AUTHENTICATED
U.S. GOVERNMENT
INFORMATION
GPO

PRESCRIPTION PSYCHOTROPIC DRUG USE AMONG CHILDREN IN FOSTER CARE

HEARING

BEFORE THE

SUBCOMMITTEE ON
INCOME SECURITY AND FAMILY SUPPORT

OF THE

COMMITTEE ON WAYS AND MEANS
U.S. HOUSE OF REPRESENTATIVES

ONE HUNDRED TENTH CONGRESS

SECOND SESSION

MAY 8, 2008

Serial No. 110–83

Printed for the use of the Committee on Ways and Means

U.S. GOVERNMENT PRINTING OFFICE

45–553 WASHINGTON : 2009

For sale by the Superintendent of Documents, U.S. Government Printing Office
Internet: bookstore.gpo.gov Phone: toll free (866) 512–1800; DC area (202) 512–1800
Fax: (202) 512–2104 Mail: Stop IDCC, Washington, DC 20402–0001

COMMITTEE ON WAYS AND MEANS

CHARLES B. RANGEL, New York, *Chairman*

FORTNEY PETE STARK, California
SANDER M. LEVIN, Michigan
JIM MCDERMOTT, Washington
JOHN LEWIS, Georgia
RICHARD E. NEAL, Massachusetts
MICHAEL R. MCNULTY, New York
JOHN S. TANNER, Tennessee
XAVIER BECERRA, California
LLOYD DOGGETT, Texas
EARL POMEROY, North Dakota
STEPHANIE TUBBS JONES, Ohio
MIKE THOMPSON, California
JOHN B. LARSON, Connecticut
RAHM EMANUEL, Illinois
EARL BLUMENAUER, Oregon
RON KIND, Wisconsin
BILL PASCRELL JR., New Jersey
SHELLEY BERKLEY, Nevada
JOSEPH CROWLEY, New York
CHRIS VAN HOLLEN, Maryland
KENDRICK MEEK, Florida
ALLYSON Y. SCHWARTZ, Pennsylvania
ARTUR DAVIS, Alabama

JIM MCCRERY, Louisiana
WALLY HERGER, California
DAVE CAMP, Michigan
JIM RAMSTAD, Minnesota
SAM JOHNSON, Texas
PHIL ENGLISH, Pennsylvania
JERRY WELLER, Illinois
KENNY HULSHOF, Missouri
RON LEWIS, Kentucky
KEVIN BRADY, Texas
THOMAS M. REYNOLDS, New York
PAUL RYAN, Wisconsin
ERIC CANTOR, Virginia
JOHN LINDER, Georgia
DEVIN NUNES, California
PAT TIBERI, Ohio
JON PORTER, Nevada

JANICE MAYS, *Chief Counsel and Staff Director*
BRETT LOPER, *Minority Staff Director*

SUBCOMMITTEE ON INCOME SECURITY AND FAMILY SUPPORT

JIM MCDERMOTT, Washington, *Chairman*

FORTNEY PETE STARK, California
ARTUR DAVIS, Alabama
JOHN LEWIS, Georgia
MICHAEL R. MCNULTY, New York
SHELLEY BERKLEY, Nevada
CHRIS VAN HOLLEN, Maryland
KENDRICK MEEK, Florida

JERRY WELLER, Illinois
WALLY HERGER, California
DAVE CAMP, Michigan
JON PORTER, Nevada
PHIL ENGLISH, Pennsylvania

Pursuant to clause 2(e)(4) of Rule XI of the Rules of the House, public hearing records of the Committee on Ways and Means are also published in electronic form. **The printed hearing record remains the official version.** Because electronic submissions are used to prepare both printed and electronic versions of the hearing record, the process of converting between various electronic formats may introduce unintentional errors or omissions. Such occurrences are inherent in the current publication process and should diminish as the process is further refined.

CONTENTS

	Page
Advisory of May 1, 2008, announcing the hearing	2

WITNESSES

Julie M. Zito, Ph.D., Professor of Pharmacy and Psychiatry, Pharmaceutical Health Services Research, University of Maryland, Baltimore	6
Jeffery Thompson, M.D., Medical Director, Washington State Department of Social and Health Services, Olympia, Washington	14
Tricia Lea, Ph.D., Director of Medical and Behavioral Services, Department of Children's Services, State of Tennessee, Nashville, Tennessee	20
Misty Stenslie, Deputy Director, Foster Care Alumni of America	27
Laurel K. Leslie, Developmental-Behavioral Pediatrician, Center on Child and Family Outcomes, Tufts-New England Medical Center Institute for Clinical Research and Health Policy Studies, Boston, Massachusetts	38
Christopher Bellonci, M.D., Medical Director, The Walker School, Needham, Massachusetts	46

SUBMISSIONS FOR THE RECORD

American Academy of Pediatrics, statement	74
Vera Hassner Sharav, statement	76
Carl Smudde, statement	84
Bruce Lesley, statement	84
Jody Leibman Green, statement	87
Tara Thomson, statement	89

PRESCRIPTION PSYCHOTROPIC DRUG USE AMONG CHILDREN IN FOSTER CARE

THURSDAY, MAY 8, 2008

U.S. HOUSE OF REPRESENTATIVES,
COMMITTEE ON WAYS AND MEANS,
SUBCOMMITTEE ON INCOME SECURITY AND FAMILY SUPPORT,
Washington, DC.

The Subcommittee met, pursuant to notice, at 11:00 a.m., in room B–318, Rayburn House Office Building, Hon. Jim McDermott (Chairman of the Subcommittee), presiding.

[The advisory announcing the hearing follows:]

ADVISORY

FROM THE COMMITTEE ON WAYS AND MEANS

SUBCOMMITTEE ON INCOME SECURITY AND FAMILY SUPPORT

FOR IMMEDIATE RELEASE
May 01, 2008
ISFS–16

CONTACT: (202) 225–1025

McDermott Announces Hearing on the Utilization of Psychotropic Medication for Children in Foster Care

Congressman Jim McDermott (D–WA), Chairman of the Subcommittee on Income Security and Family Support, today announced a hearing to examine the use of psychotropic drugs for children in the foster care system. **The hearing will take place on Thursday, May 8, 2008, at 11:00 a.m. in room B–318 Rayburn House Office Building.**

In view of the limited time available to hear witnesses, oral testimony at this hearing will be from invited witnesses only. However, any individual or organization not scheduled for an oral appearance may submit a written statement for consideration by the Subcommittee and for inclusion in the printed record of the hearing.

BACKGROUND:

Psychotropic medications have been increasingly prescribed for children in recent years, but the use of these drugs appears to be particularly elevated for children in foster care. One recent study found that psychotropic drug treatment was three or four times more common for youth in foster care than for other children receiving healthcare services through the Medicaid program. Additionally, children in foster care are often prescribed multiple psychotropic medications, and sometimes these drugs are used for off-label purposes (i.e., meaning their effects have not been demonstrated in children). These medicines are most commonly used to treat depression, anxiety and attention-deficit/hyperactivity disorder.

While the trauma associated with coming into foster care may increase some children's need for certain prescription drugs, the high rate of use of psychotropic medications in foster care has raised concerns regarding the monitoring of these drugs and whether a continuum of treatment services is being provided to these children beyond medication. It appears only a minority of States have established methods to formally regulate the use and administration of these medications among children in their care.

In announcing the hearing, Chairman McDermott stated, **"Some children in foster care may need and benefit from psychotropic medication. But these drugs should not be used as a shortcut to treat foster children when more effective treatments, including counseling, might provide long-term benefits. We need to carefully oversee the prescription of these medicines, especially when it comes to placing foster children on multiple drugs or prescribing medication for off-label use."**

FOCUS OF THE HEARING:

The hearing will examine the use of prescription psychotropic drugs among children in the foster care system.

DETAILS FOR SUBMISSION OF WRITTEN COMMENTS:

Please Note: Any person(s) and/or organization(s) wishing to submit for the hearing record must follow the appropriate link on the hearing page of the Committee website and complete the informational forms. From the Committee homepage, *http://waysandmeans.house.gov*, select "*110th Congress*" from the menu entitled, "*Hearing Archives*" (*http://waysandmeans.house.gov/Hearings.asp?congress=18*). Select the hearing for which you would like to submit, and click on the link entitled, "*Click here to provide a submission for the record*." Follow the online instructions, completing all informational forms and clicking "submit." Attach your submission as a Word or WordPerfect document, in compliance with the formatting requirements listed below, by close of business on **May 22, 2008**. **Finally**, please note that due to the change in House mail policy, the U.S. Capitol Police will refuse sealed-package deliveries to all House Office Buildings. For questions, or if you encounter technical problems, please call (202) 225–1721.

FORMATTING REQUIREMENTS:

The Committee relies on electronic submissions for printing the official hearing record. As always, submissions will be included in the record according to the discretion of the Committee. The Committee will not alter the content of your submission, but we reserve the right to format it according to our guidelines. Any submission provided to the Committee by a witness, any supplementary materials submitted for the printed record, and any written comments in response to a request for written comments must conform to the guidelines listed below. Any submission or supplementary item not in compliance with these guidelines will not be printed, but will be maintained in the Committee files for review and use by the Committee.

1. All submissions and supplementary materials must be provided in Word or WordPerfect format and MUST NOT exceed a total of 10 pages, including attachments. Witnesses and submitters are advised that the Committee relies on electronic submissions for printing the official hearing record.

2. Copies of whole documents submitted as exhibit material will not be accepted for printing. Instead, exhibit material should be referenced and quoted or paraphrased. All exhibit material not meeting these specifications will be maintained in the Committee files for review and use by the Committee.

3. All submissions must include a list of all clients, persons, and/or organizations on whose behalf the witness appears. A supplemental sheet must accompany each submission listing the name, company, address, telephone and fax numbers of each witness.

Note: All Committee advisories and news releases are available on the World Wide Web at *http://waysandmeans.house.gov*.

The Committee seeks to make its facilities accessible to persons with disabilities. If you are in need of special accommodations, please call 202–225–1721 or 202–226–3411 TTD/TTY in advance of the event (four business days notice is requested). Questions with regard to special accommodation needs in general (including availability of Committee materials in alternative formats) may be directed to the Committee as noted above.

Chairman MCDERMOTT. The meeting will come to order.

I will not further apologize but to say thank you very much for staying. As a medical doctor and a child psychiatrist, today's hearing is especially important to me because the issue before us is not some academic, text book study case. The issue is real and is defined by untold numbers of foster kids who are taking psychotropic drugs.

When at-risk children are taken into custody for their own safety, they become foster children, and we become their parents. Along with that comes a special obligation, I believe, to protect and care for them. We are here today to fulfill part of our responsibility by evaluating the use and supervision of psychotropic or mind-altering drugs for children in foster care.

This review is particularly timely, since today is National Children's Mental Health Awareness Day. While our discussion may touch on the fact that all children are prescribed psychotropic drugs, more now than in the past, that issue is now largely beyond the scope of the Subcommittee. Our focus today is on the use and regulation of these medications for foster children; and, recent research presents some troubling findings for us.

Here, foster children are three to four times more likely to be prescribed psychotropic medication than other children receiving Medicaid services. Got a pill, here's a problem. Got a pill is not the continuum of treatment options that these children deserve. Additionally, foster children are often prescribed and administered several of these drugs at the same time.

We'll hear about a case study in Texas where over 40 percent of foster children who have been dispensed psychotropic drugs in 2004 were concurrently receiving three or more drugs at one time. Finally, it appears that a significant number of children in foster care are prescribed these medications that are for off-label use; which means that its effects have not been demonstrated in children.

Now, children coming into foster care have suffered various degrees of psychological trauma. As a child psychiatrist I have no doubt that some of them may benefit from medication, but I also worry that foster children may sometimes be prescribed psychotropics, because such treatment is easy and quick as opposed to effective and really appropriate. I think we need better oversight and coordination for all healthcare needs of foster children and I include such a requirement in the legislation I recently introduced called the Invest in KIDS Act. In terms of specific reforms that address concerns about over-prescribing of psychotropic drugs, three issues come to mind.

First, every State should establish a review process for use of these medications for foster kids. Are the drugs appropriate and safe for kids? Is the quantity used appropriate; and are other treatment options available? These are questions that need to be asked.

Second, foster children need continuity in their healthcare. Their primary physician should not change every time their placement does; and their medical records should not be split between multiple doctor's offices. This idea of a consistent, single healthcare provider is sometimes called a medical home; and, these kids need more than one home.

Third, we need to ensure that foster children have access to a wide range of treatment options and a way to navigate through those options. Many believe the state's ability to achieve this goal will be undermined by the administration's regulation to limit Medicaid funding for so-called targeted case management services, which is a fancy term for helping people access services designed to promote their health and well-being.

The House of Representatives recently passed legislation by a vote of 349 to 62 to suspend this and several other Medicaid regulations that threaten to restrict access to needed care. Foster kids are our kids. Jerry and I are the Godfathers of the foster kids of this country and we should treat them accordingly.

Today, we will focus on ensuring they receive the type of treatment that best meets their needs and best supports their long-term development. I now yield to Mr. Weller.

Mr. WELLER. Thank you, Mr. Chairman.

In Spanish you say "compadre," as the Godfather. Thank you for conducting this hearing, Mr. Chairman, and to our witnesses, thank you for your patience this morning. We had votes today requested by both Republicans and Democrats, and we expect to spend a little more time on the floor than we anticipated. So, I'm sorry that you were tied up and I hope this doesn't affect your schedules this afternoon.

We appreciate the time you are committing to this important hearing today. We are here this morning to review concerns about the health of foster children and the healthcare provided them. Today, our specific topic is the use and possible overuse of psychotropic medications amongst these children. Children in foster care often have serious, mental and behavioral challenges.

As we have heard in prior hearings, too many foster children have multiple home placements, jump from school to school, and are seen by multiple caseworkers and doctors with little consistent oversight. Foster children should have access to the same range of health treatments including medicines as other children so they can overcome their challenges and grow up to be healthy, productive adults.

Through Medicaid and other programs, children in foster care are entitled to healthcare coverage; however, as we have learned from previous hearings, this does not mean that all foster children receive adequate care. At today's hearing we'll hear about the appropriateness of psychotropic medications provided to foster children and the systems in place to ensure that children are receiving proper care.

Unfortunately, recent research points to serious questions about the use and possible overuse of such drugs amongst foster children. Given the challenges they face, it's not surprising that many foster children may benefit from specialized medications to help them deal with anxiety, depression, and a host of other issues.

However, it is bracing to learn that children in foster care use these drugs at three to four times the rate as other children with Medicaid coverage. It is our responsibility to ensure the foster care and medical systems carefully and responsibly establish that foster children are being properly cared for. So we have many questions today.

For example, are we sure that all foster children receiving drugs need them?

Are we sure and confident that the drugs they are taking are appropriate for and have been proven effective in children?

Are we sure and confident that foster children are taking these drugs properly and that they benefit from the drugs they take?

Are some foster children receiving dangerous combinations of multiple drugs? Do we know whether states have proper systems to monitor the safety and effectiveness of these drugs when prescribed to foster children? Those are the types of questions any parent would want to know before his or her child takes such medications.

As Misty Stenslie of the Foster Care Alumni Association, one who has personally experienced psychotropic drugs, notes in her testimony, we are standing in the place where the parents of children in foster care belong. So we need to ask these questions and we need to get answers.

I look forward to testimony today and working with my colleagues in a bipartisan way to ensure we are doing right by these children. Again, thank you, Mr. Chairman, for conducting this important hearing and thank you to the panelists for joining us today. I yield back.

Chairman MCDERMOTT. Thank you. Your testimony will be entered in full into the record; and, the purpose of this hearing really is to give us ideas about legislation that we can craft that will be useful across the country.

One of the problems we're going to hear about, I think, here is the sort of patchwork of what we have today and we'd like to have your ideas about how best to deal with that so that we can make it not a problem whether you're raised in Kentucky, New Hampshire, Washington State, Illinois or wherever.

You should get the same kind of treatment, more or less, with respect to these medications; so, we will begin by Dr. Zito from Baltimore, Maryland, University of Maryland.

Dr. Zito?

STATEMENT OF JULIE M. ZITO, PH.D., PROFESSOR OF PHARMACY AND PSYCHIATRY, PHARMACEUTICAL HEALTH SERVICES RESEARCH, UNIVERSITY OF MARYLAND

Dr. ZITO. Thank you, Mr. Chairman.

My name is Julie Magno Zito and I am really pleased to be invited to testify today, a professor of pharmacy and psychiatry at the University of Maryland in Baltimore, and my research focus has been on pharmico-epidemiology in the area of psychiatry with a particular focus on child mental health.

We published over a hundred papers that deal with the various aspects of community-based medication used for emotional and behavioral conditions. Prior to coming to Maryland, I was at the New York State Office of Mental Health, where I developed guidelines for physician prescribing of psychotropic drugs for severe mental disorders.

In the year 2000, Carol Strayhorne, Comptroller of the State of Texas, requested an independent analysis of psychotropic medication patterns for foster care children in the State of Texas, which we agreed to conduct with data that were supplied by the Texas Department of Health and Human Services and were then analyzed at the University of Maryland. So the focus of my comments to you will reflect the study on Texas foster care, primarily, but I would like to put it a bit in the context of the general overall use of psychotropic drugs in children in the United States.

I would like to make four points in my 4 minutes, so these will be fairly brief. First, I think there is a real need for community-based studies of outcomes of psychotropic treatment, not just in foster care, but in all children, because we have had this dramatic, expanded use of psychotropics for emotional, behavioral conditions, and, most of that evidence, is based on clinical trial studies in vol-

unteer populations for short-term use. So we really don't know the extent to which children (to answer Mr. Weller's question "what do we know,") benefit based on community-based populations because they are not likely to be the same population as were in clinical trials.

The second point I'd like to make is that we have to get beyond symptom control in knowing that drugs really work well in children, so beyond symptom controls, what does that mean?

By beyond symptom control for short term use I think we want to know how well children benefit in terms of academic performance, in terms of their development, social needs and social relationships; and, also in terms of safety. Finally, in regard to this point I think we need cooperation that could take place right now within every State to link relevant foster care agencies: one that has responsibility for oversight (which in Maryland we call the Department of Human Resources) and, to link their databases with the databases that are in the Maryland Medicaid System so that we can better understand treatment services and outcomes of care.

This linkage is relatively inexpensive and could be done immediately; and, what would that allow us to do? It would allow us to see the level of continuity of care and to see these outcomes in terms of the type of placement setting that the children are in.

Also, in foster care from the data in our paper, rates of psychotropic utilization are three to four times higher than the children who are in Medicaid because of low income (TANF or S–CHIP). More interesting even than that fact is that if you look at preschoolers in Texas, foster care youth, 12 percent were receiving psychotropic meds and 67 percent of the kids in the 13 to 17 years of age.

So, I suggest that parents and advocates would be willing to say that when two-thirds of foster care adolescence receive psychotropic medication for behavioral and emotional problems, which is far, far in excess of the non-foster care population, we should be able to have assurances that the youth are benefiting from the treatments. This is not just Texas by any means. We have data from Minnesota, California, Delaware, and Pennsylvania. All of them show the same thing—relatively high rates.

So to conclude this point, I would ask why don't we have national reporting of foster care treatment so that we can look at the variation by State and by region and come to a better understanding of what might be excessive or what might be appropriate? We don't know from just looking at these numbers and we can't really make very strong inferences about appropriateness, because there's no question in anyone's mind that the needs of these children for mental health services is very, very, great.

Third point, concomitant medication use which you have alluded to, some people call it "polypharmacy," but that's a pejorative word in a lot of circles so we say concomitant, i.e., intended to be used together. Here, the Texas data were pretty compelling when 73 percent of the kids on medicine were likely to receive two or more and forty percent three or more psychotropic drug classes.

What do those concomitant classes tell you? That they are likely to be anti-depressants or anti-psychotics, although the population that's actually being treated for psychosis is far smaller than the antipsychotic use suggests; and, the third group is stimulants. So that's the story in terms of concomitant use.

Why do we worry about that? Well, first of all as you said it's virtually all off-label, so there's very little basic work that's been done to support their efficacy or safety, even in ideal populations, let alone in community-based populations.

The fourth point is that more therapeutic research is needed because pediatric populations are not the same as adults. Children are not little adults, as we all learned a long time ago, and even their adverse event profile looks remarkably different. So we're really looking at experimental experience, which may be what the SSRI safety concerns pointed out to us 2 years ago. Related to concomitant use, the fact is that more drugs used together present more opportunities for expanded adverse events. So, what could we do about drug safety?

We could get serious in the United States about drug safety, in order to look for low frequency (rare) events. You've got to look out there in the community, in the usual practice population, not only in the ideal subjects who come into clinical trials.

We need money and funding for that naturally, and that sounds very self-serving. Beyond the money and funding for it, I think we need a change in the way we approach the answer to the question "does this drug work and in whom?" Then, last point is on oversight. Here I would laud Illinois and Tennessee for their more creative approaches to the question of how to perform oversight.

In general, oversight is pretty weak. There are no consequences if a physician gets a letter in the mail. Who knows why five or more concomitant psychotropic classes for a child is an adequate cut point to signal oversight review. There's absolutely no empirical evidence—none—zero. It seems to be copied somewhere from adult standards which might be reasonable, but in children, it's a really strange number.

So we recommend that there be the kind of oversight that Illinois and Tennessee are suggesting after somebody's on three concomitant classes at one time. I'll stop there.

[The prepared statement of Ms. Zito follows:]

Prepared Statement of Julie M. Zito, Ph.D.,
Professor of Pharmacy and Psychiatry, Pharmaceutical Health Services Research, University of Maryland, Baltimore

My name is Julie Magno Zito. Thank you for the invitation to testify today. I am a Professor of Pharmacy and Psychiatry at the University of Maryland, Baltimore. I have received more than 4 million dollars in NIH and foundation support. This support has allowed me to pursue pharmacoepidemiologic research as a specialty in the area of psychiatry, with a focus in the area of child mental health. Our team of specialists includes child psychiatrist and pediatrician researchers, pharmaceutical computing experts and epidemiologists and together we have published nearly 100 research papers on population-based medication use for the treatment of emotional and behavioral conditions. Prior to this position, I was a research scientist at the Nathan Kline Institute in New York where I developed guidelines for physician prescribing of psychotropic drugs for severe mental disorders (Zito, 1994). In 2006, Carole K. Strayhorn, Comptroller of the state of Texas requested an independent analysis of psychotropic medication patterns for foster care children in Texas which we agreed to conduct with data supplied by the Texas Department of Health and Human Services and analyzed at the University of Maryland. The results of that analysis are the focus of my report today.

OBJECTIVES FOR THE PREPARED TESTIMONY

My objective for the prepared testimony is to present and support four major points.

Need for Community-based Studies on Outcomes of Psychotropic Treatment. Since 1990, the expanded use of psychotropic medication to treat emotional and behavioral problems in U.S. youth has caught the attention of the media without adequately informing the public of evidence of beneficial and appropriate use. To address this important gap in our knowledge base on the benefits and risks of such treatments requires sustained study in community-based youth populations—not just in clinical trial volunteers. Post-marketing studies are particularly important to identify and describe patient outcome in terms of academic performance, social development and avoidance of negative outcomes, e.g. crime, substance abuse and school failure—in other words, beyond symptom control. In the current U.S. research environment, most medication research focuses on symptom improvement in short-term clinical trials which is necessary but not sufficient information to establish the role of medication in community-based pediatric populations. Therefore, we recommend outcome studies of community-treated youth—for all youth, but particularly in foster care and disabled youth because they have the greatest likelihood of receiving complex, poorly evidenced, high cost medication regimens. Cooperation between the state agency responsible for oversight of child welfare and the Medicaid administration would permit databases to be linked so that the continuity of care and outcome in foster care can be assessed according to the type of placement setting.

High Foster Care-specific Prevalence of Psychotropic Medication Use. Among community-based populations, foster care youth tend to receive psychotropic medication as much as or more than disabled youth and 3–4 times the rate among children with Medicaid coverage based on family income [temporary assistance for needy families (TANF) or state-Children's Health Insurance Program, (s-CHIP)]. For example, in 2004, 38% of the 32,000+ Texas foster care youth less than 19 years of age received a psychotropic prescription (Zito et al., 2008). When 2005 data were disaggregated by age group the 2005 annual prevalence of psychotropic medication was: 12.4% in 0–5 year olds; 55% in 6–12 year olds; and 66.5% in 13–17 year olds. When two-thirds of foster care adolescents receive treatment for emotional and behavioral problems, far in excess of the proportion in non-foster care population, we should have assurances that the youth are benefiting from such treatment. Relatively high annual prevalence of psychotropic medications also has been reported for foster care youth in Minnesota (Hagen & Orbeck, 2006), Maryland (dosReis, Zito, Safer, & Soeken, 2001; Zito, Safer, Zuckerman, Gardner, & Soeken, 2005), Delaware (dosReis et al., 2005), California (Zima, Bussing, Crecelius, Kaufman, & Belin, 1999), and Pennsylvania (Harman, Childs, & Kelleher, 2000). Collectively, these patterns raise questions but do not address appropriateness and the role of medication in this vulnerable and needy population. Whether medication addresses the social, environmental and developmental needs of youth where unstable family structures are the norm is unknown.

Data for descriptive utilization studies are readily available through the Center for Medicaid and Medicare (CMS), and are relatively inexpensive to organize and analyze but as yet there is no national reporting of foster care treatment. Questions about why, typically foster care youth exceed the use of psychopharmacologic drugs observed in disabled youth deserve to be explored from a broader, societal perspective as well as from a clinical perspective. Poverty, social deprivation, and unsafe living environments do not necessarily justify complex, poorly evidenced psychopharmacologic drug regimens.

Concomitant Psychotropic Medication Patterns in Foster Care with Little Evidence of Effectiveness or Safety. Combinations of medication are prescribed in order to address multiple symptoms. The sparse data on such practice patterns suggest that it is increasing (Safer, Zito, & dosReis, 2003). To assess concomitant psychotropic classes in the Texas foster care data, we selected a one month cohort of youth in July 2004 and found 29% (n=429) received one or more classes of these medications. Of these psychotropic-medicated youth, 72.5% received two or more psychotropic medication classes and 41.3% received 3 or more such classes. In such combinations, more than half the medicated youth had an antidepressant (56.8%); a similar proportion (55.6%) had an ADHD medication (a stimulant or atomoxetine) dispensed, and 53.2% had an antipsychotic dispensed. Most psychotropic combinations lack adequate evidence of effectiveness or safety in youth. Typically, they are adopted based on knowledge generalized from adult studies or assume that the combination is as safe and effective as each component of the regimen. Such assumptions, however, are not warranted because data reveal that children and adolescents differ from adults in adverse drug reactions to psychotropic medications (Safer, 2004; Safer & Zito, 2006). In addition, pediatric research shows that increasing the number of concomitant medications increases the likelihood of adverse drug reactions (Turner, Nunn, Fielding, & Choonara, 1999; Martinez-Mir et al., 1999). Long-term safety and drug-drug interactions are also more problematic. Data show that

poorly evidenced regimens tend to increase in complexity over the age span suggesting that polypharmacy is not effective in managing the multiplicity of problems of foster care youth and others with serious social, behavioral and mental health problems who are often referred to as treatment-resistant or difficult to treat (Lader & Naber, 1999). This is particularly true when observing youth with repeated hospitalizations. In the Texas cohort, 13% had a psychiatric hospitalization in the study year and 42% of these had a psychiatric hospital diagnosis of bipolar disorder. As younger age youth receive psychotropic medications, the early introduction of medications to the developing youth (12% of preschoolers in these data from Texas), suggests the need for drug safety studies. Drug safety studies require access to large community-based data sets, formation of cohorts for longitudinal assessment over successive years and epidemiologic methods for conducting observational safety studies. Yet, funding and training of clinical scientists for this type of research is quite modest (Klein, 1993; Klein, 2006) while the FDA is largely focused on the premarketing assessment of new drugs (APHA Joint Policy Committee, 2006).

