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### Senate Select Committee

on

## Autism & Related Disorders



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# Technology & ASD Hearing: Overview and Perspectives

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## An Introduction to Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) and Pervasive Developmental Disorders (PDD) are a group of *behaviorally-defined* severe disorders of brain development affecting one in 110 children and more likely to occur in males than females at a ratio of 4:1. Some of the first signs of autism are unusual emotional behavior, reduced social interest, and poor eye contact that begin to be seen at about one year of age. By three years of age, a child may be given a diagnosis of autism if they display three core behavioral features: (i) impairments in reciprocal social interactions; (ii) abnormal development and use of language; and (iii) repetitive and ritualized behaviors and a narrow range of interests. Early warning signs of autism can now be detected in some children with this disorder during the first year for life. For example, young toddlers who subsequently develop these disorders show demonstrable differences in eye movement tracking, facial pattern recognition, and auditory stimulus responses. Other early warning signs include an absence or lack of "babbling," joyful expressions, single words or short phrases during the second year, and/or a loss of language skills at any age.

The term "Pervasive Developmental Disorders" (PDD), refers to a group of conditions, which in addition to ASD, also includes Asperger's Syndrome: difficulty with social interaction and communication; have a narrow range of interests; but usually average or above average intelligence; develop normally in the areas of language and cognition. Childhood Disintegrative Disorder: a rare condition in which children initially develop normally, but between 2 and 10 years of age there is a loss of social and language skills, muscle coordination and other functions, including bowel and bladder control. Rett's Syndrome: very rare disorder, almost always occurs in girls; loss of many motor or movement skills and poor coordination development.



Pervasive Development Disorder Not Otherwise Specified (PDDNOS): children with significant problems with communication, interactions, and play, but are too social to be considered autistic.

In addition to the core features of autism, common co-morbid neurological disorders also exist, such as epilepsy, anxiety, and sleep disorders. Furthermore, many individuals with autism have severe to moderate delays of cognitive development; and many individuals with autism have troubling gastrointestinal problems and some have dysfunction of their immune system. Although the cause of autism is unknown, researchers believe that there is a strong interaction between genetic and environmental factors. Additionally, there is increasing evidence that ASD is also associated with abnormal connections in brain pathways and brain cell functions. For example, studies of very young children with autism have shown that certain parts of the brain actually mature too fast. All of these data support the conclusion that autism is a brain-based medical disorder.

## **A Wide Range of Interventions & Treatments for ASD**

The field is in a dynamic process of assessing the efficacy of treatments for ASD. There is no known cure for these disorders. Experts agree that treatment should be tailored to address the needs of the individual, and no single intervention is best for every person with ASD. There is also widespread agreement that it is important for children with ASD to receive intensive interventions during early childhood. Research indicates that some interventions have a high degree of efficacy for treating certain symptoms of autism in some children. Our understanding of the effectiveness of interventions will advance through greater use of interventions and the monitoring of outcomes. Efforts are underway to better define effective interventions in the field for ASD and specific program elements of interventions so they can be replicated successfully in the home, at school, and in other community settings.

“Behavioral Intervention Therapy (BIT)” which encompasses a wide modality of interventions and treatments, is currently considered by many researchers, experts, and clinicians to be the most effective form of treatment for children with ASD/PDD. These interventions, which are also frequently identified as *Applied Behavior Analysis (ABA)*, may include an array of established modalities such as “*discrete trial training*,” “*incidental teaching*,” “*pivotal response training*,” and other behavioral programs designed to increase a child’s ability to communicate. Some forms of BIT, such as the “*Denver Early Start Model*,” “*Pivotal Response Therapy*,” “*DIR/Floortime*,” and “*RDI*” stress the importance of developmentally-based therapy that is frequently provided in the child’s natural environment.

According to Dr. Sally Rogers, a world renowned expert at the MIND Institute on the treatment of ASD, “People with autism of all ages and all severity levels can respond well to carefully designed, individualized interventions. This is due to the plasticity of an infant’s brain and the speed with which young children learn, and we see this type of effect in other disorders as well – e.g. deafness, brain injury. To conclude, behavior intervention therapy has applied the science of learning to change behavior. It is successful at treating a variety of medical conditions, and it is the most successful treatment procedure that currently exists for improving the core biological symptoms of ASD, for persons of all ages and all levels of severity.”

## **California Leads in Services for ASD**

In many respects California is well positioned, compared to other states, to meet the service needs of individuals with ASD and their families. In 1971, autism was added to the state’s Lanterman Developmental Disabilities Services Act, and under that law California provides more services to persons with ASD and their families than any other state. In 1974, California enacted legislation to specifically address the educational service needs of children with ASD. No other state has such an extensive infrastructure of community-based programs and services across multiple systems of care available to individuals with ASD and their families. Many dedicated and skilled individuals work within these systems to provide high quality services.

