

Considerations for Health Care Professionals in the Education of PANS-Affected Students

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A brilliant scholar, poised to create a fantastical tool that will help save our waterways and oceans from collapse; a gifted newspaper reporter, bringing cherished dispatches to his community; an astute, prize-winning filmmaker, bringing attention to critical stories of the day; a medaled long distance runner and community volunteer, who shifts effortlessly between mathematical proofs and prose—These are just a few of the stellar *twenty-somethings* that bring humanity hope as we enter the era that will likely be referred to as ‘*the time of the pandemic.*’ They are also— just a few— of the heroic survivors of that chaotic netherworld known as PANS.

As a practitioner and historian of Special Education, I write this at a time when there are multiple, and significant, turning points in the care of young people with *Pediatric Acute-onset Neuropsychiatric Syndromes* (PANS). Of course, the most pressing issue in our midst surrounds the COVID-19 pandemic— touching every aspect of our lives, including the safety, timeliness, modes, and delivery of both health care and educational services. At the same time, this pandemic has arrived when we know far more about the mechanism and effective treatments of PANS than we did, even a few years ago.^{1 2 3} Research in parallel lines of inquiry has similarly bolstered the hope of reversing neural dysfunction and mental illnesses that were once thought of as irreversible.^{4 5} Moreover, in the field of Education, along with comprehensive guidebooks,⁶ there have been two recent works (*The PANS-Network Education Toolkit*, and the equally excellent 90 minute on-line tutorial from the University of Buffalo)⁷ that bring targeted guidance to providers, families, and schools on the educational care of PANS-affected students. Perhaps the most golden finding of all, however, is that we know far more about the course of PANS in young people who, once treated, have then grown up to be functioning, well-adjusted, and independent adults.⁸ As evidenced by the stalwart survivors above, we now have ample, living proof that with appropriate medical treatment, these young people can be placed ‘back in their lives’ again,⁹ and assume the authentic trajectories they were always meant to have.

In this overview, I will describe PANS’ effects on the student’s ability to participate in his academic world, both in ‘ordinary times,’ and in the age of the COVID-19. I will also highlight the critical role of health care professionals as they advocate for their patients in the schools. However, first, I will describe how the emergence of this one condition has ultimately served to shatter long held pedagogical assumptions regarding how we teach— and perceive— individuals with educational challenges.

I. The Unique Symptomatology and Presentation of PANS in Students

Historically, PANS’ symptomatology represents a phenomenon that few educators in Special Education, much less Education, have ever seen before. Specifically, since the advent of Special Education programs in the 1960’s in the U.S. and abroad, the debilitations, needs, and behaviors of PANS-affected students emerge as distinct in three ways:¹⁰

First, in the experience of most educators, the degree to which PANS-stricken students are affected by this disability is far *less stable over time* than what is usually seen with other students. For example, educators do not ordinarily expect a student’s printing ability to go from a third-grade level to a first-grade level in the span of a week, and then a month or two later, return back to a third-grade level.

Secondly, most students— even in Special Education— rarely suffer such significant *debilitation in so many functional domains*. Yet (and predictably), PANS-induced inflammation in the basal ganglia, along with cytokine-induced sickness behaviors,¹¹ will result in the very symptoms cited in the diagnostic model of PANS itself: “*anxiety, emotional lability and/or depression, irritability, aggression and/or severely oppositional behaviors, behavioral (developmental) regression, deterioration in school performance, sensory or motor abnormalities, and somatic signs and symptoms, including sleep disturbances, enuresis, or urinary frequency*”.¹² Alone and *in combination*, PANS thwarts the very elements needed to flourish in the learning environment: the ability to remember, sustain attention, organize, and plan; behave and communicate in age-appropriate ways, complete tasks that require expected fine and gross motor capabilities, etc.¹³

