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Kathy Cooper

From: Thomas, LeeAnn <LMThomas@pcgus.com>
Sent: Monday, August 13, 2018 10:59 AM
To: IRRC
Subject: IBHS Public Comment



RE: Regulation #14-546
IBHS Public Comment

To Whom It May Concern:

While I acknowledge I am not an expert, or as versed in ABA/BHRS qualifications as many who may comment, I felt that it was important to submit a statement from the perspective of a parent.

By the time of my son's 18 month well child checkup, I had started to have concerns with his development. He had met all his milestones. He was making many animal sounds, had 20 or more words, identified objects in books by pointing and had started to identify colors. As the weeks went by however, I became increasingly aware that instead of gaining new words and skills Camden had started to lose them. Although his pediatrician did not see a concern at the time, I knew in my gut something was not right and convinced her to make a referral for him to be evaluated. I had worked in the foster care field for many years and knew that losing words was one of the "red flags" to look for when diagnosing autism.

In July 2017, we received the official diagnosis that we had dreaded and our lives were changed forever. By this time, we had been receiving Early Intervention services for almost a year. Camden had continued to lose words and had developed many of the classic signs of autism. He avoided eye contact, didn't respond to his name, and developed repetitive behaviors including rocking and clapping.

His official diagnosis came from the Children's Hospital of Philadelphia with a recommendation that Camden begin to receive ABA services. It was explained to me that in the state of Pennsylvania these services were often administered by a BHRS or wraparound provider. I was strongly encouraged to ensure I arranged services from a BCBA and staff who had specific training and experience working with children on the spectrum. I very naively set out to accomplish what I thought would be a simple task. My son had autism and a developmental pediatrician had made a recommendation for ABA services. I had made referrals for services hundreds of times in my years in the foster care field. Certainly, I could arrange for the quality services for my own son.

Within a day of his diagnosis I started to call BHRS providers, believing this was my only option to obtain the ABA services recommended. I called numerous providers and was told they had very few staff trained in ABA and those staff already had full caseloads. At this point I reached out to our managed care organization for help of where to go next. I was told that a local agency could provide the recommended services and was given their contact information. Although I had previously spoken to the intake worker from this agency and been told they had no openings, after the MCO contacted their director, I received a phone call to arrange for an intake appointment. I reluctantly proceeded with this appointment after researching the agency to find no information was available about their ABA program. My reluctance was further validated at the intake appointment when questions regarding training requirements and the longevity of their ABA program were unable to be answered. Feeling I had no other option, I accepted the services.

We are almost a year into services with the BHRS provider. I am not exaggerating when I say that our TSS worker has become and like a member of our family. She has many years of experience, is incredibly dedicated to her job and loves my son as we love her. She provides us the service that she was trained to provide and she does that well. Unfortunately, through no fault of her own, she has not been appropriately trained in ABA and we have made little progress. Camden is assigned a BCBA through this agency; however, we are lucky if we see her an hour a month.

I have spent countless hours researching ABA therapy, watching videos, reading blogs. I am certainly not an expert in ABA but I knew we needed more. We needed therapists who specialized in ABA therapy rather than a TSS staff who implemented a few ABA techniques. I continued to fight for a true ABA therapist throughout the past year. I filed complaints with our MCO, OMHSAS, DHS and even our local state representative pleading for my son to get the services he deserved.

After reaching out to a local parent support group, I was given the name of a BCBA who worked with an agency providing ABA therapy. Instead of the minimum 6 hours of online training required for BHRS staff, the staff of this agency had true credentials, certification and mandated hours of hands on training. This was exactly what we needed and what had been recommended by the developmental pediatrician from CHOP. The only problem was that they were not approved to accept medical access. My option was to put my son back on my insurance plan through work; however, the cost to do that and the copay of \$50 a session was more than I could afford. Knowing our situation, this agency agreed to meet with us and offered us pro bono services while they worked through the process of becoming an approved MA provider.

Within 10 minutes of the BCBA walking in our door, I cried as I watched my son do things I never knew he was capable of doing. For almost a year BHRS therapists have focused almost solely on attempts to get my son to say or sign the words more or open to request treats from a box of junk food. He has been given countless amounts of gummies, Doritos, and cookies as reinforcement and has yet to consistently learn to sign or speak the desired words. In less than 10 sessions of "true" ABA therapy, Camden is able to consistently use a picture (PECS) book to ask for things he wants, follow multiple commands, consistently respond to his name, mimic requested behavior and match colors and objects. My child who would struggle to sit for two or three minutes with early intervention or his TSS worker, is now continuing to sit even when offered a break, because he is truly excited about learning again and proud of his accomplishments. We have been able to track his progress from week to week and he is consistently making gains, which we have not seen before.

I search for the perfect words to convey the difference between ABA techniques used by a BHRS provider and "true" ABA therapy provided by trained and certified staff but I doubt that I could ever find them. It is also difficult to find the words to convey just how grateful we are to the agency and therapists who have sacrificed their time and resources to give my son the help that he deserves with receiving no compensation other than a "thank you." Was it not for the sacrifices made by a few passionate and selfless individuals, we would continue to be "stuck" with our unsuccessful attempts at hoping one-day gummies would be reinforcement enough for Camden to finally request his box of treats be opened.

What I know is that, if I had a child diagnosed with cancer, we would never be expected to seek treatment from a family doctor. We would be referred to and receive treatment from an oncology specialist without question. I struggle to understand why having a child diagnosed with autism should be any different. Having a child diagnosed with autism and expecting to receive treatment from BHRS staff is parallel to a cancer diagnosis being treated by a family doctor. My son deserves more than a general practitioner. He deserves to have treatment from a specialist and we shouldn't have to fight for this service. I assure you our journey is difficult enough.

Thank you,

LeeAnn Thomas