



Testimony of David Rubin, MD MSCE FAAP on behalf of the American Academy of Pediatrics

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

Foster Children and the Health Care System

Department of Federal Affairs The Homer Building 601 Thirteenth Street, N.W. Suite 400 North Washington, D.C. 20005 202-347-8600 / 800-336-5475 / Fax 202-393-6137 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 Dr. David Rubin, and I am proud to speak on behalf of the American Academy of Pediatrics (AAP) and its newly-formed Task Force on Foster Care, of which I am a member. I am an Assistant Professor of Pediatrics at University of Pennsylvania School of Medicine, a Stoneleigh Center Fellow, and a member of the pediatric faculty at the Children's Hospital of Philadelphia, where I also serve as Director of Research and Policy at Safe Place: the Center for Child Protection and Health.

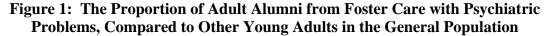
The American Academy of Pediatrics has a deep and abiding interest in the health care provided to children at every stage of the child welfare system. The Academy has published a handbook on the care of foster children, *Fostering Health*, as well as numerous policy statements, clinical guidelines, and 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. The AAP Task Force on Foster Care will examine these issues holistically over the next three years and craft a multi-pronged strategy for the Academy to improve the health of children in foster care.

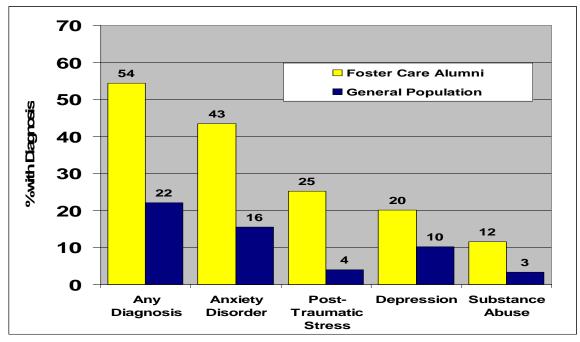
The Magnitude of Need Is Great

At any given point in time, approximately 540,000 children are in foster care, most of whom have been placed there as a result of abuse or neglect at home. Compared with children from the same socioeconomic background, children in foster care have much higher rates of serious emotional and behavioral problems, chronic physical disabilities, birth defects, developmental delays, and poor school achievement.¹ Typically, these conditions are chronic,

under-identified, and under-treated, and they have an ongoing impact on all aspects of their lives, even long after these children and adolescents have left the foster care system.² Some of these conditions are a direct result of the abuse or neglect they have experienced.

Several decades of research has firmly established that the health care needs of children in out-of-home care far exceed other children living in poverty. Nearly half of all children in foster care have chronic medical problems,^{3,4,5,6} and up to 80% have serious emotional problems.^{7,8,9,10,11,12,13,14} It is also clear that many of these needs are longstanding. In 2005, the Northwest Foster Care Alumni Study reviewed the mental health diagnoses of foster care alumni and found they were significantly more likely than the general population to experience mental illness. In that study, foster care alumni 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.¹⁵ (Figure 1)





(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 Foster Children Often Go Unmet

Despite the overwhelming evidence of need, studies consistently demonstrate that many health care needs for children in the foster care system go unmet. Stark evidence that children are not receiving timely services has come from a range of studies, from the 1995 General Accounting Office (GAO) report demonstrating that 1/3 of children had health care needs that remained unaddressed while in out-of-home care, to the recent analysis of the National Survey of Child & Adolescent Well-Being documenting that only a quarter of the children with behavioral problems in out-of-home care received mental health services within a one-year follow-up period.¹⁶

Policymakers may find it difficult to reconcile these statistics 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.^{17,18} Children in foster care account for 25-41% of expenditures within the Medicaid program despite representing less than 3% of all enrollees.^{19,20} The answer to this apparent contradiction lies in recent data from Safe Place and others, which have shown that up to 90% of these costs may be accounted for by 10% of the children.^{21,22} 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.

