Pediatric Autoimmune Neuropsychiatric Disorders

A New Frontier for Occupational Therapy Intervention

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Sensory defensiveness, handwriting deterioration, separation anxiety, and other symptoms may stem from Pediatric Autoimmune Neuropsychiatric Disorder Associated with Strep and Pediatric Infection-Triggered Autoimmune Neuropsychiatric Disorder.

Luis is a 4 year old with attention and behavior difficulties. Initial testing in June revealed mild visual perceptual and fine motor issues, but no sensory processing problems. He began occupational therapy in September. In October, the teacher identified behavior problems as Luis tried to run out of the room twice, hid under the desk during finger painting, and hit a classmate during free play. That same week, Luis' mother reported that he refused to don his socks and complained that the waistband of his pants hurt. In occupational therapy, Luis demonstrated regression in drawing and was no longer able to write the letters of his name legibly.

Ariella, a 6 year old, is diagnosed with autism and is being seen by a new occupational therapist. Ariella is nonverbal and her parents report that her behavior "fluctuates," with weeks to months in which Ariella is easygoing, makes eye contact, and cooperates with routines. They also report weeks to months when Ariella's behavior is very difficult; she appears overly sensitive and refuses to cooperate during daily activities such as bathing and brushing her teeth. During these periods, she often covers her ears and has self-injurious behaviors that are not seen during "good" periods. Her mother notes that Ariella has been sick just prior to difficult periods.

John, an easygoing 15-year-old 10th grader, has always been a good student who has many friends and takes mostly honors classes. Following the flu last November, John suddenly developed eye blinking tics and erratic behavior; he became anxious, argumentative with his teachers and parents, and suicidal, resulting in hospitalization. Although John has always been excellent in math, he suddenly missed relatively easy questions on math tests. He developed obsessions, such as pacing, setting the volume button on electronics to multiples of 5, and having everything "just so." He was put on selective serotonin reuptake inhibitor medication at the hospital, but his parents reported it did not help.

What do these seemingly different children all have in common? They all represent a new frontier in mental health: pediatric autoimmune neuropsychiatric disorder associated with strep (PANDAS) and pediatric infection-triggered autoimmune neuropsychiatric disorder (PITAND).[1]

Occupational therapy is grounded in the belief that the mind and the body are inextricably connected. Nowhere is this more evident than in PANDAS and PITAND, in which children have sudden onset obsessions, compulsions, and tics following an infection, with symptoms gradually subsiding post infection or following immune system interventions. Exacerbation also includes sensory defensiveness, handwriting deterioration (see Figures 1 and 2 on p. 15), separation anxiety, math skills regression, and emotional lability, making awareness of these conditions imperative for occupational therapy practitioners.[2–4] Recognition of PANDAS and PITAND is rising. Since 1998, more than 200 scientific papers have been written about PANDAS and PITAND, and the National Institute of Mental Health (NIMH) recently announced support of research for these conditions, calling PANDAS and PITAND a frontier in understanding mental illness.[1]

WHAT CAUSES PANDAS AND PITAND?

PANDAS and PITAND are thought to be similar to Sydenham's Chorea, an autoimmune disorder in which antibodies meant to fight strep infections attack the basal ganglia of the brain, resulting in an uncontrolled flailing of the extremities, trunk, and facial muscles, for a

period of weeks or months. The cause of PANDAS and PITAND is thought to be the following sequence of events: a genetic pre-disposition to an abnormal immune response, followed by the creation of an antibody that interferes with neuronal activity, and finally a breach in the blood brain barrier, thought to be due to inflammation, that allows the antibody to reach neuronal tissue and interfere with functioning.[2,5–6]

Typically developing children experiencing strep infections produce antibodies that assist the body in deactivating and removing the strep antigen. The immune system then "remembers" the surface of the strep antigen and antibodies are quickly produced in subsequent infections.[2]