Concomitant medication with antipsychotics and anticonvulsant-mood stabilizers is referred to as "off-label' usage, i.e., lacking FDA approved labeling for either the age group or the indication for treatment, e.g. an antipsychotic for ADHD or disruptive disorders. In the Texas foster care data, most antidepressant use was also off-label. Moreover, when the drug class use was compared among the leading diagnostic groups, there was little evidence of specificity. In youth with 3 or more medication classes, antipsychotic medications were used in 76.1% of those with an ADHD diagnosis; 75.8% of those with adjustment or anxiety diagnoses; and 84.1% of those with a depression diagnosis. If medication regimens increase the risk of adverse events without robust evidence of benefits (outcomes), prudence suggests that oversight programs monitor and review therapeutic interventions in professionally competent, individualized, and caring assessments.

Foster Care Oversight, Quality Assessment and Public Health-oriented Prescriber Education. Quality assurance programs for psychopharmacologic treatments aim to review and assess the appropriateness of therapy. Such programs are understandably weak because: 1) record reviews are not always accurate; 2) multiple prescribing physicians may account for prescriptions that are not actually in use; 3) computerized systems that trigger automatic warning letters frequently have no impact (Soumerai, McLaughlin, & Avorn, 1990) in part because there are no consequences for prescribing outside the guidelines. In the Texas Medicaid system, the Texas Department of State Health Services panel produced practice guidelines for youth in Medicaid in 2005 (Texas Dept of State Health Services, 2005). They concluded that a department review should be required if antipsychotic agents and antidepressants were prescribed for youth under 4 years of age, stimulants under 3 years of age, if 2 or more drugs from the same class were prescribed concomitantly, and if 5 or more different classes of psychotropic medication were prescribed concomitantly. Five months after promulgating these criteria, there was a 31% drop in use of 5 or more psychotropic classes among foster care youth (Texas Health and Human Services Commission, 2006). Illinois and Tennessee foster care programs have implemented oversight based on a central or regional academic reviewing process that is intended to keep prescribing physicians up to date on current practice and to discourage unnecessary or potentially unsafe regimens. This is a laudable step in the direction of more nuanced, comprehensive reviews and allows for a patient-specific, individualized review. If such programs are evaluated formally, they can provide valuable information on the feasibility and success of this approach to improve the quality of psychotropic medications for foster care.

We recommend that the criterion for triggering an individualized patient record review is the dispensing of 3 or more concomitant psychotropic medication classes in youth given that such drug use lacks supportive evidence and systematic safety studies, and is off-label in almost all instances. Essentially, 3-drug class regimens have inadequate evidence for a therapeutic benefit and safety in youth. Additional appropriate triggers include young age (antipsychotic or antidepressant in <4 years olds) and 2 or more drugs used concomitantly within the same class.

BACKGROUND

Increased Psychotropic Medications for Youth: Good News or Bad News?

Medicaid insurance covers vulnerable pediatric populations including youth with disabilities and those in foster care, as well as youth qualifying by low family income [temporary assistance to needy families (TANF) and state-Children's Health Insurance Program (s-CHIP)]. The treatment experience of Medicaid youth is accessible for population-based research because the Center for Medicaid and Medicare Services (CMS) is a repository of detailed administrative data on outpatient visits and medication dispensings along with demographic data including race/ethnicity

and enrollment characteristics. These data enable researchers to create yearly trends in health service use including psychotropic drugs across states.

Since 1990, psychotropic medication use in children and adolescents has increased dramatically across all insured youth (Zito et al., 2003). Among more than 900,000 youth with either Medicaid or HMO insurance coverage, administrative claims data from the community showed the use of a psychotropic medication was 2–3 times greater in 1996 than 10 years earlier. In general, Medicaid youth receive more mental health services including psychotropic medications than commercially-insured youth because they have more impairments (Shatin, Levin, Ireys, & Haller, 1998). Data on Medicaid-insured youth in a northeastern state showed 8.9% of youth less than 19 years old received a psychotropic medication in 2007 (Pandiani & Carroll, 2008). Remarkably, antipsychotic use increased approximately 6-fold between 1997 and 2007. While the rising use affects all age groups, the rise is particularly notable in preschoolers. Medicaid-insured preschoolers from 7 states were 5-times more likely to received an antipsychotic and twice as likely to receive an antidepressant in 2001 compared with 1995 data from 2 other states (Zito et al., 2007). The trend toward increased prevalence of psychotropic medication is similar in commercially-insured youth although the annual rate is lower. This trend is illustrated by national parent survey data [Medical Expenditure Panel Survey, MEPS] for the 1987–1996 decade and showed similar growth (Olfson, Marcus, Weissman, & Jensen, 2002). In summary, population-based analyses of psychotropic usage patterns for youth show variations in use according to region, race/ethnicity, type of insurance, as well as clinically relevant differences in age group, gender and type of condition (Zito, Safer, & Craig, 2008). When the 30% of U.S. youth with Medicaid insurance are analyzed according to eligibility, foster care is likely to be the group receiving the highest rates of psychotropic medication relative to the disabled (eligible by Supplemental Security Income) and those with income eligibility.

Foster Care Psychotropic Medication Use

Demographic Profile of Foster Care Youth in the United States. In 2005, 514,000 youth were in publicly supported foster care—less than 1% (0.7%) of the 74 million youth less than 18 years of age (Administration for Children Youth and Families, 2008). Data from 2000 showed gender is equally split. A majority is 6–15 years old: 11–15 year olds (29%); 6–10 year olds (25%); 1–5 (24%); 16–18 year olds (16%); and the remainder are less than 1 and over 18. In FY 2000, African-American youth represented the largest share of children in foster care (41%) followed by White (40%), Hispanic (15%) and Native American (2%). These race/ethnicity characteristics are disproportionately high relative to the U.S. population of African-Americans (15%) and Native Americans (1%). Length of stay data indicate that 55% of youth are in foster care for less than 2 years. As children age, their chances of reaching optimal residency (permanency goal) diminishes. A large majority of youth in foster care live in a non-relative foster home (47%) or in a relative foster home (25%). Most youth return to parental care (57%) while adoption or living with relatives occurs in 27% of cases. Against this statistical demographic profile, we will explore the medical treatments for behavioral and psychiatric conditions with a focus on psychotropic medications.

Psychotropic Prevalence in Foster Care. Among the 32,135 Texas foster care Medicaid enrollees less than 20 years old in the study year September 2003 to August 2004, 37.9% of youths had a psychotropic medication dispensing (Zito et al., 2008). This figure contrasts with 25.8% (CI 25.0–26.6) annual prevalence from a Mid-Atlantic foster care population in 2000 (Zito et al., 2005). In 1998, 34% of youth ages 3–16 in St. Louis County, Minnesota Family Foster Care had at least 1 psychotropic medication dispensing. This compared with 15% of youth receiving a psychotropic medication in the general population (Hagen et al., 2006).

Among Medicaid enrollees less than 20 years old in a populous suburban county of a mid-Atlantic state in 1996, psychotropic treatment prevalence rates for foster care youths were 1.7 (95% CI=1.4,2.2) times higher than those for SSI youths and 18 (95% CI=14.9,22.7) times higher than those for youths in the other aid group (dosReis et al., 2001). Other aid refers primarily to eligibility based on income or medical need.

In FY 1995, Medicaid claims from foster care youth 5–17 continuously enrolled youth in Southwestern Pennsylvania showed these children were 3 to 10 times more likely to receive a mental health diagnosis. They were 7.5 times more likely to be hospitalized for a mental health condition than children covered by AFDC. Prevalence of psychiatric conditions was comparable between foster care and disabled youth (Harman et al., 2000).

Foster care youth with a diagnosis of autism spectrum disorder (ASD) were twice as likely to receive concomitant drug therapy (defined as 3 or more medication class-

es overlapping for more than 30 days in the year 2001) compared with their counterparts eligible by low family income. Findings from this large national sample suggest that factors unrelated to clinical presentation may account for these prescribing practices and warrant further research ((Mandell et al., 2008).

Concomitant Psychotropic Medications: More Than One in the Same Class or Between Classes

A recent review of the sparse literature on concomitant psychotropic medication use in youth revealed that this treatment regimen was rarely used in children in the late 1980s (Safer et al., 2003). Bhatara et al. showed concomitant use for the treatment of attention deficit hyperactivity disorder (ADHD) based on national ambulatory medical care survey (NAMCS) data increased 5-fold from 1993 through 1998 (Bhatara, Feil, Hoagwood, Vitiello, & Zima, 2002). Across all conditions, there was an increase of 2.5-fold from 4.7% to 11.6% using MEPS data that was observed by Olfson et al. for the period from 1987 through 1996 (Olfson et al., 2002). In general, this review suggests that concomitant use of psychotropic medications in youth is a recent phenomenon. Common combinations include stimulants and clonidine (Zarin, Tanielian, Suarez, & Marcus, 1998) and stimulants and antidepressants (Zito et al., 2002).

Concomitant use is likely to be greater in populations treated by psychiatrists than those treated by pediatricians. (Bussing, Zima, & Belin, 1998) showed that in a Florida school district-wide sample of elementary school age special education youth, concomitant psychotropic use occurred in 48% of psychiatrist-treated youth compared with 6% of pediatrician-treated youth.

In the Texas study, in a one month cohort (July 2004), 72.5% of the medicated youth received concomitant medications (Zito et al., 2008). Among the medicated youth, 41.3% received ≥3 psychotropic medication classes concomitantly, 15.9% received ≥4, and 2.1% received ≥5 classes. The rank order of the most common concomitant psychotropic class combinations was as follows: antipsychotics with ADHD medications, antipsychotics with antidepressants, antidepressants with ADHD medications, and anticonvulsant-mood stabilizers with antidepressants (Zito et al., 2008). Generally, psychotropic treatment by medication class was not specific relative to the leading diagnostic groups (Depression; ADHD; Adjustment/Anxiety). To illustrate, 76 to 84% of youth with 3 or more concomitant classes had antipsychotic dispensings regardless of the diagnostic group and the vast majority reflected behavioral and emotional symptoms, i.e. non-psychotic use. At the time of the study, all antipsychotic and anticonvulsant-mood stabilizer use was off-label use, i.e. without FDA-approved labeling for an indication, dose or age group (Roberts, Rodriguez, Murphy, & Crescenzi, 2003).

Foster Care Oversight for Medication Quality of Care

Clinical guidelines on foster care services have been produced by professional organizations, e.g. The American Academy of Child and Adolescent Psychiatry (American Academy of Child and Adolescent Psychiatry, 2008). Their standards focus on minimal and ideal recommendations. The recommendation on requests by the prescribing physician for consultation with child and adolescent psychiatry experts is only initiated by the requesting physician. The American Academy of Pediatrics statement on healthcare of young children in foster care recommends more frequent monitoring of the health status of children in placement than for children living in stable homes with competent parents (American Academy of Pediatrics, 2002).

Clinical education teams working the public sector are known as academic detailers and have been shown to be effective (Soumerai & Avorn, 1990). Ideally, a team of clinical pharmacists led by a psychopharmacologist in child psychiatric drug therapy could work to balance drug information originating from proprietary-funded thought leaders. Such an approach could lead to a balance between a marketing perspective and a long-term public mental health perspective.

Another concern of Medicaid treatment is cost. In the Texas data we analyzed, very expensive psychotropic medications were prescribed, including antipsychotic agents (averaging $22/month) and anticonvulsant-mood stabilizers (averaging $110/month). In fact, over 50% of the Medicaid expenditures for the foster care youth in FY 2004 were for antipsychotic medications (Strayhorn, 2006). In light of the vast public expenditures and services related to medication use, public-interest academic detailing should be encouraged.

Reference List

Administration for Children Youth and Families (2008). Trends in Foster Care and Adoption—FY2000–FY2005 http://www.acf.hhs.gov/programs/cb/stats_research/afcars/trends.htm.

American Academy of Child and Adolescent Psychiatry (2008). AACAP Position Statement on Oversight of Psychotropic Medication Use for Children in State

Custody: A Best Principles Guideline http://www.aacap.org/galleries/PracticeInformation/FosterCare_BestPrinciples_FINAL.pdf.

American Academy of Pediatrics (2002). Healthcare of young children in foster care. Pediatrics, 109, 536–541.

APHA Joint Policy Committee (2006). Regulating Drugs for Effectiveness and Safety: A Public Health Perspective: Position Paper http://www.lww-medicalcare.com/pt/re/medcare/aplus.html.

Bhatara, V.S., Feil, M., Hoagwood, K., Vitiello, B., & Zima, B.T. (2002). Trends in combined pharmacotherapy with stimulants for children. Psychiatric Services, 53, 244.

Bussing, R., Zima, B.T., & Belin, T. (1998). Variations in ADHD treatment among special education students. Journal of the American Academy of Child and Adolescent Psychiatry, 37, 968–976.

dosReis, S., Zito, J.M., Safer, D.J., Gardner, J.F., Puccia, K.B., & Owens, P. L. (2005). Multiple psychotropic medication use for youths: a two-state comparison. Journal of Child and Adolescent Psychopharmacology, 15, 68–77.

dosReis, S., Zito, J.M., Safer, D.J., & Soeken, K. (2001). Mental health services for youths in foster care and disabled youths. American Journal of Public Health, 91, 1094–1099.

Hagen, S. & Orbeck, L. A. (2006). The prescription of psychotropic medications in foster care children: a descriptive study in St. Louis County. www.d.umn.edu/sw/executive/hstacy.html.

Harman, J.S., Childs, G.E., & Kelleher, K.J. (2000). Mental healthcare utilization and expenditures by children in foster care. Archives of Pediatrics & Adolescent Medicine, 154, 1114–1117.

Klein, D.F. (1993). Clinical psychopharmacologic practice. The need for developing a research base. Archives of General Psychiatry, 50, 491–494.

Klein, D.F. (2006). The flawed basis for FDA post-marketing safety decisions: the example of antidepressants and children. Neuropsychopharmacology, 31, 689–699.

Lader, M. & Naber, D. (1999). Difficult Clinical Problems in Psychiatry. London: Martin Dunitz Ltd.

Mandell, D.S., Morales, K.H., Marcus, S.C., Stahmer, A.C., Doshi, J., & Polsky, D.E. (2008). Psychotropic medication use among Medicaid-enrolled children with autism spectrum disorders. Pediatrics, 121, e441–e448.

Martinez-Mir, I., Garcia-Lopez, M., Palop, V., Ferrer, J.M., Rubio, E., & Morales-Olivas, F.J. (1999). A prospective study of adverse drug reactions in hospitalized children. British Journal of Clinical Pharmacology, 47, 681–8.

Olfson, M., Marcus, S.C., Weissman, M.M., & Jensen, P.S. (2002). National trends in the use of psychotropic medications by children. Journal of the American Academy of Child and Adolescent Psychiatry, 41, 514–521.

Pandiani, J. & Carroll, B. (2008). Vermont Mental Health Performance Indicator Project http://healthvermont.gov/mh/docs/pips/2008/documents/Pip022908.pdf.

Roberts, R., Rodriguez, W., Murphy, D., & Crescenzi, T. (2003). Pediatric drug labeling. The Journal of the American Medical Association, 290, 905–911.

Safer, D.J. (2004). A comparison of risperidone-induced weight gain across the age span. Journal of Clinical Psychopharmacology, 24, 429–436.

Safer, D.J. & Zito, J.M. (2006). Treatment-emergent adverse events from selective serotonin reuptake inhibitors by age group:children versus adolescents. Journal of Child and Adolescent Psychopharmacology, 16, 203–213.

Safer, D.J., Zito, J.M., & dosReis, S.M. (2003). Concomitant psychotropic medication for youths. American Journal of Psychiatry, 160, 438–449.

Shatin, D., Levin, R., Ireys, H.T., & Haller, V. (1998). Healthcare utilization by children with chronic illnesses: a comparison of Medicaid and employer-insured managed care. Pediatrics, 102, e44.

Soumerai, S.B. & Avorn, J. (1990). Principles of educational outreach ('academic detailing') to improve clinical decision making. The Journal of the American Medical Association, 263, 549–556.

Soumerai, S.B., McLaughlin, T.J., & Avorn, J. (1990). Quality assurance for drug prescribing. Quality Assurance in Healthcare, 2, 37–58.

Strayhorn, C.K. (2006). Foster Children Texas Healthcare Claims Study-Special Report Texas Comptroller.

Texas Dept of State Health Services (2005). Psychotropic medication utilization parameters for foster children www.dshs.state.tx.us/mhprograms/psychotropicmedicationutilizationparametersfosterchildren.pdf.

Texas Health and Human Services Commission (2006). New guidelines reduce use of psychotropic drugs http://www.hhsc.state.tx.us/stakeholder/Sep_Oct06/psychotropic_drugs.html.

Turner, S., Nunn, A.J., Fielding, K., & Choonara, I. (1999). Adverse drug reactions to unlicensed and off-label drugs on paediatric wards: a prospective study. Acta Paediatr, 88, 965–968.

Zarin, D.A., Tanielian, T.L., Suarez, A.P., & Marcus, S.C. (1998). Treatment of attention-deficit hyperactivity disorder by different physician specialties. Psychiatric Services, 49, 171.

Zima, B.T., Bussing, R., Crecelius, G.M., Kaufman, A., & Belin, T.R. (1999). Psychotropic medication treatment patterns among school-aged children in foster care. Journal of Child and Adolescent Psychopharmacology, 9, 135–147.

Zito, J.M. (1994). Psychotherapeutic Drug Manual. New York: Wiley and Sons.

Zito, J.M., Safer, D.J., & Craig, T.J. (2008). Pharmacoepidemiology of psychiatric disorders. In A.G.Hartzema, H.H. Tilson, & K.A. Chan (Eds.), Pharmacoepidemiology and Therapeutic Risk Management (pp. 817–854). Cincinnati: Harvey Whitney Books.

Zito, J.M., Safer, D.J., dosReis, S., Gardner, J.F., Magder, L., Soeken, K. et al. (2003). Psychotropic practice patterns for youth: a 10-year perspective. Archives of Pediatrics & Adolescent Medicine, 157, 17–25.

Zito, J.M., Safer, D.J., dosReis, S., Gardner, J.F., Soeken, K., Boles, M. et al. (2002). Rising prevalence of antidepressant treatments for U.S. youths. Pediatrics, 109, 721–727.

Zito, J.M., Safer, D.J., Sai, D., Gardner, J.F., Thomas, D., Coombes, P. et al. (2008). Psychotropic medication patterns among youth in foster care. Pediatrics, 121, e157–e163.

Zito, J.M., Safer, D.J., Valluri, S., Gardner, J.F., Korelitz, J.J., & Mattison, D.R. (2007). Psychotherapeutic medication prevalence in Medicaid-insured preschoolers. Journal of Child and Adolescent Psychopharmacology, 17, 195–203.

Zito, J.M., Safer, D.J., Zuckerman, I.H., Gardner, J.F., & Soeken, K. (2005). Effect of Medicaid eligibility category on racial disparities in the use of psychotropic medications among youths. Psychiatric Services, 56, 157–163.

Chairman MCDERMOTT. Thank you for your testimony.

Dr. Jeffrey Thompson is a physician in Washington State. Dr. Thompson?

Dr. THOMPSON. Thank you Representative McDermott.

Chairman MCDERMOTT. Thank you for coming all this way.

Dr. THOMPSON. Yes, well, I was actually at CMS all week so this was an easy drive, somewhat easy from Baltimore.

STATEMENT OF JEFFERY THOMPSON, M.D., MEDICAL DIRECTOR, WASHINGTON STATE DEPARTMENT OF SOCIAL AND HEALTH SERVICES

Dr. THOMPSON. My name is Jeff Thompson. I am the Chief Medical Officer for Washington State Medicaid.

I want to thank you for the opportunity to testify on this very important topic. I want to also talk about what Washington State is doing. Our leaders in Washington State are doing some great stuff; and, so, I want to cover what's happening there and how the leadership is emphasizing integration of services as well as outcomes in safety. Safety is something, I think, we can all stand on.

Second, I want to talk about our findings using pharmacy claims data, which show some serious variations in pharmacy practice and children in foster care.

Third, the importance of forming good working relationships with the family and children's communities as well as the providers, because we can't do it without them. You can't just put administrative controls, but what we have been able to do is show data that bring everybody to the table including the drug companies.

Finally, I want to talk about how we're attempting to find national best practices by working with the National Association of Medicaid Directors and Carol Clancy at the Agency for Healthcare

Quality and Research, AHRQ. I want to recognize the leadership of our Governor, Christine Gregoire, as one of the key leaders, as well as key Washington State House and Senate leaders, in particular, Mary Lou Dickerson and James Hargrove as well as my Secretary, Ms. Robin Arnold-Williams.

With their guidance, our Medicaid program is integrating mental health services under legislation house bill 1088. Simply, this State statute puts children at the center of care and ensures that the medical care, the mental healthcare, and the family services are all integrated. We are trying. It's difficult to do. We accomplish this by trying to integrate treatment protocols by increasing the amount of community-based, mental health services available to children in foster care by educating our primary care physicians and our mental health professionals, and using an evidence-based practice center at the University of Washington with Dr. Trupin to set safety standards for review of medication and prescription histories setting thresholds.

We are also piloting wrap-around programs for family services. We are equally concerned as the Committee with the trend of increased medication use in children as well as adults and the elderly. Using our pharmacy claim system, we note an increasing use of off-label drugs and medications, multiple medications, poly pharmacy, whatever the correct term is. We also note that there are many providers or prescriptions that are happening for a single client, so we are concerned about whether there is good continuity of care; and, we have questions about medication adherence. When prescribed, are they actually taking it?

These issues, in short, may or may not be in the best interest of our clients, both the children and vulnerable adults in foster care. We note that parents are seeking services from across the State, across the Cascade Mountains. They go up and down the I–5 corridor, sometimes great distances, to find care. This is not the best medical home or coordination of care.

In foster care, we note a high use of mental health medications, combinations sometimes exceeding the FDA adult doses in children of very low ages; and, finally, we have shared with the community these regional variations in poly pharmacy or concurrent use and are working with the University of Washington as well as advocacy communities, the primary care communities, the mental health communities, the target pilot programs where we see high variations in care. In short, we cannot do this without working across our agencies; so we are actually working with our children's administration our DD populations, our aging and disability agency as well as anybody we can find to bring the provider types of drug companies, our contracted services, to basically lay out the full story of what's happening.

Washington State Medicaid believes that improving care and reducing the variation can only happen by working with community providers and advocacy groups. We do this by a continuous collaboration on database snapshots from our claims data and our pharmacy data for the care of the population. The examples, I might add, are showing them that the number of children who are under the age of 5 that are getting anti-psychotics, sometimes as low as age 1 or less.

Looking at the number of foster kids that are on five or more mental health drugs concurrently, looking at adherence histories to find out whether they actually picking up the medications that are being prescribed and what are the presence of county variations and dosing variations that exceeds agreed-upon safety thresholds. We find this data actually allows us to be collaborative and bring everybody to the table; and then we have successfully set community standards across the State. We accomplish this positive change with mood stabilizers, anti-depressants, stimulant use and ADHD, and we will shortly sell safety thresholds for anti-psychotics and children's healthcare.

We note that the data is presented in a non-judgmental manner. This brings the Committee together, and I might add, the drug companies are actually at the table when we discuss this. What we want to do is stop and take a short, deep breath and review the treatment plans to ensure that there's an integrated plan for the treatment.

Recently, our safety standards for stimulants have steered as many as 56 percent of prescriptions for stimulants to lower dose, fewer medications, and sometimes to rethink prescriptions in the very young. Note that 44 percent of prescriptions that are at high dose are in the very young, when our community and us agree that this is actually the appropriate use. So, it's very complex. It's an all or nothing. There's a lot of gray here.

Finally, Washington State can't do this alone. When you look across the country you see antipsychotic use varies among states. When we look at the entire population it's as varied between 4 and 13 percent of the entire Medicaid population in some states, maybe on antipsychotics. Since there's so much variation, the Medicaid medical directors across the country have asked the National Association of Medicaid Directors and Carol Clancy at AHRQ to sponsor an up-to-date pharmacy claims review and then do a program to benchmark best practices.

If we can highlight these best practices, like the Texas algorithms, the Massachusetts provider consultations, the New York and Rutgers integration project, Arizona's mental healthcare contracts, or the San Diego project to improve medication adherence and other programs, this will help us to find the best evidence-based care with the appropriate mix of State services.

Thank you for the opportunity to testify on this important topic.

[The prepared statement of Dr. Jeffery Thompson follows:]

Prepared Statement of Jeffery Thompson, M.D., Medical Director, Washington State Department of Social and Health Services, Olympia, Washington

I want to thank you for this opportunity to testify on the important topic of medication use in children—and more specifically, children in foster care. I will be brief in my testimony, which will cover four items:

1. First, I will cover what is happening in Washington State's Medicaid program, where we are leaders in emphasizing the integration of services, outcomes and safety.
2. Second, our findings using Medicaid-paid pharmacy claims indicate serious variations of prescription practice for children and foster care.
3. Third, the importance of forming a good working relationship with the child and family's community, while using data to reduce variation and improve care.

4. Finally, how we are attempting to find "best practices" among Medicaid programs nationally by working with the National Association of Medicaid Directors (NASMD) and the Agency for Health Research and Quality (AHRQ).

I want to recognize the leadership of our Governor, Christine Gregoire, as well as key members of the Washington House and Senate (in particular, Representative Mary Lou Dickerson and Senator James Hargrove), and the Secretary of the Department of Social and Health Services (Robin Arnold-Williams). With their guidance, our Medicaid program is integrating mental health services under legislation known as HB 1088. Simply, this state statute puts the child at the center of care and ensures that medical, mental health and family services are integrating all care, communicating care plans, and tailoring individualized services with families for care of the child. We accomplish this through integrated treatment planning, increasing mental health community-based services, educating Primary Care Providers (PCPs) and mental health providers in evidence-based practices, setting safety standards to review prescriptions that exceed safety thresholds, and piloting "wraparound" services for the family.

We are concerned over the trend of increasing medication use in children as well as adults, and the elderly. Using our pharmacy claims system we note an increasing use of "off label" medications, use of multiple medications, use of multiple providers to direct care, and questions about medication adherence—issues that in short may or may not be in the best interest of our children and vulnerable adults.

We note that parents seek services across the state—sometimes very distant from their residence. In foster care we note a higher use of mental health medications and combinations—sometimes exceeding FDA dosing for adults. Finally we have shared with the community the regional variations in poly-pharmacy and are working with the University of Washington and the advocacy community as well as primary care and mental health providers to target our pilot projects to areas of variation in foster care services. These pilots will allow providers to call or seek Web-based consultations during business hours based on evidence-based standards. But, we cannot do this alone and must work across agencies, provider types, contracted services and the community to understand the full story.

Washington Medicaid believes that improving care and reducing variation can only happen by working with community providers and advocacy groups. We do this by continuous collaboration on data-based snapshots of care in the population. Examples include the number of children under 5 years old on anti-psychotics, the number of foster children on five or more mental health drugs concurrently, the lack of adherence to the medications, the presence of county variations, and dosing variations that exceed safety thresholds. This is data we share with partners including the state's Pharmacy and Therapeutics Committee, the mental health work group (which includes drug companies, advocacy groups, primary care and mental providers) and, importantly, our sister agencies. We find data and collaboration can successfully set community standards of care.

