

14-548-22
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Re: PROPOSED RULEMAKING, DEPARTMENT OF HUMAN SERVICES [55 PA. CODE CH. 5230] Psychiatric Rehabilitation Services [52 Pa.B. 3828]

To Whom it May Concern,

The Autism Connection of PA is a 27 year old, grassroots nonprofit started by parents, now led in part by a 12 person board of directors, three of whom identify as autistic. We believe in the phrase "nothing about them without them," so we write on behalf of our board and the autism community we represent. Our readership is nearly 20,000 people in our database, and our social media following, before people share our information, is 6,000 people. They live across the Commonwealth and stand to benefit, or to be left out, of the very valuable service of Psychiatric Rehabilitation Services.

This writer also licensed one of the first mobile PRS in Pennsylvania when the modality was first introduced. Due to the structured and visual nature of materials used, along with the ability to address goals in a proximal fashion, PRS poses a fantastic and most appropriate approach for many with autism, but has sadly been limited by availability which we now stand to improve. Please seriously consider the following requests for changes to the proposed regulation:

1.) Autism Spectrum Disorder is left out of regulatory verbiage which will confuse providers and those needing and deserving services. The omission directly conflicts with two parts of the Proposed Rulemaking:

a.) OMHSAS writes the following::

"Rights

Nondiscrimination (§ 5230.42)

To conform with other regulations recently promulgated by the Department, this proposed rulemaking amends the prohibition against discrimination by a PRS agency by deleting the terms "sex," "religion," "ethnic origin," "economic status" and "sexual orientation or gender identity or expression" and adding the terms "color," "creed," "religious affiliation," "ancestry," "gender," "gender identity or expression," "sexual orientation" and "National origin." This proposed rulemaking also requires PRS agencies to comply with applicable Federal and State statutes and regulations."

Comment: Please add "disability" to the list of Nondiscrimination terms as the omission of "disability" stands out in opposition to Federal and State statutes and regulations of all kinds.

b.) OMHSAS writes: *"If an individual does not have one of the specified diagnoses, the individual can still receive PRS if the LPHA's written recommendation for PRS includes documentation of serious mental illness or serious emotional disturbance with a diagnosis of a mental, behavioral or emotional disorder that is listed in the current DSM or ICD and a description of the resulting moderate to severe functional impairment in at least one of the following domains: living, learning, working, socializing or wellness."*

Comment: Please add autism spectrum disorder to the diagnoses list in bold in the following quoted paragraph. People with autism deserve parity in services in order to develop skills needed to live, learn, socialize, and work in equal measure to peers with other DSM and ICD diagnoses. Currently they do not have barrier-free nor open access to PRS. The diagnosis needs to be included in the Proposed Regulatory Changes. here:

*"This proposed rulemaking will also benefit individuals diagnosed with **autism spectrum disorder**, **posttraumatic stress disorder**, **attention deficit hyperactivity disorder**, **bipolar disorder**, **major depressive disorder** or **anxiety disorders** because individuals with these disorders will no longer need to use the exception process to be eligible for PRS. This will assist individuals diagnosed with these disorders to develop skills needed to live, learn, socialize and work in their community and improve or maintain their physical and mental health."*

2.) Telehealth has been particularly vital to autistic people (often their choice of identity first language) because it removes the barriers posed by transportation, transition from home to office or site, money (for gas, parking, or public transit) sensory, and communication issues which make going to in person appointments very difficult for many.

Comment: We strongly support adding Telehealth as a PRS option.

3.) Home as a service delivery location: the home is a perfect place for service delivery for many, especially those ages 14-18 who live at home and often experience their most challenging issues there. Research shows that skill development in real environments is often most successful vs. asking people with disabilities to transfer skills from an artificial environment to where they actually live, learn, work or recreate. Additionally, teens should not be made to attend PRS sites alongside adults

needing the same services (i.e. Clubhouse or other site based services).

Comment: We strongly support Home as a service delivery location.

4.) Families and adults with autism often struggle with keeping a schedule and practice to support their own Wellness. In fact, support for Wellness coaching, instruction, and materials is always top priority stated when we survey the needs of the autistic population. **Comment: We strongly support the addition of Wellness as a PRS domain.**

5.) *"The proposed amendments to the PRS rulemaking benefit individuals 14 years of age or older but under 18 years of age with a serious emotional disturbance by allowing these individuals to access evidence-based PRS as they transition into adulthood, which fosters engagement in PRS into adulthood and may reduce the need for or shorten the length of stay in inpatient, partial hospitalization and outpatient treatment."*

Comment: Lowering the eligibility age is vital for autistic teens and will help ameliorate the issues they experience into adulthood. We strongly support the offering of PRS to teens beginning at age 14.

Thank you for your careful consideration of the needs of the autism community,

Sincerely,

Lu Randall

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An affiliate of  **achieva**
Empowering People With Disabilities

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