Response to Additional Questions
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for the
House Subcommittee on Income Security and Family Support
Representative Jim McDermott, M.D., Chair
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"Prescription Psychotropic Drug Use Among Children in Foster Care"

What are some of the challenges that States face in obtaining informed consent for the use of psychotropic drugs among children in foster care? How have States addressed this issue? Who generally provides informed consent for these children-the biological parent, the foster parent, or the child welfare agency?

Each State has its own requirement for the provision of informed consent for psychotropic medications. Many of these policies are driven by class action lawsuits or legislative action within that State. In California, the legislature mandated that each medication be approved by a judge. In Massachusetts, a Guardian-ad-litem is appointed for children in State custody only if the medication is an anti-psychotic; for all other psychiatric medications, the child welfare case worker gives approval. In Tennessee, if the parent is not available to give consent or parental rights have been terminated, one of twelve regional health unit nurses give informed consent.

One of the challenges of this process is ensuring communication between the mental health provider making the diagnostic assessment and medication recommendation and the individual asked to provide informed consent. Ideally, the parent or guardian of the child is present for the psychiatric evaluation, has an opportunity to ask questions of the provider, understand the risks and benefits of the proposed treatment, and provides truly informed consent. The desire for an expedited decision-making process but should not trump the need for a truly engaged informed consent process. Informed consent defaults to the State if parental rights are terminated or if the parent or guardian cannot be meaningfully involved in the psychiatric assessment. States must train case workers about the risks and benefits of psychiatric medications in order for them to be able to provide informed consent for the children on their caseload. We are not aware of any States that authorize foster parents to provide informed consent.

Do most States have the capacity to obtain a second opinion from another medical expert after a foster child has been diagnosed with a mental disorder and prescribed a variety of psychotropic medications?

We are not aware of any existing surveys of State policies in this regard but the field would benefit from such a study. In Tennessee, when Dr. Bellonci started consulting in this area, the Child Welfare department did not have a consulting child psychiatrist. Since that time Dr. Bellonci was able to help draft the job description and facilitate the hiring of the Department of Children's Services first staff child psychiatrist. Similarly in

Massachusetts, the Department of Social Services was and remains without a consulting child psychiatrist. They have been 'borrowing' child psychiatrists from the Department of Mental Health. In Connecticut, children and family's services are under one administrative umbrella and they have a number of child psychiatrists both centrally and regionally allocated available to consult to the child welfare system and they are part of that State's medication review team. San Diego County in California is moving forward with having a medication clinic specifically for children in foster care under the auspices of County Mental Health.

Child psychiatrists are in short supply and high demand. The Surgeon General estimates the need at 30,000 for the nation and currently there are just 7,000 including those engaged in non-direct care activities (administration, research, teaching). Even fewer child psychiatrists are familiar with the unique needs and challenges of working within child welfare systems. The limitation in numbers and experience with children in child welfare is also true for developmental-behavioral pediatricians. Some exciting models of consultation are utilizing medical schools for consultation and treatment reviews. This serves a dual purpose of getting high caliber consultation to child welfare departments and exposing medical students, child psychiatry trainees and academic child psychiatrists and developmental-behavioral pediatricians to the mental health needs of children in the child welfare system.

Do you believe that a uniform set of standards is needed to govern how States monitor the use and administration of psychotropic medications within the foster care system?

We strongly endorse that all States should be responsible for ensuring that children in their custody are receiving appropriate treatment for their mental health conditions. Given the variety of resources, cultures, languages and settings nationwide we doubt a single approach would be applicable to all States. However, there are critical points in the decision-making process that offers States an opportunity to impact a positive outcome for youth and families in meeting their mental health needs:

1. Upon entry into care a child/youth should have a mental health screening to determine any prior mental health condition and past treatment, including current and past psychiatric medication use. In addition, any child/youth who is changing placements for non-administrative reasons, should be re-evaluated to determine if any behavioral issues are triggering the change (research suggests about 25% of children in foster care experience at least one placement change because of problems in their psychosocial functioning; see James, Landsverk, Slymen, Leslie, "Predictors of Outpatient Mental Health Service Use-The Role of Foster Care Placement Change", *Mental Health Services Research*, vol. 6, pp. 127-141, 2004).

2. For those children/youth with past or current mental health issues, a comprehensive assessment should be conducted within thirty days of placement in custody leading to a treatment or service plan on how the child's mental health needs will be addressed while they are in care.

3. If a psychiatric medication is recommended, and laws, policies or practice prevent the parent from providing informed consent, a process for obtaining informed consent from a knowledgeable, well-trained child welfare staff person must be in place. Ideally, the person providing the consent is present for the evaluation and even when parents are not able to provide consent, they are engaged in the discussion in a meaningful way. Assent should be sought from the youth if laws, policy or practice do not allow them to give consent (in some States adolescents can give their own consent).

