PANS/PANDAS INTAKE, ASSESSMENT, & REFERRAL PROCESS FOR LICENSED MENTAL HEALTH CLINICIANS

Limitations of Existing Mental Health Guidelines

Unlike medical care, mental health currently lacks formalized, consensus-based clinical guidelines for the assessment and treatment of PANS/PANDAS.

Clinicians must extrapolate from evidence-based treatments for individual symptom domains (e.g., OCD, anxiety, ADHD, eating disorders), rather than from an integrated model addressing the immune-mediated nature of PANS/PANDAS.

Purpose of These Guides Developed by my Practice

These guide represents a good-faith effort to synthesize current standards of care, available research, and clinical experience into a practical framework for mental health professionals working with PANS/PANDAS.

Commitment to Collaboration

My long-term goal is to collaborate within the mental health community to support the development of more formalized, peer-reviewed guidance for best practices in psychological assessment and treatment.

Barb Shepard, LMHC

PART I: Updating Assessment Questions in Your Biosocial Assessment

*For children presenting with OCD symptoms, restricted eating, or tics, update your intake paperwork to include screening for PANS/PANDAS. This is especially important for children who are presenting with an **abrupt-onset of symptoms** that are impairing the child and family functioning, and may be impacting the child's ability to attend school.*

SYMPTOM SCREENING

Does your child experience any of the following symptoms? If yes, please describe & include date of onset:

***Part A*:**

1. OCD symptoms (excessive reassurance seeking, contamination fears, fear of vomiting, fear of being a bad person, "just right"/symmetry concerns, needing you to complete certain rituals in an exact order, "bad thoughts" about dying or terrible things happening, etc.)

_____

2. Restricted food intake due to fears of contamination, choking, or sensory aversion to food (not related to body image or intentional weight loss):

_____

3. Tics (e.g., blinking, grimacing, throat-clearing, vocal tics, or other movements)

_____

*If **yes** to any of the above, continue to part B. If **no**, likely not PANS/PANDAS.*

***PART B*:**

1. Elevated anxiety or separation anxiety (may require parent to sleep with child; may struggle to be in a separate room even within the same home; and/or sudden school refusal)

_____
2. Emotional lability and/or depression

_____

3. Irritability, aggression, and/or severe oppositional behaviors (harming siblings, aggression towards caregivers, unprovoked rage outbursts)

_____

4. Behavioral/developmental regression (baby talk, loss of previous skills)

_____

5. Sudden deterioration in school performance (dramatic handwriting changes, math difficulties, school refusal)

_____

6. Motor or sensory abnormalities (piano fingers, extreme reactions to lights, clothing, water, etc.)

_____

7. Somatic signs and symptoms, including sleep disturbance, enuresis (daytime or nighttime wetting) or urinary urgency/frequency

_____

PART C: Illness History

1. Has your child recently been ill with strep or other infections? (Flu A, Lyme, Mycoplasma, sinusitis, other infections, other viruses)?

_____

2. *Has your child had frequent strep or upper-respiratory infections in their life, or needed frequent antibiotic treatment in childhood?*

_____

3. *Do you recall an exact time when an infection preceded the development or severe worsening of behavioral or mental health symptoms?*

_____

4. *Have any of these symptoms had an abrupt onset? (Your child was previously functioning well, then seemingly overnight or within a short period experienced a significant decline?)*

_____

Using the above information you've gathered, evaluate the following:

1. Has child experienced an **acute and dramatic onset of OCD symptoms or severely restricted food intake** from PART A?
   - Yes___ No ___

2. If yes, are there at least **two additional symptoms** indicated from **PART B?**
   - Yes__ No __

*3. If "yes" to both, **consider PANS** (Pediatric Abrupt-onset Neuropsychiatric Syndrome) and skip to #4.*

*If no to #2, assess for **PANDAS** (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infection).*

a. Are **abrupt-onset OCD and/or tic symptoms impairing functioning** for a prepubescent child, accompanied by **neurological changes** (such as choreiform movements or handwriting deterioration?) ?
   - *Yes__ No __*

*4. If yes, **consider PANDAS.** If no, likely not PANS/PANDAS. Continue with standard of care for OCD, tics, and ARFID, and monitor for new symptoms.*

5. **Discuss the possibility of PANDAS/PANS and refer to a qualified physician.** Please note that it is not within the scope of practice of mental health counselors to diagnose PANDAS/PANS. *This is a **medical diagnosis requiring exclusion of other medical conditions and interdisciplinary evaluation.***

6. Provide **preliminary psychoeducation on PANS/PANDAS,** without overpromising diagnosis. It is important to remain reserved in your diagnostic impressions until you have collaborated across disciplines.. **PANDAS Network, ASPIRE, IOCDF, and PANDAS Physician Network** have resources.

