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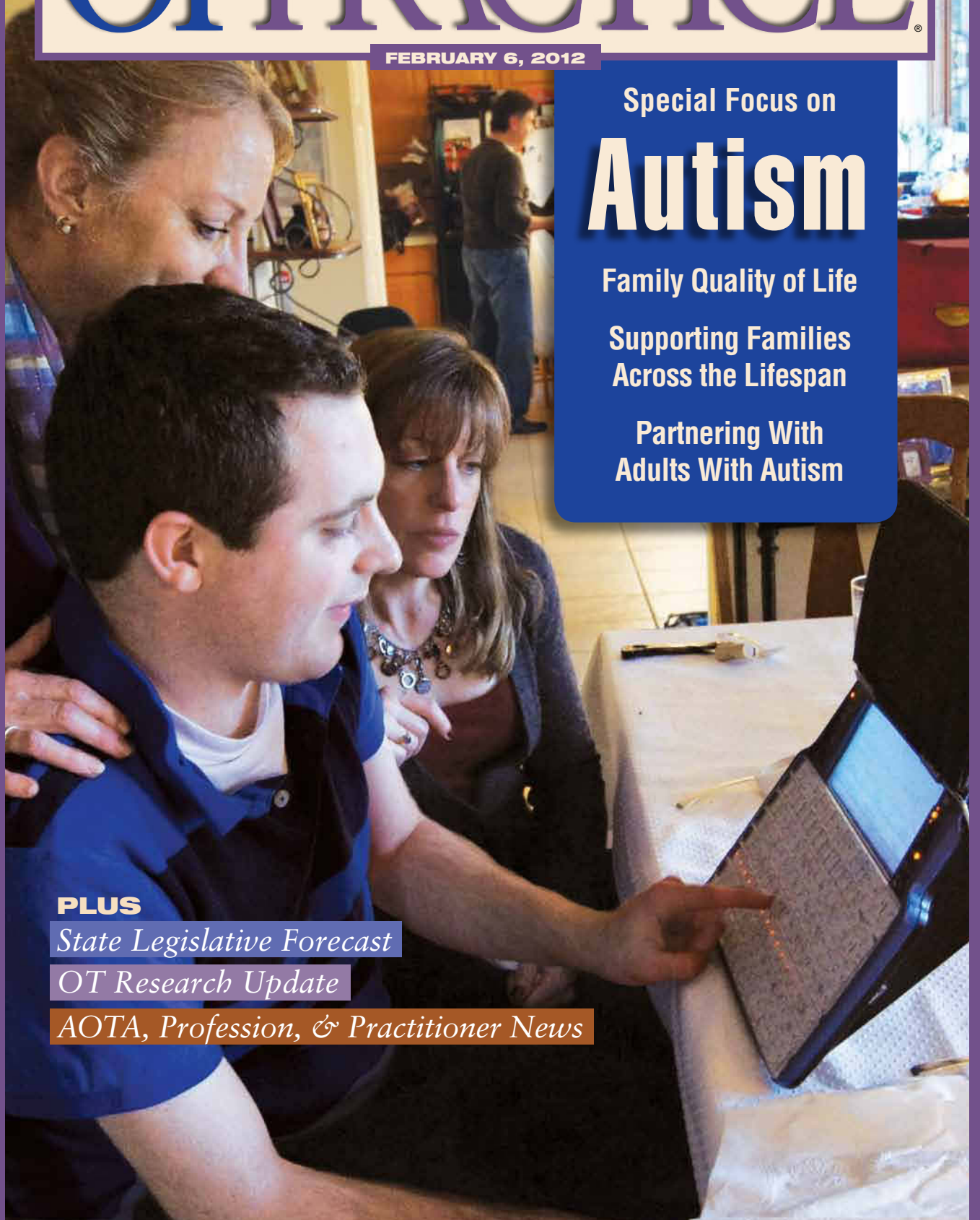
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Authentic Partnerships With Adults With Autism

