's budget proposes a five-year joint initiative between CMS and ACF to reduce reliance on psychotropic medications for children in foster care and improve their well-being. This would be accomplished by providing performance-based incentive payments to state Medicaid agencies (total of \$500 million in incentive funding across five years, FY2016-FY2020)

<sup>&</sup>lt;sup>66</sup> U.S. Congress, House Committee on Ways and Means, Subcommittee on Human Resources, *Caring for Our Kids: Are We Overmedicating Children in Foster Care?*, 113<sup>th</sup> Cong., 2<sup>nd</sup> sess., May 22, 2014.

<sup>&</sup>lt;sup>67</sup> HHS, *Fiscal Year 2016 Budget: Strengthening Health and Opportunity for All Americans*, February 2015, p. 103. The Administration had the same proposal in the FY2015 budget.

that meet certain outcomes or other requirements related to improved care coordination and delivery of evidence-based psychosocial interventions to Medicaid-eligible children who are also served by child welfare agencies. Incentive payments would be paid annually out of the Medicaid program (Title XIX of the Social Security Act) over the five-year periodm.<sup>68</sup>

States could also apply, through the state child welfare agency, for competitive grant funding under the Title IV-E Foster Care program (total of \$250 million across five years, FY2016-FY2020) to build state capacity and infrastructure to implement alternative psychosocial interventions. ACF funding would support activities that include child welfare funding for training of caregivers and caseworkers on mental health needs of children in care, screening and assessment tools, coordination between the child welfare and Medicaid systems, and fidelity monitoring of implementation of evidence-based intervention. 69

## Federal Interagency Working Group Established

In the summer of 2011, HHS convened an interagency working group to address emerging research on the use of psychotropic medication among children in foster care and to support state efforts in implementing the requirements on psychotropics in P.L. 112-34. The working group is led by the Administration for Children and Families (ACF), which administers child welfare programs, and includes representatives from other HHS agencies, including the Centers for Medicare and Medicaid Services (CMS) and the Substance Abuse and Mental Health Services Administration (SAMHSA). The working group developed a plan to expand the use of evidence-based screening, diagnosis, and interventions; strengthen the oversight and monitoring of psychotropic medications; and expand the research evidence regarding medications and psychosocial treatments for children in foster care. <sup>70</sup>

## State Interagency Cooperation and Collaboration Promoted

In November 2011, three agencies in the working group—ACF, SAMHSA, and CMS—released a letter addressed to the directors of each state child welfare, Medicaid, and mental health agency. The letter addressed actions being taken at the three federal agencies to "support effective management" of prescription medication use for children in foster care. 71 According to the letter,

<sup>&</sup>lt;sup>68</sup> Under the FY2015 proposal, incentive payments would have been paid annually out of the Medicaid program (Title XIX of the Social Security Act) over the five-year period. According to HHS, the incentive payments may be modeled on performance bonuses authorized under the Children's Health Insurance Program Reauthorization Act (CHIPRA). The proposed incentive payments would not have affected how payments are made to Medicaid providers. Those providers would continue to be reimbursed for Medicaid services through normal Medicaid reimbursement procedures. Based on CRS correspondence with U.S. Department of Health and Human Services, Office of the Assistant Secretary for Financial Resources, March 19, 2014.

<sup>&</sup>lt;sup>69</sup> According to the proposed FY2015 budget, the demonstration sought to serve at least 400,000 children in foster care over the five-year period. States would not have been able to supplant other funds used by the state to carry out the Medicaid state plan, or activities under Titles IV-B or IV-E of the Social Security Act. HHS has explained that the Secretary would have been required to evaluate the demonstration to assess the changes put in place by states; determine whether children in care receive a more appropriate mix of services; and determine whether children's social and emotional functioning is improved. The evaluation would have included a process evaluation, an outcome evaluation, and a cost analysis. Based on CRS correspondence with U.S. Department of Health and Human Services, Office of the Assistant Secretary for Financial Resources, March 19, 2014.

<sup>&</sup>lt;sup>70</sup> Leyla F. Stambaugh et al., *Psychotropic Medication Use by Children in Child Welfare*.

<sup>&</sup>lt;sup>71</sup> HHS, Joint HHS Letter from George Sheldon, Acting Assistant Secretary, ACF; Donald Berwick, Administrator, (continued...)

"State Medicaid/CHIP agencies and mental health authorities play a significant role in providing continuous access to and receipt of quality mental health services for children in out-of-home care. Therefore it is essential that State child welfare, Medicaid, and mental health authorities collaborate in any efforts to improve health, including medication use and prescription monitoring structures in particular." The letter further discussed other steps the agencies would take to raise awareness about psychotropic use among children in foster care.

ACF, SAMHSA, and CMS (in partnership with their training and technical assistance providers) subsequently took steps to provide guidance to states and other stakeholders on oversight of psychotropics through a series of webinars and information memoranda. In January and February 2012, they held webinars for child welfare and other stakeholders that presented data, research, and practices for monitoring and oversight of psychotropic medication use among children in foster care. In addition, the three agencies held a series of question and answer discussion sessions in March through June 2012 for state child welfare and mental health leaders who are working together on plans to enhance oversight and monitoring.

In late August 2012, HHS (ACF, SAMHSA, and CMS) convened state directors of child welfare, Medicaid, and mental health agencies to address the use of psychotropic medications for children in foster care and the mental health needs of children who have experienced trauma. The summit, "Because Minds Matter," was intended to provide an opportunity for state leaders to enhance their collaboration on the appropriate use of psychotropic medications. They were asked to examine what aspects of oversight needed improvement and the steps needed to implement changes. States were also asked to outline the activities they would undertake to meet their goals, the anticipated challenges, the necessary partners, and a timeline for implementation. The summit included multiple presentations from HHS staff, researchers, and selected state teams about a range of psychotropic oversight and related topics.

Since the summit, HHS has furthered its work in this area. For example, ACF awarded FY2012 funds to nine entities (state and county child welfare agencies, universities, and a children's

CMS; and Pamela Hyde, Administrator, SAMHSA to "State Director," November 23, 2011, http://www.childwelfare.gov/systemwide/mentalhealth/effectiveness/jointlettermeds.pdf.

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<sup>(...</sup>continued)

<sup>&</sup>lt;sup>72</sup> HHS, *Use of Psychotropics Among Children in Foster Care*, webinar series, January and February 2012, http://gucchdtacenter.georgetown.edu/child\_welfare-Past.html. The first two parts of the series focused on providing current data and research on the use of psychotropic medications, including data on the age of children using the medications, the types of foster care placements, and polypharmacy. They also included a presentation solely focused on child trauma and its role in treatment approach and prescription of medications. The third webinar presentation discussed the findings of a study by Tufts University on state oversight and how two states, Illinois and Texas, are overseeing psychotropic medication use by children in foster care.

<sup>&</sup>lt;sup>73</sup> HHS, ACF, ACYF, *Getting Practical: Developing Your State Plan for Psychotropic Medication Management*, webinar series, March through June 2012, http://gucchdtacenter.georgetown.edu/child\_welfare.html.

<sup>&</sup>lt;sup>74</sup> HHS, ACF, CMS, SAMHSA, *Because Minds Matter: Collaborating to Strengthen Management of Psychotropic Medications for Children and Youth in Foster Care*,

<sup>&</sup>quot;Purpose of the Meeting," https://www.childwelfare.gov/systemwide/mentalhealth/effectiveness/mindsmatter.pdf.

<sup>&</sup>lt;sup>75</sup> HHS, ACF, CMS, SAMHSA, *Because Minds Matter: Collaborating to Strengthen Management of Psychotropic Medications for Children and Youth in Foster Care*, "State Team Handouts," http://www.pal-tech.com/web/psychotropic/.

<sup>&</sup>lt;sup>76</sup> HHS, ACF, CMS, SAMHSA, *Because Minds Matter: Collaborating to Strengthen Management of Psychotropic Medications for Children and Youth in Foster Care*, "Plenary PowerPoints and Handouts" and "Workshop PowerPoints and Handouts," http://www.pal-tech.com/web/psychotropic/.

hospital) to support projects intended to provide assistance to youth in child welfare who have mental and behavioral health needs using evidence-based intervention models.<sup>77</sup> ACF also awarded FY2013 funds to six entities (state child welfare agencies, universities, and a children's organization) to promote well-being after children experience trauma.<sup>78</sup>

### Professional Protocols and Other State Best Practices Disseminated

In April 2012, ACF provided guidance to state child welfare agencies on implementing protocols to monitor the use of psychotropic medication. As part of this guidance, HHS synthesized information about use of psychotropics based on guidelines issued by child welfare and medical professionals. 79 These elements address coordinated planning, informed and shared decisionmaking, medication monitoring, mental health expertise and consultation, and mechanisms for sharing accurate and up-to-date information. 80 (As discussed in a subsequent section, HHS requires that states report on the extent to which these elements are in place as part of their monitoring of psychotropic drug use for children in foster care.) ACF also issued separate guidance in April 2012 to state child welfare agencies about the ways they can focus on improving the behavioral and social-emotional outcomes for children who have experienced abuse and/or neglect. The guidance discussed the emerging evidence on the impact of maltreatment in terms of its effect on brain development as it affects a child's social and emotional development. It also outlined the federal child welfare and Medicaid requirements (including those discussed in this report) around meeting the emotional and behavioral needs of children in foster care, and the ways in which states and child welfare agencies can respond to these needs.81

The CMS Center for Medicaid and CHIP Services issued an informational bulletin in August 2012 to make states aware of resources and opportunities to address the use of psychotropic

<sup>&</sup>lt;sup>77</sup> HHS, ACF, ACYF, CB, "Initiative to Improve Access to Needs-Driven, Evidence-Based/Evidence-informed Mental and Behavioral Health Services in Child Welfare," Application HHS-2012-ACF-ACYF-CO-0279, http://www.acf.hhs.gov/grants/open/foa/files/HHS-2012-ACF-ACYF-CO-0279\_0.pdf. These funds were awarded under the Adoption Opportunities program. For further information about the grantees, see http://www.acf.hhs.gov/programs/cb/resource/discretionary-grant-awards-2012.