We have accomplished this positive practice change for mood stabilizers, antidepressants, stimulants to treat ADHD, and will shortly set safety thresholds for anti-psychotics. We note that when data is presented in a non-judgmental manner the community can work with the state to "stop and take a deep breath" and review care plans in an integrated framework. Recently, our safety standards for stimulants have steered 56% of prescriptions to lower doses, fewer scripts or encouraged prescribers to rethink stimulant use in the young. Please note that 44% of pharmacy care is continued. This emphasizes that the clinical picture is complex—and some kids do need these medications.

Finally, this is not an issue for Washington State alone. When we look across the country we see antipsychotic use that varies between states—as much as 4% to 13% in the Medicaid populations. Because there is so much variation, the Medicaid medical directors asked NASMD and AHRQ to sponsor an up-to-date pharmacy claims and program benchmarking project. We hope this benchmarking will highlight "best practices" like the Texas algorithms, the Massachusetts provider consultations, the New York and Rutgers integration project, the Arizona mental health contracts, the San Diego projects to improve medication adherence, and other programs that will help to define the best evidence-based care and the appropriate program mix for state services.

Thank you for the opportunity to testify on this important topic.

Washington State
Department of Social
& Health Services

2008 Fact Sheet:

Improving health care of children in foster care: an ongoing collaboration

THE BACKGROUND

Nationally and statewide, children in the foster care system are more likely to have significant health concerns that can affect their ability to become healthy adults. The Northwest Foster Care Alumni Study, conducted by the Casey Foundation, found that young adults who spent time in foster care were disproportionately more likely than others their age to have disabling health conditions, particularly mental illness. In addition, children in foster placement experienced significant economic disadvantages, including household incomes beneath the poverty level, episodes of homelessness and a lack of health insurance. An additional challenge is that children in foster care may face changing placements – making it more difficult to access providers and achieve continuity of care. The Governor and State Legislature have met these concerns in their commitment to improve the health of all Washington children. For foster children, that means a guarantee of a "medical home" – a reliable provider who can be a health-care centerpiece, overseeing and coordinating health care not just for an individual but an entire family. The ongoing effort to bring all Washington State children into health-care coverage by 2010 is not directly linked to children in foster care, but the twin efforts are complementary. Allowing children access to health coverage, maximizing the links between resources, helping families find medical homes that will identify and consolidate their health needs, and increasing health literacy – all of these can help prevent the need for out-of-home placement, as well as improve children's lives in families of all incomes and walks of life. Access to health coverage means healthier kids; healthier kids mean healthier, more productive adults.

FOSTER CARE INITIATIVES

DSHS has set up a formal collaboration between the Health and Recovery Services Administration (HRSA) and the Children's Administration (CA) to promote the healthy development of children in foster care. In addition, several funded initiatives will help DSHS coordinate the health care of these vulnerable children. DSHS recognizes that when children have access to cost-effective, preventive health care -- including strong ties to a medical home -- tomorrow's citizens will have an unprecedented capacity to become productive adults in the 21st century. These initiatives include:

1. **Creation of three regional centers for foster care health in Spokane, Longview, and Seattle that will link children to medical homes, provide education for primary care providers, and refer to specialty care as needed, including mental health care**
2. **Expected funding of a foster care nurse hotline to answer questions for foster parents, give guidance to providers, and link to medical homes**
3. **Allow Children's Administration staff access to claims-based reports of health service use by children in foster care**
4. **Use phone consultation and Web-based training to educate primary care providers about behavioral health issues and concerns in foster care**
5. **Establish an improved dialogue between providers and health-care administrators**
6. **Integrate the Medicaid pharmacy benefit with mental health contractors to set quality and safety standards**

The new integrated approach will improve access to medical homes for children in foster care; provide access to basic health information for Children's Administration staff; accelerate the current working relationship of medical and mental health services within DSHS; and expand the growing partnership between the agency's mental health programs and the University of Washington, a source of expertise, resources and inspiration for the mental health system at all levels across the state.

FOR MORE INFORMATION, CONTACT:
Jeff Thompson, M.D., HRSA, DSHS 360-725-1611, thompj@dshs.wa.gov

CURRENT ACTIVITIES:

CENTERS OF FOSTER CARE HEALTH: The Health and Recovery Services and Children's Administrations are establishing centers of expertise in foster health care, beginning with three pilot programs in Longview, Seattle and Spokane. These Centers of Foster Care Health will collaborate systematically with regional CA staff and local mental health resources and follow evidence-based practices. They will improve coordination, accessibility and quality of care for foster children.

DATA SHARING: Incomplete or inaccessible medical records represent one of the biggest challenges in quick, effective care for foster children. Today, Children's Administration caseworkers are able to browse the available billing data via a "canned query" hyperlink to each child's electronic case record. While not a complete medical history, the information does include diagnosis, treatment, medications and provider names – a resource with great potential for Child Health and Education Tracking (CHET) screeners, Foster Care Public Health Nurses (formerly Passport nurses) and social workers. Other improvements are being reviewed, including direct access for medical providers to the MMIS billing data through the ProviderOne system. In addition, CA is developing a CAMIS replacement system called FamLink. FamLink will maintain a current link to MMIS billing data and other medical information. It also will have the ability to store scanned documents.

24/7 NURSE HOTLINE: Basic funding for a 24-hour, seven-day-a-week "NurseLine" is in the Governor's, Senate, and House budgets. While only simple anticipatory guidance for foster parents may be available initially, the goal is to make clinical nursing services available to caregivers or social workers involved in the transition from home to foster placement, making sure that all children in the child welfare system have regular preventive health care and appropriate medical follow-up care. Nurses will have access to medical records and other data as questions arise, and they will be an ongoing resource of reliable information about emergent concerns, non-emergent issues like compliance with EPSDT (Early and Periodic Screening, Diagnosis & Treatment Program) as well as access issues, such as helping locate a primary care provider in the child's new setting

EVIDENCE-BASED PRACTICE INSTITUTE: This University of Washington institute will work with parents, caregivers, consumers and others to develop outcome-based performance measures that will help measure the effectiveness of 1088 programs. These include decreased ER hospitalizations, decreased involvement with the juvenile justice system, reductions in prescribed medication, improved school attendance and class performance, and fewer out-of-home placements and runaways.

IMPROVED CHILDREN'S MENTAL HEALTH BENEFITS: HRSA will begin paying for 20 mental health visits rather than 12 per year for children in both fee-for-service and Healthy Options Medicaid programs. This will allow a broader set of provider types (psychiatrists and licensed mental health providers with master's degrees) outside of the public mental health system. This expanded set of counseling benefits, available to children in Medicaid, will improve assess for those children who do not qualify for care under the Regional Support Networks (RSNs). These benefit changes will begin July 1.

MEDICATION MANAGEMENT/SECOND OPINION CENTER: The children's mental health-care system is developing policies to improve prescribing policies and raise the quality overall of children's mental health therapy. Public health regulators will work with community prescribers to develop effective safeguards against potential overuse of anti-psychotic and Attention Deficit Hyperactivity Disorder (ADHD) medications, especially in children below the age of 5. The effort will include a second-opinion center at Children's Hospital in Seattle – a contracted resource available to physicians across the state.

PRIMARY CARE PROVIDER EDUCATION AND CONSULTATION SERVICES: UW also will help provide more and better information about foster children's mental health needs to Primary Care Providers. Pilots will develop a Web-based curriculum as well as other provider training in addition to phone-based consultations with a pediatric psychiatrist.

WRAPAROUND SERVICES: Three RSN pilot projects in Skagit, Grays Harbor and Cowlitz counties will provide "wraparound services" for children and youth with severe emotional and behavioral disturbances and their parents. Features include services tailored to the special needs of each child and family; unique racial, geographic or social considerations; including parents in decision-making;and flexible funding that can let the wraparound centers cross interagency or interdisciplinary boundaries.

Chairman MCDERMOTT. Thank you for your testimony.

I would like to say I realize I kept you a long time waiting. We would like you try and hold your time to 5 minutes.

Dr. Lea from Tennessee.

STATEMENT OF TRICIA LEA, PH.D., DIRECTOR OF MEDICAL AND BEHAVIORAL SERVICES, DEPARTMENT OF CHILDREN'S SERVICES

Dr. LEA. Mr. Chairman and Members of the Committee, thank you for the opportunity to talk with you today.

My name is Tricia Lea and I am here to testify on behalf of the American Public Human Services Association, it's affiliate, the National Association of Public Child Welfare Directors, and the State of Tennessee where I serve as the Director of Medical and Behavioral Services for the Department of Children's Services.

The Tennessee child welfare system has been under intense scrutiny since May of 2000 when the lawsuit was filed on behalf of children who had experienced difficulties while in State custody. One concern in the lawsuit focused specifically on the inappropriate use of psychotropic medications, and the subsequent settlement agreement required the department to hire a full-time medical director specifically to oversee the implementation of policies and procedures concerning the use of psychotropic medication for children in State custody.

I serve in this medical director position and would like to share with you our child welfare agency's progress in this area. Tennessee began a reform by conducting an in-depth evaluation of policies and practices with the assistance of Dr. Christopher Bellonci, who is also here to testify today.

He and I co-facilitated a multi-disciplinary work group that developed five policies related to the use of medication. Dr. Bellonci also drafted the initial DCS medication monitoring guidelines as a tool for our case managers to use in monitoring the psychotropic medications prescribed for children in their care.

An initial review of a sample of children's case files audited by the lawsuit's Federal monitor found that approximately 25 percent of children in custody were prescribed psychotropic medications in 2003. Despite some fluctuation, the numbers of custody-children prescribed medication have declined and currently average around 20 percent with the majority of these children being the adolescents and being prescribed one or two psychotropic medications.

Tennessee has also hired a part-time consulting child and adolescent psychiatrist, Dr. Deborah Gatlin, who has established a pharmacy and therapeutics Committee to review medication practice across the State. This Committee has also assisted in updating the DCS medication-monitoring guidelines using the standards that were developed by the State of Texas.

Cases that fall outside of the utilization parameters are reviewed at several levels in our State. DCS has a statewide network of nurses and psychologists that monitor healthcare for our children, including the use of psychotropic medication, along with the consulting child psychiatrist, a pediatric nurse practitioner, and myself.

Outside of our agency we have five centers of excellence that are partnerships with the State of Tennessee and academic medical centers and community providers. These centers were created to serve children in and at risk of custody and they provide a second opinion capacity for children regarding prescriptions of psychotropic medications.

The review of medications falling outside our parameters have also become automated via our database system, and this happened in the fall of '07. Anytime a medication regimen falls outside of the parameters, the system automatically sends an e-mail alert to our psychiatrist triggering further review. The majority of cases that she has reviewed have been found to be clinically appropriate care for our kids.

The updated child welfare database also allows for more accurate tracking of all health information and all health services for the children in custody. The system provides an ongoing summary which acts as a health passport for the child and this summary is shared with all care givers and providers serving the child and is similar to what Texas has developed.

Tennessee is able to see cases in which children and youth in our custody have benefited from the oversight and monitoring processes we have put in place regarding medication. One example that I want to share is about a child who is 14 years old. He is in full guardianship. Parental rights have been terminated and he has had multiple diagnoses, including mild mental retardation, bipolar disorder, impulse control disorder, and psychotic disorder. He was placed at a residential treatment facility, but was continuing to require frequent, acute, psychiatric hospitalizations. He was prescribed six psychotropic medications at the same time. When our DCS regional nurse reviewed these medications to give consent, she contacted our psychiatrist, because the combination fell outside several of our utilization parameters.

The psychiatrist was concerned enough about this combination and this child's care and the frequent medication changes that she wanted his psychiatric care to transfer to our regional centers of excellence. The youth has now been taken off several of these psychotropic medications, is in a family foster home, and is doing fairly well.

The State of Tennessee Department of Children's Services has made significant progress regarding psychotropic medication practices for children in custody. We continue to work to ensure that children in custody have all of their health needs adequately addressed and that those who are prescribed psychotropic medication are only done so when clinically indicated.

In those cases we want to assure that if medication is appropriate, informed consent is given and ongoing monitoring occurs. Additionally, Tennessee is working diligently to assure that psychotropic medication is not used inappropriately or as a means of control, punishment, or discipline for a child or for the convenience of staff or care givers.

Thank you very much for the opportunity to testify on this important topic.

[The prepared statement of Tricia Lea, Ph.D., follows:]

Prepared Statement of Tricia Lea, Ph.D.,
Director of Medical and Behavioral Services,
Department of Children's Services, State of Tennessee

Introduction

Thank you for the opportunity to submit testimony regarding the use of psychotropic medication among children in the child welfare system. My name is Tricia Lea, Ph.D., and I am submitting testimony on behalf of the State of Tennessee, where I serve as the Director of Medical and Behavioral Services for the Department of Children's Services (DCS), and the National Association of Public Child Welfare Administrators (NAPCWA), an affiliate of the American Public Human Services Association (APHSA). APHSA is a nonprofit, bipartisan organization representing state and local human service professionals for over 77 years. NAPCWA, created as an affiliate in 1983, works to enhance and improve public policy and administration of services for children, youth, and families. As the only organization devoted solely to representing administrators of state and local public child welfare agencies, NAPCWA brings an informed view of the problems facing families today to the forefront of child welfare policy. DCS is the agency responsible for our state's child welfare programs. The Department's mission is to empower families and support community safety and partnerships to help ensure safety, permanency and wellbeing for children in our care. The State of Tennessee is committed to protecting the children served in our child welfare system by ensuring that medical, mental and behavioral health services are provided in the least intrusive manner and in the least restrictive setting that meets each child's needs.

Background

The child welfare system in Tennessee serves over 20,000 children and youth at risk of custody each year and has approximately 8100 children and youth currently in custody. The Department of Children's Services has been under intense scrutiny since May 2000, when a civil rights class action lawsuit was filed by Children's Rights, Inc., on behalf of children who had experienced difficulties within the child welfare system. According to the complaint, Tennessee was not fulfilling its obligations to children in foster care, as children were staying in custody for long lengths of time, being placed in emergency shelters or congregate care settings rather than family-like settings, experiencing multiple placement moves, and not getting all of their healthcare and educational needs met. Additional concerns in the lawsuit focused on the inappropriate use of psychotropic medications for children in care, inadequate monitoring of psychotropic medications, and the possible use of these medications as a means of control, punishment or discipline of children or for the convenience of staff providing care to foster children.

A settlement agreement was finalized in the lawsuit in July 2001. This agreement became known as the Brian A. Settlement Agreement, as it was named after one of the eight foster youth for whom the original lawsuit was filed. This settlement established the outcomes to be achieved by the State of Tennessee on behalf of children in custody and their families. It also mandated the creation of the Technical Assistance Committee (TAC) consisting of experts in the child welfare field to serve as a resource and monitoring function for the Department in the development and implementation of its reform effort. The Settlement Agreement also required that Tennessee DCS review all policies and procedures surrounding the use of psychotropic medication, that DCS implement all recommendations made by TAC, and that the Department hire a full-time Medical Director specifically to oversee the implementation of policies and procedures concerning the use of psychotropic medication for children in DCS custody. I serve in this Medical Director position and would like to share with you one child welfare agency's progress in the area of psychotropic medication.

First Area of Reform: Evaluation of Current Policies and Practices

The first phase of reform for Tennessee was to conduct an in depth evaluation of current policies and practices regarding psychotropic medication. The Department conducted this analysis with the assistance of Dr. Christopher Bellonci, an expert child psychiatrist and consultant provided by the Child Welfare League of America. Dr. Bellonci and I co-facilitated a multidisciplinary workgroup that included psychiatrists, psychologists, nurses, and other leadership and field staff from the Department of Children's Services, the state Department of Mental Health and Developmental Disabilities, provider trade organizations, and provider agencies serving children in custody. The guiding principles developed by this group included:

- DCS will ensure that psychotropic medications prescribed for children in custody are used in combination with other therapeutic modalities contained in a multidisciplinary treatment plan.
- DCS will ensure that parents and children are offered an opportunity for meaningful participation and input in the decision making process related to the possible use of psychotropic medications.
- DCS will ensue that psychotropic medications are properly administered and that custodial children receiving the medications are properly supervised to ensure consistency and continuity in their care and treatment.
- DCS will ensure that the efficacy, safety and side effects of psychotropic medications used with children in custody are tracked and documented.
- DCS will ensure that psychotropic medications are not used as a means of control, punishment or discipline of children or for the convenience of the treating facility.
- DCS will prohibit the use of psychotropic medication s on a *pro re nata* (as needed) basis without the prior authorization of the DCS Director of Medical and Behavioral Services or his/her designee.
- DCS will ensure that direct-care staff are trained in the use, administration, and monitoring of psychotropic medications with children.
- DCS will monitor and track the prescribing practices of psychotropic medications to include ethnic, gender, age and trends for children in DCS care.

These principles were included in the "DCS Standards of Professional Practice for Serving Children and Families", which is a document outlining the vision of the Department to ensure quality care, appropriate service, safety and permanency for children and families in Tennessee.

Second Area of Reform: Policy and Practice Development

These principles also guided the development of five policies related to the use of medication, including policies about medication administration, emergency and PRN usage of psychotropic medication, medication errors and informed consent. The Brian A. Settlement Agreement outlined specific practices to follow regarding the process of informed consent and psychotropic medications, specifically that "whenever possible, parents shall consent to the use of medically necessary psychotropic medication." When parents are not available or their legal rights have been terminated, then DCS regional nurses review and provide consent to medically necessary medication. DCS developed a statewide network of nurses to monitor healthcare for children in custody, including the use of psychotropic medication.

Monitoring Guidelines and Procedures

In addition to assisting in policy development, Dr. Bellonci drafted the "DCS Medication Monitoring Guidelines" referenced in his testimony, as a tool for DCS case managers to use in monitoring the psychotropic medications prescribed for the children in their care. As Dr. Bellonci has noted, these guidelines were not meant to define prescribing practices but to help inform decision making and oversight related to psychotropic medication usage for children in foster care.

Once the DCS medication policies and monitoring guidelines were promulgated and shared with contract providers, DCS required each provider agency to complete a "self-assessment" of their compliance level with every practice mandated in each of the medication policies. The Department used these data as a baseline for ongoing monitoring that occurs each year by our internal auditors. Those providers who were not in compliance were also required to submit corrective action plans to be used by DCS for ongoing evaluation and technical assistance. In addition to annual site reviews, DCS also conducts unannounced site visits to residential facilities by multidisciplinary teams consisting of regional and central office DCS personnel. These site visits consist of interviews with staff and youth, as well as intensive reviews of personnel, training and clinical records to determine whether these programs are implementing the protection from harm policies (those dealing with psychotropic medication as well as restraint and seclusion).

Training

The Department developed specific training curricula for agency staff and contract providers in order to assist with the implementation of these protection from harm policies. One training focuses on educating DCS staff, providers, and resource parents about policies related to psychotropic medication usage. This computer-based training utilizes case vignettes, challenge questions, and expert resources to spark discussion among individuals serving children. Another training curriculum teaches resource parents how to properly administer, store, dispose of and monitor medication use for children and youth in their homes. These training modules have been

shared with the provider agencies caring for DCS children in TN, as the Brian A. Settlement Agreement suggests that all DCS staff and private agency staff serving children in custody should be trained similarly.

Audits

As part of the ongoing monitoring mandated by the Brian A. Settlement Agreement, the Technical Assistance Committee audits a sample of case records of children in custody of the state of Tennessee. Regarding psychotropic medication, these reviews focus on determining how many children are prescribed psychotropic medication, the ages and placements of these children, and whether or not appropriate informed consent was obtained for the psychotropic medications.

The first case file review conducted by the Federal Monitor was completed in 2004 and reviewed data from 2003. This review found that approximately 25% of children in custody were prescribed psychotropic medications. The next case file audit reviewed data from 2004 and was completed in 2005, finding that only 17% of children in the sample were prescribed psychotropic medication. This sample was somewhat different from the previous year, in that it reviewed children just entering the child welfare system who had only been in custody approximately six months. The TAC also conducted a review of DCS case files in 2006 (looking at practice in 2005), which found that 21% of children in custody were administered psychotropic medication. Despite some fluctuation, the numbers of children prescribed medication has declined. The majority of children prescribed psychotropic medication each year has been the adolescent population.

	2004 n = 106	**2005 n = 276**	**2006 n = 268**
Case file documents child was administered psychotropic medication during review period	25%	17%	21%
Percent of Children in Each Age Range Administered Psychotropic Medication	**2004**	**2005**	**2006**
0–3 years	0% (0 of 106)	0% (0 of 81)	0% (0 of 69)
4–6 years	11% (5 of 47)	9% (3 of 34)	3% (1 of 30)
7–9 years	25% (15 of 59)	3% (1 of 29)	32% (6 of 19)
10–12 years	33% (18 of 55)	24% (8 of 33)	37% (11 of 30)
13–18 years	40% (68 of 171)	34% (34 of 99)	33% (34 of 120)
Informed Consent for Administration of Psychotropic Medication Received	**2004**	**2005**	**2006**
Informed Consent given	69%	60%	70%
No informed consent	33%	40%	30%

Third Area of Reform: Tracking Data Trends

In order to provide additional expertise, consultation, review and oversight with regard to psychotropic medication, TN DCS employed a Child and Adolescent Psychiatrist, Deborah Gatlin, M.D. Dr. Gatlin has established a Pharmacy and Therapeutics Committee, whose membership includes psychiatrists and pharmacists with special expertise related to child and adolescent care. This group reviews medication practice across the state and advises on issues related to mental health treatment for children in custody. Our various review initiatives identified children taking as many as eight different psychotropic medications. There appeared to be, in some instances, a lack of oversight for medication management and drug interactions.

As a mechanism of tracking psychotropic medication usage for children in foster care, DCS worked with TennCare (Tennessee's Medicaid program) and TennCare

Select (the Managed Care Company serving children in custody) to receive paid claims data for children and identified psychotropic medications. Blue Cross and Blue Shield provided this pharmacy data to the Department, and this information was matched against the child welfare database (TNKids) for each month. Summary data from January—December 2006 indicates that on average, 19.8% of children in DCS custody were prescribed at least one psychotropic medication during the calendar year. The providers prescribing the most medications to Tennessee's custody children were physicians specializing in psychiatry. The classes of drugs prescribed the most during 2006 included antipsychotics and stimulants (e.g., Seroquel and Adderall). During 2006, three-fourths of the 19.8% of children on medication received only one or two psychotropic medications (44.8% and 31.0%, respectively); 16.4% received three psychotropic medications, and less than 1% received four or more psychotropic medications concomitantly. A child in the custody of the State of Tennessee who was administered medication during 2006 was more likely to be a white male, adjudicated dependent and neglected, age 13 years, and prescribed approximately two psychotropic medications by a psychiatrist. The research division of DCS is currently analyzing the pharmacy claims data for the 2007 calendar year, but trends from the second quarter of 2007 indicate similar numbers of children on psychotropic medications (an average of 20.1%). Additionally, 2007 data show that of those 20% of youths receiving psychotropic medications, the majority (an average of 75%) are prescribed only one or two medications.

Fourth Area of Reform: Updating Monitoring Guidelines and Protocols

In conjunction with the Pharmacy and Therapeutics Committee, the DCS Consulting Psychiatrist, Dr. Gatlin, has formulated updated medication monitoring guidelines for use in Tennessee. These "Psychotropic Medication Utilization Parameters" were adapted form the original "DCS Medication Monitoring Guidelines" as well as the Texas Department of State Health Services standards. These parameters outline situations in which further review of a foster child's medication regimen is warranted. These guidelines do not indicate if the treatment is inappropriate, but indicate that further analysis of the situation is needed. The new parameters include:

- Four or more psychotropic medications prescribed concomitantly
- Two or more psychotropic medications of the same class prescribed concomitantly (specifically antidepressants, antipsychotics, stimulants, and mood stabilizers)
- Medication dose exceeds the usual recommended dose (the Pharmacy and Therapeutics Committee drafted a listing of commonly used psychotropic medications used in the treatment of children and adolescents, outlining maximum dosages)
- Children under five years of age prescribed psychotropic medications

Cases that fall outside of the DCS medication monitoring guidelines are reviewed at several levels. The state of Tennessee is fortunate to have regional health units staffed with nurses and psychologists in each of the 12 regions of the state. Additionally, in central office, we have our consulting child psychiatrist (Dr. Gatlin) as well as a pediatric nurse practitioner. Outside of DCS, we have five "Centers of Excellence for Children in State Custody" that are a partnership with the State of Tennessee and academic medical centers and community providers. The Centers of Excellence (COEs) were created to serve children in and at risk of custody and provide expert guidance for the diagnosis and treatment of medical and behavioral health disorders for all community providers. The COEs also offer limited direct services for the most complex cases of children in and at risk of custody and for situations in which service gaps exist.

While reviews of individual cases that fall outside of these medication parameters have been reviewed at numerous levels for some time, the DCS child welfare database has now automated these reviews. Since August of 2007, when medication information is input into the database, a review by the psychiatrist is automatically triggered. An e-mail alert is sent to our consulting psychiatrist for further review. Dr. Gatlin's reviews of these cases have typically indicated that more clinical information is needed to understand the situation, that the treatment is within reasonable clinical community standards, that consultation with a Child and Adolescent Psychiatrist or Center of Excellence is indicated, or the child's case should be transferred from the Primary Care Provider (PCP) to a Psychiatrist. The majority of cases falling outside the psychotropic medication parameters have indicated appropriate care. The updated DCS database also mandates that consent information for each psychotropic medication is documented. In Tennessee, youths aged 16 years and older have the same legal rights to consent to mental health treatment includ-

ing psychotropic medications as adults. The database requires an explanation if a youth is 16 years of age or older and was not the person who gave consent for the psychotropic medication. Similarly, the Brian A. Settlement Agreement mandates that whenever possible, parental consent should be obtained for psychotropic medications. If parental rights are not terminated, the new data system forces an explanation if the parents did not provide the informed consent.

The updated database also allows for more accurate tracking of health information for children in custody, including allergies, medical conditions, psychiatric diagnoses, all medications (including psychotropic), and documentation of all health services rendered to the child (including medical, dental, vision, and mental health). The system allows for a summary to be developed, which acts as a "Health Passport" for the child to ensure that all caregivers and providers serving the child have clear information on the child's history and current health status. This summary is shared with case managers, healthcare providers, placement agencies, and resource parents. This is similar to the passport that the state of Texas has developed as a part of its STAR Health program.

DCS is now working on contrasting the pharmacy claims data with the data in our child welfare database to ensure that we are adequately tracking all children in custody who receive psychotropic medications. Additionally, the Pharmacy and Therapeutics Committee continues to act in an advisory capacity for this process and will be used to review individual providers who have concerning prescribing practices in comparison to the drug utilization parameters used in Tennessee.

We are able to see cases in which children and youth in our custody have benefited from the oversight and monitoring processes we have put in place. One example is that of a 14 year old boy, in full guardianship, with diagnoses of Mild Mental Retardation, Bipolar Disorder, Impulse Control Disorder, and Psychotic Disorder. He was placed at a residential treatment facility but continued to require frequent psychiatric hospitalizations and was prescribed six psychotropic medications (two antipsychotics, two mood stabilizers, one sedative, and an additional medication for impulse control). When the DCS regional nurse reviewed these medications to give consent, she contacted our Child and Adolescent Psychiatrist as the medication regimen met several of the monitoring triggers. The Psychiatrist was concerned about the youth's placement moves and frequent medication changes and recommended that his psychiatric care transfer to one of our Centers of Excellence. The youth has been taken off several of the psychotropic medications, is now placed in a foster home rather than a residential facility, and is doing fairly well.

The State of Tennessee Department of Children's Services has made significant progress regarding psychotropic medication practices for children in custody. We recognize that there is a high rate of mental illness associated with our population and that there is trauma associated with entering the foster care system. However, Tennessee is working to ensure that children in custody have their mental health needs adequately addressed and are prescribed psychotropic medication when clinically indicated. In those cases, we want to ensure that appropriate informed consent is given and ongoing monitoring occurs. Additionally, Tennessee is working diligently to ensure that psychotropic medication is not used inappropriately or as a means of control, punishment, and discipline of children or for the convenience of staff.

