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**CONNECTICUT  
GENERAL ASSEMBLY  
SENATE**

**PROCEEDINGS  
2009**

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Without objection, so ordered, sir.

SENATOR LOONEY:

Yes. And also, Mr. President, on calendar page 28, Calendar 258, substitute for Senate Bill 799, Mr. President, would to place the item on the foot of the calendar.

THE CHAIR:

Motion to place item on the foot of the calendar.  
Without objection, so ordered.

Mr. Clerk.

THE CLERK:

Calendar page 26, item marked Order of the Day, Calendar Number 224, File Number 238, substitute for Senate Bill 301, AN ACT CONCERNING HEALTH INSURANCE COVERAGE FOR AUTISM SPECTRUM DISORDERS, favorable report of the Committee on Insurance and Appropriations. Clerk is in possession of two amendments.

THE CHAIR:

Senator Crisco.

SENATOR CRISCO:

Thank you, Mr. President. Mr. President, I move for acceptance of the joint committee's favorable report and passage of the bill.

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THE CHAIR:

Acting on approval and acceptance of the bill, sir, will you remark further?

SENATOR CRISCO:

Thank you, Mr. President. Mr. President, if the chamber will allow me just to make some comments in regards to the issue of autism before I call a very important amendment. Most importantly, last year, Mr. President, three minutes before the end of the session, through the leadership of Senator Williams and Senator Looney, we were able to pass our first autism bill for the State of Connecticut. But it only got us part there, and I'd like to remind the circle that autism is an illness, it's a disorder, it's a medical condition affecting thousands of families across the Connecticut.

There are several medical diagnosis within the autism spectrum: Classic autism, asperger syndrome, and pervasive development disorder, not otherwise specified, known as PDD-NOS.

It has been estimated that 1 in 150 children in the United States suffer from ASD. The estimate is higher for boys. 1 in 94 of who may be on the autism spectrum. In Connecticut, the statistics are even

lower, 1 in 115. However, despite the fact that autism is an illness, it is a surprising and very dismaying fact that health insurers generally refuse to cover either its diagnosis or treatment unless they are forced to do so by law. And we've heard numerous times, Mr. President, and members of the circle, that it's always a cost factor, but sometimes, I wonder if it isn't a profit factor. And what we're asking of the insurance industry is to share just this very small part of the net income that they've been enjoying at an extraordinary level the past seven years.

So because of this situation, state lawmakers from across the nation have been forced to stand up for the families who represent, and required health insurance coverage for families with autism. As I mentioned, last year Connecticut took a first step in that direction by passing a partial autism insurance bill. The new law provides coverage for physical, occupational and speech therapies where there has been a diagnosis of autism. However, we do not yet require coverage for the diagnosis itself, which costs thousands of dollars. We do not yet require coverage for the absolutely critical behavior therapies for --

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need of these children, which can cost tens of thousands of dollars, and yet we do not require coverage for psychiatric and psychological treatment or for medications.

Because we do not require this coverage, Mr. President, we are allowing thousands of families in crisis throughout Connecticut to unnecessarily have their lives made more difficult, particular at this time of economic concern and disruption to our families in Connecticut. Not only are they caring for a child with autism, but also being forced to pay thousands of dollars out of pocket for their child's medical care even though they already have and are paying for health insurance coverage. That simply is not fair and it will be intolerable to allow this to continue in our state.

By passing the amendment, which I'm about to call, Connecticut will become the tenth state to require comprehensive health insurance coverage for autism. Just in the past several weeks, Montana and New Mexico have passed a version this bill, allowing their families to join families in Florida, Louisiana, Illinois, South Carolina, Pennsylvania, Arizona and Texas who are comprehensively covered. I believe that.

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our families in Connecticut are worth no less and they must be fully covered as well.

Mr. President, two weeks ago through Senator Harris' advocacy, a rally was held on the back steps of the Capitol, where families from throughout the state gathered to express their concern and their needs. And it was a young boy, a young man with rimmed glasses, a little sweater, you know, vest, sweater vests, and he was the speaker that day. And a chair was pulled up and I thought it was for him to stand up to speak through the microphone, but no, it was a chair meant to sit down. And he opened a three ring binder to, like, a ten-page presentation. And I'd just like you do hear what this young man, who is so extraordinary, have to say, and I may quote.

And it's really special to be born autistic. In fact, many people including some of the best scientists like Isaac Newton and Albert Einstein, they had autism. At the time I was born, though, I didn't know how special it was and that's because things were very hard for me, I wasn't functioning well. To be autistic is like to live in a dream all of the time. It's a really, really long dream that just keeps on going, and sometimes it's so scary.

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I remember when I was little I used to bang my head against the wall over and over as hard as I could. I thought I could get the dream to come out that way and I could leave on the wall like a smash -- smashed picture. Maybe then I could outrun it and get away fast. You know, I used to run a lot when I was little. Maybe that's why I'm such a fast runner today.

And to come to the conclusion of this extraordinary individual's comments, he states that everyone that has autism is special. Don't get me wrong, if you don't have autism, your special too. Just try to understand that autistic people function a hundred percent different. We can't always tell you what we need and when we need it, but if you try to look through our eyes, when you teach us it will make much more sense to us and we will learn. When you think I am not listening, it's only that I am thinking really hard and working on a problem in my head, so I can't answer you right away. Please give us time.

If you'd like to help us, one day we might be able to share our dreams with our parents, our families in the world. You know, autistic people are important too.

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Mr. President, members of the circle, there are times when children don't have a chance to get up at bat, and it's extremely painful for our families. You know, we idolize, you know, the Jeters and the Lebron James' and other great athletes, but I personally feel that the parents and grandparents and loved ones of these children are the true heroes, 24 hours a day. And all they're asking for is an opportunity, an opportunity to live a better life. And with that, Mr. President, I would like to call LCO 7409.

THE CHAIR:

Mr. Clerk.

THE CLERK:

LCO 7409, which will be designated Senate Amendment Schedule A. It is offered by Senator Crisco of the 17th District, et al.

THE CHAIR:

Senator Crisco.

SENATOR CRISCO:

Thank you, Mr. President. Mr. President, I ask that the reading be waived and I be -- permission to summarize, and I move for its adoption.

THE CHAIR:

Please proceed, sir.

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SENATOR CRISCO:

Thank you, Mr. President. Mr. President, this is a strike all amendment and it really is an extraordinary degree of work by many individuals. And through the leadership of Senator Looney and our legal staff, I believe we've come up with a document that will go so far in helping so many families in Connecticut.

The difference in adopting this amendment, the difference to children and even adults, will be never speaking, but to allow them to speak. Instead of being in special ed, it will allow them to be mainstreamers. Instead of requiring more support for mental and physical health, it would enhance their mental and physical health. As it will make them independent adults, living on their own, or with minimum supervision and even working, instead of being in a group home or requiring excessive care.

Mr. President, when we take -- when we took our oath of office, I believe there's no one here who did not take up the responsibility of making life better for the people of Connecticut. It's a proud experience to be a member of this circle. It's not done for fame, it's not done for money. And despite

sometimes some very difficult situations, we make life a lot better for many people in the state of Connecticut, but unfortunately, because of the nature of things, the people of Connecticut never hear about it and there are some extraordinary things that are accomplished and this is one particular extraordinary thing that can be accomplished for the people of Connecticut.

And, like that young man who said if you help us, one day we might be able to share our dreams with our parents, our families of the world. I believe that this amendment, which is strike all, will achieve that, Mr. President.

THE CHAIR:

Thank you, Senator Crisco. Will you remark further on Senate A? Senator Looney.

SENATOR LOONEY:

Thank you very much, Mr. President.  
Mr. President, in support of the amendment.  
Obviously, first of all, I wanted to thank Senator Crisco for his great leadership on this issue and Speaker Donovan, for his interest and advocacy also.

Want to make a special note that Senator Crisco attended that rally, of which he spoke that was

organized by Senator Harris two weeks ago, and very uplifting and inspiring as it was, and as we know, Senator Crisco did so on that day with a very heavy heart having lost his own grandson just two days earlier, but made the effort to be there that morning in solidarity with all of those who were advocates on this issue.

The amendment, as Senator Crisco said, Mr. President, does mandate coverage for medically necessary diagnoses, behavioral therapies and psychological and psychiatric services and physical therapy, occupational therapy, speech and language pathology services and medications and covers children up to the age of 14 in -- with the -- a level of benefits that for more intensive treatment and at the earliest ages. And we know that therapy for autism services and interventions can have the greatest impact and the greatest effect. And the behavioral therapies must be provided or supervised either by a board-certified behavioral analyst, a psychologist or by an M.D.

And it is important to recognize, Mr. President, as we know that proven -- these prevent therapies are most effective when entered into at an early stage in

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a child's life. So that children can then be rescued from being permanently disabled and being able to move into a -- into the mainstream and to reach their full potential.

One of the important things, Mr. President, to point out is the discussion of why is this necessary when some autism services are, obviously, provided in schools. And the question to be asked, why aren't the services in schools adequate and, why do we need this additional coverage of the condition or disease of autism under this bill and amendment? And the reason, Mr. President, is that educational services provided in the schools are meant to accommodate children with autism. Medical treatments, and what this bill provides for and the amendment provides for, is treatment and it's appropriate for treatment to be covered by my health insurance. And these treatments are meant to ameliorate the symptoms of autism, to go beyond a mere school accommodation and that educational services under the -- that are required in the schools are meant to provide the disabled student access to the curriculum, but they really are not intended and don't come close to treating neurological disorder like autism from a clinical perspective. And

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that is what we are proposing to do under this bill and amendment.

There is part -- we are now part of a national movement in undertaking this recognition that families are extraordinarily burdened by trying to provide out-of-pocket for the cost of autism treatment for their children. By passing this bill we would become the tenth state to require comprehensive health insurance coverage for autism. Just in the past few weeks, Montana and New Mexico passed a version of this bill, allowing families to join those in Florida, Louisiana, Illinois, South Carolina, Pennsylvania, Arizona and Texas who are already covered. And we know that certain families in Connecticut have had to make the very difficult choice about where to live based upon where, in fact, there might be treatment coverage.

So, again this is a very important advance to build upon the initial effort from last year and, Mr. President, would urge adoption of the amendment.

THE CHAIR:

Thank you, sir.

Senator Fasano.

SENATOR FASANO:

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Thank you, Mr. President. Mr. President, I rise to support this amendment and may I also say that Senator McKinney, who is also on this amendment who could not be here because of a conflict with some personal matters, he also is very supportive of this amendment and supportive of the idea that we need to do as much as we can for autism. I want to thank Senator Crişco and many of the staff who worked very hard on this amendment and getting it to the floor.

Mr. President, I don't know a lot about autism, but I will tell you I have a niece who is autistic. And four years ago, my niece was not able to verbalize, she was not able to tell you what she thought what she wanted. She couldn't communicate, social skills were basically nil.

Now, we just happened to have the wherewithal to give the necessary behavioral services, speech therapy and all of those things that are required or necessary to allow her to be, at least, as functioning as possible. Now, we just happened to have the ability to do that and I will tell you, four years later, she's in fifth-grade, and she is communicating to the point that she won't stop talking. Her social skills are abundant. She no longer fears jumping with a

group of other kids and playing ball or tag or talking about a television show or expressing how she feels about Nickelodeon. Those are things, four years ago, we could only dream about for her to do.

I think with this bill -- is allow those who probably can't afford those services to achieve some of these results. You can't really put a price tag on that and the feeling that you get, as a parent or as an uncle, is something -- it's immeasurable.

Mr. President, this goes a long way to achieving those services that we need for autism and I stand here in strong support, as I know Senator McKinney does, for this amendment. Thank you, Mr. President.

THE CHAIR:

Thank you, sir.

Senator Gaffey.

SENATOR GAFFEY:

Thank you, Mr. President. Mr. President, I also rise in support of the amendment for the circle and I would, in particular, like to commend Senator Crisco who's a great friend and someone who has been intimately involved with this bill, and attempting to bring some equity to the parents that have children with autism. I also want to commend my good friend

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Majority Leader Senator Looney and his leadership on this amendment, which will become the bill.

Mr. President, the Education Committee had legislation before the committee with regard to autism, with regard to applied behavioral analysis. And we heard, what can only be described as heart-wrenching testimony from the parents, who I would agree with Senator Crisco, he used the words "heroes." And I can only echo that word because the parents of autistic children that are involved in their child's daily activities 365 days a year, 24/7 are the heroes that come to the state capital, that lobby their state representative and state senator to have legislation like this passed.

As both Senator Crisco and Senator Looney mentioned, we will now be amongst the leaders in this nation that have advanced legislation such as this. As we heard from the parents, in the committee, and I'm sure Senator Crisco heard the same thing in his committee, a lot of these parents, for the love of their child, pour out tens of thousands of dollars a year to have their child receive the therapies that work for their children. And different children, of course, who are autistic, different therapies work for

them. Some don't work, some do work.

What this amendment does is provide a level playing field for those parents and their children to have access to all of the therapies. And there's been a great compromise and balance struck with this amendment that Senator Crisco and Senator Looney have worked on so hard. And that it includes all of the therapies, it's not limited to one particular therapy. So I want to rise in support of this.

As Senator Looney said, these are services that are outside of an individual education plan that would be crafted for a child within the school. Under the Individual Disabilities and Education Act, the federal law which created the special-education mandate in the first place years ago, they use services outside of that individual education plan that are absolutely necessary to help the children who are autistic to be able to join in with their other classmates and learn and enjoy life. And it's absolutely essential that legislation like this is advanced here in Connecticut.

I will note that putting my hat on, as the Education Chairman, that this does have language in it with regard to behavioral analysis or certified by the board of -- I'm sorry, the Behavioral Analysis

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Certification Board. That is not a board that's inside Connecticut. That is not certification or a license that's provided by a Connecticut agency or a Connecticut institution of higher education. And as this bill passes, we need to work toward that. We need to work towards that certification being provided by a Connecticut institution of higher education and we certainly have a wealth of knowledge and some of the best programs in special-education and autistic services in the country. So that will be one thing that I'm going to work towards so that we have these certifications being actually granted by entities from within the state of Connecticut.

And with that, Mr. President, I want to thank you for the attention of the chamber and thank all those who've worked so hard in support of one of the best pieces of legislation, I think, we're going to pass this year. Thank you.

Senator DeFronzo in the Chair.

THE CHAIR:

Senator Prague.

SENATOR PRAGUE:

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Thank you, Mr. President. Mr. President, it's moments like this in this chamber that make you feel very proud to be part of this process. I can just picture little Molly, who lives down the street from me, who is an autistic child.

Beautiful child, she's about ten years old. She will benefit so tremendously from this legislation. I strongly support this and I'm really -- I can't tell you how appreciative I am to Senator Crisco for putting the time and effort into this kind of bill. So it is a pleasure and an honor, really, to be part of this chamber. Thank you.

THE CHAIR:

Thank you, Senator.

Senator Meyer.

SENATOR MEYER:

Thank you, Mr. President. Senator Looney made this bill, what we call in the Senate, the Order of the Day. And for those who are observing, the concept of the Order of the Day is reserved for only the most significant and special bills. And this Order of the Day, in the five years that I've been here, is about as special as any Order of the Day that I've seen and voted upon.

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It will bring a whole new group of children into therapy at the earliest of age, and Senator Looney pointed out, at the earliest of age and bring about a new quality of life for an increasing number of children in our state and our country. I just so enthusiastically support it and thank Senator Crisco and congratulate him.

THE CHAIR:

Thank you, Senator.

Senator Debicella.

SENATOR DEBICELLA:

Thank you, Mr. President. Mr. President, I too rise in favor of the bill. Normally, I impose health-care mandates and, in fact, the other day, offered an amendment to change the way we do health care mandates in the State of Connecticut to allow for more consumer choice.

Because the reality is, and the reality of this bill is, it will increase the cost of insurance in Connecticut. The problem, Mr. President, there are some afflictions and some health-care issues that the people of Connecticut are willing to pay higher health care costs for to insure, autism is one of them. Almost one percent of the population, as Senator

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Crisco noted, has an affliction relative to autism. And additionally, an important fact that hasn't been brought out is that early treatment and early intervention can ameliorate the effects of autism. And further prevention and detection at an early age can actually dramatically improve the lives of these children as they move into their teens and young adulthoods.

So we go into this, as a circle, with, eyes wide open, that this will increase health care costs in Connecticut, but we say, I believe as a unified voice, that it is worth it to cover autism in our State. Thank you, Mr. President. I urge adoption.

THE CHAIR:

Thank you, Senator DeBicella.

Senator Boucher.

SENATOR BOUCHER:

Thank you, Mr. President. Mr. President, I also rise to support this bill, although, I do have a question if I might. I have to tell you that I was recently afforded an opportunity, actually, to see this behavioral therapy in action in my district in Westport, with a wonderful family of five children where the youngest did have a serious case and does

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have a serious case of autism.

I know it affects a lot of our extended families as well, and it is also a phenomenon that seems to be, certainly, all over the country, and in particular, in our various school systems where the rate of instance of that is causing many to take great notice and are somewhat alarmed over that fact. And in watching the process, I inquired about whether this child was involved in our birth to three program and, in fact, they were. And that the State does provide quite a bit of services, as it should, but there are more serious questions surrounding this issue that goes beyond the scope of our current legislation and this discussion, which I hope we will be focusing on in the future.

However, the question that I would have, and I think our esteemed Majority Leader did brush upon the issue that some question, and that is, does -- where does this particular service appropriately fall? Does it fall within our health care system, our private health care company system or into our social services system or our educational system? Maybe it involves all three, but particularly, when it comes to the therapeutic components, I wonder if there is someone

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in the chamber who could expound just a little bit further on how this would be more appropriately involved therapies within the private health care system, versus providing all of the services required within our, either educational institutions, through IPs and so forth. And if there could be just a little bit of discussion, Mr. President. Thank you, Mr. President.

THE CHAIR:

Senator Crisco.

SENATOR CRISCO:

Thank you, Mr. President. Through you, to Senator Boucher, it's (inaudible) of the Department of the Developmental services funds BCBA, services children on the autism spectrum and related disorders. The Department of Children and Families, both voluntary services, protective services fund BCBA. Finally, many school districts in Connecticut contract with BCBAs to provide consultative and supervisory ABA services to children on the autism spectrum.

BCBAs are well-qualified because the National Behavior Analysis Certificate Board provides a very high standard of professional competence.

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Through you --

THE CHAIR:

Senator Boucher.

SENATOR BOUCHER:

Thank you. Through you, Mr. President. Would there be some definitive areas of where we know where the services would be costed out, whether it be through the private insurance carrier for certain level of services and then the local school districts providing another part of that financial aid, or is that kind of not delineated with regards to this bill, Mr. President?

THE CHAIR:

Senator Crisco.

SENATOR CRISCO:

Thank you, Mr. President. Through you, to Senator Boucher, I would like to take the liberty of giving a more comprehensive answer to that question. Just in regards to costs, for the state insurance plan, it's a very minimal premium increase resulting from the bill, according to OFA. In fact, the state premiums will only increase 1.2 million. And given our state premiums that are currently 840 million, it's less than two tenths of one percent increase on

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our current premiums for a state plan.

In addition, because of treatment of the birth to three and other programs, there are various cost savings from the treatment of autism spectrum disorders have very conservatively, been estimated to be between 187,000 to 203,000 per child from age 3 to 22, and 656,000 to 1.1 million for people from age 3 to 55.

SENATOR BOUCHER:

Thank you, Mr. President and I thank the Senator for his answers. It's quite clear that, although it might cost something on the front end of this, it certainly could save a great deal of money for the State and for local towns, municipalities and school systems if we could address the issue very early on so that our children could have a full and more productive life further down the road. And I certainly support the initiative. Thank you, Mr. President.

THE CHAIR:

Thank you, Senator.

Senator Kissel.

SENATOR KISSEL:

Thank you very much, Mr. President. And indeed,

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you look good up there. I rise in strong support and I can only add my voice to everyone else who's spoken before me. Senator Crisco, I am so happy that you articulated what that young man had to say.

There's an awful lot of folks over the years, that the lucky 17 years that I've been able to represent my district, families that I've bumped into that have autistic children, indeed, folks with autism in their adult years -- folks, constituents that came before us, when I served as the ranking senator on the Human Services Committee for many, many years who said, Connecticut is way behind. You have got to recognize this. You've got to do something to help us out. We're doing it all on our own and we need some recognition. And finally, Connecticut is taking, as others have indicated, a leadership role.

Senator Crisco, I can't imagine what was going through that young man's head when he sat down and he spoke, but somehow he was able to be as poetic and articulating a thought and a prospective as I've ever heard. That kind of selflessness and introspection, that kind of understanding of where one is coming from, I have to say, there are times, as I am in the middle of my life, God willing, knock on wood, where

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one wonders where one is as juxtaposed with other people on career paths, other people in financial situations, other people in different parts of the world. We all get to those points in our lives where we wonder, where are we, who are we and what is our purpose in life?

And for someone to be able to do that kind of self appraisal and place themselves in a historical perspective, in a biological, psychological perspective and do it in such a way that is, at once insightful and yet so humbling, I have to tell you, anything that we can do to help that young man, all those parents that have been so patient over the years that have been in -- here in this building, I think is absolutely what being a civilized society is all about.

We can go home tonight. We can turn on the evening news and we could see people squabbling and fighting and killing one another over the stupidest things, but I can go home tonight and feel that in, at least some small way, by supporting this measure, that we here in the State of Connecticut have recognized that there are individuals that are so tremendously worthy of our support and that it is up to us, as

their leaders, as their legislators, as their representatives here in Hartford, to help clear the path and allow them to reach the highest goals that God will allow them to attain.

So Senator, I commend you. And Senator Looney, I commend you as well. Senator Fasano, Senator McKinney and everybody else, Senator Harris and anybody else in this circle who worked doggedly over the last several years to put this initiative before us. Thank you, Mr. President.

THE CHAIR:

Thank you, Senator Kissel.

Senator Frantz.

SENATOR FRANTZ:

Thank you, Mr. President. I appreciate that. Mr. President, Senator DeBicella is not the Lone Ranger in the circle when it comes to be skeptical about raising the cost of insurance for people, increasing mandates and increasing general costs, however given the breadth of this condition, we all know directly or indirectly families who have a child who is unfortunately stricken with autism. It has to be one of life's greatest challenges.

Based on what I have learned over the last few

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months, as I've learned more about this issue, it can't be more challenging than having an autistic son or daughter. And in particular, if you don't have the resources to hire someone to come and help you out on a daily basis, there is no question there is a need for this. And in my judgment, not requiring there to be a certain level, as suggested in this proposed legislation, of coverage from insurance companies, that is the equivalent of not requiring there to be coverage for cancer in terms of how broadly this condition affects all of us.

There is also another component that hasn't been addressed, which I'm not going to harp on today and that is the issue of cost and cost benefit. An investment can be made early on in a case involving autism that I would venture to say, although I'm sure the data is not out yet and this is very much a work in progress when it comes to dealing with these cases and coming up with firm, scientific conclusions, but I would venture to say that there was a big payback in terms of the State costs ultimately for someone who grows up autistic, and not being exposed to some of these treatments that are considered maybe cutting edge and maybe, hopefully, soon can set standard

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operating procedures or treatment procedures as we move forward. There are a lot of exciting advances in technology as well therapeutic approaches to autism and I'm learning more and more about those and am highly encouraged.

I would also like to thank Senators Crisco and Looney and anybody else who's been involved with this. Is a difficult, difficult issue and it's a difficult issue to try to figure out how to pay for it and cover it through the insurance companies, but it's an effort that I think is going to be well worth the while. I would also suggest to everybody sitting around the circle and challenge everybody to stay on top of this issue going forward. There are advancements, and as I understand it, some of these advancements are occurring on, almost, a weekly or a monthly basis. And when this group gets together, during the next session, I would challenge everybody to bring this up again and refine this legislation -- find out what is working, what's not working, see if the limits that we said are, in fact, appropriate.

With that, I stand in favor of this legislation, of this bill. And thank you, Mr. President.

THE CHAIR:

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Thank you, Senator Frantz.

Senator Witkos.

SENATOR WITKOS:

Thank you, Mr. President. Two years ago, when I served on the Insurance Committee with Senator Crisco, it was the first time that we had an autism bill before us and we voted that built out of this General Assembly and we were very proud of the fact that we joined a multiple of states providing some coverage for autism.

Well, two years later, as we learned more and more about the illness of autism, we learned more and more of how that original piece of legislation fell short. And today we're here to rectify that and my -- I will close with a comment that it's time we pass this bill. Thank you, Mr. President.

THE CHAIR:

Thank you, Senator Witkos.

Senator Kane.

SENATOR KANE:

Thank you, Mr. President. I too rise in favor of this legislation, of course, the amendment that we have in front of us on the underlying bill. I want to thank Senator Crisco and his committee for putting

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this forward.

I think everything has been said that has to be set on the bill with the -- a number of senators here that spoke on today's bill. What I do know is that I've met with a number of constituents in my district, a number of families, a number of individuals that are affected by this disease and I think it's a very important step in the right direction that we need to follow today. So I will be supporting this bill. Thank you, Mr. President.

THE CHAIR:

Thank you, Senator Kane.  
Senator Harris.

SENATOR HARRIS:

Thank you, Mr. President. I rise in strong support of this amendment and the underlying bill. Mr. President, 1 in 123 kids in the state of Connecticut are born on the autism spectrum. Just think about it -- 1 in 123. Nationwide actually, it's 1 in 150. Here in Connecticut, 1 in 123, an incredible number of our family members, friends, neighbors.

I want to thank also, Senator Crisco for his leadership on this and Senator Looney and all the

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members of the circle for the way that they have attacked this problem, understanding the impact of 1 in 123 of our children born on the autism spectrum. But Mr. President and my colleagues, the real thanks goes to the children and families that are dealing with autism on an everyday basis.

They are incredible. I've seen their work, I've seen their efforts, I've seen and felt their love and their dedication to, not only their families, but all of the families in Connecticut and all the kids of Connecticut.

I'd like to pay particular tribute to Shannon Noll who, through her work with Autism Speaks, motivated by the tremendous love for her son, Jack, has spread the word, raised awareness, built coalitions, led to action, and as we move forward here today to achievement to deal with this issue, to address autism head on and make the lives of the children and families, adults too, that are dealing with it on an everyday basis, that much better.

I don't want people thinking that are listening to this, that this is just, "uh" -- government coming in again and government doing it all, and we pass laws and bills and that's the only way that this gets done.

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Because again, if those families out there that are really getting it done. They are the true example of that amazing phrase that God helps those that help themselves. Besides the out-of-pocket expenses that were described by some of my friends in the circle, they are also out there, as I said, building awareness, raising funds and advocating.

Jordan, the young man that Senator Crisco described, actually, is one of my constituents. He is an incredible human being, I'll tell you. Jordan actually represents all that I'm talking about and all the reasons that we have to be thankful for the children and families and all the reasons that they are really getting the work done. Jordan, him, has himself in two years, raised thousands of dollars for the effort. One year he had a garage sale and this past year, I attended, actually, an arts sale, art for autism that Jordan put on. If anyone wants to come by my office, I have an Autism Speaks puzzle soap that I proudly display. He has artwork. He sells other people's jewelry. He does everything he can, because he knows that he has to help himself. And as Jordan would say and what he said in his speech, he has a responsibility to reach out and help others. He is

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the example. He is what inspires me. Thank you,  
Jordan.

