

### **PM 508: Policy Paper Project Final Draft**

Autism spectrum disorder (ASD) is a neurodevelopmental and behavioral condition that is characterized by persistent deficits in social communication and reciprocity as well as repetitive and restrictive patterns of behaviors.<sup>1</sup> The national surveillance for ASD prevalence started in 1996, initially as a part of the Metropolitan Atlanta Developmental Disabilities Surveillance Program in Georgia. In 2000, the Center for Disease Control (CDC) expanded on this initiative and created the Autism Developmental Disabilities Monitoring (ADDM) Network to continue to observe ASD prevalence across the United States. The observed ASD prevalence data is published every two years and is also presented in the Morbidity and Mortality Weekly Report (MMWR) at the CDC.<sup>1</sup>

The prevalence of ASD has been rapidly increasing over the past two decades, from one in 150 in 2000 to one in 36 in 2020.<sup>1</sup> This pattern is mainly considered a result of rising awareness of ASD and an increase in universal screening leading to timely diagnoses. Starting in 2007, the American Academy of Pediatrics recommended screening all children for developmental delays including autism during their primary care visits.<sup>2</sup>

Furthermore, significant health disparities exist among children diagnosed with ASD. Initially, in the early 2000s, the overall ASD prevalence was 50% higher among White children than Black or Hispanic children, but this gap narrowed and the prevalence of ASD among Black and Hispanic children matched the prevalence among White children since 2016.<sup>1</sup> This is thought to be owing to the effort towards equitable provision of screening services to the socioeconomically vulnerable groups, specifically expanding diagnostic testing to all children that included those facing greater social, financial, or geographic barriers. It has also been consistently observed that among children with ASD, Black children have the highest proportion of having comorbid intellectual disabilities.<sup>1</sup> This highlights the importance of the provision of adequate educational and family support services for individuals with ASD as a public health initiative.

Historically, autism policy advocacy efforts have focused on enhancing the quality of and expanding access to ASD treatment. The Individuals with Disabilities Education Act (IDEA) in 1975 granted access to free public education for all children with disabilities including autism, and the act was further enhanced by the Americans with Disabilities Act (ADA) in 1990 which prohibited discrimination against individuals with disabilities in their daily lives in terms of employment settings and public accommodations. The Combating Autism Act (CAA) in 2006 established federal funding for autism research and was reauthorized by the Autism CARES Act in 2019, providing further financial support for autism research, surveillance, and treatment programs.

In the setting of increased awareness and public health support, over the past two decades, all fifty states have now come to mandate insurance coverage of ASD diagnosis and treatment.<sup>3</sup> However, providing accessible, equitable, and adequate treatment for children with ASD has long been a challenge, as ASD is a developmental disorder that requires lifelong support and education with a multidisciplinary approach including speech and language therapy, occupational therapy, physical therapy, applied behavioral analysis (ABA), and other

supportive developmental and behavioral therapies such as play-based therapy and nutritional therapy.

Specifically, Applied behavioral analysis (ABA), an intervention service based on a behavioral model, is a mainstream treatment of choice for ASD.<sup>4</sup> ABA entails careful assessment of an individual's interaction with environments and individualized intervention planning to improve positive social behaviors, and its effectiveness has been empirically validated in improving communication, social skills, and maladaptive behavior management.<sup>4</sup> ABA is most effective for individuals with ASD when it is started before age 5, and when it is implemented consistently for 20-40 hours per week, over five to seven days weekly, for two or more years.<sup>4</sup> Unfortunately, despite increased insurance coverage for ASD diagnosis and treatment, a significant deficit in the number of qualified providers compared to the overall need has remained a major barrier for children with ASD in receiving ABA therapy services.<sup>5, 6</sup>

The Behavioral Analyst Certification Board (BACB) was formed in 1998 to provide professional credentials for ABA providers and provide data on the total number of certified ABA providers on its online database. ABA providers are comprised of the independent Board-Certified Behavioral Analyst (BCBA) at the doctoral level (BCBA-D) and master level (BCBA), assistant analysts at the baccalaureate level (BCaBA), and assistant Registered Behavioral Technicians (RBTs).<sup>5</sup> The BACB has also set up a guideline for a maximum caseload per analyst: for comprehensive treatment, the recommended maximum is 12 children per analyst without an assistant and 16 children with an assistant, and for focused treatment, the maximum recommended caseload increases to 15 children per analyst without an assistant and 24 children with an assistant.<sup>6</sup>