The state developmental services system provides treatment, habilitation, and other services to Californians with developmental disabilities so that they may lead more independent, productive, and integrated lives. Persons with full spectrum autism are eligible for services. Individuals with other forms of ASD are not eligible unless they are assessed to have impairments that constitute a substantial disability. The California Department of Developmental Services contracts with 21 regional centers across the state that coordinate, purchase, and provide community-based services for eligible consumers with developmental disabilities.

Nearly 56,000 Californians with autism are now served through the developmental services system. The system now serves more persons with autism than individuals with a primary diagnosis of cerebral palsy. Roughly 85 percent of the consumers with autism are under age 22, indicating a large wave of persons with autism will enter adulthood beginning in a few years. The number of individuals with autism in the system has more than tripled since 1998 and increased more than twelvefold since 1987. During the past five years, the system experienced an annual net increase of about 3,200 persons with autism. Currently about two-thirds of all new cases entering the regional center system have been diagnosed with ASD.

California's Early Start Program provides service coordination and screening, diagnostic, assessment, and various early intervention services to children from birth up to 36 months of age who have a developmental delay or are at risk of delayed development or a developmental disability and their families. The program is implemented in the community by the regional centers under contract with the California Department of Developmental Services

California's public education system is responsible for the education of children with ASD beginning at age three. Local education agencies, primarily school districts, educate many children with high-functioning ASD through regular education programs. The agencies also provide specialized educational interventions and related services to many children with ASD and other disabilities so they can benefit from a free and appropriate public education. Nearly 60,000 California preschool and school-age children with ASD between the ages of 3 and 22 currently receive special education services from local education agencies. Most school districts have seen a doubling in the number of students with ASD in the past four years alone. During the six years between 2001 and 2007, the number of children with ASD in California's special education system increased by 183 percent, representing an average increase of more than 4,000 children each year. The growth in the special education population with ASD far outpaced the 3.9 percent rate of growth in K-12 enrollment from 2000-01 to 2006-07.

Pediatricians and other health care and mental health care professionals in California have an important role to provide individuals with ASD and their families with a "medical home" that provides and coordinates medical care, including services for the detection and treatment of ASD. Families may obtain assistance in covering the cost of services through their private health insurance coverage.

SB 946 (Steinberg), which was enacted last year, mandates the coverage of behavioral health treatment for ASD by private health plans. In addition, California's mental health parity law of 1999 requires the majority of private health plans and insurers to provide covered individuals with coverage of health care and mental health care services for the diagnosis and medically necessary treatment of ASD. Low-income Californians who are eligible for health care and mental health care coverage through the state's Medi-Cal Program may access services for the diagnosis and medically necessary treatment of ASD through the Medi-Cal Program.

## **ASD: A Public Health Crisis with Significant Challenges for California**

The dramatic growth in the number of children diagnosed with ASD in California and the United States is a public health crisis that must be addressed. Nationally, ASD now

affects an estimated one in every 110 children across all racial, ethnic, and socioeconomic backgrounds. The spectrum of ASD represents the fastest growing serious developmental disability in California and the nation. ASD is more common than childhood cancer, juvenile diabetes, and pediatric AIDS combined. In 2007 the California Legislative Blue Ribbon Commission on Autism estimated that approximately 3,300 to 3,700 of the more than 500,000 children born in California every year would be identified with ASD. Current data now estimate that about 5,000 newborn children in California will be diagnosed with ASD annually.

Although the etiology of ASD is unknown, experts believe there is more than one cause for ASD. Genetics appear to play a role, and there is growing scientific evidence about the role of environmental influences. Research is underway to investigate the extent genetic and environmental factors contribute to ASD. There is also discussion about how much of the growth of ASD is due to an increase in the prevalence of these disorders versus other changes such as better detection techniques and increased awareness, which has broadened the ASD diagnostic category. Notwithstanding this debate, there is no question about the importance of providing services to persons with ASD throughout their lives to mitigate the impacts of ASD.

Prior hearings and reports by the Senate Select Committee on Autism and Related Disorders, as well as the report by the California Legislative Blue Ribbon Commission on Autism, have underscored that significant gaps and issues currently impose serious barriers and challenges to the health and well-being of individuals with ASD and to the support needed by their families. Many of the issues are evident for individuals with ASD and their families across their life span and involve multiple systems of care and can be summarized as follows:

1. There are many children with ASD who have not been screened, assessed, or referred to early intervention services in an appropriate and timely manner. These delays are longer and occur with more frequency in underserved populations and communities.
2. In many communities, public awareness, education, and outreach efforts on ASD programs and services must be intensified and expanded.
3. Many existing systems of care are very complex, and a significant number of families confront major barriers in accessing and navigating programs and services. Transitions across systems and programs are especially difficult for children with ASD at age three. In addition, families report problems accessing ASD services through their health insurance coverage.
4. There are many ASD programs and services that require greater coordination and integration to comprehensively and effectively serve individuals with ASD throughout their life span.

