April 13, 2026

Dear members of the Interagency Autism Coordinating Committee (IACC),

Public Comment – Integration of PANS/PANDAS Screening in Autism Evaluations

I urge the Interagency Autism Coordinating Committee (IACC) to address a critical and persistent gap in autism evaluation: the lack of systematic assessment for underlying medical conditions such as Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and PANDAS.

Children with autism spectrum disorder (ASD) are susceptible to the same medical conditions as other children, including PANS and PANDAS. However, these conditions are frequently overlooked in practice, largely due to overlapping behavioral and psychiatric symptoms. This gap leads to significant consequences.

PANS/PANDAS is characterized by an abrupt new onset or newly worsening of neuropsychiatric symptoms, including obsessive-compulsive disorder (OCD), severe anxiety, food restriction, regression, irritability, cognitive decline, and somatic symptoms such as sleep disturbance and urinary frequency. These symptoms are often misattributed to autism progression, co-occurring psychiatric conditions, or behavioral issues, particularly in children already diagnosed with ASD.

Due to this symptom overlap, children with autism are at increased risk of:

- Delayed or missed diagnosis of PANS/PANDAS
- Inappropriate psychiatric-only treatment approaches
- Worsening symptoms due to untreated underlying medical causes

As noted in ASPIRE's Professional Advisory Board guidelines on PANS and Autism (https://aspire.care/clinicians/pans-pandas-guidelines-for-children-with-autism), diagnosing PANS/PANDAS in children with autism is more challenging due to these overlapping presentations. However, **no child should be denied appropriate evaluation for PANS/PANDAS solely because of an autism diagnosis**. Despite these challenges, there is currently no standardized expectation that children undergoing autism evaluation or re-evaluation are screened for PANS/PANDAS. This represents a significant omission.

Recommendation
I respectfully recommend that the IACC incorporate the following measures into its guidance and strategic priorities:

- Implement routine screening for PANS/PANDAS in all autism evaluations, particularly when there is:
    - Developmental regression
    - Sudden onset or worsening of symptoms

- New psychiatric or behavioral presentations

- At minimum, implement a **brief clinical checklist** to identify red flags for PANS/PANDAS during autism assessments.
- Include **medical rule-out guidance** in autism diagnostic frameworks to reinforce that behavioral symptoms may reflect underlying neuroimmune conditions.
- Increased **education for clinicians** (developmental pediatricians, psychologists, neurologists, and psychiatrists) on recognizing acute-onset neuropsychiatric presentations

Why this matters
Failure to identify PANS/PANDAS early can result in prolonged suffering, inappropriate care, and progression to more severe or chronic illness. In contrast, early recognition and appropriate treatment are associated with improved outcomes. Children with autism are not exempt from medical conditions and are often more vulnerable to being overlooked. A dual diagnosis of autism and PANS/PANDAS is possible, as is misdiagnosis. Without systematic screening, both scenarios may be overlooked.

Closing
Improving autism care requires a more integrated and medically informed approach. Incorporating PANS/PANDAS screening into standard autism evaluations is a practical, low-burden measure that can significantly enhance diagnostic accuracy and patient outcomes.
Thank you for your consideration of this important issue.

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