You know, we talk about the cost and we all know there is a cost and that's an important thing to do as we deal with an economic crisis, as we try to help taxpayers stay in their homes, get their health care and all of the pressures that we're feeling. But you know something, you get what you pay for. You get what you pay for. We know that early intervention works. Early intervention is successful. Now, I think the real question that we have to say is, do we want to make this investment in our families or not? And the real question is, what is the cost of not doing this? What does that cost? Without early intervention, Mr. President, the costs sky rocket. If we don't invest and address the problem on the front-end, then the services and the problems and the isolation and the ripple effect is going to cost us all, as taxpayers, as human beings, as a community in Connecticut, much more. And as Jordan shows, with a little early intervention, a lot of love and a lot of support, everybody on that spectrum can be a productive member of our community. That's what this bill is about and that's why I'm proud to support it

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here today.

THE CHAIR:

Thank you, Senator Harris.

Is there further discussion? If there's no further discussion, we'll move to a vote on Senate A.

SENATOR CRISCO:

Mr. President.

THE CHAIR:

Senator Crisco.

SENATOR CRISCO:

Thank you, Mr. President. Just one additional comment. In regards to the amendment, it is a strike all and I also want to give anybody who has a doubt a level of comfort with the term that we use "medical necessary."

Two years ago, this circle approved the term of "medical necessary" in order to reduce costs in health care, in order to reduce unwarranted care that is just not needed. So I think it's very important that we pay particular attention to the term "medical necessity," because for diagnosis, behavioral therapies, psychological and psychiatric services, for PT and OT speech and language pathology services and then occasions -- all have to come under the

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definition of medical necessity.

Also for these to be reimbursed, to be identified as a treatment plan, they must be medical necessary. So I just thought that was extremely important to bring to the attention of the circle.

In addition, this amendment provides caps for children from 9 to 14 and from children from to -- for certain ages and children older will get -- I'm sorry. Children age 8 and younger will have a cap and children from 9 to 14, they'll have a cap.

In regards to behavioral therapies, therapies must provided or supervised either a board certified behavior analyst, a psychologist or an M.D. The bill specifies that supervision must entail at least one hour of face-to-face supervision for every ten hours of treatment. In this respect, our bill is much more stringent than any other law or pending bill in the country.

And Mr. President, I must give an amount of great credit to our Attorney Joel Rubicoll, who has done so much work. And like other staff members, we're so fortunate to have a person who has he expertise and commitment. And Mr. President, when the vote is taken, I request a roll call vote.

THE CHAIR:

Thank you, Senator. Mr. Clerk, will you announce the roll call vote in the Senate on Senate A.

THE CLERK:

Immediate roll call has been ordered in the Senate. Will all senators please return to the chamber. Immediate roll call has been ordered in the Senate. Will all senators please return to the chamber.

THE CHAIR:

Have all senators voted? Have all senators voted? We will close the vote and ask the Clerk to announce the tally.

THE CLERK:

Motion is on adoption Senate Amendment Schedule A.

Total Number Voting	35
<u>Those voting Yea</u>	<u>35</u>
Those voting Nay	0
Those absent and not voting	1

THE CHAIR:

Thank you. Mr. Senator Crisco.

SENATOR CRISCO:

Thank you, Mr. President. May I request a roll

call vote on the bill, and let's mark it up for  
Jordan. Thank you.

THE CHAIR:

Thank you, Senator.

Will the Clerk please announce the roll on Senate  
Bill 301.

THE CLERK:

Immediate roll call has been ordered in the  
Senate. Will all Senators please return to the  
chamber. Immediate roll call has been ordered in the  
Senate. Will all Senators please return to the  
chamber.

THE CHAIR:

Have all senators voted? We'll close the vote  
and ask the Clerk to announce the tally.

THE CLERK:

Motion on passage, Senate Bill 301 as amended by  
Senate Amendment Schedule A.

Total Number Voting	35
Those voting Yea	35
Those voting Nay	0
Those absent and not voting	1

THE CHAIR:

Measure is adopted.

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Senator Looney.

SENATOR LOONEY:

Yes. Thank you, Mr. President. Mr. President, move for suspension for immediate transmittal to the House of Representatives of Senate Bill 301.

THE CHAIR:

Without objection, so ordered.

REP. LYDDY (106th):

Thank you, Mr. President. If we might change a few calendar markings and then, we'll be moving for the -- a couple of additional items before voting the consent calendar.

First of all, Mr. President, on calendar page 21, Calendar 103, that had been placed on the consent calendar previously, would move to remove that item from the consent calendar and to mark it passed temporarily.

THE CHAIR:

Without objection, so ordered.

SENATOR LOONEY:

Yes. Thank you, Mr. President. Also, Mr. President, on calendar page 30, calendar page 30, Senate Bill 2 -- Calendar 298, Senate Bill 154, that had been referenced for the Appropriations Committee,

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**CONNECTICUT  
GENERAL ASSEMBLY  
HOUSE**

**PROCEEDINGS  
2009**

**VOL.52  
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please call Calendar 623.

THE CLERK:

On page 20, Calendar 623, substitute for  
Senate Bill Number 301, AN ACT CONCERNING HEALTH  
INSURANCE COVERAGE FOR AUTISM SPECTRUM  
DISORDERS, favorable report on the Committee on  
Appropriations.

DEPUTY SPEAKER McCLUSKEY:

The gentlelady from Meriden, Representative  
Abercrombie, you have the floor, madam.

REP. ABERCROMBIE (83rd):

Thank you, Mr. Speaker.

Mr. Speaker, I move for the acceptance of the  
Joint Committee's favorable report in concurrence with  
the Senate and passage of the bill.

DEPUTY SPEAKER McCLUSKEY:

Question before the chamber is acceptance of the  
Joint Committee's favorable report and passage of the  
bill.

Will you remark?

REP. ABERCROMBIE (83rd):

Thank you, Mr. Speaker. The Clerk has an  
amendment, LCO 7409.. I would ask the Clerk to please

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call the amendment and that I be granted leave of the chamber to summarize.

DEPUTY SPEAKER McCLUSKEY:

Will the Clerk please call LCO 7409, previously designated House Amendment Schedule "A" -- Senate Amendment Schedule "A".

THE CLERK:

LCO Number 7409, Senate "A," offered by Senator Looney, et al.

DEPUTY SPEAKER McCLUSKEY:

The gentlelady has asked leave of the chamber to summarize Senate Amendment "A".

Is there any objection? Is there any objection?

If not, madam, please summarize Senate "A".

REP. ABERCROMBIE (83rd):

Thank you, Mr. Speaker. This bill this bill broadens what group health insurance policies must cover regarding autism spectrum disorders.

It requires a policy to cover the diagnosis and treatment of autism spectrum disorders, including behavioral therapy for a child 14 or younger and certain prescription drugs and psychiatric and psychological services for insureds with autism.

I move adoption.

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DEPUTY SPEAKER McCLUSKEY:

The question before the chamber is adoption of Senate "A".

Will you remark? The Distinguished Chair of the Insurance Committee, Representative Fontana tan in a, you have the floor, sir.

REP. FONTANA (87th):

Thank you, Mr. Speaker. I rise to support the amendment and the bill. I would like to at this point begin by thanking Representative Abercrombie for her work on this, along with Senator Crisco.

Senator -- Representative Abercrombie has done signal work on this issue, and she really has done this chamber and this General Assembly credit.

There is hardly a person in this body who knows more about the issue than she does, and she has been a tireless advocate for people who suffer from autism, as well as an advocate for pursuing sound public policy.

And in every step in the process this year, from the proposed bill in the committee to the bill out of committee, to the bill we see before us today in this amendment, Representative Abercrombie has done a fantastic job working to represent those who suffer

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from autism as well as those who want to pursue sound public policy.

So I'd just like to thank her for that and state simply, Mr. Speaker, that our understanding of autism is rapidly evolving as the incidence of autism continues to increase in society.

Formerly we viewed it primarily as an educational responsibility. As we learned more about it, we come to define its health-related components.

This legislation I believe builds on last year's legislation we did here in the General Assembly, moves it forward.

And again I'd like to just thank Representative Abercrombie for her leadership and again encourage my colleagues to support this amendment and the bill.

Thank you.

DEPUTY SPEAKER McCLUSKEY:

Thank you, sir, for your remarks.

Will you remark further on House -- Senate Amendment Schedule "A"? Will you remark?

If not, I'll try -- try your minds.

All those in favor of Senate "A," please signify by saying aye.

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Aye.

DEPUTY SPEAKER McCLUSKEY:

All those opposed, nay.

The ayes have it. Senate "A" is adopted.

Will you remark further on the bill as amended in  
will you remark further on the bill as amended?

If not, will staff and guests please come to the  
well of the House. Will the members please take your  
seats.

Excuse me, Representative D'Amelio, I didn't see  
your button -- light on. Now it is. Representative  
D'Amelio, you have the floor, sir.

REP. D'AMELIO (71st):

Thought I had it on. I must have by mistake  
turned it off.

Mr. Speaker, I rise in support of this  
legislation. Let's not kid ourselves. This is going  
to be a very expensive proposition. I look forward to  
continuing to work with everyone involved to tighten  
up this legislation, to make it even better.

But we feel very strongly -- all the stories that  
came before us in the public testimony of the family  
and their struggles with this disease and all the --  
all the great strides that are being made, it's just

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at this time I think this is the right thing for us to do and to adopt -- there's a new light shed on autism here at the capital. We understand it. Lunch many families are struggling. And this goes a long way in helping those families, so I urge adoption

Thank you, Mr. Chairman.

DEPUTY SPEAKER McCLUSKEY:

Will you remark further on the bill as amended?  
Will you remark further --

The honorable gentleman from the 100th,  
Representative Lesser, you have the floor, sir.

REP. LESSER (100th):

Thank you, Mr. Speaker. Through you, Mr.  
Speaker, question to the proponent of the bill?

DEPUTY SPEAKER McCLUSKEY:

Please proceed, sir.

REP. LESSER (100th):

Thank you, Mr. Speaker.

Through you, in the bill it specifies behavioral therapy. Is behavioral therapy the only treatment available currently for autism spectrum disorders?

DEPUTY SPEAKER McCLUSKEY:

Representative Abercrombie.

REP. ABERCROMBIE (83rd):

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Through you, Mr. Speaker. No.

DEPUTY SPEAKER McCLUSKEY:

Representative Lesser.

REP. LESSER (100th):

Through you, Mr. Speaker, just to clarify the legislative process, I believe at some point, this bill contained provisions for physical speech and occupational therapy, and I just wanted to ask for -- for clarification why those therapies are not accounted for in this version, the final version of the bill as amended.

DEPUTY SPEAKER McCLUSKEY:

Representative Abercrombie.

REP. ABERCROMBIE (83rd):

I'm sorry, I couldn't hear him. I'm sorry.

Through you, Mr. Speaker.

DEPUTY SPEAKER McCLUSKEY:

Representative Lesser, would you please rephrase your question, sir.

REP. LESSER (100th): .

Thank you. Through you, Mr. Speaker, I'm just trying to navigate the legislative process.

I wanted to know if physical speech and occupational therapies were removed from the bill, if

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there was a -- just clarify why that happened. That would be helpful.

Thank you. Through you, Mr. Speaker.

DEPUTY SPEAKER McCLUSKEY:

Representative Abercrombie.

REP. ABERCROMBIE (83rd):

Through you, Mr. Speaker. No, they are not removed from the bill. That was legislation that we did last year that went into effect as of January.

DEPUTY SPEAKER McCLUSKEY:

Representative Lesser.

Thank you, Mr. Speaker.

DEPUTY SPEAKER McCLUSKEY:

Thank you, sir, for your remarks.

Will you remark further on the bill as amended?  
Will you remark further on the bill as amended? If not, will staff and guests please come to the well of the House. Will the members please take their seats?

The machine will be open.

THE CLERK:

The House is Representatives is voting by roll call. Members to the chamber. The House is voting by roll call. Members to the chamber, please. Service.

DEPUTY SPEAKER McCLUSKEY:

Have all the members voted? Have all the members voted? Will all the members check the board to determine if your vote has been properly cast?

If all the members have voted, the machine will be locked.

Will the Clerk please take a tally?

Will the Clerk please announce that tally?

THE CLERK:

Senate Bill Number 301 as amended by Senate "A" in concurrence with the Senate.

Total number voting	142
Necessary for passage	72
Those voting yea	140
Those voting nay	2
Absent not voting	9

DEPUTY SPEAKER McCLUSKEY:

The bill passes in concurrence with the Senate.

Will the Clerk please call Calendar 194.

THE CLERK:

On page 4, Calendar 194, substitute for House Bill Number 6481, AN ACT CONCERNING THE EMERGENCY MORTGAGE ASSISTANCE PROGRAM, favorable report of the Committee on Banks.

DEPUTY SPEAKER McCLUSKEY:

**JOINT  
STANDING  
COMMITTEE  
HEARINGS**

**INSURANCE AND  
REAL ESTATE  
PART 3  
626 - 956**

**2009**

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down?

BARBARA GILBERT: We will be around \$998,000 for the 2009/2010 year.

REP. FONTANA: Very good, thank you.

Are there questions for Barbara from members of the committee?

Seeing none, thank you.

BARBARA GILBERT: You're welcome.

REP. FONTANA: I believe that concludes testimony on House Bill 5442. So seeing no one else at this point, we will proceed to Senate Bill 301. And just for the benefit of those who are here, at roughly 10 after 3:00 we will go to that hour of testimony for public officials. So we will begin with people testifying on Senate Bill 301, and then we will break for an hour or thereabouts to allow the public officials to testify, as we'd indicated we would.

So with that let me start with the Starkel family. Welcome. Please just state your name and proceed.

PHYLLIS STARKEL: My name is Phyllis Starkel. Good afternoon, gentlemen. I'm sorry, I didn't know all of your names. I'm grandmother of eleven-year-old Molly Sullivan Starkel, a student of the Gengras Learning Center in West Hartford, Connecticut. My husband and I are here to support SB 301 and help to make it a reality. Also with us today is our granddaughter Michaela Harbec, a freshman at Bolton High School, Bolton, Connecticut. Michaela has chosen to research autism for her

health class paper. This shows the interest and involvement of all family members.

Molly is one of the bright lights on the autism spectrum who along with parents and family members suffer from the emotional and exhausting physical stress of autism. She has experienced shunning from classmates at her previous school, not being included in birthday parties with the other girls and expressing how much she missed going, the extensive and sometimes painful blood tests, hospital and doctor visits. The most emotional moment was when with a very serious face she asked me what happened to her when she was born and why she wasn't like the other kids..

The worry of expenses if you are not fortunate enough to have health insurance, and even if you do, there are generally caps on the services most needed. Limited number of office visits for the special services such as occupational and physical therapy, the exorbitant cost for autism physicians, medications, educational materials, possible co-pays and transportation to out-of-area physicians and hospitals. Please give the importance of this bill your time and consideration.

Thank you for the opportunity to share Molly's life with you.

REP. FONTANA: Thank you, Phyllis. And before you go away let me just ask, I believe we passed a law in the last year or two that addressed autism to some degree. Can you comment on how well that bill has or hasn't worked to this point? Can you comment at all?

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PHYLLIS STARKEL: No, I really can't. I just know that the Department of Retardation has helped, but my son has been trying to get in touch with the case worker and it's been a year and a half since he's been trying to get in touch with her. She has not responded to him. He's still calling. And because they do need some extra help but they have not gotten it.

REP. FONTANA: Okay, good. Thank you. Thank you for your testimony.

Other questions for Phyllis from members of the committee?

Seeing none, thank you, Phyllis.

PHYLLIS STARKEL: Thank you.

REP. FONTANA: Next we have Jessica Rhodes. And then, like I said, at five after we will then proceed to the public officials.

Jessica, please proceed.

JESSICA RHODES: Thank you. Good afternoon, my name is Jessica Rhodes. Thank you for the opportunity to testify today. I'm here to support Senate Bill 301, health insurance coverage for children -- people with autism.

I'm a school counselor for Focused Alternative Learning Center in Canton. We are a therapeutic day treatment program for school-aged children with autism. I'm also here as a parent of twins who are wonderful but they both deal with autism issues. We live in Simsbury. I'm here to advocate for the families I serve and here to ask for what my children deserve. Not one child with ASD is alike. However, after much experience in

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the field, I can say with some authority that parents of children with ASD are extremely alike. We never get used to our children not getting play dates --

REP. FONTANA: Take your time, Jessica. It's okay. It's all right, just take your time.

JESSICA RHODES: -- or birthday invitations, we cried when our children are bullied on the playground and sad because we know bullies will continue to target them. We get embarrassed when our normal looking children throw a tantrum in the grocery store and people stare questioning our parenting abilities. Because of this we avoid going out in public with our children, and if we do we never do more than one errand at a time. We do not sleep because our children do not sleep. We educate the people who misunderstand our child's inappropriate behaviors. We hate the autism but we love our children fiercely. We face the dilemma of choosing an expensive intervention for one of our children knowing that our other typical children will be without extracurricular activities.

We fear our death only because we do not want to leave our autistic children to be cared for by a system that has already failed them. We neglect our marriages because our children need us more. We rarely have full-time jobs because no daycare can handle our kids. Because of this we do not have income to pay for services. If we have the good fortune of working, we have the good fortune of getting insurance. We know that insurance is good for the rest of our family but will deny claims for our child with autism so we go into debt to cover the cost of treatment, or worse, we

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don't get the treatment because we already have too much debt. We all know that what works for one autistic child may not work for ours, but we are willing to try anyway. While we waste too much of our limited precious time fighting for services our children are entitled to receive, we will not waste time on a treatment that is not working. We know that autism is a thief that steals our child's potential, and we know the right interventions can replace that potential. Any one of us parents can tell you that autism stinks, but we are also able to see the blessings that it has brought into our lives.

We learn to celebrate every milestone as they are few and far between. Our ears never tire of hearing I love you as we know we are among the lucky if we are able to hear it. We have become experts at hoop jumping even if we are uncomfortable doing it. We celebrate the few service providers who do accept our insurance and lovingly work with our children. We do not stop believing that someone out there holds the key that unlocks our child's potential. We never stop advocating because we can continue to hope that agencies, corporations, Federal and State Government will stand up and do the right thing for our children. And because we parents are all members of the autism club, we welcome all new incoming members with open arms, shoulders to cry on, earfuls of advice and strategies to beat the system. And we share hopeful thoughts that with mounting numbers like ours people will no longer be able to ignore our plight.

Some people are afraid that if this bill passes schools will feel as if they can get away with doing less. I ask less than what no

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one, no agency, no school system, no government program, and no insurance company has yet committed, financial resources to consistently support this population. Schools already do less than they should. They are required to deal with the academic success of our children for 180 days of the year for seven hours a day. Lucky kids get extended services for no more than six weeks of half days during an 11 week summer. Some school systems are better than others but none of them are catering to adaptive life skills or social skills as is recommended by autism experts. This bill is about getting insurance companies to stop denying our claims because the word autism is attached to our child's name. Much to our distress, no one does enough to help our children. This bill is the place we need to start. Thank you.

REP. FONTANA: Jessica, thank you. And just one quick question from me. Maybe you mentioned it in passing, but are any other states currently providing the level of support -- and if you can't answer, maybe somebody else will be able to answer after you but are there any other states that you're aware of providing the level of support that you're seeking from us?

JESSICA RHODES: Yes, yes.

REP. FONTANA: Okay. All right, we'll focus on getting the names of those states from somebody else, but you've at least told us that there are, so thank you.

Questions for Jessica from members of the committee?

JESSICA RHODES: And you did ask an earlier

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question that I can answer for you. The bill that was passed last year covered OT, PT and speech for children, and it only started in January of this year so not too many of us had the opportunity to benefit from that. This bill requires ABA neuro psyche evaluations and medications for our kids.

REP. FONTANA: Okay. And if you'd like to answer or I'll let somebody else answer what the difference is between the ABA, the neuro psyche evaluations and the other things. So if you don't want to answer that, feel free, I'll defer, but if you could just go through each of the things that you're seeking and why they are important that it would help me because I'm really not well versed in this subject.

JESSICA RHODES: Okay. Each child on a sector responds differently to different intervention. But the one evidenced based intervention that's been proven in the scientific community to make some difference in children is called ABA, which is applied behavior analysis. In it a series of repeating the same thing over and over again, breaking big tasks into smaller tasks, that I'm sure you have people here who are going to come testify who are experts in that. OT is occupation therapy. PT is physical therapy and speeches, speech therapy. Neuro psyche evaluations are what we need to get our children diagnosed. We need to take them to a developmental pediatrician or a developmental agency to get our child a diagnosis so that we can get service by the school, and those evaluations are not typically covered by insurance, and they usually run between, gosh, 1,000 to \$3,000.

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I think I've spent in my lifetime probably about \$15,000 on my twins on neuro psyche evaluations and they are seven. And medications, any medications that are given to a child with autism are typically medications that might be used for other disabilities like ADHD or even schizophrenia. Now, if your child has a different diagnosis, you would be able to get those medications covered, but insurance companies can deny your child medication if autism is attached to --

REP. FONTANA: Okay, that was a very concise primer for me, so thank you, and I appreciate that.

Other questions for Jessica from members of the committee?

JESSICA RHODES: Thank you.

REP. FONTANA: Thank you very much for your testimony.

It is now five after, so we'll go to the public official portion of the agenda today for the next hour. We'll start with Senator Looney, if he's available; and if not, we'll go to Representative Ayala.

REP. AYALA: Good afternoon, Chairman Fontana, Crisco, ranking members and the members of the insurance and real estate committee. I am testifying today in regards to HB 5433, An Act Concerning Health Insurance Coverage For Stepchildren. This bill is important to me because I have been contacted by many constituents who are currently having this problem. In some cases when a couple marries and one of the spouses chooses to add a stepchild to their insurance plan, it happens

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asked for, what it says is that a stepchild is supposed to be looked at under the term of as a child, but unfortunately what happens is that because it doesn't explicitly say so, it's a gray area, so some folks kind of get lost in the translation. And a quick and easy way to ensure that they don't get lost is to just explicitly include it and say listen, the stepchild is just as equal as a biological child and if the parent, the spouse, chooses to include them in the health insurance coverage, we should allow that to happen.

REP. FONTANA: Thank you for clarifying that. And certainly if you want to support healthy families, we want to encourage people to, you know, get married or remarried, build stronger family bonds, and this is one way perhaps to do is. So thank you for your testimony on that and submitting the bill.

REP. AYALA: Thank you, Mr. Chairman, I appreciate the -- we had letters and E-mails going back and forth, and I appreciate your attention to the details and raising this bill for a public hearing. Thank you.

REP. FONTANA: That's not a problem. I'm glad you brought it to our attention.

Are there questions for representative Ayala from members of the committee?

Seeing none, thank you very much. I look forward to working with you on it.

REP. AYALA: I appreciate that. Thank you.

REP. FONTANA: You're welcome.

We've been joined by Speaker Donovan so please

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step forward, Speaker Donovan.

MR. DONOVAN: Thank you, Mr. Chairman.

REP. FONTANA: Welcome.

REP. DONOVAN: Nice to see you, members of the committee, pleasure to be here before you today. Thank you for allowing me to testify. In support of legislation -- I'm sure I'll be joined -- we'll be joined later in the afternoon by Senator Looney who is on his way here. But we've been working on this legislation. I want to thank you for raising it, Senate Bill 301, which deals with insurance coverage for autism spectrum disorders, and it follows up on legislation we passed last year. It deals with insurance coverage for treatment for people who have autism, and I think it compliments that very well by dealing with some of the coverage that was in that bill that is not available to everyone, so make sure those aspects of the bill, last year's bill dealing with speech, occupational therapy and physical therapy, are in insurance policies as well and also deals with other treatments that are available that could really help out. I think the key to this bill and other bills that deal with health insurance is that we know that early detection on certain illnesses can really make a difference and certain treatments can really, when taken early enough, will really help with the long-term development and outcomes for people. So it's a good piece of legislation before us. I'll be happy to work with you on it. And I really think for the families who are out there who have been educating all of us about this disorder over the past few years, it would be a great help. They deal with this every day, and we're

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learning how we can be helpful, and I think through an insurance policy that provides these treatments it will help all of us and help society. So I want to thank the committee for your strong consideration of this legislation.

REP. FONTANA: Thank you Mr. Speaker. And certainly having you here says a lot about the bill and I'm learning as we speak about autism, so this is a great opportunity for me to find out a lot more about something that I know actually very little about. And I'm sorry to say that, but I know in two or three hours I'll know a heck of a lot more than I know now.

REP. DONOVAN: I'm sure you will.

REP. FONTANA: So it's --

REP. DONOVAN: There are really good people doing really great work, and I'm really grateful for all the information they provided me and I'm sure they'll provide you.

REP. FONTANA: Any questions for Representative Donovan?

REP. DONOVAN: Thank you. Have a great afternoon.

REP. FONTANA: Seeing none, thank you and thank you for coming.

As we are waiting or hoping that Senator Looney at some point will join us, let me ask is Kevin Lembo -- I don't see Kevin here so we will skip over Kevin Lembo of the Office of the Health Care Advocate. And I had seen Representative Conway here, so I don't know if I have you on the list but why don't you step

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forward and testify if you're -- are you testifying on a bill? I apologize for not having you on the list, but I'm sure you're here for a reason, so let me ask you to invite you to testify before us.

REP. CONWAY: Thank you, Mr. Chairman. No, I was not here to necessarily testify but here in support, but I appreciate the offer to testify and will certainly take you up on that.

As you know I'm -- I've just taken office this past January and the previous eight months in campaigning in my district became very much more aware myself of the autism and the impact it has on families and not just on the parents but the other children within those families, and I was somewhat alarmed by the number of individuals in the homes that I went to that were experiencing this with a child with autism in their family.

And it was back a few weeks ago I received a call from a constituent who is here in the room with us and Melissa Sullivan with regards to issues she was having getting services and found herself where services may be cut off from the Department Children and Family and not having the funding to be able to then go out and get those services herself. And that's why this bill is so very important because if we as the governing body of state agencies limit funding or otherwise make it difficult for people to get the services that we currently provide and they are forced to then go out and get them on their own without the financial means, the end result is that individual child suffers much more greatly than they would if they had the services. And especially in the birth to three area where even our public schools are not available to

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step in and provide those services. So I think it's very, very critical that we support this bill and that we continue to pool all of our resources, our Department of Social Services, Department of Children and Families, public schools, to accomplish in a group effort along with our insurance companies making sure that there is no interruption in these services and no putting people in a position where they are mortgaging their -- second mortgage, third mortgage on their home to be able to provide their child with these services.

So I thank you very, very much for your time and very much appreciate your consideration and support of this bill.

REP. FONTANA: It's great to have you here, and I'm glad you came to testify.

I'm assuming there are no questions for Representative Conway, so I appreciate that.

Seeing that we have exhausted our list of public officials who wanted to testify, cognizant of the fact that Senator Looney may join us, at which time we will ask him to testify, we will at this point go back to the public list of people to testify. And I have Randy Ewart, is that correct, Randy Ewart, or perhaps not. In any case, then Matt Katz to be followed by Beth Lambert. Beth Lambert is here.

MATTHEW KATZ: Representative Fontana and members of the Insurance and Real Estate Committee, my name is Matthew Katz and I'm the executive vice president to the Connecticut State Medical Society. And on behalf of the more than 7,000 members, thank you for the

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opportunity today to present testimony in strong support of Senate Bill 301, An Act Concerning Health Insurance For Autism Spectrum Disorders.

