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From: Lisa Sportelli <gutbrain@gmail.com>
Sent: Tuesday, September 4, 2018 4:56 PM
To: RA-PWIBHS@pa.gov
Cc: IRRC
Subject: Comments on Regulation No. 14-546

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To Whom it May Concern,

I am a parent as well as an advocate of many children directly affected by these regulatory changes as well as being part of the IBHS Workgroup. I have read and fully support the comments, suggestions and concerns of both Disability Rights Pennsylvania (DRP) and Pennsylvania Health Law Project (PHLP).

The sad truth is that my 19 y/o son (after receiving 40+ hours/week of BHRS for 12 years of what I THOUGHT was ABA, (prescribed medically necessary by his physician), costing the department over \$1 million dollars, had behaviors steadily increasing to a level of hospitalization or placement. By the age of 15, our provider of 12 years discharged him because he was "too behavioral" for Behavioral Health Rehabilitation Services. Today, even with these new regulations as written, his behavior would be "too intensive" for Intensive Behavioral Health Services.

We were lucky enough to be accepted into The Neurobehavioral Unit at Kennedy Krieger Institute, which started with a thorough Functional Behavioral Assessment (FBA). This is where we finally learned the FUNCTION of his behavior. This is where I also learned my son had NEVER HAD ABA. His therapy had never consisted of a BCBA or implemented by an RBT. After a month of intensive services, my son had a 96.2% of reduction of behaviors, and continuing progress...not only with behavior reduction, but ADL's (including toileting) where he is learning the skills he needs to be as independent as possible.

I think many of these regulatory changes are positive, however, I feel clarifications need to be made for "behavioral consumers" when Activities of Daily Living (ADL's) and restrictive procedures need to be taught and implemented for safety, especially with IBHS, as this is meant to be a transfer of skills from provider to families and consumers.

First, there should be a mechanism when the BCBA needs more time for ITP. Consumers, like my son, who have complex medical conditions, a long history of past interventions that were ineffective...The BCBA should not be forced by time-constraints to develop a plan without the ability to ask for more time if needed to complete the FBA and to properly know the individual and their history in order to make programming recommendations.

Then, after a thorough FBA, and the BCBA has implemented the treatment plan and determined all parties to be safe, a restrictive plan should be allowed/encouraged to be implemented, as well as intensive 2:1 staffing, when necessary. The only way is for everyone (families included) be trained and certified on the same chosen physical management training protocol. Most companies have a "watered down" "family training". Two companies that not only allow but ENCOURAGE ALL NATURAL SUPPORTS to be trained exactly the same as the trained staff (Professional Crisis Management (PCM) and Handle With Care.

There is an entire population of children like my son who, because proper services, as prescribed by a physician were not/could not be delivered at all, let alone with integrity and the proper tools. Unfortunately, like my son, many of these "behavioral" young adults are ended up being placed in facilities instead of empowering families with the proper skills, so that the children can remain in the family home.

My son is also nonverbal and behaviors ARE communication. Now, with "real" ABA, my son can now spontaneously communicate with a communication app, Proloquo2Go on his iPhone. Our current BCBA made the targeted skills, made sure all staff and family are on the same page. Communication needs to be expanded as well as appropriateness of speech for those who have language, but it's inappropriate (social skills). Being taught and understanding appropriate language skills is also a critical component.

Individuals may also have medical issues. Families have also been told by providers that they won't help with anything that involves bodily fluids (toileting, emesis, etc). Many providers refuse to assist in some of the most important life skills. If it is an identified need of the child, the provider should provide and clarifications need to be made, so that it is not up to each providers interpretation.

Thank you for your consideration,
Lisa Sportelli
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