Thank you very much for the opportunity to speak to this important issue affecting the children of our country.

Chairman MCDERMOTT. Thank you.

I apologize for making somebody from Tennessee talk that fast! [Laughter.]

Dr. LEA. I kept it under 5 minutes.

[Laughter.]

Chairman MCDERMOTT. Our next witness is Misty Stenslie, who is the Deputy Director for the Foster Care Alumni Association of the United States.

Misty?

STATEMENT OF MISTY STENSLIE, DEPUTY DIRECTOR, FOSTER CARE ALUMNI OF AMERICA

Ms. STENSLIE. As one of the twelve million adults in the United States who grew up in foster care, the government did service as my parents; This Committee, your colleagues in Congress, have stood in the places where our mothers and fathers belong and we thank you for that.

We ask you to consider the recommendations that come from this panel and, in all of your decisions about foster care, to consider them both from a lawmaker's point of view and from a mom or dad's point of view, because you really do have that responsibility for us.

So, hearing you say that you are our godfathers took me back a little bit, because that's something that I'm still not used to. I felt it and I appreciate it.

I am the deputy director of Foster Care Alumni of America. We're a national association that brings together those of us who share the foster care experience to be that extended family network for each other. Thank you.

We also work with other social workers, foster parents, other professionals, in order to improve foster care practice and policy for the ones who come after us because those really are our younger brothers and sisters having shared the same parents, the government.

In addition to having grown up in foster care, I am a masters-level social worker and I have worked in child welfare for the last 19 years. I am also proud to be the foster mother to three young people who came to me in their teen-age years and are now in their middle twenties, 22, 23, and 26. So the thing I know the most about in the world is foster care, and on this topic of the use of psychotropic medications and anything else in the foster care system or child welfare system. There's just not going to be a simple answer and I think you already know that.

As the community of alumni of the foster care system, we do ask you to remember to wear your parent hat too when you're making these decisions. My own childhood, I spent about 12 years total living in 30 different placements. I lived in group homes and kinship care and foster homes and residential treatment and juvenile correction facilities, just about at least one of every kind of placement that's available.

Through those unstable years, I had probably a couple of hundred people who were responsible for me, and I still left foster care at 18, even with no family, even with a couple hundred people who looked out for me at least for a little while. During my time in care I had a long list of diagnoses, including post-traumatic stress disorder, oppositional defiant disorder, conduct disorder, sleep disorder, mood disorder. I got to have a lot of those kinds of things too.

Due to the instability of my living situation, it seemed like sometimes the only choice the professionals in my life could see that they had, because they couldn't fix my life, would be that they would prescribe medication. So, over the years, I was on more medications than I can count. Most of the time that was without me knowing what they were for, how I should expect to feel dif-

ferent, what side effects to watch out for, what the plan was, whether I was supposed to take them forever, and whether I was supposed to just take them this week.

So it wasn't until I was a senior in high school and about my 30th placement that I even found out that I had the right to question or challenge what all those diagnoses were and what all that medication was about. My very last foster home dutifully gave me my handful of pills every night for the first week or two I was there. Then, one night, the foster dad said to me, "What are all these pills for?" I went, "I don't really know. I know they're supposed to help me sleep." He said, "Why don't you sleep?" I said, "I get really anxious at night and I have a really hard time getting any rest." So, he said, "Let's stay up. Let's figure out what happens." So, we made cocoa.

We sat up playing cards half of the night, and every time there was a bump in the night, I had my typical anxious response, because I really did have post traumatic stress disorder. So every time that anxious response came up, he would explain to me what the noise was. He would say it's the water softener regenerating. It's the furnace kicking on. It's the dog upstairs getting a drink of water and explaining these things to me that I had no way of knowing myself.

The other thing that those foster parents did was they acknowledged that I was actually really smart. I was really smart to have figured out that if I never went to sleep too deeply, I was less likely to be hurt in the house where I came from and that it wasn't a disorder in me that I had so much trouble with sleeping. It was a disorder in my life and that I really responded to my life's realities in the best way I could to keep myself safe.

So, as you'll see in my written testimony, a lot more information, both about what I have to say and about what we hear from other alumni of the foster care system all around the country, but a few things I want to make sure that you know, is it's a really common thing to hear from our alumni members, our brothers and sisters from foster care around the country, that they received diagnoses and medications in response to their disordered lives and we do know about foster children is that many of us do actually have psychiatric needs due to the trauma of abuse and neglect and the trauma of living in placement away from everything that's familiar and the trauma of growing up with no family. We also know that young people in foster care are coming from families having histories of psychiatric problems, so whether it's a result of the trauma or a matter of the genetic predisposition or a collision of those factors, we do know that children in foster care often have needs that must be addressed. Sometimes, medication is the very best way to do that, but, what we hear so much from people who actually have lived the experiences, the medications are way too often given as a substitute when we can't give kids what they really need, and that's love, stability, power, hope; someone who sees them; somebody who hears them; somebody who will stick with them.

So I have a couple of specific recommendations I want you to hear. First is that consistency is the key to adequate and appropriate mental healthcare. We need stable placements. We need people who love us and who will stand with us and we need a medical

home. I don't know why it's taken so long for this country to catch on. I don't know anybody who thinks it's a bad idea.

Why are we having such a hard time making that up?

We need a medical home. Those of us from foster care, we don't typically have things like photo albums and family scrap books. Sometimes the closest thing we have to that is whatever official records exist about us, so why don't we put them all in one place?

The second thing I want to make sure you hear is medication should not be the first option considered and should never be the only option considered; pills can't change what happened to us. We need access to well-trained and supportive professionals who provide culturally competent services. We need ongoing access to healthcare even after we've been adopted, reunified, and especially after we've emancipated.

We need to know about our own lives. We need access to our records, to information, and we need the power to seek or refuse the treatment that we get based on what we know and the support that we have. So, again, on behalf of all of us from foster care, thank you for standing where our parents belong. It really does matter.

Thank you.

[The prepared statement of Misty Stenslie follows:]

Response by Misty Stenslie, MSW
Foster Care Alumni of America
Deputy Director

May 8, 2008

INTRODUCTION AND SUMMARY

Thank you, Chairman McDermott and members of the sub-committee for holding this important hearing today. As one of 12 million adults in this country who grew up in foster care, the government served as my parents. This committee and your colleagues in congress have stood in the places where our mothers and fathers belong for generations of foster youth, including the more than 500,000 children who live in care right now.

I am the Deputy Director of Foster Care Alumni of America. We are a national non-profit association that brings together those of us who share that foster care experience in order to be the permanent extended-family community for each other, something that many of us growing up never had. We also work with others—foster parents, social workers, policy makers, community members—to influence foster care practice and policy. Our goal is to erase the differences, the stigmas, the disparate outcomes that are faced by our brothers and sisters from care compared to the general public.

In addition to having grown up in foster care, I am a master's level social worker and have spent the last 19 years working in the child welfare system. I have worked in group home facilities, as a child protection worker, as a clinical social worker for young people in treatment foster care and their families. I now live in Minnesota and work around the country to improve the lives of those who come after me in foster care.

I am also proud to have been the licensed foster mother for three young people—Chris, Sean, and Tomikia. They came to me in their teen age years and are now 23, 24 and 26 years old.

The thing I know the most about in this world is foster care, having experienced it from so many different sides. On the topic of the use of prescription psychotropic medications with youth in foster care—and nearly any other topic related to child welfare—I have to start by acknowledging that there is simply no one right

answer. But I do want to make sure that you hear from many different perspectives about what we, as the community of alumni, ask you to consider on this topic. Remember, you have taken on the very real role of parents for people in and from foster care and your careful deliberations—both as law makers and as mothers and fathers—is what we need.

In my childhood, I spent 12 years in approximately 30 placements. I lived in placement in MN, ND, SD, ID, UT, MT, WY, and NE. I experienced foster homes, group homes, shelter facilities, detention and correctional institutions, kinship care, and psychiatric/residential treatment. Through those unstable years, I probably had a couple hundred people who were responsible for me—yet no family. I emancipated with no permanent connections and very few resources. My time in care resulted in a long list of diagnoses, including Post Traumatic Stress Disorder, Oppositional Defiant Disorder, Depression, and a sleep disorder. Because of the instability in my living situation, it seemed that the only option the professionals in my life were able to take for treating all of the diagnosed conditions was prescribing medication. Over the years I was on more medications than I can count--usually without my knowing what the meds were for, how I should expect to feel, side effects to watch out for, or any plan for follow up.

It was not until I was a senior in high school and in my last foster home that I even knew that I could question the medications or challenge the diagnoses. In that home, the foster parents dutifully gave me my handful of pills each night for the first week or two and finally asked what they were for. I said I didn't really know, other than that they were supposed to help me sleep. My foster father asked me why I don't sleep well without them and I told him that I get so anxious at night when I hear noises that I can't get any rest. These foster parents did something incredible. They skipped the medication one night, made cocoa, and sat around playing cards with me late into the evening. As we got into the deepest part of the night, we sat together and listened to all of the noises in the house. I could feel the familiar anxiety--but my foster dad patiently helped me figure out what all those noises were. It was the dog getting a drink of water upstairs. It was the furnace turning on. It was the water softener regenerating. My foster parents reassured me of my safety. They listened to my stories about how unsafe I had been in the home I came from. They acknowledged that I was actually very smart to be so vigilant and protective of myself that I didn't fall into such deep sleep that I could be hurt at my home. They helped me make sense of my reaction--which on paper looked like a disorder, but in the reality of my life had been the very best thing I could do for myself. They helped me to learn and believe that I didn't have the same reality anymore and I could let go of some of that vigilance.

Because of the insight and creativity of those foster parents, I was able to see my world in a brand new way. I was able to ask that my medications be decreased and eventually discontinued, and they supported me in getting the kind of

treatment that would make a sustainable difference in my life--learning new ways to cope, recognizing what is good and right in myself so that I could do more of it, identifying ways to keep myself safe without having to hide or fight. By the time I went off to college, I was no longer on any medications and I actually had the skills and knowledge I needed to take the place of the medications.

As you'll see in my testimony, we know from alumni that it is a common occurrence for youth in care to have an experience like this--receiving diagnoses and medications in response to their disordered lives. We know that sometimes that medication serves as a lifeline--it makes it possible for the young person to get through a particular crisis. They then have the opportunity to come out on the other side of the crisis to develop healthy strategies for coping. We also know that medications often are given as a substitute for what young people really need--stability, love, power, hope, and someone who sees them and hears them.

What is known about the mental health of people in and from foster care is that many of us have psychiatric needs due to the trauma of abuse and neglect. It is also true that youth in care face the additional trauma of removal from their homes and all of the people and places that are familiar and placement in the system. When youth experience placement instability, these traumas are compounded. The best treatment for this trauma is stability, patience, compassion, and safety.

We also know that young people in foster care are often coming from families of origin that are facing significant mental health issues. Whether as a result of trauma, a matter of genetic predisposition or a collision of those factors, many youth in care do have valid mental health disorders and do require treatment, sometimes including medication. Research conducted by Casey Family Programs[1] has shown that mental health outcomes for adult alumni of foster care are disproportionately poor compared to the general population. Among the findings:

- The rates of post-traumatic stress disorder (PTSD) among foster care alumni are about twice as high as PTSD rates in war veterans and nearly 5 times the rates of the general public.
- Alumni experience panic disorder at rates more than three times that of the general population.
- People in and from foster care have particularly high rates of ADHD, chemical dependency, conduct disorder and depression and other mood disorders.

There are no easy answers, but there are some recommendations we'd like to share as a community of alumni.

---

[1] Pecora, P. J., Williams, J., Kessler, R. C., Downs, A. C., O'Brien, K., Hiripi, E., & Morello, S. (2003). *Assessing the effects of foster care: Early results from the Casey National Alumni Study*. Seattle, WA: Casey Family Programs. Available at http://www.casey.org. Revised January 20, 2004.

Recommendations from alumni of foster care about the use of psychotropic medications:

1. **Consistency is the key to adequate and appropriate mental health care. We need stable placements, we need a 'medical home', and we need professionals who know us and our circumstances—and who care about us enough to be effective advocates.**

2. **Medication should not be the first option considered and should *never* be the only mode of support we receive. Pills cannot change the experiences we've faced or the life situations we've been put into.**

3. **We need access to well-trained and supported professionals who can provide culturally competent services. The culture of foster care includes both challenges and victories that need to be recognized and supported by the people responsible for our care.**

4. **We need ongoing access to health care even after we've been adopted, reunified, or emancipated. Our needs don't change just because the court order or case plan does.**

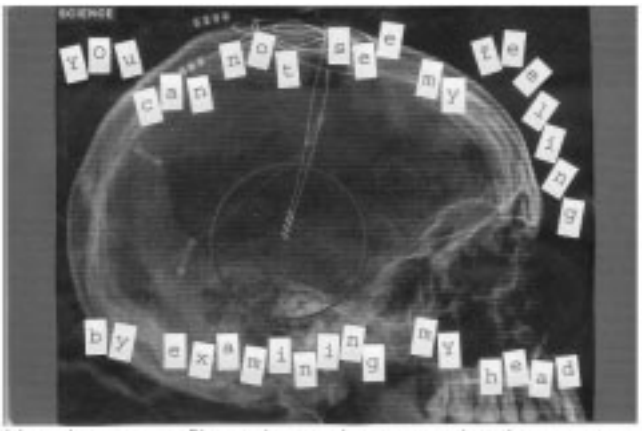
5. **We need to know about our own lives, and need to be the primary voice in planning and decision-making. We need access to our records, information about our diagnoses and medications, and the power to seek or refuse treatment based on an educated and supported knowledge about our own lives.**

What alumni of foster care want you to know:

Foster Care Alumni of America is proud to be a member of the national Task Force on Foster Care through the American Academy of Pediatrics. As part of our work with the AAP, we've been conducting a survey of our members about their experiences and recommendations regarding health and mental health care access and services. In addition, we have a national community art project where people in and from foster care have submitted postcard art about what they've learned, what they want to share in connection to their foster care experiences. Here are some of the insights we've gathered.

"I was over-diagnosed and over-medicated. I was depressed and emotional when I first entered care and I did not respond to antidepressants. So they thought I had something more serious, but what I had was a life problem."
--Alumna of care, mid-20s, Ohio

"Don't assume that foster children are "damaged" and need to be "fixed". Do your homework and learn as much as you can about the culture of foster care. Often individuals who are privileged in our society overlook even the simplest of things that foster children must deal with every day (e.g., who loves me? where do I belong?). Society continues to send messages to foster children about the value of family (e.g., home is where the heart is - family is the key to happiness) however, those who live outside of secure committed families feel marginalized and disempowered."
--Alumnus of foster care



"Scary things in my case file made people assume that there were scary things inside my head. I really was struggling, but I needed time with people, attention, someone who loved me, somebody to talk with who wasn't there for a paycheck."
--Alumna of care, late 30s, Virginia

"I was put on medication as soon as I entered the system. Did they understand I was grieving, scared, confused about my life? No, they figured let's give her a pill. All I ever wanted was for someone to listen."
--Alumna of care, California

"Once I left the system I became homeless and without money to afford medication I was left to my own devices: self-medicating with drugs. Luckily, the law "helped" me to learn my lesson. As an adult, my own children are in foster care. I don't think this would have happened if I'd gotten what I needed as a child and I'm working so hard to make it different"
--Alumnus of care

"Pills can't take away what happened to me."
--Alumna of care

"The system enabled me to become chemically dependant to my meds. I sought out ways to feel numb once the system was gone, once my medical was cut off -- -- alcohol and drugs."
--Alumnus of care

"The best care I got was people accepting me where I was at...not trying to change me as though I was broken/damaged, but being allowing me the room to express my experiences without judgment from the doctor or counselor. The most helpful experience was one in which the counselor or doctor did not assume they knew me based on a file."
--Alumnus of care

UNCONFIDENTIAL

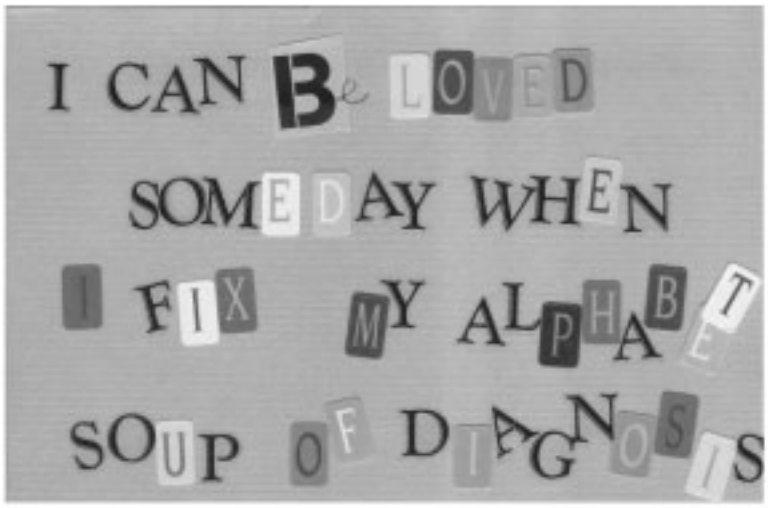
CASE HISTORY

Assessment of the Child:
My childhood is documented in a file filled with painful details. My foster parents and social workers defined me in their reports: "Inappropriate." "Defiant." "Defensive." "Manipulative." "Demanding." "Belligerent."

Transition to Adulthood:
After leaving foster care, it took a while to finally believe in myself and understand who I am. *Passionate. Honest. Caring. Intelligent. Articulate. Resolute.*

"My case file made me look very oppositional--I had a long criminal history as well as chemical abuse issues. What seemed to escape the notice of the system was the fact that any criminal or using behaviors were all connected to my biological family--either activities done WITH them or as a method of coping with them. I think because of that, I wasn't taken seriously. I wasn't respected or heard."

--Alumnus of care



"I had 8 diagnoses. I wish they would have had compassion and realized group homes were tough...and so was my childhood...and just given it time....or provided me with an adjustment disorder diagnosis."

--Alumnus of care

On behalf of all of us in and from foster care, thank you for standing in the place where our parents belong. Thank you for considering the expertise we have to offer as people who have learned about foster care from the inside. Know that our organization, Foster Care Alumni of America, is available any time policy related to foster care is being considered. We have members from all 50 states, with our youngest members being 18 and our eldest in their 80s. It matters to us that the youth who come after us in foster care have the best that the system has to offer—stability, love, safety, and peace—and we want to help you make that happen.

Chairman MCDERMOTT. Thank you for that testimony.

Laurel Leslie is a physician who is at Tufts New England Medical Center Institute for Clinical Research And Health Policy. Welcome, Dr. Leslie.

Dr. LESLIE. Thank you.

STATEMENT OF LAUREL K. LESLIE, M.D., DEVELOPMENTAL-BEHAVIORAL PEDIATRICIAN, CENTER ON CHILD AND FAMILY OUTCOMES, TUFTS-NEW ENGLAND MEDICAL CENTER INSTITUTE FOR CLINICAL RESEARCH AND HEALTH POLICY STUDIES

Dr. LESLIE. Mr. Chairman, thank you very much for the opportunity to testify at this hearing on the healthcare needs of children in foster care. As you mentioned, my name is Laurel Leslie, and today I am proud to speak on behalf of the American Academy of Pediatrics and its Task Force on Foster Care of which I am a member.

The academy recognizes that psychotropic medication can be an appropriate and effective part of a treatment plan for some children in foster care. It's critical, however, that these children receive thorough evaluations and comprehensive treatments that address all aspects of their physical, mental, developmental/educational and behavioral health, and that any treatment is evidenced based where evidence is available.

Congress should support and fund quality, comprehensive care for all aspects of health and well-being of children in foster care, including their mental health. The few research studies available show rates of psychotropic medication use ranging from 13 to 50 percent among children in foster care, which is much higher than the approximately 4 percent rate of youth in the general population.

A report prepared by the government Accountability Office found that 15 states have identified the overuse of psychotropic medications as one of the leading issues facing their child welfare system in the upcoming years. Soon-to-be published data from Safe Place, which is in Philadelphia, also demonstrated in the Medicaid program children in foster care who have autism were more likely to use three or more psychotropic medications than children who qualified through the Supplemental Security Income program. These data show alarming interstate variation in prescription pattern rates of psychotropic medication used for children in foster care.

It's difficult to know from these preliminary data or the multitude of reports that are emerging in the media whether the use of these medications is appropriate, although at the very least, the use of a combination of three or more medications is controversial. Clearly, medication can be helpful for some children, but with the increasing use of these medications among the population in general there comes the added responsibility to ensure that children have an access to an array of treatment strategies.

Furthermore, the failure to coordinate and provide continuity in services and the absence of clear guidelines and accountability to ensure that treatment decisions are in a child's best interest create a greater risk that medications will be prescribed to control chil-

dren's behavior in the absence of individualized service plans that offer these vulnerable children their best chance for success. These critical questions don't have simple answers and addressing them will require sustained collaboration between healthcare and child welfare professionals as well as the funding streams to support this collaboration.

Allow me to share with you three stories from my own experience as a clinician that demonstrate where I think we as a system have failed or succeeded in addressing appropriately the mental health needs of children in foster care.

Four-year-old Carrie came to see me because of violent temper tantrums. She had broken windows, doors, and televisions, in different foster-care homes. Since she was so difficult to control, she had already been through multiple placements.

Working in close collaboration with her foster parents, we were able to wean her down to one psychotropic medication and we educated her foster parents in intensive behavioral interventions that they could put in place to help shape Carrie's behavior. However, when Carrie was placed for adoption in a neighboring county, neither her foster parents nor I were given the opportunity to share what we had learned with the adoptive parents or with any prospective medical or mental health provider who might be seeing her.

Her behavior returned with a vengeance, and because her prospective parents did not know how to cope with her behavioral problems, that adoption fell apart within 2 weeks. She was placed with yet another foster family, because the family she had previously been with had already filled their beds.

When Jenelle aged out of the foster care system, like Misty, she had had 22 mental health diagnoses and was on four different medications. She had no idea why any of the drugs were being given to her and she stopped them all immediately—a very dangerous move to make, considering that some psychotropic medications can have serious side effects if stopped suddenly. Jenelle met with me after aging out of the foster care system and asked me why she'd been on so many medications and why no one had ever taken the time to educate her about her own health or how to care for her healthcare needs. I did not have a good answer for her.

Nine year old Jacob had been in foster care for several years while his mother was in jail because of drug use. He had hearing loss, ADHD, a reading disability, and needed medical, mental health, and school-based services that were coordinated and we were able to put together. When his mother was released from jail I was able to transition Jacob's care and meet together with Jacob, his mother, and the foster parents.

Interestingly to me, Jacob's mother had received no help with parenting while she was in jail and shared with me her own inability to set limits or discipline, as she had been a victim of child abuse herself, an all-too-common story. We worked with her to learn parenting skills, find mechanisms of coping with stress that did not include using substances, and take over the many care coordination needs of her son. By improving her parenting skills, we were able to help her better manage her child's ADHD symptoms.

Mr. Chairman, in conclusion, our Nation has a moral and a legal responsibility to provide better care to these vulnerable children. The Academy has identified priorities in healthcare for children in foster care that include the following:

One, all children, including children in foster care, should have a medical home.

Two, comprehensive physical development and mental health assessment should be given to every child within thirty days of entering State custody. Mental health assessments should also be conducted on any child for whom psychotropic medications are being considered.

Three, care coordination must be a priority. The Academy strongly supports section 421 of H.R. 5466, the Invest In KIDS Act, which requires states to improve care coordination for children in foster care. We were pleased to work closely with you, Mr. Chairman, and your staff, to develop this section and hope it can be passed expeditiously.

Four, if children in State custody—am I out of time?

Chairman MCDERMOTT. You already have been over.

Dr. LESLIE. Okay. We feel an established protocol should be set up and there are details related to that in my written testimony.

Thank you again for the opportunity to testify, and I stand, or sit, ready to answer any questions you may have.

[The prepared statement of Laurel K. Leslie, M.D., follows:]

Prepared Statement of Laurel K. Leslie, Developmental-Behavioral Pediatrician, Center on Child and Family Outcomes, Tufts-New England Medical Center Institute for Clinical Research and Health Policy Studies

Mr. Chairman, I am grateful for the opportunity to testify at this important hearing on serving the healthcare needs of children in foster care. My name is Laurel Leslie, MD, MPH, FAAP, and I am proud to speak on behalf of the American Academy of Pediatrics (AAP) and its Task Force on Foster Care, of which I am a member. I am an Associate Professor of Medicine and Pediatrics at Tufts Medical Center, a practicing pediatrician, and a researcher on children's mental health needs. A particular focus of my clinical work and research has been children in foster care.

The American Academy of Pediatrics has a deep and abiding interest in the healthcare provided to children in the foster care system. The Academy has published a handbook on the care of foster children, *Fostering Health*, as well as numerous policy statements, clinical guidelines, and studies regarding child abuse, neglect, foster care, and family support. In addition, the Academy has recognized the unique challenges faced by children in foster care by designating the special healthcare needs of children in foster care as one of the five issues highlighted in its Strategic Plan for 2007–2008 and establishing a Task Force on Foster Care that will craft a multi-pronged strategy for the AAP to improve the health of children in foster care.

The AAP recognizes that psychotropic medication can be an appropriate and effective part of a treatment plan for some children in foster care. It is critical, however, that these children receive thorough evaluations and comprehensive treatment that address all aspects of the child's physical, mental, developmental/education, and behavioral health, and that are evidence-based where evidence is available. Congress should support and fund quality, comprehensive care for all aspects of the health and well-being of children in foster care, including their mental health.

Our Nation Must Address the Health Needs of Children in Foster Care

On any given day, approximately 540,000 children are in foster care, most of whom have been placed there as a result of abuse or neglect at home. Several decades of research has firmly established that the healthcare needs of children in out-of-home care far exceed those of other children living in poverty. Compared with children from the same socioeconomic background, children in foster care have much higher rates of birth defects, chronic physical disabilities, developmental delays, se-

rious emotional and behavioral problems, and poor school achievement.[1] In fact, nearly half of all children in foster care have chronic medical problems,[2,3,4,5] about half of children ages 0–5 years in foster care have developmental delays,[6,7,8,9,10,11] and up to 80% of all children in foster care have serious emotional problems.[12,13,14,15,16,17,18,19]

Typically, their history of abuse and neglect and the accompanying health, developmental and behavioral problems they experience have an ongoing impact on all aspects of their lives, even long after these children and adolescents have left the foster care system.[20] For example, the 2005 Northwest Foster Care Alumni Study reported that alumni from foster care were six times more likely to suffer post-traumatic stress disorder, four times more likely to turn to substance abuse, twice as likely to experience depression, and more than two-and-a-half times more likely to be diagnosed with an anxiety disorder.[21] (Figure 1) Other examples of poor health outcomes in adulthood that have been linked to childhood abuse and neglect include heart disease, tobacco use, substance abuse, sexually transmitted diseases, unintended pregnancy, delinquency, obesity, and work absenteeism.[22]

The healthcare needs of children in foster care are often under-identified and undertreated, despite the overwhelming evidence of need from research. Stark evidence that children are not receiving timely services has come from a range of studies, from the 1995 Government Accountability Office (GAO) report demonstrating that 1/3 of children had healthcare needs that remained unaddressed while in out-of-home care, to the analysis of the National Survey of Child & Adolescent Well-

---

[1] Committee on Early Childhood, Adoption and Dependent Care. Healthcare of Young Children in Foster Care. *Pediatrics*, Vol. 109, No. 3, March 2002.