<sup>&</sup>lt;sup>78</sup> HHS, ACF, ACYF, CB, "Promoting Well-Being and Adoption After Trauma," Application HHS-2012-ACF-ACYF-CO-0637, http://www.acf.hhs.gov/grants/open/foa/view/HHS-2013-ACF-ACYF-CO-0637. These funds were awarded under the Adoption Opportunities program. For further information about the grantees, see http://www.acf.hhs.gov/programs/cb/resource/discretionary-grant-awards-2013.

<sup>&</sup>lt;sup>79</sup> For example, the American Academy of Child and Adolescent Psychiatry (AACAP), which represents professionals that work in the field of child psychopharmacology, developed basic principles on the psychiatric and pharmacologic treatment of children in care. See American Academy of Child and Adolescent Psychiatry, *AACAP Position Statement on Oversight of Psychotropic Medication Use for Children in State Custody: A Best Principles Guideline*, no date, http://www.aacap.org/App\_Themes/AACAP/docs/member\_resources/practice\_information/foster\_care/ FosterCare\_BestPrinciples\_FINAL.pdf. In addition, the Reach Institute convened an expert panel to develop best practices for addressing the mental health needs of children involved in child welfare. See Lisa Hunter Romanelli et al., "Best Practices for Mental Health in Child Welfare: Screening, Assessment, and Treatment Guidelines," *Child Welfare*, vol. 88, no. 1 (2009).

<sup>&</sup>lt;sup>80</sup> HHS, ACF, ACYF, CB, "Oversight of Psychotropic Medication for Children in Foster Care; Title IV-B Health Care Oversight & Coordination

<sup>&</sup>lt;sup>81</sup> HHS, ACF, ACYF, CB, "Promoting Social and Emotional Well-Being for Children and Youth Receiving Child Welfare Services," Information Memorandum ACYF-CB-IM-12-04, April 17, 2012, http://www.acf.hhs.gov/sites/default/files/cb/im1204.pdf. (Hereinafter HHS, ACF, ACYF, CB, "Promoting Social and Emotional Well-Being for Children and Youth Receiving Child Welfare Services.")

medication in vulnerable populations, including children in foster care. The informational bulletin noted that all states are required to have Drug Utilization Review programs in place to oversee the prescribing of drugs for Medicaid beneficiaries and provided examples of the way some states have used this review to provide oversight of psychotropic medication use. For example, automated system "edit checks" may be used to ensure prescriptions are consistent with accepted medical practice (e.g., special authorization must be granted for prescriptions of children younger than a given age). The bulletin alternatively noted that some states have multidisciplinary teams (drawing from public and private entities) to review cases and ensure appropriate prescription of psychotropics. Further, the bulletin advised states that "robust screening and assessment practices that are attentive to trauma and social/emotional functions, careful and coordinated treatment planning, and the judicious and thoughtful use of all treatment options available to the youth, especially those with a strong evidence base" are practices most likely to support health and well-being of youth in foster care who have potential behavioral health problems. 

\*\*Review Programs\*\* in place to oversee the prescription of the way some states and provided examples of the way some states have multidisciplinary teams (drawing from public and private entities) to review cases and ensure appropriate prescription of psychotropics. Further, the bulletin advised states that "robust screening and assessment practices that are attentive to trauma and social/emotional functions, careful and coordinated treatment planning, and the judicious and thoughtful use of all treatment options available to the youth, especially those with a strong evidence base" are practices most likely to support health and well-being of youth in foster care who have potential behavioral health problems.

CMS, ACF, and SAMHSA issued joint guidance in July 2013 to convey the importance of making psychosocial interventions available to children who have experienced "complex trauma"—described in the guidance as "children's exposure to multiple or prolonged traumatic events, which are often invasive and interpersonal in nature"—and to highlight how states may use existing federal funding and authority to provide those interventions. The guidance noted that children in foster care may be more likely to receive psychotropic medication, and may not be prescribed psychotropics properly, because of the complexity of their symptoms and the lack of appropriate screening, assessment, and treatment. The guidance promoted the use of functional assessments (periodic evaluation of a child's well-being using standardized, valid, and reliable measurement tools), trauma screening (brief evaluation of potential trauma symptoms and/or history), mental health assessment (in-depth clinical evaluation of an individual's mental health status), and outcome measurement and progress monitoring (measuring success by tracking child-level well-being outcomes to ensure treatment services are achieving desired improvements in children's health and functioning).

Finally, the July 2013 interagency guidance discusses existing federal programs and policies in each of three systems (child welfare, mental health, and Medicaid) that can be used to serve children with mental health treatment needs associated with complex trauma. These include funding for services provided to state child welfare agencies under Title IV-B (of the Social Security Act), which among many other things may be used to fund family or individual counseling that responds to the trauma-related needs of children involved in child welfare. Further, child welfare agencies can use Title IV-E funding under the Social Security Act to support child welfare training concerning the nature and consequences of child trauma, the use of screening and assessment tools, and evidence-based practices to address trauma. (However, Title IV-E training dollars may not be used to train workers to provide services that respond to children's mental health needs.) Medicaid offers states a way to finance screenings, assessments, behavioral health services, therapy, and case management for children with complex trauma needs (many of these services are mandatory for eligible children), and it may also be used to pay for prescription drugs. Finally, SAMHSA administers block grant funding that may support non-Medicaid covered treatment services, and it supports other technical assistance and projects

<sup>&</sup>lt;sup>82</sup> HHS, CMS, Center for Medicaid and CHIP Services, Informational Bulletin, "Collaborative Efforts and Technical Assistance Resources to Strengthen the Management of Psychotropic Medications for Vulnerable Populations," August 24, 2012, http://medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-08-24-12.pdf.

related to understanding trauma experienced by children and providing evidence-based and effective treatment.<sup>83</sup>

## **State Oversight Efforts**

Recent studies have focused on the role of states in overseeing the use of psychotropic medication for children in foster care. For example, some research has addressed the issue of obtaining consent for using psychotropics or examining how certain states are carrying out their monitoring procedures. Researchers have also conducted surveys of states to learn about their policies related to the oversight of psychotropic medications. Some of these surveys predate the specific requirement for oversight of prescription medications and others have been conducted since then; however, none of these surveys address how states have responded to the federal provision (added to the law in September 2011) on oversight of psychotropic medications specifically.

In 2009 and 2010, researchers surveyed states to learn about the status of policies and guidelines for overseeing the use of psychotropic medication by children in foster care, as well as related challenges and solutions that were identified by states. Researchers collected information from 48 states, including the District of Columbia. Of the states surveyed, more than half (58.7%) rated psychotropic medication use to be of high concern (a rating of 8 to 10 on a scale of 1 to 10). About a quarter of the states rated the issue of moderate concern (a rating of 5 to 7), and about 13% rated it of low concern (a rating of 1 to 4). At the time of the survey, 26 of the 48 states had a written policy or guideline regarding psychotropic medication use; 13 states were currently developing a policy or guideline; and 9 states had no policy or guideline. Slightly more than half of states used at least a "red flag" marker to identify problems with the safety and quality of psychotropic drug use. Red flags that states described using included the use of psychotropic medications in young children, the use of multiple medications before the use of a single medication, use of multiple psychotropic medications simultaneously, use of multiple medications within the same class for longer than 30 days, and dosage exceeding current maximum recommendations. Researchers concluded that states were implementing a wide variety of approaches, and that there was little evidence that these approaches were being implemented or studied in a systematic way to identify which approaches helped improve outcomes for children in foster care.85

On the other hand, researchers have raised concerns about the availability of policies and procedures that respond to psychotropic medication use. As reported in a 2014 study, these researchers reviewed the statutes, rules, and statements of policies on oversight of psychotropic drug use among children in care from 16 states (which have 72% of all children in care nationally). They were unable to locate many of the policies that had been reported in other studies, and when they did exist, the policies were "extremely underdeveloped and failed to

<sup>83</sup> HHS, ACF, CMS, SAMHSA, "Dear State Director."

<sup>&</sup>lt;sup>84</sup> Michael W. Naylor, Christine V. Davidson, and D. Jean Ortega-Piron, et al., "Psychotropic Medication Management for Youth in State Care: Consent, Oversight, and Policy Considerations," *Child Welfare*, vol. 86, no. 5 (September/October 2007), pp. 175-192.

<sup>&</sup>lt;sup>85</sup> Thomas J. Mackie, "Psychotropic Medication Oversight for Youth in Foster Care: A National Perspective on State Child Welfare Policy and Practice Guidelines," *Children and Youth Services Review*, vol. 33., no. 11 (2011) and Laurel K. Leslie et al., *Multi-State Study on Psychotropic Medication Oversight in Foster Care*, Tufts University, Tufts Clinical and Translational Science Institute, September 2010, http://160.109.101.132/icrhps/prodserv/docs/ Executive Report 09-07-10 348.pdf.

include many of the 'red flag' criteria that both experts and states identified as essential to protecting children, such as the use of psychotropic medication for young children, dosage level, and whether multiple psychotropic medications were prescribed simultaneously."86

# Current Federal Requirements Related to the Oversight of Health Care for Children in Foster Care

As noted above, under the Stephanie Tubbs Jones Child Welfare Services Program (Title IV-B, Subpart 1 of the Social Security Act) states must develop a coordinated strategy and oversight plan to ensure access to health care, including mental health services and dental care, for all children in foster care. This coordinated strategy and oversight plan must be developed via a collaborative effort between the state child welfare agency and the state agency that administers Medicaid, in consultation with pediatric and other health care experts, as well as experts in, or recipients of, child welfare services.<sup>87</sup> The coordinated strategy must outline

- a schedule for initial and follow-up health screenings that meet reasonable standards of medical practice;
- how health needs identified through screenings, including emotional trauma associated with a child's maltreatment and removal from home, will be monitored and treated:
- how medical information for children in care will be updated and appropriately shared, which may include the development and implementation of an electronic health record;
- steps to ensure continuity of health care services, which may include the establishment of a medical home for every child in care;
- the oversight of prescription medicines, including protocols for the appropriate use and monitoring of psychotropic medications (italics added for emphasis);
- how the state actively consults with and involves physicians or other appropriate
  medical or nonmedical professionals in assessing the health and well-being of
  children in foster care and in determining appropriate medical treatment for the
  children; and
- steps to ensure that the components of the transition plan development process related to the health care needs of children aging out of foster care are met.

