

Considerations Regarding Academic Accommodations/Compensatory Strategies, and Services for Students with PANDAS/PANS

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Getting Started : What is the General Process of Obtaining Special Education Services in the US?

In the US, under **Section 504**, most students with a medical condition (such as PANS) will be eligible to obtain accommodations (such as extended time on tests etc.) without an Individualized Educational Plan (IEP). It needs to be recognized only that the medical condition (PANS) substantially hinders the student's ability to participate in, and/or keep up with the regular education curriculum.

However, if special services or special education is warranted (even for a short period of time per week), one goes through the following steps under what is called the **Individuals with Disabilities Act (IDEA)**:

- Referral/Notification *(Even if parents speak to school staff personally or by telephone, notification by letter will be helpful in establishing time lines for follow-up meetings and services. These time lines are defined under the procedural safeguards related to IDEA. The letter should include information regarding parental concerns re: PANS, and the effect it may have on their child's school performance.)*
- Planning and Placement Team Process *(determines the need for- and type- of evaluations- see next page.)*
- Evaluations *(If the team decides on the need for more evaluations, these take place in efforts to guide decisions on obtaining special education and related services. Even without additional testing, however, the primary disabling condition of **Other Health Impairment (OHI)** should provide for accommodations to take place under Section 504.)*
- Eligibility *(The team uses the results of testing, which of course include outside testing, as well as input from treating physicians, behavioral health professionals, and others, to determine types of special education services needed/allowed under law.)*
- Individualized Educational Plan *(If the child is found eligible for services special education and/ or related services must be implemented within a given time from the initial date of Referral (above).)*

Student Study Team Planning and Testing Considerations

- Collaboration with Treating Physician/Medical Provider to determine the nature of the illness, and to learn how this condition would affect the child's work/ stamina at school.
- Close Collaboration with the School Nurse (to collect and interpret health information to the team, and to serve as an appropriate liaison between the medical provider, the parent, and the school).
- Academic Portfolio of work, and assessments that the student has completed (in the past, and under the constraints of the illness).
- Age of the Child (Generally the younger the child, the more useful and critical testing will be in terms of guiding treatment and providing educational services from the school district, which may include Speech Therapy and Occupational Therapy etc... Very generally speaking, older children (in college, for example) will primarily need a doctors diagnosis of PANS to allow for accommodations, modifications, or reduced course load to take place.)
- Stamina Levels for School and for Testing Sessions (The child may have limited cognitive and/or physical stamina to complete long batteries of testing, which may also affect the validity of testing results).
- Financial Resources.
- Outside Testing (Binocular vision clinics, Neuropsychological testing, ImPACT testing, etc. - The results and recommendations from outside testing would at least "get the ball rolling," in terms of providing 504 accommodations, at the very least.
- How is testing going to guide or provide services? (The question must be **"How would these testing results inform a discussion of how may child can better keep up with the regular education curriculum- to the best of his/her ability?"**.)
- Testing as a Transitional Glimpse. (It must be acknowledged by all parties that dips in performance are associated with the illness, but that the long term trajectory is good. Also, what provisions will there be for follow up testing as symptoms improve?)
- Little Likelihood of 'Specific Learning Disability' (Most children with PANS - at this point in time anyway- will **not** qualify for special education services under "Specific learning disability" because their achievement scores in reading, writing, and arithmetic, etc., will be "too high.")
- Emphasis on OHI as the Primary Disabling Condition. (In most cases, the "learning disability" is symptomatic (and secondary) to PANS. Our children do need services, and they qualify under OHI.)
- Close Collaboration with Medical/Mental Health to identify concerns, and support and work with staff and student.

Considerations Regarding the Selection of a Possible Educational Advocate

- Experience, Experience, Experience (special ed., administrative, neuropsych, and/or legal background helpful. A good advocate will know current changes in special education law and implementation, and will often be aware of potential hurdles surrounding particular local school district policies and personnel.)
- Referrals from other parents or parent advisory boards dealing with Procedural Safeguards in special education can be very helpful.
- The inclusion of psychologists and other providers, religious leaders, and family members may serve in both positions of advocacy and more importantly, parental and student moral support.

Areas of Testing Most Relevant to PANDAS/PANS (In other words- What areas are getting in the way of our children keeping up with their regular education school curriculum?)