4. States need information technology systems that can monitor child-specific and aggregate medication use for children in custody. At the State level, teams should be responsible for reviewing concerns regarding prescription of psychiatric medications. This team can establish triggers that would result in a review of the types of medication prescribed, dosages, combinations of medications, age of the child, appropriateness of medication to diagnosis, what other services and supports are being provided, prescribing trends for individual practitioners or programs, etc…The team would have the responsibility of interfacing with the community providers in order to ensure best practice approaches are being utilized for children in State custody.

5. A mechanism for accessing a second opinion from an experienced clinician when an identified trigger(s) is noted must be in place. This might include telephone or web-based consultation or referral to a Center of Excellence, as is currently done in Tennessee.

6. Treatments for children in State custody should be evidence-based where evidence is available and otherwise based on expert-developed guidelines for care. As many of the evidence-based treatments for the types of problems commonly seen among children in child welfare are not medications, child welfare systems should work with Medicaid and mental health to assure these non-pharmacologic treatments are accessible and employed for children in child welfare. Examples of evidence-based psychotherapeutic programs of applicability to children in child welfare include Parent-Child Interactive Therapy (PCIT), Multidimensional Treatment Foster Care, Trauma-focused Cognitive Behavioral Therapy, Multi-Systemic treatment (MST) and others. Please see the California Evidence-based Clearinghouse for Child Welfare's excellent website for more information (http://www.cachildwelfareclearinghouse.org).

Are foster youth who are placed in group home facilities more likely to be prescribed psychotropic medications than foster children who are placed in other settings?

It makes sense that children at higher levels of care are prescribed more psychotropic medications. In Dr. Bellonci's own practice which is considered a tertiary care setting, it is not uncommon for children to be admitted on 4-5 medications with as many as 10-20 prior medication trials. Data over the last 10 years show that children under his care

leave the residential setting on 40% **less** medication compared to admission. Dr. Tonniges, the Medical Director of Boys and Girls Town in Nebraska, has similar examples that could be shared with the Committee. With shorter inpatient hospital stays and challenges to community mental health settings, we believe one role for residential settings can be to reassess a child's psychiatric medication regimen in a thoughtful way, considering what other services and supports are needed to foster emotional and behavioral gains. We urge the Committee to recognize the importance of both evidence-based psychotherapeutic treatments and medications in the management of behavioral issues in children in child welfare.

We additionally include some analyses provided to us by nationally recognized researchers examining mental health needs of children in child welfare to address the question of higher rates of medication use among children in group homes/residential facilities compared to children placed with non-relatives or kin in foster care.

Dr. Leslie examined data from the National Survey on Child and Adolescent Well-being (NSCAW, http://www.acf.hhs.gov/programs/opre/abuse_neglect/nscaw/index.html), a longitudinal study following 5504 children in 92 communities across the U.S. The study was authorized under the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) of 1996 (PUBLIC LAW 104-193) and funded by the Federal Administration on Children and Families; data collection was conducted by the Research Triangle Institute (RTI) from 1999-2004. The data presented here looked at rates of psychotropic medication use five months after an investigation for abuse or neglect. Among the 878 children ages 2 and greater living in out-of-home care at this time point in the study, approximately 17% of children in a non-relative foster care homes, 8.5% of children living with kin, and 58% of children in group homes were taking psychotropic medications.

These rates are relatively similar to rates in data provided by Dr. Ramesh Rahgavan and Dr. Curtiss McMillen of youth in the Missouri child welfare system. Their findings suggest psychotropic medication rates of 52% among youth in congregate care, 28% among youth residing with non-relative foster parents, and 14% among youth residing with kin (R. Rahgavan, Personal Communication, June 4, 2008).

These data do not tell us if children and adolescents in congregate care were: 1) receiving appropriate psychotropic medication and psychosocial interventions prior to entering care, 2) have greater rates of disorders for which medication is an evidence-based treatment, and 3) are stabilizing/improving with medication and admission to a congregate care setting. These would be important questions to seek answers to in future research.

Dr. Julie Zito, one of the other expert witnesses at the Congressional hearing, has access to state Medicaid data and may also be able to comment on rates of psychotropic medication use among children in group homes/residential care compared to non-relative foster care and we would highly recommend contacting her as well.

We would urge Congress to also encourage the National Institutes of Health to promote research on the identification and treatment of mental health problems in these very vulnerable youth. Currently, there are limited federal dollars earmarked to research the types of questions for which Congress is seeking answers.

We very much appreciate the opportunity to respond and would be happy to provide any additional assistance in the future.

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