Additionally, federal child welfare law requires that the state child welfare agency have a written plan for each child in foster care, including certain health-related records. These records must include the names and addresses of the child's health providers, a record of the child's immunizations, information about the child's medication, and any other relevant health information concerning the child.<sup>88</sup> These records must be reviewed, updated, and supplied to a

<sup>&</sup>lt;sup>86</sup> Kathleen Noonan and Dorothy Miller, "Fostering Transparency: A Preliminary Review of "Policy" Governing Psychotropic Medications in Foster Care," *Hastings Law Journal*, vol. 65 (August 2014).

<sup>87</sup> Section 422(a)(15) of the Social Security Act.

<sup>88</sup> Section 475(1)(C) of the Social Security Act.

child's foster care parent or provider at the time of each foster care placement. Additionally, a copy of the record must be provided to a youth at the time he/she leaves care due to age. 89

# State Protocols Related to Use of Psychotropic Medications for Children in Foster Care

The Congressional Research Service (CRS) reviewed state policies on oversight of psychotropic medications. The review looked at the first set of annual reports (known as Annual Progress and Services Reports, or APSRs) submitted by states to HHS following the 2011 enactment of the requirement for protocols specific to psychotropic medication and as such provide a baseline scan of state policy just after the law was changed. The reports are required each year for states seeking federal funds under a number of child welfare programs, including the Stephanie Tubbs Jones Child Welfare Services Program. The 2012 reports that were reviewed by CRS discussed state plans for FY2013 and were the first reports in which HHS required states, consistent with the new requirements added by the Child and Family Services Improvement Act, to describe specific protocols for the appropriate use and monitoring of psychotropic medications for children in foster care (and to identify, through health screenings, whether children have experienced emotional trauma). As shown in the text box below, state oversight protocols must address screening and evaluation to identify mental health needs; consent and assent to treatment and ongoing communication; medication monitoring; availability of mental health expertise; and mechanisms for sharing current information and education materials.

<sup>89</sup> Section 475(5)(D) of the Social Security Act.

States must develop a five-year Child and Family Services Plan (CFSP) to describe how they intend to provide child welfare-related child and family services, including meeting requirements of child welfare services programs. In addition to program funding for the Child Welfare Services Program, submission of this report is required for states to receive federal formula funding under the Promoting Safe and Stable Families Program (Title IV-B, Subpart 2 of the Social Security Act), Title I of the Child Abuse Prevention and Treatment Act (CAPTA), and the Chafee Foster Care Independence Program, including Education and Training Vouchers. The most recent five-year plan was developed in 2009 to cover FY2010-FY2014. Additionally, in each year other than the year in which the initial CFSP is submitted, the state must submit an Annual Progress and Services Report (APSR) to discuss how the state is accomplishing the goals and objectives of the CFSP and include other assurances related to federal funding for child welfare-related services. Federal regulations at 45 CFR 1357 apply to the CFSP. The CFSP process began in 1994. Since this time, HHS has issued annual Program Instructions (PI) regarding how to meet the CFSP and annual update requirements.

<sup>&</sup>lt;sup>91</sup> For the report submitted in 2013, states were asked to provide information on these same protocols and to inform HHS whether they have been updated in light of the "Because Minds Matter" summit hosted by HHS in August 2012. For the final report submitted for the FY2010 through FY2014 period, and the CFSP for FY2015 through FY2019, HHS requested information about the oversight of prescription medicines, including protocols for the appropriate use and monitoring of psychotropic medications.

## Program Instructions for the Annual Progress and Services Report, 2012

States must submit information to HHS on their plans to provide child and family services by June 30 of each year. The report to be submitted for June 2012 (describing plans for FY2013) was the first in which states were required to provide their protocols for oversight of psychotropic medication use among children in foster care. According to HHS, these protocols were developed from guidelines put forth by the American Academy of Child and Adolescent Psychiatry and the Reach Institute, among others. They include the following:

- Comprehensive and coordinated screening, assessment, and treatment planning mechanisms to identify children's mental health and trauma-treatment needs (including a psychiatric evaluation, as necessary, to identify needs for psychotropic medication).
- Informed and shared decision-making (consent and assent) and methods for ongoing communication between the prescriber, the child, his/her caregivers, other healthcare providers, the child welfare worker, and other key stakeholders.
- Effective medication monitoring at both the client and agency level.
- Availability of mental health expertise and consultation regarding both consent and monitoring issues by a
  board-certified or board-eligible Child and Adolescent Psychiatrist (at both the agency and individual case
  level).
- Mechanisms for accessing and sharing accurate and up-to-date information and educational materials related to mental health and trauma-related interventions (including information about psychotropics) to clinicians, child welfare staff, and consumers.

**Source:** Title IV-B Child and Family Services Plan; Child Abuse Prevention and Treatment State Plan; Chafee Foster Care Independence Program; Educational Training Vouchers Program, ACYF-CB-PI-12-05, April 11, 2012.

## CRS Review of State Plans: Process and Limitations

HHS provided CRS with the 2012 APSRs between March and September 2013. The 2012 APSR includes information about state procedures that were in place at least through the submission deadline of June 2012. The review examined portions of the APSR that addressed the five oversight areas shown in the text box above. In addition, CRS used specific search terms, such as "psychotropics" or "medications," to identify other possibly relevant sections of the report. CRS sought to identify common themes within each of the protocols and discuss these across states. If states provided information CRS deemed relevant to more than one protocol, it included this information in its discussion of all relevant protocols. Additionally, in some cases states referenced other state policy manuals or guidance when explaining a protocol for a specific oversight area. CRS reviewed this additional information only when states provided a website address for the document.

CRS's ability to make comparisons across states was limited in a number of ways, including variability in detail, format and style, and reporting by states. In addition, states did not use uniform definitions for some key terms. (For more information about these limitations, see **Appendix B**.) Additionally, while states may have strengthened their oversight protocols since they submitted the 2012 APSR, this CRS review provides a baseline or benchmark of state procedures immediately after the law changed to require states to have such protocols.

<sup>&</sup>lt;sup>92</sup> Thirty-seven states have APSRs with final dates that are between July and November 2012.

## **Overview of Findings**

### Mental Health Screening and Treatment Planning

Thirty states indicated that they provide a mental health evaluation (a screening and/or assessment) for children in care. Ten of these states indicated that they had a trauma screening tool to screen children for traumatic events. The evaluations appear to be available for all children, though some states limit them to children of a minimum age (e.g., age three or older).

States most frequently indicated that evaluations are conducted by the child's primary care physician or a "qualified" (not defined) physician; mental health professional such as a psychiatrist; or staff at community mental health centers, among other types of professionals. States that indicated a time frame for evaluations generally reported that they occur within 30 days of a child being removed from home. Less than half of the states provided information about the steps they take in responding to health care evaluations, which include referrals for services, providing services, and medication.

## Consent, Assent, and Ongoing Communication

Thirty-four states provided information concerning their policies related to consent and assent to treatment with psychotropic medication and their methods for ongoing communication between stakeholders involved in the child's health care. States indicated that consent involves one or more of the following parties: a parent/legal guardian, the child, the child welfare agency, and a court/judge. Over half of these states reported that a parent or legal guardian is involved in providing consent. Some states reported requiring a pre-authorization process for the use of psychotropics, in addition to consent or as part of consent. This generally requires the prescriber to submit a request with details about the child, the diagnosis, and the medication to a board, committee, team, or other designated authority that must approve the request before treatment can begin.

Fourteen states provided a description of the information shared among stakeholders as part of the consent process, including type of diagnosis, medication and dosage, benefits or expected results, and potential side effects, among other topics. Most states indicated that a "provider" or "prescriber" could prescribe psychotropic medications. A small number of states were more specific about who could prescribe, indicating that a licensed or licensed and certified physician or a board certified or board eligible specialist in psychiatry, among others, could prescribe psychotropics for children in foster care.

Almost half of all states provided some information about methods for ongoing communication after a child has begun treatment with psychotropic medication. Among others, these include specific databases, a child's medical passport or medical record, and caseworker visits with a child and his/her caregiver family. The types of information shared as a part of ongoing communication include medication details, treatment notes, medical histories, medication benefits or side effects, and changes in medication.

## **Medication Monitoring**

States were asked to describe any written policies related to effective medication monitoring at both the client and agency level. Thirty-six states provided information about monitoring use of

psychotropic medication at the client level. States described monitoring both the child and the child's prescriptions.

Monitoring of the child is primarily focused on determining how the medication is affecting him/her. States most frequently mentioned monitoring for side effects and whether targeted symptoms have improved, remained the same, or deteriorated. Thirty-six states described processes used to monitor how medication is affecting an individual child, such as through conversations between the child and caregiver and between the child, caregiver, and caseworker; and logs maintained by the caregiver.

Twenty-five states provided information about medication monitoring at the agency level. Such monitoring can be conducted by the child welfare agency, the overall health program for children in foster care, or special committees or review boards. These entities examined specific aspects of prescribing patterns or trends that they track such as rates of polypharmacy, <sup>93</sup> types of medications, or the number of children receiving medications.