CSMS has constantly testified over the last few years before this and other committees regarding this issue. This is one of medical necessity. It is our policy that any service determined to be medically necessary by a treating physician or other medical provider should be covered under health insurance policies. Unfortunately the unwillingness of health insurers to routinely cover medically necessary services because of preexisting conditions or other exclusions such as definitions, have led us to the need to work with you to seek this legislation to require coverage for individuals who have autism and related disorders and other conditions.

Recently in fact yesterday CNN has reported that traditional therapies for autism can cost as much as 70,000 to \$80,000 a year in out-of-pocket costs for families with autism -- with children with autism. However, it also was reported that some of these therapies, some costing as little, and it's still a lot, as \$20,000, have shown promise in providing further development for children so they can actually perform activities or daily living, such as brushing their teeth, performing general hygiene and carrying out basic health and wellness measures, a small price to pay to ensure a greater quality of life for children with autism.

All people with developmental disabilities, regardless of definition, especially children, need to be able to provide general activities of daily living, need to be able to take care

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of themselves as best as they can. We need to afford them this opportunity. An individual's medical condition and welfare must be the basis of any medical decision, and medical necessity decisions must rest with the patient's physician and in concert with their parents in this case. CSMS believes very strongly that this legislation should pass. Early diagnosis is imperative to ensuring proper treatment for an appropriate intervention. We know more today than we did yesterday about autism and other spectrum and related disorders, but we do not know everything, but we do know that early detection and treatment is necessary. We ask Connecticut to follow the lead of other states including Texas and Indiana and recently South Carolina who have passed bills to allow for the coverage of these types of conditions. Thank you very much and please support Senate Bill 301.

REP. FONTANA: Matt, thank you very much.

MATTHEW KATZ: You're welcome.

REP. FONTANA: Let me just ask you one question, if I could --

MATTHEW KATZ: Sure.

REP. FONTANA: In your capacity. Someone told me perhaps erroneously that there is some gray area in between the responsibilities of our school systems to deal with autistic children and our medical and health insurance system. Can you comment on the tension or the overlap, if any, or the relationship between our school and health systems as it relates to autism?

MATTHEW KATZ: First of all, I think both are

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critically important. I'm not a clinician, I'm not a physician, I'm an advocate for physicians and patients, but I believe they need to work in partnership. The educational system is imperative for these children and young adults and actually well into adulthood, but also their medical providers are critically necessary in helping them navigate the system, not only the educational system, but our general system of health and welfare. I do not see a conflict, in fact, I see a supportive system, a wonderful partnership, and I do believe that we need to provide adequate assistance within the educational system. But just as importantly, if not more importantly, adequate diagnosis, treatment monitoring and maintenance through our medical system which includes health insurance coverage.

REP. FONTANA: Well, I guess that's one of the good things about being a chairman is you get to throw questions out and people in the audience who have the answer and are dying to give it to you hopefully when they get up to testify will be able to give you the answer. Well, thank you, Matt, for that.

MATTHEW KATZ: Thank you very much, Mr. Chairman.

REP. FONTANA: Questions from members of the committee for Matt?

Seeing none, thank you.

MATTHEW KATZ: Thank you very much.

REP. FONTANA: Again, is Beth Lambert here?

Seeing no Beth Lambert, Kathleen Dyer. Okay, well, when she comes back just give me the

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high sign. Denise Smith. Denise will be followed by Thomas Carty. I think he's still here.

DENISE SMITH: Good afternoon, Senator Crisco, Representative Fontana and members of the Insurance and Real Estate Committee. I am submitting this testimony in support of Senate Bill 301, mandating insurance coverage for people with autism spectrum disorder.

Connor, my five-year-old son was diagnosed with autism at age three. We were given names of various professionals to take Connor to in order to help facilitate the best recommendations for the school system. We made an appointment with a well-known pediatric psychologist and borrowed the \$1,800 required for the visit. The great news is that we took his advice and applied it to our son's life. It did not happen exactly the way the doctor intended it to happen, but for reasons I will not give them to you here, the bottom line is our son was imposed upon for at least 30 hours a week by the school system and by outside therapies provided by Talcott Center for Child Development. These services included OT, PT, speech in a social skills group. We also take him out every weekend and impose on him some more. It took him over a year and a half to be able to consistently transition into school and many other places without tantruming. But in following this doctor's recommendations, he did it and he did so much more.

Currently Connor is a success story. It all stems back to that initial diagnosis and recommendations made and follow through when he was three years old. He's doing terrific. Parents of his typical peers cannot believe

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the transformation. We have been told several times that we would be greatly served to have Connor reevaluated every year so that new recommendations could be made that take into consideration his successes and adjusted for other issues that have arisen or may arise in this wonderful world of autism. We have not been able to afford that luxury for the past two years. We recently questioned some things that we noticed at home and that therapists noticed during their sessions with him and were told that our son is potentially having issues with processing and coding and retrieving information. He has come so far and it would be very helpful to have recommendations from a pediatric psychologist to deal with these issues as he is preparing to enter kindergarten next fall.

Kindergarten brings on academic expectations that he has not had to deal with to date and where problems with processing and coding and retrieval would have a negative impact on his ability to learn. An evaluation would provide an accurate diagnosis of the problem and then a plan of attack to conquer it. The various approaches are also scientifically proven to work. We can testify that they worked at the first stage of Connor's life and we would appreciate the opportunity to allow them to work at the next stage of his life. We are struggling to find the \$2,000 which is currently needed for this reevaluation. With the passing of this bill, we will no longer have to worry about this issue and will be able to focus on putting into place the recommendations necessary for Connor to have the continuing success we now know is possible and that every child deserves.

REP. FONTANA: Denise, thank you, you did a great

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job. Don't go, I have a couple of questions for you, low pressure questions. First, I'm sorry, I didn't get a chance to meet Connor, so I'm sorry about that, but I see his picture but it sounded like he's five?

DENISE SMITH: He's five.

REP. FONTANA: All right. Could you just comment briefly on what kind of experience you had with the school system because it sounded like you said you took him to a -- did you go through the school system or you did it independent? Could you just talk a little bit about that?

DENISE SMITH: The decision came first and the hours that they recommended for Connor to receive I was told were not adequate to serve Connor well in regards to his autism diagnosis. Actually he wasn't diagnosed with autism, he was diagnosed with sensory issues before he turned three. It was pretty clear at that point that he had autistic tendencies so we decided that we were told by friends and people that are in the field that we should see a neuropsychologist. So we got on a list and with this report the school system did so much more than they had offered prior to and we also had what we needed to have him get speech and OT and PT. We actually had decent insurance so it was covered prior to the bill that you passed last year, and we got his 35 that was recommended via the school and these outside services.

REP. FONTANA: So your feeling is the school system was fairly supportive but not as prepared to do what he needed until you got the evaluation done, is that -- I'm not trying to put words in your mouth, I'm just trying to get a sense

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of things.

DENISE SMITH: The school system was as supportive as the budget would allow it to be and that's all. I feel like they would have done more if they had more money to do it with, and unfortunately our kids are part of a business in more ways than one in the school system and in the insurance companies, and that's the way they stand. It's not fair.

REP. FONTANA: Without naming the town that you live in, could you tell me like is it a small town, a medium size, big city?

DENISE SMITH: I live in Simsbury.

REP. FONTANA: Okay, well, now I know. But thank you, that's interesting. Thank you.

Are there other questions for Denise from members of the committee? None.

Thank you very much for coming up and sharing.

Thomas Carty to be followed by Beth Lambert. Is it Beth or Beverly? Beth Lambert, Beth, okay. So we'll talk to Thomas first. Is Thomas here? I see no Thomas. Okay, Kathy Dyer is back. Okay, very good, we'll do Beth Lambert and then we'll do Kathy Dyer, and then we'll do Matt Hall if Matt is here.

So welcome.

BETH LAMBERT: Good afternoon, Representative Fontana and committee members, my name is Beth Lambert. I'm president of Connecticut FEAT, which is Families for Effective Autism Treatment. We're an organization that for over ten years now has provided families with

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help getting effective autism treatment and Connecticut FEAT strongly supports ABA, Applied Behavior Analysis. And the reason we do is it works.

I'd like to share my own family's experience with autism and ABA so that you can understand just how well it works. My son did not start an intensive ABA program until he was four and a half. At that time he was not toilet trained, he did not talk, he could not participate in simple social situations such as eating dinner with the family. He's now -- at that time he also had daily temper tantrums because he was so afraid and didn't understand what was going on. When he was four many people found him frightening to be around, even family members felt that way. He's now fifteen.

He's had pretty much an ABA program for the last 11 years, and he is not only independent and toileting and bathing and dressing himself, but he also not only eats dinner with the family but he sets the table, he helps to clean up afterwards. He bowls weekly. He is included in birthday party invitations. And when I talk to friends and family and his teachers they tell me what a pleasant and affable young man he is to have around. I can tell you that if the behaviors he showed at four were still going on now that he's fifteen, 5' 10", 150 pounds, if those behaviors were still going on, he would be in an institution and costing the state a lot of money. At a time that we're now passing on more and more of the cost of the present to our children, this bill is a chance to improve the quality of life not only for autistic people but their families, to increase the viability of the autistic people's lives and

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to mitigate the costs that we're passing onto our children. I strongly urge you to support Bill 301 on behalf of Connecticut FEAT, on behalf of all these struggling families dealing with autism and my own views. Please support it.

REP. FONTANA: Thank you, Beth. And I'm sorry he's not here as well, but maybe one day we'll get a chance to meet him, but thank you.

And so he was doing ABA you said for a decade. And so are there a lot of entities that provide ABA in the state?

BETH LAMBERT: There are not a tremendous number. Dr. Dyer, who's going to be speaking after me, was actually the director of his old school which is a correct school and he's now moved on to the River Street School in Windsor. I believe there are about four schools that are either public or private that specialize in ABA here in the state and many of the towns have ABA programs. The question that really seems to come up is the quality of those ABA programs because to really do it well, and Dr. Dyer can talk more about how you do it well, but you need that BCBA, which is board certified behavior analyst. It means they have taken certain courses, they've done over a year's worth of internship working with kids with autism and they're really professionals at doing that. If it's not done right, it can mess things up worse than if you hadn't tried it at all. My son had made progress at the local school and then they switched consultants to someone who was not a board certified behavior analyst and he fell apart. They ended up having to keep him in a room by himself so he wouldn't hurt others or hurt himself, and that's when we moved him to Dr.

Dyer's program.

REP. FONTANA: Thank you. Are there questions for both from members of the committee? None.

Thank you, Beth.

BETH LAMBERT: Thank you.

REP. FONTANA: Kathleen Dyer to be followed by Vincent Flynn, if he's still here.

KATHLEEN DYER: Good afternoon, Representative Fontana and members of the committee. Thank you so much for taking the time to listen to the testimony of myself and other family members that want support of Bill 301.

The year 2000 report from the Surgeon General states that 30 years of research demonstrates the efficacy of Applied Behavior Analysis methods in reducing inappropriate behavior and increasing communication, learning and appropriate social behavior in individuals with autism. This evidence includes intensive experimental studies of individual children as well as randomized trials comparing groups of children. In a study conducted with our own children in Connecticut, greater gains in child functioning and quality of life were reported when children received higher quality treatments based upon Applied Behavior Analysis. So we ask this question: Why should we support this bill? Why should we go along with the decision made by other states to provide insurance coverage for this debilitating disorder, a decision made by the State of Indiana, the State of Minnesota as well as a decision adopted by Canada Nationwide. A study in the Journal of Behavioral Interventions reports cost benefit

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estimates for early intensive behavioral intervention for young children with autism. The report states the problem, that without effective intervention most people with autism require life-long specialized services at a total cost estimated at upwards of \$4 million in some states. So it is prudent to ask how investments and services are likely to pay off in the long run and how to make use of the limited resources available for treating people with autism.

The behavioral interventions article reports that the net savings for a child with autism who achieves normal functioning through behavioral intervention is over \$1 million and for a child who realizes partial effects is still over 1 million dollars.

So I'll conclude that like effective treatments for other severe child disorders such as cancer, early behavioral intervention can be described as aggressive and intrusive and expensive and necessitate a high level of specialized expertise for effective delivery, but if a child with a major disorder needs treatment, cost is usually not a major factor and various and private resources are typically made to cover the cost. So for the sake of all individuals with autism and for our families and for our communities in the State of Connecticut, it's time to insist that this same consideration apply to the treatment of autism. Thank you.

REP. FONTANA: Thank you, Kathleen. And just in case -- I haven't looked at your written testimony -- but in case it's not in there, would you please give the information, you mentioned it, it's scientific or evidenced-based evaluation of ABA and its

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efficacy? And I'd like seeing that. So it's in the testimony?

KATHLEEN DYER: It's all there on the back of the written testimony.

REP. FONTANA: And does that include the citation to that cost benefit analysis that you mentioned?

KATHLEEN DYER: The citation of the cost benefit analysis is in the front page of the testimony.

REP. FONTANA: Very good. I've got a stack this thick, as you might imagine, so I haven't found your testimony. That's good because I'll look for both of those things. Thank you.

Questions for Kathleen from members of the -- Senator Caligiuri.

SENATOR CALIGIURI: Thank you, Mr. Chairman. Doctor, thank you for testifying today.

I want to make sure, when I look at the way the bill is drafted, it leads me to want to ask you a few questions. Is ABA Applied Behavior Analysis, a treatment or is it also a diagnostic tool or can it be both?

KATHLEEN DYER: It's a treatment.

SENATOR CALIGIURI: It's a treatment. Okay. I ask that because the bill talks about coverage for diagnosis and treatment of autism spectrum disorders, including but not limited to applied behavior analysis so I wanted -- not knowing a lot about this, I want to make sure I understood. Your testimony has focused a

lot on the value of Applied Behavior Analysis and it sounds like that's one of the big things that is being asked for today. And I'm sorry when someone testified earlier that I didn't put the list of everything she mentioned, but as someone who works in this field, is there something other than Applied Behavior Analysis that you think should be covered that isn't covered currently that we would want to cover in this kind of an insurance mandate bill that you're aware of that would be useful to families that are dealing with autism as an issue?

KATHLEEN DYER: Well, if you ask me, I think that I believe the wording of the bill has evidence-based treatments or science-based treatments in it.

SENATOR CALIGIURI: It talks about I'll just -- it talks about requiring coverage for, and I'll quote, "the diagnosis and treatment of autism spectrum disorders including but not limited to applied behavior analysis, psychological evaluations and medications."

KATHLEEN DYER: I support science-based treatments. Applied Behavior Analysis is currently the only intervention that has a solid evidence base that has what we call the gold standard in our field which is randomized clinical trials. If there were any other treatments that also had that same gold standard, I would support those being included.

SENATOR CALIGIURI: So when you say Doctor, that you support science-based treatments, I think what I just heard you say is that ABA is the only one currently that qualifies as a science-based treatment because it's been vetted so thoroughly and so effectively?

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KATHLEEN DYER: Correct.

SENATOR CALIGIURI: Okay. And I'm only asking because if we're going to expand the mandate, and I don't use that in a pejorative way, I want to make sure that we have a good handle on everything that we would want to include in an expanded mandate, hence my question. Thank you, Doctor.

Thank you, Mr. Chairman.

REP. FONTANA: Thank you. Other questions for Kathleen?

Seeing none, thank you.

Is Vincent Flynn -- excellent, to be followed by Shannon Knall.

VINCENT FLYNN: Good afternoon, Representative Fontana, Representative Megna, Senator Caligiuri, I'm Vincent Flynn, I live in Cheshire.

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I don't have prepared testimony because I think you want to hear from the heart. My life changed about eight years ago when my son got an autism diagnosis. And since then we discovered he has an expressive disorder. And I think I speak probably for most parents of autistic children that we feel like we all have an expressive disorder, we're not hurt, we're very busy, our children are our lives. I spend a lot of my time going back and forth from speech therapy and occupational therapy for my son which is done after school.

I don't wish to contest the testimony of Dr. Dyer, but I certainly hope there's no

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legislation that would limit access to insurance coverage for those therapies. They are very good for my son. They've helped a great deal. I believe they may have been covered in last year's legislation. I've learned a lot since I've been here this afternoon.

I now realize that a few years ago I would have had better insurance coverage to deal with had I had a dog that bit somebody than my son would have had to deal with speech therapy. I was between jobs with the state at that point in time, and it looked like I'd have to go on my wife's insurance which was at Anthem at Saint Raphael. That was limited to 30 visits of speech therapy, 30 visits which he was going twice a week, they would have been gone in about four months. That's just not enough. We have to be resourceful, we have to take advantage of what the school systems are providing, what the health insurance systems are providing, what we can bring to the table ourselves. What we don't want are barriers. We don't want to be told we can't do something for our children that no, we can't do that, you can't do that. We want to do something. We want to make our children the most productive that they can be. I don't want my son to be a drain on the State of Connecticut when he gets older, but you know what, the only way we're going to be able to do this is if we're allowed to do it by the system. And I appreciate the time to speak. Thank you.

REP. FONTANA: Vincent, thank you very much and we appreciate you speaking from the heart.

VINCENT FLYNN: Okay, thanks.

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REP. FONTANA: It is helpful. Before you go, are there any questions.

Senator Caligiuri.

SENATOR CALIGIURI: Thank you for testifying. I just want to follow up. In your experience as a parent, is there any treatment that's been useful to your son that for which you haven't been able to have insurance coverage that you think insurance coverage should be expanded to include?

VINCENT FLYNN: Well, right now I'm on the state Anthem Blue Cross which has been excellent insurance. We have not had a problem with denial of coverage for things that professionals have recommended. I will say that someone who mentioned, I think it was Representative Fontana mentioned, is there a gray area between education and medical care, yes, there is. And some people would say, for instance, the speech therapy I should be getting the Cheshire school system to cover. You know what, if I can run it through some other program to get it paid for, I'm not going to spend my time and energy fighting, I'm going to work to try and get my son as well as he can be and that's a more productive use of my time and energy. So yes, there's gray areas, and I would say that probably most of the parents here we're busy trying to fill them in on our own.

SENATOR CALIGIURI: Thank you very much, Vincent.

VINCENT FLYNN: Thank you, Senator.

REP. FONTANA: Thank you. Seeing no further questions, thank you Vincent.

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Shannon Knall followed by Laura DeAngelo, if she's here.

SHANNON KNALL: Hello. Representative Fontana, members of the Insurance and Real Estate Committee, my name is Shannon Knall, I'm the Connecticut advocacy chair for Autism Speaks and the mother of almost an eight-year-old with autism. And I'm submitting this testimony today in support of Senate Bill 301 mandating insurance coverage for people with autism spectrum disorders.

We began this process last year, and some of you heard the horror stories of financial burden for many people impacted by autism, and today you will continue to hear many of the same stories, parents paying up to \$5,000 out-of-pocket for medical diagnosis, up to \$150 an hour for 40 hours weekly of applied behavior analysis as recommended by a physician and possibly upwards of \$120 per month on medically prescribed drugs for the treatment of autism, and you have heard and will continue to hear stories about families who simply have to opt out of these critical treatments because it is just too costly. Autism is first and foremost a medical condition. It needs to be treated medically just as any other medical condition. It's treatment should be covered by insurance, just as any other medical condition is. Make no mistake, families with autism have insurance. We pay insurance premiums. The fact that we are being denied services that should be covered under insurance plans is nothing short of discrimination. There are seven states that have done this already, that have passed this legislation. There are 30 other states in this country on the books waiting to pass this legislation, as we speak. You will hear

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the myths about insurance premiums skyrocketing as a result of the possible passage of this legislation. You will see evidence to the contrary, evidence that indicates the rate would be nominal. It's time for Connecticut to lead the charges that will end this discrimination. I thank you for your time and I urge your very careful attention to this legislation. Thank you.

REP. FONTANA: Shannon, thank you very much. And first you mentioned, again, you talked about the states. You mentioned there are seven states?

SHANNON KNALL: Yes.

REP. FONTANA: Will you be able to pick them off for me?

SHANNON KNALL: I sure can.

REP. FONTANA: I'm not trying to -- very good. I was hoping you might. Would you mind?

SHANNON KNALL: Florida, South Carolina, Illinois, Indiana, Pennsylvania, Texas -- am I missing one?

REP. FONTANA: Minnesota one of them?

SHANNON KNALL: No, Arizona.

REP. FONTANA: That makes seven, great, all right.

The second thing I wanted to ask is, and again I apologize if it's in your testimony, but you touched on in your testimony the issue of impact on insurance premiums and you said the impact will be nominal. Is that in your testimony? Can you provide us additional

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information on that while others testify to that because that's of interest, of course, to us as you might expect?

SHANNON KNALL: There have been studies done by Autism Speaks, and we're still working on the specific figures for the State of Connecticut that indicate an across-the-board insurance premium increase would be half a percent, so it's really very nominal, as I said.

REP. FONTANA: So would you be able to forward that analysis to us when it's done?

SHANNON KNALL: Uh-huh.

REP. FONTANA: Okay, that would be great. Thank you.

Questions for Shannon? Seeing none, thank you. We'll look forward to getting that, and great job.

SHANNON KNALL: Thank you.

REP. FONTANA: Laura DeAngelo -- we had Jessica Rhodes already, so I won't give you two bites of the apple -- Laura DeAngelo followed by Grace Simpson.

LAURA DEANGELO: Good afternoon, Representative Fontana, members of the Insurance and Real Estate Committee, my name is Laura DeAngelo. I'm speaking to you today as both a parent of a child on the autism spectrum and also as a professional in the field of autism. I'm speaking not only in support of Senate Bill 301 but also in support of broadening the scope of this bill to allow families to choose the type of autism intervention that best fits the needs of their child and the family.

There is no doubt that ABA, Applied Behavior Analysis, has more research behind it than any other autism intervention and is effective for many children.

However, this research clearly shows that not all children with autism derive significant benefit from ABA. It is not clear yet why some children do not benefit from ABA or only derive limited benefit, but this is a fact. Even in the best outcome studies, over 50 percent of the children involved in early intensive behavior intervention still did not attain an independent level of functioning. My son was diagnosed with autistic disorder at age two and a half.

Through a well respected ABA based school program supplemented by me at home, he gained many skills and much language, however after several years we realized that this method was not effective for us in addresses the core issues of his autism which led to his rigidity, social aloofness, great need for control, aggression and self injuring. To deal with these core issues we found a much newer intervention, relationship development intervention or RDI, a parent-centered approach to the remediation of the core deficits of autism.

RDI does not yet have independent peer reviewed research backing it, but the principles on which it is based, guided participation, the importance of the infant parent bond in cognitive development, experience sharing communication, challenging the child at his level of competence, are all well documented in the literature and accepted by the mainstream autism community.

It is worth noting that ABA is a 50-year-old approach, but the first widely accepted research on this method for treating autism was not published until 1987. For my son a combination approach was the answer. He derived benefit from both ABA and RDI. Now he is transitioning out of the autism program in school, able to function without one-on-one support and without intensive behavioral interventions. Last year I attained my certification as an RDI program certified consultant, and in my professional practice I've worked with a number of families for whom ABA alone has limited effectiveness for their child, especially in the area of social competence, emotional regulation and flexible thinking, areas critical to independence in life. With RDI these families are seeing positive results in these areas. So please support expanding Senate Bill 301 to provide families a choice of covered autism intervention treatments to ensure that more children and their families have a chance for a long-term quality of life. Thank you.

REP. FONTANA: Laura, thank you for your testimony.

Are there questions?

Senator Caligiuri.

SENATOR CALIGIURI: Thank you, Mr. Chairman. Thank you for your testimony. I'm trying to -- help me to understand how it works as a practical matter, and I'm sorry for not knowing. When you're at the beginning of this process do you have, for example, a primary care physician who may refer you to someone who can help diagnose a child as being autistic? And when you're trying different treatments like the one you describe that worked in your case, is

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that through the referral of a physician? Here's why I ask that question: The more open-ended we make the mandate, the more difficult it becomes to sort of circumscribe it and make sure that you're limiting it to things that have actual usefulness, and so the issue becomes what's the right gatekeeper, who's the right gatekeeper for making that determination. And so if you were to tell me that in the normal course a primary care physician makes the referrals and helps to manage the process and is sort of a gatekeeper, that might give us some insight into how the process works as opposed to having it work some other way. Could you help me to better understand how that all works?

LAURA DEANGELO: Primary care physicians right now in the State of Connecticut do not have a good understanding of autism.

I think most of the families will agree with that. My primary care physician missed diagnosed my son, although I respect him and his general medical knowledge. He missed my son's diagnosis. The ear, nose and throat physician we were taking him to for his ear tubes missed his diagnosis. The birth to three team never told me about his autism, although they suspected it. They just were referring to him as a developmental delay and were treating him as such for a year even though he had the signs of autism. It took me -- that he had autism through doing my own research and I think most of the parties in this room will testify that it's really them, it's their own efforts, they have to do their homework, they have to connect with other parents. The developmental pediatricians in this state are knowledgeable about the different interventions. There are several in

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the state I know who endorse and recommend RDI, deep Lemay and Ann Milanese have both recommended RDI as a valid intervention. So, yes, it is endorsed by at least some of the physician professionals in the state, but I had to do my homework. I knew that there was a core issue that wasn't being addressed and I went to find the intervention that I thought would meet my child's needs. It's a parent-centered home-based intervention, generally costs less money than ABA because it doesn't involve outside interventionists, but I am supporting ABA as well because I think that ABA provides a lot of benefit for a lot of kids and it did help my son learn a lot of skills and increase his language.

SENATOR CALIGIURI: Just for the sake of my own thinking and discussion, let's say we were to draft this in such a way as to say that it's covered if the treatment is referred by a developmental pediatrician. You said developmental pediatricians. Would that be a useful way of doing it? Here's what I'm afraid of: If a parent is on their own because there is really no one around who can help guide them and they are trying to find help and making their own decisions on what's working and not working, it's just a lot harder to define the mandate that way in terms of how it works and how we make sure that the insurance companies have a system in place to make it workable and systematic. So I'm trying to think through how do we put a system in place that would really work, and that's why I throw out that idea.

LAURA DEANGELO: I think that's reasonable. I don't know how other parents feel about it. I think it's reasonable. I think you're going to find differences of opinion with different

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physicians in terms of what is the best course of treatment, but certainly I know that there are some in the state that are advocates of this approach.

SENATOR CALIGIURI: Thank you very much.

Thank you, Mr. Chairman.

REP. FONTANA: You're welcome.

Other questions for Laura?

Seeing no further questions for Laura, other than from our assistant clerk, I would ask if Grace Simpson could come up now to follow followed by Christine Levine, if she's still here.

GRACE SIMPSON: Thank you for the opportunity to talk with you today. I feel compelled to deviate a bit from my submitted testimony to really more specifically talk to you about some of the issues I've been having with insurance, but I do want to talk briefly about ABA.

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This is my son Cash'an. He's five years old. Cash'an was diagnosed with autism spectrum disorder at age two, typical looking rambunctious, happy, loving boy, and Cash'an didn't have any words. His ability to communicate was significantly impaired. It continues to be, lots of delays with him as well. He remains significantly developmentally delayed. Cash'an didn't know what to ask for instead of without warning he'd pinch and bite out of frustration, just not being able to be understood. He needed to learn life skills. He was the first -- and I'm going to deviate here a little bit -- he

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was the first student in my town to go to a private school. That whole process was very, very difficult. School systems are not eager to pay for such private therapy that he needed but with ABA therapy he's been able to learn social skills.

