October 16, 2016 - Pennsylvania House of Representatives

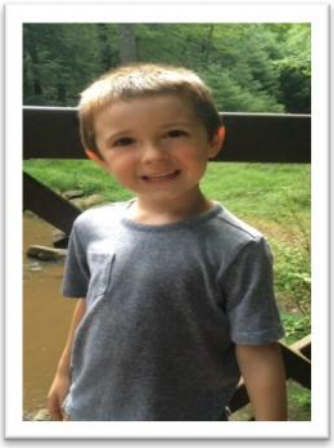
Dear Chairwoman Pickett, Democratic Chair DeLuca, and the esteemed Members of the House Insurance Committee:

Thank you for the invitation to provide testimony at today's hearing on HB 2010 and HB 1559. My name is Dr. Cheryl Tierney and I am both the Section Chief of Behavior and Developmental Pediatrics at Penn State Children's Hospital in Hershey PA and the President and Founder of ABA in PA Initiative, a 501(c)3 advocacy organization. This testimony is based on both my professional training and expertise and collaborations with doctoral level board certified behavior analysts and other experts in applied behavior analysis. For the sake of brevity, my education and credentials have been provided in Appendix I at the conclusion of my written testimony.

To encapsulate our findings, it is our informed and expert opinion that if both bills move forward, allowing people who lack the 1000 hours and mandated training to obtain "temporary" licensure, it will result in real harm to children and families, and would betray the legislature's responsibility to the taxpayer as prudent stewards of the State's revenue. Before we offer the research, the data, and the academic justification for this conclusion we would like to share the testimony of parents who have been directly affected by this very question:

Parent Stories

Sarah Elizabeth Confer *My son was diagnosed with ASD at 2. Getting intensive, effective therapy going was our top priority. It took us two long years to make that happen. After countless hours…. we finally wound up purchasing private insurance for ABA coverage. My son has made more progress this past year than he did from ages 2-4 with BHRS. Our first TSS had no prior experience and my son was her very first client. Turnover rates and finding staff to take the few hours that we were approved for left us with interrupted services for months at a time. We went through three different agencies, experiencing the same problems with each. The whole BHRS system in our rural area is a mess. For the past year, we have been doing 25 hours per week with an amazing team comprised of our head BCBA and two BCaBAs. Last week, we cut 5 hours per week off of the schedule. My son is mastering all of his goals. He no longer qualifies for an IEP or speech services because of his latest evaluation scores, all within average ranges. We will be phasing out of ABA in the coming year and he will be able to start mainstream kindergarten next year, most likely without support. There is no way I would be able to say this now if it weren't for the skill-building, habilitative nature of the ABA we have now.*



In our experience, there is a huge difference between ABA delivered by a BCBA and ABA-style methods used by some BHRS agencies. Even with an LBS, BSCs will not have the same training as BCBAs, and BCBAs in BHRS agencies are scarce because MA is only reimbursing them at BSC rates. There should be a consistent standard for working with individuals with autism. It's long overdue. I want to be sure our Representatives realize that providing substandard treatment for children with ASD only inhibits progress and increases the amount of money spent, and wastes precious time on methods that don't work. The whole idea that autism should be treated as a behavioral disorder needs to end.

Megan Henry-Wilson *I would like to add that we need ABA for my 10 year olds self-care skills and feeding behaviors. We rarely have meltdown behaviors anymore but with ASD and Intellectual disability he does very little for himself. I work on it with him, but think he could really benefit. We have a BSC who says he is experienced ABA but not a BCBA and we don't see any goals, outcomes etc. Seems to be a bit of a waste for us. And not sure where we turn*

Sarah Drennan Nicastro Kelly *I called BHRS in April and was told that they don't do ABA therapy. They said that my son may be able to get therapy from someone who is familiar with ABA, but it's not guaranteed. So I decided to put that option on hold and focus on finding a BCBA to do at least a few hours a week with. We are so lucky to have found a wonderful BCBA that is in network with our private employer insurance. However, we are only approved for 5 hours a week with her and the coinsurance on those 5 hours a week is equivalent to a car payment that we can't afford. We almost stopped, but he's getting better with just 5 hours a week with a BCBA. He was nonverbal a year ago. Now he's speaking in sentences, sharing his emotions in words, asking questions and waiting for the answers.*

I'm going to nursing school and when I'm done with that at the end of next year, I will work full time so he can have all of the therapy he needs. The change in routine is going to be so hard on my son and I hope it doesn't set him back, but I don't see any other option unless BHRS or MA will pay for a BCBA that has the proper training. His attention span is so short. There's no medication to treat attention span issues in a 3 year old. We don't have a minute of therapy time to waste with someone who isn't trained. It would set him back.