## Availability of "Board-Certified" Child and Adolescent Psychiatrists

States did not provide a great deal of detail about the availability of mental health expertise and consultation. Most of the information provided addresses the availability of mental health expertise for individual children rather than for the child welfare agency overall. Seven states specifically reported having access to "board-certified" or "board-eligible" child and adolescent psychiatrists for consultation or review related to the use of psychotropic medication. Thirteen states reported having access to a psychiatrist, a child/adolescent psychiatrist, or a psychiatric consultation service but did not specifically use the term "board-certified" or "board-eligible." Several states generally described the role of the psychiatrist or psychiatric consultation service for an individual child, as well as the specific ways that psychiatrists are involved in consent and monitoring for individual children. Three states described how psychiatrists provide consultation at the agency level.

## **Education and Training about Psychotropics**

Finally, 35 states provided some information about mechanisms for accessing and sharing accurate and up-to-date information and educational materials. These included training, publications, or other materials about psychotropic medications. The 35 states indicated that training is available for child welfare staff; clinicians; and other child welfare stakeholders, including foster parents, staff at residential facilities, juvenile justice agency staff, and children's advocacy groups. States generally did not indicate that information and educational materials are provided to children in care, although one state indicated that it had plans to provide information to foster children.

More detailed findings from the CRS review of state APSRs are discussed in **Appendix B**.

<sup>&</sup>lt;sup>93</sup> Polypharmacy is the practice of prescribing multiple drugs to be taken concurrently to treat one or more health problems. *Mosby's Dictionary of Medicine, Nursing, & Health Professions*, "polypharmacy," http://www.credoreference.com/entry/ehsmosbymed/polypharmacy; *Dictionary of Medical Terms*, "polypharmacy," http://www.credoreference.com/entry/acbmedterm/polypharmacy.

## **Concluding Thoughts**

The findings from the state plans raise policy issues that may be relevant to Congress as it considers the next steps in oversight of psychotropic use among children in foster care. These issues include the use of medical homes and electronic health records to improve oversight of psychotropic medications, and the role of Medicaid in improving screenings and services for children in care with mental health needs. Other potential considerations are the involvement of children and youth in their mental health care and the extent to which states should report to HHS on their oversight policies.

### **Health Homes or Medical Homes**

Children in foster care often lack consistent adults in their lives due to changes in living situations that result in new caregivers and possibly new caseworkers and health care providers. This may mean that no adult is fully aware of a child's current or prior mental health diagnoses or treatments, which creates an additional challenge in trying to identify and provide for a child's mental health needs. The concept of a "health home" or "medical home" is one way to address this challenge.

A "health home" is a strategy for helping people with chronic conditions, including mental health conditions, better manage those conditions through the provision of integrated services. <sup>94</sup> A health home can be a single person or a team of people that have access to the same information about a client or patient and coordinate treatment based on that information. In addition to addressing a person's physical and mental health conditions, health homes are meant to provide connections to community care services and supports, social services, and family services. Section 2703 of the Affordable Care Act, which enacted health care reforms, provides states with the option to cover health home services under Medicaid for eligible beneficiaries with target chronic conditions identified by each state. CMS has approved Medicaid state plan amendments for 12 states that have established health homes to coordinate care for these beneficiaries. 95 In guidance about the development of protocols for the appropriate use and monitoring of psychotropic medications, ACF indicates that state plans for ongoing oversight and coordination of health care services for children in foster care can incorporate a medical home for these children. Specifically, the plan must describe how states will "ensure a coordinated strategy to identify and respond to the health care needs of children in foster care placements ... and provide for continuity of health care services, which may include establishing a 'medical home' for children who are in foster care."96 It is unclear the extent to which states in general are establishing health or medical homes for

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<sup>&</sup>lt;sup>94</sup> HHS, SAMHSA, "Health Homes," http://beta.samhsa.gov/health-reform/health-care-integration/health-homes; HHS, SAMHSA, "What Is a Health Home?" SAMHSA Blog, December 4, 2010, http://blog.samhsa.gov/2010/12/04/what-is-a-health-home/; HHS, SAMHSA, "Health Homes: A Strategy to Improve Care," *SAMHSA News*, vol. 12, no. 2 (Spring 2013), http://www.samhsa.gov/samhsaNewsLetter/Volume\_21\_Number\_2/improve\_care.aspx; HHS, CMS, "Health Homes," Medicaid.gov, http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Integrating-Care/Health-Homes/Health-Homes.html.

<sup>&</sup>lt;sup>95</sup> For a list of these State Plan Amendments, see http://www.medicaid.gov/State-Resource-Center/Medicaid-State-Technical-Assistance/Health-Homes-Technical-Assistance/Approved-Health-Home-State-Plan-Amendments.html.

<sup>&</sup>lt;sup>96</sup> HHS, ACF, ACYF, CB, "Oversight of Psychotropic Medication for Children in Foster Care; Title IV-B Health Care Oversight & Coordination.

children in care under the authority of the Affordable Care Act or otherwise, though some states appear to have taken steps to do so.<sup>97</sup>

#### **Electronic Health Records**

One of the ways that health homes provide integrated services is by ensuring that all members of an individual's health home team have access to the same information. An important mechanism for providing that access is electronic health records (EHRs). The use of electronic health records has the potential to greatly improve information sharing among the stakeholders responsible for serving children in foster care. Separately from the protocols related to the oversight of the use of psychotropic medications, HHS instructed states to report in their state plans on "How medical information will be updated and appropriately shared, which may include developing and implementing an electronic health record." The enhanced information sharing afforded by electronic health records could potentially improve the accuracy and efficacy of medical diagnoses and treatments, and provide easier access to data on the use of psychotropic medications for children in care. "99"

Existing federal health care law may be relevant to this issue. The Health Information Technology for Economic and Clinical Health Act, which was passed as part of the American Recovery and Reinvestment Act of 2009 (HITECH Act, P.L. 111-5), promotes the adoption of health information technology for the electronic sharing of clinical data through incentives and, in some cases, penalties. <sup>100</sup>

#### Medicaid

Most children in foster care receive medical care through the Medicaid program. As such, child welfare agencies, via the health care plans they provide children, would presumably be subject to or would have to incorporate or mirror Medicaid guidelines and policies in a wide range of areas, including the monitoring of psychotropic medications. The law requires that states must develop their health care oversight and coordination plan with the state Medicaid agency, among other stakeholders. Some states discussed how certain features of the Medicaid program—namely, Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services and the Drug Utilization Review (DUR)—are used to diagnose and respond to children in foster care with mental health needs. Nonetheless, HHS did not specifically request, and states generally did not address, how child welfare policies regarding oversight of psychotropic medications are connected to or comply with Medicaid policies.

<sup>&</sup>lt;sup>97</sup> See for example, information about a statewide medical home model in Illinois: Paula Kienberger Jaudes et al., "Expanding medical home model works for children in foster care," *Child Welfare*, vol. 91, no. 1 (2012), pp. 9-33.

<sup>&</sup>lt;sup>98</sup> HHS, ACF, ACYF, CB, Program Instruction ACYF-CB-PI-12-05, April 11, 2012, p. 12, available at http://www.acf.hhs.gov/sites/default/files/cb/pi1205.pdf.

<sup>&</sup>lt;sup>99</sup> HHS, ACF, ACYF, CB, Information Memorandum ACYF-CB-IM-12-03, April 11, 2012, p. 16, http://www.acf.hhs.gov/sites/default/files/cb/im1203.pdf.

<sup>&</sup>lt;sup>100</sup> For further information, see CRS Report R40161, *The Health Information Technology for Economic and Clinical Health (HITECH) Act*, by C. Stephen Redhead.

#### Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)

The EPSDT program is a required benefit for all children under age 21 who are covered by Medicaid. The program covers health screenings and services, including assessments of each child's physical and mental health development; laboratory tests (including lead blood level assessment); appropriate immunizations; health education; and vision, dental, and hearing services. The EPSDT program is intended to make health care services available and assist eligible children and their families in effectively using health care resources. <sup>101</sup>

However, it is unclear from the APSRs whether all states actually provide the screenings part of the program and include mental health as a component of these screenings. A 2010 report by the HHS Office of Inspector General (OIG) found that many Medicaid-eligible children did not receive all the EPSDT services, and this is consistent with earlier studies by the HHS OIG showing inconsistent receipt of basic health care services for children in foster care. CMS has taken steps to work with states to promote access to mental health services for children through EPSDT, such as by forming a national EPSDT workgroup and issuing guidance to help inform states about resources available to help meet the mental health (and substance abuse) needs of children through EPSDT. In conducting oversight on the use of psychotropic medication by children in care, Congress may choose to examine the extent to which these children in particular are receiving EPSDT services, and the extent to which mental health screenings and services are provided for this population.

## **Drug Utilization Review**

The Medicaid Drug Utilization Review (DUR) Program is a process through which state Medicaid agencies electronically monitor prescription drug claims to identify problems such as polypharmacy (the use of multiple medications at one time), incorrect dosage, or potential adverse drug interactions and analyze claims data to identify fraud or abuse. CMS requires all states to have DUR programs in place and to report annually on their state's pharmacy program operations, including the monitoring of prescription drugs. DURs could be useful for the child

<sup>&</sup>lt;sup>101</sup> HHS, ACF, CMS, SAMHSA, "Dear State Director," July 2013.

<sup>&</sup>lt;sup>102</sup> HHS, OIG, "Most Medicaid Children in Nine States Are Not Receiving All Required Preventive Screening Services," May 2010 (OEI-05-08-00520). The report cited a need for improved documentation of certain screenings as well as better provider knowledge of what a screening entails (among other things) as ways to improve services. In December 2010, CMS convened a National EPSDT Improvement Workgroup to help identify areas for improvement of EPSDT and to work at the federal level and with states to improve both children's access to EPSDT services and the quality of the data reporting on receipt of those services. See http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-Periodic-Screening-Diagnosis-and-Treatment.html.

<sup>&</sup>lt;sup>103</sup> GAO, Children's Mental Health: Concerns Remain about Appropriate Services for Children in Medicaid and Foster Care, GAO-13-15, December 2015, pp. 23-24. HHS, CMS, Center for Medicaid and CHIP Services, "Prevention and Early Identification of Mental Health and Substance Use Conditions," Informational Bulletin, March 27, 2013, http://www.medicaid.gov/federal-policy-guidance/downloads/CIB-03-27-2013.pdf.

