Dealing Effectively with Coalitions:
An Autism Case Study

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Introduction

As State Maternal and Child Health (MCH) and Children with Special Health Care Needs (CSHCN) leaders develop, implement, and evaluate programs and policies for children and families, they often work with a variety of state and local coalitions and interest groups.

Ideally, coalitions can provide an ear to the ground, providing state programs with valuable feedback and important criticism about the effectiveness of policies and programs. They are also able to publicize policy and programs and reach key (and sometimes hard to identify) consumers.

At the same time, working with coalitions and interest groups can pose challenges for state Title V programs. Coalitions often consist of volunteers and consumers working with limited nonprofit budgets. While some coalitions may receive state funding, they do not operate under the same restrictions as state employees, particularly on budget and advocacy matters. In working with states, coalition members sometimes misunderstand or misinterpret the goals of state programs as well as influence of state Title V staff, setting up unrealistic expectations.

State MCH leaders face a delicate balance of working closely with coalitions, acknowledging and addressing concerns, but not over promising. On the other end, State MCH leaders may not always be able to make valuable contributions because of limited time and may lose credibility with the coalition. The balance is particularly tricky for Title V leadership who often work with families and coalitions representing families but now must do so in an era of scare resources. For these coalitions, who are advocating for families and children, the cause is deeply personal—and egos and feelings can be easily bruised or angered.

To complicate relations, consumers and state government leaders don’t always understand each other. Some in state government view consumers simply as folks who want to complain and criticize, while some consumers are unable to move beyond “telling their own story” to represent a broader array of families and consumers.

This case study uses a real-life scenario—a state program working with a variety of consumer groups to implement a federal autism grant—to present issues and strategies for working effectively with coalitions. The issue of autism was chosen because the greater autism community consists of a variety of organizations often advocating for vastly different strategies and approaches to meeting the needs of children with autism. Unlike other public health issues such as injury prevention where the fundamental problem may be lack of awareness and/or funding, autism presents greater challenges because there is no known cause or cure and no universally accepted treatment. (See the Appendix for more information on autism spectrum disorders as well as background information on federal funding and advocacy for autism.)

In this scenario, the Title V program is looking to establish the agency’s credibility with key coalitions while implementing an autism grant in the face of a severe budget shortfall. Among the issues that the Title V leadership must address are the following:

1) How to build trust and forge an honest working relationship between state government and the grassroots community.
2) How to work with coalitions in the context of bureaucratic limitations, including funding shortfalls.
3) How to reconcile the needs of a specific population (i.e., children with ASD) with broader public health goals.

**Cast of Characters (as they appear):**
Pete Carver ................................................................................ State Title V CSHCN Director
Molly Stapleton .......................................................................... State Autism Society
Nancy Page ............................................................................... Family Voices
Libby Cockrell ............................................................................ Governor’s Appointee
Scott Sanchez ............................................................................ Special Education
Nina Prince ................................................................................ American Academy of Pediatrics

**The Case**
It is late January 2009. Barack Obama has been elected president as the nation’s economy continues its massive freefall. In a mid-size western state, a new governor has just been elected to face major downturns in the construction and housing industry that have fueled recent growth in the state. Representatives from the state budget office are warning of a huge budget shortfall in the coming fiscal year, and a possible 25% across the board cut for state government. A hiring freeze is in effect, and all state Departments are embarking on a head-to-toe analysis of potential reduction areas within their departments.

For the Department of Health’s Division of Family Health, which houses the Title V MCH and CSHCN programs, the budget reductions are particularly disappointing. The Children’s Health Insurance program in the state was recently expanded to cover 300% of the poverty level. The Title V CSHCN program was finally able to get approval to create a full-time state-level family involvement coordinator, but the position is now frozen at the part-time level. The CSHCN program’s recent application for an integrated services grant from the Maternal and Child Health Bureau was not funded. While funding has been tight for several years with the declining funding from the MCH Block Grant, the programs had made inroads in family involvement and in data surveillance. At this point, Title V directors are desperate to maintain their fragile system in spite of such massive reductions.

One potential bright spot is that the Division of Family Health was recently awarded funding to address autism statewide through a state demonstration grant from HRSA’S Maternal and Child Health Bureau (funded under the Combating Autism Act). Dr. Pete Carver, a developmental pediatrician and Director of the CSHCN program wrote the application. The application primarily proposed piloting a new system of care for children with autism through care coordination, consumer involvement and other mechanisms.