Thirdly, PANS, once and forever, banishes the common pedagogical assumption that every student will generally progress on an ‘onward and upward path’— developmentally, intellectually, motorically, and socially. The calling card of PANS, in contrast to this generally sustained, steady, academic trajectory, results instead in *jagged levels of dysfunction; but* equally as striking, *also improvement* (and for many, full recovery) *of functioning over time*, once given appropriate medical treatment.^{14 15}

In sum, in its stunning depth and breadth of characteristics; erratic waxing and waning nature; and jagged descent and potential for full recovery, the presence of PANS in the classroom has broadened pedagogical assumptions and practices in the following ways: Educators now more readily acknowledge the phenomena of jagged levels of dysfunction and improvement across the functional domains (for both known and unknown reasons). Next, there is greater awareness that for some students, their *actual knowledge* of subject matter will not be equivalent to what they *actually know*, but rather, what they are *able to*

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demonstrate, given, as in the case of PANS, the constraints imposed by brain inflammation and ‘sickness behaviors.’¹⁶ Moreover, there is greater acknowledgement that students’ medical illnesses are not just limited to *physical* symptoms only. Most significantly, the emergence of PANS in the schools has facilitated far greater awareness that behavioral/learning/emotional issues can have *medical causes* at their root. Accordingly, there is recognition that without the application of appropriate medical care, the efficacy of any other therapies (including educational services) may be limited, unlikely to help, and even be counterproductive.

II. Collaboration with the Schools

In ordinary times and in ideal academic settings, the collaboration between the health care provider and the school might look like this: First, the provider would speak candidly with the parent and the patient¹⁷ about issues that are seen to affect (or even might be affecting¹⁸) the patient’s education and wellbeing. The provider would then, with the agreement and collaboration of the parent and/or patient, communicate in writing to the patient’s school, college, or university.¹⁹ This document would usually include the diagnosis, and pertinent medical information surrounding the health of this patient (such as related diagnoses, status of treatment, medications, dietary restrictions, allergies, etc.). It would also include any symptomatology that is known or suspected to affect the student’s ability to obtain an appropriate education.²⁰

This discussion might include questions such as, “Currently, how does this young person...?”

- Demonstrate age appropriate self-care and daily living skills surrounding grooming, transportation, nighttime routines, 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 overwhelm while traveling, etc.?)
- Adapt to transitions and stresses common in the educational, home, and other environments, including, or involving, decision-making, attendance, scheduling, and interactions with others?²¹
- Follow, understand, and remember written, oral, and visual information (and combinations of the three)?
- Sleep and eat in ways that produce required levels of wakefulness and nutritional intake, respectively?
- Maintain prior levels of urinary frequency during the day and night? How do these levels compare with peers?
- Experience sensory overwhelm to light, sounds, textures, odors, etc.?
- Maintain social relationships. (In what ways has his or her social life changed or stayed the same?)
- Communicate effectively with others, and interact and behave in ways that are age-appropriate?
- Maintain prior levels of mental and physical stamina and coordination, (independently and in group activities)?
- Sustain focused attention (on non-stimulating, ‘non-fun’ tasks) for longer than 10 minutes?
- Complete chores and educational routines (i.e. homework) in a timely manner?
- 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? Is the parent concerned about how the patient’s behaviors are being interpreted at school?²²
- 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)?²³

The responses to the above questions will go far to document the types of limitations that will determine the scope of assessments, services, accommodations, adjustments, and modifications that the student may receive through educational institutions.²⁴ Just as importantly, it will bring critical attention to everyone involved, that in this case, it is a *medical condition*, (and not a specific learning disability, poor student attitude, weak parenting skills, etc.) that is primarily responsible for current levels of academic performance, behavior, and attention.²⁵ The provider may also specifically point out recommendations (based on symptomatology) that would be appropriate (or even *inappropriate*) for this student, such as a part time school day, home hospital instruction, in-class assistance from an aide, testing accommodations; and in college, separate living quarters, etc.