According to a report by Zhang and Cummings in 2020, there currently is a significant shortage of ABA providers across the United States compared to the number of children with ASD. The national supply of certified analysts (BCBA and BCBA-D) was 25,591 in 2018, and certified assistant analysts (BCaBA and RBT) were 1,979.<sup>6</sup> This data demonstrates that only about 7.7% of behavioral analysts were receiving support from an assistant. Furthermore, when compared to the total number of children with ASD as provided by the CDC's prevalence data, significant shortages of ABA providers were noted across all states except for Massachusetts.<sup>6</sup> Massachusetts was the only state in which the supply exceeded the demand, with 8.8 certified ABA providers per 100 children with ASD. The per capita supply of certified ABA providers was highest in the Northeast region. However, all states in the mid-west region had less than one-third of the expected demand for ABA providers when compared to the total number of children with ASD.<sup>6</sup> Approximately 16 states including Idaho, Wyoming, and Oklahoma had less than 1 ABA provider per 100 children with ASD.<sup>6</sup>

There is a need to increase the ABA workforce to close these supply-demand and public health inequity gaps, calling for policy action. Therefore, this brief aims to propose a five-year pilot grant program that will provide financial support for students pursuing ABA provider training programs, with the reassessment of the needs gap at the end of the five years.

This five-year pilot grant program would provide eligible candidates a financial award to complete (1) an 18-month master's program in BCBA, (2) a 15-month certification program in BCaBA, or (3) a one-month training in RBT certification. At the end of the five-year program, the effectiveness can be reassessed using the BACB ABA provider database and

tracking the number of certified ABA providers and assistants, along with their geographic distribution and in the context of respective demand of ASD prevalence. In addition, as an effort to address health disparity, the pilot program may encourage applicants from disadvantaged racial and ethnic minorities, low-income families, rural areas, or mid-west and southern states.

As a cost-saving balancing measure, the pilot program can primarily focus on expanding assistant training for BCaBA and RBT. BCaBA and RBT respectively require bachelor's and high school equivalent degrees, making these certificates more attainable for students. Furthermore, RBT only requires 40 hours of training, which is more easily attainable than other upper-level ABA certifications which require 1,000-2,000 fieldwork hours along with 200-300 course hours.

Traditionally, national and state scholarship programs to increase healthcare workforce supply have proven to be successful and equitable solutions for the healthcare provider shortage problem, especially in underserved areas. Scholarship programs incentivize students to pursue a career in healthcare by providing financial support. Among the most notable examples include the California State Loan Repayment Program (SLRP), which repays education loans for healthcare providers who work in areas with healthcare provider shortages for a specified time. The program helped address the healthcare provider shortage by recruiting quality candidates and promoting their retention in geographically underserved areas.

Considering this example, the ABA scholarship grant may also require the recipients to commit to working as a certified or assistant ABA provider for a designated time, for example, about two to three years, to promote the retention of certified ABA providers to continue to practice in the field.

Anticipated criticism of this proposal may revolve around how to allocate limited budgets among competing issues. Supporting individuals with ASD requires multifaceted policy efforts, such as increasing the home-based care workforce, promoting employment of individuals with ASD by incentivizing employers, and providing financial and service support to families who live with individuals with ASD. These issues deserve equivalent consideration and carry comparable importance.

Reflecting this, the pilot program is proposed to be short-term at this stage and to include the reassessment at the end of the five years. Regular reassessment will include measuring the number of certified ABA providers in relation to the total number of children with ASD using the BACB database and the CDC prevalence data. This will allow for modification of the policy in the context of shifting supply-demand trends and changing priorities at different time points. The reassessment would also provide insight into the effectiveness of the program in terms of recruitment and retention of the ABA providers, as successful implementation of the policy will increase the number of ABA providers and will help reduce the degree of the ABA provider deficit. Based on the findings from the reassessment, the program may be expanded, reduced, extended, or terminated. Lastly, the financial support offered should be stratified based on the recipients' economic and social circumstances and may range from partial to full support, to help ensure equitable and efficient distribution of the grant funds.

## References

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