There is one typical little girl who in the public school that he attended wanted to be his friend and the mom called me out of the blue and just said, you know, she wants to get to know your son. Well, he had his first play date and at that play date he basically sat on the other side of the room and played with the rug. He eventually got engaged and bouncing on a ball and he was so excited about that but didn't know how to say that he was happy playing that he bit her. ABA has allowed him to learn how to be in a room with other children to be able to interact with them and start to learn what it's like to be in a typical situation.

On a note of evaluations, before I get to the insurance issue for a moment, that is an area that we spent almost \$10,000 on out-of-pocket. You'll find, and particularly underserved communities and communities of color that's a real issue. Autism knows no color, it knows no economic status. So I implore you to support this bill for that reason as well.

With regard to insurance coverage, as I said, my son does not have any words. We recently had Anthem Blue Cross Blue Shield, but my husband's company changed that insurance. Now the insurance does not cover additional speech services that we're seeking. Also other therapies such as sensory integration, my son used to chew on window sills and he used to bounce himself really hard and there are

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things that you can teach a parent to do at home to help him not do those kind of injurious behaviors. The insurance company that we have now does not cover it and so we're stuck and my son continues to not have these words. Thank God he's at the school that he's at because they continue to do things for him. For parents on limited income it's very difficult because as it is now I cannot find any coverage for him. He needs -- I thank you for listening to that.

REP. FONTANA: Thank you for your testimony. So your struggle is both with the insurance company and your school system it sounds like; is that true?

GRACE SIMPSON: Yes. Initially the school system had a program in place and so they felt like it was appropriate and for him it wasn't. The therapist that they had in the public school they weren't trained enough and so we had to seek legal action to, you know, pursue other avenues and also had to get a psychological evaluation again which we paid for initially to show what he needed. And so, yes, that was a struggle for us.

REP. FONTANA: And he's five now.

GRACE SIMPSON: He's five now.

REP. FONTANA: Okay. And he's in school you said?

GRACE SIMPSON: He is, and he's made significant gains. I can tell you that he's at the school where Dr. Kathy Dyer is a clinical director and he's made significant gains. He's learned life skills, he's using the bathroom on his own -- we won't share the details of his story prior to that -- dressing, learning how to sit

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at the table, again being able to sit with other children, even preschool skills. He technically should be in kindergarten but he's not ready but again he is making gains and he's at a place where there is high amount of training that can meet him and understand his needs and take him to the next level.

REP. FONTANA: Is he receiving ABA services?

GRACE SIMPSON: Yes, that's the primary service that he receives. He gets ABA at school. He also has ABA at home and those home services are covered right now by the state, but I understand that the budgets are being cut and I don't know how long we're going to have that, so that's a concern because it's not only for the child, it's for the parent too. So having that ABA, that kind of therapy, and principles at home, it helps us -- you know, I have an eight-year-old daughter who didn't know and now she knows to use certain kind of reinforces that ABA promotes in helping him, and so it's for the whole family. But again, if we don't have the coverage and it's gone, then what do we do and where does that leave him, and especially when you have a child who is nonverbal because of his autism.

REP. FONTANA: Great. Thank you, Grace. Are there questions for Grace from members of the committee?

Seeing none, thank you, Grace, very much.

Christine Levine. Christine is here to be followed by Michael Meehan. Michael is here.

CHRISTINE LEVINE: Good afternoon, my name is Christine Levine. I'm clinical director of Creative Interventions. Creative

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Interventions provides primarily ABA services to children on the autism spectrum, age about sixteen months up through eighteen years of age. The services provided are both individual and dyads, which is two children and small group therapy, depending on the children's needs, so it's not all one-to-one ABA service.

Applied Behavior Analysis is the only scientifically proven treatment for autism spectrum disorders. Research supports that close to 50 percent of children with autism can reach normal levels of functioning with intensive ABA programs. The goal of ABA is to teach children with autism to learn the way other children do, primarily through imitation, so that they no longer need the treatments. ABA treatments work well with children on the autism spectrum for several reasons: First, it offers a high level of reinforcement. Children with autism are not reinforced just by somebody saying, you know, good job or by completing a task, doing a puzzle by themselves and feeling proud of themselves, they need much higher levels of reinforcements initially and then you phase that out.

In addition, the intensity of services needs to be much greater. While the typical three or four-year-old may learn a new skill when you present it to him or her one or two times, a child with autism may need 2,000 to 3,000 trials before they learn that skill. ABA is also used to decrease inappropriate behaviors such as aggression and noncompliance. It is important to note that many families of children with autism spectrum disorder are unable to take their child into the community which dramatically affects their quality of

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life. The treatment of a child with ASD with problem behaviors reduces the stress of a family and can increase the family's ability to participate in community activities with their child. ABA can also help children at all levels on the spectrum. An early learner's curriculum may focus on increasing attention to task, imitation of actions, and learn to request one's needs.

Do you want me to stop?

REP. FONTANA: Since you asked, I would like to ask you a question and then --

CHRISTINE LEVINE: Sure.

REP. FONTANA: The general question I have, Christine, if you can comment on it, is are you familiar with the range of services that school systems provide? I mean, are you familiar -- I mean --

CHRISTINE LEVINE: Yes, as --

REP. FONTANA: -- can you comment on the range of services?

CHRISTINE LEVINE: As part of my job I have gone in and evaluated school district's programs.

REP. FONTANA: And can you characterize the quality of those programs as a rule?

CHRISTINE LEVINE: It varies. I would say most programs don't have a high quality structured ABA program with related services at the level that they are needed, and the schools that do the problem is the quality of the person delivering the services they hire someone with a high school degree to carry out all of the

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programming as opposed to if someone is receiving services through us, the person is much more qualified.

REP. FONTANA: So, it really varies dramatically by school district what kind of services you get. Some may have no services, some have services, but they have a person who's unqualified or under qualified producing them?

CHRISTINE LEVINE: Implementing it. And many times they don't have a qualified person supervising the program like a board certified behavior analyst or someone with an equivalent training and background in autism and ABA.

REP. FONTANA: Are there entities spread throughout the state that can provide ABA, in other words, if -- I live in North Haven, so I know I'm generally speaking in the middle of the state, so I'm never too far from anyplace, but if you happen to live in say Windham or Goshen or, you know, Ledyard --

CHRISTINE LEVINE: I think it's difficult. There is a shortage.

REP. FONTANA: Do they have access to ABA?

CHRISTINE LEVINE: Yes, there is a shortage of certified behavior analysts. But I think if this bill were to pass, more people might get into the field and might be able to start private practice knowing that it's covered by insurance.

REP. FONTANA: Okay, thank you.

Other questions?

Senator Caligiuri.

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SENATOR CALIGIURI: Thank you, Mr. Chairman.

Thank you for testifying today.

CHRISTINE LEVINE: Sure.

SENATOR CALIGIURI: You along with a lot of others have focused a lot on ABA as being proven, for lack of a better term, as being effective, yet we've heard some testimony from others that other treatments have been effective for them as well. Is it your experience that even though other treatments may not have had the kind of verification over the years that ABA has had as being proven to work, is it nevertheless your experience that other treatments do work notwithstanding that level of kind of scrutiny that ABA has withstood?

CHRISTINE LEVINE: Well, this is what we've done. The only other therapy aside from OT, PT and speech is relationship development intervention. There are some key components of that therapy that we incorporate into our ABA program and we look at it behaviorally, we take data on it, we see if it's successful. If it works, we continue it. So we kind of embed some of that in what we do. I don't really know the efficacy of an RDI program. That's just an RDI program without the ABA component.

SENATOR CALIGIURI: And just by way of educating me because I don't know the answer to this, are treatments basically either ABA or RDI, or are there --

CHRISTINE LEVINE: No, there are a lot of other different treatments out there.

SENATOR CALIGIURI: But you're focusing on ABA, I presume, because in your practice you've concluded that's the most effective treatment that's out there?

CHRISTINE LEVENE: Correct, correct. And I do think there is some benefit to the RDI. I just think we need further research. And like I said for now, we embed some of that into our curriculum and what we use with our kids.

SENATOR CALIGIURI: Uh-huh. Okay, thank you.

Thank you, Mr. Chairman.

REP. FONTANA: Thank you, Senator.

Other questions for Christine?

Thank you, Christine.

CHRISTINE LEVINE: Thank you.

REP. FONTANA: Michael Meehan followed by Aurora D'Angona. And then if there is anyone else here who would like to speak on Senate Bill 301 who's not -- who if I haven't called on you yet thus far, I may not have you on the list.

So Michael, please proceed.

MICHAEL MEEHAN: Good afternoon. My name is Michael Meehan. I am a lifetime citizen of the State of Connecticut. I was here last year when I saw the previous bit of legislation that was passed. I'm here to tell my story.

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Essentially I'm a father of three girls. My youngest daughter, Nina, who is

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three-and-a-half was diagnosed when she was two years old as having autism. I am a licensed practicing lawyer here in the State of Connecticut. I've been doing it for over 15 years. I live down in Fairfield, Connecticut. I, like many of these families here, got to this tangled web of trying to get this diagnosis and used a developmental pediatrician to get her diagnosed who's actually a doctor out of New York State. That doctor had recommended that Nina get 40 hours of ABA therapy a week. At the time she was in birth to three. Birth to three promised that they would give her 20 hours, 20 hours only really became ten and of the ten it really wasn't even ABA as what I had since come to know after the fact.

Ultimately I had to retain an advocate. We found a facility in Norwalk, Connecticut which is a private facility called the center for development where they have a BCBA, actually they have two on staff, and properly trained therapists, not the individuals with just the high school degree but people who have invested their lives to do this and I saw tremendous gains for my daughter. Unfortunately the cost of those services, even for that limited period of time, was astronomical. I spent from January of last year up until July about \$60,000 out-of-pocket, and for me to generate that kind of income I have to earn about \$110,000 to net \$60,000 to pay for that and the cost of that kind of therapy and services is just overwhelming. There is a greater than 80 percent divorce rate for families on the autistic spectrum. Unfortunately I am now one of those 80 percent of families. I have unfortunately had to sell my house as a result of this.

My daughter is now in the public school system where she has a competent program, but she has lost a lot of the milestones that she was able to reach in the previous program and as a result I've taken some drastic steps, including moving back in with my parents, to try to free up additional funds to get her back in that program for which was documented just by the data that she was speaking and now she's not talking. So I'm just here to share my story. It's not a pity party, but it's truthfully what happens unfortunately to a lot of people.

REP. FONTANA: Thank you. It's a testament to the cost of this illness, both to your daughter and to your family.

MICHAEL MEEHAN: Thank you.

REP. FONTANA: Questions for Michael?

Thank you, Michael.

Aurora.

AURORA D'ANGONA: Good evening. I just recently, about in July or so, started working at this nonprofit for people with spectrum differences called Get Ready for This, the Autism Spectrum Differences Institute of New England. It took me a few days to get that one down. But we're known as ASDI New England. And we feel -- I'm here on behalf of our nonprofit. We feel it's very critical that ABA is not the only therapy funded. Other evidence-based things such as developmental and functional, not only just behavioral such as the ABA, are also very important for children to be covered by. For example, evaluations and services by

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developmental psychologists and even early childhood autism specialists with special training in PECS, floor time and other evidence-based are really appropriate and also need to be considered for this bill.

We have somebody, a coworker of mine, and he goes to different conferences with and will talk about how he is autistic. He had ABA very early on and as I like ABA it's not always the answer I think for every individual with autism, just as you can't have one answer for everything. It didn't really work for him. He still actually suffers from it. He tends to repeat things such because I think how he was trained was from somebody that didn't actually have proper training, and from what I have experienced in the last few months of being at the nonprofit as I talk to a lot of parents and I thank you so much. Everybody that was here that's a parent you are very strong and I've talked to many people over the phone and in person and it affects the whole family, it really does, and the problem that I've seen with school systems is that if you don't have the diagnosis which costs a lot of money and families can't always afford it, especially now, if you don't have that, you don't get the services in school. If you can't get through school, how are you ever supposed to have your own life? I think we all know education is very important.

So I do support the Senate Bill 301 and I'm just very happy to hear from everybody today. I feel like we should exchange numbers because I can give you a call when I get home from work and I'm stressed out. But thank you so much for hearing from me.

REP. FONTANA: Thank you for your testimony as

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well. For the record, could you please identify yourself and spell your last name, if you wouldn't mind?

AURORA D'ANGONA: My name is Aurora D'Angona. The last name is D apostrophe A-n-g-o-n-a.

REP. FONTANA: Great, thank you.

Are there questions from members of the committee for Aurora?

No? Okay.

I understand Melissa Sullivan is here to testify and then -- yes, you'll speak to Ann and then we'll make sure that we've got your name. So I apologize, Melissa, please proceed and then we'll --

MELISSA SULLIVAN: Hi. Good afternoon, my name is Melissa Sullivan. I'm the parent of a five-year old son who is on the autism spectrum. I'd like to play clean-up crew. I wasn't preparing to say anything and I do have a written testimony which hopefully you have.

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In my experience there is definitely an issue between what the school systems offer us and then what we need in what we call our home program. The schools will only provide so much. My son is five. He's in a half day of preschool for the most part and then he would be home all afternoon. So what do you do with your autistic child is you provide that child with a home program. When he was in the birth to three system, they fulfilled his needs with 25 hours of therapy which encompassed most days Monday through Friday. I even had some therapists that would come out on Saturdays. Once we got into the school system, however,

you have your child home a lot more which isn't really how it should work. It should be the same level of service but in most towns it's not. So your child turns three, is dumped into the local school system and you have more time on your hands and it's up to you as a parent to fund alternatives to keep your child busy, whether it's with any of these services. I like the wording of this bill. I like the fact that it's all encompassing. Whichever therapy my pediatrician will write down or my developmental pediatrician will write down, if my insurance would pay for it, that would do a world of good.

I sought services. Matt Conway was here representing me. I saw him through the Department of Children and Families through the State. It's worked out very well. The State has provided me with ten hours of a combination of ABA and RDI therapy, however, I just lost that state funding, so I am refinancing my house for the third time and just cleaned out my daughter's college fund to continue that program. The program was costing the state ten hours a week at \$95 an hour, \$950 an hour. We are a one-family income. There is no way we could provide that level of service.

Now my son just turned five last week. He will go into a full day hopefully of kindergarten in the fall. We'll need services. So there is just an area a short span for a lot of families that you need some intensive home stuff. But then as the children get older and they do have a full day of school as they get older, you can provide services at night in your home so that they can generalize their skills across all

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domains. It's one thing to learn something at school, but what we all know as parents is they are different beings at school, they come home, there is different behaviors, there is different things. We as their parents now need to know how to handle these situations in our homes.

REP. FONTANA: Melissa, thank you very much for your testimony.

Senator Caligiuri.

SENATOR CALIGIURI: Thank you, Mr. Chairman. Thank you for your testimony.

Just one quick question because I want to make sure I understand something you said. You said you liked the bill being worded as broadly as it is.

MELISSA SULLIVAN: I don't want to limit it to any one thing. I like all these therapies.

SENATOR CALIGIURI: I understand. Let me ask you, in your experience would it make sense if we structured this to make all of these things available upon the recommendation or referral of a developmental pediatrician, would that kind of a system work?

MELISSA SULLIVAN: Absolutely. I think we've all worked with a developmental pediatrician or a good psychologist in the state who takes us as smart human beings, as parents of these children, knowing them better than any school system, any therapist that's ever come across them and value our input and our opinion and say, you know, what do you think RDI is going to work? I think RDI might work too. And as Shannon Knall testified, we don't stick to

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something if it doesn't work. We are get-it-done people. We are this works, we continue it, oh, we tried that, it didn't work, it wasn't the piece of the puzzle. You know, we refer to autism as a puzzle. It's a great analogy. Every one of these children is different. Every piece varies. So ABA does work for the vast majority of them. I have a combination of ABA and RDI. My son is amazing. He's amazing. He's doing so good, but now I have a state that won't fund the program anymore, you know, so there is lots of -- yes, I like the broad, I like that you're not going to limit us to any particular therapy. Any one of these could really be good and there is hope for these kids. There is hope. They can become people in our society. We don't have to institutionalize these kids. We can take care of them in our home with these therapies and they will become successful adults and not people that the state is going to have to take care of for the rest of their lives.

SENATOR CALIGIURI: Thank you very much.

Thank you, Mr. Chairman.

REP. FONTANA: Thank you, Senator.

Other questions? Seeing none, I think Melody Lattimer is up. And unless I'm mistaken, she's the last person to testify on this bill. So welcome, Melody.

MELODY LATTIMER: Thank you. I apologize, I wasn't able to get on the list sooner because my kids were getting out of school at the same time that you were doing sign up, and I live in Torrington. You do have a copy of my written testimony. I did make sure to get that in for

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you to read. I wanted -- I am a person with Asperger's. That is on the higher functioning end of the autism spectrum.

I have two children. They will be four and five in April and they are both on the spectrum. My family has decided to move to Texas because it's one of the states that covers the ABA by insurance, and I will have to echo that I definitely agree that this should encompass developmental pediatrician recommendations. Everyone keeps on saying how different each autistic child is. You should see my two. They respond to two totally different methodologies. My oldest, he has had a good ABA program in school and has really excelled in that. My younger son has not had the ABA program but had more of the -- it wasn't strict RDI, it was more like I believe somebody else mentioned it, floor time. It does basically the same thing where it gets down on the level of the child. And they both have blossomed. They have conversations together which is amazing to me, three and four, and they are having conversations. It's incredible.

But the reason I support this is not just for them but I look at my life. I did not get my diagnosis when I was young, heck, I got it last year. I know that people on the spectrum can function in society. I do it pretty well, I think, but it's taken me a lot of time to get here because I didn't have the interventions early on. I have to see a therapist once a week. I have to take several medications daily just to function at this level. I can't work -- or I had a job out of college even because it just became too overwhelming. So this is not just because my child has autism, but I know the life that

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they will eventually lead if they don't get the intervention now. Thank you.

REP. FONTANA: Thank you, Melody. And with all due respect to Melissa, that's why I'm glad you batted clean up because your testimony was a nice way to in theory conclude the testimony on this bill.

But are there questions from members of the committee for Melody?

Thank you very much for making it from Torrington, and I'm glad we got you on the list.

Unless there is anybody else here who would like to testify on Senate Bill 301, that will conclude our testimony on Senate Bill 301, and we will proceed to the next bill on the agenda, House Bill 5093.

Is Greg Grusse here? I'm sorry, Gross. That's hardly an excuse but Greg Grusse will be followed by Morgan Sheets.

Welcome Greg.

GREG GRUSSE: Thank you. My name is Greg Grusse and I'm appealing to the Committee on Insurance and Real Estate to enact the proposed House Bill 5093.

My sixteen-year-old daughter, Rachel, is a bilateral below knee amputee. Actually she's here with me. I don't have a photo. She decided to come in person. Due to a severe illness Rachel had to have both of her legs amputated when she was fifteen months old. She's been wearing prostheses for over 14 years now. She's currently on her 14 set of



*Quality is Our Bottom Line*

**Insurance Committee Public Hearing  
February 5, 2009**

**Connecticut Association of Health Plans**

**Testimony regarding**

- SB 292 AAC Health Insurance Coverage for Certain Acupuncture Treatments.
- SB 296 AA Requiring Health Insurance Coverage for Bone Density Screenings.
- SB 299 AA Expanding Health Insurance Coverage for Routine Patient Care Costs for Clinical Trial Patients.
- SB 301 AAC Health Insurance Coverage for Autism Spectrum Disorders.
- SB 638 AA Requiring Health Insurance Coverage for Colonoscopies for Colon Cancer Survivors.
- HB 5093 AAC Prosthetic Parity.
- HB 5242 AAC Health Insurance Coverage for Required Vaccines.
- HB 5433 AAC Health Insurance Coverage for Step Children.

The Connecticut Association of Health Plans respectfully urges the Committee's rejection of the above mentioned bills. While every mandate under consideration by the legislature is laudable in its intent, each must be considered in the context of the larger debate on access and affordability of health care. Both the General Assembly and the Administration have pledged this year to address the needs of the approximately 400,000 Connecticut residents who lack health insurance coverage. As we all know, the reasons people go without insurance are wide and varied, but most certainly cost is a major component. As you discuss the proposals above, please consider the following:

- Connecticut has **49 mandates, which is the 5<sup>th</sup> highest** behind Maryland (58), Virginia (53), California (51) and Texas (50). The average number of mandates per state is 34. (OLR Report 2004-R-0277 based on info provided by the Blue Cross/Blue Shield Assoc.)
- For all mandates listed, the total cost impact reported reflects a range of **6.1% minimum to 46.3% maximum**. (OLR Report 2004-R-0277 based on info provided by the Dept. of Insurance)
- State mandated benefits are not applicable to all employers. Large employers that self-insure their employee benefit plans are not subject to mandates. **Small employers bear the brunt of the costs**. (OLR Report 2004-R-0277)
- The National Center for Policy Analysis (NCPA) estimates that **25% of the uninsured are priced out of the market by state mandates**. A study commissioned by the Health Insurance Assoc. of America (HIAA) and released in January 1999, reported that "...a fifth to a quarter of the uninsured have no coverage because of state mandates, and federal mandates are likely to have larger effects. (OLR Report 2004-R-0277)

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- **Mandates increased 25-fold over the period, 1970-1996, an average annual growth rate of more than 15%. The Health Insurance Portability & Accountability Act (HIPAA) alone will add billions of dollars in new compliance costs to the healthcare system. (PriceWaterhouseCoopers: The Factors Fueling rising Healthcare Costs- April 2002)**
- **National statistics suggest that for every 1% increase in premiums, 300,000 people become uninsured. (Lewin Group Letter: 1999)**
- **“According to a survey released in 2002 by the Kaiser Family Foundation (KFF) and Health Research and Educational Trust (HRET), employers faced an average 12.7% increase in health insurance premiums that year. A survey conducted by Hewitt Associates shows that employers encountered an additional 13% to 15% increase in 2003. For 2004, the outlook is for more double-digit increases. If premiums continue to escalate at their current rate, employers will pare down the benefits offered, shift a greater share of the cost to their employees, or be forced to stop providing coverage.” (OLR Report 2004-R-0277)**

Furthermore, health plans are currently adhering to the intent of many of the mandates listed above including those related to immunizations, step children and many of the screening proposals. Having said that, please note that statutory mandates only apply to a select group of employers – namely small employers. Large employers who self insure are exempt from such mandates and may design their own benefit packages. We question whether the genesis of some of these proposals is derived from members covered under these types of plans in which case any new law wouldn't apply.

With respect to the autism mandate, we simply point out for the Committee's consideration that many of the treatments and services contemplated under the bill do not constitute typical medical treatment, will be difficult to operationalize and should fall perhaps, more appropriately, under the category of special education. We do not question the need for such coverage, just whether it should be borne by employers and their carriers given the level of the expense or whether we as a society should shoulder the responsibility to care for these children.

Thank you for your consideration.

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## TESTIMONY SUBMITTED BY:

Shannon Knall  
Chapter Advocacy Chair  
Autism Speaks, Connecticut  
connecticutcac@autismspeaks.org  
860-573-7600

Stephanie Sinclair  
Avon, CT

February 3, 2009

## To Whom It May Concern:

I am the mother of a 5 year old boy with autism. His name is Clay and he was diagnosed at the age of three. My story is not unlike many others whose will be told today and I wish I could be there in person to tell mine as well. His name is Clay and very early on I knew that there was something "different" about him but I couldn't put my finger on what it was. Before even being able to walk he would sit up in his crib and would turn over intricate and brightly colored objects for 45 minutes at a time. There were those who would say "oh, he's going to be so smart" but it felt odd to me and the red flags started going up then. He hit the milestone of being able to walk at 16 months and started exhibiting what I now know are called "ritualistic" behaviors. For example, when walking up and down our staircase, he would have to touch the same hinge, screw, bolt and banister the exact same way every time and if we were in a hurry and couldn't indulge him in this behavior he would completely melt down to the point of not being able to get on with our day until we caved in and let him repeat the behavior. When frustrated, he would have what I called "rigor mortis" tantrums (this is the best way I can describe them) which when compared to my friends children's tantrums were not at all the same. His made him appear to literally be in pain and he would become stiff as a board and I regularly would exit a play date or a public place carrying him like a stiff board under my arm in order to escape from the embarrassment. When I expressed to my pediatrician my concerns he told me that Clay was hitting all of his milestones (late but he was hitting them) and that he wasn't concerned but to his credit he gave me the number of birth to three and told me that he believes in mother's intuition and that I should call them. And with that call there began our journey into the world of autism.

He was in a "typical" pre-school at the time for 3 year olds and they didn't seem to notice anything unusual about his behavior or demeanor but when the birth to three representative who was assigned to our case went out for a school visit she was mortified. She observed the kids doing a craft and when completed they were all to ask to be excused and then they could go and have free play time. They all finished, asked to be excused and were. Except Clay who sat there for 15 minutes waiting until someone came and told him what he was supposed to do. But no one did and so she went over and told him he could be excused. She said she felt like he would have sat there all day had she

not been there. She recommended we remove him from the school and place him in an "integrated pre-school program." These are programs that have 50% children with special needs and 50% without, the premise being that the children with special needs will emulate the typical children's appropriate behaviors. When I informed the pre-school he was in that I needed to pull him out and the reason why, they refused to give us a refund and thought I made an arbitrary decision to put him into another program in town.

Shortly after this horrifying experience, we took him to a developmental pediatrician recommended by his new school. After 3 sessions with Clay and me she dropped the bomb on us that he has autism. You never expect to hear words like that about your child who the minute he was born you had so many hopes and dreams for. The day you receive that news all of those dreams are completely shattered and your world is never the same. My husband, who now admits that he didn't want to believe that this hunch of mine was true, was devastated. We did decide to get a second opinion from a more multi-disciplinary approach and we were lucky enough to get him into the Yale Child Study Program. They too after a two day, intensive 8 hour evaluation concurred with the first doctor that he has autism. Only they said he was worse than we thought after the first evaluation because he is very intelligent and was able to make you believe that he understood what you were saying to him but in fact was much lower functioning than the first doctor stated. They explained it to us like this, "It's as if you're speaking in Martian to him - he's been able to memorize canned responses to questions that he's memorized but he doesn't understand most of what you're saying." And this than explained the "rigor mortise" tantrums when he got frustrated. They recommended for our course of action that he remain in the integrated program that we'd started him in and that he have 40 hours of ABA (Applied Behavioral Analysis) per week. That evening when we returned home with Clay was surreal. He was still the same child whom we loved and adored but yet now he was also quite different because he had so many needs that we needed to figure out how to fill. We felt this gun to our heads to help him quickly because all of the current research shows that if you can help a child with intensive and early intervention they have the best shot of improving and leading the best possible life they can lead.

I made Clay my full-time job as I am lucky enough to stay home and raise Clay and his at the time of Clay's diagnosis 1 year old brother. I scoured the internet, joined support groups and talked to anyone who would talk with me about how to help kids like Clay. My first steps were to find an excellent ABA therapist as well as placing him on a Gluten Free Casein Free diet. In the circles that I was fortunate enough to find and the internet research that I did I came across an incredible woman board certified in ABA therapy who had started her own company to help kids on the autism spectrum. She met Clay and they had an instant connection it seemed. She has been working with Clay since he was three (he turned five this past October) and he has improved immeasurably. She has spent an average of around 6 hours per week with him and it has changed his and our lives. The only downside to ABA therapy that we've found is the fact that it is not covered by insurance policies. I shudder to think where Clay would be today had he not received such early intervention and as intensively as he has.