When the grant was finally awarded last summer, the State CHSCN program, struggling for several years to address increasing numbers of autism diagnoses, was relieved finally to have an opportunity to address autism within the context of the CSHCN performances measures.

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1 *Family Voices*: Family Voices is a non-profit organization which aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through their national network, Family Voices provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care. Family Voices state coordinators often work closely with state Title V programs.
Currently, the Title V program pays for diagnostic evaluation of autism but not treatment services. All along the thought was that strengthening the system of care for children with autism would strengthen the system of care for all CSHCN through better data and planning. But there is pressure from some in the autism community to develop a separate system for what they see as the unique needs of their children. Long time advocates of the CSHCN program are concerned that the needs of the children with autism and their powerful interest groups will overwhelm the strained system.

**GRANT DEVELOPMENT PROCESS:** In developing the grant proposal, Dr. Carver sought input primarily from the Autism Society and the Family Voices state coordinators. He has relied on the leaders of these two groups, Molly Stapelton and Nancy Page, to provide him candid feedback from the grassroots community about Division proposals and to publicize new initiatives. These initial discussions raised issues that spoke to the distrust between Title V and the autism community as well as between interest groups.

In the preliminary discussions, Molly Stapleton, director of the State Autism Society, spoke of the need for the CHSCN program to include mechanisms in the grant to develop a stronger relationship with the autism community, many of whom are wary or simply unaware of CSHCN program. These parents, she explained, have typically had stronger ties to the Special Education division of the Department of Education and the Developmental Disabilities Council, since the CHSCN program does not pay for services beyond the diagnostic evaluation of autism. Moreover, she argued, the autism community may be confused as to why the funding is coming to the Title V program and may question how the needs of children along the autism disorder spectrum can be met by a program they see as serving children with primarily physical disabilities. As a result of Molly’s concerns, Pete Carver included a small amount of funding for the Autism Society to publicize information about the Autism grant.

The grant development planning also included spirited discussions about the role of Family Voices, with Family Voices coordinator Nancy Page strongly and successfully advocating for a piece of the grant to help fund both a state-level Family Involvement Coordinator and funding for Family Voices to provide leadership training to parents in the autism community. While Family Voices has worked with many parents of children with autism, as well as Molly Stapleton of the Autism Society, the organization is not as familiar to the greater autism community as a whole. In the proposal process, Molly Stapleton candidly stated that some parents might be skeptical about whether Family Voices is able to address the unique needs of families with autism. Moreover, she is concerned that they will question how Nancy Page, whose child is now grown, can provide leadership training when the system of care that she navigated for her son twenty years ago is so radically different.

Pete Carver also invited Scott Sanchez, Director of the Division of Special Education in the State Department of Education, to participate in the grant development process. Even before the housing market collapsed (drastically reducing local funding for education), Special Education was struggling to keep up with the needs of this growing population of school children. Scott has concerns that in some cases, local school districts (particularly in rural areas without enough trained experts) are over-diagnosing autism. Due to the many demands on his time, Scott was able to attend only a brief planning session. At the session, Scott shared his concerns about how autism funds from the health sector could be coordinated with special education efforts in a meaningful way.
A key element of the grant proposal, and the most important to Pete Carver personally, is strengthening the care coordination services available to kids on the autism spectrum. He is excited about the prospect of getting a better handle on the prevalence of autism in the state and approaching the rise in autism cases in a more systematic way. But in the new climate, when care coordination for the existing CSHCN population is threatened, it is unclear how a new system will be developed.

**IMPLEMENTING THE GRANT:** The task that Pete Carver faces now is the difficult one of actually implementing the demonstration under a different governor and a far different budget outlook. His superiors are putting pressure on him to ensure that the autism pilot is coordinated as closely with the Title V program as possible and does not develop a completely separate system.

The first order of business will be to start allocating funding for the various pieces of the demonstration. This will be especially tricky for Pete because his boss, Ellen Richardson, Director of the Family Health Division, has asked him to investigate ways to rearrange the autism grant allocation in order to cover impending cuts to the care coordination program. Pete recognizes that any changes to the grant allocation could jeopardize the grant funding as whole but feels compelled to at least explore the possibility.