Taylor's Mom *On January 23, 2013, when my son was 2, he was diagnosed as having autism. Taylor was nearly non-verbal, and spent his days isolated playing with strings, and having horrible tantrums. After Taylor's diagnosis, I was given a list of BHRS providers, and told I needed to find him aba therapy. The first BHRS provider that actually answered my calls, heard the word BCBA and ABA in my list of questions and responded "let me tell you, what you are looking for doesn't exist here." At the end of 100s of calls, I found one BHRS provider that had a BSC who at least had heard of aba and I had a glimmer of hope. However, that hope faded. Taylor spent the next nearly two years, with a BSC and TSS who were able to minimize his "behaviors," but little else. After two years, he was "trained" to sit quietly in a circle with peers for about 10 minutes, but he learned nothing. He could not recognize letters, or speak in any manner that resembled typical. During the same period, I searched endlessly for a private BCBA to assist. When Taylor was four, we were able to find a private BCBA that could do intensive ABA for 20 hours a week. Within months, Taylor was coming out of his shell, interacting with people, speaking in small sentences, and we could finally understand at a minimum what he needed. Our private BCBA began to train our BSC and TSS on how to deliver ABA. Now a year later, Taylor can hold a conversation and interact with peers. He can write all his letters, and is learning some very basic math and reading skills.*

That said, Taylor lost two critical years of development and still has huge gaps to close. The time and money paid by Medical Assistance, prior our BCBAs involvement delivered no true results. The consequence to that is a young boy that had the potential to not need intense special education now is in full-time special education struggling to catch up. It did not need to be this way, and should not have been this way. A disservice was done to my son, and many more like him, as well as to the State. To continue to pay for quantity without quality defies logic and serves no one. When properly delivered ABA can make the difference between a few years of quality to a lifetime of quantity. Without true change and commitment to quality the State is condemning an ever-growing population to not reach their full potential and instead to be reliant on continued care. I ask that you take the time to truly build a system that delivers results, not only for the children, but because anything less is a disservice to everyone.

The State can do better. My dreams for Taylor and all the kids like him is a system without a fight, but rather a system that is designed to help them, to help them become successful and reach their fullest potential.

As one interprets this issue, it is important to understand that a “Behavior Specialist” is the provider type that was designated to design, implement and evaluate a behavior modification treatment plan including those “based on ABA.” The state also indicates that same Behavior Specialist must be licensed by the state. To be clear, many provider types use principles of applied behavior or treat children with approaches “based on applied behavior” but do not meet the standards thus are ill-equipped and unable to treat the unique problems these children face. Children we should agree must be held to a higher standard of care.

The Behavior Specialist License (LBS), established May 26 2012 in response to ACT 62 of 2008, created a standard of training and experience for the delivery of ABA that is significantly lower than the standards established by Behavior Analysts themselves. As a result, many well-meaning but under-qualified professionals are engaging in a sort of “patchwork delivery of programming” that may resemble ABA, but is not. Few dispute this point, and I know of no one in this field who would argue that the LBS is equivalent to the standard of Board Certification as a Behavior Analyst.

Evidence is clear that ABA, Speech therapy, OT and social skills programming are the most important interventions for children with autism. Each therapy has its own provider-type that delivers that therapy. For ABA, the provider type is a BCBA and RBT (Registered Behavior Technician). The BCBA is the Master’s level provider and the RBT the undergraduate level provider. These providers work together to implement an ABA program, not “based on ABA principles” but based on a comprehensive series of coursework and supervision that allows one to develop a complex plan, analyze its effectiveness and modify it as needed. Behavior analysts use the scientific principles of behavior analysis to change broad classes of an individual’s repertoire, including language, functional skills, and problem behavior. In addition that individual needs to be able to supervise and oversee ABA programs delivered by RBT’s so that a child’s progress can be clearly monitored and ensured.

How did we get to this point?