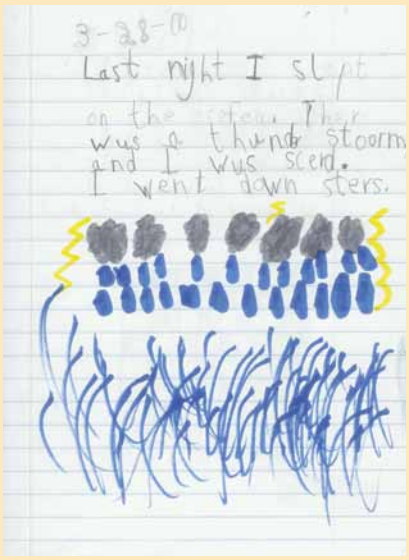
This process becomes problematic in children with PANDAS or PITAND. Basal ganglia cells have a surface that is similar to the surface of the strep antigen. When antibodies from the blood of children with PANDAS or PITAND cross over the blood–brain barrier, they mistakenly "recognize" the basal ganglia cells as strep antigen, sending antibodies to deactivate the antigen. Rather than deactivating and destroying the basal ganglia cells, the antibodies appear to attach to neurons and interfere with neuronal signaling by increasing calcium–calmodulin dependent protein kinase II (CaM Kinase II) production in the basal ganglia, eventually affecting production of neurotransmitters, such as dopamine (see Figure 3 on p. 16).[7–8] In fact, when comparing antibodies in the blood serum of children who had strep infections and met the criteria for PANDAS to typically functioning children and children with obsessive-compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD), and tics, researchers have found significantly higher levels of the antibodies that trigger basal ganglia neuronal cell CaM kinase II production in children with PANDAS,[8–9] indicating that PANDAS is different from traditional OCD, tics, or ADHD. This finding may one day lead to a blood test for diagnosing PANDAS. Currently, the clinical diagnosis of PANDAS is based on all of the following criteria[3]:

- Obsessive-compulsive behaviors, tic behaviors, or both
- Pediatric onset
- Episodic course with abrupt onset or dramatic symptom exacerbations
- Temporal association with group A beta-hemolytic streptococcal (GABHS) infection
- Association with neurological abnormalities during symptom exacerbations

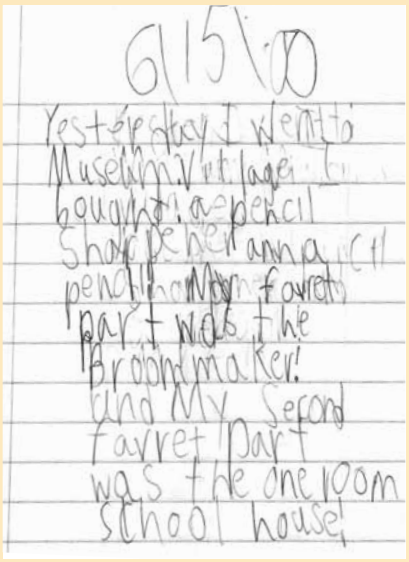
The diagnosis of PITAND has the same criteria, with the exception that the temporal association can be with any infection, not just strep, as many children who have met the criteria for PANDAS have been found to have an exacerbation of symptoms with other infections and inflammation, including bacterial infections and viral infections such as sinusitis or influenza.[2–3,5]

Exacerbation of PANDAS and PITAND tends to be sudden and severe, with a gradual return to baseline, followed by another spike in symptoms with the next infection, representing a "saw-toothed" pattern when plotted on a graph.[10] This is different from the wave-like waxing and waning of OCD and Tourette syndrome. Children with PANDAS or PITAND may initially be diagnosed with OCD, Tourette's, ADHD, or autism based on presenting symptoms,[11] but are later identified as having PANDAS