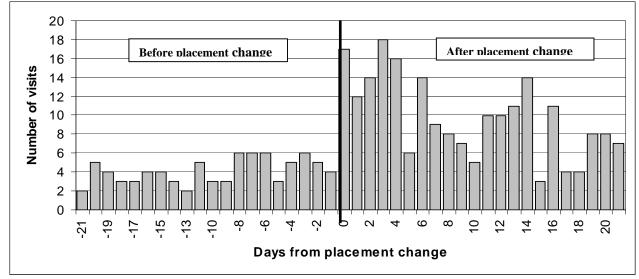
The Urgency of Access to Care

The timeliness of service receipt, particularly for mental health services, strikes at a fundamental principle for providing health care to children in foster care: the urgency of access to care. Removal from their homes and the frequent placement changes that often follow are times of great transition and crisis in the lives of these children. The emotional trauma of failed attachments, the injuries sustained from cumulative maltreatment, and the loss of information about pre-existing health care problems all compound to make these transitions critical emergencies for care coordination and timely service receipt. In 2004, my colleagues and I published a study that examined the records of almost 2400 children over their first year in foster care. Twenty-seven percent of those children had no visits to any doctor's office or clinic during that year. Of particular note, we found a close correlation between placement changes and visits to the emergency department. Of those emergency department visits that occurred within 3 weeks of a placement change, nearly 75% occurred in the days immediately after a placement change, suggesting that placement changes were precipitating, at least in part, these visits.²³ (Figure 2)

Although we could not document all the reasons for these visits in the study, my personal experience has provided vivid examples of how a foster child can easily end up in the emergency department around a placement change. Working in the emergency department (ED) as a physician in training, I saw a child having a seizure because his foster care parent did not know that he was supposed to be receiving an anticonvulsant medication. Other times, I have seen a

child dropped off in the ED by a foster care parent or a grandparent because the behavioral problems had reached a crisis in the home and they could no longer care for the children. In my mind, these ED visits represented our collective failure to these children and to the responsibility we had to stabilize them and move them toward healthy permanency as soon as possible.





From Rubin DM, Alessandrini EA, Feudtner C, Localio AR, Hadley T. Placement changes and emergency department visits in the first year of foster care. *Pediatrics*, 114(3): e354-e360, 2004.

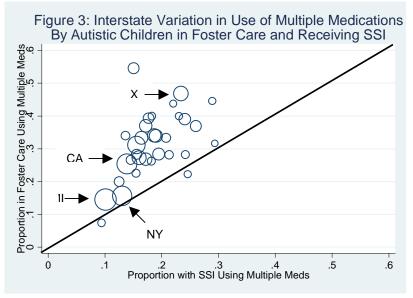
Improvements Are Happening, But They Bring New Challenges

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 result of that legislation was a federal mandate 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 Academy of Child and Adolescent Psychiatry, and the Child Welfare League of America to provide the assessment and referral necessary to meet the goals for timely access to appropriate care. Specialized health programs have also been demonstrated with good outcome data to improve the referral of children to treatment services.²⁴

As we have begun to achieve some success in improving access to care, new challenges have emerged. One that has captured national attention recently has been the concern for the overuse of psychotropic medications by children in foster care. Last year, a report prepared by the GAO 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.²⁵ Soon-to-be-published

data from Safe Place also demonstrates that in the Medicaid program, children in foster care were much more likely to use three or more psychotropic medications than children who qualified through the Supplemental Security Income program. (Figure 3) Those data



* in states with >1000 children, size of circle proportional to sample size

have shown alarming interstate variation in the prescription patterns of psychotropic medications for children 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 combination therapy 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.

Recent legislation passed by Congress has further complicated efforts by states to employ innovative structures for delivering quality health care services to children in foster care. For example, the interdisciplinary programs that are developing on a case-by-case basis throughout the country have largely been the result of self-initiated efforts by child welfare systems to improve access to health care services for children. These efforts have relied heavily on the flexibility afforded by the Medicaid program, particularly in case management and rehabilitative funding, which permits reimbursement for the coordination of health care services within child welfare systems. Currently, up to fifteen cents on every dollar for case management in the Medicaid program is used by child welfare systems.²⁶

Last year, however, the Deficit Reduction Act (DRA) introduced ambiguity into the availability of such funding to support cross-system collaboration by invoking a third party liability standard with respect to the use of case management funds by other public programs. This standard followed a section that had enumerated permissible uses of case management funding for care coordination in child welfare systems. The uncertainty provoked by the DRA's provisions creates an opportunity for the administration to render their own interpretation of the third party liability standard and therefore may endanger marked progress made in the coordination of health services for children in foster care if states are unable to access the federal match for case management services.

