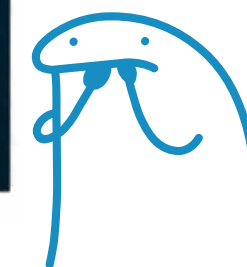
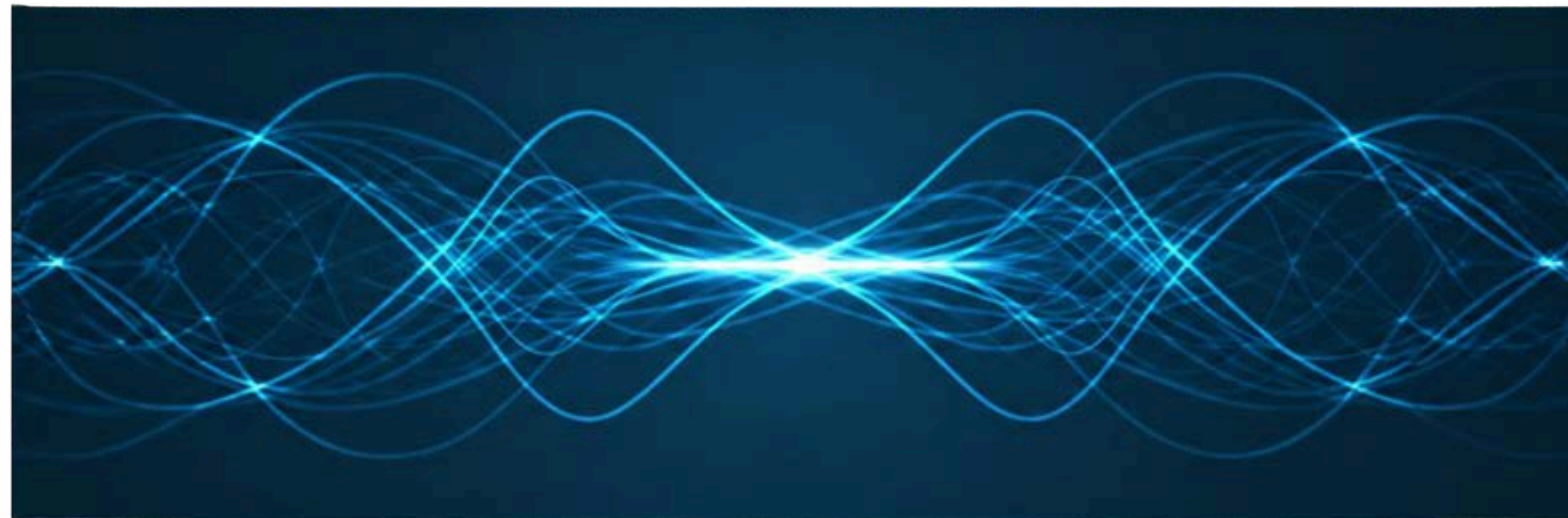


From Crisis to Connection:

A Dynamic Framework for PANS and PANDAS in Schools

PANDAS Physicians Network

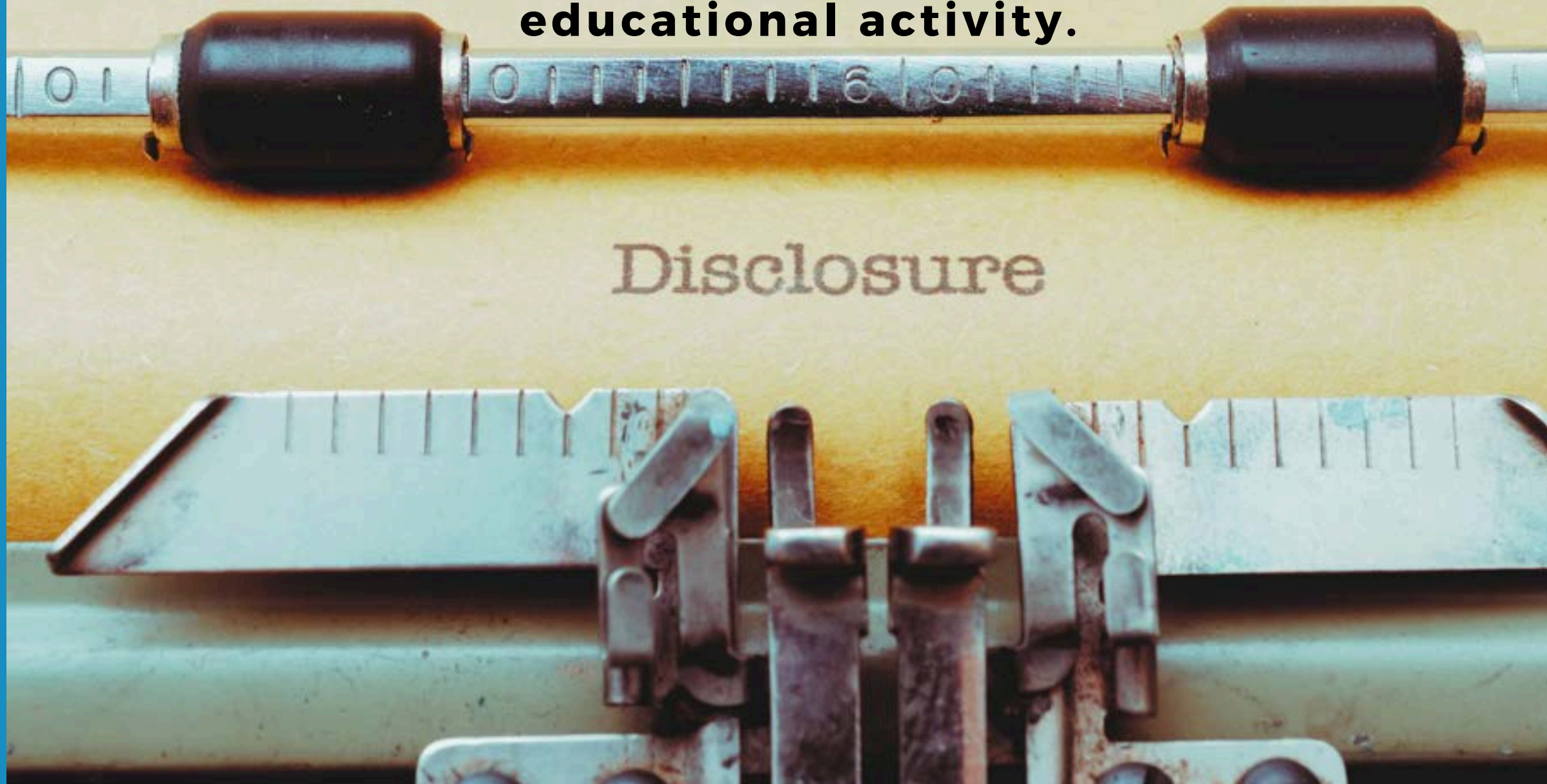


Presenter:

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October 8, 2026

These presenter has no conflicts of interest or relevant financial relationships to disclose in relation to this educational activity.



AI-assisted literature search and image generation were used. All content and conclusions are the original work of the author.

AGENDA

01

Understand PANS and PANDAS in school settings

02

Recognize functional, behavioral, and academic impact

03

Align educators, clinicians, and families

04

Use targeted assessment and screening questions

05

Build crisis plans and communication pathways

06

Support flexible accommodations and return to learning

Why This Matters in Schools

PANS/PANDAS symptoms can create significant functional impairment in school, symptoms fluctuate over time, and coordinated school-family-clinical planning improves support.