[2] US General Accounting Office. *Foster care: health needs of many young children are unknown and unmet.* Washington, DC: (GAO/HEHS–95–114); 1995.

[3] Takayama JI, Wolfe E, Coulter KP. Relationship between reason for placement and medical findings among children in foster care. *Pediatrics.* 1998;101(2):201–207.

[4] Halfon N, Mendonca A, Berkowitz G. Health status of children in foster care. The experience of the Center for the Vulnerable Child. *Archives of Pediatrics & Adolescent Medicine.* 1995;149(4):386–392.

[5] Simms MD. The foster care clinic: a community program to identify treatment needs of children in foster care. *Journal of Developmental & Behavioral Pediatrics.* 1989;10(3):121–128.

[6] Chernoff R, Combs-Orme T, Risley-Curtiss C, Heisler A. Assessing the health status of children entering foster care. *Pediatrics* 1994;93(4):594–601.

[7] Hochstadt NJ, Jaudes PK, Zimo DA, Schachter J. The medical and psychosocial needs of children entering foster care. *Child Abuse & Neglect* 1987;11(1):53–62.

[8] Horwitz SM, Simms MD, Farrington R. Impact of developmental problems on young children's exits from foster care. *Developmental and Behavioral Pediatrics* 1994;15(2):105–10.

[9] Leslie LK, Gordon J, Ganger W, Gist K. Developmental delay in young children in child welfare by initial placement type. *Infant Mental Health Journal* 2002;23(5):496–516.

[10] Swire MR, Kavaler F. The health status of foster children. *Child Welfare* 1977;56(10):635–53.

[11] Szilagyi M. The pediatrician and the child in foster care. *Pediatrics in Review* 1998;19(2):39–50.

[12] Halfon N, Mendonca A, Berkowitz G. Health status of children in foster care. The experience of the Center for the Vulnerable Child. *Archives of Pediatrics & Adolescent Medicine.* 1995;149(4):386–392.

[13] Landsverk JA, Garland AF, Leslie LK. *Mental health services for children reported to child protective services.* Vol 2. Thousand Oaks: Sage Publications; 2002.

[14] Glisson C. The effects of services coordination teams on outcomes for children in state custody. *Adminstration in Social Work.* 1994;18:1–23.

[15] Trupin EW, Tarico VS, Low BP, Jemelka R, McClellan J. Children on child protective service caseloads: Prevalence and nature of serious emotional disturbance. *Child Abuse & Neglect.* 1993;17(3):345–355.

[16] Clausen JM, Landsverk J, Ganger W, Chadwick D, Litrownik A. Mental health problems of children in foster care. *Journal of Child & Family Studies.* 1998;7(3):283–296.

[17] Urquiza AJ, Wirtz SJ, Peterson MS, Singer VA. Screening and evaluating abused and neglected children entering protective custody. *Child Welfare.* Mar-Apr 1994;73(2):155–171.

[18] Garland AF, Hough RL, Landsverk JA, et al. Racial and ethnic variations in mental healthcare utilization among children in foster care. *Children's Services: Social Policy, Research, & Practice.* 2000;3(3):133–146.

[19] Pecora P, Kessler R, Williams J, et al. *Improving family foster care: findings from the Northwest Foster Care Alumni Study.* Seattle, WA: Casey Family Programs, available at http://www.casey.org; 2005.

[20] Centers for Disease Control and Prevention. Adverse Childhood Experiences (ACE) study. http://www.cdc.gov/od/oc/media/pressrel/r980514.htm.

[21] Ibid.

[22] Felitti VJ, Anda RF, Nordenberg D, et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. *Am J Prev Med.* 1998; 14:245–258.

Being documenting that only a quarter of the children with behavioral problems in foster care received mental health services within a one-year follow-up period.[23]

Children in foster care are at risk for having inadequate healthcare provided to them. Most children enter foster care under precipitous and adversarial conditions; little may be known about their medical history and their parents may be ambivalent about partnering with an investigative case worker to address their child's well-being.[24] If medical information is obtained, it may not be transmitted to subsequent caseworkers or foster parents who bring a child to see a clinician. As a result, physicians find themselves trying to identify and treat conditions without access to the child's medical history. Appropriate treatments may be delayed or clinicians may need to order otherwise unnecessary laboratory work-ups or referrals to subspecialists.

Despite a bewildering number of adults participating in these children's lives (e.g. investigative case workers, social workers, birthparents and/or foster parents, primary care clinicians, specialists, school personnel, judges, lawyers, and court-appointed child advocates), they often lack a single, clearly designated individual to monitor their health-related needs and care. Because foster parents have no legal authority to make medical decisions, they are frequently not informed regarding the outcomes of the child's physical and mental health assessments, including the decision to prescribe medication.

Many children experience multiple changes during their episode in foster care, with more than 25% experiencing three or more placement changes per year.[25] Each placement change results in a change in caregiver, and possibly a change in social worker and any involved healthcare providers, thus increasing the potential for an uninformed diagnosis, poor communication and coordination of health-related needs and inconsistent, duplicative delivery of care.

Policymakers may find it difficult to reconcile these statistics regarding unmet need with other data on healthcare financing and utilization among children in foster care. Mental health service use by children in foster care is 8–11 times greater than that experienced by other low-income and generally high-risk children in the Medicaid program.[26,27] Children in foster care account for 25–41% of expenditures within the Medicaid program despite representing less than 3% of all enrollees.[28,29] The answer to this apparent contradiction lies in recent data which have shown that up to 90% of these costs may be accounted for by 10% of the children.[30,31] The services are being shifted to the back end of the system to children living in residential treatment, group homes, and psychiatric facilities. A small number of children are receiving intensive, expensive services because the system has neglected them until their needs became catastrophic. This is ultimately a failure to screen adequately and provide services to the overwhelming majority of children who would be excellent candidates for treatment and would likely respond to more modest levels of treatment if such services were provided at the earliest possible time.

Improvements Are Happening, But They Bring New Challenges

Although the landmark Adoption and Safe Families Act of 1997 is rightly heralded for its focus on improving pathways to permanency and adoption for children in foster care, a less discussed but equally important mandate of that legislation was that states focus on the well-being of children under their care. This spurred the development of more coordinated approaches to providing healthcare to children in the child welfare system. The last decade has seen the emergence of different models of care, from healthcare and mental health professionals inserted into child welfare units to screen adequately and provide oversight to the healthcare needs of

---

[23] Burns BJ, Phillips SD, Wagner RH, et al. Mental health need 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.* 2004;43(8):960–970.

[24] Leslie LK, Kelleher KJ, Burns BJ, Landsverk J, Rolls JA. Foster care and Medicaid managed care. *Child Welfare* 2003;82(3):367–92.

[25] Institute for Research on Women and Families. Health services for children in foster care. Sacramento, CA: California State University, 1998.

[26] Harman JS, Childs GE, Kelleher KJ. Mental healthcare utilization and expenditures by children in foster care. [see comments]. *Archives of Pediatrics & Adolescent Medicine.* 2000;154(11):1114–1117.

[27] Halfon N, Berkowitz G, Klee L. Mental health service utilization by children in foster care in California. *Pediatrics.* 1992;89(6 Pt 2):1238–1244.

[28] Ibid.

[29] Takayama JI, Bergman AB, Connell FA. Children in foster care in the state of Washington. Healthcare utilization and expenditures. *JAMA.* 1994;271(23):1850–1855.

[30] Ibid.

[31] Rubin DM, Alessandrini EA, Feudtner C, Mandell D, Localio AR, Hadley T. Placement stability and mental health costs for children in foster care. *Pediatrics.* 2004;113(5):1336–1341.

children, to specialized health centers that provide screening services to all children entering out-of-home care and timely follow-up to children, particularly during periods of placement change. These units have been responsive to guidelines published by the American Academy of Pediatrics, the American Academy of Child and Adolescent Psychiatry, and the Child Welfare League of America to provide the assessment and referrals necessary to meet the goals for timely access to appropriate care. Specialized health programs have also been demonstrated to improve referral of children to treatment services.[32]

As we have begun to achieve some success in improving access to care, new challenges have emerged. One that has risen to national attention recently has been the concern for the overuse of psychotropic medications among our nation's youth in general, with a potentially disproportionate increase among children in foster care. The few research studies available show rates of psychotropic medication use ranging from 13–50% among children in foster care,[33,34,35,36,37,38,39] compared with approximately 4% in youth in the general population.[40] In fact, a report prepared by the Government Accountability Office found that 15 states identified the overuse of psychotropic medications as one of the leading issues facing their child welfare systems in the next few years.[41] Recently published data from Texas suggests that the use of multiple medications concurrently is occurring at high rates among children in foster care.[42] Soon-to-be-published data from Safe Place also demonstrates that in the Medicaid program, children in foster care with autism were much more likely to use three or more psychotropic medications than children who qualified through the Supplemental Security Income program.[43] Those data have shown alarming interstate variation in the prescription patterns of psychotropic medications for children in foster care across our nation.

It is difficult to know from these preliminary analyses or the multitude of reports that are emerging in the media whether the use of these medications by children in foster care is appropriate, although at the very least the use of combinations of three or more medications remains controversial. Clearly, medication can be helpful to some children, but with the increasing use of these medications among children in general, there comes the added responsibility to ensure that children have access to an array of treatment strategies, from medication to community-based services that may augment or replace the need for medications in many circumstances. Furthermore, the failure to coordinate and provide continuity in services and the absence of clear guidelines and accountability to ensure that treatment decisions are in the child's best interest, create a greater risk that medications will be prescribed to control children's behaviors in the absence of individualized service plans that might offer the best chance for success. These critical questions do not have simple answers, and, addressing them will require sustained collaboration between healthcare and child welfare professionals, as well as the funding streams to support such collaboration.

---

[32] Horwitz SM, Owens P, Simms MD. Specialized assessments for children in foster care. *Pediatrics.* 2000;106(1 Pt 1):59–66.

[33] Ferguson DG, Glesener DC, Raschick M. Psychotropic drug use with European American and American Indian children in foster care. *J Child Adolesc Psychopharmacol*. 2006;16(4):474–481.

[34] Zima BT, Bussing R, Crecelius G M, Kaufman A, Belin TR. Psychotropic medication treatment patterns among school-aged children in foster care. *J Child Adolesc Psychopharmacol*. 1999;9(3):135–47.

[35] McMillen JC, Scott LD, Zima BT, Ollie MT, Munson MR, Spitznagel E. Use of mental health services among older youths in foster care. *Psychiatr Ser.* 2004;55(7):811–817.

[36] Breland-Noble AM, Elbogen EB, Farmer EM, Dubs MS, Wagner HR, Burns BJ. Use of psychotropic medications by youths in therapeutic foster care and group homes. *Psychiatr Serv.* 2004;55(6):706–708.

[37] Zito JM, Safer DJ, Sai D et al. Psychotropic medication patterns among youth in foster care. *Pediatr.* 2008;121(1):e157–e163.

[38] Raghavan R, Zima BT, Andersen RM, Leibowitz AA, Schuster MA, Landsverk J. Psychotropic medication use in a national probability sample of children in the child welfare system. *J Child Adolesc Psychopharmacol.* 2005;15(1):97–106.

[39] Zima BT, Bussing R, Crecelius GM, Kaufman A, Belin TR. Psychotropic medication use among children in foster care: relationship to severe psychiatric disorders. *Am J Public Health.* 1999;89(11):1732–5.

[40] Olfson M, Marcus SC, Weissman MM, Jensen PS. National trends in the use of psychotropic medications by children. *J Am Acad Child Adolesc Psychiatry.* 2002;41(5):514–21.

[41] US Government Accountability Office. *Child Welfare: Improving Social Service Program, Training, and Technical Assistance Information Would Help Address Long-standing Service-Level and Workforce Challenges.* Washington, DC: US GAO; 2006.

[42] Zito JM, Safer DJ, Sai D et al. Psychotropic medication patterns among youth in foster care. *Pediatrics* 2008;121(1):e157–e163.

[43] David Rubin, MD, MPH, FAAP, personal communication, April 2008.

Children in Foster Care Must Have a Medical Home

Beginning in the 1960s, the American Academy of Pediatrics pioneered the concept of the "medical home," which is defined as "accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective."[44] In a medical home, the physician should be known to the child and family and should be able to develop a partnership of mutual responsibility and trust with them. In the case of children in foster care, a medical home can provide a critical source of stability and continuity in a child's otherwise chaotic life. The medical home's efforts should include the following:

- **Obtaining health records**. Too many children in state care arrive in a physician's office without any medical history or documentation.
- **Obtaining educational records**. Educational records, including an Individualized Education Plan, can contain critical information about the child's care, development, and physical and mental health needs and current service use.
- **Attempting to include the birth parent or legal guardian**. If possible, close family members should be part of discussions and can often provide at least portions of health history, family history and consent for use of medication.
- **Communicating with the child's caseworker**, who may have access to information about the child's health and well-being.
- **Obtaining any health history available from the foster parent**.
- **Ruling out medical issues** that may contribute to the behaviors of concern (e.g. hearing loss).
- If appropriate, **making a mental health referral** to a qualified mental health provider. The medical home should communicate with the mental health provider. If psychotropic medication is to be prescribed, it should ideally be done by a child psychiatrist, psychiatric nurse practitioner, a developmental/behavioral pediatrician, or a highly skilled and knowledgeable pediatrician with access to mental health consultation.
- **Following good medical practice in medication management**. Any clinician prescribing psychotropic medications for children in foster care should exercise good clinical judgment and follow evidence-based guidelines, including recommendations for both psychotherapeutic and psychopharmacological treatment.
- **Obtaining assent from the child or teen** who has been well-informed about the medication. Too many children in foster care have no idea what their diagnoses are or why they are taking medication.
- Detailed practice parameters are available through the Academy publication, *Fostering Health*.[45]

Experience has taught us that a medical home can play a critical role in the lives of children in foster care. Allow me to share three stories with you from my own experience as a clinician that demonstrate where we as a system have failed or succeeded in addressing appropriately the mental health needs of children in foster care:

- Four-year-old Carrie* first came to see me because of violent tantrums. She had broken windows, doors, and televisions in previous foster homes. Because she was so difficult to control, she had already been through several foster care placements. Working in close cooperation with her foster parents, we were able to wean Carrie down to one psychotropic medication and educate her foster parents in intensive behavioral interventions to help shape Carrie's behavior. However, when Carrie was placed for adoption in a neighboring county, neither her foster parents nor I were given the opportunity to share what we had learned with her adoptive parents or her pediatrician or mental health clinician. Her behaviors returned with a vengeance and, because her prospective parents did not know how to cope with them, the adoption fell apart within two weeks. Carrie was then placed with yet another foster family.
- When Janelle* aged out of the foster care system, she had 22 mental health diagnoses and was on four different medications. She had no idea what any of the drugs were for and stopped all of them—a dangerous move, considering that some

[44] American Academy of Pediatrics Medical Home Initiatives for Children With Special Needs Project Advisory Committee. The Medical Home. *Pediatrics*, Vol. 110 No. 1 July 2002.

[45] American Academy of Pediatrics District II Task Force on Healthcare for Children in Foster Care. Fostering Health: Healthcare for Children and Adolescents in Foster Care. 2nd Edition. American Academy of Pediatrics, 2005.

*Not the child's real name.

psychotropic medications can have serious side effects if stopped suddenly. Janelle met with me after aging out of the foster care system and asked me why she had been on so many medications and why no one had ever taken the time to educate her about her own health and how to care for her health needs. I did not have a good answer for her.

• Nine-year old Jacob* had been in foster care for several years while his mother was in jail because of drug use. He had hearing loss, Attention Deficit Hyperactivity Disorder, and a reading disability and needed medical, mental health, and school-based services which we had been able to put in place. When his mother was released from jail, I was able to transition Jacob's care and meet together with Jacob, his mother, and foster parents. Interestingly, Jacob's mother had received no help with parenting while in jail, and shared with me her own inability to set limits or discipline as she herself had been a victim of child abuse, an all-too-common story. We worked with her to learn parenting skills, find mechanisms of coping with stress that did not include substance use, and take over care coordination of the many needs of her son. By improving her parenting skills, we were able to help her better help her son to manage his ADHD symptoms.

Recommendations

Our nation has a moral and legal responsibility to provide better care to these most vulnerable children. We must ensure that, in removing them from their homes, we improve the health and well-being of foster children and do not further compound their hardship. While the AAP Task Force on Foster Care will issue additional recommendations in the future, the American Academy of Pediatrics has identified priorities in healthcare for children in foster care that include the following:

Comprehensive Care for Children in Foster Care

• All children, including children in foster care, should have a medical home that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.[46] For children in foster care, a medical home can provide a crucial source of stability, continuity of care, and information.[47]

• Comprehensive physical, developmental, and mental health assessments should be given to every child within 30 days of entering state custody.[48] Mental health assessments should also be conducted on any child for whom psychotropic medications are being considered.[49]

• Care coordination must be a priority. The Academy strongly supports Section 421 of H.R. 5466, the Invest in KIDS Act, which requires states to improve care coordination for children in foster care. We were pleased to work closely with Chairman McDermott and his staff to develop this section and hope it can be passed expeditiously.

  • The Academy is profoundly concerned that the recent Centers for Medicare and Medicaid Services interim final rule on Case Management Services represents a step away from care coordination. While the rule states that its purpose is to improve care coordination, the significant limits it imposes are likely to restrict state flexibility and deny the child welfare system valuable tools to coordinate health and related services for children in foster care. The Academy strongly endorsed the legislation passed by the House to place a moratorium on this rule.

• Financing should reimburse healthcare professionals for the more complex and lengthy visits that are typical of the foster care population. Financing must also cover the cost of the healthcare management to ensure that this medically complex population receives appropriate and timely healthcare services.[50]

---

*Not the child's real name.

[46] Medical Home Initiatives for Children With Special Needs Project Advisory Committee. The Medical Home. Pediatrics, Vol. 110, No. 1, July 2002.

[47] American Academy of Pediatrics. Fostering Health: Healthcare for Children and Adolescents in Foster Care. 2nd edition. American Academy of Pediatrics, 2005.

[48] American Academy of Pediatrics. Committee on Early Childhood, Adoption, and Dependent Care. Healthcare of young children in foster care. *Pediatrics* 2002;109:536–41.

[49] New York State, Office of Children and Family Services. The use of psychiatric medications for children and youth in placement; authority to consent to medical care. 2002. Available at http://ocfs.state.ny.us/main/sppd/health_services/manual.asp

[50] Ibid.

• Child welfare agencies and healthcare providers should develop and implement systems to ensure the efficient transfer of physical, developmental, and mental health information among professionals who treat children in foster care.[51]

• Health insurance for children and adolescents in foster care must include a comprehensive benefits package, such as the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) package, to cover the wide array of services needed to ensure optimal physical, emotional, developmental, and dental health.[52]

Mental Health Services for Children in Foster Care

• If children in state custody are placed on medication, there should be an established protocol for obtaining consent and monitoring the use of that medication. Depending on the state, parties authorized to provide this consent could include a juvenile court officer, social services commissioner, or other authorized guardian or agency with assistance from a clinician knowledgeable of the evidence regarding psychotropic medication use. Pediatric and mental health providers should have ongoing communication with the child and caregivers to monitor treatment response, side effects and potential adverse reactions. Caseworkers also should maintain documentation regarding recommendations for prescriptions, changes in dosage and side effects, and child's response to medication as a treatment option. Youth should be involved and educated about the risks, benefits, and side effects of taking psychotropic medications. When appropriate, the assent of youth should be documented in addition to consent of the caretaker and/or caseworker.[53]

• Financing should include funds for developing family-based approaches to mental health and developmental services.[54]

• Both the National Child Abuse and Neglect Data System (NCANDS) and the Adoption and Foster Care Analysis and Reporting System (AFCARS) should track at least basic information on the use of psychotropic medications among children in foster care. At present, neither system collects any data in this area. The Academy filed comments with the Administration on Children, Youth and Families on March 5, 2008 that included recommendations for new AFCARS data elements on psychotropic drug prescriptions for children in foster care.

Mr. Chairman and Members of the Subcommittee, I deeply appreciate this opportunity to offer testimony on behalf of the American Academy of Pediatrics. I stand ready to answer any questions you may have, and I thank you for your commitment to the health of the children of our nation.

Chairman MCDERMOTT. Mr. Weller points out, perhaps I could do some education. Green is for five minutes. When it goes to yellow, that means you got a minute. When it's red, it's over. It's a little late for show and tell, but thank you very much for your testimony.

Christopher Bellonci is the medical director at the Walker School in Needham, Massachusetts.

STATEMENT OF CHRISTOPHER BELLONCI, M.D., MEDICAL DIRECTOR, THE WALKER SCHOOL

Dr. BELLONCI. Thank you, Mr. Chairman and Members of the Committee.

I am pleased to be here on National Children's Mental Health Awareness Day to discuss this important issue. I am prepared to speak today as a child psychiatric practitioner, a consultant to the child welfare system, and a medical director of a residential treatment center. One possible explanation for the apparent overuse of

---

[51] Ibid.
[52] Ibid.
[53] American Academy of Pediatrics. Committee on Early Childhood, Adoption, and Dependent Care. Healthcare of young children in foster care. *Pediatrics* 2002;109:536–41.
[54] Ibid.

psychiatric medications for children in the child welfare system is the high rate of mental illness found in this population.

Studies indicate that 60 to 85 percent of the children being served by the child welfare system meet criteria for a DSM4 psychiatric diagnosis. In many cases, this is related to the trauma that resulted in the removal from their family, but in the significant number of cases, the mental illness appears to have pre-dated their removal. These children's families are often significantly affected by mental illness and substance abuse. These familial conditions lead to a genetic predisposition to mental illness in their children. This risk can then be multiplied by in utero exposure to alcohol and other drugs. Often, these children then suffer neglect and abuse, which compound their genetic and biological risk to develop emotional and behavioral disorders.

Multiple placements within the foster care system add additional burdens to healthy emotional development and impair coordinated mental health treatment. Early detection and assessment of the mental health needs of these children are critical in order for them to receive necessary mental health interventions.

Unlike mentally ill children from intact families, these children rely on the State to provide informed consent for their treatment, to coordinate treatment planning and clinical care, and to provide longitudinal oversight of their treatment. The State has a duty to perform this protective role for children in State custody. However, the State must also take care not to reduce access to needed and appropriate services.

Many children in State custody benefit from psychotropic medications as part of a comprehensive, mental health treatment plan. As a result of several highly publicized cases of questionable prescribing practices, treating youth in State custody with psychopharmacological agents has understandably come under increased scrutiny. Many states have implemented consent, authorization and monitoring procedures for the use of psychotropic medications for children in State custody.

Unfortunately, these policies have unintended consequences, such as delaying the provision of or reducing access to necessary medical treatment. I believe the critical question in this discussion is whether medication is being prescribed appropriately in ensuring that all the child's mental health needs are being adequately addressed.

Most psychoactive medications do not, as yet, have specific approval by the FDA for children under age 12. This approval requires research demonstrating safety and efficacy, and, the research so far lags behind the clinical use of these medications. Long-term studies are needed to adequately determine the safety and efficacy of psychoactive medications in this age group.

In making decisions to prescribe such medications, child psychiatrists are often left to evaluate data from studies in adults, even though there are documented cases of medications that were safe in adults causing unanticipated side effects in children.

The lack of data supporting current prescribing trends makes the informed consent process all the more critical for children in State custody. In my consulting work in Tennessee I drafted medication monitoring guidelines for use by that state's child welfare workers.

These guidelines are meant to be used by child welfare caseworkers in their monitoring of psychotropic medications prescribed for children in care.

They are similar to those developed in other jurisdictions; and, frankly coming up with a common agreement for thresholds that should trigger a clinical review should not be that difficult. These guidelines are not intended to dictate treatment decisions by individual providers. Every child or adolescent has unique needs that require individualized treatment planning.

At times in my own practice, the appropriate treatment for a specific child will fall outside of the parameters of these guidelines, but, I would expect that if anybody questioned why a specific child was on a medication under my care, I could give a rational explanation.

State child welfare agencies need to develop a second opinion capacity for times when prescribing practices fall out of established guidelines for community systems of care. In Tennessee the State contracts with five university medical centers in five different regions of the State to provide expert second-opinion capacity regarding all aspects of a child's mental health diagnosis and treatment planning, including psychiatric medication.

I've included the guidelines I developed for Tennessee in my written statement and would be happy to discuss them in more detail during the question and answer period of this hearing.

Thank you.

[The prepared statement of Christopher Bellonci, M.D., follows:]

Prepared Statement of Christopher Bellonci, M.D., Medical Director, The Walker School, Needham, Massachusetts

Mr. Chairman and Members of the Committee, my name is Christopher Bellonci, M.D. and I am pleased to be here to discuss the important issues related to psychotropic medication use among children in America's foster care system. I am a board-certified child and adolescent psychiatrist and the medical director at Walker, a multi-service agency in Needham, Massachusetts where I work directly with children in the child welfare system. I am a member of the American Academy of Child and Adolescent Psychiatry as well as a member of the Mental Health Advisory Board of the Child Welfare League of America. For several years I have been consulting to the State of Tennessee's child welfare agency helping that State to revise their policies and procedures regarding psychotropic medication use and behavior management.

As Dr. Zito has outlined in her testimony, children in child welfare appear to be prescribed psychotropic medication at higher rates than children who are not within the child welfare system. In Tennessee, unpublished data indicated that approximately 25% of the children in that system were taking psychiatric medication. As you have heard from Dr. Zito, her most recent study of children in the Texas child welfare system showed 34.7% of the children were taking psychiatric medications with 41.3% of those children on psychiatric medications taking three or more medications.

One possible explanation for the apparent overuse of psychiatric medications for children in the child welfare population is the high rate of mental illness found in this population. Studies indicate that 60–85% of the children being served by the child welfare system meet criteria for a DSM–IV Psychiatric diagnosis. In many cases this is related to the trauma that resulted in their removal from their family but in a significant number of cases the mental illness appears to have predated their removal. With such a high prevalence of mental illness in this population, screening for mental disorders is superfluous and instead providers time would be better served moving to a comprehensive assessment of the child and family's strengths and needs that can be used for treatment planning and service delivery.

The families from which these children were removed are often significantly affected by mental illness and substance abuse. These familial conditions lead to a ge-

netic predisposition to mental illness in their children. This risk can be multiplied by in-utero exposure to alcohol and other drugs. Often these children then suffer neglect and abuse compounding their genetic and biological risks to develop emotional and behavioral disorders. Multiple placements within the foster care system add additional burdens to healthy emotional development and impair coordinated mental health treatment. Early detection and assessment of the mental health needs of these children is critical in order for them to receive necessary mental health interventions.

Unlike mentally ill children from intact families, these children rely on the state to provide informed consent for their treatment, to coordinate treatment planning and clinical care, and to provide longitudinal oversight of their treatment. The state has a duty to perform this protective role for children in state custody. However, the state must also take care not to reduce access to needed and appropriate services. Many children in state custody benefit from psychotropic medications as part of a comprehensive mental health treatment plan. As a result of several highly publicized cases of questionable prescribing practices, treating youth in state custody with psychopharmacological agents has come under increased scrutiny. Many states have implemented consent, authorization, and monitoring procedures for the use of psychotropic medications for children in state custody. Unfortunately, these policies can have unintended consequences such as delaying the provision of, or reducing access to, necessary medical treatment.

