



Indiana – The Autism Health Insurance Reform Pioneer

Autism health insurance mandate laws came about because of long-standing, institutionalized discrimination against persons with mental health conditions and persons with autism and developmental disabilities by the health insurance industry.

When children were diagnosed with autism, some parents were stunned and devastated to receive letters from their health insurance company stating that their child was determined to be “uninsurable” because of the autism diagnosis, and that the child was dropped from the health plan, becoming uninsured for **any** health treatment. If the child was “lucky” enough to be able to keep his or her health insurance, insurance companies would frequently restrict or deny coverage for any claim that could be remotely related to the autism diagnosis – any testing or services related to the brain, neurological system, or mental health, regardless of whether it was actually related to autism. For example, an MRI to determine if the child had a brain tumor often would be denied. Any seizure treatment or testing often would be denied.

This discrimination resulted in physicians under-diagnosing autism because they did not want their patients to risk losing health insurance coverage. This discrimination also resulted in children going uninsured or underinsured, family financial issues and increased stress, and more children on state-funded high-risk plans and taxpayer funded Medicaid than there should have been. It also resulted in more pressure on public schools to provide what are medical treatments, *not* educational services.

As the science of autism emerged and autism was accepted by the medical community as a neurological condition as well as a mental health condition, discriminating against persons with autism by refusing treatment coverage became unsupportable. With the Lovaas and Sallows replication studies and decades of research supporting Applied Behavior Analysis (ABA) as an effective medical treatment, denying ABA therapy as “experimental” and “educational” became unsupportable.

Getting the First Autism Health Insurance Reform Passed – A David vs. Goliath Story

The Arc of Indiana (Kim Dodson), The Indiana Resource Center for Autism (Dr. Cathy Pratt), and a group of parents who included several scientists from Eli Lilly, physicians, and schoolteachers joined forces to ask the Indiana State General Assembly to pass the nation's first comprehensive autism treatment coverage law. A core group of moms – Nan Daley, Penny Githens, Susan Hansen, Liz Freeman-Floyd, Leah Helvering, and Susan Pieples worked tirelessly with Kim Dodson from The Arc of Indiana to gather information, assemble research, educate legislators, and build a coalition of supporters.

Initially, the parents did not ask for a treatment mandate. They just wanted their children to be able to keep their health insurance and not be declared “uninsurable” solely based on a diagnosis of autism. Dr. Pratt contacted Dan Burton, a U.S. Congressman from Indiana, who has a grandchild with autism, for assistance. He was supportive of the concept, and he approached The Arc of Indiana to assist the parents. Mr. Burton committed to testifying and asking for Republican support at the Indiana State House if the parents could get the law through the various General Assembly House and Senate committees and up for a vote. The parent and advocacy group coalition engaged in an education campaign to garner support for a treatment mandate based upon non-discrimination. During this process, the group decided that a treatment mandate was the only way to truly address the discrimination against persons with autism in the health insurance industry.

As state legislators learned more about autism and the available autism treatments, such as Applied Behavior Analysis (ABA), they were astounded at the level of discrimination. The sponsors of the law, Craig Fry and Vanessa Summers, agreed that the treatment mandate was a necessary anti-discrimination measure. After the parent led group secured enough votes in the various committees, Representative Dan Burton traveled from Washington to Indiana to testify before the General Assembly to encourage state legislators to pass health insurance reform that added autism treatment to all state regulated health plans sold in Indiana. The insurance industry, the Chamber of Commerce, and the Manufacturer's Association vigorously opposed the bill. The business interest groups testified that coverage would raise the cost of insurance exorbitantly. Health insurers testified that they and numerous businesses would go bankrupt if forced to cover autism treatment. Thanks to the hard work and diligent research of the parent and advocate coalition group, the bill was passed with wide bi-partisan support.

The Indiana Autism mandate went into effect in 2001; however, even with the protection of the new law, it required three years of appeals and administrative court hearings with the IDOI for Michele Trivedi, representing her child, to receive payment for claims for ABA therapy. Even though ABA was discussed extensively during the legislative process, and it was clear that the legislature considered ABA to be one of the covered services under the law, the insurers insisted that ABA was not covered because

it was not specifically mentioned in the law (no specific treatment was mentioned, the law states – “coverage is limited to what is prescribed in a care plan by the treating physician”). Next insurers objected to ABA coverage stating ABA was “experimental,” then they argued that ABA was “educational”, and finally they objected because the providers were not licensed (no licensure existed). Each of these objections was fought successfully by Mrs. Trivedi in appeals, external appeals, and via complaints for the Indiana Department Of Insurance to engage in enforcement action. Dr. Eric Larsson and Vince LaMarca from The Lovaas Institute for Early Intervention provided essential clinical information and research to assist in these test cases.

During the three years that Michele Trivedi was fighting these test cases to ensure enforcement of the law, she was also working with Kim Dodson from The Arc of Indiana as the lead parent advocate to defeat so-called “mandate lite” bills that would have, in effect, repealed the hard fought and hard won autism treatment mandate. The “mandate lite” bills, that would allow employers to “opt out” of certain state mandates and cut them from their health plan, were supported by the insurance industry as a means to gut the new autism mandate. The mandate lite bills were defeated in three consecutive sessions of the General Assembly. The autism mandate would stand.

Due to widespread non-compliance with the new law, Mrs. Trivedi convinced the Indiana Department of Insurance Commissioner that a bulletin to outline the responsibilities of health plans and providers under the autism mandate would help families to be able to access services without undue delay – some families were waiting up to 18 months for their insurer to respond to a request for coverage. Michele was the sole consumer advocate on a committee of health insurance lobbyists and health insurance company representatives that was appointed by the IDOI Commissioner to draft a bulletin.

While the insurance industry representatives tried to add multiple limitations to coverage via the bulletin, the original intent of the mandate bill – full treatment coverage based upon medical necessity and “no less favorable” financial terms - remained intact and Bulletin 136 was published.

Autism Speaks Takes Up the Cause

In 2005, three moms in South Carolina rallied their community to introduce a bill after learning about the Indiana law and contacting Michele Trivedi for assistance. In 2008, they passed the second autism mandate. One of the moms, Lorri Unumb, an attorney, later joined Autism Speaks to head their efforts to assist states in passing meaningful autism health insurance reform laws. Lorri Unumb and her team at Autism Speaks have assisted state based advocates to pass some form of autism mandate coverage in at least 43 additional states, as of this writing. The Autism Speaks Legal Resource Center, headed by Dan Unumb, assisted states to advocate for Medicaid coverage for ABA therapy, and provided assistance to state advocates on legal issues regarding health

insurance coverage for autism treatment. Regrettably, Autism Speaks abruptly shuttered The Autism Speaks Legal Resource Center in September 2016, even though enforcement of state mandate laws and wide-spread non-compliance with federal mental health parity law remains a serious concern for families in their efforts to secure medically necessary services for their loved ones with autism.

This year, Indiana celebrates over 15 years of state mandated health insurance coverage for persons with autism, and Indiana based advocates remain at the forefront of ensuring that all people with autism across the country who need and want treatment are able to access that treatment. The Arc of Indiana established the Insurance Advocacy Resource Center (INARC) headed by Michele Trivedi, who works with families, providers, and advocates across the country to advance the rights of persons with autism and all developmental disabilities to equal coverage and equal access to medical treatment and clinical services.

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