



By Caryn Sullivan

IN THE AUTISM WORLD, IT'S TIME FOR A COHESIVE MESSAGE FROM A COHESIVE COALITION

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Recently, national radio talk show host Michael Savage caused an uproar when he called autism a 'racket,' the 'illness du jour' and a 'fraud.' Parents and professionals reacted by suggesting that he be ignored and that he be fired. I was not surprised by the conflicting reactions. This is, after all, the autism world, in which there is little consensus. It's regrettable that Savage, with more than 8 million listeners, squandered the chance to generate meaningful discussion about how to help those with autism spectrum disorder (ASD). If I'd had the microphone, this is what I would have said:

I'm concerned about how our state is addressing the needs of thousands of people with ASD. I'm troubled by the ongoing disagreement within the autism world (due to lack of irrefutable explanations for the cause of the condition and universally accepted treatment protocols for it) and that disagreements often become personal, not philosophical. I'm frustrated that there are significant issues that need to be addressed by our leaders but there is no cohesive message being delivered to them and no visible effort to address them comprehensively and expeditiously.

I am grateful for the many professionals who are doing difficult and important work. Researchers are investigating the cause of and treatments for ASD, and professionals are providing diagnostic, therapeutic, educational, advocacy, transition, housing and medical services. Yet there seems to be no coordinated approach to optimize their efforts. Each group is driven by its particular mission or methodology, subject to financial limitations. There are increasingly more organizations vying for limited philanthropic and government support.

The needs of one with ASD are comprehensive and enduring. At the outset, parents receive a diagnosis with no clear game plan for addressing their child's long-term needs. Understanding how to navigate the complicated social services system is difficult for families already dealing with social, communication, medical and behavioral challenges. County programs are not uniformly available and are subject to budgetary changes. Many people with ASD need 24/7 supervision. Parents need support at home and respite services to keep their health and families intact.

The special education system has become a quandary for administrators encumbered by state and federal guidelines. Educators must implement the educational plans of ASD students who share the same diagnosis but have different needs. Savvy parents may obtain more services for their children than those who are less tenacious or astute.

As youngsters with ASD become adults, they need coaching on how to hold jobs, assume responsibility for their daily needs, and manage their own medical issues. After

years of working to create independence, many may not be able to live alone. Creative, affordable housing solutions are necessary if parents are not going to lodge their ASD children forever.

Inevitably, the Minnesota Legislature will be called upon to mandate insurance coverage for autism-related services. If enacted, such legislation will impact families and professionals, as well as taxpayers and policyholders.

With the ASD numbers increasing from 1 in 10,000 when our son was diagnosed in 1993 to 1 in 150 today, Minnesota's finite resources will be drained if they are not used efficiently and strategically. To effectively address these challenges, it's imperative that Minnesotans form an ASD coalition to advocate for this constituency with one strong voice and to persist in shaping the discussion and outcomes.

Composed of parents and professionals from public and private entities, a coalition could succeed if members acknowledge, then table, their disagreements and focus on mutually agreeable principles. Areas of discussion should include how to:

- Sustain or increase funding for research into etiology and treatments
- Provide both a diagnosis and a substantive treatment plan
- Create educational alternatives
- Offer affordable medical care and treatment options
- Plan for long-term needs of the aging population.

To achieve these goals, turf battles must yield to impartial assessments of how services can be streamlined and sustained.

There is an opportunity for a person or organization to step forward and provide leadership to make this concept a reality. Leadership could come from the governor's office, the Legislature, the University of Minnesota or one of the state's advocacy groups. While ambitious, with hard work, creative thinking and public/private partnerships, a Minnesota ASD collaborative could succeed. With a uniform voice, it could drown out shock jocks like Michael Savage and effectively advocate for those who can't do so for themselves.

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