PART II: Navigating Referrals for Medical Evaluation

1. Refer to pediatrician for medical workup.

A. **Provide resources to parents from PANDAS Physician Network** – including the PPN flowchart and treatment guidelines https://www.pandasppn.org/flowchart/#treat

Write a **clinical summary** to provide patients to give to their pediatrician with notes from your assessment. Include infection history, abrupt-onset information, and checklist of potential PANS/PANDAS symptoms

B. Encourage the family to inquire about **strep culture AND evaluation for other potential viral or bacterial causes.**

- Notes about strep testing (source: PANDAS physician network): An official diagnosis of PANDAS includes an episodic course; however delaying treatment until a second onset is not recommended
- Approximately 35% of pediatric patients will not generate ASO or Anti-DnaseB titers and therefore can be a false negative for strep.
- PANS AND PANDAS are clinical diagnoses: meaning they do not require any specific test to begin care.

If a physician suspects PANS/PANDAS, a three-pronged approach may be considered on the medical side of treatment, utilizing guidelines from PANDAS Physician Network for Mild, Moderate, or Severe Cases (https://www.pandasppn.org/flowchart/#diagnose)

- Antibiotics
- Anti-inflammatories
- Immune treatments such as IVIG for severe or life-threatening cases

2. Following an initial appointment with the child's pediatrician, families and providers can collaboratively determine whether the pediatrician is comfortable proceeding with further assessment and management, or whether referral to a specialist is preferred.

A. If the pediatrician determines that specialist care is indicated, families may be directed to clinicians with experience in PANS/PANDAS, such as those listed in the PANDAS Physician Network Practitioner Directory: **https://www.pandasppn.org/practitioners/**

Part III: Mental Health Treatment Planning for PANS/PANDAS

1. Assess for Immediate Safety Concerns:

- Assess for **psychosis signs** such as hallucinations, indicating acute risk.
- Evaluate **self-harm or suicidal thoughts** requiring immediate safety planning.
- Monitor **aggression** toward family necessitating protective measures.
    - Ask about **siblings** in the home and create care plans to emotional & physically protect siblings during flares.
- Identify **eating restrictions and dehydration from ARFID** that may need inpatient care.
- Hospitalization may be needed for medical monitoring and stabilization during acute symptom flare-ups.
    - Hospitalization can unfortunately be a traumatic event for PANS/PANDAS families – it is important to be an advocate for the family if HLOC is warranted to ensure all providers are aware of PANS/PANDAS diagnosis.
- Educate families on warning signs about when to seek emergency help – provide local crisis numbers.
- Incorporate **DBT and crisis intervention techniques** to address acute symptoms.
- Keep in mind that logic, reasoning, and consequences/rewards may be less effective when child is in acute flare state, and safety should be the highest priority.

2. ACUTE EPISODE INTERVENTIONS

- **Minimize transitions** and limit the number of activities to reduce stress during flare-ups.
- Provide **ample rest time** to help the child recover from neuropsychiatric episodes.
- **Decrease sensory stimuli** by dimming lights, reducing noise, and avoiding crowded environments.
- **Remove or secure objects** that could potentially harm the child during episodes.
- **Reduce expectations** on child and recognize that typical parenting strategies involving consequences, talking about emotions and problem-solving in the heat of the moment may not be effective during a flare.

3. SYMPTOM SPECIFIC MENTAL HEALTH INTERVENTIONS

A. OCD

- **Exposure and Response Prevention Therapy (ERP) i**s the gold-standard for OCD symptoms in children and the only evidence-based treatment for pediatric OCD.
- Research supports ERP for PANS/PANDAS related OCD. Clinicians must be prepared to adapt a **flexible approach** during flares and tailor treatment in collaboration with physician treating the medical side.
  - The IOCDF directory is a resource to refer patients to a clinician trained in ERP: https://iocdf.org/find-help/
- **SPACE (Supportive Parenting for Anxious Childhood Emotions)** is for parent support in reducing OCD accommodations. Recquires flexible approach relative to flares and treatment is non-linear.

B. EATING DISORDER FOR AVOIDANT RESTRICTIVE FOOD INTAKE DISORDER (ARFID)

- Note that medical interventions for PANS/PANDAS can be curative for ARFID symptoms when there is an acute infection causing them – however, often ongoing psychological support is needed to maintain the gains & to address relapse.
  - **FBT-ARFID - Family-Based Treatment for ARFID**
  - **CBT-AR - Cognitive Behavioral Therapy for ARFID**
- Refer to PCP for **physical health assessment,** hydration & overall intake concerns.
- Assess whether eating restriction is life-threatening & consider ED referral.
- Referral to **dietician**.
- Monitor for need for higher level of care if health is at risk.
- Utilize National Eating Disorders Association (https://www.nationaleatingdisorders.org/) to search for programs by location (IOP, residential or inpatient).

