



**Statement for the Record
Subcommittee on Wellness and Human Rights
House Committee on Government Reform
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Health Resources and Services Administration

*Activities to Support Persons with Autism Spectrum
Disorders*

Statement of

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I am Dr. Peter C. van Dyck, the Health Resources and Services Administration's (HRSA) Associate Administrator for the Maternal and Child Health Bureau (MCHB). Thank you for the opportunity to testify today about the HRSA programs to assist persons with Autism Spectrum Disorders (ASD).

Since 1912, HRSA programs have provided a foundation and structure for assuring the health of mothers and children. The Maternal and Child Health Bureau (MCHB), one of five Bureaus within HRSA, is charged with promoting and improving the health of our Nation's mothers and children. The legislative authority for our programs is found in title V of the Social Security Act, section 501.

Our mission today is to provide national leadership and to work in partnership with States, communities, public-private partners, and families to strengthen the maternal and child health infrastructure, ensure the availability and use of medical homes, and build knowledge and human resources in order to assure continued improvement in the health, safety, and well-being of mothers and their children. This population includes children with special health care needs, including children with autism, pregnant women, infants, children, adolescents, women of reproductive age and fathers. Section 501 (1) (D) of title V authorizes appropriations "to provide and to promote family-centered, community-based, coordinated care for children with special health care needs and to facilitate the development of community-based systems of services for such children and their families".

By statute, 30% of the Maternal and Child Health Services Block Grant under title V is designated to support programs for children with special health care needs, including children with ASD. All States meet, and most far exceed this requirement. Indiana, for

example, receives a total federal allocation that exceeds \$12 million through the Block Grant and the percentage Indiana earmarks for children with special health care needs (CSHCN) is 33.2%, an amount exceeding \$4 million. Nation-wide, the total federal allocation to the States through the title V Block Grant is approximately \$600 million. The percentage that States earmark for CSHCN is 34.8%, or in excess of \$200 million.

With regard to children with special health care needs, HRSA plays a leadership role in the development and implementation of comprehensive, community-based, family-centered, coordinated systems of care. Children with special health care needs are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and also require health and related services of a type or amount beyond that required by children generally. This includes children with autism. It is estimated that 18 million children in the United States have these special health needs.

HRSA is responsible for developing and implementing a plan to achieve appropriate community-based service systems for children and youth with special health care needs, including those with autism, and their families. This plan is organized around six components. The total fiscal year 2003 budget for this initiative is approximately \$22 million. HRSA provides funding for these six components as follows:

1. Develop inclusive community-based systems of services. HRSA administers a grant program that supports a national network of communities dedicated to developing and improving service integration for young children with special needs. The program also works with the Federal Interagency Coordinating Council (FICC), funded and coordinated by the Department of Education, to identify barriers to coordinated service delivery for CSHCN, including children

with ASD, and to disseminate successful strategies for integrated services. One mechanism for dissemination is a demonstration grant program. Current discretionary grant funding includes grants to States for statewide implementation, a national resource center, and contracts to address multiple issues related to interagency collaboration, community recognition and inter-professional practice. \$1.9 million was funded in 2003.

2. Develop partnerships in all aspects of decision-making. Work in this area has two purposes: (1) to promote family-centered care through collaboration between families with CSHCN and health professionals and policy makers to improve the quality of life for CSHCN, including children with ASD, and their families as well as that of the health care delivery system; and (2) to promote the integration of culturally competent values, practices and policies into existing service systems to address issues related to quality, access, and disparities. Activities are initiated through integrated services leadership, national cooperative agreements, grants, and a variety of local, State, and national partnerships. Current discretionary grant funding includes grants to support family-to-family health information centers, two national resource centers on family/professional partnerships and cultural competence, and issues related to family-centered care for children with special health care needs and their families. \$1.8 million was funded in 2003.
3. Ensure access to comprehensive health care through the Medical Home Program. This program was developed in partnership with the American Academy of Pediatrics (AAP), to improve access to appropriate sources of routine health care and the integration of medical services with the community services required by

CSHCN. It is a collaborative effort among child health professionals, CSHCN, including children with ASD, and their families to assure universal access to medical homes, as well as support systems for the providers who serve these children. Partnerships with families have been established for the planning, development, and oversight of the medical home. Current discretionary grant funding includes grants to States for statewide implementation, a national resource center, and contracts to address multiple issues related to impact, cost and quality. \$3.6 million was funded in 2003; an additional \$1.5 million is planned for 2004 of which \$300,000 will support a resource center on service delivery issues specific to autism.

4. Ensure access to adequate sources of insurance and financing for needed services. Increasingly, CSHCN, including children with ASD, are receiving their care in managed care plans. The unique health problems of these children challenge managed care organizations to provide the full continuum of medical, health, and social services within cost and utilization constraints. This program seeks to address these issues, including the identification of children with special health care needs, quality assurance systems, provider networks, and financing strategies. Current funding totals \$3 million in grants to States for implementation and two national resource centers, one located at the University of Florida and the other located at U.C.L.A., to develop identification and financing strategies with health plans and technical assistance to address unique issues.
5. Provide early and continuous screening, identification and early intervention. Infants and children with high risk health conditions must be identified early in

order to help assure that they and their families receive the care and assistance to prevent future morbidity and promote optimal development. Advances in brain research, the Human Genome Project, and increased effectiveness of early intervention have expanded our capacity to identify children with special health care needs and offer an opportunity for early intervention. Fiscal year 2003 funding at \$10 million includes grants to all States that apply to achieve universal newborn hearing screening and assure linkage to medical home, early intervention and family-to-family support.