Phase I of the demonstration program is slated to begin in one month and includes the first official meeting of the Autism Coordinating Council. Members of this group, some of whom who met unofficially during the grant writing process, include representatives from the state Department of Education’s Division of Special Education, the state Autism Society, Family Voices, and the State Chapter of the American Academy of Pediatrics (AAP). In addition, the Governor has added his own appointee.

In this highly charged atmosphere, Pete must tread carefully but deliberately. He must work to develop this pilot system of care for children with autism while promoting the values of creating a system of care for all children with CHSCN. Pete needs to present himself as an honest broker and convince his partners that the CSHCN program has the capability to meet the needs of all children with special health care needs.

**The Stakeholders**

**AUTISM SOCIETY:** Molly Stapleton, parent of a grown son with autism, has led the State Autism Society for several years. She has had a relationship with the CSHCN program for several years and has often helped Title V leaders navigate the autism community. However, others in the Autism community are wary or simply unaware of the CSHCN program. Molly will have to ensure that she communicates the needs of the autism community and the realities of the funding situation effectively to both families and the state.

**FAMILY VOICES:** Nancy Page, an advocate for children with disabilities, has led Family Voices for more than twenty years. She has been instrumental in helping the CSHCN program revamp its service system and is relied on and trusted to provide honest, candid feedback about how new proposals will play with parents. She is frustrated, however, that the Title V program has yet to create a family involvement coordinator position.
GOVERNOR’S APPOINTEE: The newly elected Governor has asked that Libby Cockrell, the wife of one of his long-time supporters, be added to the Council. Libby is the parent of a teenager with severe autism and operates a web-based discussion group on autism issues. She is skeptical of public health programs because she believes they force immunizations and only support limited behavioral therapies. She is not familiar with the CSHCN program or Family Voices. Libby would like to see a completely separate system of care for children with autism because she is not sure what the CSHCN program can do to address the unique needs of children with autism.

SPECIAL EDUCATION: Scott Sanchez is the Director of the Division of Special Education. The state Department of Education’s Division of Special Education is under tremendous pressure because of the rise in autism cases. He is well acquainted with the autism community and familiar with Pete Carver, but he had limited involvement in the grant proposal process and is not sure what, if any, value the demonstration grant will have for Special Education.

AMERICAN ACADEMY OF PEDIATRICS: Nina Prince is the head of the state chapter of the AAP. She is a developmental pediatrician and a strong advocate of early detection for autism. Nina Prince is generally regarded as an articulate advocate, sensitive to the needs of parents and kids. However, she admits that she has little patience for the growing grassroots movement that links vaccines to autism and the effect it is having on her practice, including a small measles outbreak last winter.

First Meeting
Since officially receiving the grant, the Autism Coordinating Council has had one meeting. The meeting occurred on the same day Pete Carver learned of the Budget Office’s proposed 25 percent budget cut in an emergency Division directors meeting. Because of the emergency meeting, Scott was less prepared than he wanted to be and did not have time to touch base with key participants, such as Nancy Page and Molly Stapleton, prior to the meeting.

In attendance were the following: Molly Stapleton, Pete Carver, Amy Brennan, Libby Cockrell, Scott Sanchez, Nancy Page and Nina Prince. The goal of the meeting was to present the goals of the grant with a focus on the first phase of outreach to recruit families and involve practitioners.

However, as he entered the meeting room, several of the participants were already discussing the proposed 25% cut, news of which had traveled quickly through state government channels. Nancy Page cornered Pete and asked for reassurance about the Family Involvement Coordinator position, which Pete said he hoped to maintain—in a tone unconvincing to Nancy.

Pete tried to refocus the group on the outreach issue, and to ensure that AAP, Special Ed, Family Voices, and the Autism Society each agreed to play a role in promoting the autism pilot and recruiting families.

AAP chair Nina Prince agreed to help promote the pilot through active AAP members throughout the state, but she wondered aloud whether the pilot should include, “families of children with autism who are skeptical of vaccines and therefore public health.”

Nancy Page, flustered and concerned by the impending budget cuts, offered some ideas for outreach through Family Voices grassroots channels, but played an uncharacteristically limited
role in the first meeting. Meanwhile, Molly Stapleton spoke of the need for a coordinated effort that will “engage and not confuse already overwhelmed families.”

