



By Caryn Sullivan

### **An effort to balance competing (and compelling) interests**

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"I would rather be in a gunfight than have to watch my grandson go through what he is going through."

This statement expressed the sentiments of many at a November meeting of the Minnesota Autism Task Force. The state-Senate-appointed panel is investigating the causes and statewide incidence of Autism Spectrum Disorder (ASD) and assessing availability and effectiveness of services for screening, diagnosis and treatment. In 2009, it will make recommendations to the governor and Legislature for improving, coordinating and funding services.

In its first public forum, the task force, composed of a physician, public school representative, service provider and parents, advocates, legislators and designees from the Health, Human Services and Education departments, listened as family members opened their hearts in the packed meeting room. For 2 1/2 hours, young people with ASD, parents and grandparents shared sobering accounts of how they struggle to deal with the condition. Rural families, single parents and Somali immigrants related unique challenges in dealing with similar medical issues and developmental challenges. I left the meeting exhausted by the personal accounts of strangers with whom I share a bond called autism.

The thread in the narrative was ASD's toll on families. Kids are isolated. Parents are fatigued and often divorced. Many are broke. National data show middle-class families spend \$200,000 to support a child until adulthood. In contrast, lifetime support for one with ASD averages \$1.5 million to \$5 million. Recently, the journal Pediatrics reported that roughly 500,000 U. S. children between ages 3 and 17 have both ASD and chronic health issues.

When combined, they cause extraordinary strain on parents' finances, employment and time.

Gov. Tim Pawlenty considers the state's \$5.3 billion deficit "an opportunity to reform, prioritize, streamline and shrink state government." Given ASD parents' difficulties in accessing a complex system, the autism task force's work seems timely and consistent with the governor's goals.

While more than 11,300 ASD students received special education services in 2007, many believe there are considerably more who are unaccounted for. How can government effectively address a need it has not quantified? Is the prevalence of ASD unmeasured or immeasurable? A systematic approach to identifying the number of people with ASD, fundamental to understanding the size and scope of the need, would be an invaluable outcome of the task force's work. With an accurate measure of the

demand for funding and services, the governor and the Legislature could make informed decisions about how to produce the biggest bang for the shrinking buck.

Funding for services is another area in need of reform. Families rely upon third-party payers for most services provided outside of public schools. The scope of covered services varies. Some access private health insurance, while others access state health plans. Most rely upon Medical Assistance, which is funded equally by state and federal dollars and imposes an income-based parental fee.

A few families obtain scarce Consumer Support grants; thousands more are on waiting lists for them. Accessing different systems can be as confusing and exhausting as caring for one with ASD. Cuts in funding will have a dramatic impact on families and providers who rely upon it to meet costly needs.

Recently, federal lawmakers allocated billions to solve marketplace crises that seemed to have materialized overnight. Many private citizens ask, "Where's my bailout?" but the truth is, families and policymakers alike must accept that the Treasury can print only so much money to avoid painful decisions. We all must be realistic about government's limitations — and creative and efficient so we can garner more from less.

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