6. Assure successful transitions to all aspects of adulthood, including adult health care, work and independence. Children with special health care needs, including children with ASD, as they become adults, must be able to expect good health care, employment with benefits, and independence. Health care services must not only be delivered in a family-centered manner, but must prepare individuals to take charge of their own health care and to lead a productive life as they choose. Current discretionary grant funding includes grants to States for implementation, a national resource center and technical assistance to address special issues such as availability and access to adult health care. \$1.8 million was funded for this effort in 2003.

All State title V programs that receive funding from HRSA must report annually on their activities that address these 6 components to achieve appropriate community-based service systems for children with special health care needs. Other HRSA activities that provide support for children with ASD include:

- In response to the Children's Health Act of 2000, the Interagency Autism Coordinating Committee (IACC) was formed. HRSA serves on the IACC and meets on a semi-annual basis to enhance coordination and effectiveness of autism research and service activities across the federal government and with public stakeholders. One of the main goals of this committee is to promote the integration of autism services throughout the lifespan. Current challenges that are addressed include the issues raised for those living with autism who must confront fragmentation of services, especially at the interface between those services provided through the health, education and social service systems.
- As part of the National Training Curriculum on medical homes, The National Center for Medical Home Initiatives has recently completed a specific module to provide early, developmental and behavioral screening. This Center receives approximately \$700,000 annually to support universal implementation of the medical home concept for children with special health care needs.
- In fiscal year 2003, HRSA awarded a \$1 million grant to the Geisinger Health System in Danville, Pennsylvania to develop a medical home model of care and a related set of tools that will be used to improve early detection, access to diagnostic and evaluation services, and continuity and appropriateness for care for individuals with ASD and their families. Educational tools from this grant will be disseminated to State programs and communities to strengthen and expand integrated community services for children with autism.
- HRSA recently held (October 27-28, 2003) an expert workgroup meeting for families of children with autism. The primary goal of the workgroup was to

- provide us with information on service needs from the families' perspective and to discuss with families potential strategies to address the identified needs. The information obtained from the workgroup meeting will be shared with the IACC.
- HRSA has two long-standing programs that are relevant to the training of health professionals to serve persons with autism and other developmental disabilities. The Leadership Education in Neurodevelopmental Disabilities (LEND) program funds 35 LEND programs across the United States to train individuals from a wide variety of professional disciplines to assume leadership roles and to ensure high levels of clinical competence to improve the health of children who have, or are at risk of developing, neurodevelopmental or other related disabilities such as autism and mental retardation. Interdisciplinary faculty and trainees include audiologists, dentists, health administrators, nurses, nutritionists, occupational therapists, physical therapists, physicians, psychologists, social workers, special education professionals, and speech language pathologists. These programs are currently funded at \$18 million.
 - HRSA funds nine programs at institutions of higher learning to enhance the behavioral, psychosocial and developmental aspects of general pediatric care. These programs support fellows in behavioral pediatrics to help in their development for leadership roles as teachers, researchers, and clinicians. Over the long term, we believe this will aid in the identification and treatment of children with ASD. This program is currently funded at \$1.3 million.
 - HRSA currently funds a study addressing autism entitled, *Early Detection of Autism: Comparison of Three Screening Instruments*. This University of

Connecticut 5-year study involves the comparison of three parent checklist screening instruments for 24-month olds; (1) the Checklist for Autism in Toddlers (CHAT) – parent report section; (2) The Modified Checklist for Autism in Toddlers (M-CHAT); and (3) The Yale Autism/PDD Screener. A projected 120 children will be evaluated at 24 months and again at 42 months. We are confident that this study will provide useful information for support services for children with ASD.

- HRSA funds Health Centers in all States. Once a child, as a primary care patient, presents suspected symptoms of ASD, primary care clinicians seek a specialty referral, generally outside the purview of the health center. The primary care clinician may tap any available resource such as a community mental health center or other federally funded program. The clinic would also be expected to make referrals to and coordinate with individuals responsible for providing services under programs authorized by the Individuals with Disabilities Education Act, including the Grants for Infants and Families program. However, primary care clinicians maintain oversight of the patient with the diagnosis. Although treatment for autism is not under the purview of the health center, the health center will continue to address the primary care needs of the child such as immunizations, screenings and treatment for acute conditions. Also, as a medical home, while the health center may not treat autism, it is responsible for the linkages and ongoing follow-up.

This is a summary of HRSA's activities to provide assistance to persons with autism. These activities adhere to applicable law protecting personal and medical data.

We call upon our partners to join us in a common effort to develop and improve community-based systems of care for all children with special health care needs and their families. It will take the joint efforts of all partners to make a difference for these children and their families. Thank you for the opportunity to appear before the Committee.