

 301

TESTIMONY OF NANCY A. TAYLOR
RE: SB 301: AN ACT CONCERNING HEALTH INSURANCE COVERAGE FOR
AUTISM SPECTRUM DISORDERS
February 5, 2009

To the Insurance Committee:

I am writing to you as the mother of a child on the autism spectrum asking you to **OPPOSE** the autism insurance bill (SB 301). While you may think it is odd that someone with a child on the autism spectrum would not support this bill, I hope you will see after reading this testimony that there are very good reasons to **OPPOSE** this bill.

First, the state of CT needs to stop legislating the disability "du jour" and instead, take a holistic approach to people with disabilities. As a member of the CT Council on Developmental Disabilities (appointed by Gov. Rell 4 years ago), I know first hand the problems that many in this state face who have disabilities and there are many more disabilities than autism. Many, if not all, of these disabilities also get limited insurance coverage for things like speech therapy, occupational therapy and physical therapy, not to mention the significant need for personal care assistants, accessible transportation and housing, and major changes in our education system to provide an appropriate education to all children with disabilities. Every time you enact legislation for just one disability, you pit disabilities against each other because you are limiting the pool of money for others to get. Why is it fair that only the "hot" disability of autism should get all the money? Just because Autism Speaks has well-funded coffers and there is a very vocal minority of moms who are pushing this do not mistake this bill for good public policy.

Second, it is a very dangerous precedent to legislate the kind of so-called "treatment" available for autism. While some parents will claim that Applied Behavioral Analysis is the only "treatment" for children with autism, nothing could be further from the truth. In fact, there are many therapies and educational programs that are used for children on the autism spectrum and not one is the right thing for any given child. However, the ABA "lobby" has managed to get more money behind their program and thus more research and more trained individuals have gone into that field. But other parents and experts will tell you that it is not right for every child and even if it is, it is not the only thing.

For example, while my almost 7 year old son is technically on the autism spectrum, ABA did not work for him at all. In fact, when he was at the River Street School/Coltsville (a rigid ABA program) he regressed. He also regressed in ABA programs in other schools. Now that he is in a more eclectic program he is thriving. What you need to understand is that if you've seen one child on the spectrum, you've seen one child on the spectrum. No two are alike and therefore, no two children respond the same way. But if you put into law that ABA will be covered you are, in effect, saying that it is the only "program" to be used, thus limiting the research that will go into developing other therapies or educational programs or the people who will go into these fields. It will also be impossible for parents like me to make a case to school districts that other therapies or programs should be tried. On the other hand, if you mandate insurance coverage for all so-called "autism therapies," you are opening the door to many

unproven and possibly dangerous things to be eligible for coverage and it will be a nightmare to sort out what is real and what is not. Frankly, all of this will serve only one purpose – to make lawyers rich as they sue insurers over the definition of “medical necessity.” Better to allow individual parents, health care providers and other experts, along with school systems to determine what works best for any child and develop an appropriate educational plan for that child as is mandated by IDEA.

Third, and perhaps most important, ABA is NOT a medical treatment. We need to be very clear on this. It is an educational program used for children in a school based system. Therefore, it should not fall under medical insurance coverage. The people who practice ABA need not be certified at all. While there is an ABA “degree” of sorts (called a BCBA), those who administer ABA programs in schools are untrained para-professionals and special education teachers who often have little or no training in it. This contrasts dramatically with covered medical benefits where a trained and certified person administers the medical therapy, such as SLPs, OTs and PTs. Like doctors, nurses and other therapists, these people have state certification and licenses to perform the therapy they do. How will you guarantee that only “certified” people are administering ABA programs? Forcing insurers and employers (and ultimately workers) to pay for this coverage amounts to having them pay for special reading programs for children with dyslexia or special math programs for children with other learning disabilities. Let me reiterate: ABA is not a medical treatment.

Furthermore, looking at the insurance coverage for ABA have you thought about the complexity of how insurers could actually cover ABA services? As I noted, the people who administer ABA programs are not licensed therapists or doctors who would be part of any insurer’s panel of providers. Even as an out of network benefit, an actual “provider” must provide the services. So, for example, if my son’s teacher happens to do speech therapy with my son during the day, I cannot submit a claim to my insurer for those services because that person is not an SLP. One needs to have appropriate credentials in order to have a service covered by insurance.

Finally, if you mandate insurance coverage for ABA educational programming, you will then completely remove all responsibility from school districts to provide this programming in schools, or actually provide any educational programming in schools for children on the spectrum. If my insurance will pay for this, why should any school pay exorbitant sums to hire ABA consultants, set up special programs, or even work with parents to develop educational programming?

And this is not even getting into the debate on mandated benefits of which we all know the perils. In this economy, how can we possibly think of burdening our state’s fragile employers with what will amount to an extremely expensive benefit that may be never-ending? We can’t afford to let more people fall off the insurance rolls due to costs or to have employers stop offering benefits.

As I mentioned, my son Ryan is technically listed on the autism spectrum. However, his main disability is called apraxia, a complex neurological disability that severely impacts his motor planning skills, especially his speech. He is only now beginning to speak full words and sentences with enormous help from daily

speech therapy (paid for by our district) and an excellent education program in a private school. My husband and I currently have very generous insurance coverage through his employer and they cover unlimited speech, occupational and physical therapies for a co-pay. That is wonderful and it would be fabulous if all insurance coverage was like that, regardless of the disability. Several years ago my employer had a different insurance coverage and, while speech therapy was a covered benefit, my son, who was almost totally without speech, did NOT qualify for coverage. The coverage was only to "restore" speech, not to obtain it. So a non-verbal child was denied coverage for speech therapy. So, you see, it had nothing to do with the diagnosis of "autism" – it was actually his diagnosis of apraxia.

This is true for other disabilities where people cannot access a myriad of proven medical therapies. So, please understand that the autism lobby may be the best funded and most vocal right now, but these issues affect all people with disabilities. And please understand that – despite what you have heard or will hear from dozens today – autism is not singled out for denials of coverage. All disabilities face the same challenges.

So I urge you to not pull out one disability and say that if we mandate coverage for one so-called "therapy" for one disability that we are making good public policy. Again, I know I am probably one of the few you will hear from who oppose this bill but I wanted you to understand that there are many people with disabilities in CT who get virtually no services and limited insurance coverage. There are so many things the state should be doing to help all people with all disabilities, not pitting us against each other for the limited pot of money. And you shouldn't be forcing insurers and employers to pay for what amounts to an educational program, thus taking away all responsibility from school districts from complying with their IDEA mandate.

Sincerely,

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