

Dealing With Conflict: An Autism Case Study

The State Health Department's Division of Family Health, which houses the Title V MCH and CSHCN programs, has received a demonstration grant from HRSA's Maternal and Child Health Bureau to address autism statewide. This grant will allow the program to pilot a new system of care for children with autism through care coordination, consumer involvement and other mechanisms. Currently, the Title V program pays for evaluation and diagnosis but not treatment services. Pete Carver, Director of the Division of Family Health, anticipates that strengthening the system of care for children with autism will strengthen the system of care for all CSHCN and is promoting an integrated system that fits into the framework of the CSHCN performance measures. He is under instruction from his boss to maximize resources and avoid "silos."

Pete has convened a meeting of the newly formed Autism Coordinating Council—including representatives of Family Voices, the State Autism Society, the state chapter of the American Academy of Pediatrics, and the Special Education Division of the Education Department—to present the goals of the grant and achieve commitment from the participating organizations to help with outreach to families and practitioners.

At the outset of the meeting, Molly Stapleton of the State Autism Society says that she doesn't think it makes sense to move forward in planning without more family representation. She relays her concern that Family Voices will not be able to engage successfully with families affected by autism; many in the autism community are not aware of the CSHCN program or simply don't see how it can meet their needs, typically having stronger ties to Special Education and the Developmental Disabilities Council. She suggests bringing in Libby Cockrell, the parent of a teenager with severe autism and founder of a web-based discussion group on autism issues. Libby is not familiar with the CSHCN program or Family Voices but is well known in the autism community and looked to as a resource by parents across the state.

AAP Chair Nina Prince rolls her eyes when Libby's name comes up and points out that Libby has been a vocal critic of public health programs for "forcing" immunizations and has promulgated through her website the idea that vaccines cause autism. Nina says that she will do what she can to help promote the pilot, but that the involvement of vaccine skeptics in the Coordinating Council will severely tarnish its credibility in the medical community. Molly counters that the effort will fail if it can't engage families, whatever their beliefs. She is concerned about how to convince families of children with autism that a program geared toward children with physical disabilities can meet their needs, especially if it is seen as an offshoot of a system that families view as the problem, not the solution. She herself is not convinced that an integrated system is preferable to a separate system of care for autism, at least in this pilot stage.

Nancy Page of Family Voices mentions that many CSHCN advocates are concerned that the needs of children with autism will overwhelm the already-strained system. Scott Sanchez, head of the Special Education Division, agrees and points out that schools are struggling to keep up with the growing numbers of children diagnosed with autism. He also notes that the Education Department has its own established system for providing services and muses that coordination between the health and education sectors can be "like pulling teeth from a hen."

The meeting ends without achieving any concrete action steps. Members of the Council leave feeling frustrated by the lack of consensus, and Pete wonders how he can reconcile his agency's vision of a single integrated system of care with the picture of separate, entrenched systems that emerged in this meeting.