<sup>104</sup> In guidance to state child welfare agencies, HHS has emphasized foster children's eligibility for screening and other services under the EPSDT program. See U.S. Department of Health and Human Services, Administration for Children and Families, Administration for Children, Youth and Families, Children's Bureau, "Promoting Social and Emotional Well-Being for Children and Youth Receiving Child Welfare Services."

HHS, CMS, Center for Medicaid and CHIP Services, "Drug Utilization Review," http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Prescription-Drugs/Drug-Utilization-Review.html; Informational Bulletin, August 24, 2012, http://www.medicaid.gov/Federal-Policy-Guidance/downloads/CIB-08-24-12.pdf

welfare population because of the potential to flag the issues outlined previously. A small number of states provided information in their plans about how they are using their DURs to monitor oversight generally of children enrolled in Medicaid, including foster children. Still, it is unclear how most states coordinate prescription drug monitoring efforts with the state DUR program.

# Youth Engagement

States were not specifically asked to discuss how they engage children and youth in oversight of psychotropic medications; however, this appears to be somewhat implied under the second protocol, which addresses informed and shared decision-making (consent and assent) and methods for ongoing communication between various stakeholders, including the child. HHS has identified "youth engagement and empowerment" as a component of strengthening management of psychotropic medications. <sup>106</sup> Few states described the involvement of young people in making decisions about their mental health treatment or taking psychotropic medications. Eleven states reported involving children in the consent process, and one state specifically mentioned that it had plans to provide information to foster children about the use of psychotropic medications.

With support from SAMHSA, AACAP developed guidance for child and adolescent psychiatrists to communicate and partner with youth about their treatment. Congress might choose to examine whether such guidance might be useful for states to distribute to stakeholders involved in the mental health care of children in foster care.

# Reporting on Oversight

In its program instructions, HHS directed states to provide fairly detailed information beyond basic information about "the oversight of prescription medicines, including protocols for the appropriate use and monitoring of psychotropic medications." HHS specifically requested information about the methods and policies states implement to coordinate screenings and assessment to identify mental health needs, availability of mental health expertise to consult with the child welfare agencies, and monitoring of medications for individuals in foster care and all children in care generally, among other items. Given the breadth of information requested and provided, an issue might be whether more specific and uniform information should be gathered from states. For example, Congress could request that HHS provide a summary of information about certain aspects of oversight and define terms that are relevant to this oversight (e.g., psychotropics, medication, screening, board-certified or board-eligible psychiatrist, training) to better capture uniform information across states. Still, more narrowly focused reporting may not necessarily yield responses that can be easily synthesized across states.

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<sup>&</sup>lt;sup>106</sup> Bryan Samuels, [former] Commissioner, HHS, ACF, ACYF, "Strengthening Psychotropic Medication Management: Another Step in Improving Well-Being of Children in Foster Care." Because Minds Matter: Collaborating to Strengthen Management of Psychotropic Medications for Children and Youth in Foster Care.

<sup>&</sup>lt;sup>107</sup> American Academy of Child & Adolescent Psychiatry, "Youth Voice Tip Sheet, Communication Between Child and Adolescent Psychiatrist & Youth: 10 Tips to Improve the Conversation," January 2012, http://www.aacap.org/ App Themes/AACAP/docs/youth resources/misc/Youth Voice Tip Sheet 2012.pdf.

# Appendix A. Use of Psychotropics Among Children in Families Investigated for Abuse or Neglect

The National Survey of Child and Adolescent Wellbeing (NSCAW) II looked at rates of psychotropic medication use among a sample of children (5,873) who came into contact with the child welfare agency because of an investigation of child abuse or neglect in their families. Initial (baseline) survey data were collected in 2008-2009 approximately four to six months after that investigation. With regard to use of psychotropic medication, data cover children who at the time of the initial survey were at least 18 months of age and up to 17 years old. A follow-up survey looked at psychotropic medication use among these same children at approximately 18 months after the investigation of abuse or neglect, and a third survey looked at those children at 36 months following the investigation. (Some of the children followed had reached age 18 or older by the second or third collection of data.)

**Table A-1** shows psychotropic medication use by age, and whether or not the child was in a foster care setting for the initial survey and for the follow-up at 18 months and 36 months. For purposes of this analysis, a foster care setting includes children who were placed in a non-relative foster family home, children placed with kin on a formal basis, and children placed in a group or residential setting. By contrast, children included in the "in home" category includes children living with their biological or adoptive parents, as well as children who were in informal kinship care settings.

# Statistical Significance

The percentage differences shown by the initial survey in use of psychotropic medication (between children in foster care and those who were not in foster care) were not statistically significant overall or for any specific age group shown in **Table A-1**. However, the differences shown for these groups at the 18-month and 36-month follow-up were statistically significant, with children in foster care more likely to be using psychotropic medications.

For children under age 6, there was no statistical significance found in the percentage differences shown for children in foster care versus those living at home in any of the surveys (initial, 18-month or 36-month). For children ages 6 to 10, the percentage difference shown between the inhome and foster care groups at the 18-month follow-up was found to be statistically significant but not those shown at the initial survey or at the 36-month follow-up. For children ages 11 through 17 years, there was not statistical significance found between the in-home and foster care groups at the initial survey but the differences shown at the 18-month and 36-month follow-up were significant.

# Table A-I. Current Use of Psychotropic Medication Among Children in Families Investigated for Child Abuse or Neglect

Percentages based on caregiver report at time of interview or youth self-report for those 18 or older

Age at Time of Survey and Placement Status of Children	Initial Survey	18- Month Follow- Up	36- Month Follow- Up
TOTAL (18 months or older)			
Foster Care	15.9%	23.1% <sup>a</sup>	32.8% <sup>a</sup>
In-home	11.6%	11.0%	12.9%
Ages 18 months to 5 years <sup>b</sup>			
Foster Care	3.7%	1.5%	8.8%
In-home	1.4%	1.6%	1.6%
Ages 6-10 years			
Foster Care	21.3%	37.0%a	27.6%
In-home	19.5%	19.2%	16.1%
Ages II-I7 years			
Foster Care	26.8%	39.9%ª	47.0% <sup>a</sup>
In-home	15.7%	13.8%	16.5%
Age 18 or older			
Include all youth age 18 or older regardless of where they lived.	NA	7.9%	11.3%

**Source:** Congressional Research Service, based on data from NSCAW II as received from the U.S. Department of Health and Human Services, Administration for Children and Families, Office of Planning Research and Evaluation (OPRE), January 2014.

**Note:** Children in the sample were not necessarily in foster care for the entire 18- or 36-month period. They may have entered and re-entered care during this time, or they could have entered care after a subsequent investigation. Children in foster care include those who were living in a non-relative foster family home, formal kinship care, or a group home/residential program. Those shown as living "in-home" were those who remained with their biological or adoptive parents or those who were living informally in kinship care.

- a. Indicates that children in this group of foster care children were significantly more likely to be taking psychotropic medication than the comparable group of children who were living in their own homes during the same point in time.
- b. The overall NSCAW sample included children as young as two months at the beginning of the study. The data on psychotropic use includes children in the sample who were 18 months and older. Some children in the sample were not yet 18 months old at the initial survey, and later aged into the sample at the 18-month follow-up. This led to an increase in the overall number of children in the sample at 18 months and 36 months.

# Appendix B. Findings from CRS Review of State Oversight of Psychotropic Medication

Beginning with FY2012, the U.S. Department of Health and Human Services (HHS) has required states to provide specific information on state protocols for use of psychotropic medication. States were required to provide this information in their Annual Progress and Services Report (APSR), which is part of the documentation states must submit to receive funding under the Stephanie Tubbs Jones Child Welfare Services Program (Child Welfare Services Program). This documentation is known as the Child and Family Services Plan.

HHS provided CRS with the 2012 APSRs between March and September of 2013. The 2012 APSR includes information about state procedures that were in place at least through the submission deadline of June 2012. The review examined portions of the APSR that addressed the five oversight areas, or protocols: (1) mental health evaluations and treatment planning; (2) consent, assent, and ongoing communication; (3) psychotropic medication monitoring; (4) availability of "board-certified" child and adolescent psychiatrists; and (5) education and training about psychotropics.

In addition, CRS used specific search terms, such as "psychotropics" or "medications," to identify other possibly relevant sections of the report. CRS sought to identify common themes within each of the five protocols and discuss these across states. If states provided information CRS deemed relevant to more than one protocol, it included this information in its discussion of all relevant protocols. Additionally, in some cases states referenced other state policy manuals or guidance when explaining a protocol for a specific oversight area. CRS reviewed this additional information only when states provided a website address for the document.

CRS's ability to make comparisons across states was limited in a number of ways. First, states were asked to provide this information as part of an annual review of their child and family services objectives. This review is provided in an unstructured narrative format. States varied significantly in both the level of detail provided on the oversight protocols for psychotropic medication and the way in which they included this information in the report. Some states included discrete sections on each or many of the protocols related to oversight of psychotropic medications, while others integrated this information into parts of their broader health oversight plans. For example, some states discussed screenings and assessment related to mental health as part of their overall discussion of health screenings rather than as part of a separate protocol for oversight of psychotropic medications. Further, states responded with varying levels of information, with some giving detailed information on most or all of the five protocols and others providing minimal information on only some of the protocols. Finally, the guidance provided to states regarding the protocols did not define key terms and states sometimes used different terms to describe apparently similar concepts. This variability limited the extent to which CRS could compare policies across states. Nonetheless, the discussion of state protocols for oversight of the use of psychotropic medication by children in foster care provides a unique scan of state policies in this area.

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<sup>&</sup>lt;sup>108</sup> Thirty-seven states have APSRs with final dates that are between July and November 2012.

The review attempted to capture the variety of responses by identifying commonalities and grouping similar information into categories. For example, the CRS analysis identified five categories for the protocol on consent and assent that seemed to capture the most frequently cited information from the APSRs on this protocol. In some cases, states provided overlapping information that was relevant for multiple protocols. The CRS analysis includes some of the same information in two or more protocols.

