

Dr. Judith E. Favell,
Chief Executive Officer, AdvoServ,
Executive Director, The Celeste Foundation,
Professional Advisory Board Member, Autism Society of America

Testimony to the
Labor, Health and Human Services, Education and Related Agencies
Subcommittee of the US Senate Appropriations Committee:
Hearing on Combating Autism, April 17, 2007

“Seeking Innovations in Service Delivery”

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Good afternoon, Mr. Chairman and members of this distinguished committee. My name is Dr. Judith Favell. I am CEO of AdvoServ, Executive Director of the Celeste Foundation, and a member of the Professional Advisory Board of the Autism Society of America. I have devoted my nearly 40-year career as a behavior analyst and psychologist to the field of autism and developmental disabilities. During this period I have specialized in the treatment of problem behaviors such as self-injury and aggression which can be associated with autism. And it is on the delivery of such treatment that I focus my comments this afternoon.

While research on the cause and course of autism continues, while its incidence and prevalence is tracked, while basic research on the underlying mechanisms of the disorder is conducted, we cannot lose site of the one and a half million children and adults who are now living with autism, and who need help now. Today they are seeking services that will help them gain the skills and resolve the behavioral challenges that will enable them to enjoy the fullest life possible.

Fortunately, across the last years, major advancements have been made in developing educational and behavioral methods to teach these skills and treat these problems. These methods, tested through decades of scientific research, confirm that children and adults with autism can be helped in meaningful and substantial ways. They can learn to communicate, to care for themselves, to achieve academic and job goals, to reciprocate love with friends and family. Likewise, people experiencing autism need not engage in behavior problems that hurt themselves or harm other people. In short, the treatment and teaching methods designed to help people with autism, notably those based on learning theory and applied behavior analysis, are available today, and each day are becoming more effective as a result of ongoing research. This picture is an optimistic one. However, improving these methods of instruction and treatment is not enough. To impact the lives of people with autism, an equally important issue must be addressed: how to actually make these services available to people who need them.

There exists not just a gap, but a chasm between what we know and what consumers receive. For example, we know that in order to be optimally effective, services should begin as early in the child's life as possible and be intensive, encompassing as many waking hours as possible. Yet families lose precious months or years waiting for services, and then must settle for

a fraction of the help that their child really needs. Too often, these supports are also not available when and where they are needed, for example at bedtime, during meals or in the midst of a weekend meltdown. The needs of people with autism do not conveniently conform to clinic hours or professional appointments. Support may be needed at any time, day or night.

Further, we know that effective services and positive outcomes for people with autism depend on qualified caregivers, and yet despite widespread training of families and service personnel and extensive recruitment of professionals to the field of autism, there remains a serious shortage of qualified professionals to guide the treatment process.

Thus, though we know a great deal about how to help, we must now increase the accessibility and availability of these services, to insure people with autism actually receive that help. If we are to truly meet this ever expanding need, if we are to insure that services are available early, in sufficient amounts, and targeted when and where they are most needed, traditional solutions such as increased training of professionals are simply not enough. To meet the challenge, new service delivery models must be explored.

Our own work at the Celeste Foundation serves as an example of possible new approaches to improving the scope and cost-effectiveness of delivering services to people with autism and their families. With support from the Department of Education we have recently completed a demonstration project investigating the use of telehealth systems to provide professional services directly into homes. In this model, after a brief phase of on-site training, families were linked to professionals by an interactive video system that enabled live training, consultation and support directly into the home when and where it was needed.

Through this telehealth model, families received help in teaching their children and coping with their challenges from professionals located hundreds of miles away, insuring rapid and responsive assistance. This demonstration, utilizing technology developed by the Cnow organization proved to be an extremely reliable and effective vehicle for helping families and their children. Children learned and maintained skills ranging from communication to toilet training, parents reported relief from stress due to the availability of support, and families and professionals alike affirmed the effectiveness and ease of using the system. This very brief news feature provides a more graphic picture of the model and benefit of using telehealth to facilitate services.

(INSERT FILM)

Work such as this by the Celeste Foundation, demonstrating the efficiency and effectiveness of utilizing telehealth technology in service delivery, exemplifies the type of innovative approach we must pursue if we are to truly meet the ever increasing needs of children and adults with autism, bridging the current chasm between knowledge and actual practice, moving services from the paper to the people. I ask all those in a position of influence, including members of this distinguished committee, to support efforts to find innovative solutions to service delivery, so that those living with autism now will receive the best we have to offer, leading to the brightest futures possible.