- Fine Motor/Visual Motor/ (usually conducted by an occupational therapist)
- Visual Processing (*acuity, convergence, tracking, closure, speed, etc.*)
- Auditory Processing/ Language Processing (involving receptive language (What are they understanding?) and expressive language (What and How are they effectively communicating with others?))
- Memory Skills (*Visual and Auditory- separately, together, and sustained.*)
- Executive Functioning Skills (*attention, planning, self-monitoring*).
- Sensory Integration/Sensory Defensiveness (*tactile, visual, auditory and olfactory: The team has to know how to recognize certain triggers that will result in sensory overwhelm for the child; the team then has to put a plan in place to mitigate triggers or help the child accordingly.*)
- Adapted PE/Gross Motor/Recreational (*Don't forget what is happening on the playground.*)
- Functional Behavior Assessment Social/Emotional Development
- Psychiatric referrals (AB 3632? *Some legislation provides opportunities to receive these off campus*)
- Assistive Technology (*How could computer software etc. aid them academically?*)
- Comparison of present academic achievement levels in reading, writing, mathematics, and other academic portfolio work with past achievement.

Organizational Support

- Preferential/assigned seating (*up front on the side/opposite dominant ear*).
- Use of assignment notebook planner/ Daily Assignment Sheets, Lists/use of school websites.
- Projects Broken down, use of mnemonics (i.e. HOW).
- Leaving classes/last class of the day early.
- **Discreet** use of Cues/prompts of what's needed next
- Home/school communication system.
- Extra set of School books at home; Color coding books materials; Extra supplies available.
- Structured classroom: organize distraction-free study areas at home/school work carrels.

Attentional Supports

- Organizational Supports
- Directions, short, concise, written if possible.
- Ear phones blocking out distracting stimuli and use of study carrels.
- Positive feedback for what they are doing right.
- Too *much* attentional support/praise is **TMS** (*Too Much Sensory Input*), and may be overwhelming for our children.
- Check in with teacher/ student/parent by SPED to determine waxing/ waning levels of attention and adjust/accommodate accordingly; Opportunities for breaks and movement when needed.
- May be secondary to poor stamina, listening skills.

Behavioral Supports

- Consider /Acknowledge/document waxing/waning nature of behaviors during the day, and over weeks and months as illness regresses and heals.
- For Tic Symptoms- Testing modifications, providing refuges, breaks, and when necessary, brainstorming the management of socially inappropriate behaviors, educating others regarding tics/PANDAS/Tourettes Syndrome (SEE SITES RE: Tourette Syndrome Association).
- For Obsessive Compulsive Symptoms- Assess the nature of behavior (what, when, where) and brainstorm possible solutions; allow transition time between activities; consider modifications re: attendance.
- For Sensory Overwhelm, Storms/Tsunamis, Meltdowns Avoiding information overload (TMS) (visual, auditory, movement, etc.); Structure in Learning Environment; Extra Time to Transition; Organizational Help/Emergency plan; Removing Layers of Sensory Input (light, sound, movement); **Diffuse...Diffuse...Diffuse**; Liaison at School (Counselor, Behavioral Health Provider, Nurse, or Guidance Services); Collaboration with Community Mental Health Provider .

Considerations for Behavioral Health Providers

- Identifying Triggers (Determining what precipitates/exacerbates sensory overwhelm, OCD, tic, or other unexpected behaviors, as a step towards treatment or behavioral management.)
- Cognitive Behavioral Therapy, Dialectical Behavior Therapy, Exposure-Response Prevention, etc. Take into account limitations from regressed levels of executive function (planning, self-monitoring, etc.) Also encourage/facilitate self-calming strategies to better allow for treatment to take place.)
- OCD Behaviors as Moving Targets (Behaviors may remit or change as illness wanes and waxes).
- R/O Post Traumatic Stress Syndrome for all family members over time.
- Recognition of Different Perspectives as valid (influenced by cultural, developmental, gender, health issues, etc.)
- HIPPA Considerations (Facilitate or guide family/care giver in having/getting access to child's records, even if the child is an adult.)

(Thanks to Dr. Mary Candelaria, Psy.D., Clinical Psychologist, Bellevue, WA, for her collaboration on the section above.)

Sensory Supports

- Auditory overload or distraction: including the use of carpeting, tennis balls on chair legs, P.A. systems muted or turned off, headphones, etc.
- Visual overload or distraction: including the use of muted colors in working areas, the use of blinds, and the reduction of visual clutter.
- Awareness of olfactory and tactile stressors.
- OT/PT and Adapted PE recommendations for helping proprioceptive, tactile, and vestibular challenges (hypo/hyper). For example, Weighted Belts help children and adults to feel more focused and grounded, in that they provide proprioceptive feedback, allowing the user to be more aware of their body position and balance.

Memory Supports

- Reduce stress/anxiety/distractions as much as possible.
- Direct instruction to student in memory aids such as mnemonics i.e..PAR (Picture it, Associate it, Review it).
- Repetition/ review.
- Teach only as much as they can handle at one time *adding only one more bit of information*.
- Present new information in a meaningful context.
- Help them identify personal strengths and weaknesses in memorizing as illness waxes and wanes.
- Use calculator, math facts sheets, digital tape recorder, smart pens, lists, etc.