Based on communications brought forth by the medical provider, the school may then initiate **assessments** to further determine levels of needs and services. In some cases, a student’s testing abilities may be limited due to the constraints of the illness itself (such as thwarted energy levels, etc.). Moreover, many postsecondary settings are not required to offer testing, and, of course, during the current pandemic, assessments may not be feasible. In such circumstances, the provider’s letter may often suffice to make adjustments to the student’s educational plan, without additional evaluations. Otherwise, the following assessments may be initiated.²⁶

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1. A school nursing plan, so that the district nurse can evaluate and monitor aspects of nursing needs related to PANS and the student's education. The School Nurse would also collaborate with the family and other team members on assessments and services related to parameters of the student's physical health and mental health diagnoses, status of energy, stamina, affect, and mood, and unintended/non-purposeful physical movements and utterances, such as tics.
2. A psycho-educational evaluation, to determine present levels of processing strengths and weaknesses (such as in the areas of perceptual reasoning; processing speed; visual and auditory memory (separately, together, and sustained), etc.
3. Evaluations in specific areas of visual processing,²⁷ to include visual analysis, discrimination, analysis/synthesis, short term, long term, and working memory, visual-spatial orientation, and scanning.
4. Evaluations to determine levels of functional behavior, social/emotional development, and executive functioning.
5. Assessments to determine the need for psychiatric and counseling referrals (for both student *and parent*²⁸), and to address any reported symptoms of anxiety, Obsessive Compulsive Disorder, emotional lability and/or depression, irritability, aggression and/or severely oppositional behaviors, and behavioral and developmental regression.
6. Assessments to determine present levels of academic skills and achievement, such as in reading, math, and writing.
7. Evaluations to evaluate fine motor weaknesses, (including handwriting difficulties), appropriate *Assistive Technology* applications, levels of skills of daily living (including grooming, dressing, and eating), and current levels of sensory integration, dysfunction, or overwhelm, and proprioception and vestibular issues.
8. Evaluations to determine levels of gross motor ability, and the need for *Adapted Physical Education* to manage symptoms of poor coordination, hypoactivity, hyperactivity, and to facilitate the student's participation in recess, on field trips, and in group sports.
9. Evaluations by a *Speech and Language Pathologist* to determine (verbal and non-verbal) receptive and expressive language abilities, oral motor abilities, articulation, social pragmatics, non-purposeful vocalizations or tics, etc.

The results of these evaluations will signal appropriate **services** related to this student's areas of need. These can include, but are not limited to, supports, assistance, and therapies in the areas of organization, attention, memory, fine motor and gross motor skills, visual processing, and result in services for speech and language, school nursing, counseling, and math, reading, and literacy supports. Moreover, 'Home Hospital' instruction may also be warranted, where an instructor comes to the home.

Accommodations/Adjustments/and Modifications are specific to the student's needs, and can include a broad array of measures. A very few include: *Testing accommodations* (such as extended time on tests and testing in a distractive free environment), prioritization of assigned work to show competence, especially during PANS flares, *Assistive Technology* to accommodate for fine motor and processing speed weaknesses, *a scribe*, *attendance modifications*, *a modified school day*, the accompaniment of *a service animal*, and *devices to assist with sensory overwhelm*, etc. At the post-secondary level, accommodations might also include accommodations for *Priority Registration* for upcoming classes, *extra time on 'short turn around' assignments*, *single dorm rooms*, etc.).

