

The Critical Importance of School Nurses
In the Care and Academic Support of Students with PANS/PANDAS: An Educator's Thoughts
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At far too many of our public schools, the once comforting figure of a university- educated school nurse has morphed into a benevolent 'health aide' with the rumor of a first aid kit. As I mourn this increasing loss of medical expertise in our schools here in the Great State of California, I am compelled to state, first off, that *any* student with PANS who is lucky enough to have a real, live, *School Nurse* on his or her Student Study or IEP team is *very fortunate* indeed. These students are at a distinct advantage that comes with having someone on the team, who by training, skill, and experience, recognizes the critical interplay of physiological systems that not only allows human development to exist at all, but gives rise to the stunning feat of cognitive development that makes any academic achievement possible.

When I am asked about the most important thing that the school can do to help a PANS/PANDAS- stricken child, my response is pretty automatic. *Talk with the parent.* Certainly, the child's own input should be sought out; however, it is important to consider that this student's perspective may be significantly altered or limited by a number of factors, including general health status, language deficits, cultural/social expectations, gender differences, developmental stage/ imperatives, cognitive deficits specific to PANS, etc... Simply put, students suffering from PANS may not always be the best witnesses to their own symptoms of regression or recovery, and loved ones must be looked upon to provide additional perspective.

Enter... the wonderful School Nurse, whom I believe is in the best position to lay the necessary ground work towards the most appropriate educational plan for that child. A scheduled, unrushed, time to talk (at least by phone, but better, in person at the school - and better even yet, at the child's home if the parent is comfortable with it) will offer the person *who knows the student best* the opportunity to expand on concerns and information presented in initial requests for services. Hopefully, the school will have already received letters from the parent and medical providers validating the need for services, and signaling possible referrals, programs, and types of testing. The information gleaned from such documentation will certainly vary, however. Supportive and clarifying conversations with parents and providers will shed more light on how this condition not only affects the student's ability to function *during the school day*, but in *preparation* for the school day, which means- of course- during all of the other hours when he is not at school.

More than any other medical condition I have seen in thirty years of special education, PANS stands alone in the ways that it produces sudden, jagged, and alarming regression in so many domains. Depending upon where the child is at in the disease/treatment process*, the advancement of his or her former skills and performance, age, and other factors, one may see a broad constellation of deficits, or one may not. In looking over academic portfolios, report cards, and standardized measures, you may notice fluctuating patterns of math grades, rates of task completion, handwriting skills, and social skills- especially as the warmer weather moves into the cold and flu season.

**The average age of onset is between 4 to 7 years old, although PANS strikes later too. It's considered to be a finite, transient illness (of up to one year) if treated early. However, if left untreated, the student may suffer from related symptomatology indefinitely.*

You may even notice *increased* abilities in some areas, (especially if the student has been previously undiagnosed for years), such as improvements in types of auditory memory skills.

Conversations will yield important information that will establish how the following abilities, many of which are significantly affected in the PANS stricken child- have regressed, changed, or stayed the same since its onset. In particular, how does the student currently:

- Demonstrate age appropriate self care and daily living skills surrounding grooming, transportation, eating, etc.? (How long is it taking for the student to carry out grooming activities such as bathing, dressing, and tooth brushing? Does the student experience upset, anxieties or sensory overload in cars? Are adjustments in attendance required?)
- Adapt to transitions and stresses common to the educational, home, and other environments, including and/or involving decision making, attendance, scheduling, and interactions with others. (Is a late-slip needed to be on file? Can the treating physician write a note to the effect that attendance in the morning is illness related?)
- Follow, understand, and remember written, oral, and visual information (and combinations of the three).
- Sustain focused attention for longer than 10 minutes (including activities that require listening, fine motor, and gross motor skills).
- Communicate effectively with others, and interact and behave in ways that are age-appropriate.
- Maintain social relationships. (In what ways has his or her social life changed or stayed the same? How many times per month is the student invited to peers' homes, and what friends come to his home? Are friendships sought out?)
- Complete chores, educational routines (i.e. test-taking and homework), and other tasks of daily living in a timely manner.
- And, of course, acquire, and demonstrate academic knowledge (indicating the degree to which s/he may need additional assistance, direction, and time to learn and to participate in an academic setting).

