14-546-28 REA Champa, Heidi From: Marie Mambuca <marie@autismofpa.org> AUG 2 0 2018 Sent: Wednesday, August 15, 2018 2:12 PM To: PW, IBHS Independent Regulatory Review Commission Subject: Chapters 1155 and 5240 public comments!!

Hello! I am the single mother of a 27-year-old man with autism and intellectual disabilities. Although it has been a long, hard road I am grateful for all the services Pennsylvania has offered my son. He received Medical Assistance and BHRS both of which has helped him become a strong, healthy, kind man. The wraparound my son benefited from was an intensive ABA approach, discrete trial training. He needed intensive, one on one physical intervention to learn the structure of the day, daily functional living skills, attention skills, communication and language and to stay safe.

I have been fortunate to work for the Autism Connection of PA for 18 years. My job as the Family Supports Coordinator is to help families with services, supports, laws, siblings, social, employment, living etc.

The proposed regulations, Chapters 1155 and 5240 relating to intensive behavioral health services, seem cumbersome in lieu of the lack of support personnel. I appreciate the importance of educated professionals to work with children with intensive behavioral needs but when desperate I took what was offered and did the training myself.

I trust the regs include a pay raise to the agencies that currently provide these services under medical assistance. They provide an invaluable service, under exorbitant pressure, with progress sometimes in baby steps! I also encourage educating primary insurance companies on the medical necessity of autism therapies/services as well. If my son had not had BHRS, he would cost more monies to support as an adult.

I have a few more points:

• Section 5240.41-5240.43 – will the child abuse and criminal checks be done yearly even if employee stays with same agency? (I've heard folks who work for same agency for years and they don't have to redo their clearances.)

• Section 5240.81 – 5240.83 and 5240.87 – ABA is much more than just manipulating environments. And thank you for acknowledging that BHRS is important for producing socially significant improvement in human behavior. Many families are told their child doesn't qualify

for BHRS because the child doesn't exhibit negative/self-injurious/aggressive behaviors.

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- For a parent, the amount of acronyms is overwhelming.
- Please include from Kirk et al. "DPW will adopt a statewide sixty-day standard to govern the delivery of BHR services, to be measured from the date of a request for service to the date services as authorized are initiated." Parents may have the opportunity to get an evaluation with a prescription for BHRS but there's no staff to fill the prescription.

How does this compare to the movement by ABA in PA initiative?

https://abainpa.com/news/38-better-access-to-treatment-bat-act

Our mission within the ABA in PA Initiative has always been: to increase access to qualified professionals, increase access to behavior analytic services and ensure that our ABA providers have the highest level of expertise. Over the past few months our group has been working tirelessly to meet these objectives. We are excited and pleased to announce that the ABA in PA Initiative, in conjunction with Rep. Tom Murt and Rep. Tom Mehaffie are putting forth legislation for licensing Behavior Analysts! The Better Access to Treatment Act will differ from the current "Behavior Specialist" licensure created in Act 62. The Act 62 licenses focuses on providing treatment to children with Autism, however the Better Access to Treatment Act will provide help to the millions of individuals that need quality ABA treatment regardless of diagnosis or age.

Our mission is twofold: to task our team of professionals and academics to review this bill and ensure that the language within the bill provides high quality ABA services to those that truly need it; our leadership team is also tasked with meeting local legislators to explain to them why this bill is important, why they need to co-sponsor the bill and how this bill will improve the overall quality of services available in PA.

The Better Access to Treatment Act (BAT) will be voted on in committee in September!

I look forward to your answers, and I would love to be included in a stakeholders group.

Thank you,

Marie Mambuca

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PLEASE VOTE!!