It is also important that medical providers are aware of local, state or provincial, and national governmental policies that determine access to health services for their patients. In the U.S., for example, a 'Free and Appropriate Public Education' (FAPE) is mandated for every child; however, 'free and appropriate public health care' is not. This carries special significance for PANS-affected students, regarding not only the delivery of educational services, but also of '*designated instructional services*' (such as speech therapy, counseling, etc.). By law, U.S. schools *must* provide an 'appropriate' education to every student, regardless of the severity or breadth of his needs.²⁹ This holds true, whether the student *is* being appropriately medically treated for PANS, or whether the student *is not* (but still having associated symptoms being played out in the classroom). Schools must also provide supportive services and therapies, whether or not the family has the resources to provide them on their own. *In their communications with the schools then, U.S. providers should be mindful of the weight that their communications hold in validating the need for these assessments and services, as they may be otherwise unobtainable elsewhere.*

III. PANS, Education, and COVID-19

...However, these are not ordinary times. As we face special challenges surrounding the COVID-19 pandemic, here are a few highlights to consider:

Families and providers who have long dealt with the phenomena of PANS will recognize the devastating neuropsychiatric outcomes that can result from pathogens. Emerging information on the COVID-19 also suggests that like PANS, a delayed and powerful immune response can be involved³⁰ and that like PANS, the individual, along with his 'vector,' may be totally

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asymptomatic of the pathogen that precipitates this onslaught. As a result, the school environment must be mindful of safety surrounding both PANS and COVID-19.

In collaboration with the parent, and the patient as appropriate, the provider may consider the following:³¹

1. Many of our students will continue to receive what is called *Distance Learning* (involving virtual teaching platforms, workbooks, phone calls, and other non in-person communications, to continue education during school closures. In the US, IDEA provides that Distance Learning may be an option for a student with a disabling condition or illness that warrants a physical absence from school.
2. As certain types of assessments will be limited due to distancing precautions, the health provider's role in identifying limitations associated with this student's illness will be paramount. Such information will help facilitate or confirm the need and modes for educational services. He or she will also be an important point of contact regarding the documentation of worsening symptoms (that can warrant additional needs or services from the school, such as counseling, etc.). Moreover, the provider may cite the need for extended periods of Distance Learning for the student after the current COVID-19 crisis lightens up- even for siblings who may bring the illness home to the vulnerable student.
3. The wearing of a face mask may be exempted for students who, because of their disability's limitations (directly related to symptoms, age, or hearing/communication impairment, etc.) may make them otherwise unable to wear a mask.
4. 'Compensatory education' may be appropriate for students once they resume their education, to help them 'catch-up'.
5. Educational meetings in the US (such as IEP's, Individualized Family Service Plans (IFSPs) Addendum meetings, Transition Plans, etc.) should continue according to stated timelines. However, they may be held virtually or by telephone, for example, when needed.
6. With the parent, establish a main point of school contact during Distance-Learning and Shelter in Place periods.
7. Identify public health guidelines that will directly affect services and modes of education, transportation, etc.
8. In collaboration with the parent, your feedback on the efficacy of in-class learning, Hybrid Learning, and Distance Learning for your patient will be important. Safety, of course, is the number one priority. Even after the current pandemic crisis subsides, issues surrounding the needs of anyone vulnerable to infection may continue to warrant some levels of Distance Learning. *At the same time, programs used in Distance Learning require adequate levels of executive functioning and sustained attention to be effective.* As these are abilities our students often struggle with, there may need to be someone from the school to help facilitate this student's progress in certain online programs (such as in math, etc.).³²

IV. In Closing

In closing, I would leave health care providers with this final sentiment: There is a scene at the end of the classic film, *Apocalypse Now*, where the one remaining soldier stands apart; disconnected from reality and oblivious to the deadly peril that surrounds him. The Martin Sheen character finds this young man, and recognizing his altered state, gently, and without judgment, leads him calmly out of the chaos into safety. Similarly, while suffering through its worst manifestations, many PANS-stricken young people have little awareness of how dangerously close to peril they can become, especially during times of acute anxiety and debilitation. It will be those unsung health care providers who take these young sufferers' hands, and lead them out of the chaos into refuges of safety. It is their letters, communications, and collaboration with families and schools, that will elucidate, and *validate*, that it is ultimately a *medical condition* that is responsible for this student's altered learning ability and behavior. Their life-changing words and actions will forever alter the trajectories of these irreplaceable young people- no less than those healers who profoundly changed the lives of the writer, the film maker, the inventor, and the mathematician at the beginning of our story. For these fragile young people, it will be the health care providers' compassionate care and expertise that will secure a safe passage from illness to wellness. Once there- and back to their *authentic* selves- they will progress onward and upward, on their own.