# Protocol 1: Comprehensive and Coordinated Screening, Assessment, and Treatment Planning Mechanisms

For protocol 1, states were asked about their efforts to provide "comprehensive and coordinated screening, assessment, and treatment planning mechanisms to identify children's mental health and trauma-treatment needs." The guidance does not define the terms *screening*, *assessment*, *mental health*, or *trauma treatment needs*, or describe for whom screenings and assessments should be conducted. Based on responses from states, screenings and assessments often are used interchangeably, but a few states indicated that a screening was a method for determining whether the child needed further assessment (sometimes called an evaluation) to identify any mental health needs.

In total, 40 states reported some information on how they identify children's mental health and trauma-treatment needs through screenings and assessments (hereinafter, "mental health evaluation"). Another 12 states had little or no information on evaluations. Generally, the responding states discussed evaluations and treatment planning as part of their overall discussion of psychotropics; however, when little information was provided, CRS expanded its review to sections of the APSR that address health care screenings generally for children in foster care. As part of the health screenings, states must report on "a schedule for initial and follow-up health screenings that meet reasonable standards of medical practice" and "how health needs identified through screenings, including emotional trauma associated with a child's maltreatment and removal from home, will be monitored and treated."

States addressed various aspects of evaluations and treatment planning, including

- the type of evaluations used and what they entail;
- who conducts evaluations;
- evaluations based on age;
- the time frame for conducting evaluations, including any follow-up activities;
- whether evaluations are coordinated through Medicaid as part of the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program;
- what the treatment plan entails; and

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<sup>&</sup>lt;sup>109</sup> At least one study refers to a "mental health evaluation" for children in foster care as "screening and/or assessment for emotional and behavioral problems." In Laurel K. Leslie et al., *Multi-State Study on Psychotropic Medication Oversight in Foster Care*, Tufts University, Tufts Clinical and Translational Science Institute, September 2010, http://160.109.101.132/icrhps/prodserv/docs/Executive Report 09-07-10 348.pdf.

the extent to which evaluations seek to identify trauma.

## Type of Mental Health Evaluations Used

Thirty states indicated that they provide a mental health evaluation for children in care, and the evaluations appear to be available for all children in those states. These states indicated that they conduct evaluations for "mental health," "behavioral," or "emotional" concerns. Many of the states indicated that the evaluations were used to identify emotional, behavioral, mental health, or substance abuse issues; identify instances in which the child sustained trauma; or determine the appropriateness of prescribing medication.

Fourteen states indicated that children in care receive a mental health screening through their Medicaid program. <sup>110</sup> The EPSDT program is a required benefit for nearly all Medicaid beneficiaries under the age of 21, and among other services it covers health screenings, including assessments of a child's physical development and mental health. <sup>111</sup>

Ten states specified that they had a trauma evaluation tool only, or a trauma screening tool in addition to the mental health screening tool. A few states discussed having a clinical assessment specifically for children before they are prescribed psychotropic medications, and provided little additional information. The remaining states specified that they conduct physical health exams, but did not indicate whether the exams include a mental health component, or states were ambiguous about whether they conducted evaluations. For example, one state indicated that the child welfare worker is to ask the caregiver to encourage the medical provider to identify any mental health care services the child may need.

Some states discussed that the evaluations are conducted through conversations with caregivers or by requesting caregivers to complete behavioral checklists; interactions with the child; and gathering information about the child's health history. Six states identified the particular type of evaluation tool used, such as the Pediatric Symptom Checklist (PSC) and Child & Adolescent Needs and Strengths Methodology (CANS).

#### Who Conducts Evaluations

Twenty-six states provided some information about who conducts mental health evaluations. Five of those states had ambiguous or limited responses, and therefore CRS was unable to determine

screenings and services must be provided at regular intervals that meet "reasonable" medical or dental practice

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standards.

<sup>&</sup>lt;sup>110</sup> Nearly all children in foster care are eligible for Medicaid, which is a means-tested entitlement program administered by the federal government in partnership with states. Medicaid finances the delivery of primary and acute medical services as well as long-term care. Anne M. Libby et al., "Child Welfare Systems Policies and Practices Affecting Medicaid Health Insurance for Children: A National Study," *Journal of Social Science Research*, vol. 33, no. 2 (2006), p. 33.

<sup>&</sup>lt;sup>111</sup> Children in foster care are categorically eligible for Medicaid because they qualify for assistance under the Title IV-E foster care program, or via other mandatory or optional pathways that are available under each state's Medicaid plan. Children in care are generally entitled to the same set of "traditional" Medicaid state plan services available to other categorically needy children enrolled in a given state's Medicaid program. Central among these benefits is a provision in the law requiring that children receive all medically necessary services authorized in federal statute through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. The EPSDT program covers health screenings and services, including assessments of each child's physical development and mental health; laboratory tests (including screening blood lead test); appropriate immunizations; health education; and vision, dental, and hearing services. The

who is responsible. States indicated that a variety of individuals perform evaluations for children in foster care, as listed below:

- a primary care physician or "qualified" (not defined) physician (five states);
- mental health professionals including psychiatrists, child and adolescent psychiatrists, and licensed clinical psychologists, among others (five states);
- staff at community mental health centers (five states);
- Medicaid agency or contracted Medicaid provider (three states);
- child welfare workers, other social workers, or child welfare-licensed residential providers (seven states); and
- public health nurses with the state department of health (two states).

Some states indicated that multiple types of professionals could conduct the evaluation. Nevada discussed that the person who conducts the screening can vary based on the county in which a child resides and the type of setting in which he or she is placed. In addition, some states explained that professionals (e.g., public health nurse, primary care physician) worked in collaboration to conduct the assessment

### Age Criteria

Generally, states that provided information about evaluations appear to make them available for all children in care; however, eight states indicated that evaluations were available for children who were of a specific age. Generally, these age criteria specify that children can be screened or assessed once they reach a certain age (e.g., age 2 or older) and one state indicated a separate screening for children under age 3.

### Time Frame and Follow-Up

Twenty-eight states indicated the time frame in which the evaluations must be conducted; one of these states was ambiguous about when they occur (i.e., "shortly after removal"). Seven states indicated that evaluations are to be conducted within 10 days; 3 states require them within 14 or 15 days; 11 states require them within 30 days; 3 states require them within 45 days; and 1 state requires them within 60 days. The state that indicated the screening within 60 days noted that the state was likely changing the timeframe to within 30 days. Two other states indicated two different timeframes, depending on the type of assessment and the child's location in the state.

Eight states mentioned that they provide follow-up mental health evaluations and did not provide much detail. Some of these states specified the follow-up period (every six months, biannually, etc.) while others indicated that the screenings/assessments are conducted periodically.

# **Treatment Planning**

As part of the first protocol, states were asked to discuss their efforts at carrying out treatment planning for children's mental health needs. Eighteen states provided information about steps they take in responding to health care screenings and assessments. Some states indicated that children are referred for additional evaluations, while other states indicated that children are referred for or are provided services. Services were sometimes specified, and included substance

abuse services, inpatient psychiatric care, and other mental health interventions. Two states mentioned that psychiatric medications may be appropriate to respond to children's mental health needs. Further, two states indicated that information from the screening or assessment is incorporated into the child's case plan.

#### Trauma

As specified above, 10 states specified that they had a trauma screening tool only, or a trauma screening tool in addition to the mental health screening tool. Generally, states did not define trauma except to say that children may be traumatized by certain events. Two states addressed how children in care who have experienced trauma receive treatment, such as through trauma treatment centers and community mental health centers. Nine states indicated that they have plans to develop trauma screening tools or to implement such tools soon.

# Protocol 2: Informed and Shared Decision-Making (Consent and Assent) and Methods for Ongoing Communication

For protocol 2, states were asked to describe any written policies that address "informed and shared decision-making (consent and assent) and methods for ongoing communication between the prescriber, the child, his/her caregivers, other healthcare providers, the child welfare worker, and other key stakeholders." *Consent* and *assent* were not defined in the program instructions but these terms are commonly used in medical literature. In the context of medical care and research, *consent*, or *informed consent*, refers to the process through which a person receives information about a particular health condition and treatment options, including benefits and risks; understands that information; and agrees to receive one (or more) of the treatment options. The research literature stated that *consent* has legal force and generally involves obtaining a signature from the person who will receive treatment. *Assent* is similar to *consent* in that it involves informing a person about a health condition and treatment options and obtaining agreement from the person to pursue a particular treatment. However, *assent* does not have legal force. *Assent* generally refers to agreement obtained from a minor or from an adult who does not have the legal capacity to provide *consent*.

More than half of the states (34 of 52) provided some information about this protocol in their APSR. States addressed various aspects of consent, assent, and communication, including

- who provides consent or assent;
- pre-authorization processes;
- communication during the consent process;
- who may prescribe psychotropic medications; and

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<sup>112</sup> Committee on Bioethics, "Informed Consent, Parental Permission, and Assent in Pediatric Practice," *Pediatrics*, vol. 95, no. 2 (February 1995), pp. 314-318; *A.D.A.M. Medical Encyclopedia*, "informed consent," http://www.nlm.nih.gov/medlineplus/ency/patientinstructions/000445.htm; *Oxford Concise Medical Dictionary*, 8<sup>th</sup> ed., "assent," http://www.oxfordreference.com/view/10.1093/acref/9780199557141.001.0001/acref-9780199557141-e-11145; Laurel K. Leslie et al., *Multi-State Study on Psychotropic Medication Oversight in Foster Care*, Tufts University, Tufts Clinical and Translational Science Institute, September 2010, http://160.109.101.132/icrhps/prodserv/docs/Executive Report 09-07-10 348.pdf.

• communication after a child has begun treatment with a psychotropic medication.

