



American Academy of Pediatrics



***TESTIMONY OF
PAUL LIPKIN, MD, FAAP***

on behalf of the

AMERICAN ACADEMY OF PEDIATRICS

before the

SOCIAL SECURITY ADMINISTRATION

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Department of Federal Affairs
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Good morning. I'm Dr. Paul Lipkin, an assistant professor of pediatrics and developmental pediatrician specializing in the care of children with disabilities at the Johns Hopkins University School of Medicine. I am also director of the Center for Development and Learning at the Kennedy Krieger Institute in Baltimore, Maryland, a health care facility and federally-funded University Center for Excellence in Developmental Disabilities (UCEDD) completely dedicated to children with disabilities. I am also immediate past chair of the American Academy of Pediatrics' Council on Children with Disabilities. As someone who takes care of children who are eligible for disability benefits from Social Security on a daily basis, I come today with first hand experience knowing the struggles families can face when accessing benefits, including prolonged waits for determination, information gathering, examination, and uncertainty regarding their child and his future. This is just one more burden for families who must struggle with their child's health, education, and therapy every day.

I look forward to hearing Sissy Langford's experience as a parent in working with her pediatrician and Social Security.

The 60,000 members of the American Academy of Pediatrics are on the front lines with families in diagnosing and treating children with rare diseases and other disabilities that limit their ability to function and develop in the same manner as their peers. AAP has had a long history of identifying and caring for children and youth with special health care needs and of supporting the Supplemental Security Income (SSI) program as a way to help children and families with resources and access to needed medical coverage through Medicaid. We have worked collaboratively with the SSA in developing an information booklet on the program for physicians, released in 2002, and have authored policy statements guiding pediatricians in the referral of children in their care to SSI. (Our last such statement was 2001, with a revision anticipated in the coming year.)

For a family with a child facing the need for increased health care services, frequent medical appointments and tests, prescription medications, medical devices, structured educational services and social supports, the resources provided through the SSI program and its linkage to Medicaid can be an enormous benefit – indeed it can make the difference for families and preserve the ability to remain in care.

The first thing that a child diagnosed with a rare disease or other severe medical condition needs is access to health care in a medical home. The medical home is our approach to primary health care that ensures that children's health care services are comprehensive, high quality and coordinated with community services, and was, in fact, first developed as a model for children like those we are talking about today, children with special health care needs. For all children, but especially children with disabilities, coordinated care that connects them to all necessary health care and community resources through a medical home is essential to maximizing their health and functioning.

The medical home is also an important linkage between families and Social Security. Pediatricians play an important role in identification and encouraging families

to apply for benefits on behalf of their children. They also provide the evidence Social Security needs to determine eligibility and advocate for families during the determination process. They can provide the critical information needed regarding how a child lives every day with his or her rare disorder and or disability. Enhancing the relationship between Social Security and a child's medical home should be an important part of any policy change Social Security is considering to streamline the application process.

Beyond the diseases and conditions already in the published medical criteria used by Social Security to determine eligibility, it is challenging to identify the additional number of children that could be made eligible under a new category of "compassionate allowance." We know that children with special health care needs make up approximately 12.8 percent or 9.4 million of children and youth in the United States. This means that approximately 1 out of every 5 homes in the United States has a child or youth with special health care needs living there. This does not mean that these children are now or will ever be "disabled" according to Social Security's standard of severity and duration.

Similarly, a child diagnosed with a rare disease or disorder may have immediate functional deficits, no functional deficits, or may be a risk of diminishing functional capacity as they age.

The critical issue from the pediatrician's perspective is that processing of an SSI application should be as expeditious as possible, linked closely with the child's medical home. Care should be taken to ensure that only the minimal numbers of duplicate medical appointments or diagnostic tests necessary are required. Children and families with disabilities including rare disorders face an array of complex and demanding network of health care providers and community resources. A medical home can help to coordinate and streamline this to the extent possible -- Social Security should be willing work with the medical home to gather needed medical evidence thereby reducing the burden on children and families.

We are on the cusp of an important new era in health care for children. We now can better identify children with rare disorders with exotic names such as MPS, OTC deficiency, and Gaucher's disease. Thanks to advances in neuroscience and genetics, we can now identify these children earlier and provide new, although expensive, specialized medical treatments, and thus improve their short- and long-term health, social integration, and daily functioning in ways not previously available. We also expect these advances to continue in the coming decades.

The compassionate allowance program being considered should spare these families prolonged uncertainty and unnecessary hardship and delay. We look forward to your consideration of these factors as you proceed and I thank you for the opportunity to address these issues. I look forward to answering any questions you may have.

Paul Lipkin, MD, FAAP