THIS IS WHY WE NEED DYNAMIC PLANNING.

PANDAS

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections

Criteria

- 1 Temporal Association -Group A Strep infection
- 2 Onset between ages of 3 and puberty
- 3 Sudden onset OCD and/or tics
- 4 Often accompanied by additional neuropsychiatric symptoms

Considered a clinical condition characterized by a specific pattern of symptom onset and association with Group A Streptococcal infection. Proposed immune-mediated mechanisms continue to be investigated.

Diagnostic Features

- 1 Abrupt onset of OCD, or dramatic, disabling tics
- 2 An episodic symptom course, or relapsing-remitting course of severity
- 3 Pre-pubertal onset
- 4 Presence of neurologic and neuropsychiatric abnormalities
- 5 Occurrence of a strep infection before symptom onset

Diagnosis of Exclusion

Symptoms are not better explained by another neurologic, medical, developmental, or psychiatric condition. Proposed immune-mediated mechanisms continue to be investigated. No biomarker currently confirms PANDAS, and diagnosis is based on clinical presentation, symptom course, and differential diagnosis.

PANS

Pediatric Acute Neuropsychiatric Syndrome

PANS describes a clinical syndrome characterized by abrupt-onset neuropsychiatric symptoms. Multiple infectious, inflammatory, metabolic, and environmental triggers have been proposed; an infectious trigger is not required for diagnosis.

Criteria

- 1 Abrupt, dramatic onset of OCD and/or severely restricted food intake (and/or sudden exacerbation from baseline)
- 2 Concurrent presence of at least two additional neuropsychiatric symptom categories
- 3 Symptoms are not better explained by another medical, neurologic, developmental, or psychiatric condition

Common Associated Symptoms

- 1 Anxiety
- 2 Emotional Lability and/or Depression
- 3 Irritability, Aggression, Oppositionality
- 4 Developmental Regression
- 5 Sudden Academic Regression Performance
- 6 Motor or Sensory Abnormalities (tics, dysgraphia, etc.)
- 7 Somatic Signs and Symptoms: sleep disturbances, urinary frequency, enuresis

Diagnosis of Exclusion

No laboratory test or biomarker currently confirms PANS. Diagnosis is based on clinical presentation, history, and exclusion of alternative medical, neurological, and psychiatric explanations

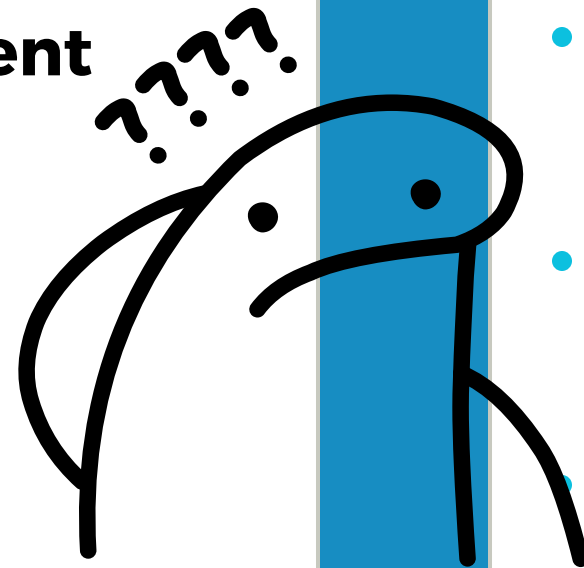
(PANDAS Network, 2025a)

Swedo et al. (1998); Swedo et al. (2012)

WHAT WE KNOW

What We Know

- **Acute-onset presentations occur sometimes without clear trigger.**
- **Significant functional impairment occurs.**
- **Family burden is substantial.**
- **School impact is substantial.**



What We Are Still Learning

- **Exact biological mechanisms.**
- **Biomarkers.**
- **Predictors of treatment response.**
- **Long-term trajectories.**

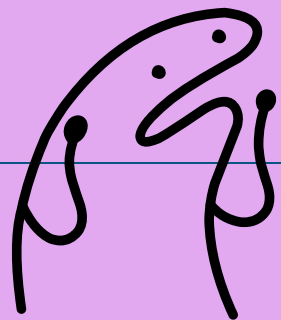
AND WE STILL TAKE CARE OF STUDENTS

COST OF DELAYED RECOGNITION



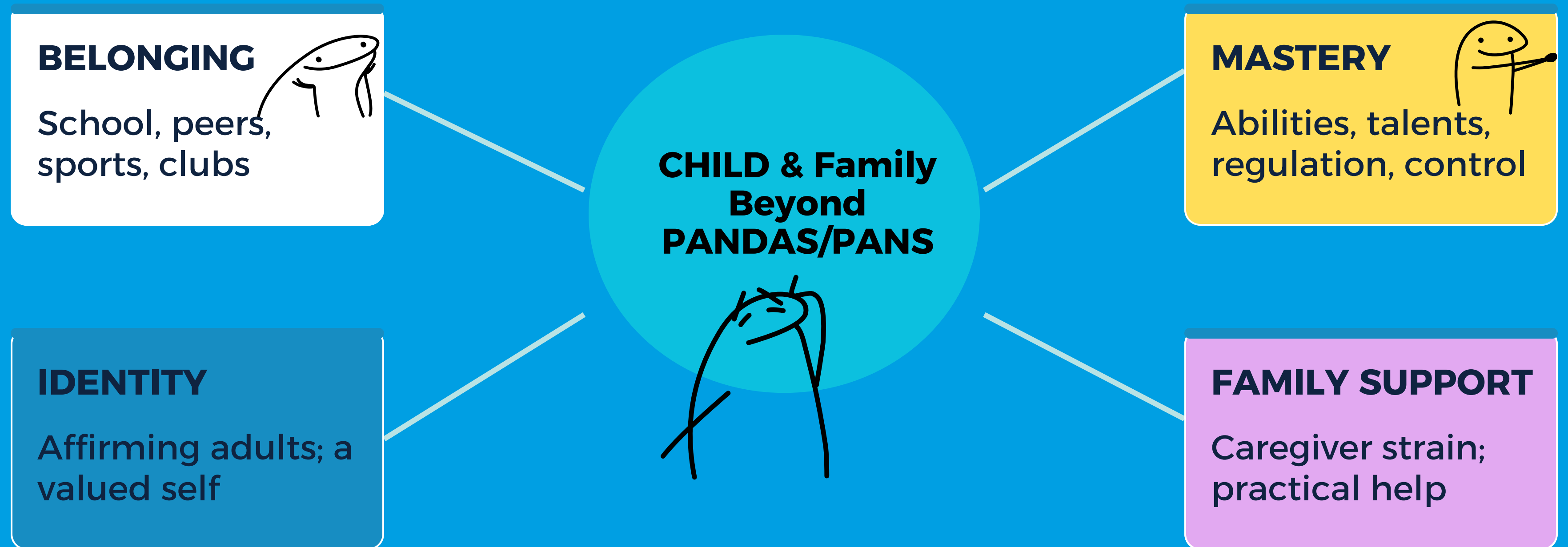
- **Academic decline**
- **Increased school avoidance**
- **Family strain**
- **Greater caregiver burden**
- **Social isolation**
- **Misattribution as oppositional behavior**
- **Delayed access to supports**

What Happens When We Miss It?