It's been a very difficult road for our entire family. Clay's brother,(now 3) out of necessity has spent much of his life being driven around to appointments for Clay who the focus has had to be on. We try to keep the balance between them but when one child has such enormous needs they have to be addressed. But I'd be lying if I said he's had the same amount of attention and it's a tremendous guilt trip daily. The divorce rate for parents of children on the spectrum is now up to 85% because between the stresses of trying to help your child coupled with the financial burden there isn't much of you left over at the end of a typical day. The costs associated with Clay's needs so far are roughly the following:

Evaluations - \$6,500 \*not covered by insurance  
 ABA Therapy - \$43,000 for 57 months (so far) \*not covered by insurance  
 GFCF Diet - \$8,000 \*not covered by insurance  
 Special Classes, Social Skills Groups,etc... - \$1,500 \*not covered by insurance

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Total So Far = \$59,000 \*not covered by insurance

We just received the news that he also has ADHD (this is considered to be a "medical diagnosis" and we will be able to receive reimbursement from our insurance provider should we decide to treat him medicinally for this).

We consider ourselves lucky that my husband is employed and that I have been able to stay home and dedicate myself to Clay's needs but it feels like an uphill battle when you're delivered the dreadful news that your child has autism because there is very little financial help available to help you with your efforts. It seems incredibly unjust that people with autism and families of children with autism are not granted any kind of insurance reimbursement for these necessary evaluations and therapies these children so desperately need and that are proven to work. We pay our premiums and our children deserve to have the help that they need without their families struggling financially.

I hope that my testimony and that sharing my story today is a step in the right direction towards finding that relief. It is difficult enough just being told that your child may never have the life that you envisioned for him the day that you brought him home from the hospital full of hope. But then when you start down the road of raising a child with autism you quickly find that you are in many ways very much alone in your battle to help him and financially is one of the most difficult ways that you find yourself alone. This is now an epidemic and it is time for our lawmakers to recognize it as such and help those of us who are just simply struggling to help our children.

Stephanie Sinclair  
 Avon, CT



**Clay at Age 3  
(This is the month that he was diagnosed)**



**Clay at Age 5**

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## TESTIMONY SUBMITTED BY:

Shannon Knall  
Chapter Advocacy Chair  
Autism Speaks, Connecticut  
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Attorney Jennifer D. Laviano  
Sherman, CT  
lavlaw3@aol.com

My name is Jennifer Laviano, and I am an attorney who represents children with autism and other special education needs in securing appropriate services with their school districts. I have been advocating for children with autism spectrum disorders (ASD) for over 12 years. I am unable to appear personally today, and greatly appreciate your consideration of my remarks and concerns.

In theory, I support the idea of having autism treatment funded by insurance companies. However, I am extremely concerned that the Legislature be clear in their intent that such a requirement does not release our public school districts from their obligations under the IDEA or Connecticut special education laws.

We have some, though not nearly enough, decent programs for children with ASD operating in our schools in Connecticut. These programs did not happen overnight. They are the result of hard-fought, painful, and often expensive battles that many parents have had to wage over the last decade to convince local and state educational agencies that children with autism require intensive services and support in school, their home, and their communities, in order to make meaningful educational progress. My fear is that that, without additional language that clearly states that this legislation is not intended to substitute special education obligations, school districts will be financially incentivized to scale down or close effective programs and services for children with ASD, which will turn back the clock on progress for children with autism in CT by a decade. Moreover, I envision school districts telling parents who ask about services for their children with ASD that they should just call their insurance company instead of asking for special education services.

I am greatly worried that school districts will now attempt to characterize **all** autism treatment services as "medical," even though such services clearly fall within the definition of special education and related services under the federal IDEA (Individuals with Disabilities Education Act) and CT special education laws. Further, I am concerned that parents will find themselves with little recourse, in terms of appeal, if they disagree with their insurance company's determination as to what is appropriate for their child, whereas under the IDEA and state law there is a strong infrastructure already in place to address such disagreements.

Please understand, I am not opposed to having requirements for insurance companies to cover autism treatment, especially when we consider how many children with ASD will soon become adults no longer entitled to services through their school districts. Rather, I feel the Legislature **MUST** add language to make it very clear that the ongoing mandates by the federal and state governments regarding special education are not impacted by this legislation. Without very strong and definite language in this regard, I am terribly concerned that a piece of legislation which is designed and intended to help families of children with autism will, in fact, harm them greatly.

I thank you for your consideration of my views on this very important issue.

Attorney Jennifer D. Laviano, Sherman, CT

TESTIMONY SUBMITTED BY:  
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Grace Simpson  
Media and Public Relations Consultant  
Mobile: 860.543.0747  
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Testimony for Proposed Senate Bill 301  
Public Hearing – February 5, 2009

Grace Simpson

My 5 year old son was diagnosed with Autism Spectrum Disorder at age 2. A happy, loving, rambunctious, smart boy with an infectious laugh, Cash'an did not have any words. His ability to communicate and socialize was significantly impaired.

Cash'an did not know how to ask for what he wanted. Instead, without warning, he would pinch and bite out of frustration, when he could not be understood. While Cash'an's receptive language was about 80%, he needed to learn life skills, such as sitting at a table to eat, using the bathroom, and dressing.

At his public preschool, while other children played with blocks, Cashan was often sprawled out on the floor in the classroom. He was overwhelmed by all of the "information" in the room that he couldn't quite process, like the number of children, the noise, the lights. He couldn't comprehend instructions for what a teacher wanted him to do. He didn't know how to sit with other children or share a crayon. Instead of looking at a book, he'd sometimes bite the pages. Still, a typically developing little girl wanted to be Cash'an's friend. He had never spoken a word to her. At his first ever play date, Cash'an sat on one side of the room, never looking up at the girl, and instead played with the rug. Eventually, when no toy seemed to work, she got him interested in bouncing on a big ball. Laughing as he bounced, he didn't know how to tell her he liked playing, so instead, he bit her.

Since then, Cash'an was outplaced to a private school in Hartford that helps children learn through Applied Behavior Analysis, or ABA. The therapy breaks concepts down in small steps.

Tuition fees are so expensive, however, that we, along with many other parents, cannot afford it. School systems, with their limited budgets, are not eager to pay the fees regardless of how much it could help a child, like my son to navigate, learn about and contribute to his world. Evaluations that can provide diagnoses, and outline specific learning techniques needed also costs thousands of dollars.

Today, my son's ABA program has helped him learn how to answer to his name or respond a peer's "hello" with a wave. Through ABA, Cash'an has learned how to communicate with a picture system and other techniques. He has learned life skills - dressing himself, eating at a table, and using the bathroom on his own. With the help of an ABA therapist, he participates in some activities with other children.

And the little girl that he bit, has come over to play with Cash'an who, with the help of an ABA therapist, sits and paints with her. ABA has given Cash'an an opening to a world of potential. I implore you to give other children the same opportunity with support of Senate Bill 301.

## TESTIMONY SUBMITTED BY:

Shannon Knall  
Chapter Advocacy Chair  
Autism Speaks, Connecticut  
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Kimberly Lombardo  
klombardo6@att.net

My Name is Kim Lombardo Im the mom of 4 children my triplets were born August 9th 1997 at 30 weeks and 5 days. I knew as I watched them grow up after several months of going to the hospital and leaving without them and then getting to take one at a time home. I knew over time there were things that were wrong but the system for me was broken.

I called in birth to three who at the time may not have been versed in the type of autism my boys had but one was a toe walker and things but I was told he was just a little slower and would catch up and my other son who didnt want to sit up even at almost a year I was told he was lazy.

It took many years and a lot of talking to people to get my children what they needed my triplets will be 12 soon and its been 3 years since they were diagnosed with asbergers syndrome.

My daughter was just diagnosed with NLD so to say the least my hands are full and I have an almost 4 year old who I now watch like a hawk for anything that may be wrong with her because so many people wouldnt listen to me.  
Treatments are expensive testing is expensive.

My son Ian I had to take him to a doctor that my Insurance company wouldnt pay for because he was out of network he was a specialist in the area of my sons problems and I wanted him tested by someone who could outright know if this is the issue he has without going to one doctor and have him say I think its asbergers but Im not sure.  
It took me almost 3 years to pay the doctor back because of all the other medications and things I have to pay for for my children. On top of the autism there is medications for adhd and worry medications as I call it and natural herbs to help with sleep at night and its very costly. My Insurance will only pay so much and Im out of work right now so the burden falls to my husband who works 2 jobs and still doesnt bring home enough for us to get what we need. I work Perdiem right now to supplement till I find something more.  
We need coverage out there that pays everything our children need.

We need help we need it now our kids are not being service properly in the schools they are overworked, overwhelmed and the teachers are not trained properly to handle our kids and I have had more fights with teachers telling me your child is so bright if he would

just apply himself. I said if he didnt have autism we wouldnt have these problems but hes doing the best he can.

The schools cant do a lot they do what they can. I cant afford out of pocket resources that our children desperatly need. Help us help me and all the other families out there hurting and suffering in silence because there is no one listening to us .

Please help us get the funding thats needed for research and health care and things that our children need as they grow older they need more they have to cover more there needs to be special programs just for our children and families please help us.

Thank You,

Kimberly Lombardo

Mom of Barbara, Peter, Ian, Lizzy

Two who have autism, one learning disabled and one who is just Lizzy

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TESTIMONY SUBMITTED BY:  
Shannon Knall  
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Autism Speaks, Connecticut  
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Susan D. Pawloski-Burke  
South Glastonbury, CT  
sdpb@cox.net

Hello. We would like to submit the following written testimony in support of Senate Bill 301.

My name is Susan D. Pawloski-Burke and my husband is Ed Burke. We have a 7 year old son named Toby. He is the light of our lives. Toby was diagnosed with mild to moderate classic autism shortly after his 3rd birthday. My husband and I knew something wasn't quite right with our son at an early age, but we weren't sure exactly what it was. He wouldn't make eye contact, he wouldn't point at objects and show us things and he wasn't talking. When he was 18 months old our pediatrician suggested we contact Birth to Three to see if he would qualify for any of their early intervention services.

Toby did qualify for Speech Therapy and Occupational Therapy. Even with the services provided by the Birth to Three professionals, Toby was still slipping away from us with his behavior getting more and more unusual. We would find out later that the spinning, hand flapping, looking at objects from odd angles and the awful meltdowns were all quite typical behaviors of a child on the autism spectrum, but at that time they were quite mystifying. There came a point when Toby was 2 ½ that Toby seemed to be totally out of control—like a whirling dervish—and my husband and I looked at each other and wondered what we were going to do. There seemed to be no way to reach him or teach him. We told our Birth to Three Case Manager about this and she recommended that we supplement Toby's plan with Applied Behavioral Analysis techniques as overseen by the Benhaven School.

The consultant from Benhaven and the trainer came to our house to meet our son and to draw up a teaching plan. From the first time the trainer worked with our son using discrete trial instruction methodology, we saw positive results. For the first time ever, we began to see our son respond to a teaching method. He was actually able to focus and attend to tasks and accomplish them. For us, it was the first ray of hope to appear in what had been what had seemed like a hopeless situation.

When our son turned three, at the urging of our pediatrician, we had him evaluated by a developmental pediatrician and a developmental psychologist. Our pediatrician was particularly insistent that we see the developmental psychologist because he would be the

one who would be able to recommend the most appropriate methodology to utilize for Toby's education program, which turns out to be the most successful treatment to mitigate the symptoms of autism and allow individuals to learn activities of daily living.

The diagnosis offered by both professionals was the same: mild to moderate classic autism. We had done some research prior to the evaluations so the diagnoses did not come as a shock. What did come as a shock was that the evaluation appointment with the developmental psychologist was not covered by our health insurance. The first thing I found surprising was that this sort of illness was classified as a psychological disorder and as such was covered under the behavioral health portion of the health insurance contract. I could not believe that a disorder that you are born with that affects your activities of daily living was not considered medical in nature.

In the health insurance industry, different rules apply for behavioral health. The first thing I did before we even went for the evaluation was contact our health insurance provider to see if we needed preapproval. The insurance representative assured me that we did not need prior approval and to send in the bills when we received them. I followed these instructions when we received the bill for the evaluation (\$1300) and received a letter back indicating that our claim was rejected because we did not precertify the visit. After numerous phone calls and letters, we got that straightened out. Finally we received our reimbursement check for \$160. Needless to say, we were stunned! The only scientifically proven way to address autism was through an appropriately designed therapeutic learning program using the principles of Applied Behavior Analysis and the only one qualified to do that was a developmental psychologist and our health insurance paid only about one tenth of the cost?? It couldn't be! Fortunately, we were in a position to pay this in 2004 and have paid another \$1300 in 2006 and \$2000 in 2008 for follow up evaluations to make sure that he is making progress. These evaluations have been instrumental in our efforts to ensure that his school program is the most appropriate educational methodology as indicated by federal education laws. We have fought long and hard to have a Board Certified Behavior Analyst oversee our son's school program and the evaluation reports from his developmental psychologist are the key elements to our successes. I can't help but wonder what parents who are unable to pay do?

As for ABA services—what can I say? We tried and the school tried for three years to toilet train my son. After 3 years of meetings and two evaluation reports from our developmental psychologist including an ecological assessment of his school environment, the school finally agreed to contract with a Board Certified Behavior Analyst. After observing my son and interviewing his teachers and my husband and I, the consultant drew up a plan using ABA techniques and trained all of us to implement it consistently. My son was fully trained (and out of diapers—even at night!) within two weeks. This happened one month before his 6th birthday and I can only describe it as a miracle. But it's a miracle we can duplicate--it just demonstrates what can happen when the right teaching methods are used. Many individuals would be able to make similar gains if ABA therapies were available to them. Individuals with autism may not have to end up in group homes if we can provide services that will help them attain independence. The only way most of us as parents will be able to afford these services is

if they are covered by health insurance. I urge you all to support Senate Bill 301 to make sure this happens. The work we do now to ensure that these services are affordable and available will prevent more extreme and much costlier measures from being necessary in the future.

On behalf of my whole family, I wish to thank you for your attention and support in this matter.

Sincerely,

Susan D. Pawloski-Burke  
39 Kimberly Lane  
South Glastonbury, CT 06073

Ps—This is our beautiful son, Toby. Please help him--he's counting on you!



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## TESTIMONY SUBMITTED BY:

Shannon Knall  
Chapter Advocacy Chair  
Autism Speaks, Connecticut  
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860-573-7600

Judey Yudkin  
Woodbridge CT  
judeyyudkin@optonline.net

To the Insurance and Real Estate Committee Staff members,

I want to thank you for taking the time to hear from the public concerning the passing of SB301. Unfortunately, I can not attend the hearing; because, I could not get the time off from work. I hope that my written testimony will be just as effective.

I am a parent of a 8 year old boy diagnosed with High Functioning Autism. High Functioning Autism is part of the Spectrum of Autism. This Neurological Disorder effects all of our children differently; however, there are certain deficits that all of our children have in common. They all have social skills deficits, they all have behavioral problems, and they all have some sort of sensory integration issues. Some of them may be more deeply effected then others. However, regardless of where they lye on the spectrum they all require intensive therapy. Without this they will not learn the skills they lack. They will not merely pick up these skills as other children do naturally.

The programs which are used to teach our kids the skills needed to function appropriately within school and function in society are extremely costly but necessary. What makes this cost even higher is that the public school systems often are not equipped to provide our children the services they are guaranteed to receive under the laws of FAPE and IDEA. Left with the lack of services within the school systems, we are forced to spend even more money to seek these services at our own cost outside of the school or pay exorbitant attorney fees to fight for our children's rights; and, in some cases, to stop the abuse our children suffer in these schools.

Many of us have to pay for Physical Therapy, Occupational Therapy, Speech Therapy, Psychiatrists, Psychologists and the medications which unfortunately often become necessary to deal with the medical and behavioral problems common with Autistic children. This does not even include the cost of setting up a program to provide ABA therapy, RDI therapy, listening programs, social skills groups, music therapy, and the list goes on for your choices of therapy to help your child. There is also the cost of the many books or tools you need to buy to assist your child with the special needs he or she has. Then there is the cost to have your child evaluated, which has to be done periodically throughout his life. An evaluation costs anywhere from \$2000 to \$5000 (not covered by insurance). An evaluation is necessary to have in order to get services for your child

within the public school system. Without it the schools often take advantage of your not having this and provide little to no services for your child's special needs.

I am lucky. My son is not as impacted by this disorder as he could have been. Thus my expenses for his disorder are not as great as others that I know; however, they are still so large that I can not afford them. Last year alone we spent over \$30,000 on expenses toward his Autism. Sadly, Insurance covers very little of this. I chose to pay for those services rather than the payments for my home and our house went into foreclosure. The medical, and psychological services our son requires will continue and not suddenly stop. He will never be cured! What scares me the most is that I can not provide him all that he needs during his early years to hopefully make enough of an impact so that he might be able to some day hold a job and live on his own. I read that teenage suicide is highest amongst teenagers with High Functioning Autism and Aspergers (another type of Autism.) It scares me that not having enough money to provide these services, could lead toward my child possibly being one of those statistics.

I have had many long conversations with the insurance company about the coverage's for my son's disability. The insurance carrier for our Policy is covered by ERISA, which enables them to choose to bar coverage for Autism, although your policy does stipulate you have such coverage for your child. It is a devastating blow to an already difficult situation to find out that you can not afford to provide the medical, psychological, and therapeutic needs your child requires because your insurance carrier will not even cover a portion of a necessary treatment.

While the passing of this bill will not effect our situation directly because our carrier is protected by ERISA, I pray that this bill will be passed for those families it will help. This neurological disorder, called Autism, is a medical disorder that affects our children. The insurance companies should be required to provide coverage for this disorder just as they would for other childhood disorders.

Please support the passing of SB301.

Thank you,

Judey Yudkin  
(A parent who is struggling to provide the medical and therapeutic needs my child has)  
15 Sanford Road  
Woodbridge CT 06525

301

## TESTIMONY SUBMITTED BY:

Shannon Knall  
Chapter Advocacy Chair  
Autism Speaks, Connecticut  
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Frances Sullivan  
fbsull@comcast.net

Our Grandson was diagnosed with an autism spectrum disorder shortly after his 1st birthday.

His journey has been rough, including all the deficits in behavior along with severe gut disease (requiring a Gastric feeding tube), & severe allergies.

Now, after 4 long years, the perserverence, love, hard work, & diligence of his parents, with the help of his extended family has created an improved life for him, however, the financial burden has been "ASTRONOMICAL."

I am outraged that most treatments that have worked for him were & are not covered by medical insurance---he continues to need care & services.

On behalf of Sean & all others on the autism spectrum you must do what is necessary to provide health insurance coverage.

Fran & Bill Sullivan

301

## TESTIMONY SUBMITTED BY:

Shannon Knall  
Chapter Advocacy Chair  
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860-573-7600

Denise Smith  
Simsbury, CT

Senator Crisco, Representative Fontana and members of the Insurance and Real Estate Committee:

I am submitting this testimony in support of Senate Bill 301, mandating insurance coverage for people with autism spectrum disorders.

Connor, my five year old son, was diagnosed with Autism at age 3. We were given names of various professionals to take Connor to in order to help facilitate the best recommendations for the school system. We made an appointment with a well-known pediatric psychologist and borrowed the \$1,800 required for the visit. The great news is that we took his advice and applied it to our son's life. It did not happen exactly the way the doctor intended it to happen, for reasons I will not get into here, but the bottom line is that our son is imposed upon for at least 30 hours a week by the School system and by outside therapies provided by Talcott Center for Child Development. These services include OT, PT, Speech and a Social Skills group. We also take him out every weekend and impose on him some more. It took him over a year and a half to be able to "consistently" transition into school and many other places without tantruming but in following his recommendations he did it and so much more. "Currently" Connor is a success story, it all stems back to that initial diagnosis, and recommendations made and followed through on when he was 3 years old. He is doing terrific! Parents of his typical peers cannot believe the transformation.

We have been told several times that we would be greatly served to have Connor reevaluated every year so that new recommendations can be made that take into consideration his successes and adjusted for other issues that have arisen or may arise in the "wonderful" world of autism. We have not been able to afford that "luxury" for the past 2 years. We recently questioned some things that we noticed at home and that therapists noticed during their sessions with him and were told that our son is potentially having issues with processing, encoding and retrieving information. He has come so far and it would be very helpful to have recommendations from a pediatric psychologist to deal with these issues as he is preparing to enter Kindergarten next fall. Kindergarten brings on academic expectations that he has not had to deal with to date and where problems with processing, encoding and retrieval would have a negative impact on his ability to

learn. An evaluation would provide an accurate diagnosis of the problem and then a plan of attack to conquer it. The various approaches are also scientifically proven to work. We can testify that they worked at the first stage of Connor's life and we would appreciate the opportunity to allow them to work at the next stage of his life. We are struggling to find the \$2,000, which is currently needed for this reevaluation. With the passing of this bill, we will no longer have to worry about this issue and will be able to focus on putting into place the recommendations necessary for Connor to have the continuing success we now know is possible and that every child deserves.

Thank you for your time.

Denise Smith  
Simsbury, CT  
Mom to a 5 year old with Autism

## TESTIMONY SUBMITTED BY:

Careen Jennings  
careenjennings@sbcglobal.net

Dear Senators Fontana and Crisco,  
I am writing concerning the bill SB 301 up for a hearing today. I desperately want to come, but on Thursdays I go to prison. I volunteer with Wally Lamb at York, and both the need and the good that I can do there is great. (I digress; that's another letter.)

But autism touches all of us. As the grandmother of an autistic 4-year-old already getting special education services I can verify the desperate need for this legislation. My grandson has had two years of ABA, and it has helped him immeasurably. With the bio-meds we are also giving him (some 30 supplements and a DAN! doctor who is worth the \$400 an hour she charges), we are well on the way to getting him OFF the spectrum. If and when we achieve this, we will have a whole person who will not need 13 years of special education and lifelong assisted living support.

But our boy is lucky, because we have had the educational and financial resources to have provided his care. I use the past tense because my son and daughter-in-law have burned through their savings (\$60,000 and climbing) and took out a second mortgage. Now we're starting on my savings. And I'm just a retired teacher. (gotta stay healthy, gotta stay healthy...)

Getting ABA paid by insurance (which has been virtually useless with all his treatments) will be a tremendous help, and in the long run it will save tax money. Our story is not unusual. Actually, most stories are worse.

One child out of 150 is now autistic. We can't afford to lose these kids--autism CAN BE TREATED! But it's not easy, not fast, and especially not cheap. Insurance companies will lobby hard, but the choice is stark:  
Let insurance companies continue to deny coverage or save these children's brains.

Thanks for your hard work in Hartford. It's a tough time to be a legislator.

Careen Jennings  
careenjennings@sbcglobal.net

SB 301

Good afternoon,

My name is Christine Levine. I am the clinical director of Creative Interventions Creative Interventions specializes in the treatment of children on the autism spectrum. I am a board certified behavior analyst, an attorney and special education teacher who has been working with the autism spectrum population for 14 years. Creative Interventions provides ABA based services to children from birth to 18. We provide individual, dyad and small group therapy.

Applied Behavior Analysis (ABA) is the only scientifically proven treatment for autism spectrum disorders. In 1987 a study by Lovass it was found that 47% of children with Autism that received an intensive ABA program had normal levels of intellectual functioning and were participating in regular first grade without support, as compared to 2% of the control group. In 2006 a study by the Wisconsin Early Autism Project confirmed that ABA treatment resulted in 48% of children with autism reaching normal levels in IQ, social skills, language, adaptive and academic skills and were succeeding in regular classrooms without support. Many more research studies exist that confirmed the ABA model as being therapeutically beneficial.

ABA is designed to address the core deficits of autism, as outlined in the DSM IV. These are impaired social interaction, impaired communication and a restricted set of interests. ABA also addresses related deficits often found in individuals on the autism spectrum such as challenging behaviors – (Aggression, self-injurious behaviors, noncompliance, pica, obsessive behavior, stereotypic movements) self-help skills(dressing, toileting, washing, cooking, etc.) motor skills and cognitive skills. This methodology is data driven and specifically designed to meet an individual child's needs.

This treatment methodology is designed to teach new skills by breaking down skills into component parts and reinforcing performance of those component parts. Several different teaching strategies are used within an ABA program. These include discrete trial instruction, task analysis, verbal behavior, natural environment teaching, learning dyads, small group instruction and inclusion. The goal of ABA is to teach children with Autism Spectrum Disorder (ASD) to function as independently as possible in the natural environments. This is accomplished by teaching children with autism to learn the how typical children learn (through imitation, questioning, group instruction, life experiences and social interactions). As children begin to learn in a more typical manner, ABA services usually decrease of over time and the child will become included in a more natural learning environment at both home, school and in the community. Family training is an important piece of this process. For a child to really "Own" a skill, it needs to be generalized across a variety of settings, including the home manner. Most children don't naturally generalize into other settings and require direct therapy to make the generalization occur in the home and community.

ABA treatment works well with children with Autism Spectrum Disorder for several reasons. First, it provides a significantly higher level of reinforcement, including tangibles and edibles. This is necessary for children with Autism Spectrum Disorder who, due to existing social deficits, aren't motivated simply by internal motivation for completing a task or by pleasing an adult. In addition, ABA offers intensity in the opportunities to learn and practice the skills, that aren't offered in other therapies or

methodologies. A prompting hierarchy is used and faded so that children receive the correct amount of assistance to master a new skill. Moreover, ABA proved a high level of structure that many children with Autism Spectrum Disorder require. Finally, many children with Autism Spectrum Disorder need the breakdown of skills, due to an inability to learn complex skills as a whole. It also enables the children to learn to focus on a specific task, which is often difficult for them to do in other learning environments that are over stimulating.

ABA is also used to decrease inappropriate behaviors using antecedent and consequential strategies. ABA consultants complete a Functional Behavioral Assessment to determine what is causing/maintaining the aberrant behavior. With information gathered, a behavioral intervention plan is developed and implemented by therapists and family members. It is important to note that many families of children with ASD are unable to take their child in the community, which dramatically affects their quality of life. The treatment of a child with ASD with problem behaviors reduces the stress of a family and can increase the family's ability to participate in community activities with their child.

ABA can help children at all levels on the spectrum. An early learner's curriculum may focus on increasing attention to task, imitation of actions and learning to request one's needs. I just received an email this morning from a mother with an 8 year old daughter with autism and significant cognitive deficits. The schools she has attended continued to use teaching programs for requesting with her that were unsuccessful. We just developed an object exchange program for her and for the first time in eight years she is communicating with her mother. Her mother expressed that she used to feel that she didn't exist to her daughter. Now she actually feels a connection.

An advanced learner may be focused on conversation (Maintaining topic), cognitive flexibility, making friends and job skills. For example, we have 16 year old, very bright boy with Asperger's Syndrome. He has very significant social deficits and severe behavioral concerns. He is now coming to our office once a week to do an internship, with the support of a behavior therapist. He is doing a great job with various tasks around the office and is really enjoying it. This is wonderful for a child who generally doesn't like people, refuses to do homework. Just last year, he threatened to kill his mother with a knife. He has come a long way and I now feel that he will be able to hold down a job.