Gross Motor Supports and Considerations

- Emphasis on as much movement as stamina will allow. Emphasis on crossing midline.
- Adapted PE/physical therapy to promote and facilitate as much movement and ease of gross motor skills/games as possible through waxing/waning.
- Opportunities to exercise during the day to mitigate hyperactivity/agitation.
- Assistance/monitoring on field trips, negotiating new terrain, monitoring student's stamina/hydration.
- Sufficient and proactive playground supervision to promote fairness and access to physical activity, and recreational sports.

Fine Motor Supports

- Extended time for all projects involving writing.
- Use of word processor, note taker, recording equipment, use of graph paper.
- Shorten long assignments; every other item, etc.
- Use of oral responses, scribe, or recorder for tests.
- Raised lined paper, *Handwriting without Tears*.
- Use of voice recognition Software.
- The importance of an Assistive Technology workup.
- Occupational therapy (inc. sensory integration, *Brain Gym*, etc.)
- Musical Instruments when stamina allows.

Speech and Language

- Speech Therapy w/articulation.
- R/o auditory sensitivities/sensory overloads.
- Listening activities (ear to voice/Sensory Integration).
- Social Language Groups.
- OT /or Speech therapy to improve (or manage) hypersalivation, dysfluency, and tic related utterances/movements.
- Teach the child appropriate phrases; role play.
- Music Therapy.

Math Supports

- Sharing Data validating *extra time* for tests (requiring memory, fluency, fine motor, attention)
- Training in the use of graph paper, weighted pencils, computer programs, assistive technology (in the use of *Book Share, Livescribe Echo Smart Pen, etc.*)
- Shortened assignments, where problems are prioritized, reduce the demands for writing whenever possible. Allow for dictated responses, mnemonics (such as GEMDAS- Order of Operations (grouping, ex^2 , \times , \div , add, sub).
- Use of Math Facts, Formula Sheets, and Calculators when this knowledge is not the primary purpose of test.
- One to one tutoring as needed. Review steps. Manipulatives use may be difficult because of poor visual motor skills.
- Self questioning and self monitoring strategies with each step prompted and checked by student (use of summary charts and checklists, that student checks off as they do their work)
- **Track** Math scores as much as possible. **NEVER** decide on advancement/retainment of math level based on one or two data points.
- Particularly related to math, consider the use of computer online programs that generally allow for individually paced work. Such programs can also reduce workloads that pose heavy demands on fine motor skills (such as writing out math problems and formulas by hand) and weakened memory skills (that will also slow progress). At the same time, this student is at high risk of having weakened attentional and organizational skills, and so either a *home/hospital teacher or other type of tutor will still be needed to help facilitate and clarify instruction.*

Reading and Literacy Supports

- Assistive Technology (in the use of *Book Share /Dragon Dictate etc.*).
- Extra time to process texts, tests, homework projects, etc.
- The accommodation to write directly on **test protocols** (as opposed to a transfer sheet)
- Shortened assignments, allow dictated responses.
- **Eliminate crosswords, Hangman or other “fun” puzzle type assignments that require sustained amounts of fine motor, memory, and visual processing .**
- Mnemonics (e.g. SQ3R (Survey, Question, Read, Recite, Review) HOW (Heading, Organization, Writing).

Health Supports

- Involve school nurse, parents, teachers, and staff.
- Re-evaluate/update/periodically. Develop health care and emergency plan.
- Identify and share information regarding allergies and food sensitivities (i.e. gluten, peanuts) with all providers so that "treats" or edible rewards will be appropriate for that child.
- If necessary, modify attendance policy.
- Establish health alert - every staff member involved with this student is aware of the health problem and of proper procedures.
- Make available homebound services/instruction. Consider half day if possible to continue school interactions.
- Begin a disability awareness program as per parent and student request.
- Provide school counseling.

- Arrange for trained personnel on school field trips. Provide assignments to hospital/ school. Schedule periodic home-school meetings.
- Arrange for student to leave class early to get to next class. Excuse from or adapt physical education program.
- Provide an interactive system - computer, e-mail, T.V.
- Provide peer assistance for social involvement (keep child informed of social activities).
- Furnish life-skill assistance (*Some of the above taken from Davis Unified Farmington Utah from 504/IDEA comparisons*).

About the Author:

Dr. Candelaria-Greene has served students with special needs from all ages and developmental levels. Her work as a teacher and professor of Special Education has spanned thirty years and three continents. Her research and writing has focused attention on effective educational practices, literacy, language acquisition, and the effects of health conditions and the environment on learning ability. In her private practice, she provides educational assessments, academic support for adults re-entering education, and multi-sensory readiness skills for children at risk. In addition to her clinical practice, Dr. Candelaria-Greene is a Visiting Scholar Researcher at UC Berkeley, where she continues to investigate the effects of PANS on learning; an evolving and passionate inquiry ignited by her own child's difficult journey with the illness.