Report to the Pennsylvania State Roundtable

To Each What They Need: Monitoring and Oversight of Psychotropic Medication for Dependent Children

Psychotropic Medication Workgroup

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To Each What They Need:
Monitoring and Oversight of Psychotropic Medication for Dependent Children

A Report to the State Roundtable of Pennsylvania

"The mission of the psychotropic medication workgroup is to recommend a system of collaborative oversight focusing on children and youth involved in the dependency system to ensure that those with mental and behavioral health needs have a plan for appropriate and effective intervention to achieve healthy development."

Background

In 2011, through the roundtable system utilized by the Commonwealth of Pennsylvania, leaders in the child welfare system began to talk about their concerns with the usage of psychotropic medication for children in the dependency system. Along with a national focus on the disturbing trend of increased medication for children in the child welfare system, Pennsylvania leaders felt it was time to explore the usage of psychotropic medication with its dependent children and its impact on their health and well-being. As such, the Pennsylvania State Roundtable commissioned a workgroup with the goal of surveying both national and state concerns and identifying measures that are underway to ensure the appropriate monitoring and oversight of psychotropic medication.

The Psychotropic Medication Workgroup, a multi-disciplinary committee under the leadership of the Honorable Kathryn Hens Greco, Administrative Judge, Court of Common Pleas of Allegheny County and first the Honorable Alice Dubow, Court of Common Pleas of Philadelphia County then David Schwille, Administrator, Department of Human Services of Venango County, convened in August 2011. Meeting seven times prior to the 2012 State Roundtable, the group was able to study several national reports and Pennsylvania reports on the subject of psychotropic medication. Additionally they explored protocols from a number of states that have addressed this issue, consulted with medical experts from various systems within Pennsylvania, held focus groups to get input from the parents and youth in Pennsylvania, and researched best practice recommendations from the American Academy of Child and Adolescent Psychiatry and the American Academy of Pediatrics as well as the American Bar Association's Center on Children and the Law.

National Perspective

During the last several years, there has been a considerable amount of national attention given to the increasing usage of psychotropic medication with children in foster care. These children often present with a complex set of issues, both from their lives or environments prior to entering the dependency system and then with issues of separation

and loss that occur upon entry into the system. Careful consideration of all aspects of their mental health needs is often balanced against limited resources and the need to ensure stabilization in placement. Such tension can lead to the primary treatment of the most apparent issues, often those that are behavioral in nature. Psychotropic medication is one tool used to address the symptoms with which these children present.

Several major studies are either underway or have been completed. These studies explore the issue of psychotropic medication particular to the foster care population. Most notably are the studies by Tufts University (*Multi-State Study on Psychotropic Medication Oversight in Foster Care),* Rutgers University (*Antipsychotic Medication Use in Medicaid Children and Adolescents: Report and Resource Guide from a 16-State Study)*, PolicyLab at the Children's Hospital of Philadelphia (*Interstate Variation in Trends of Psychotropic Medication Use among Medicaid-enrolled Children in Foster Care*) and the United States Government Accountability Office (GAO) Report to Congress (*HHS Guidance Could Help States Improve Oversight of Psychotropic Prescriptions).* Each of these reports share a similar concern that foster children are being medicated at a higher rate than children in the general population.

While there is no way to uniformly capture the information on foster children at this time, studies estimate that children and youth in foster care are prescribed medication at the estimated range of 13-52% compared to the general children and youth population which is 4% (as based on Medicaid data, Tufts, p. 1). While children in foster care only account for 3% of the under 18 year old Medicaid population, they account for 32% of the recipients of behavioral health services (Analysis of Medicaid Claims Data, 2005) and by age 17, 62% of foster youth will display symptoms of both mental illness and trauma (Samuels testimony, December 1, 2011). Data from the National Survey of Child and Adolescent Well-Being (NSCAW) Baseline II Report (2011) notes that 60.9% of youth 11 to 17 years old showed need for behavioral health services. Concerning is the fact that the same study found 57.5% of all children ages 1.5 to 10 years shown to be at risk for behavioral, emotional or substance abuse problems are not receiving any behavioral health services and 48.1% of those youth ages 11 to 17 were reported to not be receiving any (p. 12). Such a difference in rate of prescription and possible level of need coupled with the responsibility of the state to provide for the well-being of foster children raises the need for enhanced oversight and monitoring of mental health services including the use of psychotropic medication.

