

American Academy  
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN™

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Testimony of  
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On behalf of the  
**American Academy of Pediatrics**

Before the  
**Institute of Medicine**  
**Committee on Determination of Essential Health Benefits**

Let me begin by thanking the committee for the opportunity you've afforded to the American Academy of Pediatrics to respond to your inquiries regarding our written comments with respect to essential health benefits for children. I understand the committee has asked us to be brief this morning and I intend to respect that request by restricting my remarks to the specific questions raised by the committee. The essential message that I would ask the committee to take away from our responses is this: the health care needs of infants, children, and adolescents are sufficiently distinct from those of adults that a health care system designed for adults will not meet the needs of America's children and should not be imposed upon them. Care for children is different – the number one cause of death in U.S. children is injury, not heart disease or cancer. Obesity is epidemic and children and youth with special health care needs constitute around 15% of the population but 40% of the pediatric "spend." Specific consideration of the unique characteristics of children must and should frame all plans for the design and financing of health care services for this segment of the population. As to the committee's specific inquiries:

**1. State mandate inclusion criteria:**

This portion of our comments was intended to indicate 2 things: a) that the essential package of benefits should be modeled after the comprehensive, fully inclusive set of services provided by the Early and Periodic Screening Diagnosis and Treatment (EPSDT) regimen embodied in Medicaid and the recommendations contained in *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents* as stipulated in Section 2713 of the ACA; and b) that state variation regarding the obligation of insurance companies to cover these services for children should be minimized by mandating state based insurance companies to adhere to this standard.

**2. Medical necessity criteria:**

The AAP's Policy Statement on Contractual Language for Medical Necessity for Children addresses the unique needs of children relative to adults and the unique challenges associated with establishing medical necessity for them. Several points

are worth emphasizing in this regard: 1) medically necessary services includes prevention, diagnosis, treatment, amelioration or palliation of physical, mental, behavioral, genetic or congenital conditions, injuries or disabilities and needs to be age appropriate; and 2) interventions should be evidence based but since large scale randomized controlled trials are significantly less plentiful for children than for adults, when that standard is lacking observational studies, professional standards of care, or consensus of pediatric expert opinion must serve as acceptable substitutes. And again, EPSDT should serve as the standard along with *Bright Futures* recommendations.

### **3. Interpretation of “Essential”**

Children manifest specific characteristics that set them apart from adults. They are uniquely *dependent* upon caregivers to detect medical problems, to access health care, to translate the nature of their symptoms to clinicians, to receive recommendations for care, and to arrange for and monitor ongoing treatments. As infants and children are in constant stages of development, their capabilities, physiology, size, cognitive abilities, judgment, and response to interventions constantly changes and must be continuously monitored to insure that these changes are proceeding within an acceptable trajectory. Most children are healthy so that the epidemiology of disease is different than in adult population.

Nevertheless an important segment of children suffer from chronic conditions that affect their development and that require specific attention to generating, maintaining, and restoring age appropriate functioning to maximize their potential. Finally the economic, ethnic, and racial demographics of the pediatric population in the U.S. put them at risk of adverse outcomes due to existing health care disparities that must not be ignored. To account for these specific differences between children and adults essential services for infants, children and adolescents must include not just preventive care but the full range of diagnostic, therapeutic, and ongoing counseling and monitoring not only of well children but of those patients with

developmental disorders, chronic conditions, behavioral, emotional and learning disabilities.

#### **4. Medical Necessity Definition: Advantages and Disadvantages**

We've mentioned the relative paucity of randomized controlled trials in pediatrics relative to adult medicine. In consideration of experimental or investigational treatments for which no systematized studies have been conducted, the American Academy of Pediatric believes it is imperative that individuals with the requisite knowledge of pediatric medical necessity be included in all coverage or benefit reviews of these types of protocols or interventions. The inescapable actuarial reality is that the benefits of certain interventions in children become manifest only with a significant time lag. This creates a built in incentive for enterprises with limited time horizons to minimize the importance of these interventions placing children at a distinct disadvantage when coverage decisions are being entertained.

Additionally, the IOM Committee requested comments on the following questions:

- How to provide clinical evidence supporting coverage of interventions that meet the needs of the individual child;
- How to incorporate appropriate pediatric medical or surgical specialty or expert opinion or testimony supporting coverage of interventions;
- How to assist families or physicians who wish to appeal medical necessity denials; and,
- How and when coverage decisions are made.

The following are responses to these questions:

- 1) The Academy is the trusted resource for evidence-based and/or informed information on pediatric services. It welcomes the opportunity to work with the IOM , federal agencies, and other key organizations in creating a national framework that defines and describes a pediatric-focused set of criteria and

methods that all insurers can use in applying medical necessity determinations to benefit decisions.

- 2) The Academy would urge that any new structure be required to consult with the Academy whenever a children's benefit issue is raised.
- 3) Pediatricians often become the advocates for parents as they struggle with health plan medical necessity decisions and this collective set of experiences can help inform the IOM and other organizations in shaping a system that reflects and responds to the needs of children.
- 4) The Academy supports the NAIC Model Act related to timely Internal Appeal and External Review of negative medical necessity determinations.

#### **5. Allowable limits**

In recognition of the existence of resource constraints we wished to distinguish between what is necessary to insure the growth and developmental potential of a child from what is redundant, duplicative, inefficient, or unnecessary to achieve that goal. What we wanted to call attention to, however, is that because infants and children are constantly evolving and growing, what might be considered sufficient in an adult context may not be so for a child. The example of the wheelchair was to illustrate that a mobility conveyance suitable for a 2 year old with cerebral palsy will not suffice for that same child when she is eleven. Durable medical equipment is just one such example.

#### **6. Updating Criteria**

We wished to emphasize here that the mechanisms created in the Affordable Care Act to monitor the contents of the essential package should include input from physicians and that the mechanisms for receiving and processing this information should be placed on a schedule of periodic review to insure that they reflect ongoing changes in our understanding of clinical science in a timely manner.