Scott Sanchez offered to engage Special Education in outreach, but warned that at the local level, Special Education is already overwhelmed with autism “resources” but not enough autism services.

As the meeting progressed, Libby Cockrell appeared frustrated and confused by the state government acronyms used and openly questioned how “a program for kids with physical disabilities [the CHSCN program] can possibly meet the profound mental, behavioral and educational needs of children with Autism.” She also questioned why Molly Stapleton would not support a separate system of care for the pilot.

The meeting ended abruptly two hours later when Pete’s Blackberry buzzed with news of another emergency budget meeting to attend. Members of the Council left the meeting frustrated by the lack of consensus on outreach—or on the pilot as a whole, for that matter. The meeting was not a complete disaster, but Pete knows he is treading on fragile ground. He also knows that he has some work to do to reassure Nancy Page that he will support the family coordinator position. In addition, Pete recognizes that he cannot completely discount Libby’s concerns about the CSHCN program if he wants to gain stronger support from the Governor for the Title V program as whole. And with Libby questioning the role of the CSHCN program, Pete realizes he must find a way to help Molly Stapleton promote the pilot to the greater autism community.

**What next**
Pete’s boss, Ellen Richardson, and the Governor will be soon be requesting a report on the progress of the Autism Coordinating Council. Pete is torn between his role as an advocate for CSHCN, fiscal pressures, and his recognition of the special needs of the autism community. To weather the coming months and effectively implement the autism pilot, he will need Family Voices and the Autism Community in his corner and is struggling to figure out how to be an effective and honest broker between these groups and others. How can he reassure all participants that this is a collaborative process, but one that must be realistic given budgetary realities?
APPENDIX: AUTISM BACKGROUND

RISE IN AUTISM DIAGNOSES: Autism is often grouped with similar disorders, all of which may be referred to collectively as autism spectrum disorders (ASD). ASD’s are developmental disabilities that “cause substantial impairments in social interaction and communication and the presences of unusual behaviors and interests.” In the past decade, there has been a marked increase in the proportion of children diagnosed with an ASD although it is unclear if the increase is due to better detection or because of a true rise in case numbers. A recent estimate from CDC found that one out of every 150 eight year-old children in communities surveyed has an ASD.² At the local level, the unique ways that autism manifests in each child presents challenges for local providers in identifying and diagnosing autism.

IMPACT ON STATE TITLE V PROGRAMS: Rising numbers of children identified and diagnosed with ASD present major challenges to Title V Maternal and Child Health (MCH) and Children with Special Health Care Needs (CSHCN) programs, particularly in such tough economic times. In addition, Title V partners in other state programs such as Part C and Special Education and Developmental Disabilities are facing considerable pressure.

FEDERAL INITIATIVES: At the federal level, the CDC recently launched a Learn the Signs, Act Early Campaign focusing on helping providers and parents notice the signs and behaviors (as early as 19 months) that may warrant further evaluation for ASD. In 2006, Congress passed the Combating Autism Act for early detection, education and intervention activities. Funds were appropriated for the Act in 2008 through a $20 million reduction in the MCH Services Block Grant. Critics say this categorical approach to funding limits the states’ flexibility in determining and addressing issues for all CSHCN in general, and directs funding to only select states who are awarded state demonstration grants.

AUTISM ADVOCACY: The increase in numbers of children diagnosed with autism has given rise to a number of different interest groups representing different facets and perspectives on autism. The most long-standing (and perhaps most mainstream) organization is the Autism Society of America, founded in 1965. ASA advocates a “living with autism” approach until a cure becomes available. The Autism Research Institute, founded in 1967, is one of the largest “cure-driven” organizations. More recently, in 2005 the former CEO of NBC and his wife founded Autism Speaks. Autism Speaks raise public awareness of the disorder and develops funding for research. Autism Speaks believes that vaccines have been proven to be safe in the vast majority of children but recommends continued research in this area. There are a number of smaller more grassroots organizations such as Generation Rescue that also argue that autism can be cured. Some of these smaller groups advocate controversial treatments and/or argue the vaccine-autism link.

² Autism Information Center (Centers for Disease Control and Prevention): www.cdc.gov/ncbddd/autism/overview.htm