Many states are addressing the need for oversight and monitoring by developing protocols that outline structured utilization review and/or authorization for psychotropic medication for children in foster care. These states, including Georgia, Texas, Kentucky, Tennessee and Connecticut, have devised systems for flagging outliers related to the use of psychotropic medication with foster children. Warning flags have been identified for the various stages of psychotropic medication usage including the prescription,

authorization, monitoring and consent processes. Themes in national studies have supported the need for this type of flagging system.

Key areas of concern, or "red flags" raised in national reports involve the following:

- ***Informed consent and assent of the use of psychotropic medication lacking documentation***: the discussion of risk and benefits of using psychotropic medication and the likely effects and side effects between the prescribing doctor and youth or the person authorizing the usage of the medication, and the youth's assent (understanding and agreement) if under the age of consent
- ***Off-label usage of psychotropic medication***: using medication for a purpose for which it is not FDA approved
- ***Atypical anti-psychotic medication usage***: atypical anti-psychotics require careful medical monitoring and have been shown to increase the risk of weight gain and metabolic syndrome in children and adolescents
- ***Poly-pharmacological treatment***: the use of multiple psychotropic medications at the same time; this can be multiple medications from different classes or within the same class for a period of more than 30 days
- ***Use of psychotropic medication for young children***: the use of any psychotropic medication in children under the age of 5
- ***Psychotropic medication prescribed by primary care doctors for disorders other than Attention Deficit Hyperactivity Disorder and Depression***: many experts believe that all but the most routine psychotropic medications need to be prescribed under the guidance of a psychiatrist who is familiar with complex issues of trauma and needs of children and youth in foster care.

While psychotropic medication monitoring and oversight is one area of focus in assessing foster children's mental and emotional well-being, it is just one piece of a complex puzzle of interventions for children who may have considerable risk factors. The American Academy of Child and Adolescent Psychiatry (AACAP) includes in these risk factors "genetic predisposition, *in utero* exposure to substances of abuse, medical illness, cognitive deficits, a history of abuse and neglect, disrupted attachments, and multiple placements." (AACAP Position Statement on Oversight of Psychotropic Medication Use for Children in State Custody) The process of oversight becomes an issue, not just for one person in the child welfare system, but also for all the system partners, to strive to provide the most appropriate and high quality mental and behavioral health services possible; this may include, but is certainly not limited to, psychotropic medication.

Pennsylvania Perspective

In addition to the national focus on psychotropic medication for children in foster care, Pennsylvania has begun the process of examining the usage of psychotropic medication for all children, particularly those served by Medicaid. In 2009, at the direction of the Secretary of the Pennsylvania Department of Public Welfare (DPW), the Office of

Mental Health and Substance Abuse Services (OMHSAS) convened a group to develop recommendations regarding pediatric psychotropic medication. Their report, Pennsylvania Department of Public Welfare Pediatric Psychiatric Medication Workgroup Report (2012), was written within the context of the bio-psychosocial theory of treatment. As such, the group believes that psychotropic medication "should always be *considered* for youth with behavioral problems within the context that includes appropriate treatment services and supports…Even when it is indicated, psychotropic medication as a sole intervention should be the exception, given the need to address the youth's psychological-and social-as well as biologically-based needs." (p. 7) Through the use of subcommittees, the group made recommendations in three areas: family and youth education, informed consent, and prescribing practices. Among the many recommendations are those that relate to the theme of communication; patients should communicate with their doctors, doctors with their patients and/or guardians, systems need to communicate with each other and with the consumers that they serve, courts need to have information communicated to them from parties and others to ensure appropriate oversight of the children under their supervision. The flow of information will ensure a better quality of coordination and care for those involved.

While seeing communication of information as paramount, education is another theme discussed in the report. Patients and caregivers should be educated about options, interventions and psychotropic medications. Mental health professionals should become educated about the issues of children in the child welfare system. Child welfare professionals and judges should be educated about informed consent and the psychotropic medications most commonly prescribed for the children they serve. The benefit of such a cross-systems training is a better understanding of the roles and responsibilities for each participant and a common understanding of the expectations and outcomes of psychopharmacological intervention.