Finally, in focusing on the new challenges to providing health services to children in outof-home care, the difficulty in encumbering all of these children with respect to federal policy is a very important subject. Historically, Congress has attempted to exempt foster care families from having to incur extra financial responsibility for children in their care, whether these be exposure to cost sharing or alternative benefit plans that might limit access to needed mental health services. While such an exemption, identified on the basis of Title IV-E funding, is wellintended, it fails to cover all families and children who need such assistance. Children in kinship care, perhaps the most rapidly growing demographic within child welfare systems, rarely benefit from such exemptions. Children in kinship care are already known to access health and mental health services at an alarmingly lower rate than children in foster care,^{27,28} and such exemptions that help only children in non-relative out-of-home foster care are likely to exacerbate this disparity. It also sends a puzzling message that kinship care is not valued to the same degree as other forms of out-of-home foster care. Children in kinship care achieve permanency more quickly than children in non-relative care, preserving a vital link to siblings and family.²⁹ But

grandparents and other relatives need assistance in caring appropriately for their charges. The needs of these populations of children are the same; children should have the same access to care whether they are in foster care or kinship care.

Recommendations

Our nation has a moral 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 health care for children in foster care that include the following:

- All children, including children in foster care, should have a medical home that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.³⁰ For children in foster care, a medical home can provide a crucial source of stability, continuity of care, and information.³¹
- Health care financing for children and adolescents in foster care should support child welfare goals of health, safety, and permanency for children and adolescents.³²
- The health care system must work in partnership with child welfare agencies to ensure that children in foster care receive the full range of preventive and therapeutic services needed and participate in all federal and state entitlement programs for which they are eligible.
- States should ensure that all children entering foster care have an initial physical examination before or soon after placement focused on identifying acute and chronic conditions requiring expedient treatment. All children in foster care should receive

comprehensive physical and mental health and developmental evaluations within one month of placement.³³

- 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.³⁴
- Financing should provide a structure within which accountability occurs, including tracking compliance with health care standards, ensuring the quality of services, ensuring frequent communication among all parties involved in the child's care, promoting fiscal management, and ensuring confidentiality.³⁵
- Congress and the states should establish universal presumed eligibility for Medicaid at entry to foster care, including for children in kinship care. Moreover, insurance coverage should extend automatically beyond foster care for 12 months. All states should extend Medicaid coverage to adolescents exiting foster care to age 21, as provided under the Chafee Foster Care Independence Act.³⁶
- Child welfare agencies and health care providers should develop and implement systems to ensure the efficient transfer of physical and mental health information among professionals who treat children in foster care.³⁷
- Financing should include funds for developing family-based approaches to mental health and developmental services.³⁸
- 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.³⁹

• Congress should support research into foster care health issues, including systems, utilization, services, and quality, to ensure that future improvements are evidence-based.

These recommendations are not new and have been consistently endorsed by the AAP. A persistent challenge, however, is that even if we screen children and develop the evidence base to identify strategies to improve well-being, significant barriers remain for children accessing care. Most notable is the limited availability of providers who are willing to see these children because of the intensiveness of caring for them and often poor reimbursement for services, particularly in mental health. The AAP Task Force on Foster Care is currently considering this barrier and identifying potential strategies to address it. It is expected that some legislative action will be required and might include direction or incentives in developing strategies to improve the reimbursement for physicians who care for foster children and a more consistent message to protect the case management and rehabilitative funding needed for integrated reforms.

Beyond the limited availability of providers, one cannot underestimate the difficulty in providing continuity of care to children who are traversing the system. Certainly, we recognize that paramount to improving well-being is addressing the need for timely permanency for these children, and short of that, to improve placement stability for those children who will remain in foster care for considerable time. Reducing the placement moves that have been associated with poor outcomes will only make our job easier, and Congress could demand better accountability in states' reporting on the movement of their children between placements and the efforts to reduce such movement. Congress could also endorse a more prevention-focused approach that would protect access to services for all families in the child welfare system, be they birth

families, kin families, or foster families. Pending legislation to create kinship navigator programs, for example, are a step in that direction. Finally, Congress must consider that when foster care ends, our commitment to these children does not. Perhaps the greatest transition a child faces is when they age out of foster care. Much as we as parents would extend health coverage to our own children beyond adolescence, our government has a responsibility to extend coverage to our adolescents aging out of foster care if we wish such a transition to be successful. The Chafee Independence Act made this extension voluntary to states; today, the majority of states provide such an extension of coverage to age 21.⁴⁰ Congress could take the next step and make such coverage mandatory.

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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