PANDAS/PANS DISRUPTS A CHILD'S WORLD

Protective factors for resilience may be weakened—not inevitably lost.



“You are a great kid having a hard time.”

STUDENT IMPACT

Child Struggling

Frequent Absences
& Missed Days

Unpredictable
Flare Patterns

Decreased Endurance
Limit Participation

Falling Behind
Academically

Social Isolation
from Peers

Loss of
Confidence

Anxiety About
Returning

Reduced
Independence

School Refusal /
Avoidance

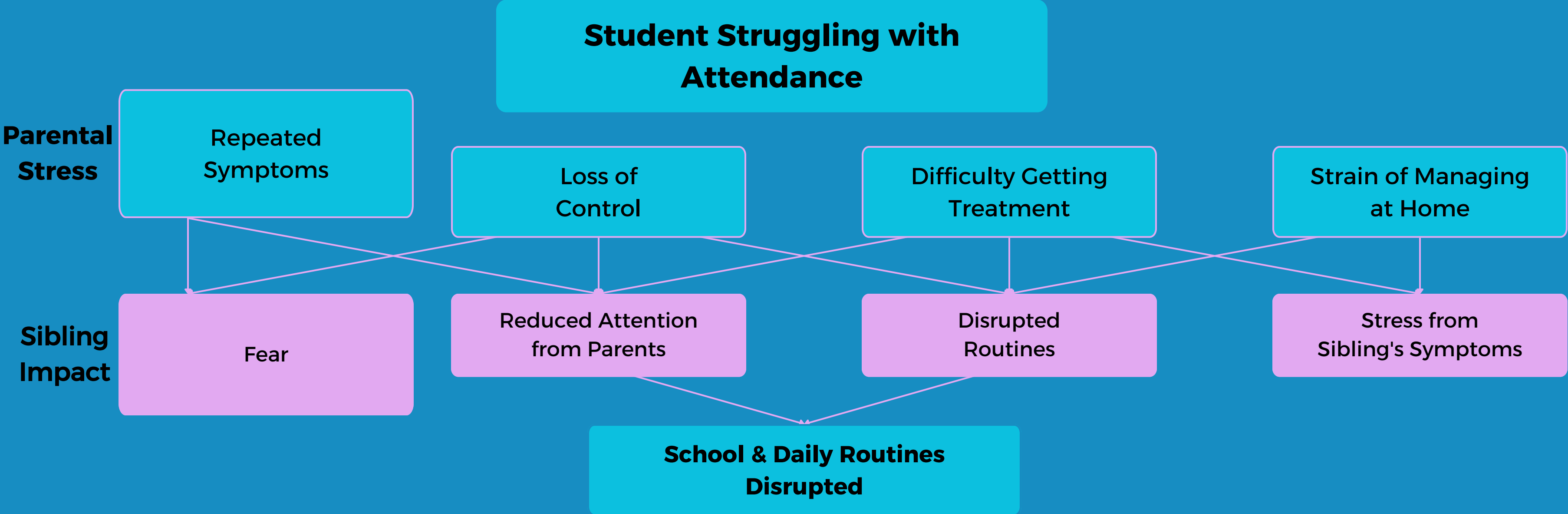
Mental Health
Decline

Long-term
Educational Gaps

Chronic illness creates a cycle of absence, academic decline, and psychological distress that compounds over time without intervention.

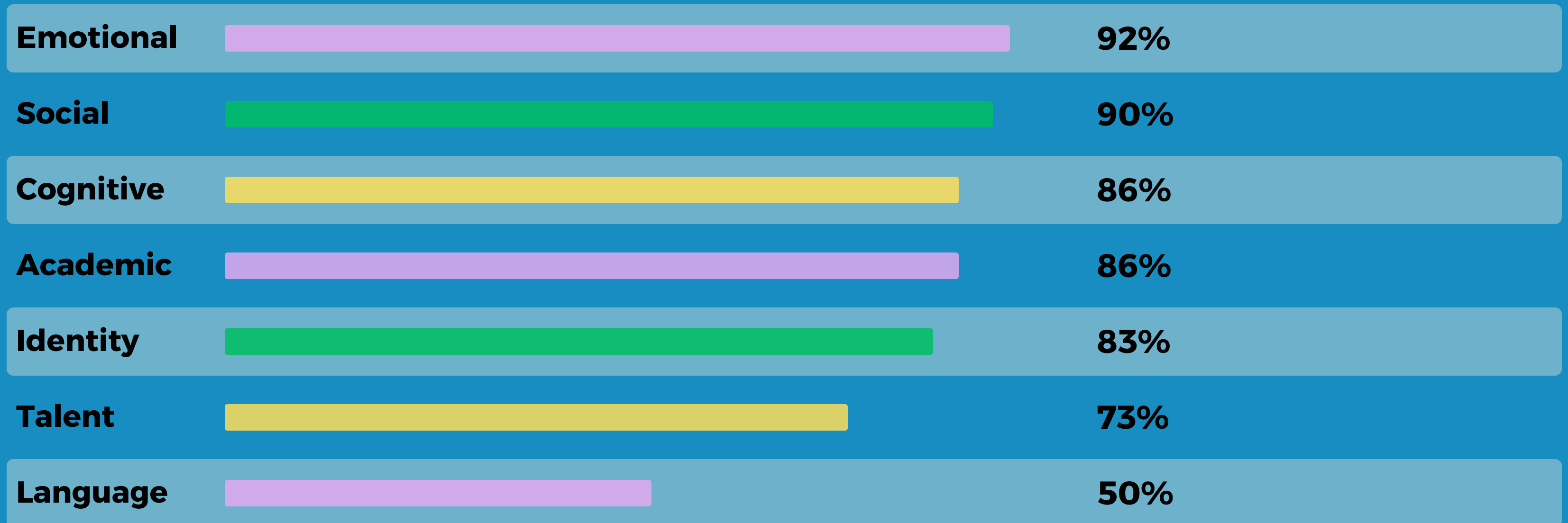
Dolce, J et al, 2021, Lum et al., 2019; LaRusso et al., 2024; Ringer et al., 2022

FAMILY IMPACT



Key Finding: PANS affects the whole household (Ringer et al, 2022)

THE DEVELOPMENTAL IMPACT



Key Finding: Fewer supports → more severe developmental impacts
Parent-reported data: 402 children

PANDAS/PANS CAREGIVERS

Emotional & Physical Strain

- Managing severe dysregulation & aggression at home
- Extraordinary emotional demands of caregiving
- Sleep deprivation & chronic exhaustion

Systemic & Social Pressures

- Overwhelming workload & advocacy burden
- Chronic invalidation & feeling disbelieved
- Social isolation, stigma & misconception

Life & Role Conflicts

- Conflicting demands & competing responsibilities
- Lack of control, unpredictability & financial strain
- Disenfranchised grief for the child's changed path

SHARED SUPPORT

PANS/PANDAS create complex challenges across family and school environments: Everyone plays a role.

Educators

Standard testing rarely captures relapsing neuroinflammatory symptoms, making targeted assessments and precise screening questions critical.

Clinicians

Establishing early crisis plans replaces reactive stress with structure, keeping lines of communication clear during flare-ups.

Parents

By recognizing this complex constellation of behaviors as a medical condition, multidisciplinary teams can implement the flexible accommodations and meaningful support students and families need to thrive.