Through the use of focus groups with youth and caregivers involved in an advisory capacity in Pennsylvania, the DPW workgroup reported that both youth and their caregivers wanted to feel they had a voice in the treatment decision making process. The youth and caregivers reported wanting to develop a relationship with the prescribers and be treated with dignity. Surveys of physicians prescribing psychotropic medication to children and adolescents reported wanting to collaborate with the patients that they serve and their caregivers. All recognized the limitations of time and resources that may interfere with the development of those partnerships. The DPW workgroup recommended that practitioners and system professionals prioritize the need for communication between doctor and patient and make every effort to ensure youth and caregiver understanding, consent, commitment and active partnerships.

Together with members of the prescribing community and other system partners, the State Roundtable Workgroup on Psychotropic Medication will look specifically at the recommendations made by the DPW Pediatric Medication Workgroup and work

towards incorporating them as appropriate in developing best practice protocols, the goal of the workgroup during the coming months.

Focus Groups

The Psychotropic Medication Workgroup of the Pennsylvania State Roundtable also held a series of focus groups with youth and caregivers involved specifically in the child welfare system. The themes that surfaced were, not surprisingly, similar to those identified by the general population focus groups. Themes included understanding, communication, information and empowerment. Generally, caregivers reported:

- They would have liked to understand the medications better, especially the side effects and positive benefits
- They would have liked to communicate more with the prescribing professional
- They would have liked to know if there were any alternatives
- They noted that in most cases the medication made a difference in the behavior of the child

Youth that participated in the focus groups reported:

- Not understanding why they were taking the medications they were taking
- Taking more than one medication at a time
- Feeling they were prescribed medication to make a school, provider or caregiver happy
- Most reported that they received medication but not therapy
- Those that received therapy did not find it useful
- Some reported that medication made a positive difference, particularly in paying attention but often medication made them feel "like a zombie"
- Most wanted to feel like they had a real choice about taking medication

Data

Much of the data analysis emphasis in Pennsylvania has been on the use of antipsychotic medication for children in foster care, particularly when prescribed to young children (those under age 5). Antipsychotic usage in children can be associated with an increase in health risk with glucose and lipid levels in the blood. As part of the Rutgers study, Pennsylvania provided data on the use of antipsychotics for children in foster care. Drilling down into data, Pennsylvania found concerns with the prescribing of low dose antipsychotics where no mental health diagnosis supported its use, non-guideline use for difficult behavior disorders and episodic non-guideline use generally as a sedation agent. Additionally, data from PolicyLab on Pennsylvania found that between 2002 and 2007 antipsychotic use for children in foster care aged 3-18 increased 17% (Rubin, 2012, p. 5). Pennsylvania's data confirmed their implementation of a prior-authorization request for the use of antipsychotics in children under age 6.

Two of the managed behavioral health care organizations in Pennsylvania, Community Care Behavioral Health (CCBH) and Value Behavioral Health (VBH) completed studies of their members. Similar concerns were found in both organizations including the prescribing of antipsychotic medication, particularly atypical antipsychotics, to young children and the lack of FDA support for the use of antipsychotic medication for the indicated diagnosis. Comparative findings can be found in the table below. Notably, these studies used different populations of Medicaid-enrolled children in Pennsylvania.

	VBH	CCBH
Prescribed by PCP	33%	30%
Prescribed by Psychiatrist	Unavailable	87%
In some form of other treatment	76%	92%
Most common antipsychotic	Risperidone	Unavailable
Most common diagnoses	ADHD-36% Autism-30% Disruptive Behavior Disorder-19%	ADHD-54% ODD-25% Depression-18% Bipolar Disorder-16% Autism-15%

PolicyLab of the Children's Hospital of Philadelphia, under the direction of Dr. David Rubin, is currently leading a national study on the psychotropic medication use of children receiving Medicaid. In the study, PolicyLab will examine "trends in psychotropic medication use, identify whether system level factors influence exposure to psychotropic medication among children and explore the risk of adverse events, diabetes and hypertension among children exposed to antipsychotic medication." (Noonan & Zlotnik presentation, October 6, 2011). The first report from this study has been published in Children and Youth Services Review (April 2012) and examines data on psychotropic medication use among children in foster care in 48 states. Building on this analysis and in partnership with the Department of Public Welfare, Casey Family and the Office of Children & Families in the Courts, PolicyLab will further analyze Pennsylvania data, sorted by county. It is anticipated this county specific data will be available in early 2013 and will be distributed to counties accompanied by a discussion guide developed by this workgroup. The guide will assist local jurisdictions as they discuss the use of psychotropic medication with children in foster care.