Figure 1. Handwriting of 7-Year-Old Boy Before and During Exacerbation

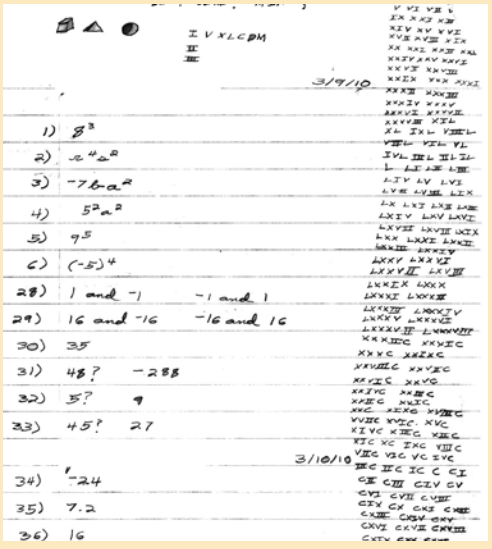


March 2000—Spacing is even; left margin is vertical; few erasures



June 2000—Spacing is inconsistent; left margin drift is present; many erasures and writing over

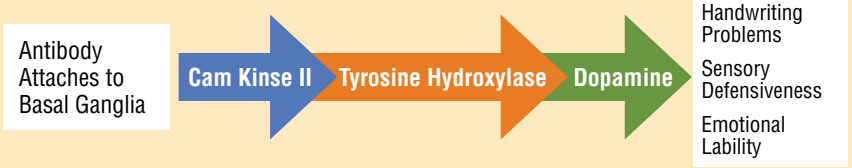
Figure 2. Teenage Male With Compulsive Writing of Roman Numerals During Exacerbation



This young man experienced a compulsion to sequentially write out Roman numerals, which interfered with his ability to complete math homework. In his case, the Roman numerals are written with great precision.

Figure 3. Effects of Increased Cam Kinase II Activation[17]

Proposed Pathology in Pediatric Autoimmune Neuropsychiatric Disorders



or PITAND based on all symptoms, and taking into consideration the temporal association with infection, response to treatment, and the pattern of abrupt onset followed by slow recovery.

WHAT ARE THE SYMPTOMS OF CHILDREN WITH PANDAS OR PITAND?

Although there is no typical clinical course for children with PANDAS or PITAND, families have identified the following behaviors:[5,12]

- Tics
- Obsessions (e.g., preoccupation with a fixed idea or an unwanted feeling, often accompanied by anxiety)
- Compulsions (e.g., an irresistible impulse to act, regardless of the rationality of the motivation)
- Choreiform movements (e.g., milkmaid grip, fine finger playing movements in stressed stance)
- Emotional lability (e.g., irritability, sudden unexplained rages, fight/flight)
- Personality changes
- Age-inappropriate behaviors, particularly regressive bedtime fears/rituals
- Separation anxiety
- Oppositional behaviors
- Tactile/sensory defensiveness
- Hyperactivity, impulsivity, fidgetiness, or inability to focus
- Major depression
- Marked deterioration in handwriting or math skills
- Urinary frequency/enuresis
- Anorexia (particularly fear of choking, being poisoned, contamination fears, fear of throwing up)
- Joint pain, stiffness, and fatigue similar to other autoimmune disorders

Some families report functioning that returns to baseline after infection, whereas others report continued problems, especially with repeat infections.[12]

MEDICAL TREATMENTS

Generally, GABHS infections are treated with antibiotics, and ibuprofen is often used to reduce inflammation. Some children with PANDAS or PITAND use prophylactic antibiotics to prevent infection, or short-term bursts of steroids to halt exacerbation. Plasmapheresis, plasma exchange, and/or intravenous immunoglobulin therapy (IVIG) are reported to be beneficial, but the risks include headache, nausea, and possible infection.[13] A current NIMH treatment study seeks to better understand the risks and benefits of IVIG.[1] Families should discuss treatment with a physician who is knowledgeable about PANDAS and PITAND.[5]

HOW CAN OCCUPATIONAL THERAPY HELP?

