

14-546-45

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Champa, Heidi

**From:** Larisa Geiss <laraasta@yahoo.com>  
**Sent:** Sunday, August 26, 2018 2:33 AM  
**To:** PW, IBHS  
**Subject:** Regulation No. 14-546



Dear Ms. Pride,

As a parent of a child with ASD I really like this proposed rulemaking, particularly the educational requirements for ABA providers. However, what I did not find is that this rulemaking did not specify the need of ABA facility based providers, or how to pay for the facility based ABAs. At this point we, as parents of kids with mental disability, have no choice but accept the fact that if our kids need/require facility based ABA, we have to pay for it. MA will not pay. The only other choice (in our community) we have - wrap around programs (they often do not have enough ABA trained stuff), or our ABA program would have to start offering 100% home/ community based services and **withdraw our kids from a group setting where they could learn how to communicate under supervision of highly professional ABA trained specialists without being abused by untrained staff or kids with normal development.** Your proposed rulemaking stated that it will "support children, youth and young adults with mental, emotional and behavioral health needs by improving their functioning, promoting their resiliency and enhancing their quality of life, which will allow the children, youth and young adults to live and participate in the community with their families." But it does not cover a full spectrum of programs (and a facility based ABA is most successful). We also have another great law here in PA, ACT 62. But in reality, despite that we have recommendations from doctors that our kids have to have facility based ABA, we have to pay for it (including copay). My autistic daughter does not have siblings, her contacts with kids her age are very limited. Kids with normal development do not want to play with her, because she does not understand how to play, she is too strange. She was physically pushed numerous times when I was around, kids in front of her told her that she is not normal and she better stay away. It is very hard for me as a parent to watch it. At this point she goes to a facility based ABA program (unfortunately only 2 times a week for 3 hours, because I cannot afford a full program). During her classes she is around kids with the same level of social development (and nobody makes fun of her, nobody pushes her away), with ABA trained instructors, and ABA trained behavioral specialist at the same time for 3 hours. She started answering questions, she is getting more independent, she has friends now and can play with them. Her games dramatically changed: she does not roll cars any longer, she plays with dolls: she feeds them, walk with them, talk to them. She started using a spoon a little bit. However, soon she would have to leave this great program (I will not be able to afford it). I am being pushed into "more appropriate program," covered by MA - "community based program". What it means for me and my daughter: only me, her and a one therapist will be at home, or in a park 100% of time. It could be in a library for example, but with kids with normal development (but my daughter is not ready for it yet, she has to learn how to communicate first without being abused). As a parent of a child with mental disability I think we should have a choice, and a facility based ABA a must have for our kids for their future success. It does not have to be 100 % facility based, and it is not in our program. But we desperately need a group setting, facility based ABA, as more appropriate and way more successful.

Sincerely,

Larisa Geissler