Conclusion

The nation is becoming increasingly interested in the monitoring of psychotropic medication for children in foster care. One can see this in recent legislation requiring states to develop oversight for this population. The Fostering Connections to Success and Increasing Adoptions Act of 2008 requires states to "strengthen medical oversight for children in the child welfare system." The Child and Family Services Improvement and

Innovation Act of 2011 (Public Law 112-34) uses language specific to the mental health needs of maltreated children by requiring states to provide "details about how emotional trauma associated with maltreatment and removal is addressed, as well as a description of how the use of psychotropic medications is monitored." (DHHS letter, November 23, 2011) Most recently, the Department of Health and Human Services provided guidance to states in the form of an Information Memorandum that states could use in developing protocols for the appropriate use and monitoring of psychotropic medication. States need to pay attention to psychotropic medications because too many children are receiving too much, especially when they are too young.

Moving forward, we need to consider if psychotropic medication monitoring is enough. David Rubin, MD, Director of PolicyLab at the Children's Hospital of Philadelphia, suggests the more fundamental question is what types of interventions do we want for children in foster care? (Personal communication, December 1, 2011) Honorable Bryan Samuels, Commissioner for the Administration on Children, Youth and Families under the U.S. Department of Health and Human Services in testimony before a U.S. Senate subcommittee on December 1, 2011 said:

> ***"It is impossible to discuss the use of psychotropics without addressing the impact of maltreatment on the overall social and emotional well-being of children who have experienced abuse or neglect….Certainly this includes strengthened protocols for the prescription and monitoring of psychotropic medication; more broadly, though, it requires the child welfare systems have increased ability to deliver effective psychosocial interventions, such as Trauma-Focused Cognitive-Behavioral Therapy, as treatment strategies alone or, when appropriate, in conjunction with pharmaceutical treatments to improve the well-being of the children and youth that they serve. Such a focus on social and emotional well-being increases the likelihood that the children who enter foster care exit to reunification, guardianship, or adoption sooner and better equipped to become healthy, contributing adults."***

While the systems serving the foster child population face many challenges, it remains clear that the time these vulnerable children spend in the system has a lifelong impact on their well-being. The ability to cope, to think, to interact, and to act wisely is learned in its most basic fashion during childhood. Children in the foster care system are learning and growing while they are with us; we have a responsibility to ensure they receive everything they need to do this to the fullest and most robust extent and not one thing they do not need.

While developing best practices and protocols that address the issues of oversight and monitoring of psychotropic medication for dependent children, everyone, at every step of the way, must recognize their share of the responsibility. At minimum, the following questions, suggested by Dr. David Rubin, can serve as a guide and be very quickly implemented into the information gathering and reporting process occurring regularly for dependent children on psychotropic medication:

The Questions to Ask When a Child is on Psychotropic Medications

What is the child's diagnosis? Is it the correct diagnosis?
What is the medication's intended effect? Is it effective?
Are we monitoring for adverse effects?
If the child is doing well, have we thought about tapering the medication?
What is the opinion of the treating physician?

- David Rubin, MD

Recommendations:

The Psychotropic Medication Workgroup requests the authorization of the State Roundtable to continue to meet and work on issues pertaining to the oversight and monitoring of psychotropic medication for children in the dependency system. *In addition, the workgroup respectfully submits to the Pennsylvania State Roundtable the following recommendations:*

1. Collaboratively develop guidelines and/or policy regarding oversight and monitoring of psychotropic medication for the dependent children in Pennsylvania.
2. Explore the possibility of providing incentives to providers who attain positive outcomes for children in the dependency system relating to mental and behavioral health treatment, including psychotropic medication.
3. Facilitate the development of training on oversight of psychotropic medication to support what is expected of all partners in the child dependency system.
4. Collaborate with the Children's Hospital of Philadelphia's PolicyLab as supported by Casey Family Programs to provide counties with data specific to the usage of psychotropic medication with their child welfare population. Provide counties a guide to assist them in discussing their county-specific data and protocols around psychotropic medication for children in the child welfare system.
5. Develop a resource section on psychotropic medication on the Office of Children and Families in the Courts website while exploring the possibility of a more comprehensive, multi-functional and multi-disciplinary web site.