The critical question in this discussion is whether medication is being prescribed appropriately and ensuring that all of the child's mental health needs are being adequately addressed. Most psychoactive medications prescribed for children under age twelve do not as yet have specific approval by the Food and Drug Administration (FDA); such approval requires research demonstrating safety and efficacy. Such research, so far, lags behind the clinical use of these medications. Long-term studies are needed to adequately determine the safety and efficacy of psychoactive medications in this age group. In making decisions to prescribe such medications child psychiatrists often are left to evaluate data from studies in adults even though there are documented cases of medications that were safe in adults causing unanticipated side-effects in children. The lack of data supporting current prescribing trends makes the informed consent process all the more important for children in state custody. The prescribing of multiple psychotropic medications ("combined treatment" or "polypharmacy") in the pediatric population is on the increase. Little data exist to support advantageous efficacy for drug combinations, used primarily to treat co-morbid conditions. The current clinical "state-of-the-art" supports judicial use of combined medications, keeping such use to clearly justifiable circumstances (AACAP policy statement 9/20/01).

In my consulting work in Tennessee, I drafted medication monitoring guidelines for use by that state's child welfare workers. The guidelines were meant to be used by child welfare caseworkers in their monitoring of psychotropic medications prescribed for children in care. They were not intended to dictate treatment decisions by providers. Every child or adolescent has unique needs that require individualized treatment planning. At times, the appropriate treatment for a specific child will fall outside the parameters of these guidelines. State child welfare agencies need to develop a second opinion capacity for times when prescribing practices fall out of established guidelines or community standards of care. In Tennessee, the state contracted with four university medical centers in four different regions of the state to provide expert second opinion capacity regarding all aspects of a child's mental health diagnosis and treatment including psychiatric medication.

It was the intent of the following guidelines that children in care receive necessary mental health treatment, including psychotropic medications, in a rational and safe manner. The guidelines reflect common practice wisdom in the field of child psychiatry:

- Medication should be integrated as part of a comprehensive treatment plan that includes:
  - Appropriate behavior supports and treatment
  - Symptom and behavior monitoring
  - Communication between the prescribing clinician and the youth, parents, guardian, foster parents, child welfare case manager, therapist(s), pediatrician, school staff and any other relevant members of the child or youth's treatment team
- Medication decisions should be appropriate to the diagnosis of record, based on specific indications (i.e., target symptoms), and not made in lieu of other treatments or supports that the individual needs. There should be an effort, over

time, to adjust medication dosages to the minimum dosage at which a medication remains effective and side effects are minimized. Periodic attempts at taking the child off medication should also be tried and, if not, the rationale for continuing the medication should be documented.

- Medication decisions need to be based upon adequate information, including psychiatric history and assessment, medication history, medical history including known drug allergies and consideration of the individual's complete current medication regimen (including non-psychoactive medications, e.g., antibiotics).
- Polypharmacy, or the use of multiple psychiatric medications, should be avoided.
- When a recommendation is made for a child to take more than one medication from the same class (e.g., two anti-psychotic medications), the recommendation should be supported by an explanation from the prescribing clinician and may warrant review by a consultant to the child welfare system.
- A child taking more than three psychotropic medications should prompt an explanation from the prescribing clinician and may warrant review by a consultant to the child welfare system.
- Medication dosages should be kept within FDA guidelines (when available). The clinical wisdom, "start low and go slow" is particularly relevant when treating children in order to minimize side effects and to observe for therapeutic effects. Any deviations from FDA guidelines should be supported by an explanation from the prescribing clinician and may warrant review by a consultant to the child welfare system.
- Unconventional treatments should be avoided. Medications that have more data regarding safety and efficacy are preferred over newly FDA-approved medications.
- Medication management requires the informed consent of the parents or guardians (unless parental rights have been terminated in which case the state must provide informed consent) and must address risk/benefits, potential side effects, availability of alternatives to medication, prognosis with proposed medication treatment and without medication treatment and the potential for drug interactions.
- The risk versus benefit of a medication trial needs to be considered and continually reassessed, and justification should be provided, where the benefit of a medication comes with certain risks or negative consequences.
- Children on psychotropic medications should be seen by their prescribing clinician no less that once every three months. This is a bare minimum and children in acute settings, displaying unsafe behavior, experiencing significant side effects, starting on SRI's or not responding to a medication trial or in an active phase of a medication trial should be seen more frequently.
- If laboratory tests are indicated to monitor therapeutic levels of a medication or to monitor potential organ system damage from a medication these lab studies should be performed every three months at a minimum (maintenance phase). If the medication is being initiated, these lab studies will need to be performed more frequently until a baseline is achieved.

In addition to developing the guidelines, a computerized, interactive state-of-the-art training curriculum was developed for all child welfare staff in Tennessee. The curriculum used clinical vignettes to teach child welfare staff about the revised psychotropic medication policies and procedures as well as the medication guidelines. The Department is also working to update its information technology system to be able to embed the guidelines into their database so that when a child's psychiatric medications fall out of the guidelines an alert is sent to the case manager or supervisory staff. This system would work similar to a pharmacy's computer program alerting the pharmacist to possible medication contraindications.

State child welfare agencies should create websites that can provide ready access for clinicians, foster parents, and other caregivers to pertinent policies and procedures governing psychotropic medication management, psycho-educational materials about psychotropic medications, consent forms, adverse effect rating forms, reports on prescription patterns for psychotropic medications, and links to helpful, accurate, and ethical websites about child and adolescent psychiatric diagnoses and psychotropic medications (AACAP Position Statement on Oversight of Psychotropic Medication Use for Children in State Custody: A Best Practices Guideline).

States should develop the capacity to monitor the rate and types of psychotropic medication usage by children in state care as well as the rate of adverse reactions to prescribed medications. States should establish a process to review non-standard, unusual, and/or experimental psychiatric interventions with children who are in state custody. States should collect and analyze data and make quarterly reports to

the state or county child welfare agency regarding the rates and types of psychotropic medication being prescribed to children in their care. Making this data available to clinicians in the state could serve as a vehicle to improve the quality of care provided to children in state custody.

Thank you for the opportunity to address this important area of concern impacting America's most vulnerable youth.

Chairman MCDERMOTT. Thank you.

Mr. Weller, would you like to ask the first question?

Mr. WELLER. Sure, Mr. Chairman, recognizing that the delay of our hearing may have made it difficult for other Members of the Subcommittee to attend because of various obligations in their schedules, can I ask unanimous consent that Members of the Subcommittee have five legislative days to submit questions to the witnesses for the record?

Chairman MCDERMOTT. Without objection, it's ordered.

Mr. WELLER. I should say written questions to the panelists.

Ms. Stenslie, thank you for your testimony. You had personal experiences both as a foster youth, but also as a foster parent, and clearly you are very committed to foster children because of your role with the alumni association.

You know, Mr. Chairman, she spoke eloquently about the need for the ability of foster youth to be able to somehow maintain their records if they're going to change foster homes, and be able to take those medical records with them if they change positions as well. Of course, we've been working in the Ways and Means Committee and there's been a bipartisan effort on electronic records and other capabilities with technology we have. I've often wondered why can't we do that. So perhaps that's an area you and I can work together on.

Ms. Stenslie, why do so many foster youth end up being prescribed medication, both from your personal experience, but also from your observation?

Ms. STENSLIE. I'm glad you asked that and I don't think there's a really predictable answer, but what I've seen in the foster care system, a lot of times we end up doing things to make it easier for the adults. The adults are overworked and they're underpaid, and they have all kinds of commitment and idealism when they start. Then they get squashed by our system and how hard it is to work in, and I've been there.

So we do a lot of things in child welfare to try to make things easier for the adults; and, so, I think a lot of times managing a young person's behavior through the use of medication is a way to try to make it possible for foster parents to stick with this kid just a little longer, or for the group home to not send them to a higher level of care, that we do it so the adults in their lives can figure out how to cope with them.

I think that a lot of times medication is used as a chemical restraint for children whose behavior get out of control. Dr. Leslie talked about a little girl who broke windows and televisions, and certainly we know that's not safe or healthy for anybody, but, we also know that we can't take away what she went through by giving her a pill. So, maybe the pill is the stopgap measure, but we

have to help her figure out how to negotiate what she went through, because her reality is not going to change.

Mr. WELLER. I have a 20-month-old daughter and there's days we're a little tired when we get home. So, I think I understand where you're coming from on that.

You state in your testimony: "Over the years, I was on more medications than I can count, usually without my knowing what the meds were for, how I should expect to feel, side effects to watch out for, or any plan for follow-up." You had questions.

Did anyone in your life ever give you answers to those questions?

Ms. STENSLIE. No. It wasn't until I was an adult and I was in college that I actually found a therapist myself and she told me that I would be able to go and get some of my records and find out what all of that was about, because I didn't leave the system with any of that information. So she helped me to at least get a clinical profile from my last stint in placement; and, it said right on there that I had post-traumatic stress disorder and depression. That's something that no one ever told me.

Mr. WELLER. Your caseworker never discussed this with you, your foster parents never discussed it with you?

Ms. STENSLIE. No.

Mr. WELLER. Your doctor never discussed it with you that prescribed the medicine?

Ms. STENSLIE. No.

Mr. WELLER. For me it's very frustrating, because for a better job and better life, a person needs a high school diploma, and so many foster youths go from school to school to school. It makes it difficult for them not only to socialize, but to develop friends.

Ms. Stenslie. I've been to at least 25 schools.

Mr. WELLER. 25 schools in your own personal experience.

How many doctors did you encounter during that period of time? You went to 25 different schools?

Ms. STENSLIE. Right. Probably fewer than you would expect, because much of that time I was completely without health or mental healthcare, so I didn't have as many doctors as I did social workers, because the social workers were required. The doctors were seen as a luxury.

Mr. WELLER. So, do you think the process worked in your own experience or as it currently exists does it work for kids when it comes to their exposure to psychotropic drugs that may be prescribed in their case?

Ms. STENSLIE. I think it works for some. I think there are a lot of really highly qualified and invested doctors out there; and, obviously, many of them are here today, but I think it takes a special set of skills and knowledge to be competent in dealing with youth who come from very highly traumatized backgrounds.

I think you also have to, on top of the trauma informed care expertise, know about foster care, because it brings its own set of life circumstances that you can't possibly understand unless you purposely tried to.

Mr. WELLER. Thank you.

Mr. Chairman, you've been generous and my red light's been on for some time.

[Laughter.]

Mr. WELLER. Thank you.

Chairman MCDERMOTT. Thank you.

In listening to this it's interesting that I had written down the same questions that Mr. Weller explored. That is, why is it we can't have a medical home? So I'd like to move to the pros here for a second and ask. Well, not that you're not a pro, because you are a social worker, but those of you who have been roaming around the country looking at various systems, where have they gotten it together best?

I understand there may be some desire to pump your own balloon, but if you could give us a clue as to where they have figured out how to coordinate the records and get a decent review system of what's going on and maybe peripherally get the kids involved in understanding what it is they're on and why, because that really is a part of the medical home situation. So I'd like to hear what you think.

Does it take a law suit like Tennessee to bring you up to the tips of your toes? Or, is there someplace where they really worked it out? So, it's really a blue book question for any one of you to jump in on. I'd like to hear what we should look at to emulate or encourage or, whatever.

Dr. LESLIE. I'd be happy to comment on something. I'm not going to be commenting from the State level but just from what you asked initially about what is the medical home. So just for everyone's review, what we see is a medical home is a site where your care is continuous, coordinated, accessible, comprehensive.

That's what should make a medical home. So, from the pediatrician's perspective, there's about three models I would say out there, again, from the pediatric perspective of what is a medical home. Several communities have come up with systems where there are multiple disciplines of people located at those settings where they're evaluating kids. So, you have somebody who is looking for developmental problems; somebody who is looking for educational problems; somebody who is looking at mental health; somebody who is looking at what medications a child is on for chronic health problems, and all that is put together. L.A. has one of those systems. Philadelphia does. Connecticut does; where kids who are entering foster care come and are evaluated in a comprehensive manner and then followed on a more routine basis over time.

That's not always feasible in every community. In Rochester, for example, we have what some would call a foster care champion, Moira Szilagyi, has set up a clinic that specifically addresses the needs of children in foster care, so she may not be a part of a comprehensive center, but she is doing that on her own as a clinician. That's a second example.

A third example would be mechanisms of making sure kids are evaluated in getting evidenced-based treatments in partnerships with other settings. Some states or counties have set up where child welfare and mental health, or child welfare and Medicaid, partner together around meeting those needs. Massachusetts, for example, somewhat like Tennessee, has just hired a whole group of nurses who are going to work and provide oversight within child welfare for what are the medical problems and what medications children are on. That would be a third example where it is actually

housed in Medicaid mental health or child welfare. I think those are three different models.

The other thing I'd say is I think the comprehensiveness of care is really important to stress. One of the things I was very lucky about when I mainly worked in California, but we worked to develop highly evidenced-based treatments for children in foster care. So, for example, I was lucky as a clinician to be able to refer a child and their foster parent to a program that's been developed out of Oregon where they actually train foster parents in the 16-week session on how to handle behavior problems. We've been able to show that 80 percent of children will respond to that. About 20 don't, and those are the kids that have pretty serious mental disorders and need more than what a foster parent can provide, but that's using the person who's with the child the most as an intervention agent and I'd be happy to share information with that with any of you as well.

Dr. LEA. Tennessee has been mentioned several times, so I want to make sure that I get a chance to comment. I think we've done some things right. The law suit has given us some financial means to make some steps that might otherwise not have been available.

We also appreciate the house support of the moratorium on TCM as we're facing losing $73 Million for the care that we provide kids. I think we've been able to do, one of the things Dr. Leslie mentioned, was all children coming into custody getting a health screening within 30 days. That is something that we mandate and is done at our health department within links onto mental health health assessments in the community as needed.

I mentioned in both my written and oral testimony about the centers of excellence that we have, those were actually created by a different lawsuit that we have but have really served us well. They were created specifically for kids in imminent risk of custody and our most complex cases go there.

Those kids that have not only numerous mental health diagnoses that are aggressing in treatment, not progressing in treatment, nobody knows what to do with. Foster parents are at a loss, and the team of professionals that are psychology, neurology, medical take a look at that child. They do provide some ongoing care. Unfortunately, they are not able to see every child coming into custody or provide ongoing care for every child who remains in custody, but they have been a fabulous resource above and beyond the nurses, psychologists and psychiatrists that we have in-house in Tennessee.

Chairman MCDERMOTT. Ms. Stenslie, you commented that at one point you wound up in detention, to some kind of a detention situation.

I worked for a number of years at the center in the State of Washington where we dealt with all the kids who came through the juvenile justice system. We gave them a comprehensive work-up at that point. I don't think we had a comprehensive work-up. This was Cascadia; that's now closed. I don't know whether they're still doing that in the State or not.

Did you receive anything different when you got to that level of dysfunction?

Ms. STENSLIE. You know, I'm not so sure, because people weren't discussing that with me directly. So I don't know for sure.

In those correctional facilities there were certainly more people with doctor in their title than I had seen in other kinds of places; and, so, as an adult, someone who has worked in those systems, I know that there was more mental healthcare available right there on campus, but I don't know that I actually received it.

I do remember very vividly standing in line with nearly every other resident of those facilities at eight o'clock every night and eight o'clock every morning to each get our little white paper pills in a little white cup. I'm not aware of receiving any more or better health or mental healthcare while I was there. The fact that I grew up without knowing about what my own diagnoses were and what the meds were for, I'd have to say as an adult then learning about that PTSD diagnosis, then I was able to take some control about it.

Then I went and did some research and found out what it was and was able to look at those books and to ask questions and say, you know what? That does describe me and there are some ways to fix that out there and I'm not just crazy and I'm not just destined for a whole life of nightmares and not sleeping at night. Then I could claim what belonged to me and get rid of what didn't and address it, but I had no chance to even do that until somebody talked to me.

Chairman MCDERMOTT. Dr. Thompson?

Dr. THOMPSON. Well, medical home also would be the naysayer. It's the new buzz word. We went through chronic care management. We went through disease management and now we're at medical home, and quite frankly, I'm still perplexed about what this is, but I think it's a good idea. For me it's three things.

I absolutely agree with records management, whether it's electronic or whether it has to be portable and it has to go, because how can you really tell what's going on. The other thing I think is missing is medical home has to be putting the client at the center with mental health, medical, and family services integrated.

Most of the time, I don't know of any service that actually mixes and matches all those three together well. I think there are pieces and parts and we're trying to find those. We certainly are trying, but we haven't figured out Washington State.

Chairman MCDERMOTT. What's the place that you wind up with the problem in coordinating the three?

Dr. THOMPSON. Well, I think its contracts are separate. Budgets are separate. You fund mental health differently than medical and sometimes differently than family services; and, therefore, you contract differently. There are multiple mixes of people in this discussion and there is not really good integration. That's fundamentally what I see.

So when you can write contracts and funding streams where they all have to talk, then I think that's a medical home. Whoever wants to be at the center, at the top, whatever, fine, but, right now, I see it as, "Is it the pediatrician that wants to be at the center?"

As far as I'm concerned, the client's at the center, and everybody's got to talk around that client. My take-home point is that we have not done a good enough job of explaining med man-

agement to the families and the clients. I'll take that home, and that's going to happen.

The third thing is standards. You can send him off to a medical home, but if we don't all agree on what the standards are, what the care is, and we see it in our State, in some places it's a whole bunch of meds. In some places it's not many meds. In some places it's meds combined with mental health treatment. So I think standards are really important. I know it's probably a dirty word, but, people have got to. What we demand of banking and what we demand of our automobile industry and our space industry is that we've got to take an industrial approach or an engineering approach. There can't be the standard of variation that we see in medicine.

I know that's probably not the best thing to say, but as I look at it, we've got to do what we've done really well in banking and automobile; and, we can push that into medical. I think we're going to do a much better job.

Chairman MCDERMOTT. Is that happening in the pediatrics association, the National Association of Pediatrics?

Dr. LESLIE. In terms of setting standards?

Chairman MCDERMOTT. Yes.

Dr. LESLIE. Well, both the American Academy of Child and Adolescent Psychiatry and the American Academy of Pediatrics routinely publish guidelines on what's appropriate treatment and try to get those into the community.

Chairman MCDERMOTT. So you've got the guidelines. You've published them. They simply are not filtering down to the practitioners or there's no oversight.

Dr. BELLONCI. There's a great deal of variability, and I don't know that any of the states have all the components that I would like to see implemented. I think there are good examples of some best practice and merging some of what you've heard today.

This doesn't have to be that complicated. We need to have screening at intake and point of removal. Was the child already diagnosed with a psychiatric condition? Are they already taking psychiatric medication so they continue on those, if they had a preexisting condition?

Do they have an emerging trauma related to the removal itself?

If you believe the statistics that 60 to 85 percent of these kids are going to be diagnosed with a psychiatric condition, when I was trained in medical school you skipped screening and you just go to comprehensive assessment of their needs and strengths and move to treatment planning, because why waste your dollars screening at such a high incidence rate?

We then need to have comprehensive treatment plans that may include medication recommendations, but, states should not assume that just because a doctor is prescribing this psychiatric medication that that precludes their need to have a second opinion capacity. I think there are some very scary stories of medication practices that you're hearing about.

I recently admitted a three-year-old who was on three psychiatric medications including lithium; and, when I brought that to the attention to the child welfare agency I couldn't even get a response

from them. The child left on a small dose of a stimulant medication.

There needs to be informed consent by knowledgeable, trained, child welfare staff if and only if the parent or guardian can't be there. There clearly needs to be information sharing with the child themselves, even when I'm working with four and 5-year-olds as best as I can in a developmentally appropriate way. I'll talk about why I am giving them that medication and what they should expect, and what they might need to look for. I meet with them frequently to monitor their side effects or their response.

There needs to be an IT system that can actually tell the child welfare system what are the medications these children are taking in the individual case as well as in the aggregate. Then there needs to be a Committee that actually reviews that data periodically so that they can inform practice and engage the child psychiatric community.

Chairman MCDERMOTT. Thank you all for your testimony. Mention was made of the section in the Invest in KIDS Act about the healthcare coordination and Mr. Weller and I are working on trying to bring. We may not get the huge bill out of here. This Congress is a little bit confusing in terms of trying to do something big, but we're trying to do some thing that we think can help the system, particularly in this area before the end of the session.

So, thank you very much for not only coming but waiting and participating and we thank you for coming. Thank you very much.

The meeting is adjourned.

[Whereupon, at 1:37 p.m., the Subcommittee was adjourned.]

[Responses to Questions for the Record posed by Chairman McDermott to Julie M. Zito, Ph.D. follow:]

Julie M. Zito, PhD
Professor, School of Pharmacy
Pharmaceutical Health Services Research
School of Medicine, Dept. of Psychiatry
220 Arch Street
Baltimore, MD 21201

Phone +1 (410) 706-0524
Fax +1 (410) 706-5394
jzito@rx.umaryland.edu

June 8, 2008

Representative Jim McDermott, Chairman
Subcommittee on Income Security and Family Support
Committee on Ways and Means
U.S. House of Representatives
Washington, DC 20515

Dear Representative McDermott:

Thank you for the opportunity to participate in the Ways and Means hearings on foster care. The following discussion responds to your May 23, 2008 questions concerning foster care children and psychotropic medication.

Question #1. ***What are the reasons for the increase in psychotropic medication in youth?*** Some of the factors that may account for the increased utilization are: 1) more social acceptance of medication treatment of children by their parents; 2) an end to the moratorium on direct-to-consumer prescription drug advertising in 1997; 3) the shift, since the 1980s in psychiatric theory from a biopsychosocial treatment model to biological psychiatry which seems to have produced a greater emphasis on somatic (drug) therapy; 4) the evolution of the Diagnostic and Statistical Manual (DSM) categorization of mental disorders. This is reflected in the widening of diagnostic categories into spectrum disorders, e.g., autism; 5) the profound involvement of academic psychiatrists (thought leaders) in drug company-sponsored clinical trials and company consultation endeavors producing potential conflicts of interests. Ironically, the New York Times today provided us with yet another example (see Harris and Carey, 06/08/08, front page, Researchers Fail to Reveal Full Drug Pay). 6) fewer uninsured children permit more health services to be accessed.

Question #2. ***How has this affected the methods that are used to treat children in foster care?*** Foster care youth have more developmental, social and behavior problems which increases their likelihood of being candidates for behavioral and psychiatric interventions including psychotropic medication treatment. Virtually all such youth are Medicaid-insured and they generally receive more medication than commercially insured youth. In addition, Medicaid prescriptions have fewer co-payment restrictions.

Question #3. ***Why are foster children more likely to be prescribed these medications?*** Foster care children have significantly more emotional and behavioral problems as their Medicaid-insured non-foster care counterparts and they receive psychotropic medication at a rate 3-4 times that of youth enrolled in TANF or SCHIP. In addition, oversight of Medicaid "appropriateness" of use is woefully inadequate so that as many as 5 concomitant

psychotropic drugs do not trigger an exception report. And, exception reports generally have little or no impact on changing physician prescribing behavior.

Question #4. ***Why are they more likely to be treated with 2 or more classifications of medications, many of which are "off-label" drugs?***
Concomitant medication use has contributed to the increased prevalence of psychotropic medication. Physicians tend to add medications when the response to treatment is inadequate, although discontinuation or switching may be more useful. Another factor responsible for multiple classes of medication use in psychiatry is the tendency of the DSM system to emphasize the co-occurrence of several diagnoses which then justifies several medications. The off-label status of such combinations creates serious uncertainty of either effectiveness or safety. Managing complex pharmacologic therapy is particularly challenging where continuity of care is not possible. Off-label use is common in children because the pharmaceutical industry has had (until recent Best Pharmaceuticals for Children Act (BPCA) legislation and exclusivity incentives) little interest in financing clinical trials to assess efficacy in children. Consequently, physicians tend to generalize from adult experience which unfortunately has been shown to be inadequate for major psychotropic classes. Examples include atypical antipsychotics, selective serotonin reuptake inhibitor (SSRI) antidepressants and anticonvulsants used as mood stabilizers.

Question #5. ***Do you believe that states are conducting the appropriate level of oversight and evaluation of the use of these drugs for children in foster care?***
The level of oversight by state officials appears to be severely limited for child psychotropic drug use since the criteria adopted by many states were created by a group of experts having little or no empirical basis for their review criteria. There are few/unknown consequences to practitioners with exceptions to the criteria. Also, many association-based clinical guidelines tend to be consensus recommendations among leading practitioners and, thus far, lack attempts to relate revised criteria to either physician behavior or patient outcome. Recently, there are several efforts to improve the oversight for foster care, in particular, in Illinois, Tennessee, Texas, and Massachusetts. Illinois stands out because the model they have adopted uses a single academic-based expert as the clinical reviewer for all psychotropic drug prescriptions for youth in state custody. This arrangement heightens accountability and also permits exchange of information between medical peers. This is a model I favor based on my 9-year experience within the New York State Office of Mental Health system. There, I worked with the automated exception reporting system of oversight of psychotropic medications for severely mental ill individuals hospitalized in state psychiatric centers.

Question #6. ***What is the general consensus within the medical community on the use of anti-psychotic drugs to treat children with behavioral and emotional problems?***
The leaders in academic child psychiatry and at the NIMH and FDA tend to support the existing evidence that antipsychotic medications are useful for seriously disruptive youth. The potential adverse effects from these drugs can be serious. For example, the atypical antipsychotics carry risks of drug-induced diabetes and lipid abnormalities but the

community standard implies that the benefits outweigh the potential risks. Additional study of the risks and benefits in community-treated populations is warranted.

Please contact me if you have additional questions. On a personal note, I congratulate you on bringing your professional training well beyond the individual child to the most vulnerable population among U.S. children today.

Sincerely,

Julie M. Zito, PhD
Professor of Pharmacy and Psychiatry

3

[Responses to Questions for the Record posed by Chairman McDermott to Christopher Bellonci, M.D. and Laurel K. Leslie, M.D., MPH follow:]

Response to Additional Questions
Christopher Bellonci, M.D. and
Laurel K. Leslie, MD, MPH
for the
House Subcommittee on Income Security and Family Support
Representative Jim McDermott, M.D., Chair
June 13th, 2008

"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

[Responses to Questions for the Record posed by Chairman McDermott to Tricia Lea, Ph.D. follow:]

Response to Additional Questions
Tricia Lea, Ph.D.
Director of Medical and Behavioral Services
Tennessee Department of Children's Services

Before the House Subcommittee on Income Security and Family Support
Ways and means Committee
U.S. House of Representatives
Jim McDermott, M.D., Chair

"Managing Psychotropic Medication Usage in a Child Welfare System"

June 10, 2008

The Department of Health and Human Services recently published an interim final rule governing the use of case management services provide by State Medicaid programs. The regulations place new limitations on the use of targeted case management to treat children in he foster care system. What impact would this proposed rule have on State's ability to use psychotropic medications to treat foster children with mental health disorders?

The impact of the proposed rule is significant overall as the State of Tennessee Department of Children's Services is losing approximately $73 million in funding. This is over 10% of our annual budget and is resulting in the loss of over 160 staff positions. While the impact on the ability of Tennessee to use psychotropic medication to treat mental disorders for children in foster care will not be directly affected by the loss of federal funding for targeted case management activities, the overall process of care coordination for children in custody could suffer. The Department of Children's Services will no longer be able to deliver targeted case management services for children in its care and will have to rely on other entities to assist. Children in state custody will still be able to receive health services from contracted providers and from providers in the community but ensuring continuity of care and that the care for these children is coordinated will be more challenging.

What is Tennessee doing to ensure that foster children who are prescribed psychotropic medications are also receiving a continuum of other treatment services to address their mental health needs?

Tennessee is committed to ensuring that foster children who are prescribed psychotropic medications also receive a continuum of other treatment services to address their mental health needs. Several things are in place to help make this happen.

- First of all, this premise is clearly stated in our DCS Medication Monitoring Guidelines: "Medication should be integrated as part of a comprehensive treatment plan that includes: appropriate behavior planning; symptom and

behavior monitoring; communication between the prescribing clinician and the youth, parents, guardian, foster parents, DCS case manager, therapist(s), pediatrician and any other relevant members of the child or youth's treatment team."