C. PSYCHIATRY FOR MEDICATION MANAGEMENT

- Prescribers can consider **SSRIs** – PANS/PANDAS literature currently recommends going **"low and slow,"** as PANS/PANDAS kids can anecdotally experience **more sensitivity to SSRIs** and can increase aggression & suicidal thoughts if administered during a flare (source: Dr. Kiki Chang).

D. IRRITABILITY/AGGRESSION/SELF-INJURY

- Manage and reduce stressors/demands during flares.
- Promote nutrition and sleep.
- **Dialectical Behavioral Therapy** skills training may be helpful to child and family (distress tolerance, mindfulness, emotion-regulation, and interpersonal effectiveness).
- Antipsychotics or mood stabilizers may be considered to manage symptoms with aggressive episodes under guidance of psychiatrist.

E. SLEEP DISTURBANCE

- Sleep issues in PANS may stem from anxiety, OCD bedtime rituals, enuresis, nightmares, or REM Sleep Behavioral Disorder. Emphasize sleep hygiene with consistent schedules, screen time reduction, a comfortable environment, and calming pre-bedtime routines.

F. TICS

- Tics are generally not a high-priority treatment target unless they cause significant interference with functioning. Comprehensive Behavioral Intervention for Tics (CBIT), Habit Reversal Training (HRT), and pharmacotherapy are treatments of choice. Medical treatments may reduce tics without behavioral treatment.

PART IV: ADVOCACY WITHIN THE SCHOOL SYSTEM

- PANS/PANDAS symptoms often cause frequent absences and fluctuating cognitive stamina.
- Common difficulties include anxiety, OCD symptoms, tics, urinary urgency, and handwriting challenges.
- **Clinicians help families initiate and navigate the IEP/504 process for appropriate accommodations.**
  - **IEP and 504 plans** can address needs like extended test time, note-taking assistance, and permission for frequent bathroom breaks.
  - Advocacy includes writing plans mindful of the child's **worst symptom days** and variability.
  - Children may need **accommodations** such as shortened school days or reduced homework load.
  - Examples of supports: preferential seating, alternate assignment formats, rest breaks, and parent support during separations.
  - **Sensory sensitivities** may require modifications in lighting, noise, or classroom seating arrangements.
- Collaboration with educators ensures consistent support during flare-ups and baseline periods.
- **ASPIRE** has many online resources and handouts to aid advocacy within the school system and for parents to give to teachers:https://aspire.care/resources/schools-educators-pans-pandas/

PART V: INVOLVING OTHER PROVIDERS

- **Occupational therapy:** Focuses on improving fine motor skills, handwriting, and sensory processing challenges that fluctuate with PANS/PANDAS exacerbations to support daily functioning.

- **Physical therapy:** Addresses coordination, gross motor development, and physical stamina to help children maintain mobility and physical health during symptom flares and remission.

PART V: PARENT & FAMILY SUPPORT

- PANS/PANDAS is a disease that impacts the entire family. **Parents are at high-risk f**or burnout and traumatization.
- Clinicians should either provide individual support sessions for parents when appropriate, or refer parents for their own therapy.
  - **CBT or EMDR for trauma processing**
- Connect parents to **support groups,** whether local or virtual (ASPIRE), online Facebook groups, and other options to reduce isolation and encourage peer support.
- Assist parents in referrals to therapy for **siblings** who are impacted. Provide family therapy sessions involving other siblings when appropriate.
- The **International OCD Foundation** has a yearly conference that features several talks on PANS/PANDAS, including clinicians and individuals with PANS (open to both clinicians and the general public to attend).

PART VI: STAYING UP-TO-DATE ON THE LATEST RESEARCH

- **Massachusetts General Hospital Pediatric Neuropsychiatry and Immunology Research Program:** /https://www.massgeneral.org/children/research/pediatric-neuropsychiatry-and-immunology-research-program

- **Stanford Medicine Department of Pediatrics - Division of Allergy, Immunology, & Rheumatology:** https://med.stanford.edu/pans/research.html

- **Department of Neurology at Columbia University Irving Medical Center:** https://www.pandasppn.org/research-award-akcan-agalliu-lab/

- **The University of Sydney (Russell Dale)** - https://www.sydney.edu.au/medicine-health/about/our-people/academic-staff/russell.dale.html#collapseprofileprojects

- **PANDAS Physician Network (latest research 2018-2025)** - https://www.pandasppn.org/research-updates/

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