PANS & PANDAS FLARES: CLINICAL REASONING

Recognize a flare

A flare is the abrupt/dramatic onset of neuropsychiatric symptoms and functional impairment. Both pieces matter — it's not just symptom presence, it's symptoms plus impairment, arriving suddenly.

Establish baseline

Baseline functioning is what the client looked like before PANS/PANDAS and possibly between flare states.

Knowing baseline helps identify the recovery target, guide treatment, and determine when medical treatment may be needed.

Interpret change in context

Episodic worsening alone - Pay Attention.

Look for change from baseline, multi-domain symptom involvement, and associated functional impairment.

Interpret symptom fluctuation within the broader developmental and medical context.

Recovery status

Not at or near
pre-PANS baseline
(chronic)



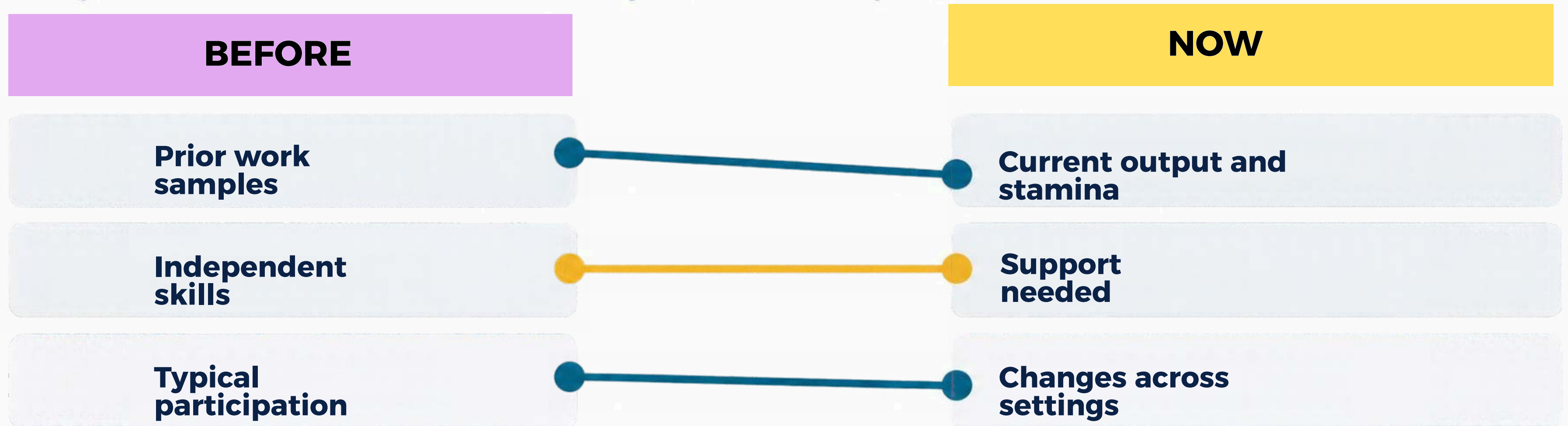
Significantly improved
from flare
(partial remission)



Return to
pre-PANS baseline
(remission)

WHEN SKILLS BECOME LESS ACCESSIBLE

Compare with the child's own baseline—not just classroom expectations.



Distinguish: output difficulty • symptom interference • cognitive change

Respond to documented difficulty; do not assume noncompliance or permanent loss.

DISTINGUISHING "CAN'T" FROM "WON'T"

OBSERVE:

- Cognitive slowing
- Motor impairment
- Processing delays
- Fatigue
- Emotional dysregulation
- Regression

QUESTION:

Is this a skill deficit, performance deficit, avoidance pattern, or medical impact (from medication, illness, unknown)?

EXECUTIVE FUNCTION DURING FLARES

Initiation

Organization

Working memory

Processing speed

Task completion

Cognitive flexibility

This bridges medical symptoms to classroom behavior.

ASSESSMENT REALITY



Monitoring tools

PANS/PANDAS-specific measures are symptom-monitoring tools rather than definitive diagnostic tests.



Comprehensive evaluation

Screening tools complement, rather than replace, comprehensive clinical evaluation.

Standard testing may not fully capture fluctuating symptoms and functional impairment across settings and over time.

Key Limitation

Normal testing does not necessarily rule out functional impairment during relapsing illness.

Cognitive weaknesses observed during testing may not specific to PANS/PANDAS.

Findings must be interpreted alongside medical history, symptom course, and functional data.

Additions to MH Clinical Intake - PANDAS/PANS

Onset Timing	Exact date/week of onset; abrupt (hours-days) vs. gradual (weeks-months)
Concurrent Symptoms	Screen all PANS symptom categories; PANS 31-Item Rating Scale
Infection Timeline	Any illness in 2-4 weeks preceding onset or exacerbation
Motor Changes	Tics, handwriting changes, motor restlessness, unusual movements
Autoimmune/Family Hx	Personal and family autoimmune disease history
Treatment Response	Prior SSRI/ERP trials - adequacy and response
Severity Tracking	Y-BOCS or CY-BOCS at baseline and serially; PANS Global Impairment Score; Wearable devices; Sleep Scales, UNHIDE or PTEC, Adaptive Functioning Scale (Vineland), Sensory Profile

Key Insight: If onset is acute and multi-domain, ask more questions.

SCREENERS/ASSESSMENTS

There is no standardized assessment or screeners. Some deficits improve when symptoms remit, but recovery is variable and may be incomplete in prolonged or severe cases.

OCD

- **CY-BOCS-II / Y-BOCS-II** OCD severity measure
- **OCD severity** Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS-II)

Tics

- **PUTS (Premonitory Urge for Tics), YGTSS** Screens for tic-related urges, tics
- **Tic severity** Yale Global Tic Severity Scale (YGTSS)

Caregiver burden

- **Caregiver Burden Inventory** Assesses family accommodation and stress
- **Quality of Life/Caregiver Burden** Sensory Profile 2, Caregiver Burden Questionnaire, Vineland Adaptive Behavior Scale (VABS)

Anxiety

- **SCARED / MASC/RCADS** Broad anxiety screening tools
- **Behavioral/emotional screening** Strengths and Difficulties Questionnaire (SDQ), CBCL, BASC-3, handwriting/clock