- In addition, every case of a child in custody is reviewed on a monthly basis in individual supervision between the Case Managers and their supervisors. Part of this supervision focuses on whether or not children in foster care are receiving all needed treatment services.
- The State of Tennessee Department of Children's Services has recently updated its statewide data system to allow for better documentation and tracking of all health services children receive. This system also allows for the recording and tracking of recommended services and identified service needs, with reports to ensure that these are accomplished.
- Tennessee DCS contracts with provider agencies to deliver services to children in state custody. These contracts delineate scopes of services for every level of care, all of which mandate an array of services to children so that no child is receiving medication as the only intervention.
- Tennessee requires that appropriate informed consent be obtained prior to a child in custody being placed on psychotropic medication. If parental rights have been terminated or if the parents are unavailable, then the DCS Regional Health Unit Nurse provides consent. As part of this consent process, the nurse reviews the child's placement and treatment needs. This review helps ensure that children are receiving all needed treatment services and not just taking medication as the only intervention.

How does Tennessee ensure that children under their supervision receive a medical evaluation and health screening prior to being placed on psychotropic medications?

Tennessee DCS emphasizes the importance of health screening and evaluations for all children in custody. As a child enters the custody of the state, a Well-Being Information and History form is completed with the child's parents/guardians. This form documents initial health history of the child, including allergies, current medications, current and upcoming health services, mental health treatment history, and education status. The DCS Regional Psychologists and Nurses review this information and make recommendations regarding any immediate medical or mental health needs and communicate this information to the DCS Case Manager so that follow-up can occur. These identified service needs are tracked via our child welfare database.

Tennessee also has implemented the use of a standardized assessment process for all children in custody. Through collaboration with a nationally recognized expert, Dr. John S. Lyons, DCS developed an assessment tool derived from the CANS (Child and Adolescent Needs and Strengths). This assessment is completed on all children entering custody and is used to inform the Child and Family Team (CFT) about the needs of the child to assist in placement determinations. The CANS is also completed at any initial, transition or decision making point in the care of a child in custody. Every CANS

assessment is reviewed by the case management supervisor, as well as by clinical staff at the five Centers of Excellence across the state.

The CANS assessment is part of the EPSDT health screening process that all children entering care receive. The CANS looks at psychological symptoms that drive depression and other mental illnesses but also assesses causative factors like trauma that produce a more broad-based approach to treatment rather than just focusing on psychopharmacology.

Additionally, all children entering the custody of the State of Tennessee are required to receive an Early Periodic Screening Diagnosis and Treatment (EPSDT—well-child check up) screening within 30 days of entering custody. These screenings are usually completed at the local health departments, but some children may receive them from their Primary Care Provider if needed. Information obtained from the Well-Being Information and History Form as well as from the CANS assessment is shared with the healthcare professional completing this EPSDT examination. Results of this examination are communicated directly to the DCS regional nurses, who identify and communicate any identified service needs for the children. One result of the CANS and EPSDT screening may be the referral of a child to a local mental health center for a formal mental health evaluation, which could lead to the child receiving therapy services as well as being evaluated for the need for psychotropic medication.

You noted in your testimony that the use of psychotropic medications in Tennessee's foster care system has declined since 2004 when the State first began auditing the use of these drugs. Do you believe that the decline is directly related of the State's increased regulation of these drugs?

I believe that the work that Tennessee DCS has done in developing policies, implementing best practices, and providing ongoing monitoring of the use of psychotropic medications for children in custody has had an effect on the decline in the percentage of custody children being prescribed psychotropic medications. However, I cannot attribute direct causality. By engaging private providers, community partners, and other state agencies in the development and implementation of our policies and monitoring process, DCS has increased the awareness of the issue of psychotropic medication usage with children in the state of Tennessee. This increased focus has led to increased monitoring and oversight by other entities in the state. For example, Tennessee's Medicaid program (TennCare) instituted changes in its formulary that mandated prior authorization anytime more than one antidepressant medication or more than one antipsychotic medication were prescribed for children. Also, Tennessee's Department of Mental Health and Developmental Disabilities promulgated new licensing regulations for residential treatment facilities serving children and youth that required facilities to have nurses administering medication to children and overseeing the medication process. The ongoing monitoring provided by DCS as well as continued advancements in policies and practices related to psychotropic medication usage keeps this issue as a priority focus for all entities serving our children.

[Responses to Questions for the Record posed by the Subcommittee to Misty Stenslie follow:]

June 13, 2008

Dear Chairman McDermott and Members of the Sub-committee,

Thank you again for the opportunity to be part of the recent hearings on the use of psychotropic medications among children in foster care. As a part of the national community of alumni of the foster care system, it is a privilege and an honor to share our voices and our experiences with you in the hope of improving the lives of the ones who come after us in foster care.

I especially want to thank you and Congressman Weller for your particular commitment to being 'the godfathers of all foster children'. I was incredibly moved by your comments at the hearing where you claimed that role to us. For me, and for so many others of the 12 million foster care alumni in the United States, it was a powerful experience to hear you take that place in our lives. The further statement made through House Resolution 1208 (sponsored by Congressman John Lewis) actually has brought a great deal of happiness to the national alumni community, many of us moved to tears at the thought that we were loved, supported, and not forgotten.

Attached you will find responses to the additional questions from the Sub-committee. I hope you will find this information helpful in your work.

Again, thank you for the opportunity to share our experiences and please contact us anytime you are working on issues related to child welfare—our community is highly invested in looking after our younger brothers and sisters in care.

Sincerely,

Misty Stenaha, MSW
Deputy Director
(218)445 6067

RESPONSES TO ADDITIONAL QUESTIONS FROM THE SUBCOMMITTEE ON INCOME SECURITY AND FAMILY SUPPORT RE: THE USE OF PSYCHOTROPIC MEDICATIONS AMONG CHILDREN IN FOSTER CARE

How do youth who age out of the foster care system and who are prescribed psychotropic medications fare once they leave care? Do these youth continue to receive their medications and an appropriate level of medical care to treat their illness once they emancipate from the system?

There have been too few formal studies that look at what happens to young people once they leave the foster care system, particularly as it applies to the use of medication and the access to ongoing health care. The existing evidence, along with the anecdotal evidence within the community of alumni of the system and the professionals who work with us makes clear that this is an area of major concern.

As you heard at the Hearing on May 8, there are extremely high rates of psychotropic medication use with youth in care. For those of us from foster care, we are typically overmedicated during placement and then underinsured upon emancipation. We are in the position to fend for ourselves in regards to accessing—and paying for—ongoing mental health care. Studies of emancipating youth indicate a great risk for unemployment/under employment, which in turn increases the risk that the young person would not have health insurance. Both the overmedication while in care, and the lack of insurance at emancipation can serve as an incentive for the young person to NOT continue to fill medication prescriptions or secure ongoing psychiatric care. A related issue is that there may be dire consequences for sudden withdrawal from certain psychotropic medications.

The Chafee Foster Care Independence Act allows for ongoing health care coverage for youth in transition, but this is only available in some states. In states where the Chafee option is not in place, young people may be able to apply for Medicaid, however, there are often complicated and conflicting rules in place—for instance, in NY, one cannot get Medicaid and be in college at the same time.

There are many layers of consideration in answering this question:

1. Does the young person know about his diagnosed mental health conditions and their treatment? Too often, the answer to this is 'no'. The empowerment of young people in regards to their own lives is absolutely necessary to ensure that they can make informed decisions for themselves upon emancipation.
2. Are there ongoing resources to support the transitioning youth with their mental health care—for instance, is there insurance available? Are there people responsible for ensuring the young person knows how to access those resources? Are there appropriately trained mental health professionals available as service providers?

3. When young people emancipate into 'independent living', they often find their way back to their birth families, which brings the risk of an increased need for mental health support—possibly including medication intervention—at the very time when access to these supports is taken away.

Do most foster parents and other caretakers generally have the resources that are necessary to monitor the health care needs of children placed in their care who have been prescribed these medications?

There is a broad spectrum of caretaker knowledge, skill, and access to adequate and appropriate mental health resources. While there are some foster parents and kinship caregivers who are well-informed advocates for the young people in their homes, many are extremely unprepared, under-trained, and under-supported in this area. Foster parent training and record-keeping generally requires that licensed foster parents follow specific protocol in the administration of prescribed medications, but there is not a typically a requirement beyond this. Given the instability in placements and professionals responsible for individual youth, it is too often the case that no single person in the child's life has either all of the information they need or the authority they need to meaningfully advocate for the mental health needs of youth in care.

Coordination between the mental health and child welfare systems is lacking—and likely needs to be incentivized to find sustainable and significant improvements.

One area of particular concern in the alumni community is the sense that foster children are frequently misdiagnosed with disorders and/or over prescribed medications when their difficulties are really their attempts to adjust to the very abnormal life situations connected to being in foster care. We often see that children are prescribed medications when caretaker-focused behavioral interventions would likely be safer, more effective, and lead to greater long-term benefit. As we've heard from a member of Foster Care Alumni of America, "pills can not take away what happened to me". Ensuring that the training and supervision of caretakers includes support for these behavioral interventions is a top recommendation from people in and from foster care.

Are states effectively addressing the needs of foster youth who suffer from mental health disorders? If not, what are some of the initiatives that states should undertake to effectively meet the needs of these youth?

Youth in foster care have better access to mental health services than youth in kinship care. Ensuring the passage of the Kinship Caregiver's Support act would be an important way to address this disparity.

We are really not meeting the psychotropic needs of youth of color in care – especially for African American youth. There's evidence to suggest they are often misdiagnosed AND overmedicated. From the child and family services reviews, we know that the stability of foster care placements is based on the mental health of the child, and the reverse relationship is true as well. So, to help youth manage their mental health in order to encourage permanency, foster parents and kinship caregivers may need additional skills to help youth be successful. Also, children and youth in care have higher rates of mental illness than the general population. If states were effective at addressing the needs of youth with mental disorders, there wouldn't be such a huge disparity.

Based on the literature, conversations with alumni of the system, and consultation with a number of experts in the field, successful system improvements would require a multi-prong strategy with considerations to cultural responsiveness in each area:

1. Increase interventions to promote & maintain mental health prior to the onset of mental health challenges (prevention);
2. Implement more reliable and valid screening instruments (there is some research that shows this is a missed opportunity in states to catch challenges early);
3. Through training, heighten the awareness of mental health needs among child welfare professionals and stakeholders (birth parents, foster parents, social workers, and administrators) especially regarding psychotropic medication, adolescent development, mental health diagnoses & appropriate treatment modalities;
4. Empowerment training and support with young people that increases the resiliency and coping strategies of youth in foster care (protective factors);
5. Create platforms for sharing and implementing the best evidence-based practices among child welfare and mental health professionals (such as Trauma-Focused Cognitive Behavioral Therapy, Multi-Dimensional Treatment Foster Care etc.); and,
6. Establish medical homes for each young person in foster care where they have consistent caregivers over time, their records are kept in a safe and complete manner, and where they have relationships that are empowering and skills-building for youth as individuals.

[Responses to Questions for the Record posed by Chairman McDermott to Jeffery Thompson, M.D. follow:]

STATE OF WASHINGTON
DEPARTMENT OF SOCIAL AND HEALTH SERVICES
Health and Recovery Services Administration
Olympia, WA 98504-5502

June 13, 2008

The Honorable James McDermott
Chair, Income Security Subcommittee
U.S. House of Representatives
Washington, D.C. 20515

Dear Rep. McDermott:

Here are the answers to the questions you posed following my appearance before your subcommittee on May 8, 2008:

What is Washington State doing to regulate the use and administration of psychotropic medications among children in the foster care system?

Under the legislative direction of HB1088, the Department of Social and Health Services (DSHS) is authorized and funded for five programs that address psychotropic medications:

- An Evidence-Based Practice Center housed at the University of Washington is tasked with defining and communicating evidence-based clinical/prescription strategies.
- A phone-based consultation service pilot is allowing primary care providers to call a pediatric psychiatrist during business hours in two regions of Washington State. The regions were selected because they both have high rates of psychotropic medication prescribing.
- The state has created a second opinion process in which prescribers (Primary Care Provider, Advanced Registered Nurse Practitioner and psychiatrists) who want to exceed age, dose and combination safety thresholds must get a review by a contracted community child and adolescent psychiatrist.
- Statewide provider education programs were created based on Washington State treatment guidelines for appropriate diagnosis and prescribing with psychotropic medications.
- A "wraparound" pilot program is being set up in three areas of the state to service families of children with mental health issues and help design an integrated program.

Washington Medicaid has also formed a Pediatric and Adolescent Mental Health Workgroup made up of community providers, University of Washington experts and agency staff. The workgroup has reviewed

statewide prescribing data and developed a series of safety thresholds that will reduce psychotropic medications in children who are too young, or dosed too much, or using too many.

Finally, we have gone to great lengths to integrate all the above programs and others listed below so foster care children will get the best set of interventions for their unique issues, which may include psychotropic medications.

Washington State recently enacted legislation that would guarantee that children in foster care will have a "medical home." How could this benefit those foster children who are suffering from a mental disorder and are prescribed psychotropic medications?

Washington Medicaid has several pilots using a medical home model for adults. We intend to use that experience in adding that dimension to pediatric and PCP practices for children in foster care

- DSHS is setting up three Centers of Foster Care Health (CFCH) across the state to provide specialized and targeted services to children, their foster care families, and the providers who serve them. The CFCH will provide consultation and coordination for children with complex health issues. In addition, the centers will have capacity to provide primary health care for children who do not have an assigned primary care provider.
- Children's Administration and Medicaid fund and work with a group of five contracted pediatric specialists across the state to assist primary care providers and other providers in facilitating foster care services. (The Children's Administration also has six part-time pediatricians who are DSHS employees.)
- Washington Medicaid recently increased several pediatric service rates by 48 percent, allowing clinics and offices to hire additional staff to assist in coordinating mental health services. We know of several practices that have part-time psychologists on staff, which may be a "best practice" for medical homes where mental health issues are frequent,
- Finally, the Children's Administration funds additional mental health services in Foster Care for special needs programs.

You noted in your testimony that there are a number of best practices being used across the country related to the use of psychotropic medications. Can you please describe some of these?

Several states have instituted treatment guidelines, step therapies and algorithms to assist providers in diagnosing mental issues, in defining followup care and in prescribing psychotropic medications. These states include Texas, New York, Washington and California.

- Washington State and Massachusetts have mental health phone consultation services for providers with questions regarding diagnosis, treatments, and prescribing of psychotropic medications.
- Several states have prior authorization programs with generic field-first processes, step therapies and algorithms for psychotropic medications. One of these states is Ohio, which has a prior authorization program for atypical anti-psychotics.

- Two states require second opinions by an internal or contracted provider when safety thresholds are exceeded with psychotropic medications. These states include Washington and Missouri.
- Finally, Washington State is directing a project called "Kids Getting Anti-Psychotics" that will survey Medicaid programs in up to 20 states -- including California, New York, Pennsylvania and Washington -- on their utilization of psychotropic medications as well as their policies to determine whether there are any "best practices." This project is funded by AHRQ; has sponsorship with National Association of State Medicaid Directors, National Association of State Medicaid Mental Health Directors and the Medicaid Medical Directors Network.

Sincerely,

Jeffery Thompson, M.D.
Chief Medical Officer
Washington Medicaid Program, HRSA, DSHS

cc: Rep. Dickerson

[Submissions for the Record follow:]

American
Academy of
Pediatrics
601 Thirteenth Street, N.W.
Suite 400 North
Washington, DC 20005

News Release

For Release: May 8, 2008
Contact: Macon Morehouse (202-724-3303; mmorehouse@aap.org)

AMERICAN ACADEMY OF PEDIATRICS: FOSTER CHILDREN NEED BETTER COORDINATED HEALTH CARE TO ENSURE APPROPRIATE USE OF PSYCHOTROPIC MEDICATIONS

Washington, D.C.—Children in foster care need coordinated medical care to ensure that any treatment they receive, including psychotropic medications for behavioral and emotional problems, is appropriate and part of a comprehensive health plan for these children, according to testimony provided today by the American Academy of Pediatrics.

"All children, including children in foster care, should have a medical home," said Laurel K. Leslie, MD, MPH, FAAP, a member of the American Academy of Pediatrics' Task Force on Foster Care. "We must ensure that, in removing them from their homes, we improve the health and well-being of foster children and do not further compound their hardship."

Thursday's hearing, before the House Ways and Means Subcommittee on Income Security and Family Support, focused on reports of potential overuse of psychotropic medications among foster children.

Responding to recent analyses and media reports that too many foster children are being prescribed too many psychotropic medications, Leslie said that at this time, "it is difficult to know…whether the use of these medications by children in foster care is appropriate.

"Clearly medication can be helpful to some children," she said, noting it can be a useful part of a more comprehensive treatment strategy for these children. But, Leslie warned, if these children continue to have fractured care—that is, having their care overseen by a revolving door of doctors, caseworkers and other adults—"there is a greater risk that medications will be prescribed to control children's behaviors in the absence of individualized service plans that might offer the greatest chance for success."

Leslie recounted the heartbreaking story of one of her young patients, a 4-year-old whose violent tantrums stabilized when Leslie was able to wean her down to one medication and teach her foster parents effective behavioral interventions. But when the child was placed for adoption in a neighboring county, none of that information was passed on to her new family or doctor. The tantrums returned and the adoption fell apart.

AAP recommendations to protect such children include:

- Provide a medical home—that is a physician who would have an ongoing relationship with the child no matter where he or she is placed—to give foster children "a crucial source of stability, continuity of care and information;"
- Require that children receive a comprehensive physical, developmental and mental health assessment within 30 days of entering state custody;
- Establish a protocol to be followed when prescribing psychotropic medications to foster children;
- Create a system to ensure the effective transfer of physical, developmental and mental health information among professionals who treat foster children;
- Provide comprehensive health insurance to foster children to ensure they receive optimal care;
- Create a system to track the use of psychotropic medications among foster children.

"Our nation has a moral and legal responsibility to provide better care to these most vulnerable children," Leslie said.

###

The American Academy of Pediatrics is an organization of 60,000 primary care pediatricians, pediatric medical subspecialists and pediatric surgical specialists dedicated to the health, safety and well being of infants, children, adolescents and young adults.

ALLIANCE FOR HUMAN RESEARCH PROTECTION

www.ahrp.org http://ahrp.blogspot.com

142 West End Avenue, Suite 28P
New York, NY 10023
212-595-8974

Testimony Submitted for the Record
by
Vera Hassner Sharav

Hearing on the Utilization of Psychotropic Medication for Children in Foster Care

COMMITTEE ON WAYS AND MEANS
SUBCOMMITTEE ON INCOME SECURITY AND FAMILY SUPPORT

May 8, 2008

My name is Vera Hassner Sharav. I am a public advocate for human rights. I head the Alliance for Human Research Protection (AHRP), a not-for-profit national network of lay people and professionals dedicated to advancing responsible and ethical medical research and full disclosure of drug safety information. The AHRP board of directors includes physicians, a pediatrician, child psychiatrists, an ethicist, and professors of social work and education. The AHRP serves as a credible information resource, disseminating daily e-mails called "Infomails" that provide information about medical research ethics and drug safety issues. Of particular concern are vulnerable populations, especially children, the elderly, and people with disabilities.

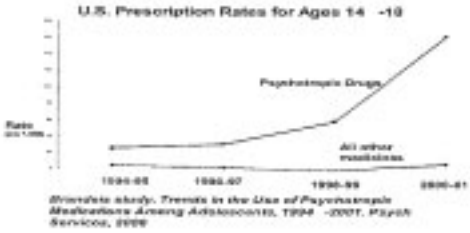
The AHRP Infomails have a wide following among patient advocacy organizations, members of the scientific community, public officials, the media, medical journal editors, and lawyers. The AHRP also maintains the website ahrp.org and a blog at ahrp.blogspot.com.

Our advocacy efforts have been undertaken on behalf of individuals victimized in unethical research experiments or harmed by concealed hazards of prescribed drugs. I have testified before national advisory panels—including the Institute of Medicine, the Office of Human Research Protection, and FDA Advisory Committees. I have served on the Children's Workgroup of the National Human Research Advisory Committee, and made presentations before the American Public Health Association, interns of the National Academy of Science, an ethics forum of the United States military, the New York Bar Association, and numerous

academic forums around the country. I have also authored articles appearing in Ethical Human Psychology and Psychiatry, Journal of Disability Policy Studies, and American Journal of Bioethics.

This committee is to be commended for holding this hearing to help bring to public attention that children are being irresponsibly prescribed drugs that induce debilitating life-shortening diseases.

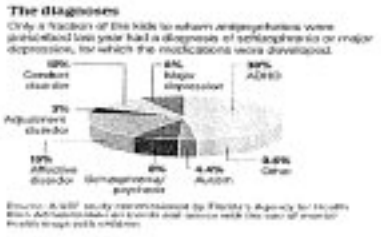
Millions of American Children Are Prescribed Drugs Whose Toxic Hazards Are Undisclosed to Parents



There is no medical explanation for the meteoric rise, beginning in 1994, in the rate of psychotropic drugs prescribed for American children.[1] Studies have found that 1 in 10 teenage boys visiting a doctor leaves with a psychotropic drug prescription—although 1 in 4 "did not have any associated mental health diagnosis." Another survey showed that child psychiatrists prescribe psychotropic drugs to 9 of 10 (91%)[2] children referred to them; **only 9% of children received psychotherapy.**

Worse, a 40-fold increase in prescriptions for the so-called 'atypical' antipsychotic drugs for children has been observed. They are prescribed indiscriminately for off-label behavioral issues—not psychosis for which they were approved for adults.[3]

Rampant Rx of Antipsychotics for US Children



A Vanderbilt University study reported that in 2001-2002, 2.5 million prescriptions were written in the United States for antipsychotics for children—and 53% of these prescriptions were for unapproved, "off-label" indications.[3] The drugs have been called "a chemical sledgehammer." As early as 1998, when children were exposed to Zyprexa in a UCLA study,[4] ALL children suffered adverse effects, none were helped, and the study was halted before 6 weeks.

Until now, the nature and scope of physiological harm and cognitive damage produced by antipsychotics has been denied or trivialized by psychiatry, the pharmaceutical industry, and the FDA. But evidence of profound harm is indisputable and leading scientists acknowledge that antipsychotics are the drugs with the most severely debilitating effects in the psychiatric arsenal. **Antipsychotic drugs disrupt normal functions of the central nervous system which controls all cognitive, emotional and neurological functions and most bodily systems** (including cardiovascular, endocrine, hormonal, pulmonary, gastrointestinal, urinary, and sexual.) As a result, a host of profound metabolic and bodily disturbances, some of which are fatal, may result.

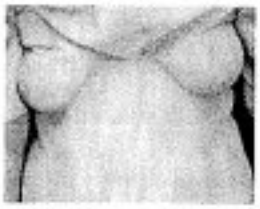
The authoritative government-sponsored CATIE study[5] found that adult patients receiving the antipsychotics Risperdal, Zyprexa, and Seroquel suffered severe adverse effects: 64%-82% dropped out. Risperdal induced "substantial increase in prolactin [hormone] levels" and **Zyprexa caused** "greater increases in weight and glucose and lipid metabolism than the other treatments…effects consistent with the potential development of the metabolic syndrome."

Adding insult to injury, these drugs' benefits have never been clinically demonstrated. They were approved without clear evidence of efficacy, only "proof in principle," that is, evidence of some effect over and above that of placebo. A 15-year follow-up study[6] confirms that even in adults for whom they were approved for psychosis, the drugs only help 5% to recover compared to a 40% recovery rate in those NOT on the drugs. Antipsychotics' labels now carry warnings about acute weight gain (>100 lbs), Type II diabetes, insulin resistance in children, hyperglycemia, liver / metabolic abnormalities, neuroleptic malignant syndrome, cardiovascular complications, stroke, early death in older frail patients…**However, parents are not told about those warnings.**

Pediatric data—from the Johnson & Johnson **Risperdal** trials and Eli Lilly **Zyprexa** trials—show that children and adolescents appear more likely than adults to suffer the most severe, life-threatening drug induced effects:[7] in one study, insulin resistance in all six children on **moderate** or **high** doses of antipsychotics, and in 3 of 5 children on **low** doses was observed. Dr. Mark Riddle, Director of Child Psychiatry at Johns Hopkins stated: "The

insulin resistance seen in these children was greater than what would be expected from weight gain alone, suggesting there is a factor distinct from excess weight that directly induces insulin resistance."

Though not life-threatening, a serious adverse effect—especially in boys—is the risk of developing breasts (gynecomastia). The picture below is of patient "J." Treated with Risperdal, at age 9.5 he developed breasts that required surgical removal at age 14.



A physician reported[8] that **"among 10 psychotic adolescents treated with Risperdal (risperidone) in our unit, we had 3 cases of gynecomastia in 3 male patients with risperidone-induced symptomatic hyperprolactinaemia in adolescents." The risk is not disclosed to parents—evidence comes from plaintiff lawyers.**

Antipsychotic drugs diminish the quality of children's lives, possibly forever. Black Box labels warn about strokes and death in the elderly, but there is no evidence that the same risks of death don't apply in children. The drugs have not been tested long enough in children to detect uncommon but potentially lethal effects.

Two experiments testing Risperdal in children show the range of alarming adverse effects suffered by the children. The reports were published in the *New England Journal of Medicine* (2002)[9] and in *Pediatrics* (2004).[10]

% of Risperdal Adverse Events Over 8 Weeks: Children Aged 5-17 Yrs

Adverse Event	*Risperdal (n= 49)*	*Placebo (n=52)*
Fatigue	59%	27%
Drowsiness	49%	12%
Constipation	29%	12%
Skin irritation	22%	14%
Drooling	27%	6%
Dyskinesia (involuntary movements)	12%	6%
Tremor	14%	2%
Tachycardia	12%	2%
Muscle rigidity	10%	2%
Respiratory infection	10%	4%
Sore throat	10%	2%

From: McCracken et al. (2002). *NEJM* 347:314-321.

% of Risperdal Adverse Events Over 8 Weeks: Children Aged 5-12 Yrs

Adverse Event	*Risperdal (n= 40)*	*Placebo (n=39)*
Somnolence	72.5	7.7
Abdominal pain	20	7.7
Constipation	12.5	2.6
Apathy	12.5	0
Tachycardia	12.5	0
Flu-like symptoms	10	5.1
Fatigue	10	2.6
Weight gain	10	2.6
Tremor	10	0
Involuntary movements	27.5%	12.8

From: Shea et al. (2004). *Pediatrics*, 114:e634-e641.

Responsible voices are raising alarm bells: Dr. Steven Hyman, a neuroscientist and Former NIMH Director: *"We have to realize that we are risking treating children who could turn into obese diabetics with involuntary movements."* **Dr. John March** Chief of Child Psychiatry, Duke University: *"We are using these medications and don't know how they work, if they work, or at what cost.* ***It amounts to a giant experiment with the lives of America's children****… with no data to know whether these drugs are effective or safe over the short term, much less the long term."*

Despite antipsychotics' demonstrably **poor clinical performance**, despite "staggering" adverse effects, that are even worse in children and adolescents, off-label prescriptions for US children / adolescents surged by 82% from 2001 to 2006 (Medco).[11] A 2006 Columbia University study[12] confirms that psychiatrists and other prescribing physicians are disregarding the staggering risks for children. Between 1994-2004, the diagnosis of bipolar disorder in adults increased twofold. By comparison, in children, which had virtually never received such a diagnosis, it increased 40-fold (two thirds of children labeled as "bipolar" are boys). Treatment for such an alleged condition in children is virtually always with antipsychotic or anticonvulsant drugs, usually in combination. "One in five psychiatric visits by young people includes a prescription for antipsychotics—90% were prescribed by psychiatrists." The study's principal investigator, Dr. Mark Olfson, stated: "There is an urgent need to evaluate the drugs' safety and effectiveness."[12]

This is not quite so. The jury is in already, and the drugs are neither safe nor effective. As mentioned, most prescriptions for antipsychotics are for off-label indications, such as ADHD. Yet, a 1998 UCLA Zyprexa trial in children with ADHD had to be suspended because ALL children suffered adverse effects and NO child was helped.[4] If the drugs are so helpful and the risk-to-benefit ratio is acceptable to parents, where are the independent, controlled

studies showing such clear benefits? There are none. Aside from the high profits these drugs bring, their drugs' widespread use among troubled children is, as Texas Comptroller **Carole Keaton Strayhorn**[13] declared: "... a **chemical sledgehammer** that makes children easier to manage."