Dr. Candelaria-Greene is a researcher, educator, and clinician in Special Education in the San Francisco Bay Area. She has been a major collaborator with the 'PANDAS Network Working Group on Educational Access' since its inception. As a Visiting Researcher Scholar at UC Berkeley (2013-2015), she investigated the effects of PANS on learning and behavior. Her findings led to the book, "PANS, CANS, and Automobiles: A Comprehensive Reference Guide for Helping Students with PANDAS and PANS." A second edition is forthcoming. Her website can be reached at: drcandelariagreene.com.

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On-Line Resources:

- *The PANS-Network Education Toolkit (This targeted guide for educators, school nurses, related service providers, and counseling professionals, is the result of a three year effort by subject matter specialists (many of whom also parents of PANS-affected children). <https://bit.ly/39KVEqb>
- *An excellent 90 minute tutorial of PANS and Education produced by Dr. Jan Tona and her team at the University of Buffalo in the Division of Occupational Therapy. <https://bit.ly/3fijnPI>
- *Questions and Answers on Providing Services to Children with Disabilities during the Coronavirus Disease 2019 Outbreak March 2020 <https://bit.ly/3hVZU8Z>
- The April DREDF Newsletter, with many helpful tips: <https://bit.ly/2Dpo9NI>

Books:

- *Candelaria-Greene, J.F. (2016). *PANS, CANs, & Automobiles: A comprehensive reference guide for helping students with PANDAS and PANS*. Sarasota, FL: First Edition Design Publishing.
- *Doran, P.R. (Ed). (2016). *PANDAS and PANS in the school setting: A handbook for educators*. London: Jessica Kingsley Publishers.
- Weiss, M.S. (2015). *In a pickle over PANDAS*. Sarasota, FL: First Edition Design Publishing.