A major theme that quickly emerges in these conversations surrounds the loss of executive functioning. This loss results in the parent taking on a tremendous logistical load in order for the child to complete many basic functions of daily living. Without their prior abilities to efficiently think, plan, coordinate, and organize their world and their lives, these children succumb to- for all intents and purposes- developmental regression. Especially during times of illness and inflammation, and whether or not it is observed by the school staff, it should be considered a given that in these families, loved ones are providing their child with Herculean levels of support to bolster whatever remaining function their child still has. As a result, the parents themselves are at very high risk of physical and emotional exhaustion.

As part of their health work-up, consider some of the following areas that may be affecting the child's participation in school. Such areas include the functioning and any hyper/hypo sensitivities surrounding the sensory systems. Again, consider how these aspects have changed or stayed the same pre- and post diagnosis and/or treatment.

- How many hours is the child *actually* sleeping each night? (Sleep disturbances include night terrors, getting up to go to the bathroom, lying in bed awake, restless leg syndrome, etc. ...)
- How has his or her diet and eating changed? Has the parent noted that certain foods are suddenly not tolerated any longer by the child? Have allergies, gluten or other sensitivities been noted by the parent or medical provider? How *coordinated* is s/he in handling food? Is s/he a messy eater, and if so, is s/he aware of being messy? Does s/he clean self and eating area afterwards?
- In addition to addressing and monitoring status of hearing levels and visual acuity, consider other aspects of these sensory states on behavior and function, such as sensitivities to certain sounds or lights. (Should tennis balls on chair legs be considered? Is he particularly sensitive to certain lights (halogen, florescent) or at certain times of the day? Would curtains, a hat, or tinted sunglasses help?)

- Also regarding vision, a Binocular vision examination is strongly urged, because regardless of their visual *acuity*, most will experience significant weaknesses in visual fluency (especially when paired with fine motor demands). Also rule out convergence insufficiency.
- Consider any and all changes in mood, parameters of mental health diagnoses, energy, stamina, affect, agitation, and unintended physical movements and utterances.
- Inquire as to the effectiveness of, and any observed side effects of medications, including those prescribed for ADHD, anxiety, and other mood, or other disorders. It's important to keep in mind that many parents may not associate certain behaviors or conditions with medications, especially medications for children.
- Has there been an increase in urinary frequency or bed wetting? (At school, can he be excused to go to the bathroom when needed in a non- 'spotlighted' kind of way?)
- How is this condition affecting the rest of family? Is the parent concerned over the child's safety, or the safety of those around him? (How will the school apply federal safeguards and protections to ensure that any behaviors secondary to the diagnosis of PANS will not result in inappropriate disciplinary techniques by the staff? A discussion with the parent on the disclosure of this illness to the police, should they be called, may also be very helpful.)
- Thorough Assessments Yield Productive Interventions. Regarding an onset or improvement of problematic behaviors, lack of attention, and changes in physical and/or mental health, assessments and interviews with providers, should, to the extent possible, identify *what* of those can be attributable to *changes in medication, diet, or other interventions, the PANS condition itself* (such as anxiety), and/or the *"sickness behavior"* (such as fatigue) associated with a specific infection (such as strep or Mycoplasma, etc.). Whereas some of these symptoms truly overlap, others can be specific to one factor.

PANS is a medical condition that poses significant threat to various areas of student functioning. Therefore, regarding IEP plans, strongly consider the premise that PANS/PANDAS falls under **OHI** (*Other Health Impairment*), and that it either **is**, or **accompanies** the "primary disabling condition" (that warrants educational modifications, accommodations, or attentional supports.)