#### Who Provides Consent or Assent

States indicated that consent involves one or more of the following parties: a parent/legal guardian, the child, the child welfare agency, or a court/judge. These parties may be involved concurrently, their involvement may depend upon the child's legal status, and their involvement may be required or recommended. In Connecticut, for example, consent is obtained from the parent, legal guardian, or child welfare agency (depending on the child's legal status) and assent must be obtained from children age 14 or older. In Indiana, the parent, guardian, or custodian and the child welfare agency must give consent. Arizona recommends that the person from the home where the child is currently residing provide consent.

Of the states that provided information on this protocol, over half (18 of 34) reported that a *parent* or legal guardian is involved in providing consent, most often as the first or primary consenting authority. With regard to parental consent (versus that of a legal guardian), multiple states indicated that parental consent is not sought or is not required under one or more of the following circumstances: parental rights have been relinquished or terminated, a parent cannot be located or is not available, or a parent is unable to make a decision due to physical or mental impairment.

Eleven states reported involving *children* in the consent process. What this involvement looks like varies significantly from state to state. For example, Connecticut and Alabama require assent or consent from children of a certain age in addition to consent from a parent or guardian. In New Mexico and Washington, children of a certain age have sole authority to consent to being treated with psychotropic medications. Other states, such as Florida and New Jersey, require or suggest that children be involved in discussions about the use of psychotropic medications.

Sixteen states reported that the *child welfare agency* is involved in some way in providing consent. In eight states, the child welfare agency provides consent in some or all instances where parental rights have been terminated or relinquished or a parent is not available. The consent may be provided by an agency director or commissioner, a caseworker or social worker, an agency medical director or nurse, or a special consent unit within the agency. In five states, the child welfare agency is the only consenting authority in some or all instances where psychotropics are prescribed. In three states, it appears that the child welfare agency and the parent or guardian must both provide consent.

Thirteen states reported that a *court or a judge* may be involved in authorizing the use of psychotropic medication for children in foster care. In 11 states, a court order is required when parental rights have been terminated or relinquished, when a parent is unavailable to provide consent, or when consent has been denied by a parent/guardian and/or child. California law requires judicial approval prior to the administration of psychotropic medications under any circumstances. Massachusetts requires judicial approval for treatment with psychotropics that are antipsychotics.

Two states take a slightly different approach to consent. In Nevada, a "Person Legally Responsible" (PLR) is designated as the only party who may provide consent for a child. The PLR could be a foster parent, an attorney, a relative of the child, an employee of the child welfare agency, or any other person who a court determines is qualified. Texas law requires that each child in state child welfare conservatorship have a designated "medical consenter" who makes

medical decisions for the child. Typically the medical consenter is the child's caregiver or a caseworker, though it could be another party.

Eight states noted in their APSR that psychotropic medications may be administered without consent in an emergency where a child may harm himself/herself or others and the medication is deemed to be the only way or the best way to treat the child. In Tennessee, however, the emergency use of psychotropic medication is allowed only for children in hospital facilities or facilities designated as psychiatric residential treatment facilities per federal guidelines.

#### Pre-authorization

Some states reported requiring a pre-authorization process for the use of psychotropic medications, in addition to consent or as a part of consent. The process varies from state to state, but it typically requires the prescriber to submit a request with details about the child, the diagnosis, and the medication to a board, committee, team, or other designated authority that must approve the request before treatment can begin. Eight states reported requiring pre-authorization for the use of certain psychotropic medications or for the use of psychotropics with children under a certain age. Three additional states reported having plans to implement a pre-authorization process.

### **Information Sharing During the Consent Process**

Fourteen states provided a description of the information that is shared among stakeholders (parents/legal guardians, child, child welfare agency, health care providers) as part of the consent process. Most of these states described communication where a health care provider or child welfare agency employee provides information to the parent/legal guardian and/or child. Some states indicated that the sharing of certain information is required as part of the consent process, while others indicated that it is suggested or recommended. The types of information most frequently mentioned in the APSRs include the following:

- nature of diagnosis,
- name of medication and dosage,
- benefit(s) or expected result(s),
- potential side effects,
- long-term and short-term risks, and
- alternative therapies.

## Who May Prescribe Psychotropic Medications

When describing who may prescribe psychotropic medications, most states used the term "provider" or "prescriber." Eight states provided more specific descriptions about who may or who should prescribe, such as a licensed or licensed and certified physician; a board certified or board eligible specialist in psychiatry, neurodevelopmental pediatrics, or pediatric neurology; a qualified psychiatrist; a psychiatric nurse practitioner; or a developmental pediatrician. Some states indicated that who may prescribe depends upon the type of medication. For example, Arizona explained that "[o]nly physicians (psychiatrists), physician assistants, or nurse practitioners credentialed and licensed by the Tribal and Regional Behavioral Health Authorities

may prescribe psychotropic medications. A child's primary care physician may write prescriptions for patients with minor depression, anxiety disorders and treatment of ADHD without comorbidity."

## **Methods for Ongoing Communication**

For the purposes of this report, "methods for ongoing communication" is interpreted as referring to communication that takes place after a child has begun treatment with a psychotropic medication, as distinguished from communication and information sharing that takes place as part of the consent process. Twenty-two states provided some information about methods for ongoing communication, and there was a great deal of variation among the descriptions. Notably, aspects of "ongoing communication" are also closely tied to monitoring issues, which are addressed in the next section of the report.

Some of the specific mechanisms that states cited as facilitating communication include databases, a child's medical passport or medical record, caseworker visits with a child and his/her caregiver family, phone calls between stakeholders, child and family team meetings, websites, email messages, and reports or forms. The types of information shared as a part of ongoing communication include medication details, treatment notes, medical histories, medication benefits or side effects, changes in medication (type, dosage, frequency, stopping use), medication administration, agency policies and procedures, and contact information for stakeholders. The people mentioned in the APSRs as being involved in ongoing communication include representatives of child welfare agencies (caseworker, social worker, supervisor, etc.), health care providers (primary care physician, nurse, prescribing provider), the child or client, and the caregivers or foster parents. The flow of information among these people was most often described as going from a child welfare agency representative or health care provider to the child and/or caregivers.

# **Protocol 3: Effective Medication Monitoring at the Client and Agency Level**

For protocol 3, states were asked to describe any written policies related to effective medication monitoring at both the client and agency level. The program instructions did not provide any further detail about what was meant by "medication monitoring" or client-level versus agency-level monitoring. Based on the CRS review of APSRs, "medication monitoring at the client level" seems to encompass monitoring of how a specific medication affects the client as well as monitoring of a client's overall medication treatment plan. "Medication monitoring at the agency level" seems to refer primarily, though not exclusively, to the monitoring of prescribing patterns across a child welfare agency's entire caseload.

Thirty-eight states provided some information about this protocol. Of those 38, 13 provided general or limited information and the other 25 provided broader or more detailed information. States addressed a number of different aspects of monitoring, including what is being monitored, who is doing the monitoring, and mechanisms used to conduct monitoring. The following two subsections look at these aspects, first in relation to client-level monitoring and then agency-level monitoring.

## **Client-Level Monitoring**

Thirty-six states provided information about medication monitoring at the client level. States described monitoring both the child and the child's prescriptions. Monitoring of the child is primarily focused on determining how the medication is affecting him/her. Specifically, states most frequently mentioned monitoring for side effects (15 states) and whether targeted symptoms have improved, remained the same, or deteriorated (11 states). States also mentioned monitoring of specific physiologic measures such as a child's weight, height, body mass index, blood pressure, heart rate, respiratory rate, glucose levels, and lipid levels, as well as being alert to potential drug interactions, and identifying any issues that the child or caregiver might have with administering medications.

Twenty-five states provided information about who conducts the monitoring of individual children. These include health care providers (prescriber, nurse, physician, medical director, psychiatrist, pharmacist); child welfare agency staff (caseworker, supervisor, manager); third-parties (medical consultant, medical expert, independent reviewer); caregivers (foster parent, legal guardian); and the individual child. Some states described a team that is involved with monitoring, which can be a combination of individuals from one or more of the previous categories.

Thirty-six states described mechanisms used to monitor how medication is affecting an individual child. These include conversations between the child and caregiver and between the child, caregiver, and caseworker; logs maintained by the caregiver; medical check-ups; medical records; databases; and team meetings. Fourteen states mentioned the frequency of visits or check-ups with either a caseworker or a health care provider. Twelve of the fourteen states gave a specific time frame such as "at least once a month" or "one to two weeks after starting the medication," while two stated that the frequency of follow-up appointments would vary by client depending on factors such as the medication, the diagnosis, and how the child was responding.

States explained that the monitoring of a child's prescriptions involved establishing guidelines for prescribers to follow and then identifying red flags in prescriptions that could necessitate further review of the child's diagnosis and treatment plan. The following were identified by states as possible sources of concern in a prescription: polypharmacy<sup>113</sup> (12 states), use of certain medications with children under certain ages (9 states), dosage exceeding what is recommended (6 states), potential adverse drug interactions (3 states), and a mismatch between prescription and diagnosis (3 states). According to states, the parties involved in the monitoring of a child's prescription could include pharmacists, caseworkers, health care providers other than the prescriber, third-party reviewers or consultants, and, somewhat indirectly, committees or review boards. Committees or review boards typically conduct agency-level monitoring (see the next section), but their work can identify particular cases that require further review, which in turn could lead to changes in an individual child's treatment plan. States described a number of different mechanisms that could be used to monitor a child's prescriptions. These include review of a child's medical record; tracking prescriptions in databases; committee or review board

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<sup>&</sup>lt;sup>113</sup> Polypharmacy is the practice of prescribing multiple drugs to be taken concurrently to treat one or more health problems. *Mosby's Dictionary of Medicine, Nursing, & Health Professions*, "polypharmacy," http://www.credoreference.com/entry/ehsmosbymed/polypharmacy; *Dictionary of Medical Terms*, "polypharmacy," http://www.credoreference.com/entry/acbmedterm/polypharmacy.

meetings within the child welfare agency or across state agencies (see the next section); and a pre-authorization process for medication consent (as discussed under protocol 2).