Early learner's and advanced learner's with significant behavioral concerns, generally required one to one therapy. Overtime, many early learners develop the skills that allow them to participate in a small group therapy session.

In a random sample of children receiving ABA services through Creative Interventions for an average of 5 hours per week for a period of 6 months during 2008, 62% made significant progress as evidenced by

the mastery of 20 new skills, 15% made good progress as evidenced by the mastery of 10-19 new skills, 23% made fair progress as evidenced by the mastery of 5-9 skills and 0% made limited progress as evidenced by the mastery of less than 5 skills. Thus, 100% of the children sampled made progress learning new skills with an average of 5 hours per week of ABA services. In that same group, 36% made a 75% decrease in targeted aberrant behaviors, 57% made a 50% reduction in targeted aberrant behaviors, 7% made a 25% decrease in targeted aberrant behaviors and 0% made less than a 25% decrease in targeted aberrant behaviors. Thus, 100% of cases, there was a least a 25% reduction in targeted behaviors during a six month period, while receiving an average of 5 hours of ABA per week.

It was possible for these children to be successful, but it needed to extend beyond the school program. Schools tend to focus on academic skills, as opposed to addressing the social, language and lifeskills that are most critical to a child's success in the real world. In addition, most school districts don't offer ABA programs. Those that do, employ individuals with only a high school diploma to implement the entire program. Also, the programs are generally not supervised by a board certified analyst.

Passing of the proposed bill would make a huge difference in many children's lives, whose families cannot afford to pay the costs of ABA therapy.

Christine Levine, M.S., J.D., BCBA  
Clinical Director, Creative Interventions, LLC



SB 301

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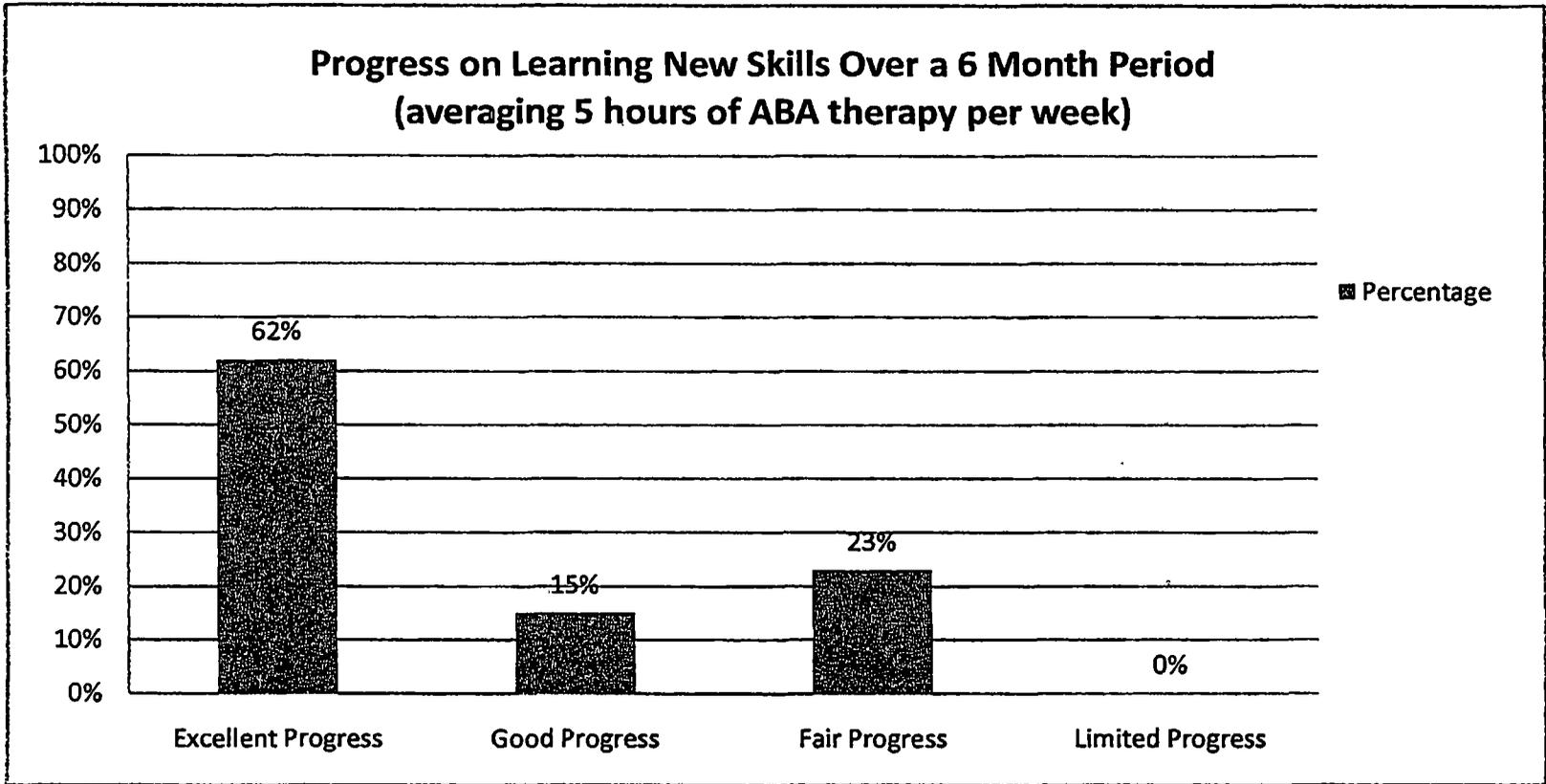
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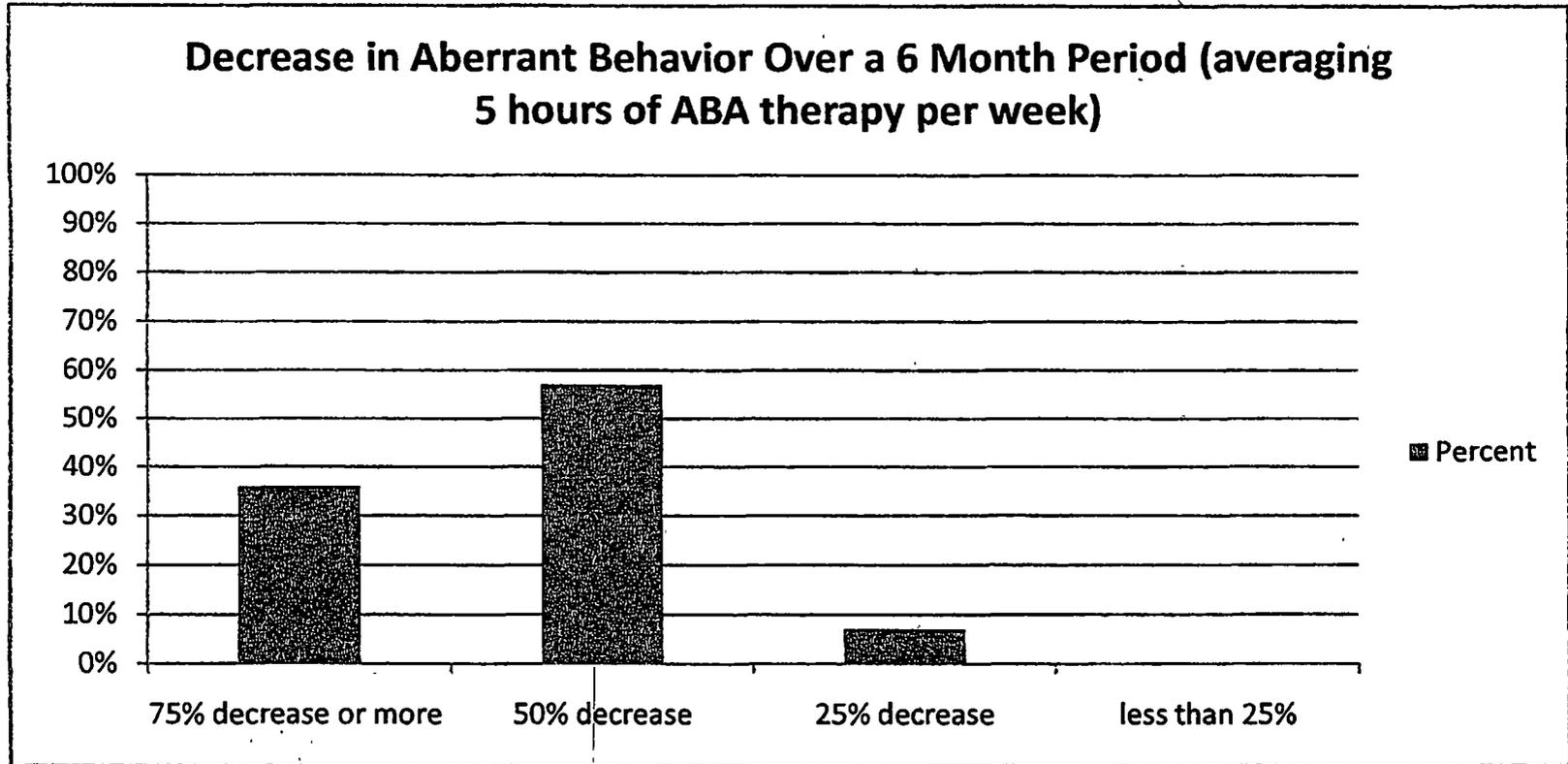
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In a random sample of children in ages 3 through 14 receiving ABA services through Creative Interventions, for an average of 5 hours per week for a period of 6 months during 2008; 62% made excellent progress as evidenced by the mastery of 20 new skills, 15% made good progress as evidenced by the mastery of 10-19 new skills, 23% made fair progress as evidenced by the mastery of 5-9 skills and 0% made limited progress as evidenced by the mastery of less than 5 skills. Thus, 100% of the children sampled made progress learning new skills with an average of 5 hours per week of ABA services. In that same group, 36% made a 75% decrease in targeted aberrant behaviors, 57% made a 50% reduction in targeted aberrant behaviors, 7% made a 25% decrease in targeted aberrant behaviors and 0% made less than a 25% decrease in targeted aberrant behaviors. Thus, 100% of cases, there was a least a 25% reduction in targeted behaviors during a six month period, while receiving an average of 5 hours of ABA per week.

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Testimony for Senate Bill 301  
February 5, 2009

Dr. Kathleen Dyer, BCBA, CCC-SLP  
Clinical Director-River Street Autism Program at Coltsville  
Associate Clinical Professor-Elms College

The 2000 report from the Surgeon General states that thirty years of research demonstrates the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior in individuals with autism. This evidence includes both intensive experimental studies of individual children as well as randomized trials comparing groups of children.

In a study conducted with our own children in Connecticut, greater gains in child functioning and quality of life were reported when children received higher quality treatments based on applied behavior analysis. (The River Street Autism Program: A Case Study of a Regional Service Center Behavioral Intervention Program. Kathleen Dyer, Gayle M. Martino, & Tom Parvenski, Behavior Modification, 2006, Vol. 30, No. 6, 925-943).

We ask the question-Why should we support this bill?

Why should we go along with the decision made by other states to provide insurance coverage for this debilitating disorder?-a decision made by the state of Indiana, the state of Minnesota, as well as a decision adopted by Canada nationwide.

A study in the journal "Behavioral Interventions" reports cost-benefit estimates for early intensive behavioral intervention for young children with autism. The report states the problem-that without effective intervention, most people with autism and other pervasive developmental disorders require lifelong specialized educational, family, and adult services, at a total cost estimated at upwards of \$4 million in some states. It is prudent to ask how investments in services are likely to pay off in the long run, and how to make use of the limited resources available for educating and treating people with ASD. The article reports that the NET SAVINGS for a child with autism/PDD who achieves normal functioning through behavioral intervention is \$1,475,791. The NET SAVINGS for a child with autism/PDD who realizes partial effects is \$1,036,013. (Cost-benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism John W. Jacobson, James A. Mulick, and Gina Green. Behavioral Interventions, 1998, Volume 13, 201-226).

We ask the question one final time-why should we support this bill?

The authors of the cost-benefit analysis conclude that, "Like effective treatments for other severe childhood disorders, such as cancer, early intensive behavioral intervention can be described as aggressive, intrusive, expensive, and necessitate a high level of specialized expertise for effective delivery. However, if a child with a major disorder needs treatment, cost is usually not a major factor--various and private resources are typically made to cover the costs. For the sake of all individuals with autism, for their families, for our communities and for society as a whole, it is time to insist that this same consideration applies to the treatment of autism. We should all recognize that the most expensive interventions are those that fail to produce meaningful, measurable, lasting benefits, regardless of cost.

## Autism and ABA

The following references provide evidence for effectiveness of science-based treatments based on principles of applied behavior analysis for autism.

- Anderson, S. R., Avery, D. L., DiPietro, E. K., Edwards, G. L., & Christian, W. P. (1987). Intensive home-based early intervention with autistic children. *Education and Treatment of Children*, 10, 352-366.
- Bimbrauer, J. S., & Leach, D. J. (1993). The Murdoch Early Intervention Program after 2 years. *Behaviour Change*, 10, 63-74.
- Dyer, K., Martino, G., & Parvenski, T. (2006). The River Street Autism Program: A case study of a regional service center behavioral intervention program. *Behavior Modification*, 30, 925-943.
- Fenske, E.C., Zalenski, S., Krantz, P.J., & McClannahan, L.E. (1985). Age at intervention and treatment outcome for autistic children in a comprehensive intervention program. *Analysis and Intervention in Developmental Disabilities*, 5, 49-58.
- Howard, J. S., Sparkman, C. R., Cohen, H. G., Green, G., & Stanislaw, H. (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities*, 26, pp. 359-383.
- Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, vol. 55, pp. 3-9.
- Matson, J. L., Benavidez, D. A., Compton, L. S., Paclwaskyj, T., & Baglio, C. (1996). Behavioral treatment of autistic persons - A review of research from 1980 to the present. *Research in Developmental Disabilities*, vol. 7, pp. 388-451.
- McEachin, J. J., Smith, T. & Lovaas, O. I., (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal on Mental Retardation*, vol. 97, pp. 359 - 372.
- Maurice, Catherine, Green, Gina & Luce, Stephen C. (1996). Behavioral intervention for young children with autism - A manual for parents and professionals. Austin, TX: Pro-ed.
- Smith, T and Lovaas, O. I. (1998). Intensive and early behavioral intervention with autism: The UCLA Young Autism Project. *Infants and Young Children*, January, 67-78.
- Smith, T. (1999). Outcome of early intervention for children with autism. *Clinical Psychology: Research and Practice*, 6, 33-49.
- Smith, T., Eikeseth, S., Klevstrand, M & Lovaas, O. I. (1997). Intensive behavioral treatment for preschoolers with severe mental retardation and pervasive developmental disorder. *American Journal on Mental Retardation*, vol. 102, 238-249.



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**Connecticut State Medical Society Testimony in Support of**  
**Senate Bill 301 An Act Concerning Health Insurance Coverage for Autism**  
**Spectrum Disorders**  
**Presented to the Insurance and Real Estate Committee**  
**February 5, 2009**

Senator Crisco, Representative Fontana and members of the Insurance and Real Estate Committee, on behalf of the over 7,000 members of the Connecticut State Medical Society (CSMS) thank you for the opportunity to present this testimony in support of Senate Bill 301 An Act Concerning Health Insurance Coverage for Autism Spectrum Disorders.

CSMS has consistently testified before this and other committees regarding the issue of medical necessity. It is our policy that any service determined to be medically necessary by a treating physician should be covered under insurance policies. Unfortunately, the unwillingness of health insurers to routinely cover medically necessary services because of "pre-existing conditions" or other exclusionary efforts has led to the need for us to seek legislation requiring coverage for individuals who have autism and related disorders and conditions.

Recently, CNN has reported that traditional therapies for autism can require \$70,000 to \$80,000 in out of pocket costs for families with autistic children. However, also reported is the fact that therapies costing \$20,000 have shown promise in providing further development for children so they can perform activities of daily living and do things such as brush their teeth, perform general hygiene and carry out basic health and wellness measures; a small price to pay to ensure a greater quality of life for children with autism.

All people with developmental disabilities, especially children, regardless of the degree of their disability, should have access to appropriate and affordable quality medical and dental care. An individual's medical condition and welfare must be the basis of any medical decision and medical necessity decisions must rest with the patient's physician or physicians.

The CSMS, along with the American Medical Association, continues to work with appropriate medical specialty societies to educate and enable physicians to identify children with developmental delay, autism and other developmental disabilities, and we have urged physicians to assist parents in obtaining access to appropriate individualized early intervention services.

TESTIMONY SUBMITTED BY:  
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301

Dan Tedesco  
Shelton, CT  
(203) 218-6314  
dantedesco@handholdadaptive.com

I write in support of SB 301 regarding insurance coverage for Applied Behavior Analysis (ABA) treatment for autistic children. I am the father of a 4 year old boy, Evan, who is on the autism spectrum.

Our experience is not unlike other parents who are devastated when their autistic children are diagnosed. We felt extremely isolated, hopeless and confused. Autism is bewildering, certainly, but out of the tens of thousands of dollars we spend annually to help Evan, I can say without hesitation that ABA therapy has been the only therapeutic intervention which has demonstrated measurable and clear results. We continue to pay out-of-pocket at the rate of \$85/hour for ABA therapy, for 4-5 hours per week, although his prescription is for almost double the amount of therapy. This is an incredible financial burden despite my full time position as the General Counsel at Walker Digital, the founding research laboratory behind pricelinc.com. We continue to slide further into debt precisely because of the uncovered cost of ABA therapy.

We are currently in the protracted process of seeking ABA coverage for Evan from the Shelton Board of Education through the Individuals with Disabilities in Education Act's IEP process. However, the IEP process is slow, and filled with traps for the unwary and vulnerable parent. I have been a member of the Connecticut bar since 2002, practicing sophisticated corporate and transactional law, and can say firsthand that the IEP process is downright daunting, requiring me to hire a special education attorney to represent Evan. Every day that goes by during this legal appeal without complete ABA coverage for Evan is a tragic waste, as research shows that "early intervention" is critical for long term outcomes.

So, you can see why ABA coverage through insurance is necessary. I hope that you pass the bill, but add language clarifying that the departments of education in the towns and cities throughout Connecticut would not be absolved of their responsibilities under the Individuals with Disabilities in Education Act despite SB 301's passage. After all, not everyone has insurance.

Finally, I note that in my capacity as the founder of a company whose mission is to develop software aids for children with autism, I have surveyed the market for every

alternative product and therapy under the sun. ABA therapy is by far and away the leader in terms of allowing autistic kids to reach their maximum potential. An investment in ABA early in a child's life will reduce the downstream costs to Connecticut taxpayers very significantly. As more and more kids are diagnosed as on the autism spectrum every day, failure to act now will make today's economic challenges pail in comparison to what life will be like when the taxpayers have to support the millions of moderately to severely autistic persons who will not be able to hold jobs or care for themselves because they didn't receive ABA treatment at an early age.

If I can provide any further information about our experience with ABA, or answer any questions, please do not hesitate to contact me at the below address.

I appreciate your consideration.

Respectfully,

Dan Tedesco  
Founder & CEO  
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Elizabeth and Mark Lambert  
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 February 5, 2009

SB301

Insurance and Real Estate Committee  
 Room 2800, Legislative Office Building  
 Hartford, CT 06106

Dear Committee Members:

My name is Beth Lambert, and I am the President of Connecticut Families for Effective Autism Treatment (CT FEAT). Connecticut FEAT is a non-profit organization staffed by parent volunteers who provide families with information on effective treatment for their children. We are strong supporters of Applied Behavior Analysis.

I would like to share with you the personal experience of my family with the use of Applied Behavior Analysis, ABA, with our autistic son, Eric.

First, ABA does not cure autism. Second, if not done under properly qualified supervision it will yield mixed results, some potentially negative. But done properly, supervised by a board certified behavior analyst, the improvement in behavior and skills of an autistic person can be no less than breathtaking.

My son began intensive ABA therapy when he was 4 ½ years of age. On the autistic spectrum, my son is considered severe. At 4 ½ he was not toilet trained, did not speak, and was unable to participate in simple social experiences such as eating dinner with the family. Wild and uncontrollable tantrums were a part of daily life. The quality of our family life was poor. Today at 15 our son is still severely autistic, but he is fully independent in toileting, bathing, dressing, and making his bed. He not only joins the family for dinner but also sets the table and assists in clearing the table. Each week Eric bowls at the local bowling alley and has been included in birthday party invitations as well. He is not conversational but is able to tell us his wants and needs. The tantrums, anger and fear that so punctuated his early life are rare. At 4 years of age many, even family members, found him sometimes frightening to be around. Today, at 15 he is certainly not loquacious, but family, friends and teachers find him affable and a pleasure to have around. The individually tailored intervention programs targeted at the skills and behaviors our son needed, with carefully gathered behavioral data guiding the therapists as to when interventions worked and when they did not have made an incalculable improvement in the quality of his life and of that of our family. We can say unequivocally that the behaviors our son demonstrated routinely at 4 would have required us to institutionalize him years ago without the gains he has made from ABA.

Properly implemented and supervised ABA quantifies what works and points to the type of intervention that will be successful, then even quantifies when it is successful. It makes teaching a quantifiable science.

ABA should be practiced by experienced professionals. We would never consider allowing medical procedures for our children be performed by inexperienced or unqualified persons. Likewise we should not entrust the practice of behavioral science to those unqualified and untrained.

ABA will not cure autism. It is the best tool we have for living with a terribly debilitating condition.

I would like to recognize and thank the ABA professionals at CREC's River Street Autism Program at Coltsville and River Street School for their dedication and professionally disciplined teaching that has meant so much to my son and my family.

My husband and I very much appreciate the investment the education system and people of Connecticut have made in my son. But over his lifetime, that investment will be paid back by the contribution (if humble) that he will be able to make as well as the control of the extraordinary expense of total care that has been avoided.

As effective as ABA has been for our son, we cannot help but wonder about what skills he would have developed if he had started ABA at 2 years of age. Developmental specialists have demonstrated that a child's ability to learn language skills are most successful at ages two through 5 and is unlikely to learn language skills after age 10. The best results come from the earliest possible intervention with ABA. Insurance coverage of ABA will make this possible. This will not cure, but will unlock the minds and skills of many autistic children.

The struggles my family has endured because of autism are too extensive to discuss in this short time slot. Families confronted with a child with this diagnosis are faced with, first, coming to terms with the tremendous challenge, next navigating a path not clearly delineated to effective treatment, and finally finding a way to pay for it. I believe this bill has the means to help families struggling with autism in a profound way.

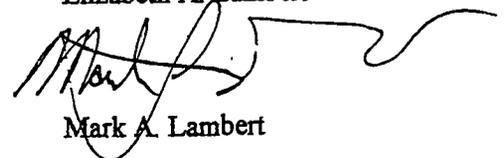
This bill will certainly cost insurance companies more money and have a measured impact on insurance premiums overall. But our children will soon be adults. The cost of caring for adults with autism is best mitigated when they are small children. In a time when we are clearly passing on more and more of the cost of the present to our children, this is a chance to improve the quality of life of autistic people and their families, to increase the viability of the lives of autistic people and mitigate some of the costs our children will bear.

On behalf of Connecticut FEAT, families struggling with autism across Connecticut, and my-family, we strongly urge your support for this bill. Thank you.

Very truly yours,



Elizabeth A. Lambert



Mark A. Lambert

# CBIA

Connecticut Business & Industry Association

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TESTIMONY  
BEFORE THE  
INSURANCE AND REAL ESTATE COMMITTEE  
LEGISLATIVE OFFICE BUILDING  
FEBRUARY 5, 2009

My name is Eric George and I am Associate Counsel for the Connecticut Business & Industry Association (CBIA). CBIA represents approximately 10,000 businesses throughout Connecticut and the vast majority of these are small companies employing less than 50 people.

Both nationally and in Connecticut, the health care system is in need of repair.

More needs to be done to improve the health of our citizens. Employers find health care costs rising faster than other input costs. Some providers are unable to generate sufficient patient revenue to cover costs. Some patients cannot get timely access to optimal care. And too many individuals remain without health insurance, engage in unhealthy behaviors and live in unhealthy environments.

For the business community, the issues of health care quality, cost and access are critical. After numerous years of double-digit and near-double-digit increases, health insurance has quickly become a product that many people and companies find they can no longer afford. In addition, the cost of health care directly affects businesses' ability to create new jobs. In fact, according to CBIA's latest membership survey, over two-thirds of our members indicated that rising health benefit costs alone are negatively affecting their ability to hire additional workers.

Therefore, CBIA asks this committee to reject **SB 301, AN ACT REQUIRING HEALTH INSURANCE COVERAGE FOR AUTISM SPECTRUM DISORDERS.** The business community and other stakeholders are calling for significant reforms to Connecticut's costly and inefficient health care system. As you consider the various proposals to reform the state's health care system, CBIA asks you to refrain from making the already high cost of health care even more unaffordable for the state's companies and residents.

Every health benefit mandate, while providing a benefit to the individuals who utilize those services, increases health insurance premiums for all state-regulated group and individual policies. In fact, the Council for Affordable Health Insurance (CAHI) reported in its 2006 report on state mandated benefits that

health benefit mandates increase health insurance premiums between less than 20% to more than 50%. Connecticut ranks fourth in the country in terms of overall number of health insurance mandates according to CAHI and those mandates increase group and individual health insurance premiums by as much as 65%.

Connecticut's employers are already struggling to afford health insurance for their employees. The hardest hit among these companies are small employers whose revenues and operating budgets make affording employee health insurance extremely difficult. However, when the legislature adopts new health insurance mandates, it makes affording health insurance particularly difficult for these small employers. This is because state mandated benefits only impact plans that are subject to state regulation. If a company has the financial ability to self-insure, then that company's health plan is governed solely by federal law, including the Employee Retirement Income Security Act (ERISA), and does not have to comply with state health benefit mandates. Companies that are able to self-insure (and therefore not subject to Connecticut's health insurance mandates) are typically larger companies that can afford taking on such risk. Smaller companies usually cannot and are forced to be fully insured and subject to state regulation.

So, Connecticut's health insurance mandates impact smaller employers in the state to a greater degree than larger employers. When the legislature either creates a new mandate or expands an existing mandate, it is making health insurance less affordable for those small companies that can least afford to shoulder these cost increases.

CBIA asks this committee to reject all new or expanded mandate proposals and to enact a moratorium on health insurance mandates. It is crucial that as the state moves forward toward major health care reform, that the General Assembly refrain from taking any actions that would increase the cost of already skyrocketing health insurance premiums.

Again, please reject SB 301 thank you for the opportunity to offer CBIA's comments on this legislation. I look forward to working with you on this and other issues related to the reforming Connecticut's health care system.

BILL 301 AN ACT CONCERNING HEALTH INSURANCE COVERAGE  
FOR AUTISM SPECTRUM DISORDERS

Our son, Gabriel Ewart, is 29 months old. He is mostly happy, loves to play the piano, loves to be hugged, and throws the ball sometimes when prompted.



**Diagnosis**

- Diagnosed with ASD on Dec 12, 2008 at age 27 months
  - Lowest 1% across all fields
  - Visual Reception score: 11 months
  - Fine Motor score: 14 months
  - Receptive Language score: 8 months
  - Expressive Language score: 9 months
- At 1 year old he would say “dada”, “mama”, “aqua”, “ball”, and “eat.” 17 months later he does not say words. Dada is now “Dee” and eat is “eee”. The vast majority of the time he will not look us in the eye and will not come when we call his name.
- He has had clear reactions to cow’s milk, bread, and various other foods. His stools have been clearly abnormal for a long time. He often scratches and has rashes.