Executive functioning

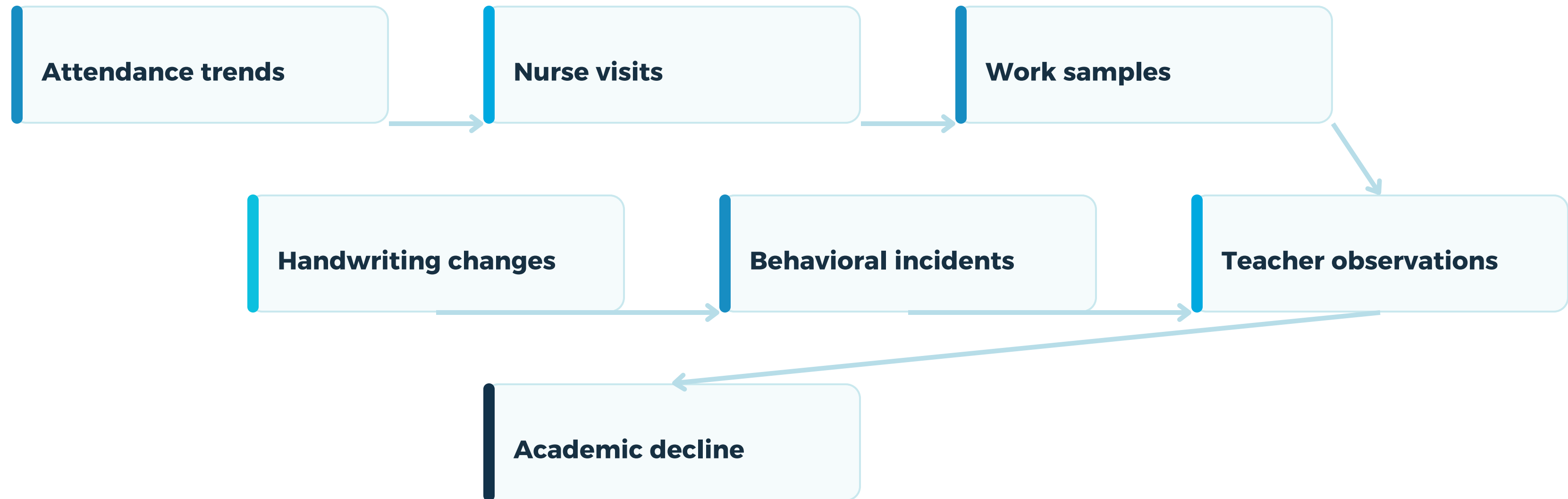
- **BRIEF-2** Executive function behavior rating
- **Conners Rating Scale** Attention and executive function screening
- **ADHD symptoms** ADHD Rating Scale (ADHD-RS), SNAP-IV, Child Mind has a free version

Sleep/Eating Restrictions/Adaptive Functioning

- **Sleep/Eating Restrictions/Adaptive Functioning** Sleep disruptions

SCHOOL DATA AS CLINICAL DATA

A school-based view can reveal patterns across settings, time, and behavior



Schools often have information that families and physicians cannot easily observe.

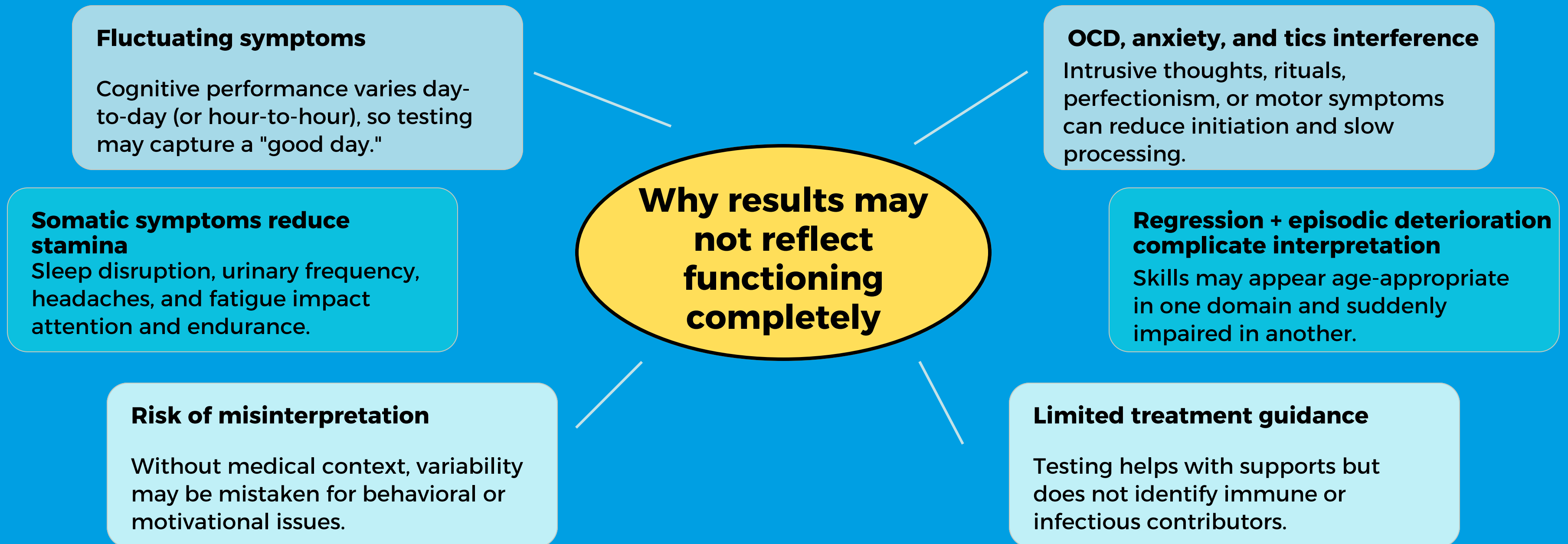
NEUROPSYCH TESTING

Purpose	Identify cognitive decline vs. primary learning disabilities; School, work or disability evaluation
Key Domains	Processing speed, working memory, executive function, fine motor
Timing	Baseline at diagnosis; repeat when? during flares and post-treatment, unlikely
Differentiates From	ADHD, autism, primary anxiety, OCD, Tics, learning disabilities
Instruments	WISC-V, NEPSY-II, D-KEFS, Beery VMI, CVLT-C
No Standardized Battery	No single validated battery exists; tailor to presentation since PANS/PANDAS are clinical diagnoses; Neuropsychological testing may be used selectively to assess cognitive or academic impact



Neuropsychological findings may document impairment but are not diagnostic of PANS/PANDAS.
May help characterize cognitive and academic functioning but is not diagnostic of PANS/PANDAS.

NEUROPSYCHOLOGICAL TESTING: LIMITATIONS



Standard testing may not fully capture fluctuating symptoms and functional impairment across settings and over time.

EDUCATIONAL DECISION-MAKING

Schools support impairment, not diagnoses.

Eligibility is based on function.

Focus on educational access.

Functional impact should drive supports.

- **Function often changes across settings and across flares.**
- **Documentation should focus on observable impairment.**
- **The 504 Plan should be individualized and tied to the student's actual limitations and needed supports.**
- **Eligibility and support should focus on documented educational needs and access barriers.**
- **Similar principles apply for many chronic medical conditions with fluctuating symptoms.**

SUPPORT AND ACCOMMODATIONS

Flexible Attendance	Modified schedule, reduced days, late arrival, early dismissal as needed due to medical appointments &/or illness
Academic Adjustments	Extended time, shortened assignments, modified grading during flares that are symptom responsive
Testing Accommodations	Distraction-reduced environment, extended time, breaks during testing
Assistive Technology	Keyboarding, speech-to-text, audiobooks, calculator access
Regulation Considerations	Nurse access, rest breaks, Quiet space for de-escalation to maintain school engagement
Behavior Supports	De-escalation strategies, reduced stimulation, predictable routines, clear language, scheduled meetings to discuss functioning
Return to School	Schedule to reach teacher and discuss plan, temporary home instruction, Plan for re-entry after flares
Care Coordination	Individual Health Care Plan connecting medical needs with school-day supports
Sensory Supports	Sensory profile and supports for functional support, work with School OT

Accommodations should be flexible, symptom-responsive, and regularly reviewed. Create plans that include the most impactful symptoms of flares.

ACCOMMODATIONS VS. SUPPORT

ACCOMMODATIONS

Change in expectations or environment that reduces distress in the moment. reinforces avoidance, compulsions, or symptom-driven behavior

Illness - mild, moderate, severe

Adaptive Functioning Impairment

Family Goals

Presenting Symptoms/Crisis Level

Develop Treatment plan

Supports should preserve access to education while avoiding unnecessary reinforcement of symptoms.

vs.