# **Agency-Level Monitoring**

Twenty-five states provided information about medication monitoring at the agency level. Ten of the 25 provided general or limited information and 15 provided more specific and/or broader information. In terms of what is being monitored, 18 states referred to monitoring prescribing patterns or something similar. Other terms used include drug utilization patterns, prescribing trends, prescribing practices, and compliance with prescribing guidelines. Some states cited specific aspects of prescribing patterns or trends that they track such as rates of polypharmacy and co-pharmacy (Illinois) or types of medications and the number of children receiving medications (Montana).

States also described other aspects of medication monitoring such as tracking consent request outcomes (Illinois and Connecticut), the use of emergency medications (Illinois), and FDA medication cautions (Utah). Six states specifically mentioned that agency-level monitoring is used to identify prescriptions or prescribers that do not comply with established guidelines. States identified a number of different parties that could be involved in conducting agency-level monitoring. Eleven states indicated that the child welfare agency is responsible for agency-level monitoring. Of these 11 states, 3 identified a specific subunit within the agency that handles monitoring. For example, Illinois has a Centralized Psychopharmacology Consent Program through which board certified child psychiatric consultants provide an independent medication review of all psychotropic medication consent requests. Three of the 11 states indicated that the overall health care program for children in foster care is responsible for agency-level monitoring. Three states identified individuals involved in agency-level monitoring, such as a chief psychiatrist, chief medical officer, or child psychiatry consultant. Seven states described special committees or review boards that are involved in agency-level monitoring (for example, the Psychopharmacology Advisory Committee in Kansas). These committees or review boards may include members from the child welfare agency as well as other state agencies and outside consultants. In some states, these entities originate in the state Medicaid program as a part of required Drug Utilization Review Programs. 114

States described using a number of different mechanisms to conduct agency-level monitoring. Seven states referred to reports containing aggregate and/or individual case information over a specific period of time. Three of these seven states specifically mentioned that the reports were based on claims data. Eight states indicated that claims data was a source of information used in monitoring, and five states specifically mentioned using Medicaid claims or payment data. Four states reported that meetings of monitoring bodies are used to review and discuss the use of psychotropic medications. For example, Iowa's Drug Utilization Review Board reviews 300 member profiles at each of its six annual meetings.

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Medicaid.gov, Drug Utilization Review, http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Prescription-Drugs/Drug-Utilization-Review.html; Center for Medicaid and CHIP Services, Informational Bulletin, August 24, 2012, http://www.medicaid.gov/Federal-Policy-Guidance/downloads/CIB-08-24-12.pdf

# Protocol 4: Availability of Mental Health Expertise and Consultation

The fourth protocol asked states to describe policies related to the "availability of mental health expertise and consultation regarding both consent and monitoring issues by a board-certified or board-eligible child and adolescent psychiatrist (at both the agency and individual case level)." The 2012 HHS program instructions do not define "board-certified or board-eligible child and adolescent psychiatrist." According to the American Board of Psychiatry and Neurology (ABPN), a nonprofit medical organization that oversees doctor certification in psychiatry and neurology, a board certified psychiatrist is one who has completed the required training in a specialty of psychiatry and has passed an exam administered by the ABPN. The term "board-eligible" refers to a doctor who has met the requirements to stand for a certification exam, but who has not yet taken the exam.

Seven states specifically reported having access to "board-certified" or "board-eligible" child and adolescent psychiatrists for consultation or review related to the use of psychotropic medications. Thirteen states reported having access to a psychiatrist, a child/adolescent psychiatrist, or a psychiatric consultation service but did not specifically use the term "board-certified" or "board-eligible." (Nevada falls into both groups of states as child welfare services in the state are provided by three entities whose policies are not identical.) States did not provide a great deal of detail on this protocol, and most of the information addresses the availability of mental health expertise for individual children rather than for the child welfare agency overall.

Nine states described in general terms the role of the psychiatrist or psychiatric consultation service for an individual child. For example, South Dakota explained that the child welfare agency is able to consult with board certified child psychiatrists and psychiatric nurses from the South Dakota Foundation of Medical Providers and Peer Review Organization and child psychiatrists contracting with Psychiatric Residential Care providers.

Several states described more specific ways that psychiatrists are involved in consent and monitoring for individual children. Florida, Oklahoma, and Wyoming have hotlines through which primary care providers or, in the case of Oklahoma, child welfare agency staff, can obtain a psychiatric consultation. Connecticut, Hawaii, and Illinois describe in-person consultations with psychiatrists on specific cases. These consultations could be conducted with prescribers, child welfare agency staff, or other stakeholders. Illinois and Connecticut have centralized medication consent processes, and board certified child psychiatrists play a role in the approval of consent requests. Four states involve psychiatrists in reviewing specific cases if one or more red flags have been triggered by a prescription.

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<sup>&</sup>lt;sup>115</sup> American Board of Psychiatry and Neurology, Inc., "Frequently Asked Questions," no date, http://www.abpn.com/faqs.html.

<sup>116</sup> American Board of Medical Specialties, "Board Certification Editorial Background," March 29, 2013, http://www.abms.org/news\_and\_events/media\_newsroom/pdf/abms\_editorialbackground.pdf. This document states that "[t]he amount of time a candidate can declare him/herself as Board Eligible ranges from five to seven years, depending on the Member Board." The American Board of Psychiatry and Neurology has set the time limit at seven years. See "ABMS Member Boards' Board Eligibility Periods and Transition Dates," http://www.abms.org/ News and Events/downloads/ABMS Board Eligibility Policy by Board 021313.pdf.

Only three states described how psychiatrists provide consultation at the agency level. In Connecticut, a board-certified child psychiatrist serves as Chief of Psychiatry for the child welfare agency and is responsible for policy development and supervision of the Centralized Medication Consent Unit. In Michigan, the child welfare agency has a board-certified child and adolescent psychiatrist who provides education and outreach to physicians and health liaison officers throughout the state. New Jersey's child welfare agency has a child and adolescent psychiatrist who "provides leadership around quality assurance efforts ... and ongoing efforts to strengthen the agency's psychotropic medication policy."

# Protocol 5: Mechanisms for Accessing and Sharing Accurate and Up-to-Date Information and Educational Materials

States were further asked to provide information about mechanisms for accessing and sharing mental health and trauma-related information with clinicians, child welfare staff, and consumers. Thirty-five states provided a response to this protocol; 17 states did not. The APSR guidance does not define what these mechanisms entail, and states generally responded that such mechanisms include training, publications, and other materials about psychotropic medications. States indicated that training is available for child welfare staff; clinicians; and other child welfare stakeholders, including foster parents, staff at residential facilities, juvenile justice agency staff, and children's advocacy groups. "Consumers" is not defined in the APSR guidance; however, it appears to refer to the children who are prescribed psychotropic medications. States generally did not indicate that information and educational materials are provided to children in care, although one state (Hawaii) indicated that it had plans to provide information to foster children.

#### Information for Child Welfare Staff

Twenty-six states provided information about training that is provided or will be provided to child welfare staff about policies on psychotropic medications and/or treatment planning, including on trauma-informed interventions. Some states provide or plan to provide training to all child welfare workers, new child welfare workers only, supervisors, or selected child welfare staff. For example, Connecticut stated that it provides training for all new workers regarding psychotropic medication policies. In addition, the training for area child welfare directors and social workers includes information about prescribing trends for children in care. South Carolina indicated that one area of the state was in the process of carrying out a pilot program to identify protocols for psychotropic monitoring. Training was provided for one and a half days to social workers, supervisors, and a regional clinical coordinator in the pilot area on the use of psychotropic medications. Twelve states specifically mentioned that training addressed trauma, including treatment of trauma.

Some states provided information about which individuals or entities conduct the training for workers: the state child welfare agency, including health personnel or a health unit within the child welfare agency; a state health or mental health agency; mental health consultants; or an outside entity that specializes in treatment of trauma (Chadwick Center for Children & Families at Rady Children's Hospital in San Diego, Children's Trauma Assessment Center at Western Michigan University, and Kennedy Krieger Family Center in Baltimore). Texas discussed that an online training is available for child welfare staff and other stakeholders that is accessible via the state child welfare agency website. Louisiana indicated that it had plans to adapt this online training for its staff and other stakeholders.

A small number of states provided information about the publications and materials that have been provided to child welfare staff about oversight of psychotropic medications, including

- an online child welfare manual about informed consent and best practices for use of psychotropic medications;
- materials for child family team meetings that involve children who are prescribed psychotropic medications;
- the AACAP guidelines;
- state child welfare agency guidelines (which reference the AACAP guidelines) about oversight of psychotropic medications; and
- policy transmittals about psychotropics.

#### **Information for Clinicians**

Nine states discussed the information that is disseminated or will be disseminated to clinicians about child welfare or other state policies about psychotropic medication use by children in foster care. States indicated that clinicians receive or will receive information about the child welfare agency's system for prescribing psychotropic medications for children in foster care, including the consent process and oversight; changes in state child welfare policies on prescribing medications; where state policies are available online; best practice guidelines for prescribing; new label information on psychotropics and warnings by the Food and Drug Administration (FDA); and data on children in foster care who are prescribed psychotropic drugs. According to states, this information has been or will be conveyed via phone calls between child welfare staff and clinicians, state Medicaid program publications, faxed forms, the child welfare agency website, and teleconference.

#### Information for Other Stakeholders

Finally, 12 states indicated that they provided information to other child welfare stakeholders about policies on psychotropic drug use for children in foster care, or had plans to do so. These other stakeholders included foster parents, staff at group homes and other group-care settings for children in care; biological parents; child-serving community organizations; and other state agencies and individuals that may interact with children in foster care. Hawaii indicated that it plans to provide information and awareness about the dangers of the use of psychotropic medications to children in foster care, judges, lawyers, teachers, guardians ad litem, court appointed special advocates, and the general public. States explained that these other stakeholders received information through a written guide, an online training, training for state agencies or child-serving organizations, and foster parent training. In some cases, the training focused on trauma and treatments for trauma

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