- Especially for those on the team who may be unfamiliar with PANS, it can be very helpful if a one sheet overview is presented to the team members that includes a general statement regarding what it is and it's most common characteristics. -Then, with the help of provider documentation and parent and staff observations, zero in on how this student's specific symptoms may affect or impede full participation in the regular school day. This could include verbal or motor tics (Is this resulting in anxiety, or taunting from classmates? Is a place of refuge needed during the day?); saliva pooling -(Could a speech, or other type of therapist be brought in to work with the student on ways to reduce the sensitivity, or come up with ways to accommodate the behavior, such as spitting in Kleenex, etc.?), weakened fine motor skills (Is his handwriting worse? Is assistive technology needed, or can the student orally provide test responses?), or weakened gross motor skills, and where listening and following directions in a group activity is difficult- (Would it help if an Adapted PE specialist came in and advised staff on supportive activities to allow the student to move about during the day?) - Also if riding in cars produces sensory overload, vestibular/ propiocentric symptoms, or intense debilitating anxiety symptoms/OCD- this should be addressed too- (Could the child be helped with related therapies and/or by developing coping mechanisms? How can we help the family and the school reduce or modify similar triggers in the classroom, on the playground, or on the school bus, etc? Are modifications needed for attendance? Is the transportation problem severe enough to support the need for home/hospital instruction all or part of the day?)
- Consider Occupational Therapy, Physical therapy, 'Bridge programs' (for Social skills), Study hall, Speech and

Language, modified day, assistive technology, Behavioral Health, outside resources, home study, etc). Consider 504 and Special Education when called for. You may need to remind others that Special Education is not a place!

- Consider that, for many of these families and students, the concept of "Special Education" or "504" may be brand new, and fraught with misunderstandings, especially fears surrounding the student being ostracized and bullied. On this point, it's very important to consider what the school culture *really is* regarding Special Education and students with disabilities; and, of course, to clarify what the *student's* perception of Special Education is in that school. Are there any "cool" kids getting services in resource rooms or getting extra time on tests? Do kids with tics, or those who exit the "*short bus*," get laughed at or mocked? Is the administration at the school proactive when it comes to Special Education and 504 implementations, protections, and related staff? The best, most comprehensive (and costly) educational plan can quickly go down in flames if the student fears shame and condescension when receiving services. In this regard, the School Nurse is in an excellent position to serve as liaison between parents and staff on these sensitive but critical issues. Students too, must feel knowledgeable and confident regarding what safe avenues of support are available, should help be needed.
- Recognize the need for teacher, special educators, nursing, and administration collaboration, and periodic clarification of authorized accommodations and modifications. How and Who is implementing the changes to the school work? Also be cognizant of the ways in which services may be unwittingly exacerbating sensory overloads/ anxiety/OCD for the child; for example, assistants who may hover, touch, 'breathe on', constantly redirect, or in *any way* draw undue attention amongst the students peers.
- If the condition is significantly impeding attendance, consider a partial day at school with home/ hospital instruction before jumping into a full day. This would allow for continued participation in the school community for the student, while providing desperately needed respite for the parent, who must otherwise be at home while the instructor is teaching.
- Remember that outside advice is available. On the PANDAS network site, for example, there are sections under *Resources* that offer considerations to the school regarding appropriate and reasonable interventions. If this is a new condition for your district, it can be helpful to talk with public or nonprofit agencies to see what parameters of services are typically available for students with traumatic brain injury (TBI), Tourettes, or encephalitic conditions, etc. Remember that in reality, there is *broad* latitude for teams to allow for services, modifications, and accommodations. Disabilities Rights groups too can also add additional perspective, and for the initial consultation, they are often free.

In closing, if PANS stands alone in its unique, diagnostic hallmark of profound and deleterious effects on behavior and cognitive abilities, so it also stands alone- *mercifully*- in its equally stunning potential for healing and recovery. It is the fragile academic limbo that connects these two disparate states that we are charged to address. We are sought out for help by desperate loved ones surviving in a world of dysfunction and chaos; where the child, and perhaps even the parent, may have already lost sight of the calm, vibrant, and thriving landscape ahead. Those entrusted to ensure this student's safe academic passage as he transitions from illness to wellness will determine the nature and extent of its educational repercussions. With her expertise, vision, and the conviction of doing what is appropriate and right for her students, the School Nurse will have the steady hand necessary to help navigate secure passage to the other side, where the students will, once again, sustain themselves.