

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™



WRITTEN STATEMENT

**ON BEHALF OF THE AMERICAN ACADEMY OF
PEDIATRICS**

**PRESENTED TO THE INSTITUTE OF MEDICINE
COMMITTEE ON DISABILITY IN AMERICA**

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This statement is submitted on behalf of the American Academy of Pediatrics (AAP), an organization of 60,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists who are dedicated to the health, safety, and well-being of infants, children, adolescents, and young adults. The AAP is grateful for the opportunity to provide written and oral comments to the Committee on Disability in America and would welcome the opportunity to provide further information as the Committee completes its work.

Children with disabilities are often overlooked, and as we provide answers to the specific questions posed by the Committee below, the AAP urges the Committee to include children with disabilities in all aspects of its analysis of disability in America and to prioritize children with disabilities in its recommendations.

1. During the past 15 to 25 years, what positive or negative social, demographic, or policy trends have most affected people with disabilities? What are the most important social, demographic, or policy trends that will affect people with disabilities—positively or negatively—in the next 20 to 30 years?

The AAP recognizes several important trends and changes that have affected children with disabilities over the past 15 to 25 years and will continue to be important in the coming decades:

1. Children and Youth with Special Health Care Needs (CYSHCN) and the Medical Home

As a result of advances in health care delivery and medical technology, children with complex medical problems are living longer, with survival into adulthood. This increased survival has brought with it a population of children with living with chronic medical conditions and related disabilities, commonly referred as children and youth with special health care needs (CYSHCN). As defined by the Maternal Child Health Bureau (MCHB), “children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” The AAP adopted this definition in 1998. Children with special health care needs are now estimated to account for 13% of all children, yet they represent 70% of health care expenditures.

With the increase in this population of children, a greater need for establishment of comprehensive and coordinated health care was identified, with such chronic care management being provided in the “medical home.” The medical home is intended to provide care coordination for the child and family and to foster closer family-professional collaboration to ensure the best services for the child and the family. When CYSHCN are referred for a consultation or additional care, the medical home physician assists CYSHCN and families in communicating clinical issues. The medical home physician evaluates and interprets the consultant’s recommendations for CYSHCN and families.

Further development of and ongoing adoption of the medical home as the model of care will be needed in the coming decades, particularly for CYSHCN. Although the AAP, the MCHB,

and others in the health care community are currently promoting this concept, it is appropriate for all individuals with disabilities, including adults, and merits application to the entire lifespan.

2. CYSHCN and Transition

The numbers of CYSHCN have increased dramatically over the past three decades as a result of improvements in medical care and technology and possibly because of better identification of previously undiagnosed conditions. With longer child survival, one million youth with special health care needs transition to adulthood each year. As a result, the need for systematic transition of health care and related services to adult care providers has emerged. It is important for health care providers to prepare youth with special health care needs to enter the adult-oriented health care system.

Despite some attention to this issue, significant transition needs remain, including development and validation of clinical tools, training in fostering self-help skills, and implementation of system-wide processes that facilitate a planned and coordinated transfer of care to adult-oriented providers. Continuing provider education and system changes relevant to health care transition must occur in both pediatric and adult-oriented settings. Adult providers need to develop facility in treating pediatric conditions. Pediatric providers need to enhance their knowledge of adult health systems. Both must develop skills in fostering health care independence, such as teaching children and youth to be more active in health care decision making. Both must engage in building systems that promote successful transition for all youth, including a smooth transfer of care to adult-oriented health care providers.

Transition to adulthood is one of six priority areas the MCHB has targeted as part of the Healthy People 2010 goals for children with special health care needs. Its 10-year action plan states "All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including health care, work and independence."

The AAP believes that an important next step toward achieving successful transition of all youth to adulthood is promoting collaboration between pediatric and adult-oriented health care providers, both in education and in clinical practice. Continuing medical education and training in adolescent transition issues will need to occur for both pediatric and adult-oriented health care clinicians. Adult clinicians need to develop their expertise in treating pediatric conditions, and pediatric clinicians need to develop their knowledge of adult health and other systems and develop skills in smoothly transferring patients to adult clinicians.

