

IBHS: We Must Be Better Together **March 12, 2025**

In 2019, the Department of Human Services (DHS) and the Office of Mental Health and Substance Abuse Services (OMHSAS) promulgated regulations for Intensive Behavioral Health Services (IBHS) which set a standardized platform for the delivery of mental health services for youth, many of whom have been diagnosed with autism spectrum disorder (ASD).

These standards were a result of the *Sonny O. v. Dallas* lawsuit, which resulted in a settlement that sought to guarantee access to quality care for the autism spectrum disorder community. Families from around the state engaged in a class action lawsuit on behalf of children with autism alleging that the failure to provide medically necessary Applied Behavioral Analysis (ABA) to these children violated Title XIX of the Social Security Act. The resulting IBHS regulations are exhaustive, with detailed requirements of staffing qualifications and supervision standards that have proven to be impossible to meet, despite all of the attempts to improve recruitment and retention of IBHS providers through financial incentives and other means.

Since the promulgation of the IBHS regulations, with its unrealistic requirements for staff qualifications, supervision, and administrative burden have actually led to a decrease in access to autism services. The regulations for these aforementioned standards were put in place to ensure high quality and accessible care. Unfortunately, these guidelines were established at a time when there were not enough clinicians in the state to effectively deliver ABA services, and the pandemic workforce challenges exacerbated an already limited pool of clinical professionals. According to a survey conducted by the OMHSAS' Children's Mental Health Planning Committee, more than fifty percent of families seeking IBHS services of any type are waiting more than six months for treatment services. In some extreme circumstances families have waited a year just to get an evaluation from a provider, and more than a year for actual service option.

Although the *Sonny O.* lawsuit specifically addressed access to ABA services, it is clinically recognized that there is not one universally successful treatment model, or definition, for ASD. The IBHS service continuum also includes Individual Services, an alternative treatment milieu, separate from ABA therapy. Whether intentional or not, the payment structure for Individual Services was changed to a bundled rate that would no longer permit billing for previously covered treatment services, under the pretense that the formerly billable charges would be reasonably "covered" by the bundled billing rate, which proved to be insufficient. As a result, many organizations providing IBHS Individual Services were forced to eliminate these programs as they were not financially sustainable. This further decreased access to care; and precisely impacted the type of access outlined in the lawsuit settlement. It has been the position of OMHSAS that the comparisons between ABA services and Individual Services are not on equal scientific footing, yet the treatment modalities utilized in Individual Services, primarily Cognitive Behavioral Therapies (CBT), are evidence based and recently recognized by the National Institutes of Health as the gold standard for mental health treatment. The best programs often incorporate several research-based interventions and attend to the individual needs of children exclusive of the diagnosis of ASD or non-

ASD. Without any change to the regulations, providers of Individual IBHS Services are becoming obsolete, leaving children who do not thrive in the narrowly confined realm created by the IBHS regulations for ABA therapy without an effective service.

The lack of qualified ABA service providers and the diminishing number of Individual Service providers continues to contribute to the growing IBHS access issue. The settlement of the *Sonny O.* lawsuit emphasized that the regulations should “not impede access to these services but rather open the door to greater access”. The IBHS regulations have failed to uphold the stipulations of the settlement as providers are unable to serve families due to the burden created by the regulations. The provider’s inability to hire and retain the clinical professionals as required by the regulations has resulted in the number of families served being cut in half since the introduction of the IBHS regulations. The State’s proposed solution has resulted in greater access issues than prior to the lawsuit.

These IBHS access issues have been brought forward by the Rehabilitation and Community Providers Association (RCPA) on behalf of its members, and the tens of thousands of children and families they serve in the form of departmental and policy clarification waiver requests, legislative advocacy, and a request to the Independent Regulatory Reform Commission (IRRC) to reopen the IBHS regulations in 2022. In September 2024, after a nearly two-year review, the IRRC denied the request, though OMHSAS has since publicly stated that the IBHS regulations, at some point, would need to be reopened. The *Sonny O. v. Dallas* settlement guaranteed “open, on-going, and transparent pathways for communication regarding progress and challenges in implementing this settlement.” Aside from an OMHSAS IBHS FAQ from 2021, there has been little to no effort to address the current plight of vulnerable children and families in Pennsylvania.

RCPA makes the following recommendations:

- OMHSAS to engage its Federally mandated Children’s Mental Health Planning Committee or another designated group to prioritize the review of the barriers to access created by the IBHS regulatory standards.
- OMHSAS will guide the Primary Contractors and Behavioral Health Managed Care Organizations to reinstate billing code H0032 to allow for payment code equity for services delivered outside of a face-to-face context in the delivery and billing of Individual IBHS treatment. The billable activities for Individual Services should be on an equitable plane with those accepted in ABA.
- DHS/OMHSAS will establish a statewide IBHS steering committee to evaluate, plan, and implement any and all activities to address access issues as outlined in the original settlement of *Sonny O. v. Dallas*.

In closing, it is our hope that all stakeholders will finally come together to create meaningful and sustainable pathways for those entrusted to our care. RCPA stands willing and able to be a part of any initiative that seeks to ensure the equitable delivery of Intensive Behavioral Health Services.