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PLEASE SUPPORT S.1266 & H.1975

An Act Relative to PANS/PANDAS

SIGNIFICANCE OF INVESTIGATING THE PREVALENCE AND OUTCOMES OF CHILDREN WITH PANS/PANDAS RECEIVING DEPARTMENT OF MENTAL HEALTH SERVICES

INTRODUCTION

Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS) are debilitating medical conditions brought on by an infectious or viral trigger that creates a misdirected immune response resulting in brain inflammation. This inflammation then leads to sudden and sometimes severe neuropsychiatric symptoms in children. However, when properly diagnosed and treated, these children heal.

This legislation requires the Department of Mental Health (DMH), in conjunction with the Department of Education (DOE), now known as the Department of Elementary and Secondary Education (DESE), to conduct a study of pediatric and adolescent psychiatric hospital settings and therapeutic day schools to determine if any children within these settings had root causes in missed or known neuroimmune issues or PANS/PANDAS while accessing the DMH services.

To conduct this study, the DMH and DESE will use established clinical criteria developed by experts in the field. Interviews will be conducted of children and families who had previously been misdiagnosed and subsequently found to have PANS/PANDAS while they were accessing support through the DMH. Further, the departments shall consult with the Department of Public Health's PANDAS/PANS Advisory Council and professionals in pediatric and adolescent psychiatric hospital settings and therapeutic day schools.
This legislation aims to understand the profile of children receiving DMH support with PANS/PANDAS diagnoses and the DMH barriers to recognition and treatment. This insight underscores the significance of proactive PANS/PANDAS screening, ultimately improving pediatric mental health outcomes.

SIGNIFICANCE OF PANS AND PANDAS IN PEDIATRIC MENTAL HEALTH:

PANS and PANDAS are underdiagnosed conditions that profoundly affect children's mental health and cognitive functioning. These disorders are characterized by the abrupt onset of obsessive-compulsive disorder (OCD), tics, anxiety, and emotional dysregulation, often following a bacterial or viral infection. Failing to identify these cases promptly can lead to long-term consequences, loss of educational opportunities, and impaired quality of life.

IDENTIFYING THE PREVALENCE OF PANS/PANDAS IN CHILDREN RECEIVING DMH SUPPORT

DMH services students with the highest level of mental health need in the Commonwealth of Massachusetts. According to the state website:
"The Department of Mental Health, as the State Mental Health Authority, assures and provides access to services and supports to meet the mental health needs of individuals of all ages; enabling them to live, work and participate in their communities." DMH is the leading state expert on mental health and treatment of children with serious mental health conditions.

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PANS/PANDAS is not an illness well understood in this agency.Many PANS/PANDAS families who have sought services report being told that the DMH “does not support the diagnosis of PANS/PANDAS.” DMH is a critical state agency for PANS/PANDAS families as this illness often presents primarily with significant mental health needs.

Understanding and supporting this illness is critical for DMH given their role in servicing children in the Commonwealth with mental health issues. Further, there are many children who receive DMH support who are missed as having PANS/PANDAS. Many children have been diagnosed with PANS/PANDAS while receiving DMH support. DMH must understand how these children presented, how they were missed, and what they can do to ensure children are not missed going forward.

The caregiver burden index (CBI) for parents and guardians of children with PANS/PANDAS was found to be higher than for caregivers of patients with Alzheimer’s. DMH allows access to in-home clinicians, crisis support, hospital level of care, and peer and parent mentors.

UNDERSTANDING THE OVERLOOKED CASES BY THE DEPARTMENT OF MENTAL HEALTH

We're currently facing a pediatric mental health crisis, with suicide ranking as the second leading cause of death among youth aged 10-24. Additionally, 1 in 5 U.S. youth between the ages of 6 and 17 grapple with a mental health disorder each year. For children with PANS/PANDAS, the ultimate risk is suicide, and we cannot afford to miss any of these cases.

Furthermore, schools play a unique role in this scenario, as they are obligated to care for the complete well-being of a child. While other systems may disengage, schools cannot. The number of students in special education has doubled in the United States over the past 40 years, resulting in a growing portion of public school students requiring special education services, rising from 3.6 million in the 1976-77 school year to almost 7.3 million in 2021-22.

As the primary state agency that many families turn to for mental health support, DMH must gain insight into the cases they've missed, the reasons behind these oversights, and commit to improving their approach.

CONCLUSION

This legislation is of paramount importance to understand the prevalence of PANS/PANDAS in children who were & are beneficiaries of DMH services. This knowledge is instrumental in developing best practices for diagnosing, treating, and supporting these children, ensuring that no child goes overlooked. Furthermore, it has the potential to revolutionize how the Commonwealth provides assistance to children with PANS/PANDAS.

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