According to Dr. **Joseph Woolston,** Chief of Child Psychiatry at Yale University, *"Tens of thousands of kids are on random combinations of psychoactive drugs...**We're using them as guinea pigs, and not even keeping track of them.**"* Those at greatest risk of such irresponsible prescribing are children in foster care and those covered by Medicaid.[13]

In 2006, *USA Today* reported that a MEDCO analysis of FDA's voluntary adverse reporting system, MedWatch—which had been mandated by Congress—revealed that 45 children's death reports between 2000-2004 suspected a link to antipsychotics. There were another 41 reports of neuroleptic malignant syndrome—which, if unrecognized or untreated, poses a fatal risk within 24 hours. There were more than 1,328 reports of antipsychotic-linked serious side effects in children. Reports to MedWatch represent a mere fraction—estimated at between 1% and 10%—of the actual adverse effects observed by physicians. Dr. Laughren's response, reported in *USA Today,*[14] speaks for itself: "we haven't been alerted to any particular or unusual concern...The effects (in kids) are similar to what we're seeing in adults."

Despite all these known risks and concerned voices, and the lack of effectiveness of the drugs in adults and children, the FDA approved Risperdal for use in autistic children in October 2006, and Abilify for mania in teens in November 2007 based on a 6-week study. Perhaps, as alarming as the approval of the drug for children, is the process that led to the approval. FDA failed to impose any restrictions on the use of Risperdal for irritability in autistic children—and they conducted their deliberations in secret.

FDA issued the Risperdal marketing license after the company withdrew its application in the UK on June 8, 2006,[15] following the determination by UK Medicines Authority (MHRA) that "safety problems" necessitate strengthened restrictions on conditional approval for: "the short-term treatment of severe aggression and violence whether directed towards self or others in autistic children where available nonpharmacological methods have first been tried and failed." The MHRA further specified monitoring requirements "under black triangle status" and submission of "a full risk management plan with defined milestones for data... which would include a registry of children on risperidone so that the effects of longer term risperidone therapy could be adequately monitored." Shouldn't concerns about the safety of Risperdal andother newer antipsychotics for children have compelled the FDA to be especially conservative and

cautious in the transparency of their proceedings?

On April 29, 2007, Dr. Thomas Laughren overruled FDA's team of safety officers and issued an approvable letter to Eli Lilly for pediatric use of Zyprexa (olanzapine) despite serious concerns about the integrity of the data obtained in Russia.[16] Encouraged by the approval of Risperdal for children, other competitors filed similar applications. On June 9, 2007, Bristol-Myers announced that FDA granted priority review for its application to market Abilify (aripiprazole) for teenagers; on June 21, 2007 FDA issued an approvable letter to Johnson & Johnson to expand the use of Risperdal to teens. On October 20, 2006, the FDA approved AstraZeneca's application for the use of Seroquel® (quietiapine) in the treatment of major depressive episodes associated with bipolar disorder[17]—**despite the fact that a major government review of off-label prescribing of antipsychotics found no evidence demonstrating clinical efficacy for bipolar depression.**[18] Strangely, at the time that the FDA was issuing approvals for use of antipsychotic drugs in children, officials deferred the pediatric study requirements for Abilify until December 2011.

Were these approvals science-based decisions or marketing decisions? Clearly, American children's physical and mental health is being undermined by toxic drugs prescribed by child psychiatrists and other physicians under the undue influence of the pharmaceutical industry.

AHRP's June 27, 2007 letter to FDA Commissioner, Dr. Andrew von Eschenbach, informed him that an AHRP investigation uncovered an apparent conflict of interest by the official in charge of FDA's psychiatric drug approval division. The letter, posted on the AHRP blog, http://www.thejabberwock.org/blog/2/20070627ahrpfda.pdf documents evidence that raises questions about whether Dr. Thomas Laughren, FDA's highest ranking official in charge of psychiatric drug products, has a conflict of interest contributing to the problem of children's exposure to antipsychotics. Dr. Laughren's close ties with industry and his name penned to industry-sponsored consensus conference reports (ghost-written, we should add) may explain the recent inexplicable surge of FDA administrative approvals for the expanded use of toxic antipsychotic drugs for children.

These approvals were determined after secret deliberations—without disclosure of scientific data, without an advisory panel or open public discussion. No credible evidence of a clinical benefit for any childhood "condition" has ever been presented by independent, non-industry generated studies to offset the well-documented evidence of the debilitating and disabling effects produced by these drugs.

References:

[1] Thomas CP, Conrad P, Casler R, Goodman E. Trends in the Use of Psychotropic Medications Among Adolescents, 1994 to 2001, Psychiatric Services 2006 pp. 63-69.

[2] Stubbe, DE, Thomas WJ. A Survey of Early-Career Child and Adolescent Psychiatrists: Professional Activities and Perceptions. Journal of the American Academy of Child & Adolescent Psychiatry 2002;41(2):123-130.

[3] Cooper WO, Arbogast PG, Ding H, Hickson GB, Fuchs DC, Ray WA. Trends in Prescribing of Antipsychotic Medications for US Children. Ambulatory Pediatrics 2006;6:79–83.

[4] Krishnamoorthy J, King BH. Open-label olanzapine treatment in five preadolescent children. Journal of Child and Adolescent Psychopharmacology 1996;8:107-113.

[5] Lieberman JA, Stroup TS, McEvoy JP, Swartz MS, Rosenheck RA, Perkins DO, Keefe RSE, Davis SM, Davis CE, Lebowitz BD, Severe J, Hsiao JK, for the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) Investigators. Effectiveness of Antipsychotic Drugs in Patients with Chronic Schizophrenia. New England Journal of Medicine 2005; 353:1209-1223.

[6] Harrow M, Jobe TH. Factors Involved in Outcome and Recovery in Schizophrenia Patients Not on Antipsychotic Medications: A 15-Year Multifollow-Up Study, The Journal of Nervous and Mental Disease 2007;195(5).

[7] Johns Hopkins Press: http://www.sciencedaily.com/releases/2004/10/041021084911.htm

[8] Holzer L, Eap, CB. Risperidone-induced Symptomatic Hyperprolactinaemia in Adolescents. Journal of Clinical Psychopharmacology 2006;26(2):167-171.

[9] McCracken JT et al. Risperidone in Children with Autism and Serious Behavioral Problems, New England Journal of Medicine 2002:347:314-321.

[10] Shea S, et al. Risperidone in the Treatment of Disruptive Behavioral Symptoms in Children With Autistic and Other Pervasive Developmental Disorders. Pediatrics 2004; 114: e634-e641.

[11] Medco Health Solutions, Inc. Release: New Data: Antipsychotic Drug Use Growing Fastest Among Children 5/2/200: http://www.biospace.com/news_story.aspx?StoryID=172018&full=1

[12] Olfson M, Blanco C, Liu L, Moreno C, Laje G. National trends in the outpatient treatment of children and adolescents with antipsychotic drugs. Archives of General Psychiatry 2006;63(6):679–685.

[13] Keaton-Strayhorn. Forgotten Children: Texas http://www.window.state.tx.us/forgottenchildren/

[14] Elias M. New antipsychotic drugs carry risks for children, USA Today, May 2, 2006: http://ahrp.blogspot.com/2007/08/fda-approval-of-risperdal-for-children.html

[15] Committee on Safety in Medicine. Risperdal Assessment Report. December 10, 2006. http://www.mhra.gov.uk/home/idcplg?IdcService=GET_FILE&dDocName=con2025027&RevisionSelectionMethod=Latest

[16] Thomas P. Laughren, MD. Director, Division of Psychiatry Products. Memorandum. Recommendation for approvable actions for Zyprexa Pediatric Supplements for bipolar disorder (acute mania) and schizophrenia. April 29, 2007.

[17] Thomas P. Laughren, M.D., Director, Division of Psychiatry Products. Letter to Gerald R. L. Limp, Regulatory Affairs Director, AstraZeneca Pharmaceuticals, LP. October 10, 2006: http://www.fda.gov/cder/foi/esum/2007/020592S040S041_Olanzapine_Clinical_BPC

[18] Agency for Healthcare Research Quality (AHRQ). Efficacy and Comparative Effectiveness of Off-Label Use of Atypical Antipsychotics. AHRQ Publication No. 07-EHC003-EF, January 2007.

Thursday, May 08, 2008

This is to be added to the House Ways and Means Committee hearing on " the use of psychotropic drugs for children in the foster care system".

I am a dentist and just got off the phone about a foster child who just became my patient. I was talking to the foster mother to get a corrected list of drugs that her foster child was prescribed.
This is a 10year old boy who has been removed for his mother because of his behavior. This 10 year old patient is on Rxs: Lithium 300 mg 2x/day, Lamictal 23mg /day, and Fluoxetine 20 mg/ day. I was astonished and called the foster mother to verify the medication for accuracy.
. She stated that he is diagnosed as Autism, Mood DX, and ADHD.
If you have given any observation of child behavior, you would have empathy for this case.
During treatment this patient was quiet and well behaved. I assume the standard we want for all children is quiet children who go unnoticed and who have no ambition to get into trouble.
We have an abused child who is angry and acting out to get attention and the doctor gives him psychotropic drugs to handle him. Well this is the wrong correction for the age of child.
Would it not be nice to find any physical maladies he may have and get him treatment if needed? Would it not be nice for a caring person to work with him to develop loving relationships with others and learn that he can help others and in turn he gets help as his reward? Would it not be nice to have a child have projects as a 10 year old level to get in exchange with society?. Would it not be nice to have a sane, well adjusted boy ready for a fruitful future and to produce this in others?
This is absurd for any child to be on this many medications, especially Lithium and Fluoxetine. These are adult medications.

So the answer is drugs to all our unwanted behavioral actions. This child is trapped in drugs forever and never can break free. Look at the adults who are on lithium. They only exist and get worse with time. The fate of many children is in your hands. May god be with you.

Carl Smudde
812 208 3866

Statement of Bruce Lesley

Mr. Chairman, Ranking Member Weller and Members of the House Subcommittee on Income Security and Family Support, thank you for this opportunity to submit comments for the record regarding the May 8, 2008 hearing on the *Utilization of Psychotropic Medication for Children in Foster Care.*

First Focus is a bipartisan advocacy organization committed to making children and their families a priority in federal policy and budget decisions. Our organization is dedicated to the long-term goal of substantially reducing the number of children entering foster care, and working to ensure that our existing system of care protects children and adequately meets the needs of families in the child welfare system. We are especially concerned with ensuring access to appropriate and high-quality health and behavioral healthcare for foster children.

As you know, children who have been abused or neglected often have a range of unique physical and mental health needs far greater than other high-risk populations, including physical disabilities and developmental delays. For instance, foster children are more likely than other Medicaid children to experience emotional and psychological disorders and have more chronic medical problems. In fact, studies suggest that nearly sixty percent of children in foster care experience a chronic medical condition, and one-quarter suffer from three or more chronic health conditions.[1]

[1] Simms, M.D., Dubowitz, H., & Szailagyi, M.A. (2000). Needs of children in the foster care system. *Pediatrics ,* 106 (Supplement), 909–918.

In addition, nearly 70% of children in foster care exhibit moderate to severe mental health problems,[2] and 40% to 60% are diagnosed with at least one psychiatric disorder.[3]

Given that a large number of children in foster care exhibit behavioral problems, it is not all too surprising to see high psychotropic medication usage rates for this population. Studies have shown that kids in foster care are prescribed psychotropic medications at a much higher rate than other children—2 to 3 times higher.[4] Yet youth in foster care are often prescribed two or three medications, the effects of which are not well-known in combination.[5] In fact, in the Medicaid program, children in foster care are much more likely to use psychotropic medications than children who qualify through other aid categories.[6]

A number of states have reported alarmingly high rates of psychotropic medication use for foster children. For instance, in 2004, 37.3% of children in the Texas foster care system were prescribed psychotropic medications.[7] In a random sample of 472 Texas foster children prescribed psychotropic medications, researchers Zito and Safer found that 41.3% received 3 or more different psychotropic medication classes concomitantly, and 15.9% received 4 or more.[8] Furthermore, in 2006, Texas Comptroller for Public Accounts, Carole Keeton Stayhorn issued a comprehensive special report on the treatment of foster children in the state. The report found that psychotropic drugs accounted for well over 76% of all medications prescribed to Texas children in foster care, and a number of the medications prescribed to children in care had shown little to no efficacy in research studies.[9]

Similarly, a California study found that in comparison to a statewide sample of children enrolled in Medicaid, children in foster care were nearly 3 times more likely to receive psychotropic medication. Additionally, their use of methylphenidate (a prescription stimulant commonly used to treat ADD and ADHD) in the past year was twice as high as the national estimates.[10] A study of Iowa's foster care population found that 42% of children in foster care had been prescribed psychotherapeutic medication within the 20 month study period.[11] A 2001 study of a Florida county foster care population found that 23% of the sample was using medication at the time, and, 57% of the sample had multiple prescriptions.[12]

Nationally, we see a similar and all too disturbing trend. Prescriptions for psychotropic medications have increased dramatically for children with behavioral and emotional problems over the last 20 years, a trend evident for younger age groups—even preschoolers.[13,14,15] Many have expressed alarm about the safety, efficacy and long-term consequences of psychotropic medication use in children, especially concerning younger age groups.[16,17,18] Specifically, researchers have voiced concerns about the effects of these medications on the developing brain, and the safety and

---

[1] Kavaler, F. and Swire, M.R. (1983). Foster Child Healthcare. Lexington, MA: Lexington Books; 1983.

[3] dosReis, S., Zito, J.M., Safer, D.J., & Soeken, K.L. (2001). Mental health services for foster care and disabled youth. *American Journal of Public Health* , 91, 1094–1099.

[4] Raghavan, R., Zima, B.T., Anderson, R.M., Leibowitz, A.A., and Schuster, M.A. (2005). Psychotropic medication use in a national probability sample of children in the child welfare system. Journal of Child and Adolescent Psychopharmacology, 15, p. 97–106.

[5] dos Reis, S., Zito, J.M., Safer, J.M., Gardner, D.J., Puccia, J.F., Owens, K.B., and Pamela, L. (2005). Multiple psychotropic medication use for youths: a two-state comparison. Journal of Child and Adolescent Psychopharmacology, 15 (1), p. 68–77.

[6] dosReis, S., Magno Zito, J., Safer, D.J., and Soeken, K.L. (2001). Mental Health Services for Youths in Foster Care and Disabled Youths. American Journal of Public Health, Vol. 91, No. 7.

[7] Zito, J.M., and Safer, D.J. *External Review: A pharmacoepidemiologic analysis of Texas foster care.*

[8] Zito, J.M., and Safer, D.J. *External Review: A pharmacoepidemiologic analysis of Texas foster care.*

[9] Stayhorn, C.K., Texas Comptroller of Public Accounts (2006). *Texas healthcare claims study—special report: Foster children.*

[10] Zima, B.T., Bussing, R., Crecelius, G.M., Kaufman, A., and Belin, T.R. (1999). *Psychotropic medication use among children in foster care: Relationship to severe psychiatric disorder.* American Journal of Public Health, vol. 89, No. 11.

[11] University of Iowa, Public Policy Center (2004). *Health policy brief: A study of Iowa's children in foster care.* No. 4.

[12] Green, D.L., Hawkins, W., and Hawkins, M. (2005). *Medication of children and youth in foster care.* Journal of Social Work in Disability and Rehabilitation.

[13] Zito, J.M., Safer, D.J., dosReis, S., Gardner, J.F., Magder, L., Soeken, K., Boles, M., Lynch, F., and Riddle, M.A. (2003). Psychotropic practice patterns for youth: a 10-year perspective. Archives of Pediatrics & Adolescent Medicine, 157(1): 14–6.

[14] Olfson, M., Marcus, S.C., Weissman, N.M., and Jensen, P.S. (2002). National trends in the use of psychotropic medications by children. Journal of the American Academy of Child and Adolescent Psychiatry. 41(5): 514–21.

effectiveness of medications tested in adults for attenuating behavioral and emotional symptoms in children.

Moreover, between 50% and 75% of psychotropic drugs are not approved for use in children or adolescents.[19] For certain newer classes of drugs, medications have not been licensed for use in children. As a result, providers are often prescribing drugs for children "off-label"—the practice of prescribing meds for use other than the intended indication.

Overmedication for children in foster care is especially a concern given that they often go without adequate healthcare, little monitoring or adjustment of medications, and are offered few alternative treatment options, such as psychotherapy. In fact, a 1995 Government Accountability Office (GAO) report found that despite regulations requiring comprehensive routine healthcare for foster care children, 12 percent receive no routine healthcare and 32 percent have unmet needs.[20] Moreover, in a recent survey, HHS found that more than 30 percent of foster care cases reviewed did not demonstrate the provision of adequate services to children.[21]

A study by Stahmer and colleagues found that although toddlers and preschoolers in child welfare exhibit significant developmental and behavioral needs, few receive services. In fact, in this sample, 41.8% of toddlers and 68.1% of preschoolers exhibited deficits, yet only 22.7% received services.[22] The National Survey of Child & Adolescent Well-being similarly documented that only a quarter of children exhibiting behavioral problems in out-of-home care actually received mental health services within a one-year follow-up period.[23] Comparable findings have been reported by a number of other researchers. For instance, Zima and colleagues (2000) found that 80% of children in a random sample received a psychiatric diagnosis, but only half actually received mental health or special education services.[24]

Moreover, data indicate that psychotropic medication use in foster children is often not appropriately monitored. In a sample of over 1,100 child welfare case files reviewed, more than half of the children were taking at least one psychotropic medication. Sadly, forty-four percent of these children had no record of a medical evaluation and had not received a medical diagnosis. In addition, proper consent for administering medication had been obtained in less than half of the cases.[25]

We have a unique responsibility when it comes to foster children. Children in foster care are legal wards of the state courts or social service agencies, and it is our responsibility to ensure that every child in foster care receives the services, resources, and supports he or she needs. No child should be prescribed psychotropic medication without proper consent. It is critical that a child receives a comprehensive medical evaluation and a medical diagnosis before beginning treatment for a mental or behavioral disorder. Non-pharmacological interventions (e.g. psychotherapy) should be considered as an alternative to psychotropic medication, or if appropriate, in combination with pharmaceutical treatment. Children on psychotropic medications should receive routine follow-up care and their prescription dosages should be regularly monitored and adjusted as appropriate. Any potential side-effects of medications should also be carefully monitored.

A recent GAO report identified over-prescribing of psychotropic medications to foster children as one of the leading issues facing child welfare systems in the coming years.[26] We urge you to request a GAO report on the practice of prescribing psychotropic medications for foster children to determine if these prescriptions are safe and cost effective, and examine the practice of prescribing these medications to young children. The study should also examine the practice of providers prescribing medi-

---

[12] Green, D.L., Hawkins, W., and Hawkins, M. (2005). *Medication of children and youth in foster care.* Journal of Social Work in Disability and Rehabilitation.

[13] Zito, J.M., Safer, D.J., dosReis, S., Gardner, J.F., Magder, L., Soeken, K., Boles, M., Lynch, F., and Riddle, M.A. (2003). Psychotropic practice patterns for youth: a 10-year perspective. Archives of Pediatrics & Adolescent Medicine, 157(1): 14–6.

[14] Olfson, M., Marcus, S.C., Weissman, N.M., and Jensen, P.S. (2002). National trends in the use of psychotropic medications by children. Journal of the American Academy of Child and Adolescent Psychiatry. 41(5): 514–21.

[15] Zito, J.M., Safer, D.J., dosReis, S., Gardner, J.F., Boles, M., and Lynch, F. (2000). Trends in the prescribing of psychotropic medications to preschoolers. JAMA, Vol 283, No. 8.

[16] Vitiello, B. (1998). *Pediatric psychopharmacology and the interaction between drugs and the developing brain.* Can J Psychiatry, 43:582–584.

[17] Jensen, P.S. (1998). *Ethical and pragmatic issues in the use of psychotropic agents in young children.* Can J Psychiatry,43:585–588.

[18] Greenhill, L.L. (1998). *The use of psychotropic medication in preschoolers: indications, safety, and efficacy.* Can J Psychiatry, 43:576–581.

[19] Schirm, E., Tobi, H., de Jong-van den Berg, L.T. (2003) *Risk factors for unlicensed and off-label drug use in children outside the hospital.* Pediatrics, 111(2):291—5.

[20] Foster Care: Health Needs of Many Young Children Are Unknown and Unmet. (May 26,

cations "off-label" and the frequency of prescribing concomitant use of psychotropic medications for this population.

We believe that it is also important to invest in long-term drug safety investigations, provide ongoing clinical monitoring of psychotropic medication use in children, and develop the most appropriate and effective treatments possible for children in foster care.

In closing, Mr. Chairman and Members of the committee, First Focus stands prepared to work with you to ensure that the healthcare needs of foster children are adequately met. We thank you for your leadership in addressing this critical issue, and protecting the health and welfare of our most vulnerable children. We look forward to working with you to ensure better care for our nation's foster children. If you have any additional questions, please contact Shadi Houshyar, VP for child welfare policy at First Focus, at (202) 657–0678.

Sincerely,

Bruce Lesley
President

Statement of Jody Leibmann

Children's Law Center of Los Angeles is a nonprofit public interest legal organization that serves as the voice for abused and neglected youth in the largest foster care system in the nation. Our committed attorneys represent over 25,000 abused and neglected children in the Los Angeles County foster care system.

In addition to our daily advocacy on behalf of each child's individual needs and circumstances, we also take the knowledge and experience gained through our work to advocate for broader system reforms. In this vein, we are heartened and encouraged by the commitment of the Subcommittee on Income Security and Family

Support to improve the lives of the more than half a million children living in the nation's foster care system and specifically to address the deficiencies in the current process regarding foster youth and psychotropic medications.

We hope to draw your attention to three specific issues that we believe require attention and reform:

(1) Improved court oversight of psychotropic medications prescribed to foster youth; (2) Increased youth participation in the decision-making and monitoring process around the use of psychotropic medications; (3) Continuity of mental healthcare; and (4) Improved data collection and tracking.

Introduction

Unfortunately, as a result of the trauma they have experienced, many youth in foster care suffer from mental and emotional problems that can jeopardize their safety, well-being, success in school, and may keep them from finding stable homes. For some of these children, psychotropic medications are a key part of effective mental healthcare. However, careful evaluation and monitoring are essential to ensure that these medications are safe and effective, and that they are not over or under utilized. To achieve this goal, we direct your attention to three main deficiencies in our system as it operates today.

Court Oversight

Since the Court is considered the de facto "parent" of children in the foster care system, judges should have the authority to approve or deny any request by a doctor to have a foster child take a psychotropic medication. In order for the Court to make an informed decision, it is critical that the physician or healthcare professional requesting that the child take psychotropic medications submit a written request to the Court upon having conducted a full examination of the child. After reviewing the request against the Court's broader observations of the child throughout the duration of the case, Courts must then be sureto make orders for any needed therapy or behavioral intervention to run concurrent with the medication, and to put a plan in place to provide for regular monitoring of how well the medication is working—or not working—along with any side effects the youth is experiencing. Finally, the child's social worker should be required to submit regular reports to the court—at a minimum at each statutorily required review hearing—which include regular updates regarding progress in therapy and when the child was last seen by his or her physician so that the court can make orders that are based on updated, accurate information about the child.

Youth Participation

Youth experience a great deal of frustration and anxiety when they are excluded from the decision making process and are not given an opportunity to communicate with the judge or to ask questions. Similarly, both judges and attorneys report that without the child's participation it is difficult to know exactly what is happening in the child's life and how a prescribed medication may be impacting a child's affect or demeanor. It has been our experience that when children and youth are able to attend their hearings they actively ask questions, engage in discussion with the judge, and leave with an understanding of why certain decisions, such as the decision to have a child take a powerful medication, have been made. Further, the Court can learn a great deal by observing in-person changes in the child's demeanor, affect or attitude.

When it comes to psychotropic medications—powerful drugs that often involve serious side effects—it is critical that youth have the opportunity to provide input to the Court. This can best be accomplished by including them in the approval and monitoring process over these medications. While a doctor is the best person to decide which medication may be most appropriate for a child based on his or her medical history, weight, and other physical factors, for many foster youth who often move frequently between placements, the judge may be the only constant and consistent observer of that child's behavior and demeanor. Having the youth come to Court is therefore a critical component of ensuring appropriate Court oversight of the psychotropic medication process.

Youth should also be given age-appropriate information about medications as well as the right to be heard in court and to object to a medication request.

Continuity of Care

Continuity of health and mental healthcare is a major issue for foster children. They often move from home to home, and may see many different doctors and therapists. Some of our clients report that doctors who prescribed their medications spent little time with them and did not know their health history or prior medications. Some clients have been on medications for many years, starting when they were very young, have been prescribed multiple medications at the same time, and have experienced serious side effects.

Issues such as insurance or Medicare coverage determinations should not impact the quality of mental healthcare that foster youth receive. Our recommendation is to implement a system whereby children able to establish trusting relationships with qualified therapist, and that they continue to receive treatment from that therapist for as long as possible. In the event that the youth has to see a different provider, the transition should be done as quickly and smoothly as possible without a delay in treatment. Finally, treatment should continue on a regular, uninterrupted basis until it is no longer necessary. Placement changes and other factors unrelated to mental health should not control or cause arbitrary changes in therapists or treatment plans.

Data Collection

A cohesive system of data collection and tracking is the only way to ensure that true system reform is occurring and that outcomes for our foster youth with regard to psychotropic medications are improving. As such, child welfare agencies should be equipped with the resources to maintain records, optimally via an electronic database, that is regularly updated whenever there is a change in the child's medication or medications and contains information not only regarding all of the medications the child is taking, but also the dosage, target symptoms for which the medications were prescribed, the child's response to each medication, any side effects experienced, and the names and contact information of all treating physicians and mental healthcare providers.

Conclusion

It is our hope that your consideration of our recommendations will lead to concrete reforms so that our juvenile courts have complete and accurate information and are better able to provide needed oversight of the use of psychotropic medications for foster youth; foster youth will have a better understanding and opportunity to participate in important medical decisions that impact their quality of life; and data tracking will lead to a better continuity of mental healthcare for our most vulnerable population.

Statement of Tara Thomson

I am a Mother of four Children and a 71 year old mother that I have to care for without child support. I am on unemployment and it is about to end this month. I am going to lose it all if I can find a decent job. I lost my car and I am bankrupt. I have applied for foodstamps. Please help as we are Americans and why do we have to suffer anymore. I am a good mother and great daughter. I love my country and would like to see our fellow Americans have a better opportunity to make it in a bad economy. Plus would'nt make since to extend as when people do start spending the rebate checks and hopefully by then more jobs will be restored as well as more work needed to fill the demand for employers that have more business due to increased spending. It makes a lot of since we need to help this country get it back together. WE THE PEOPLE right . . . must I say anymore. . . . Give it a chance and I promise you will see a drop in homeless and straving kids and bankruptcy. Please help us. . . .

Respectfully,

Florida residences and Clearwater communities . . .

Tara Thomson and family . . .