**Treatment efforts**

- Gastro-intestinal doctor because he has a continuous problem with his stools
- Altered diet to avoid gluten, casein (in cow’s milk), rice almonds, corn, preservatives, and nitrates (His behavior and stools have responded dramatically at times.)
- Doctor who specializes in diet, supplements, and other physiological aspects of ASD
- ABA and speech therapy through Birth to Three (which lasts another 8 months)
- Hours each day reading and researching (it’s common for Gabriel’s mother to be up until 2AM researching)

**Costs**

- \$1200 for an initial visit to the ASD doctor
- \$600 for initial tests
- \$240 for a visit to a naturalist doctor to address diet and biological issues
- \$300 on books
- \$200+ on supplements
- Hundreds of dollars of additional costs for specialized diet
- \$70 per month on insurance to allow use of out of network providers (co pay is 30%)

To pay for treatment, we are cashing in our retirement savings. When his Birth to Three programming ends, we’ll incur additional costs. I am stunned that in a state like Connecticut, the devastation of the diagnosis can be followed by devastation of the pocketbook.



## FOCUS Alternative Learning Center, Inc.

Specializing in the treatment of children and adolescents who are on the Autism Spectrum, have anxiety disorders, experience processing and social learning difficulties; and who are otherwise, as we like to say, "creatively wired and socially challenged."

Good Afternoon. Thank you for the opportunity to testify today. I am here to support Senate Bill #301: AN ACT CONCERNING HEALTH INSURANCE COVERAGE FOR AUTISM SPECTRUM DISORDERS. My name is Jessica Rhodes. I am here as a School Counselor for FOCUS Alternative Learning Center in Canton. FOCUS provides an excellent therapeutic extended day treatment program for school aged children diagnosed with an Autism Spectrum Disorder (ASD). Just as important, I am here as a mother to wonderful 7-year-old twins, one with Autism and the other with a Learning Disability that exhibits symptoms similar to Autism. We reside in Simsbury.

I am here to advocate for the families I serve and I am here to ask for what my children deserve. Not one child with ASD is alike. However, after much experience in the field, I can say with some authority that mothers of children with ASD are extremely alike. We never get used to our children not getting playdates or birthday invitations. We cry when our children are bullied on the playgrounds and sob because we know bullies will continue to mercilessly target them. We get embarrassed when our "normal looking" children throw a tantrum in the grocery store and people stare, questioning our parenting abilities. Because of this, we avoid going out in public with our children, and if we do, we never do more than one errand at a time. We do not sleep because our children do not sleep. We educate the school systems who misunderstand our child's inappropriate behaviors. We hate the Autism, but LOVE our children fiercely. We face the dilemma of choosing an expensive intervention for one child knowing that other typical children will lose funding for extra-curricular activities. We fear that our "typical" children will have to carry the future burdens of their siblings. We fear our death only because we do not want to leave our Autistic children to be cared for by a system that has already failed them. We neglect our marriages because our children need us more. We do not stop fighting for our children because no one else will. We rarely have full time jobs because no day care can handle our kids. Because of this, we do not have income to pay for services. If we have the good fortune of working, we have the good fortune of getting insurance. We know that insurance is good for the rest of our family, but will deny claims for our child with Autism. So we go into debt to cover the costs of treatment or worse, we don't get the treatment because we already have too much debt. We know that what works for one ASD child may not work for ours, but we are willing to try it anyway. While we waste too much of our limited precious time fighting for services our children are entitled to receive, we will not waste time on a treatment that isn't working. We know

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*"Learning to embrace our differences"*

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that Autism is a thief that steals our child's potential, and we know that the right interventions can replace that potential.

And any one of us mothers can tell you that while Autism stinks, we are able to see the blessings it has brought to our lives. We learned to celebrate every milestone as they are few and far between. Our ears NEVER tire of hearing "I love you mommy" as we know we are among the lucky if we are able to hear it. We have become experts at hoop-jumping, in the hopes that it will someday become an Olympic sport. We learned how to become advocates for our children even if we feel uncomfortable doing it. We celebrate the few service providers who do accept our insurance and lovingly work with our children. We do not stop believing that someone out there holds the key that unlocks our child's potential. We never stop advocating because we continue to HOPE that agencies, corporations, federal and state government will stand up and do the right thing for our children. And because we mothers are all member of the Autism club, we welcome all new incoming members with open arms, shoulders to cry on, earfuls of advice, and strategies to beat the system. And we share hopeful thoughts that with mounting numbers like ours, people will no longer be able to ignore our plight.

I know some people are afraid that if this bill passes, schools will feel as if they can get away with doing less. I ask, less than what? No one—no agency, no school system, no government program, and no insurance company has yet committed financial resources to consistently support this population. Schools already do less than they should—they are only equipped to deal with the academic success of our children for 180 days a year for 7 hours a day. Lucky kids will get extended year services for no more than 6 weeks of half-days during an 11 week summer. Some school systems are better than others, but NONE of them are catering to adaptive life skills or social skills as is recommended by Autism experts.

This bill is about getting insurance companies to stop denying our claims because the word "Autism" is attached to our child's name. Much to our distress, no one does enough to help our children. This bill, SB#301, is the place we need to start.

Thank you for your time!

Regards,

  
Jessica Rhodes, B.S., M.A.

School Counselor/Clinician

FOCUS Alternative Learning Center

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301

TESTIMONY SUBMITTED BY:  
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The 2000 report from the surgeon general states that:

Because autism is a severe, chronic developmental disorder, which results in significant lifelong disability, the goal of treatment is to promote the child's social and language development and minimize behaviors that interfere with the child's functioning and learning. Intensive, sustained special education programs and behavior therapy early in life can increase the ability of the child with autism to acquire language and ability to learn. Special education programs in highly structured environments appear to help the child acquire self-care, social, and job skills. Only in the past decade have studies shown positive outcomes for very young children with autism. Given the severity of the impairment, high intensity of service needs, and costs (both human and financial), there has been an ongoing search for effective treatment.

The good news is that the surgeon general goes on to report that thirty years of research demonstrates the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.

Currently, methods derived from the science of ABA meet the standards of scientific proof that are required by IDEA 2004, and there are no other scientifically valid treatments for autism that produce similar treatment, educational, or outcome results.

- Metz, Mulick, & Butter, (2005); Newsom & Hovanitz, 2005; Smith, 2005

In a study conducted in our own state of Connecticut and published in the journal "Behavior Modification" in 2006 reported that greater gains in child functioning and quality of life were reported when children receive higher quality treatment based on ABA.

- Dyer, Martino, & Parvenski (2006) Behavior Modification)

Why should we support this bill?

A study in the journal "Behavioral Interventions" reports that the NET SAVINGS for a child with autism/PDD who achieves normal functioning is \$1,475,791. The NET SAVINGS for a child with autism/PDD who realizes partial effect is \$1,036,013

(Cost-benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism John W. Jacobson, James A. Mulick, and Gina Green In Behavioral Interventions, 1998, Volume 13, 201-226).

We ask the question on final time-Why should we support this bill?

Like effective treatments for other severe childhood disorders, such as cancer, early intensive behavioral intervention can be described as aggressive, intrusive, expensive, and necessitate a high level of specialized expertise for effective delivery. However, if a child with a major disorder needs treatment, cost is usually not a major factor--various and private resources are typically made to cover the costs.

For the sake of our children with autism, for their families, for our communities and for society as a whole, it is time to insist that that these same considerations apply to the treatment of children with autism/PDD.

Dr. Kathleen Dyer

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## TESTIMONY SUBMITTED BY:

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Kelly Ziano  
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We are a family from Simsbury, CT. Our youngest son has autism, but is doing very well with the support of the Simsbury school system, especially the Ready Set Go program, as well as other community programs (i.e. Simsbury Parks and Recreation camps) ...and of course, the warm embrace of all our neighbors.

We would like to see the Senate Bill 301 passed because it is obviously unfair to our families to be excluded from coverage and benefits for bio-intervention and therapy sessions that are crucial to our children's development and overall health. The financial burden that these costs place on families and individuals stuck paying out of pocket is devastating. Due to the expenses, and the shortage of qualified providers coupled with long waiting periods for appointments, most of the families we know in our situation are in dire straits. It's simply inexcusable to deny treatments and therapies and family coaching to those with ASD.

I can't imagine how this group was ever overlooked or the omission at any time rationalized, but autistic people can absolutely be helped by these services and treatments. I know firsthand, and our success is not unique.

Our son was diagnosed PDD-NOS at age 2, and we were living in Maryland at that time. We moved to Simsbury before he entered kindergarten for the inclusive school program and LOVE the school and community here. Our son spends all day in his first grade classroom with a dedicated paraprofessional. He participates independently, has many friends and even won an award for being a good role model. He loves school and his friends, is an excellent student, and is very popular among his peers. He gets full credit for his success, but what he needed from us along the way was this:

Proper teaching techniques -- ABA, DTT, RDI and a combination of multiple strategies in a specific 'therapy cocktail' made to order for him specifically Communication bridges -- Speech therapy, visual aides (i.e. PECs) and playgroups led by trained, qualified professionals OT, PT -- Not being able to pick these up in early peer play, he still requires "basic boot camp" for core movement and on-going motor training to catch up Bio-intervention -- Thankfully we found ARI and Dr. Bernard Rimland, and made some changes that gave us instant results. He could not function without these supplements and changes in diet. The waiting period to see a DAN doctor is too long, and not covered. We

need more practitioners and more accessibility to these treatments, even if it's just nutrition and vitamin/mineral supplements -- no one should be excluded because of an ASD diagnosis!

Family coaching - Essential, this was our saving grace. We paid dearly, but won big in the end.

While we are doing well now, the harsh reality is that anything can happen anytime, and in particular during his teen years. I hope there's a safety net to be had through paying so much for insurance -- one that comes through for his medical and developmental needs throughout his life. That's 1 in 150 adults in just a short decade from now, and I guarantee that our Autism Speaks community is already instilling in our youth to take responsibility and be committed to advocacy and voting for a better future for ASD families. So while you're thinking and counting on their vote then, we need your vote NOW.

Thank you.

Kelly Ziano  
Squadron Line Elem. Parent  
Simsbury, CT

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HB 5093 SB 299 SB 638  
SB 46 HB 6277 HB 5172  
SB 47

Testimony of Kevin Lembo, State Healthcare Advocate  
Before the Insurance and Real Estate Committee  
In Support of S.B. 301  
February 5, 2009

Good morning Senator Crisco, Representative Fontana, Senator Caligiuri, Representative D'Amelio and members of the Insurance and Real Estate Committee. For the record, I am Kevin Lembo, the State Healthcare Advocate. My office is an independent state agency with a three-fold mission: assuring managed care consumers have access to medically necessary healthcare; educating consumers about their rights and responsibilities under health insurance plans; and, informing you of problems consumers are facing in accessing care and proposing solutions to those problems.

I am here today to testify in favor of S.B. 301, AN ACT CONCERNING HEALTH INSURANCE COVERAGE FOR AUTISM SPECTRUM DISORDERS, the purpose of which is to provide comprehensive health insurance coverage for autism spectrum disorders. Last year, I testified in support of a bill promoted by Senator Crisco and Representative Abercrombie that required insurers to cover therapy services for children on the autism spectrum on par with therapy services provided to those with physical illnesses. That bill was a first step toward ensuring parity in treatment for people with an autism spectrum disorder. S.B. 301 will move the ball further down the field by acknowledging that Applied Behavioral Analysis (ABA), is not an experimental treatment, and must be covered if medically necessary.

Connecticut's mental health parity law requires coverage for the diagnosis and treatment of mental health disorders listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM) on par with medical surgical or other physical conditions. Autism spectrum disorders (ASD) are listed in the most recent edition of the DSM, and therefore, coverage for ASD should be on par other illnesses. Like many other mental disorders, the treatment for ASD involves more than psychological treatment. In most circumstances treatment also involves prescription medications and physical, speech and occupational therapies. It is not unlike many medical illnesses, which also require more than one modality of treatment.

While ABA has gained scientific acceptance and is recognized as a psychological treatment for ASD by the American Academy of Pediatrics, the insurers in our state still do not recognize ABA's validity and continue to deny legitimate mental health treatment to those with ASD. Our office has represented several of these consumers in front of managed care organization panels. While we were able to get coverage for ABA on a

case-by-case basis as an exception, there should be no need to have to climb over so many hurdles to get medically necessary treatment.

Physical therapy, speech therapy and occupational therapy are often provided in concert with other treatments for ASD. Last year's legislation was a step toward ensuring that adequate therapeutic treatment is available for those with ASD. This year's legislation, to provide comprehensive health insurance coverage for ASD, would go further. It is consistent with the principle that insurers should be required to cover medically necessary care, whether it means two speech therapy sessions or forty. There should be no distinction between coverage for ongoing and medically necessary physical therapy, speech therapy and occupational therapy for ASD patients and ongoing medication regimes for chronic mental illness. Both treatment regimes derive from recognized mental disorders and should be treated equivalently.

Ongoing treatment, like that for all mental disorders, may be subject to utilization review initially and at appropriate intervals for the appropriate management of care.

Lastly, it is important to note that the passage of the proposed bill would not require the substitution of insurance coverage for required and appropriate educational planning. The bill would augment the limitations of individual educational plans by balancing the obligations of school systems with the reality that ASD is a 24-hour per day mental condition. We expect to access medically necessary treatment for such chronic conditions and when we purchase health insurance, we expect our insurer to pay for that treatment. SB 301 will explicitly reinforce the insurer's obligation.

#### Other Bills We Support

HB 5093, SB 299, SB 638 would require prosthetic parity, expand coverage for routine costs in cancer clinical trials, and require coverage for more recent colon cancer screening for colon cancer survivors. Each of these bills is consistent with my office's statement that medically necessary healthcare should be covered regardless of diagnosis or service. Continuing to amend our statutes by individual diseases or treatments gives us less and less margin to ensure we cover all medically necessary care. Each of these issues should be considered as part of a larger healthcare discussion.

OHA also supports SB 46, AN ACT CONCERNING TRANSPARENCY OF MEDICAL LOSS RATIO INFORMATION. I have consistently testified that transparency on the medical loss ratio and other managed care organization information not only assists consumers in purchasing their insurance, but also informs policymakers and group purchasers of at least one measurement of an organization's operations. We don't believe this requirement is burdensome. The managed care organizations are required to include this information in their summary plan descriptions. Revealing them at the time of purchase without a separate request for the information means the addition of one additional piece information to their sales materials.

We support HB 6277, AN ACT CONCERNING HEALTH INSURANCE COVERAGE FOR SMALL EMPLOYERS, which would reduce from thirty to twenty

Testimony For 2/5/09 Public Hearing, Senate Bill 301

My name is Laura DeAngelo. I am the parent of a child on the autism spectrum and I am also a professional in the field of autism. I am speaking to you today not only in support of Senate Bill 301, but also in support of broadening the scope of this bill to allow families to choose the type of autism intervention that best fits their needs and the needs of their child.

I'd like to share a little about our family's experience with autism treatments. My son was diagnosed with autistic disorder, the most severe subclass of autism spectrum disorders, at age 2 and a half. I soon became consumed with finding out as much information as I could about the best autism treatments. One treatment kept coming up over and over: Applied Behavior Analysis, or ABA. Overwhelmingly, ABA had the most research backing it as an effective intervention. We researched ABA-based school programs and settled on Simsbury. My son started in the Simsbury autism program when he was just 3. At one of our first PPT meetings, I asked the special education administrator what she thought my son's chances were of ever attaining independence in a classroom. Her reply: Slim to none. In my head, I grieved. I also vowed to prove her wrong.

At school my son received many hours per week of discrete trials and natural environment teaching as a part of his ABA program. The school staff even assisted me in starting a home ABA program to supplement the school's program. I thought we were doing all we could. For a while I thought things were going well. Our son received glowing progress reports in his ABA program. He mastered most of his discrete trials quickly. His vocabulary grew. His motor skills improved. He learned cognitive skills such as the concepts of categories, functions and features of objects.

But things were not going well in all areas. At home his aggression and self-injury were getting worse. We had holes in our sheetrock walls from his head banging. He was extremely controlling. He would become unglued at the least little change in routine. At school, his almost constant singing and muttering interfered with his ability to learn and focus in less-structured environments. He was beginning to have tantrums and self-injure at school. A behavior plan designed by a Board Certified Behavior Analyst did not have long-term success in controlling his behaviors. Why was my son becoming more and more inflexible? Why did he still have no ability to interact socially? Why couldn't I, who had successfully managed two older children, manage his behaviors? Then, one day, my son had an hour long tantrum because I would not repeat back to him the words I was "supposed to" say from a discrete trial he had had in school. At that point, I knew that, despite his significant gains in skills with the ABA program, the central issues of his autism – his inflexibility, his social disconnectedness, his need for control – were actually getting worse. Our son needed something more, something that would address the autism at a core level. But what?

When my son was almost five, I learned of a workshop that was being given on a new autism intervention called Relationship Development Intervention, or RDI. Knowing nothing about RDI, I checked out the website. I was intrigued. The website mentioned a "core deficit" of autism – dynamic intelligence – that is not addressed in skill-based programs. It talked of "remediation" – a gradual

lessening of the core deficit area over time so that the disability no longer constitutes an obstacle to the real "quality of life" measures in the long term: True friendships and close relationships. Employment. Independent Living. Financial self-sufficiency. I noticed that there was no independent peer reviewed research on the intervention. Still, the logic of it made a lot of sense to me. I saw that it was based on hundreds of published research articles, books and studies by the most respected names in the field of child development and neuroscience. I saw that it was endorsed by a number of luminaries in the autism research community – Dr. Peter Mundy, Dr. Nancy Minshew, Dr. Peter Hobson, and others. I recognized that it generally takes many years for an intervention's effectiveness to be documented through independent peer reviewed research. The principles of applied behavior analysis, for example, have been around since the 1950s, and ABA-based treatment programs for autism have been used with success since the 1960's. Yet it was not until 1987 that Ivar Lovaas' seminal study demonstrating the effectiveness of ABA for children with autism was published. And it was not until 1995, 18 years later, that the results of that study were replicated in the Wisconsin Early Autism Project.

Through a driving snowstorm, I made my way to Dr. Nancy Schwartz' RDI workshop. At the workshop I met a mom who told me, with tears in her eyes, how RDI had transformed her child. After hearing Dr. Schwartz' talk and speaking with this mom, I knew I had found the answer to what was challenging my son.

Our involvement with RDI began four years ago. Fast forward to now. I have a child whose aggressive and self-injurious behaviors no longer occur in school and no longer present a problem at home. Our son had grown enormously in his cognitive flexibility, his emotional regulation, and his social competence. I can change plans and routines now and I know he will be OK with the changes. He has developed conversational speech, empathy, joint attention, social referencing, and a great sense of humor. He often prefers to do things together with me rather than being alone. He seeks and respects guidance from my husband, me, and the school staff. He is able to be competent on play dates with typical children with little or no assistance. He cooks us breakfast – pancakes, eggs, and bacon – unassisted! Just now, as I am typing this, he walked by and said, Hi Mom! What's happenin'?" I said "Oh, I'm just typing something on the computer. What's happenin' with you?" He said, "Oh, I'm just playing some games!" A few minutes later, he called me downstairs, excited, "Mom, come quick! They're playing our song on TV!" (We have a current favorite song we love to listen to together).

How do I know that the RDI is responsible for these gains? Because the areas that we specifically targeted, at the time we targeted them, were the areas in which we saw significant improvement.

This year, our son will be transitioning out of the autism program at school, no longer needing intensive behavioral supports, no longer needing one on one paraprofessional support. In many areas, he is fully independent in the classroom. And his independence continues to grow. At my son's recent triennial evaluation meeting, the school psychologist said "I am amazed at the growth in Matt since his last triennial."

We had no choice but to pay for RDI out of pocket. This intervention is typically much less expensive than ABA because it only involves a few hours a week of consultation to parents, at most, and no direct

therapy time with the child. The RDI consultant trains the parents how to work with their own child in their everyday life in a manner to remediate the autism. Nevertheless, we have spent about \$10,000 on RDI. The intervention worked so well for my son and for many other children I've seen and heard about, that I decided to become certified in RDI myself. I now have a practice as an RDI Program Certified Consultant and have seen the power of this intervention with the families I work with. Thousands of individuals and their families worldwide have realized improved quality of life from this intervention. Unfortunately, there are many families who wish to start RDI programs with certified consultants, but cannot afford to pay for even the minimal coaching time this intervention requires.

Our story highlights the need for families to have a choice in covered autism treatments. ABA alone is effective for some children, but not all. Indeed, despite all the research demonstrating ABA's effectiveness, it is important to note that, even in "best outcome" studies, more than 50% of the children did NOT achieve an independent level of functioning with early intensive applied behavior analysis programs. Dr. Gina Green, a board certified behavior analyst and one of the most respected clinicians in the field of applied behavior analysis, has stated that early and intensive ABA can lead to large improvements in multiple areas of functioning for many children, but that there are more children who do not respond positively and "more do not recover than do recover" from ABA.

Alexandra Rothstein, a Board Certified Behavior Analyst, on her website states: "Some who participated in early intensive ABA for at least 2 years acquired enough skills to participate in regular classrooms with little or no ongoing help. Other children in the studies learned many skills through intensive ABA, but not enough to function independently in regular classrooms full-time. Across studies, a small percentage of children improved relatively little. At this time, it is very difficult to predict in advance how far any individual child might go with this treatment. More research is needed to determine why some children with autism respond more favorably to early intensive ABA than others."

To limit coverage to ABA is to ignore newer interventions such as RDI whose principles and strategies are based on the most recent, "cutting edge" research in the field of neuroscience, typical child development, and atypical child development, but, due to their newness, do not yet have the breadth of published research of ABA, a 50-year-old discipline. If the past is any indication of the future, families may need to wait another 10 to 20 years until enough research is published that newer interventions such as RDI, which have so much anecdotal evidence, will amass a large scientific research base. Clearly, this is not acceptable for our children.

Please support expanding Senate Bill 301 to provide families a choice of covered autism treatments, in order to ensure that more children and their families have a chance for a long-term quality of life.

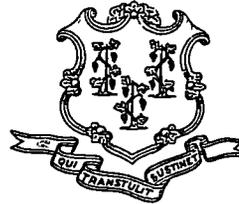
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February 5, 2009

I am testifying on behalf of Proposed Bill No. 301, *An Act Concerning Health Insurance Coverage for Autism Spectrum Disorders*, which I have co-introduced along with Speaker Donovan.

Autism is an illness – a medical condition – affecting thousands of families across Connecticut. Autism Spectrum Disorder (ASD) impacts each person differently. Some are profoundly affected and some are less affected. There are several medical diagnoses within the autism spectrum; Classic Autism, Asperger's Syndrome, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). It has been estimated that 1 in 150 children in the United States suffers from an ASD. The estimate is higher for boys, 1 in 94 of whom may be on the autism spectrum.

However, despite the fact that autism is an illness, it is a surprising and dismaying fact that health insurers generally refuse to cover either its diagnosis or treatment -- unless they are forced to do so by law. Indeed, last year this Committee heard many horror stories from Connecticut families that had been refused coverage. I'm sure that many more such stories from our families in crisis were related here today.

Thus, state lawmakers from across the nation have been forced to stand up for the families we represent, and mandate health insurance coverage for families with autism. Last year, Connecticut took a first step in that direction, by passing a partial autism insurance mandate bill that was introduced by this Committee. Our new law mandates coverage for physical, occupational and speech therapies, when there has been a diagnosis of autism.

This year we must take the next step and mandate coverage for all of the medically necessary care that our families with autism deserve and desperately need. We must ensure that the diagnosis of autism, which is now costing our families thousands of dollars out of pocket, is covered. We must ensure that our families are covered for all of

the medically necessary PT, OT and speech therapy visits that they need, and that their prescribed medications are covered. And finally, we must ensure that proven, evidence-based treatments such as Applied Behavior Analysis (ABA) – the effective provision of which literally can change children's lives -- are covered by health insurance as well.

By taking this next step, we will join the seven other states that have mandated comprehensive coverage for autism diagnoses, medications and ABA treatment over the past year. Families in Florida, Louisiana, Illinois, South Carolina, Pennsylvania, Arizona and Texas are now fully covered. I'm sure you'll agree that our families are worth no less. They must be fully covered as well.

The coverage of ABA is critical. ABA is an evidence-based behavioral intervention, administered by a Board Certified Behavioral Specialist. It has been proven effective over decades of research. It is specifically endorsed and supported by physicians and psychologists. The potential benefits of ABA are extraordinary. It appears that early, intensive ABA treatment can literally be the difference between a child speaking or never uttering a single word; the difference between participating in more mainstream education instead of solely relying on special education services; the difference between better mental and physical health or greater vulnerability to psychiatric and other illnesses; the difference between adult independent living and employment or a group home and disability compensation; and the difference between a family that can parent a child to independence or a family that exhausts all of its financial and emotional resources.

When a child receives a medical diagnosis of autism, the doctor typically recommends 20-40 hours per week of intensive ABA therapy. This level of ABA may be needed for the first few years of treatment. And, unfortunately, it is not inexpensive. Because of this, it seems highly likely that there are hundreds of families across Connecticut who are simply unable to get their child the ABA therapy they need. They cannot afford it, and their health insurance – for which they are paying premiums, just like everybody else – refuses to cover it. I believe this is intolerable -- both for these families, their children, and for the rest of our society.

It is also possible that, because of its expense, this expanded healthcare coverage may bring with it a very slight increase in insurance premiums. In the various states that have mandated ABA coverage over the past year, most have estimated that health insurance premiums will go up very slightly – around *a half of one percent*. For a typical family insurance policy costing around \$1000 a month, this will add only \$5.00.

However, any additional expense for insuring our families and children with autism -- in addition to morally and ethically being the right and necessary thing to do -- will more than pay for itself many times over.

There have been many studies showing that successful, early medical intervention for children on the autism spectrum will result in very significant future cost savings. This comes mainly from the decreased need for special education, government assistance, and

psychiatric and health care services. It also stems from the likely increased economic productivity of families dealing with autism. Many parents of autistic children often cannot work full time, or at all, because of the full time demands of caring for their afflicted child. With this bill, and their child's improved condition, their economic situation will be greatly improved.

**These various cost savings from the treatment of autism spectrum disorders have very conservatively been estimated to be between \$187,000 to \$203,000 per child from age 3 to 22, and \$656,000 to \$1.1 million from age 3 to 55.**

It's very clear that this bill is the right thing to do, for so many reasons. I urge you to support it.

SB  
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To The Members of the Joint Committee on Insurance:

My name is Matt Hall, and I am submitting this testimony in support of the Senate Bill 301, An Act Concerning Health Insurance Coverage for Autism Spectrum Disorders. I am currently the Chairman of the Town Council for the Town of Cheshire, and the proud parent of an autistic three year old daughter, Mari. In fact, Mari is the "cover girl" on the Birth to Three 2008 Annual Report you all received in December or January. Our experience with her diagnosis and her myriad improvements following the early intervention services she received last calendar year is featured in that report.