Exacerbation of PANDAS and PITAND impacts virtually every area of daily living, including self-care, school-related skills, physical function, and social–emotional well-being. Occupational therapy can be instrumental in negotiating exacerbation, but doing so requires a paradigm shift. Children often lose skills during exacerbation, and traditional remedial intervention may be ineffective.[14] Greater benefit may be found with adaptation and compensation for problems during exacerbation, followed by remediation of ongoing problems during remission. Table 1 on p. 17 depicts some interventions that have been anecdotally reported to help children with PANDAS or PITAND.

Therapeutic use of self is essential as occupational therapy practitioners interview and observe the child, family, caregivers, and teachers to ascertain the underlying difficulties, such as obsessions, compulsions, or sensory needs. When needed, occupational therapy intervention should address the following areas.

Adaptive routines. Proactive, healthy routines can help families recognize and manage exacerbation periods. Regular homework schedules help families recognize when children are having difficulty with homework, as the completion time or degree of assistance required may increase when a child is entering exacerbation. Regular bedtime routines increase the likelihood of restful sleep and alert the family to a sudden change in routine, such as needing the light on longer or requiring the parent to be present at bedtime for longer periods of time. These changes often signal the separation anxiety seen in exacerbation. A structured routine can also help families by reducing chaos during the stressful periods of exacerbation.

Environmental modification. Environmental modification may include changing the location of activities while a child is in exacerbation. For example, completing homework in the kitchen with other family members nearby for a child with separation anxiety or, conversely, completing homework in a quiet area for a child with auditory defensiveness, may be enough of a change to help the child succeed. Task modification might include reducing homework or changing an art project from finger painting to brush painting, depending on the child's individual needs.

Sensory tools. Sensory tools such as various aromas, deep pressure, and neutral warmth may help to calm a child. Fidget toys and the use of a therapy ball instead of a chair may help a child who is seeking sensation to focus better in the classroom. Gross motor breaks to move about and vestibular activities like jumping on a mini trampoline may help children experiencing lethargy to return to activities with more functional arousal.

Assistive technology. Assistive technology using low-tech devices such as raised-line paper and pencil grips are helpful for some students. Spacing may be helped by placing a piece of paper with dark, vertical lines behind the standard horizontal-lined paper,

creating visual squares similar to graph paper. The child can use this vertical-line template to place one letter in each square and skip one square between each word, thus keeping letters in line and maintaining left and right margins. Once the template is removed, the paper looks like all other papers in the class. Higher-tech word processors and voice recognition may be needed for older children during exacerbation, and "smart pens" may be used to provide an auditory recording of information when written work is illegible.

Stress management. Stress-reduction techniques such as yoga, calming music, and progressive muscle relaxation can be added to healthy routines to help even out the stress and frustration of exacerbation. These techniques may be used by children with PANDAS or PITAND and may also be useful to other family members during each exacerbation.

Table 1. Occupational Therapy Intervention for Managing PANDAS Symptoms

Symptoms*	Possible Interventions
Physical Symptoms	
Tics	Use assistive technology if tics affect function, including: • Weighted and/or built-up pens/pencils • Personal computer/word processor • Voice-recognition systems
Weakness/ Low tone/ Fatigue	• During exacerbation: – Modify activities to accommodate for the deficit – Encourage activity to maintain strength and endurance – Use sensory tools to increase arousal • During remission: – Do strengthening activities
Joint pain	• Use energy conservation techniques. • Give warm baths—some families report good results with Epsom salts. • If child takes ibuprofen or other NSAID, plan activities after medication.
Handwriting decline	Use: • Built-up pens/pencils • Graph paper/vertical lines to improve spacing in writing and to line up numbers for math • Raised-line paper • Portable classroom word processers, such as Alphasmart Dana • Smart Pen to provide an audio recording of classroom information to accompany written work • Computer/voice-recognition software for word processing
Cognitive/Executive Function Symptoms	
Memory	• Do cognitive retraining, such as Brain Builders and neurofeedback. • Create lists (on paper or dry-erase boards) and set up timers/calendars on electronic devices (e.g., smart phone, computer) to keep child on schedule. • Use school Web sites with online assignments and grades (if available).
Attention to task	• Use redirection. • Provide preferential seating in class. • Use assistive technology such as timers on cell phone/ smart phone to give occasional vibration or sound to get child's attention and return to task.
Language	• Give extra time for expression and reception. • Use augmentative communication (e.g., cue cards or picture cards) if needed.
Math skills decline	• Provide extended time on tests. • Allow calculator use for simple computation in higher grades.
Slow processing	• Provide extra time to process information and complete work. • Take multisensory approach (e.g., give information verbally, provide visual handouts, have child act things out).