5. Many ASD programs are often categorical in nature; therefore, eligibility criteria and the types of services offered may vary across the state.
6. Many ASD programs and services could be improved by the availability of additional resources, infrastructure, and supports to meet the needs of all individuals with ASD and their families.
7. Many ASD programs and services would benefit from the availability of additional professional and paraprofessional development and training.
8. Some ASD programs that involve public and private sectors require clarification about the roles and responsibilities of each group that provides ASD services.
9. In many regions of the state, some programs, services, and persons who are involved with and respond to specific emergencies, such as medical and public safety responders, require additional information and training on ASD.
10. Many programs that provide services to individuals with ASD and their families could benefit from additional resources and assistance to promote effective strategic planning, communication, and collaboration between service agencies and consumers and their families, and thereby also avoid contentious disputes.
11. Some highly effective programs and services for ASD should be identified, analyzed, evaluated, and replicated throughout the state.
12. Throughout the state, there is an intense need to plan for and address the impending housing, transportation, employment, and educational needs of the "tsunami" of young people with ASD who will soon transition into community settings.

## **Technology: New Tools to Improve Services & Outcomes**

The use and implementation of technology have truly revolutionized the practice of medicine and the healthcare industry. The initial advances in a broad array of sciences enabled dramatic advances such as the practice of open-heart bypass surgery, which is currently among the most frequently performed operations in the United States. The applications of concepts developed through nuclear science and our space travel programs have facilitated incredible advances in medical imaging, neurophysiology, and nano-molecular therapies.

Researchers and scientists are currently utilizing these modern miracles of technology to unravel the mysteries of ASD. Advances in a broad array of disciplines such as genetics, immunology, stem cell research, and environmental sciences are casting new insights into the possible causes and potential new treatments for this disorder.

However, until these definitive treatments can be identified, we must also consider innovative approaches to improve the access, efficacy and outcomes of our current treatments and "safety-net systems."

Therefore, the goals and objectives of this information hearing include the following:

1. To provide an overview of the gaps, challenges and barriers that currently exist in California for individuals with ASD and their families. The FIRST PANEL will include the following participants:
  - a. Drs. Amaral & Hansen, two eminent researchers from the MIND Institute, will provide an overview of the science, clinical manifestations, and treatments of ASD.
  - b. Mr. Rollens, parent of a young adult with ASD and advocate, will provide an overview as to the challenges currently facing a family seeking to access and navigate complex systems of care for ASD.
  - c. Ms. Degadillo, Director of the Department of Developmental Services, will discuss the Lanterman Act and the Regional Center system.
2. To provide an overview of the current use and applications of telehealth and technology. The SECOND PANEL will include the following participants:
  - a. Dr. Nesbitt, a pioneer and world-recognized expert, will discuss the current uses of telehealth within the general practice of medicine.
  - b. Ms. Shin-Lee, a Board Certified Behavior Analyst, will discuss the applications of telehealth in providing home-based behavioral services.
  - c. Dr. Granpeesheh, founder of one of the nation's largest behavior therapy providers, will review her company's use of technology in the professional development and training of her staff.
  - d. Ms. Schetter, Coordinator of ASD Education Initiatives, will review strategies that the MIND Institute is utilizing in providing parent training.
  - e. Mr. Perez, the father of two children who have been diagnosed on the spectrum of autism disorders will discuss his family's experience in a home coordination program delivered through Capitol Autism Services in Sacramento.
3. To provide an overview of legislation, public policies, and public-private partnerships that are focused on improving healthcare outcomes through the use of technology and telehealth. The THIRD PANEL will include the following participants:
  - a. Mr. Gutierrez, Director of the Center for Connected Health Policy, will review the "Telehealth Advancement Act of 2011;" discuss advancing California's leadership in telehealth policy; and evaluate potential cost savings from the expansion of telehealth.
  - b. Ms. Kattlove, Director, Strategic Health Initiatives-The Children's Partnership, will review the role of telehealth in meeting the healthcare needs of California's children.

The hearing will provide ample opportunities for questions, discussions, and interactive conversations among the Committee members and hearing participants.

Additional background information on ASD-related technology and telehealth-related legislation will also be provided.

The hearing, after questions and discussions from the Committee members with the panel participants, will conclude with “public comments” and “closing comments” by the Committee. Please do not hesitate to contact our office if we can provide additional information or assistance.

Respectfully submitted,

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