As a parent of an autistic child who has benefited greatly from the services we are fortunate enough to have had at our disposal, I strongly urge you to vote this legislation out of committee favorably. Early intervention and intensive service delivery to kids who are on the autism spectrum is crucial to their long term prospects as fully realized, self-sufficient adults. I suggest the long term return on this investment to the various communities that comprise Connecticut – for diminished service needs for these youngsters as they grow into adulthood – justifies the immediate cost to be borne by the admitted cultural change this legislation would require.

However, as the chair of Cheshire's municipal body, and as attorney with a small practice in town, I am acutely sensitive to the current economic climate, and the imposition of additional cost. Our firm offers health insurance to employees through the CBIA, and the immediate impact to our bottom line is likely to be noticeable. I fully anticipate that you will hear from folks today who will state that such an imposition today is unacceptable and bad for the economy.

In response to that argument, I suggest to you that the success of any small business depends on the productivity of its workforce. A family with an autistic child has its emotional resources drained on a daily basis, even those who are fortunate to have access to the best services. The emotional and social burden for many is compounded by the financial stress resulting from the diagnosis. From our own experience I can not imagine the additional burden without having access to any services, and the choices for individuals put in that position are not pleasant. It is safe to say that anyone without access to intervention and services in the absence of insurance coverage is facing a multi- decade financial and emotional challenge that will curtail to the point of eliminating his or her ability to reinvest or realize his or her full potential as a wage earner.

Therefore, in addition to the long term economic and societal benefit for autistic kids who will be able to receive insured services, there are additional short and long term economic benefits for those taxpayers whose families are dealing with the relentlessness of the diagnosis. Statistics indicate that the number of kids being assessed as being on the autism spectrum is growing, not shrinking. You have the opportunity to position Connecticut as a leader in recognizing that all of its residents across generational boundaries will benefit in the long term if *this* generation of autistic kids and their families have insured access to services vital to realizing their full potential.

Thank you for considering my testimony.

Sincerely,

Matthew S. Hall

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TESTIMONY SUBMITTED BY:  
Shannon Knall  
Chapter Advocacy Chair  
Autism Speaks, Connecticut  
connecticutcac@autismspeaks.org  
860-573-7600

Melissa Sullivan  
Suffield, CT  
860-668-9096  
sullfam21@cox.net

My name is Melissa Sullivan and I have a 5 year old son with a diagnosis of PDD-NOS on the Autism Spectrum. We had a very early diagnosis at the age of 15 months and we have had intense treatment including ABA, RDI, speech therapy and OT since his diagnosis. It has been a constant struggle to provide my son with the things that he needs and we have had to be strong advocates to make sure that he has gotten these therapies in hopes that one day he will become a successful adult. Therapies like ABA were until recently funded for my son through the Department of Children and Family's (DCF) Voluntary Program. DCF has made very demanding changes to this voluntary program and are now "timing out" families after a short 6 months. The DCF home program was costing over a \$1000.00 per-week for 10 hours of ABA and 1 hour of RDI. My son was making huge progress with his home program as well as attending 2 preschools. He is now left with no home services and I am left to fight yet another fight with our school system so that these programs can continue for him. We were forced to recently close out a college fund for our 7 year old daughter so that we could continue this program for our son. We have refinanced our house 3 times in the past 7 and a half years and are trying to refinance one last time right now to access the last of the equity in our home so that these crucial services can continue without interruption.

As a parent with a special needs child the daily demands are sometimes overwhelming and there is little support for families with children on the spectrum. Right now as I write this a child is being diagnosed with Autism and the current statistics say that the Autism rate is 1 in 150 children. Families need help and most of us pay very high insurance premiums which should include ABA and RDI in addition to the recently added speech, and OT therapies. These therapies have proven effective in helping children on the Autism spectrum and are research based and proven. I cannot urge everyone enough to fully support Senate Bill 301—there is nothing more important in making sure that all families are able to access treatments for their children.

Thank you for your time,  
Melissa Sullivan

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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 Insures 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,

Nancy A. Taylor  
13 High Hill Road  
Canton, CT 06109

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TESTIMONY SUBMITTED BY:  
Shannon Knall  
Chapter Advocacy Chair  
Autism Speaks, Connecticut  
connecticutcac@autismspeaks.org  
860-573-7600

Patty Dobbs Gross  
Storrs, CT  
northstarfoundation@charter.net

Hello,

I would like to apply to testify for Senate Bill 301.

My name is Patty Dobbs Gross, and in addition to being the Executive Director of a nonprofit called North Star Foundation, which is dedicated to meeting the social, emotional and educational needs of children on the autism spectrum through partnerships with assistance dogs; I am also the parent of a child on the autism spectrum named Danny.

Danny has done quite well, and is about to graduate from UConn at Storrs with hopes of attending film school in the fall. He has a severe dysfluency, however, and for the past year we have been unable to afford speech therapy for him, which totally breaks my heart. Cigna supposedly will offer Danny 20 sessions at a \$45 copay for this year thanks to being forced to by the Attorney General, but it is my understanding that they are digging in their heels to not treat dysfluency, so I am not sure we will even be covered in this small way...

I would like to testify with a North Star dog, Rory, who accompanied Danny and I to the inauguration last week in the hopes of presenting a novel, cutting edge and very effective therapy for children on the autism spectrum...Rory is a North Star dog in training to work with a child on the autism spectrum in New Hampshire..here is a short clip Danny put together to commemorate our day:

<http://www.youtube.com/watch?v=JE2hbp-eIxE>

I am attaching a handout about our philosophy for creating North Star placements with children who face social, emotional or educational challenges, and I believe that you'll also find our website helpful in understanding our nonprofit work  
[www.northstardogs.com](http://www.northstardogs.com).

You can see some North Star teams in action on the following site:

[www.youtube.com/profile?user=northstarvids](http://www.youtube.com/profile?user=northstarvids)

Our work was also profiled in September's AKC Gazette, as well as last spring's Autism Spectrum Quarterly.

I have research conducted on our placements that document their effectiveness which I can send to you upon request.

Our work was recently featured by a Japanese television program, and this informative piece can be seen at:

[http://www.suprememastertv.com/bbs/board.php?bo\\_table=download&wr\\_id=4169&go\\_to\\_url=&sfl=ca\\_name&stx=aw&sop=and&url=link1](http://www.suprememastertv.com/bbs/board.php?bo_table=download&wr_id=4169&go_to_url=&sfl=ca_name&stx=aw&sop=and&url=link1)

I have written a book about this emerging field, THE GOLDEN BRIDGE: A GUIDE TO ASSISTANCE DOGS FOR CHILDREN CHALLENGED BY AUTISM OR OTHER DEVELOPMENTAL DISABILITIES (Purdue University Press, July 2006) which will help you to understand this emerging field that hold such promise for children on the spectrum; I can get you this book along with several accompanying DVD that document our work upon request.

North Star is a nonprofit organization (EIN # 06-1589586; Conn. Charities Registration number 12811) dedicated to helping children who face challenges to achieve their social, emotional and educational goals.

Please let me know if you have any questions for me...

Kind regards,  
Patty

Patty Dobbs Gross  
Executive Director  
North Star Foundation  
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Storrs, CT 06268  
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[northstarfoundation@charter.net](mailto:northstarfoundation@charter.net)  
"We help children find their way."

AUTISM VOTES  
SB 301  
FEBRUARY 5, 2009

My name is Phyllis Starkel, Grandmother of 11 year old Molly Sullivan Starkel a student at the Gengras Learning Center in West Hartford CT. My husband and I are here to support SB 301 and help to make it a reality.

With us today is our granddaughter Michaela Harbec, a freshman at Bolton High School, Bolton Ct. Michaela has chosen to research Autism for her Health Class paper. This shows the interest and involvement of all family members.

Molly is one of the bright lights on the Autism Spectrum, who along with parents and family members suffer from the emotional and exhausting physical stress of Autism. She has experienced shunning from classmates at her previous school, not being included in birthday parties with the other girls and expressing how much she missed going. The extensive and sometimes painful blood tests, hospital and doctor visits.

The most emotional moment was when, with a very serious face she asked me what happened to her when she was born and why she wasn't like the other kids !

The worry of expenses if you are not fortunate enough to have health insurance, and if you do, there are generally caps on the services most needed, limited number of office visits for the special services, such as Occupational and Physical Therapy. The exorbitant cost for Autism Physicians, medications, educational materials, possible co-pays, and transportation to out of area Physicians and Hospitals.

Please give the importance of this bill SB 301 your time and consideration.

Thank you for this opportunity to share Molly's life with you.

The Starkel Family  
Columbia, Ct

State of Connecticut  
HOUSE OF REPRESENTATIVES



Christopher G. Donovan  
Speaker of the House

**TO:** Representative Steve Fontana, Chair of the Insurance Committee  
Senator Joseph Crisco, Chair of the Insurance Committee

**FROM:** Speaker of the House Christopher Donovan

**DATE:** February 5, 2009 – Insurance Committee Public Hearing

**RE:** Testimony in Support of Proposed Senate Bill 301

Good afternoon Chairman Fontana, Chairman Crisco and members of the committee. Thank you for the opportunity today to express my strong support for Proposed Senate Bill 301, An Act Concerning Health Insurance Coverage for Autism Spectrum Disorders.

This bill will provide many Connecticut families who have children with autism spectrum disorders with access to life-changing treatments. According to a study by the Centers for Disease Control and Prevention (CDC), one in 150 eight-year-olds in the United States had an Autism Spectrum Disorder diagnosis in 2007. While there is no cure for autism, early detection and treatment can greatly improve symptoms, development and outcomes.

Despite its prevalence, many families do not have access to the therapies or even the diagnoses they need to obtain treatment. Even families with good health insurance are being discriminated against because they have a child with a disability. Connecticut families are mortgaging their houses and bankrupting themselves to pay for effective autism treatments or tragically foregoing these therapies.

Overtime, covering these early treatments will pay for themselves. Studies show that applied behavioral analysis and the other therapies covered by this bill can transform the lives of children with autism and their families, in some cases even allowing them to participate in mainstream classes with little assistance. Overall special education and adult service costs are reduced and people with autism can participate in the workforce. Moreover, their families are more economically productive because they can spend their time earning income.

In the last two years, 7 states – Pennsylvania, Louisiana, South Carolina, Arizona, Indiana, Florida and Texas have all mandated full insurance coverage for the diagnosis and treatment of autism, including behavior therapy.

At the press conference Senator Looney and I held last week, many of us had the privilege of meeting the Latimer family. Mrs. Latimer has been diagnosed with Asperger's Syndrome (an autism spectrum disorder) and both her children are living with autism. The Latimers have insurance, but it covers so little of the therapies and medications the family needs, that living in Connecticut is no longer affordable. The Latimers will be moving to Texas, which requires coverage for the treatments they need.

I hope you will join me in supporting this important legislation. Raising a child with autism is a challenge that so many of our constituents face. They should not also have to struggle with the costs of their treatment.

Thank you for your time.

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February 4, 2009

Senator Crisco, Representative Fontana and members of the Insurance and Real Estate Committee:

I am submitting this testimony in support of Senate Bill 301, mandating insurance coverage for people with autism spectrum disorders.

We began this process last year, and you heard the horror stories of financial burden from many people impacted by autism. Today, you will hear many of the same stories. Parents paying up to \$5,000 out of pocket for a medical diagnosis, up to \$150 an hour for forty hours weekly of Applied Behavior Analysis as recommended by a physician and possibly upwards of \$120 per month on medically prescribed drugs for the treatment of autism.

And you have heard and will hear stories about families who simply have to opt out of these critical medical options because they are simply too costly.

Autism is first and foremost a medical condition. It needs to be treated medically, just as any other MEDICAL condition. Its treatment should be covered by insurance just as any other MEDICAL condition is.

Make no mistake, families with autism have insurance. We pay insurance premiums. The fact that we are being denied services that should be covered under insurance plans is nothing short of discrimination.

You will hear the myths about insurance premiums skyrocketing as a result of the possible passage of this legislation. You will see evidence to the contrary. Evidence that indicates the rate would roughly be the equivalent to \$4 or \$5, the same as what we were paying for a gallon of gas in Connecticut just less than six months ago.

It is time for Connecticut to lead the charges that will end this discrimination.

Thank you for your time.

Shannon Knall  
Autism Speaks  
Connecticut Advocacy Chair  
[connecticutcac@autismspeaks.org](mailto:connecticutcac@autismspeaks.org)  
Simsbury, CT  
Mom to an 8 year old with autism

**JOINT  
STANDING  
COMMITTEE  
HEARINGS**

**INSURANCE AND  
REAL ESTATE  
PART 4  
957 - 1263**

**2009**

301

TESTIMONY SUBMITTED BY:  
Shannon Knall  
Chapter Advocacy Chair  
Autism Speaks, Connecticut  
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860-573-7600

Laura DeAngelo  
Simsbury, CT  
lbdeang@yahoo.com

**Testimony For 2/5/09 Public Hearing, Senate Bill 301**

My name is Laura DeAngelo. I am the parent of a child on the autism spectrum and I am also a professional in the field of autism. I am speaking to you today not only in support of Senate Bill 301, but also in support of broadening the scope of this bill to allow families to chose the type of autism intervention that best fits their needs and the needs of their child.

I'd like to share a little about our family's experience with autism treatments. My son was diagnosed with autistic disorder, the most severe subclass of autism spectrum disorders, at age 2 and a half. I soon became consumed with finding out as much information as I could about the best autism treatments. One treatment kept coming up over and over: Applied Behavior Analysis, or ABA. Overwhelmingly, ABA had the most research backing it as an effective intervention. We researched ABA-based school programs and settled on Simsbury. My son started in the Simsbury autism program when he was just 3. At one of our first PPT meetings, I asked the special education administrator what she thought my son's chances were of ever attaining independence in a classroom. Her reply: Slim to none. In my head, I grieved. I also vowed to prove her wrong.

At school my son received many hours per week of discrete trials and natural environment teaching as a part of his ABA program. The school staff even assisted me in starting a home ABA program to supplement the school's program. I thought we were doing all we could. For a while I thought things were going well. Our son received glowing progress reports in his ABA program. He mastered most of his discrete trials quickly. His vocabulary grew. His motor skills improved. He learned cognitive skills such as the concepts of categories, functions and features of objects. But things were not going well in all areas. At home his aggression and self-injury were getting worse. We had holes in our sheetrock walls from his head banging. He was extremely controlling. He would become unglued at the least little change in routine. At school, his almost constant singing and muttering interfered with his ability to learn and focus in less-structured environments. He was beginning to have tantrums and self-injure at school. A behavior plan designed by a Board Certified Behavior Analyst did not have long-term success in controlling his behaviors. Why was my son becoming more and more inflexible? Why did he still have no ability to interact socially? Why couldn't I,

who had successfully managed two older children, manage his behaviors? Then, one day, my son had an hour long tantrum because I would not repeat back to him the words I was "supposed to" say from a discrete trial he had had in school. At that point, I knew that, despite his significant gains in skills with the ABA program, the central issues of his autism – his inflexibility, his social disconnectedness, his need for control - were actually getting worse. Our son needed something more, something that would address the autism at a core level. But what?

When my son was almost five, I learned of a workshop that was being given on a new autism intervention called Relationship Development Intervention, or RDI. Knowing nothing about RDI, I checked out the website. I was intrigued. The website mentioned a "core deficit" of autism – dynamic intelligence - that is not addressed in skill-based programs. It talked of "remediation" - a gradual lessening of the core deficit area over time so that the disability no longer constitutes an obstacle to the real "quality of life" measures in the long term: True friendships and close relationships. Employment. Independent Living. Financial self-sufficiency. I noticed that there was no independent peer reviewed research on the intervention. Still, the logic of it made a lot of sense to me. I saw that it was based on hundreds of published research articles, books and studies by the most respected names in the field of child development and neuroscience. I saw that it was endorsed by a number of luminaries in the autism research community – Dr. Peter Mundy, Dr. Nancy Minshew, Dr. Peter Hobson, and others. I recognized that it generally takes many years for an intervention's effectiveness to be documented through independent peer reviewed research. The principles of applied behavior analysis, for example, have been around since the 1950, and ABA-based treatment programs for autism have been used with success since the 1960's. Yet it was not until 1987 that Ivar Lovaas' seminal study demonstrating the effectiveness of ABA for children with autism was published. And it was not until 1995, 18 years later, that the results of that study were replicated in the Wisconsin Early Autism Project.

Through a driving snowstorm, I made my way to Dr. Nancy Schwartz' RDI workshop. At the workshop I met a mom who told me, with tears in her eyes, how RDI had transformed her child. After hearing Dr. Schwartz' talk and speaking with this mom, I knew I had found the answer to what was challenging my son.

Our involvement with RDI began four years ago. Fast forward to now. I have a child whose aggressive and self-injurious behaviors no longer occur in school and no longer present a problem at home. Our son had grown enormously in his cognitive flexibility, his emotional regulation, and his social competence. I can change plans and routines now and I know he will be OK with the changes. He has developed conversational speech, empathy, joint attention, social referencing, and a great sense of humor. He often prefers to do things together with me rather than being alone. He seeks and respects guidance from my husband, me, and the school staff. He is able to be competent on play dates with typical children with little or no assistance. He cooks us breakfast – pancakes, eggs, and bacon – unassisted! Just now, as I am typing this, he walked by and said, Hi Mom! What's happenin'?" I said "Oh, I'm just typing something on the computer. What's happenin' with you?" He said, "Oh, I'm just playing some games!" A few minutes later,

he called me downstairs, excited, "Mom, come quick! They're playing our song on TV!" (We have a current favorite song we love to listen to together).

How do I know that the RDI is responsible for these gains? Because the areas that we specifically targeted, at the time we targeted them, were the areas in which we saw significant improvement.

This year, our son will be transitioning out of the autism program at school, no longer needing intensive behavioral supports, no longer needing one on one paraprofessional support. In many areas, he is fully independent in the classroom. And his independence continues to grow. At my son's recent triennial evaluation meeting, the school psychologist said "I am amazed at the growth in Matt since his last triennial."

We had no choice but to pay for RDI out of pocket. This intervention is typically much less expensive than ABA because it only involves a few hours a week of consultation to parents, at most, and no direct therapy time with the child. The RDI consultant trains the parents how to work with their own child in their everyday life in a manner to remediate the autism. Nevertheless, we have spent about \$10,000 on RDI. The intervention worked so well for my son and for many other children I've seen and heard about, that I decided to become certified in RDI myself. I now have a practice as an RDI Program Certified Consultant and have seen the power of this intervention with the families I work with. Thousands of individuals and their families worldwide have realized improved quality of life from this intervention. Unfortunately, there are many families who wish to start RDI programs with certified consultants, but cannot afford to pay for even the minimal coaching time this intervention requires.

Our story highlights the need for families to have a choice in covered autism treatments. ABA alone is effective for some children, but not all. Indeed, despite all the research demonstrating ABA's effectiveness, it is important to note that, even in "best outcome" studies, more than 50% of the children did NOT achieve an independent level of functioning with early intensive applied behavior analysis programs. Dr. Gina Green, a board certified behavior analyst and one of the most respected clinicians in the field of applied behavior analysis, has stated that early and intensive ABA can lead to large improvements in multiple areas of functioning for many children, but that there are more children who do not respond positively and "more do not recover than do recover" from ABA.

Alexandra Rothstein, a Board Certified Behavior Analyst, on her website states: "Some who participated in early intensive ABA for at least 2 years acquired enough skills to participate in regular classrooms with little or no ongoing help. Other children in the studies learned many skills through intensive ABA, but not enough to function independently in regular classrooms full-time. Across studies, a small percentage of children improved relatively little. At this time, it is very difficult to predict in advance how far any individual child might go with this treatment. More research is needed to determine why some children with autism respond more favorably to early intensive ABA than others."

To limit coverage to ABA is to ignore newer interventions such as RDI whose principles and strategies are based on the most recent, "cutting edge" research in the field of neuroscience, typical child development, and atypical child development, but, due to their newness, do not yet have the breadth of published research of ABA, a 50-year-old discipline. If the past is any indication of the future, families may need to wait another 10 to 20 years until enough research is published that newer interventions such as RDI, which have so much anecdotal evidence, will amass a large scientific research base. Clearly, this is not acceptable for our children.

Please support expanding Senate Bill 301 to provide families a choice of covered autism treatments, in order to ensure that more children and their families have a chance for a long-term quality of life.

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## TESTIMONY SUBMITTED BY:

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301

Mario Montano, Jr.  
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MY NAME IS MARIO MONTANO JR. MY SON VINCENT SHOWED HIS SYMPTOMS SHORTLY AFTER HIS FIRST MMR SHOT. I HAVE NOT SLEPT SOUNDLY SINCE. THE PEOPLE WHO MOST LIKELY CAN HELP ARE TO START 1,200 TO 1,500 DOLLARS FOR JUST THE INITIAL MEETING. I SPEAK OF WHAT ARE COMMONLY KNOWN TO US AS D.A.N. DOCTORS {DEFEAT AUTISM NOW}. YALE UNIVERSITY WANTED 5,000 JUST TO BE PART OF A "TEST GROUP." THE BILLS DO NOT END. I HAVE GOTTEN VINNY A CHILD PHYSIOLOGIST WHOM I TRUST BUT CAN NO LONGER UTILIZE AS FREQUENTLY {ONLY ONCE A MONTH NOW} I ALSO HAVE AN O.T SPECIALIST WHO WORKS LIKE AN ANGEL WITH VINNY BUT AT 250.00 EACH 45 MIN SESSION, THAT WON'T LAST EITHER. WHY IS IT SUCH A PROBLEM TO PASS THIS COMMON SENSE PROP....SB 301? MY MOM IS IN THE LATTER STAGES OF ALZHEIMER AND HAS MANY, MANY THINGS SHE NEEDS TO LIVE. HER MEDICAL INSURANCE IS VERY GOOD ABOUT HELPING OUT. MY WIFE IS BIPOLAR, AND YET HER INSURANCE HELPS OUT. THESE MENTAL DISORDERS ARE REALIZED BY THE INSURANCE COMPANIES. WHY ISN'T AUTISM? FORGET THE LIABILITY ABOUT SHOTS AND VACCINATIONS, THIS DISORDER IS HERE! AND IT'S FULL BLOWN! WE NEED HELP, PERIOD! OTHER STATES HAVE STEPPED UP AS CLOSE AS MASS., OUR NEW ENGLAND BROTHERS! I CAN NO LONGER WORK BECAUSE OF MY RESPONSIBILITIES TO CARE FOR THE PEOPLE I MENTIONED ABOVE. I VOLUNTEER AT MY SONS SCHOOL EVERYDAY TO HELP PEOPLE HELP VINNY GET A FARE AND EQUAL EDUCATION.....I ACCEPT NO PAY....I FEEL ANY HELP I CAN GIVE SOMEONE WHO IS HELPING MY LITTLE BOY, DESERVES MY TIME AND EFFORT FREELY.....AGAIN I IMPLORE YOU TO STAND, STAND UP FOR THE INNOCENT CHILDREN OF CT. WHO CANNOT FOR THEMSELVES. I UNFORTUNATELY CANNOT ATTEND BUT PLEASE HEAR MY WORDS, THEY ARE WORDS ALL OF US IN THIS COMMUNITY KNOW.....MY PRAYERS AND HOPES ARE WITH THOSE OF US THAT CAN ATTEND. DO NOT STOP UNTIL WE ALL SEE SOMETHING POSITIVE COME FROM THIS DREADFUL DISORDER.....MARIO MONTANO JR.

Bill 301

My name is Tom Carty of Suffield Connecticut, and I want to thank the legislators for taking the time to hear our case for financial support of scientifically-proven autism therapy.

My wife Rosamaria and I received our son's diagnosis of autism in 2007, and we have researched intensely to find out how we can help him recover from this disorder. Applied Behavior Analysis (ABA) has proven to work best with our son. The structured, intense therapy provided by trained professionals has made a life-changing impact on our son. Therapists have helped our son overcome his obsessive isolation, focus on noise-making toys and repetitive behaviors. Prior to therapy, our son could only make requests through grunts, pushing, or pulling. He is now learning to verbalize his needs. Prior to therapy, our son avoided eye contact and seemed to take little pleasure in adults or other children. Our son has become more tolerant of social interaction with his parents, sister, teachers, and peers. These changes have vastly improved our quality of life by making our daughter and ourselves more optimistic about our son's future.

The great challenge is the financial cost. We have spent more than \$2000/month to pay therapists. While we will make any financial sacrifice possible for our son, we should not have to pay for the vast majority of this therapy out of our pocket. Our son's condition is clearly a medical disorder, and data has proven the effectiveness of ABA for our son and countless other children in studies published in professional journals and books. My wife and I both have extensive experience in research. We earned Ph.D. degrees at the University of Connecticut. I am a professor of history at Springfield College, and my wife is a Spanish professor at Yale University. Our extensive investigations and our personal experience convinces us that Applied Behavior Analysis is scientifically proven to offer our son the best chance at achieving a typical, normal life. We cannot understand why insurance companies fail to recognize the legitimacy of this treatment.

Thank you again for listening to the financial difficulties of families who have children with autism. Our children have kind hearts and great perseverance in working to overcome their disabilities. The state, nation, and world will benefit from helping these children develop and contribute to confront the spiritual, social, economic, and political challenges of the twenty-first century.

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February 5, 2009

**Insurance and Real Estate Committee**

Good afternoon, Mr. Chairman and Members of the Committee. I am Dr. Ronald Angoff, a practicing pediatrician and president of the Connecticut Chapter of the American Academy of Pediatrics. I am writing today to offer the support of Connecticut pediatricians for **H.B. 5242: An Act Concerning Health Insurance Coverage for Required Vaccinations**, which will require insurance companies to pay for vaccinations mandated for school children.

This bill will accomplish a goal that is frequently talked about, but not often acted upon – that of ensuring that preventive care is readily available to all residents, particularly children. Preventive care for children is fundamental to the health and wellbeing of not only each child, but the entire community. Any barriers to access should be removed. The National American Academy of Pediatrics recommends a regimen of preventive care for children revolving mainly around an immunization schedule. Vaccinations prevent damaging childhood illnesses such as measles, mumps, diphtheria, and polio – one need go back only two generations to see the devastation caused by letting these diseases go unchecked in the community. Particularly given the rising debt of the government and the skyrocketing costs of healthcare, preventive care is key for sustaining a cost-effective healthcare system, as the treatment costs for any of these diseases far exceeds the cost of providing the necessary immunizations to prevent them.

Health insurance, as it stands now, is somewhat of a misnomer.. The current structure of health insurance provides illness care rather than health maintenance. It is time to expand the focus to include preventive care, both as a way to reduce overall costs for patients and insurers, and to keep our children and our communities healthy. By guaranteeing that vaccinations are covered by insurance, high fees that will prohibit families from seeking the necessary preventive care for their children can be avoided, resulting in a healthier community and lower overall health costs. Please join the American Academy of Pediatrics in supporting this bill, **H.B. 5242**, to ensure that our children receive the care and services they need to live healthy, successful lives.

The American Academy of Pediatrics also requests your support of **S.B. 301: An Act Concerning Health Insurance Coverage for Autism Spectrum Disorders**. The cost of quality care for a person diagnosed with an autism spectrum disorder is prohibitively high for many families. By providing insurance coverage for the necessary care, we will be paving the road for those with autism spectrum disorder to become successful, productive members of our community. We ask you to join us in our support of **S.B. 301**.

Thank you for your consideration.