3. The Passage of the Individual with Disabilities Education Act (IDEA)

The passage of IDEA has resulted in expansion of school services to children with disabilities through its key components: 1) identification of children with learning-related problems; 2) evaluation of the health and developmental status of the child with special needs, determining current and future intervention requirements, and developing a plan to match services to needs; 3) provision of services that include educational and related

services; and 4) guaranteed due process. As a result, there is much greater inclusion of children with disabilities in schools. For example, in the 1999-2000 school year, 96% of students with disabilities were served in regular school buildings and nearly half spend 80% of their day in a regular classroom.

4. The Passage of the American with Disabilities Act (ADA)

With the passage of ADA, the needs of children with disabilities are now mandated beyond the classroom and into the community-at-large.

5. Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Services

In the 1980s, AAP led an effort to fashion a Maternal and Child Health Block Grant to plan for and deliver health services for mothers and children. It also spearheaded efforts to revise EPSDT services beyond the emphasis on screening. As a result, new regulations made EPSDT a more comprehensive health program that effectively promotes the concept of a medical home for children.

6. Recognition of Mental Health Issues in Children, Including Those with Childhood Disability

According to the Report of the US Surgeon General, more than 14 million children and adolescents in the United States, or 1 in 5, have a mental health disorder. Mental and behavioral disorders and serious emotional disturbances (SEDs) in children and adolescents can lead to school failure, alcohol or illicit drug use, violence, or suicide (Healthy People 2010). It is anticipated that approximately 70% of children and adolescents that are in need of treatment do not receive mental health services. Although many barriers to obtaining treatment exist, one area that needs to be addressed is the shortage of child mental health professionals. To fill the gaps, pediatricians and other child health professionals are identifying and treating children with SEDs and other mental health disorders. Improved education and training, as well as partnerships with other professionals, will be necessary to make a meaningful difference.

In response to this issue, the AAP, in partnership with the MCHB, has implemented the Pediatrics Collaborative Care (PedsCare) Program, Mental Health Initiative. The purpose of the program is to improve children's mental health by offering pediatricians the tools and support they need to provide community-based, collaborative care.

7. Development and Expansion of Newborn Screening for Disabling Neurogenetic Disorders

Approximately 4 million infants are born in the United States per year, and some form of screening is offered for virtually all infants to detect conditions that threaten their life and long-term health. Newborn screening is a public health activity aimed at the early identification of infants who are affected by certain genetic, metabolic, or infectious conditions. Early identification of these conditions is particularly crucial, because timely

intervention can lead to a significant reduction of morbidity, mortality, and associated disabilities in affected infants.

Newborn screening has been universally accepted for the past three decades. It represented the first population-based genetic screening program, and signaled the integration of genetic testing into public health programs. Today, advances in technology are making possible new forms of newborn screening programs, such as newborn hearing screening. These technologic advances will continue to have a significant effect on the sensitivity, specificity, and scope of newborn screening programs, including newborn heelstick screening.

Challenges are anticipated with technologic advances. It is likely that public pressure to deploy new diagnostic capabilities, such as DNA-based technology, will increase despite limited knowledge of potential risks and benefits. In addition, the ability to detect individuals with conditions for which there is no effective or necessary treatment already exists. Further, as the Human Genome Project is completed, the impetus and opportunity for the transition of genetic technology into practice will increase. These and other challenges will affect not only newborn screening tests, but also the entire newborn screening system, which includes short-term evaluation, diagnosis, treatment/management, and follow-up. Inherent to each of these components is an education process. A national dialogue and process are needed to support state newborn screening systems as they try to keep pace with new technology.

These trends can be expected to continue into the coming decades, with children with more complex medical needs and associated disabilities living longer, expanding the numbers of children with special health care needs. Similarly, today's children will reach adulthood, increasing the number of young adults with disabilities, requiring transition to appropriately trained health care and social service providers and establishment of appropriate medical homes. It is anticipated at this time that there will not be adequate numbers of medical providers for such care because of minimal training for service to the population of adults with childhood-acquired disabilities.

Other important social and demographic trends include decreases in funding of social programs for those with disabilities and their families, continued problems of access to care of those living in remote areas, and an expanding Spanish-speaking population.

