UNM SCHOOL of MEDICINE

Continuum of Care

An Interview with Javier Aceves, MD, Pediatrician
Medical Director Continuum of Care Project

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Division of Developmental Disabilities
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B.L.: How did you become involved in the fields of chronic illness and developmental disabilities.

J.A.: I was training in pediatrics at the University of Texas, working in the intensive care unit. I began to take care of a 2 year old girl named Latasha who had been burned on 90% of her body.

After a couple of months of working diligently to save her life, we finally sat down to plan her discharge. I realized that, in spite of all the extraordinary measures trying to normalize her life and make her physically appear as normal as possible, we had only been successful in saving her and putting her organs back in place. We were very ill prepared, as was her family, for Latasha to return home. We realized that support systems were not in place for a child with her condition. Also, I was greatly impacted with the realization that Latasha could survive and become a teenager. I knew at that time, she would question her body image and probably question her own identity; finding some difficulty in accepting herself. I felt very uncomfortable and even guilty, realizing that when that time came, probably none of us involved in the treatment team would be around to hold her hand and help her cope with her difficulties.

I realized that I needed to pay more attention to building support systems for children with chronic conditions and disabilities. At the University of Texas in Houston, we started a program called Chronic Health Oriented Services for Ninos. In l990, when I moved to New Mexico, I wanted to be involved in organizing a program that would offer a medical home for children with disabilities, and have an impact in training health professionals. In doing this, I felt great excitement and enthusiasm, but, also found it very hard to have an impact on the lives of more than a few individuals. So, I became involved in an initiative to link the University and the State to create training opportunities as well as a state-wide system of medical supports for persons with disabilities and chronic conditions.

In February of l995, I was appointed Director of the Division of Developmental Disabilities. My hope was to offer my vision to promote prevention and collaboration and to increase the focus on what I believe is the most important thing in medicine, which is to help people who are hurting find meaning and pleasure in their lives. I think we shouldn't necessarily invest all of our energy and resources in trying to normalize what is a broken body or mind. We should also concentrate on creating support systems that will enable people to have meaningful and pleasurable lives.

My message to physicians in the community is that people with disabilities are people with very similar needs as the rest of the population. One does not need to be a super-specialist to serve people with developmental disabilities. There are support systems in place, like the Transdisciplinary Evaluation And Support Clinic, Continuum of Care Project, Adult Special Needs Clinic and Specialized Behavioral Support Services that can assist health professionals to develop appropriate plans of care for people with disabilities.

We also need to address people with disabilities through a person-centered and family-centered approach. Although, as a pediatrician, I usually work through parents to get to the kids, it is important that I always address the individual in a personal and direct manner, emphasizing recognition of their worthiness and their role in society and in our lives.

Through training and further collaboration between the state and university we will be able to better impact the lives of health professionals who will, in turn, go out to different communities and be more sensitive, more competent, and more aware of the needs of people with disabilities. I believe, in the near future, we will see more creative ways of delivering services to people with chronic conditions and disabilities. Managed care is with us and it is possible to provide good quality of care under such a system. This will, however, be a challenge for us all.

B.L.: "What are three things that you feel can most impact the quality of lives of people with developmental disabilities?"

J.A.: We need to ensure health and safety. That should be the very first thing. Therefore we have to improve training to increase the competency of health and other support providers. We need to develop meaningful policies, standards and guidelines for providers.

Secondly, we need to develop an increased awareness and sensitivity regarding what people with disabilities experience. What are the needs of the "whole person" in addition to just the medical needs?

Third, we need to offer more options for recreation, socialization and for paid and volunteer work. If there is one need that prevails among people with disabilities, it is the need for meaningful relationships. Based on our increasing ability to offer health, safety and participation in everyday life to all people with disabilities in a sensitive and comprehensive manner, we will likely have a more positive impact on how individuals develop meaningful and pleasurable lives. This will be the standard by which the success of our society will be evaluated.