Symptoms*	Possible Interventions
Sensory and Perceptual Problems	
Somatosensory processing problems	• Encourage activity to maintain strength and endurance. • Practice proprioception, deep pressure, and neutral warmth such as weighted vests/pressure vests/weighted blankets. • If sensory seeking, provide many opportunity for tactile input (e.g., vibration, different textures, different temperatures, finger paint). • If sensory defensive, avoid light touch. • Decrease extraneous stimulation
Visual and auditory perceptual problems	• Use visual perception exercises in remission. • Use Therapeutic Listening and similar programs.
Food restriction due to oral sensory issues	• Evaluate and treat any underlying sensory defensiveness. • Practice oral desensitization such as deep pressure on hard palate with thumb. • Modify textures and flavors of foods to increase variety of diet.
Psychological/Emotional Problems	
Mood changes: • Sudden rages • Giddy • Racing thoughts	• Teach child strategies for control, such as finding "safe" places to "get away." • Use calming techniques (e.g., deep breathing, weighted blanket, pet the dog). • The Alert System/How Does Your Engine Run? book/ sensory program[16]
Anxiety	Use stress-reduction techniques such as: • Progressive relaxation exercises • Imagery • Yoga • Relaxation tapes
Obsessive–compulsive behaviors	Support and reinforce cognitive and psychological interventions developed by trained psychologists or other professionals, including: • Cognitive-behavioral therapy or exposure-and-response prevention therapy • Positive behavioral support plans • Redirection
Sleep problems	• Regulate sensory input using: – Deep pressure/weighted blanket – Electric blanket – Warm bath in Epsom salts before bed – White noise, calming music, or calming audio books – Calming routines • Provide suggestions for bedtime/wake time routines.
Anorexia/fear of choking	• Evaluate and treat any underlying sensory defensiveness. • Modify textures of food—offer moist food. • Work with family and psychology to re-establish routines as underlying infection is treated.

*Symptoms can vary, and even disappear or reappear completely when child is in exacerbation, or after medical treatment.

FOR MORE INFORMATION

Association for Comprehensive NeuroTherapy
www.latitudes.org
A nonprofit organization dedicated to exploring advanced and alternative nontoxic treatments for anxiety, autism, ADHD, depression, OCD, tics, Tourette syndrome, and learning disabilities

PANDAS Resource Network
www.pandasresourcenetwork.org
National nonprofit organization dedicated to fighting PANDAS through research, education, and awareness

PANDAS Network
www.pandasnetwork.org
A resource library created by parents for families and physicians

PANDAS Foundation
www.pandasfoundation.org
Supports research, advocacy, and awareness for PANDAS, with information for parents and doctors

Tools for Tots: Sensory Strategies for Toddlers and Preschoolers
By D. Henry, M. Kane-Wineland, & S. Swindeman, 2007. Glendale, AZ: Henry OT Services. ($16.95 for members, $24 for nonmembers. To order, call toll free 877-404-AOTA or shop online at http://store.aota.org/view/?SKU=1415. Order #1415. Promo code MI)

