WHY STATES NEED TO REQUIRE PANS/PANDAS PROVIDER EDUCATION: The Cost of Inaction

Earlier Recognition Can Reduce Avoidable Harm and Expense

PANS and PANDAS are immune-mediated conditions characterized by sudden or newly worsening neuropsychiatric symptoms, including obsessive-compulsive symptoms, restricted eating, anxiety, cognitive impairment, regression, sensory or motor changes, and severe functional decline.

These symptoms cross medical and mental health specialties, leading patients to consult multiple providers before PANS/PANDAS is considered. Without proper provider education, symptoms may be treated in isolation or misattributed to psychiatric conditions without thorough medical evaluation. When PANS/PANDAS is not identified, patients frequently undergo repeated office visits, emergency care, psychiatric services, hospitalizations, consultations with multiple specialists, and crisis interventions as families search for answers.

The Cost of Delayed Recognition

These costs affect not only the health care system but also schools, employers, families, emergency services, and state programs. The human toll is even greater when symptoms that might have improved or even resolved with earlier recognition and appropriate treatment persist for years or, for some patients, a lifetime.

Failure to recognize PANS/PANDAS can increase:

- Emergency department visits and hospitalizations
- Repeated appointments, testing, and specialist consultations
- Psychiatric treatment that may address symptoms without considering possible medical contributors
- Medical complications from severe restricted eating
- Educational disruption, including prolonged absences, homebound instruction, special education services, and outplacement
- Lost income when parents reduce work hours or leave employment to provide care
- Long-term disability and reliance on public services
- Financial and emotional strain on the entire family

Education Supports Guideline-Informed Care

Mandating education does not require providers to diagnose PANS/PANDAS or prescribe specific treatments, nor does it replace clinical judgment. It ensures providers are aware of recognized clinical guidelines and treatment frameworks.

Education should cover current information on recognition, diagnostic criteria, differential diagnosis, evaluation, and referral, as well as published guidance for treating infections, managing inflammation or immune dysfunction, and providing psychotherapeutic and psychiatric support. Existing guidelines offer treatment algorithms and flowcharts to help providers determine appropriate next steps based on clinical presentation, illness severity, and treatment response.

Too often, families are told providers do not know how to treat PANS/PANDAS or what to do after an initial course of antibiotics. Provider education can address this gap by giving clinicians access to established guidance on antibiotic selection, treatment escalation, symptom management, and when to consult or refer. While treatment remains individualized, providers should not have to proceed without guidance when clinical resources exist.

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The Cost of Inaction Is Higher Than the Cost of Education

Delayed recognition and limited access to knowledgeable treating providers already carry substantial costs. These costs appear in emergency care, hospitalization, behavioral health services, educational disruption, disability, and other publicly funded systems. Focused PANS/PANDAS education can help providers recognize these conditions earlier while also increasing the number of clinicians prepared to diagnose, treat, and coordinate care. Requiring provider education is more than an awareness initiative. It is a practical strategy for reducing avoidable harm, improving patient safety, and expanding access to appropriate care.

Provider Education Builds Recognition & Treatment Capacity

Provider knowledge is critical for timely and appropriate care. PANS and PANDAS are clinical diagnoses. There is no single laboratory test for either condition. Diagnosis relies on recognizing the clinical presentation, evaluating possible causes, and excluding other conditions.

Provider education must serve two key purposes: enabling frontline providers to recognize and evaluate potential cases and increasing the number of clinicians who can diagnose, treat, and coordinate ongoing care. Qualified providers must be available within insurance-based health care systems. Access to care should not depend on a family's ability to pay out of pocket, travel out of state, or wait months for limited specialists.

Recognition alone is insufficient. Families are often advised to seek specialists, but may face long wait lists, specialists who do not accept insurance, or a lack of qualified providers in their state. Some must travel far, pay out of pocket, or stay with a provider who recognizes PANS/PANDAS but cannot treat it. Referrals have limited value if accessible care is unavailable.

Frontline providers should be prepared to:

- Recognize when PANS/PANDAS should be considered
- Understand the diagnostic criteria and clinical presentation
- Conduct an appropriate initial evaluation and differential diagnosis
- Identify urgent medical and safety concerns
- Begin appropriate initial care within their scope of practice
- Know when and where to refer
- Coordinate medical, psychotherapeutic, psychiatric, and school supports when needed

States must also increase the number of providers prepared to:

- Diagnose PANS/PANDAS after an appropriate evaluation
- Provide guideline-informed treatment
- Use existing treatment guidelines, algorithms, and clinical flowcharts
- Appropriately identify and treat infections
- Evaluate and address inflammation and immune dysfunction
- Provide or coordinate psychotherapeutic and psychiatric support
- Monitor response to treatment and adjust care when needed
- Recognize when treatment escalation or specialty consultation is appropriate
- Coordinate care across medical specialties, behavioral health services, and schools

A Practical Approach to Implementation

A provider education requirement can use existing continuing education systems to limit cost and administrative burden. Educational content should be developed or selected in consultation with a nonprofit organization whose work specifically focuses on PANS/PANDAS, together with clinicians experienced in diagnosing and treating these conditions. A state PANS/PANDAS advisory council may also participate, but its involvement should not replace direct participation by a PANS/PANDAS nonprofit and experienced treating clinicians.