



American Academy of Pediatrics



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**Testimony of Laurel K. Leslie, MD MPH FAAP  
on behalf of the American Academy of Pediatrics**

**House Ways and Means Subcommittee on Income Security  
and Family Support**

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

**May 8, 2008**

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Mr. Chairman, I am grateful for the opportunity to testify at this important hearing on serving the health care 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 health care 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 health care 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.

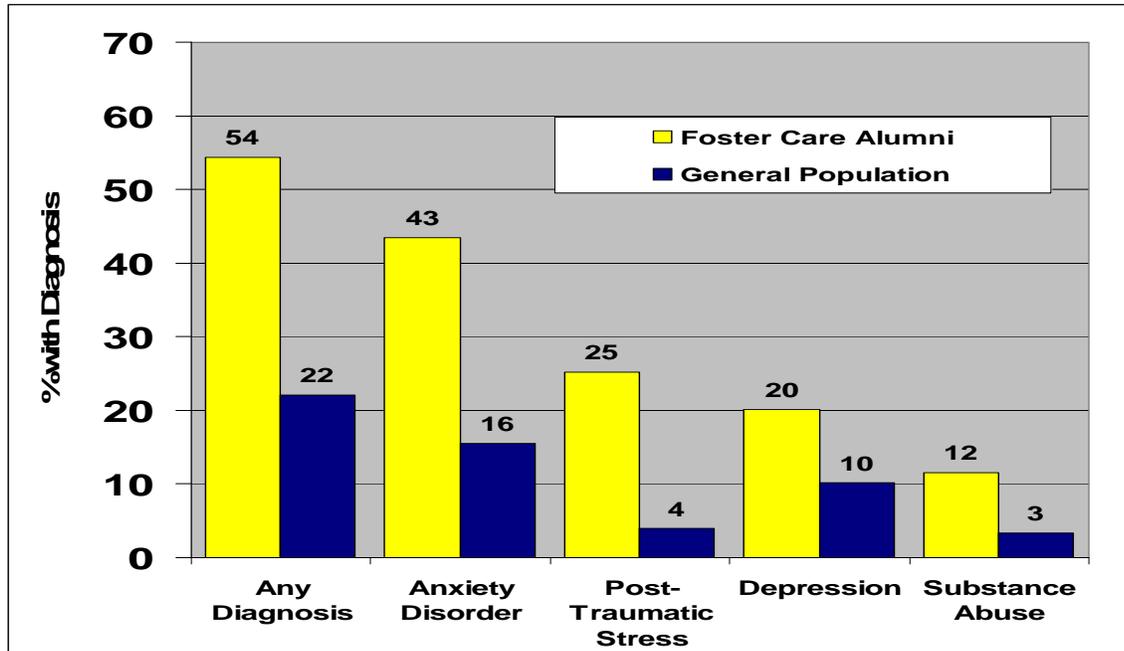
### **Our Nation Must Address the Health Needs of Children in Foster Care**

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

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.<sup>20</sup> 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.<sup>21</sup> (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.<sup>22</sup>

**Figure 1: The Proportion of Adult Alumni from Foster Care with Psychiatric Problems, Compared to Other Young Adults in the General Population**



(Source: Pecora, P.J. et al., (2005). *Improving Family Foster Care: Findings from the Northwest Foster Care Alumni Study*. Seattle, WA: Casey Family Programs.)

The health care 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 health care needs that remained unaddressed while in out-of-home care, to the analysis of the National Survey of Child & Adolescent Well-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.<sup>23</sup>

Children in foster care are at risk for having inadequate health care 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.<sup>24</sup> 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.<sup>25</sup> Each placement change results in a change in caregiver, and possibly a change in social worker and any involved health care 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 health care 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.<sup>26,27</sup> Children in foster care account for 25-41% of expenditures within the Medicaid program despite representing less than 3% of all enrollees.<sup>28,29</sup> 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.<sup>30,31</sup> 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 health care to children in the child welfare system. The last decade has seen the emergence of different models of care, from health care and mental health professionals inserted into child welfare units to screen adequately and provide oversight to the health care

needs of 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.<sup>32</sup>

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,<sup>33,34,35,36,37,38,39</sup> compared with approximately 4% in youth in the general population.<sup>40</sup> 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.<sup>41</sup> Recently published data from Texas suggests that the use of multiple medications concurrently is occurring at high rates among children in foster care.<sup>42</sup> 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.<sup>43</sup> 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 health care and child welfare professionals, as well as the funding streams to support such collaboration.

### **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."<sup>44</sup> 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*.<sup>45</sup>

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 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

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\* Not the child's real name.

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 health care 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.<sup>46</sup> For children in foster care, a medical home can provide a crucial source of stability, continuity of care, and information.<sup>47</sup>
- Comprehensive physical, developmental, and mental health assessments should be given to every child within 30 days of entering state custody.<sup>48</sup> Mental health assessments should also be conducted on any child for whom psychotropic medications are being considered.<sup>49</sup>
- 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

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\* Not the child's real name

foster care. The Academy strongly endorsed the legislation passed by the House to place a moratorium on this rule.

- Financing should reimburse health care professionals for the more complex and lengthy visits that are typical of the foster care population. Financing must also cover the cost of the health care management to ensure that this medically complex population receives appropriate and timely health care services.<sup>50</sup>
- Child welfare agencies and health care 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.<sup>51</sup>
- 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.<sup>52</sup>

### **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.<sup>53</sup>

- Financing should include funds for developing family-based approaches to mental health and developmental services.<sup>54</sup>
- 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.

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