SUPPORT

Change in expectations or environment that compensates for a loss of ability, medical impairment, or temporary functional decline due to illness or flare

Modify tasks, providing assistance, addressing symptoms

In PANS/PANDAS, includes cognitive slowing, fine motor impairment, fatigue, somatic symptoms, urinary issues, tics, executive dysfunction, or behavioral regression that reflect capacity loss, not avoidance.

Accommodations should be reviewed regularly and adjusted based on recovery and functioning.

Is the goal participation not permanent reduction of expectations?

SPEECH AND LANGUAGE AT SCHOOL

Language Affected (50%)	2024 study found language development affected in 50% of children	Relevant when looking at speech-language concerns or communication changes at school
Indirect Effects	Language indirectly affected through anxiety, processing delays, selective mutism	54.5% had new speech disfluency after onset; common symptoms: fast speech, excess talking, verbal blocks
Speech Disfluency	Vocal tics, selective mutism, 'baby talk,' articulation and intelligibility problems	Medical treatment improved fluency for some; overall impact on speech/language and quality of life was substantial
Cognitive Flexibility & Organization	Reduced cognitive flexibility and difficulty organizing thoughts	Affects expressive language output and narrative coherence

Language difficulties in PANS/PANDAS are often secondary to neuropsychiatric symptoms — assesses communication in context of the whole clinical picture.

BARRIERS AND CONCERNS

Staff Unfamiliarity	Staff may not recognize PANS/PANDAS or understand symptom variability
Symptom Misattribution	Confusion between neuropsychiatric symptoms, variability and willful behavior
Fragmented Communication	Delays in obtaining outside evaluation or treatment coordination
Beyond Behaviors	Child exhibiting anxiety-driven avoidance, motor slowing, or compulsive behaviors
Family-School Disagreement	Disagreements about severity or needed services
Documentation Needs	Shared documentation and clear function-based goals are essential

Consider whether observed behavior may reflect medical, psychiatric, cognitive, emotional, or behavioral contributors before assuming willful misconduct

SCHOOL COMMUNICATION

Family with School

Health of child

Attendance/Absences

Academic Struggles

OCD strategies for classroom

Tics impacting student/learning; restricted eating impact; gas, constipation, etc...

School with Family

Illness in the classroom; clarity on in-school and out-of-school supports; academic needs and interventions; designated point of contact; crisis-response plan.

Social gains, concerns with peers/others; Strengths and Opportunities, adaptations to classwork; inclusion of caregivers sooner

Anxiety in the Classroom: <https://anxietyintheclassroom.org/>

COORDINATED SCHOOL PLANNING

1 Evaluation

- Baseline cognitive profile & changes

2 Clinician Communication

- Clinician Letter
- Document medical necessity for school
- clear roles
- shared goals
- defined communication channels

3 504/IEP Planning

- Teacher Discussion / IEP / 504 Plan
- Formal accommodations & flare protocol

4 Support Team: OT, SLP, MH, School Advocate

- Targeted therapy for motor, language, adaptive functioning, mental health, school supports

5 Reassessment

- Ongoing Reasseesment
- Adjust supports as symptoms fluctuate

6 Designated Coordinator

- More providers do not automatically mean better care.
- One identified care coordinator can improve consistency.

ATTENDANCE, AVOIDANCE, AND RETURN TO SCHOOL

School avoidance is difficult for the student.

In PANS/PANDAS absences may relate to:

Severe anxiety

Cognitive fatigue

Sleep disruptions

Urinary symptoms

Sensory overload

Restricted eating

Medical instability

Illnesses in the classroom/illness

Chronic flares often leads to attendance problems before academic failure appears.

School avoidance, school refusal, illness, anxiety, and neuroinflammatory symptoms may overlap.

Attendance plans should be flexible and symptom-responsive.

Re-entry planning is often as important as attendance expectations.



WHEN SCHOOL ATTENDANCE IS NOT ACCESSIBLE

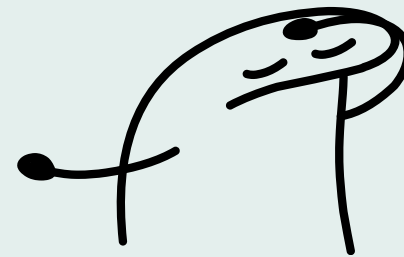
Compare arrangements—not the child's willingness to cope.

SUPPORTED ATTENDANCE

Can adapted school supports preserve access and safety?

SCHOOL HOMEBOUND

Review district eligibility, instruction, services, and reassessment.



HOMESCHOOLING

Review parent-directed teaching, resources, services, and feasibility.

Across settings: instruction + safety + connection + family capacity + review.

EMOTIONAL LABILITY: UNDERSTAND BEFORE RESPONDING

Visible behavior is not the whole assessment.

1

NOTICE

Define the behavior without a label.

2

UNDERSTAND

Assess context, capacity, and function.