Early Childhood: Occupational Therapy Services for Children Birth to Five
Edited by B. E. Chandler, 2010. Bethesda, MD: AOTA Press. ($63 for members, $89 for nonmembers. To order, call toll free 877-404-AOTA or shop online at http://store.aota.org/view/?SKU=1256. Order #1256. Promo code MI)

AOTA Online Course: ***Understanding the Assistive Technology Process To Promote School-Based Occupation Outcomes***
Presented by B. Goodrich, L. Gitlow, & J. Schoonover, 2009. Bethesda, MD: American Occupational Therapy Association. (Earn 1 AOTA CEU [10 NBCOT PDUs/10 contact hours]. $225 for members, $320 for nonmembers. To order, call toll free 877-404-AOTA or shop online at http://store.aota.org/view/?SKU=OL31. Order #OL31. Promo code MI)

Occupational Therapy Assessment Tools: An Annotated Index, 3rd Edition
By I. E. Asher, 2007. Bethesda, MD: AOTA Press. ($65 for members, $89 for nonmembers. To order, call toll free 877-404-AOTA or shop online at http://store.aota.org/view/?SKU=1020A. Order #1020A. Promo code MI)

Conduct Disorder Scale
By J. E. Gilliam, 2002. Austin, TX: Pro-Ed. ($102, members only. To order, call toll free 877-404-AOTA or shop online at http://store.aota.org/view/?SKU=1606. Order #1606. Promo code MI)

Dynamic Occupational Therapy Cognitive Assessment for Children
By N. Katz and S. Parush, 2007. San Antonio, TX: Pearson. ($660.25, members only. To order, call toll free 877-404-AOTA or shop online at http://store.aota.org/view/?SKU=1601. Order #1601. Promo code MI)

Gilliam Asperger's Disorder Scale
By J. E. Gilliam Torrence, 2001. Torrance, CA: Western Psychological Services. ($116, members only. To order, call toll free 877-404-AOTA or shop online at http://store.aota.org/view/?SKU=1608. Order #1608. Promo code MI)

The Paediatric Activity Card Sort
By A. D. Mandich, H. J. Polatajko, L. T. Miller, & C. Baum, 2004. Ottawa, Ontario, Canada: Canadian Association of Occupational Therapists. ($169.95, members only. To order, call toll free 877-404-AOTA or shop online at http://store.aota.org/view/?SKU=1610. Order #1610. Promo code MI)

AOTA CEonCD™: ***The Short Child Occupational Profile (SCOPE)***
Presented by P. Bowyer, H. Ngo, & J. Kramer, 2011. Bethesda, MD: American Occupational Therapy Association. (Earn .6 AOTA CEU [7.5 NBCOT PDUs/6 contact hours]. $210 for members, $299 for nonmembers. To order, call toll free 877-404-AOTA or shop online at http://store.aota.org/view/?SKU=4847. Order #4847. Promo code MI)

AOTA CEonCD™: ***Response to Intervention (RtI) for At Risk Learners: Advocating for Occupational Therapy's Role in General Education***
By G. Frolek Clark & J. Polichino, 2011. Bethesda, MD: American Occupational Therapy Association. (Earn .2 AOTA CEU [2 NBCOT PDUs/2 contact hours]. $68 for members, $97 for nonmembers. To order, call toll free 877-404-AOTA or shop online at http://store.aota.org/view/?SKU=4876. Order #4876. Promo code MI)

CONNECTIONS

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Infection control. Because any type of infection may trigger exacerbation, it is imperative that occupational therapy practitioners remain vigilant about infection control and consider the risk of a child contracting an infection from such ordinary play items as ball pits, bins of dried beans, and Play-Doh.