Notes

- ¹Regarding further identifying the disease model of PANS, see for example, Chain, Jennifer L et al. "Autoantibody biomarkers for basal ganglia encephalitis in Sydenham chorea and pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections." *Front. Psychiatry*. (24 June 2020)
- ²Platt, Maryann P et al. "Th17 lymphocytes drive vascular and neuronal deficits in a mouse model of postinfectious autoimmune encephalitis." *Proceedings of the National Academy of Sciences* Mar 2020, 117 (12) 6708-6716; DOI: 10.1073/pnas.1911097117
- ³Murphy, Tanya K et al. "Characterization of the pediatric acute-onset neuropsychiatric syndrome phenotype." *Journal of child and adolescent psychopharmacology* vol. 25,1 (2015): 14-25. doi:10.1089/cap.2014.0062
- ⁴See, for example, recent findings regarding neural plasticity in chronic yet reversible neural dysfunction associated with a leaky blood brain barrier and post-concussive injuries. (Senatorov, Vladimir et al. "Blood-brain barrier dysfunction in aging induces hyper-activation of TGF-beta signaling and chronic yet reversible neural dysfunction." Supplemental Information. 10.1101/537431.)
- ⁵See also findings regarding psychophysiological disorders (PPD) such as Lumley, Mark A, & Schubiner, Howard, "Psychological therapy for centralized pain: an integrative assessment and treatment model." *Psychosom Med*. 2019;81(2):114-124. doi:10.1097/PSY.0000000000000654
- ⁶Kindly see resources above.
- ⁷Kindly see resources above.
- ⁸These would include the 'wave' of PANDAS/PANS young people affected between 2005 and 2010. See Candelaria-Greene, Jamie (2015). Unpublished survey of family members, providers, and survivors of PANS regarding PANS and Education (2013-2015), collected as UC Berkeley Visiting Researcher Scholar, Berkeley, CA.
- ⁹As Dr. Ann Honigman, D.C. insightfully observes.
- ¹⁰Candelaria-Greene, Jamie (2015).
- ¹¹Murphy, Tanya K. et al. (2015).
- ¹²Swedo, Susan E. et al. "From research subgroup to clinical syndrome: Modifying the PANDAS criteria to describe PANS (pediatric acute-onset neuropsychiatric syndrome)." *Pediatr Therapeut* 2:1-8, 2012.
- ¹³Regarding numbers of students who are affected this broadly and profoundly, the (U.S.) federally mandated Individuals with Disabilities Education Act's (IDEA) designated disability of "Multiple Disabilities," comprises only 2% of those served for any disabling condition, and usually they do not have a concomitant "Emotional Disturbance" component. See *U.S. Department of Education, OSEP, (IDEA) database*, ret: 2/20/20, from <https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html#bcc>.
- ¹⁴Candelaria-Greene, Jamie (2015).
- ¹⁵Ibid. This pattern is demonstrated by standardized measures that indicate regression and improvement compared with peers, but also with their own past and future work samples. It is also demonstrated by others' observations of changes in attention, energy levels, and coordination at home and in extracurricular activities.
- ¹⁶Murphy, Tanya K. et al. (2015).
- ¹⁷Because of limitations from age, language (including cultural or gender-based protocols/strictures), and the illness itself, patients may not be the best witnesses to their regression/recovery, nor to how others are perceiving them (Candelaria-Greene, Jamie, 2015).
- ¹⁸In the US, testing of suspected areas of debilitation are also warranted under IDEA (See endnotes 21 and 26.)
- ¹⁹As PANS, of course, does not stop neatly at the Pediatrician's door. Candelaria-Greene, Jamie (2015).
- ²⁰In the US, The Individuals with Disabilities Education Act (IDEA) is a federal Special Education law for children with disabilities. It offers an Individualized Educational Program (IEP) including Special Education and related services (speech therapy, OT, etc.) to meet a child's unique needs. A child with PANS may meet this criteria under the disabling condition "Other Health Impairment." Usually, IDEA stops at the postsecondary level of instruction. Section 504 is a federal civil rights law providing services and changes to the learning environment to enable students to learn alongside their peers. It has a broader definition of a disability than IDEA, which is why a student who does not qualify for an IEP might still be able to get a 504 plan. (Most college students with a disabling condition are covered by Section 504 protections).
- ²¹The loss of executive functioning places huge demands on others to help these students compensate. (Candelaria-Greene, Jamie (2015).
- ²²How 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?
- ²³Some of the above taken from Candelaria Greene, Jamie. "The critical importance of school nurses in the support of students with PANS." (2016) Retrieval on the website: drcandelariagreene.com.
- ²⁴This includes any educational institution (U.S.) that receives federal funding, including Charter Schools. However, students who attend private schools can also receive services through their local school district.
- ²⁵The (U.S.) primary disabling condition of OHI (Other Health Impairment) may even supersede the disabling condition of Autism in having the most effect on the student's ability to participate in the learning environment.
- ²⁶All parties, including the student, must be mindful that testing results reflect ability at that point in time only, and will change.
- ²⁷Visual processing is often affected. See Murphy, Tanya K. et al. (2015). A referral for a Binocular Vision exam may be warranted.
- ²⁸As also covered under IDEA/U.S.
- ²⁹Even students in comas have a right to Special Education in the U.S.
- ³⁰Troyer, Emily A. et al. "Are We Facing a Crashing Wave of Neuropsychiatric Sequelae of COVID-19? Neuropsychiatric Symptoms and Potential Immunologic Mechanisms" *Brain, Behavior, and Immunity*. April 2020)
- ³¹U.S. federal law states that Special Education services should be provided (at least) to the same extent that regular education services are provided. Also, kindly see resources on COVID-19 and the schools above.
- ³²Candelaria-Greene, Jamie (2015).