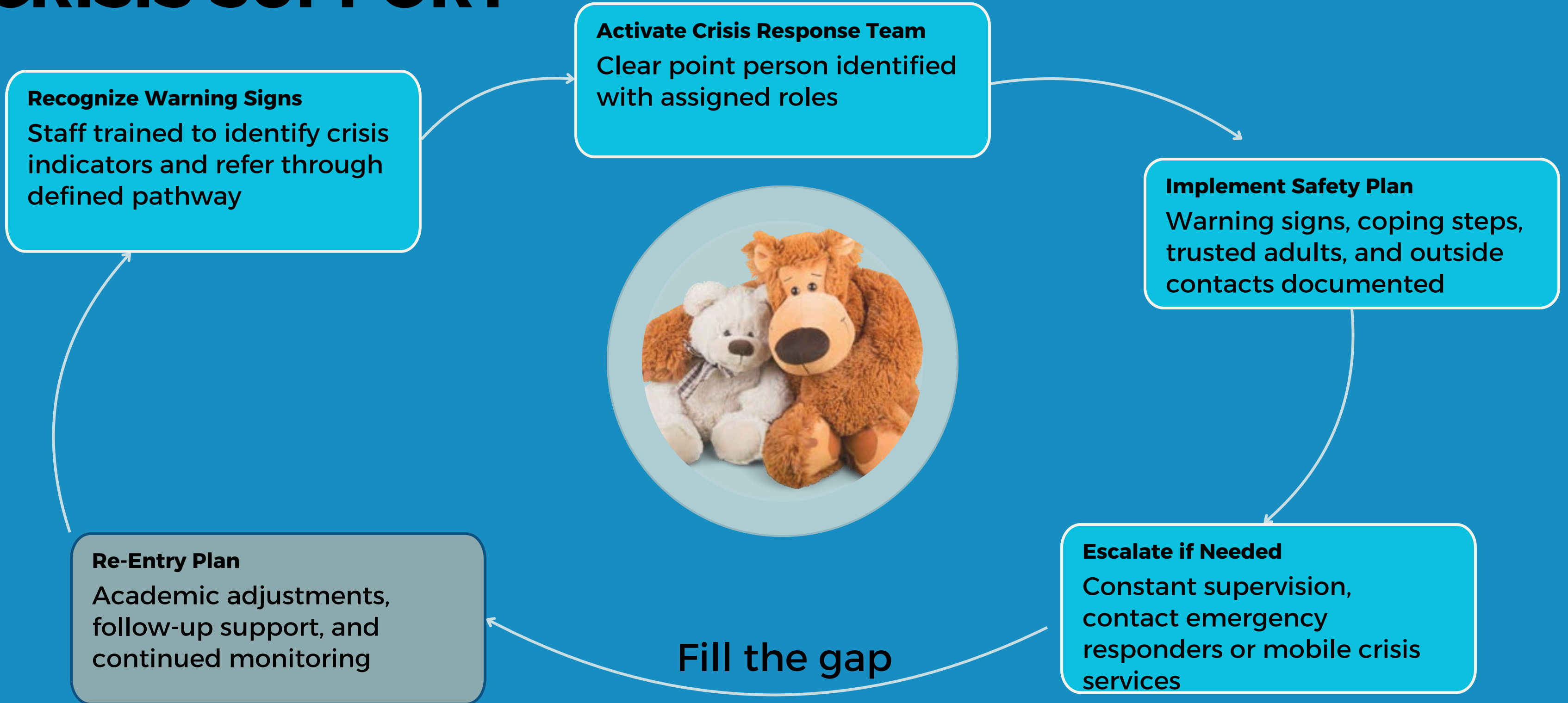
3

SUPPORT

Plan safety and usable replacement skills.

Prioritize safety and stabilization when severe symptoms limit participation.

CRISIS SUPPORT



CRISIS ACCESS FOR PANS/PANDAS

**Nurse
Check-In**

**Quiet Room
Access**

**Reduced
Demands**

**Parent
Contact**

**Quick Team
Review**

Goal: Preserve safety and access to learning without treating the episode like a disciplinary problem.

Crisis access means making it easy to trigger supports during sudden flares

For students with PANS/PANDAS or similar neuroimmune conditions, episodes may be abrupt and fluctuating – school response should prioritize safety, regulation, and restoration of access to supports and instruction.

PREDICTORS OF ESCALATION

Increased reassurance seeking

School attendance decline

Sleep deterioration

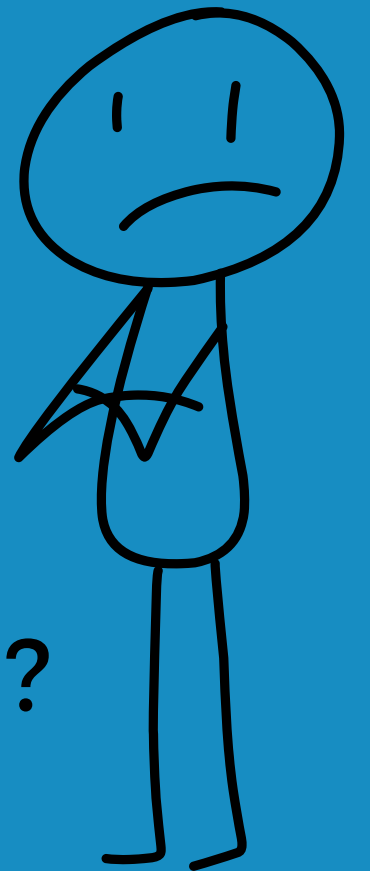
Increased irritability

Restricted eating

Increased nurse visits

Growing family-school conflict

What do you think predicts escalation?



SUPPORT ACCESS WITHOUT REINFORCING OCD

Two different purposes; one coordinated school-clinical plan.

REMOVE A LEARNING BARRIER

Example: alternative written output for demonstrated handwriting difficulty.
Target: meaningful participation.

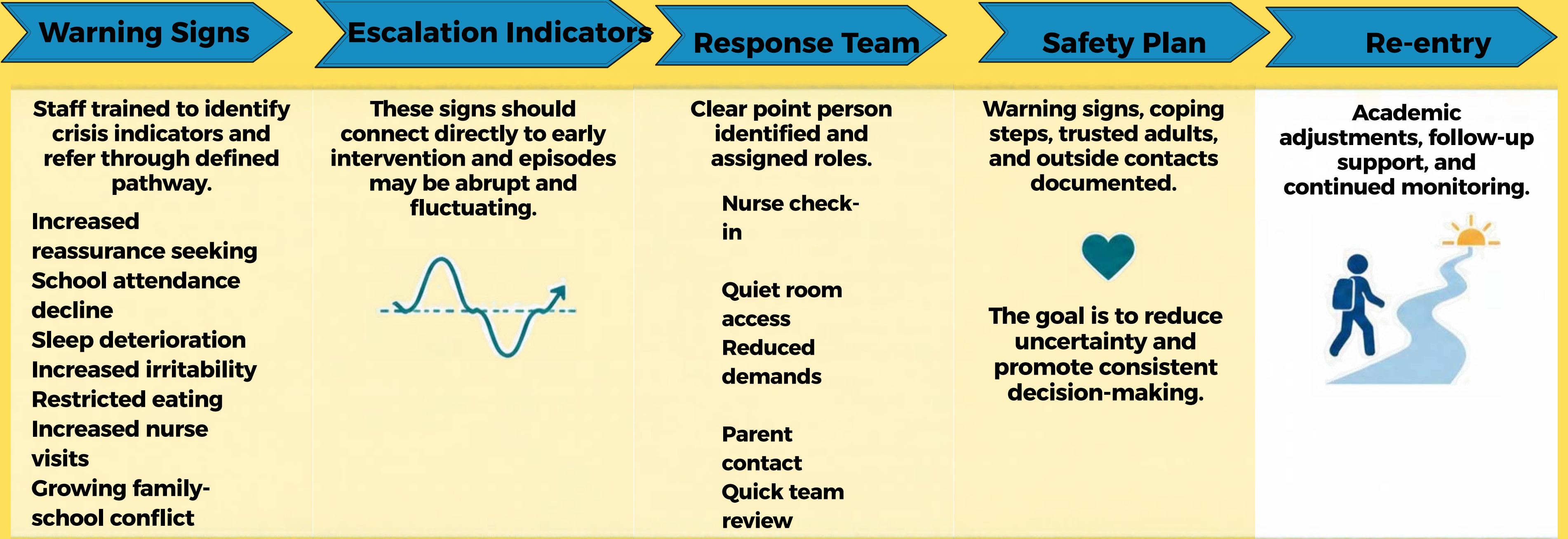
AVOID PARTICIPATING IN RITUALS

Example: a clinician-agreed response to repeated reassurance seeking.
Target: treatment alignment.

ERP readiness can change during acute illness; adapt with the treating clinician.

CRISIS RESPONSE FRAMEWORK

Preserve safety and learning access without treating episodes as disciplinary problems.



DYNAMIC SUPPORT ACROSS FLARES

School teams understand immediate adaptations because they already use similar frameworks for concussion and medical recovery.

BASELINE

Maintain necessary supports and instruction.

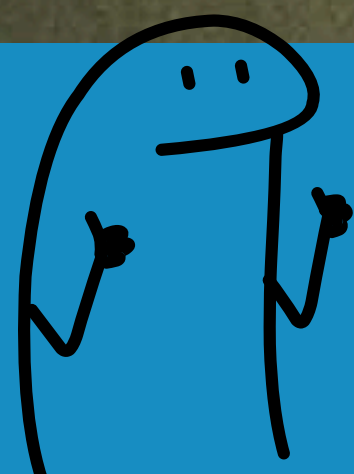
MORE INTERFERENCE

Activate agreed barrier-specific supports.

IMPROVING

Review temporary assistance; preserve access.

Make support dependable—not dependent on which adult is present.