2. What are the most important strengths and limitations of federal, state, and local policies and programs that affect the ability of people with disabilities to lead full, productive, and independent lives? With respect to limitations, what changes should be considered? What are the barriers to change, and how might such barriers be reduced?

- Although many programs have been created by the federal, state, and local governments to serve those with disabilities, many mandates exist without adequate funding, agency coordination, and technical assistance, rendering their implementation less than fully effective. This is often apparent with educational services and case management programs.

- Navigating the bureaucracy of government programs is often too complicated for individuals with disabilities and their families, including understanding eligibility and rights of appeal. This is especially true of children and their caregivers for whom bureaucratic complexity can become an absolute barrier to access.
- Transition to work: The current Supplemental Security Income (SSI) and Medicaid/Medicare policies serve as disincentives for older adolescents and adults with disabilities to join the work force. These policies need to change to support these individuals and encourage them to lead full and productive lives in today's society.
- Barriers to accessing community-based services: Individuals with disabilities must navigate several systems of care, each with its own rules, procedures, personnel, and eligibility criteria; services rarely lack a single point of entry; and frequently no single agency is responsible for all services. Balancing patient privacy protections, such as the Health Insurance Portability and Accountability Act (HIPAA), with the need for appropriate information sharing by health care providers adds increasing complexity to providing care.
- Programs designed for “one-stop shopping” should be developed, whereby families can apply at a single point for all eligible services. More uniform eligibility criteria may also prevent silo funding.
- In the health and disability communities, collaboration across disciplines and programs, as achieved successfully in the University Centers for Excellence in Developmental Disabilities (UCEDD) and Leadership Education in Neurodevelopmental Disabilities (LEND) programs, for care and education should be promoted.

3. In the private sector, including private health care providers, what practices most affect the ability of people with disabilities to lead full, productive, and independent lives? What steps should be considered to change harmful practices? What are the barriers to change and how might such barriers be reduced?

- Cap of lifetime limits for those with private health insurance present potential long-term barriers for those with lifelong chronic health conditions and disabilities.
- Private insurance plans currently do not provide reimbursement for many of the services and care management needs of CYSHCN.
- Physician workforce issues affect those with disabilities, particularly with the lack of appropriately trained subspecialists to meet the specialized chronic care needs of this population. Additionally, there is a lack of much-needed care coordination efforts for CYSHCN.

- Parity between somatic health coverage and mental health coverage does not exist, limiting access and availability of mental health services. With the common coexistence of a disability and mental health problems, this presents a special problem for this population.
- Early identification of a developmental disability is performed through developmental surveillance and screening. There is currently limited or no reimbursement for such screening through private health insurance, delaying the identification and treatment of the childhood disability.

4. In the areas of concern to your organization, what are the major gaps in the knowledge base for preventing disabling conditions and promoting the health and well-being of people with disabilities? What are the most important or promising directions for future research?

- Inadequate training exists at all levels of medical education from medical school, through residency, and into continuing medical education around the identification, treatment, and management of children, youth, and adults with special health care needs in a medical home. This also results in an inadequate size of the appropriate health care provider workforce. Improvements in such training will be critical for improving care to these individuals.
- With expanded medical knowledge in the area of genomics and improvements in health care technology, health care providers will be challenged to learn and apply this new information in the clinical arena. With the known high incidence of neurogenetic disorders among those with disabilities, this will have a strong effect on the care of those affected. It also increases the need for public debate about related moral and ethical issues and related public policy.

5. Do you have comments about technology, aging with disability, secondary health conditions, or other elements in the IOM committee's statement of task not covered by your responses to the above questions?

Several areas related to health care technology must be considered:

- Improvements in technology can assist adults with disabilities enter the work force or work from home. Such technology can also better assist parents of children with disabilities to work from home. Consideration must be given to the cost and payment for these technologies.
- Medical technology is resulting in rapid expansion of the field of medical genomics. However, its clinical application and the expense involved in such application remain unknown.
- Improved telecommunication technology creates new challenges in the area of telehealth. With this technology, consideration must be given to issues of licensure, payment, and reimbursement. Implications of telehealth are greatest for those in rural states, particularly in accessing subspecialty care.