



By Caryn Sullivan

AN EPIDEMIC, A VACUUM AND AN OPPORTUNITY

St. Paul Pioneer Press
3/26/08

The federal compensation court settlement of Hannah Poling's autism/vaccine claim has shined a spotlight on an emotionally charged controversy within the autism world. Since our son's autism diagnosis, I've sat on the sidelines of this rabid dispute, deliberately focusing on the fix, not the culprit. In the wake of the Poling settlement, however, it's hard to ignore the polarization that media coverage has illuminated. Angry parents point fingers at the Centers for Disease Control and Prevention, saying, "gotcha," while the CDC refuses to give them their fiercely sought concession — a mea culpa.

Despite emphatic statements by the CDC, the American Academy of Pediatrics and the Institute of Medicine that the thimerosal in vaccines did not cause or contribute to Autism Spectrum Disorder (ASD), many parents and organizations like the Coalition for SafeMinds, Generation Rescue and Autism United point to evidence they believe supports both a causal link and a cover-up.

The debate continues because there are many questions but few answers. It's easy to understand why some parents engage in the battle, and why the CDC is so resistant, for that matter. Much is at stake. Parents feel they followed the rules but their children's future was hijacked because those charged with protecting them failed to do so. Experts warn that failure to follow vaccination schedules subjects children and society to significant health risks. Heads spinning, all parents must decide whether to vaccinate their children. So this issue affects more than the thousands of families with ASD challenges.

When our son was diagnosed in 1993, ASD reportedly occurred in 1 in 10,000; current estimates are at least 1 in 150. The vaccine debate is one of many that thrive in the dearth of concrete answers about the cause of and treatment for ASD. The absence of answers created a vacuum that has been filled by theories, distrust and activism. Fortunately, increased awareness has resulted in increased funding for researchers. As researchers peel back the layers of the onion, there seems to be a growing consensus that both genetic and environmental factors are implicated in the disorder. Bit by bit the mystery is unfolding.

Although there are vastly more resources for families today than when autism plowed through our door, there's no playbook. Consequently, too many families must navigate this complicated disorder by the seat of their pants. Parents are given a diagnosis based on observations, not medical tests. With a few exceptions, there is scarce hope for a cure.

Frantic parents search for answers where there are few, always conscious that the earlier their child receives treatment, the better his outcome. Many deplete their emotions and finances, abandon careers and strain marriages beyond repair in a

desperate attempt to get their kids to talk, use the bathroom, find the right school, make a friend, get a job, live independently. The broad constellation of needs affects a host of Minnesota's systems that are already under siege — education, health care and social services, in particular. While the individual's needs may change over time, the cost to both families and taxpayers to manage this lifelong condition will be considerable.

There is some good news. Early intervention programs using educational and therapeutic approaches have documented success and are on the increase. Yet those approaches do not address the concurrent medical issues of a considerable segment of this population. There is not yet a universally accepted body of evidence-based medicine to guide practitioners, principally with respect to gastrointestinal and sleep issues. There are medical practitioners, however (many of them not MDs), who follow a bio-medical protocol including medicine, nutraceuticals, therapies and special diets that are presumed to do no harm but are often reported, especially by parents, to produce results. Because these treatments have not been subjected to gold standard research, they are typically not practiced by "mainstream physicians" and aren't covered by health insurance.

The bottom line is there is a critical need for evidence-based research that explains the condition and provides appropriate treatment options that will be covered by insurance and provided by well-trained physicians. To achieve this requires significant funding and staffing.

We have a world-class university and medical school in our backyard that is well positioned to make a notable contribution. While some faculty members are dedicated to the cause, the administration seems more comfortable putting a toe in the water than jumping in with both feet. It's time for our state and university leaders to acknowledge the epidemic and commit greater resources to support the work of those who are searching for causes and treatments for ASD. It's time to fill the vacuum and end the finger pointing.

Caryn Sullivan is a Minnesota attorney and writer. Her column appears occasionally on these pages. Her email address is carynsullivan@comcast.net