**QUESTION AND
ANSWERS**

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Resources

Schools, Clinicians and Medical Providers

Podcasts

- PansPandas-Hope
- PANS/PANDAS STORIES
- TAMF Podcast
- Mom & Doc Talk: Healing PANS/PANDAS
- PAN and PANDAS- Body Talk Radio Podcast
- Surviving the Flares
- Demystifying PANS/PANDAS
- Flying Through Fog

Facebook Groups

- PANS/PANDAS Support Group
- PANDAS Parents
- PANDAS PANS Support Groups
- Aspire PANS PANDAS Group
- PANS/PANDAS Therapists Collective
- PANDAS/PANS Parent Stress Relief Group
- Adult PANDAS/PANS/Lyme/Tick-Borne Diseases
- Holistic Guide to PANS/PANDAS
- PansPandas-Hope

Support Groups

- PANDAS Network
- PANDAS Physicians Network
- ASPIRE
- Neuroimmune Foundation
- PANS/PANDAS Parent Support
- The Alex Manfull Fund



THANK YOU

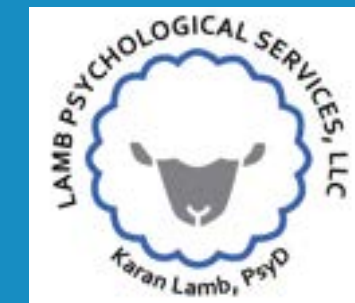
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Screeners/Assessments

PANS 31-Item Rating Scale

Screens across all 7 PANS symptom categories

PANS Global Impairment Scale

Tracks overall functional impairment

CGI-S / CGI-I

Clinician-rated global severity and improvement

SCARED / MASC/RCADS

Broad anxiety screening tools

BRIEF-2

Executive function behavior rating

CY-BOCS-II / Y-BOCS-II

OCD severity measure

Caregiver Burden Inventory

Assesses family accommodation and stress

PUTS (Premonitory Urge for Tics), YGTSS

Screens for tic-related urges, tics

Conners Rating Scale

Attention and executive function screening

Sleep/Eating Restrictions/Adaptive Functioning

Sleep disruptions

Key Insight: There is no standardized assessment

Brief Assessment: School

Clinical Interview

Developmental history, medical records, onset of symptoms

Work Samples

Products of writings, math, pre and post comparison

Rating Scales

BASC-4, YBOCS/CYBOCS, SCARED, BDI/BAI, CDI

Adaptive Functioning

Vineland/ABAS

Purpose

Define the purpose: Identify cognitive decline or primary learning disabilities

Application

School, work, or disability evaluation

Key Insight: Brief battery may identify cognitive decline patterns for school and disability planning.

Standard of Care

PANS/PANDAS Consortium's severity-tiered approach:

Mild Presentation- NSAIDs, brief oral corticosteroid burst, antimicrobials

Moderate/Severe- oral/IV corticosteroids, IVIG

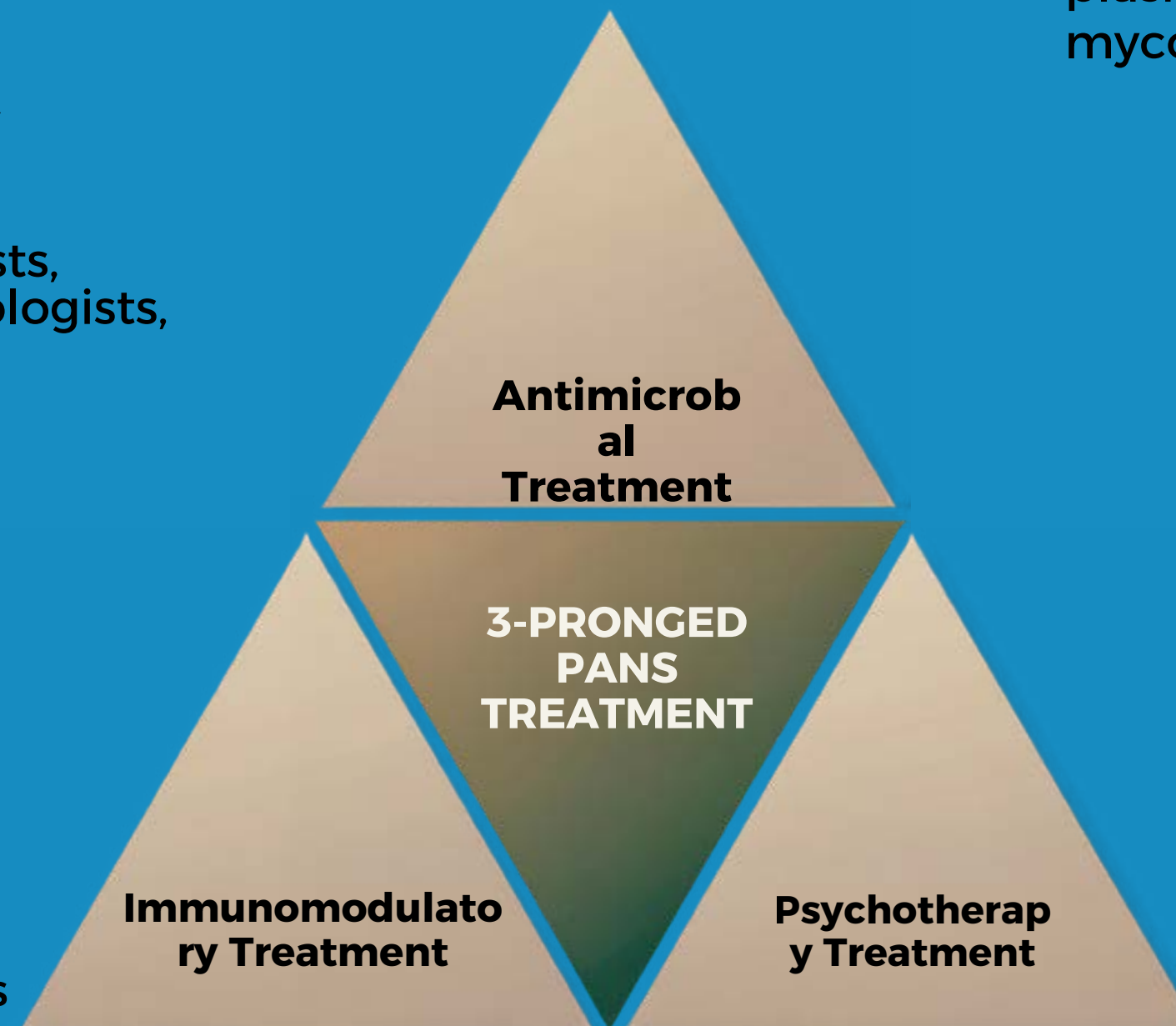
Severe/extreme, refractory- therapeutic plasma exchange, rituximab, and mycophenolate mofetil

ANTI-INFLAMMATORY

Immunologist, Oncologists, Rheumatologist, Neurologists, Infectious Disease, Dermatologists, Gastroenterologists, and more

INFECTION CONTROL

Pediatrician, Immunologist, Gastroenterologist, Rheumatologist, Pulmonologists, Dermatologists, Neurologist, Infectious Disease Specialists



PSYCHIATRIC

Psychiatrist, Therapist, Psychologist (Neuropsychologist, Clinical, School), Nutritionist, Educational Consultant, Nurse (IV Transfusions)

Treatment recommendations are derived largely from expert consensus guidelines and evolving evidence; treatment decisions should be individualized and guided by medical specialists.