As in other situations, history will help us understand the present. In 2008, Act 62 passed ensuring that children with autism could access ABA and have it covered by their insurance. The task of providing this complex, highly skilled therapy fell to private agencies and publically funded wraparound agencies within the BHRS system. The BHRS system had no prior experience with this. Rather than creating a separate service line and hiring skilled personnel they tried to use staff they already had trying to make the square peg fit in the round hole. One analogy that might help is, an agency that only delivered occupational therapy and then was charged with adding speech therapy. The agency instead of hiring speech pathologists, trained their OTs to use “speech principles” in their work and then billed insurance and claimed to be “doing speech therapy”.

However it was clear that families were suffering with this system approach. First you need to determine how many children need this service. Then you need to hire ABA therapists and RBT’s to staff the cases. If wraparound agencies actually did this and put “great effort” into developing this different service line so that when providers, like myself, ordered ABA therapy, we could obtain it for our patients that would be fine. However they didn’t and now they are stating they don’t have the staff and are looking for ways to lower standards so that more of their “current staff” or ‘trainees” can be assigned to cases where ABA is needed. Wraparound agency leadership need to understand that because ABA is medically necessary for children with autism they will need to restructure their businesses to accommodate a different service line with additional staff with different qualifications.

In Pennsylvania, some suggest that ABA can be delivered by individuals who meet the qualifications of the LBS (Licensed Behavioral Specialist); however, all professional and special interest groups for behavior analysis urge otherwise. Furthermore, since the 2008 passage of Act 62, the discipline has rapidly evolved. Even if the LBS standard was once appropriate (evidence suggests it was not) recent advances in programming for individuals with ASD highlights the need for the same level of competency associated with other professions, such as Occupational Therapy, Speech Therapy, etc.

To put the complexity of the specialty into perspective, we include a link to the task list that the BACB (Behavior Analyst Certification Board) publishes[1]. In addition the National Autism Center's National Standards Report, lists research-based, effective interventions for children with autism[2]. If the primary concern is providing service that will benefit an individual with ASD, there is little question as to what defines a minimal level of training. However, in looking at the proposal for a temporary LBS license, it seems clear that the needs of the individuals are not the prime area of focus.

There are documented problems with how children respond to therapy with providers who hold the LBS licensure but are not also board certified. Both House Bills will reward BHRS providers by allowing them to use underqualified, uncertified, and inexperienced recent graduates to staff their autism cases and obtain reimbursement for those services using the current reimbursement structure. If the goal is to improve "access", does either bill address the poor access to ABA therapy? Clearly not since these providers will not have the skillset to deliver ABA therapy. A lot of a bad thing isn't a good thing so a warm body for a child with autism is not the goal here.

Allowing temps to bill insurance creates an assembly line of new graduate students seeking supervision for their LBS. Once licensed, there is no incentive by the BHRS agency to keep them because the agency would need to raise pay to retain them, so they are replaced with another temp, and the cycle continues, outcomes be damned. Treating autism should be more than a business, and this will lead to a clear disparity in quality: if you have private insurance and can afford an experienced provider with the right credential- your child's chances at success are great.

If you have MA you are forced to turn to only the most inexperienced providers, and the outcome less certain. If Medical Assistance BHRS providers are allowed to use recent grads as licensed behavior specialists when they don't even have the training and experience currently required for licensure, these BHRS providers will become revolving door training grounds for private agencies, schools and IU's that will hire these grads after they have obtained- at the expense of Medical Assistance tax dollars- the experience and training required for full licensure. Meanwhile these poorly served children have matured into adults ill-equipped to meet the demands of adulthood, and a cycle of dependency ensues.

Under Act 62, permissible fields of study are listed. Examples include social work, special education, counseling, speech therapy and occupational therapy. Most master's level majors detailed in Act 62, and reiterated in both House Bills have very little if not nothing to do with becoming a behavior analyst. To help protect children and to help ensure that the providers assigned these cases have some autism experience, 1000 hours of direct clinical experience was added. The proposed legislation would allow providers to work with children, without the minimal education or experience needed.

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[1] http://bacb.com/wp-content/uploads/2016/03/160101-BCBA-BCaBA-task-list-fourth-edition-english.pdf

[2] http://www.nationalautismcenter.org/national-standards-project/ National Standards Report. (2009).