Family support. Families are affected by PANDAS and PITAND because parenting skills are questioned and socialization becomes restricted, necessitating coping skills to improve function of all members of the family.[15] By educating school personnel and parents about the symptoms of PANDAS and PITAND, and by offering tools to manage exacerbation, occupational therapy practitioners can support families to reduce social isolation. Similarly, siblings are affected as parental time and resources are depleted while managing PANDAS and PITAND exacerbations. Helping families to maintain routines and maintain balance of activities when possible can help siblings to maintain roles and participation. Social supports for the child with PANDAS and PITAND may include social groups to introduce and reinforce pro-social skills. Occupational therapists may also refer families to online resources (see For More Information). These resources connect families experiencing PANDAS and PITAND and allow families to better understand the condition, research, treatments, and availability of health care practitioners.

WHAT'S THE BOTTOM LINE?

Children with PANDAS or PITAND and their families are searching for effective interventions, and many are already receiving occupational therapy services. The interventions offered here are only a starting point based on anecdotal reports, and they have not yet been researched. Occupational therapy can help children and families develop and maintain occupational health, and research the impact of exacerbation on occupational functioning and the efficacy of occupational therapy intervention. Occupational therapy practitioners can, and should, be leaders in this new frontier in mental health. ■

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Trudy Posner, MS, OTR, works in private practice, primarily with children in the birth-to-5 years of age range, and specializes in working with children who have sensory integrative dysfunction. She has presented at several conferences on the subject of autism sensory integration and PANDAS/PITAND. She has been in practice since 1984.

SWITCHING AREAS OF PRACTICE

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our niche early in our practice. So if you're not in your niche, if you're not happy, then I think you should look for a different place to work. It's critical that people are performing best practice, so if [not doing so is] the reason why someone is changing their practice area, then I support [this move]."

And occupational therapy is unique because it offers so many opportunities for people in the profession to find their niche, Toto says.

"One of the perks of our profession is that when you graduate and you pass your exam, you have a multitude of practice areas open to you and you don't have to stay in one," Toto says. "Because we teach the underlying skills for how to practice occupational therapy, you can switch to a lot of settings."

Young, who mentored Schell, went through her own switch into low vision, and she did it because she wanted to have more of a personal connection with her job—she herself has vision issues. She believes if practitioners are willing to switch practice areas, the profession as a whole is more able to adapt to societal needs.

"I suggest looking for something that is a good fit for your comfort zone, but also don't have a closed mind because there might be something that you never thought of," Young says.

Elin Schold Davis, OTR/L, CDRS, AOTA's public project coordinator, says being flexible is what will allow the profession to move forward and continue to grow. Schold Davis is particularly concerned about an aging population[5] and the need for more practitioners to switch from treating the young to treating the elderly. AOTA's *2010 Occupational Therapy Compensation and Workforce Study* certainly indicates that more practitioners are working with the elderly, with 35.9% of practitioners reporting they see clients ages 65 and older, up from 29.6% of 2006 respondents who reported working with this age group. Meanwhile, practitioners reporting they work with children ages 3 to 21 fell from 35.1% in 2006 to 32.2% in 2010.[6]

Such malleability must continue, Schold Davis says.

"Learn about older drivers, learn about aging in place, learn about wellness and other senior needs, and build the programs in your communities so that we're prepared for the change and can respond. Occupational therapists need to get the education so they can see a changing array of people, and it's well within their ability to do it," Schold Davis says. "It's not okay to just say, 'We don't have a program that does that.' If occupational therapy practitioners want to be seen as the people that are really stewards of helping people make sure they live life to its fullest, if we want to have seniors live life to its fullest, we must better anticipate what services they will need so we can offer them."

Whether they are moving into geriatrics or some other popular area of practice, such as working with children with autism, occupational therapy practitioners need to embrace the involved, but necessary, process of switching practice areas.

"The one thing about transitioning is that it's going to be more work. People need to be prepared to work toward developing proficiency in the new area. That takes time, that takes effort," Louch says. "You can't just go into it and say, 'I'm here and expect to go.'

I think people need permission to take that time." ■

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