Another concern is that if you allow those with temporary licenses to delivery intervention, families may falsely believe that their child is receiving ABA when they are not. If a provider does not have their certification, they should not be able to deliver ABA because they just don't know how. The field is too complicated and complex to believe a license without certification is enough. So a parent may falsely believe that ABA doesn't really work when in fact it is the provider without the right skill set that is responsible for a child's poor response to therapy.

The state created a license that once obtained did not produce a provider that could deliver the scientific based therapy that it was trying to ensure. Instead of looking at the qualifications that the BACB (Behavior Analyst Certification Board) laid out and try and mirror those, the state set forth its own criteria, not backed in any outcomes research. So what we are seeing? We are seeing social workers, marriage counselors, special educators and others obtaining a license but no previous experience or training in applied behavior analysis. And now we have problems in several domains. The wrong professionals are obtaining the LBS. Not enough people who have the license are going to work for BHRS. And this comes on the shirt tails of a series of meetings that are currently underway to regulate higher standards for clinicians so that children with autism being treated in the BHRS system will be guaranteed a BCBA when the case calls for one.

Recommendations

In my opinion, it is far better to have fewer well trained providers to start, build capacity with quality in mind and then keep track of outcomes. Be judicious in your allocation of resources. Make sure that those who receive it really need it. Ensure that those evaluating children and prescribing it are trained to do so. Transition care to a lesser intensity of service when a child is able. Increase pay for those have the right credentials, training and certification and demand quality. Then, equal to private ABA agencies, providers will apply and accept jobs at BHRS agencies. I would like to offer suggestions on how to help BHRS agencies struggling to hire staff solve the access problem if not by lowering standards.

1. Increase pay commensurate with the standards in the industry
2. Incentivize providers in related fields to go back to obtain their certification
3. Increase continuing education opportunities
4. Reward furthering education (going from a master's level to doctoral level provider)
5. Ensure that TSS staff are RBT's so that BCBA's are working with Behavior techs trained to deliver the therapy they design and manage (similar to those in private practice and what private insurance is requiring to be reimbursed)
6. Reward providers for quality and outcomes
7. Reach out to training programs to increase acceptance for those going into ABA fields
8. Incentivize providers to work in underserved areas.

While we respect the input from BHRS agencies that are trying to provide this therapy, they are not coming from a broad enough perspective. Before the Sonny O Lawsuit settled, no agency could provide ABA, and if ABA therapists were on staff at agencies it was not intentional. Many left BHRS because the system didn't provide ABA therapy and they were disillusioned that they could once hired. So the view "we don't have enough providers" is but of course true. However, the reality is that BHRS providers have no idea how hard it will be to develop ABA programs for children in need because they have not done a needs assessment nor tried to hire staff offering compensation commensurate with training and expertise for example. And during the many years they weren't providing it, and private insurance was covering it, private agencies popped up everywhere to fill the void.

In 2015 there were only a handful of private ABA agencies in the state. Now in 2016 my personal directory lists 41 private firms in Pennsylvania (see attached) and we add between 1-5 new agencies per month as agencies learn of our directory and reach out to be listed to advertise their services and offerings. So it will be important for medical assistance to proactively reach out to contract with these private providers to begin to build capacity.

In medicine we have a saying “First Do No Harm”. While we are looking to the regulations process to improve the quality of what is delivered in Pennsylvania we urge you to “first do no harm” by working against the best one thing we have to improve the lives of children with autism.

Warm Regards,

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Appendix 1: Cheryl Tierney, MD, MPH
Biography

Dr. Tierney graduated from Tufts Medical School in Boston in 1996 and completed internships and residency in Pediatrics at Carolina's Medical Center, now Levine Children's Hospital in 1999. I immediately entered my subspecialty training fellowship at Boston Children's Hospital where I completed a combined fellowship in Health Services Research, General Academic Pediatrics and Behavior and Developmental Pediatrics in 3 years (1999-2002). During my time at Boston Children's I chose to complete a Master's in Public Health with a concentration on Child and Maternal Health at Harvard and was able to take some courses in health policy and business at Harvard Business School. Shortly after completing my education and training I sat for my boards to become a Board Certified Behavior and Developmental Pediatrician.

For the first 9 years of my career I worked in an inner city mostly Spanish speaking academic training clinic which was part of Tufts Baystate Children's Hospital and served as Medical Director, Associate Program Director and Education Coordinator for the Evidence Based Medicine Curriculum for Pediatric Trainees. I held national positions including sitting on the Board and Task Force for Continuity Clinic Directors for the American Academy of Pediatrics.

I was recruited to serve as the Section Chief of Developmental Pediatrics for Penn State Children's Hospital in 2010 and spearheaded the ABA in PA Initiative in 2012 after learning that children living in Pennsylvania did not have access to quality therapy as they did in the New England States where I trained and lived for over a decade. I am a nationally recognized expert witness for Developmental Pediatrics and have been an invited speaker at conferences across the country and abroad. I have 13 peer reviewed publications in autism and related disorders in top Journals including Journal of Developmental & Behavioral Pediatrics and Pediatrics.

Appendix II – Terms

In order to understand my testimony we first have to understand what is said in Act 62 of 2008 as well as what is considered best practice and evidence based interventions. Where possible references are included and attached. In order to inform this discussion the following is reviewed:

First, Act 62 defines "*behavior specialist*" and I would like to include that here so that we are all working from the same understanding:

(f) As used in this section:

(1) "Applied behavioral analysis" means the design, implementation and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior or to prevent loss of attained skill or function, including the use of direct observation, measurement and functional analysis of the relations between environment and behavior.

(2) "Autism service provider" means any of the following:

(i) A person, entity or group providing treatment of autism spectrum disorders, pursuant to a treatment plan, that is licensed or certified in this Commonwealth.

(ii) Any person, entity or group providing treatment of autism spectrum disorders, pursuant to a treatment plan, that is enrolled in the Commonwealth's medical assistance program on or before the effective date of this section.

(3) "Autism spectrum disorders" means any of the pervasive developmental disorders defined by the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), or its successor, including autistic disorder, Asperger's disorder and pervasive developmental disorder not otherwise specified.

(4) "Behavior specialist" means an individual who designs, implements or evaluates a behavior modification intervention component of a treatment plan, including those based on applied behavioral analysis, to produce socially significant improvements in human behavior or to prevent loss of attained skill or function, through skill acquisition and the reduction of problematic behavior.

Appendix III – Applied Behavior Teaching Modalities

Antecedent manipulation - modification of situational events that precede the target behavior. These alterations are designed to increase the likelihood of success of the targeted behavior. Examples include: prompt/fading procedures, behavioral momentum, contrived motivational operations, inter-trial intervals, incorporation special interests, etc.

Behavioral treatment -programs designed to decrease problem behaviors and to increase functional alternative behaviors. Examples include: functional communication training, chaining, discrete trial training, mand training, generalization training, reinforcement, shaping, etc.

Comprehensive intervention - low child to provider ratio (1:1, or low as appropriate) in a variety of settings, including home school and community. Effective programs are based on a treatment manual, provide intensive treatment (25hrs/wk+), and include data-driven decision-making.

Joint attention intervention - programs designed to teach a child to respond to the social bids of another, or to initiate joint attention interactions. Examples include: pointing to objects, showing items, activities to another, and following eye gaze.

Modeling - adults or peers provide a demonstration of the target behavior; the student is expected to imitate. Thus, imitation skills are a necessary prerequisite to this type intervention. Modeling is often combined with prompting and reinforcement strategies which can assist the student to acquire imitation skills.

Naturalistic teaching strategies - use of child-initiated interactions to teach functional skills in the natural environment. This intervention requires providing a stimulating environment, modeling play, providing choices, encouraging conversation and rewarding reasonable attempts

Peer training - involves training peers without disabilities strategies for interacting (play and social) with children with autism. Some commonly known peer-training programs include: circle of friends, buddy skills, peer networks, etc.

Pivotal response training - program designed to target specific, “pivotal,” behaviors that lead to improvement across a broad range of behaviors. These pivotal behaviors include: motivation to engage in social communication, self-initiation, self-management, responsiveness to multiple cues, etc.

Schedules - teaching a student to follow a task list (picture- or word-based) through a series of activities or steps in order to complete a specific activity. Schedules are accompanied by other behavioral interventions, including reinforcement.

Self-management - this treatment intervention teaches a student to regulate his or her behavior by recording the occurrence or non-occurrence of the target behavior, and secure reinforcement for doing so.

Story-based interventions - involves a written description of the situations under which specific behaviors are expected to occur. The stories seek to teach the: who, what, when, where and why of social interactions to improve perspective taking.