Shifting the Focus to Strengths

Paul David Kotler

Kristie Patten Koenig

As does everyone, children with autism spectrum disorders (ASDs) grow up, moving into adolescence and adulthood. To help occupational therapists looking for ways to address the challenges and collaborate with adults on the spectrum, personal narratives of adults with an ASD offer insight into not only their perspective on sensory and motor challenges and how they affect daily function, but also, perhaps more importantly, on the need for self-advocacy and acceptance. The traditional medical model led to people with disabilities being acted on by professional experts who defined them in terms of their impairments and then sought to remediate the impairments. Autobiographical narratives and interviews with self-advocates with ASDs suggest that although remediation may be needed at times, self-advocates have not built their lives on remediated weaknesses; rather, they seek assistance in modifying and adapting their environments, and building on their strengths and unique interests in order to engage in meaningful occupations that foster participation and social relationships. Self-determination and collaboration must be at the core of services for adults with ASDs, and intervention must focus on a strengths-based model that can improve quality of life.¹

How does the occupational therapy practitioner make that shift? It starts by listening.



Paul types with his cousin, while his mother looks on.

PAUL'S STORY

My name is Paul Kotler. I am a writer, lecturer, student, son, brother, uncle, motorcycle enthusiast, and 23-year-old adult with autism. I had my communication breakthrough at 14 when I learned to type independently. My life was changed altogether. Occupational therapy has played an important role. School-based occupational therapy helped me develop foundational skills. It helped me use my body more easily and, very importantly, regulated me. Now that I am older, I'm very interested

in taking a primary role in determining goals geared toward independence.

COMMUNICATION

Occupational therapists often work with speech-language pathologists and assistive technology specialists to improve communication in children with autism, often using simple communicative devices or picture exchange systems. As Paul recounts, working on a system of communication that is reliable and effective and presumes receptive understanding is

The challenge to occupational therapy practitioners is to partner with adolescents and adults with ASDs to foster a sense of competence by using strengths, relatedness by presuming intellect, and autonomy by assisting and encouraging the development of self-advocacy capabilities.



Through repetitive practice and with increased motivation, Paul (at far left in dark jersey) has learned to skate well and play hockey.

critical. For him, it was also crucial that the occupational therapy practitioners believed in his ability before he was able to express it. When he was 14 years old, he began spelling out words and sentences on a keyboard using the Rapid Prompting Method.² He says:

A critical factor was that Soma [developer of Rapid Prompting Method] didn't doubt my ability to respond. She made things more clear. She asked questions about facts that took the pressure off. I'm glad she made me open up and start acting capable. I am very pleased that Soma gave me a way of expressing all my thoughts that I had no way to convey previously. Lots of pressure on me after that.

When asked about what he meant by pressure, Paul articulates how indepen-

dent communication opened up a whole new world:

Before I could communicate, no one expected me to participate in conversation. But, once they knew, they had expectations for natural conversations. People were astonished that I had understood everything all my life, so that was liberating. But it came with a responsibility of having real, normal relationships. In the past, it was great being able to listen and eavesdrop on all conversations without having to participate. I could begin to be hopeful about the future the more I realized I could communicate diverse and personal thoughts.

Paul's perspective should have a powerful affect on the daily interactions occupational therapy practitioners have with individuals who are nonverbal or

have significant communication challenges. Research has highlighted the difference in receptive understanding and expressive ability in individuals diagnosed with an ASD.³ As Paul notes, his receptive understanding was completely intact, even though he could not independently express himself until the age of 14.

I started to communicate in an effort to ask about the world. I only knew what I had absorbed. I wanted tools to ask questions to better understand. I wanted to learn [about] life outside my bubble, more about my body and other people like me. Before communicating, people around me could only guess at my intelligence. Being able to communicate means that I am able to share ideas and opinions with others to dispel doubts in my intelligence. I can understand others more by talking to them. Their acceptance of me increases my interest in relating to them.

INTELLIGENCE

Recent literature has found that there is a consistent lack of accuracy in intelligence testing in those with ASDs, at all ends of the spectrum.³⁻⁴ For those who are nonverbal, there is a strong push to find alternate means of evaluating cognitive capacity, as the level of functioning has been incorrectly assumed to be much lower in those individuals who do not have a reliable means of communication. Assuming a lower level of cognitive functioning on the basis of intelligence testing that relies on expressive verbal and motor ability is a dangerous fallacy with a potentially significant impact on quality of life. Paul outlines not only the central problem with intelligence testing, but also

“Now that I am older, I’m very interested in taking a primary role in determining goals geared toward independence.”

the effects that failure to presume intellect can have on those who experience it on a daily basis.

Being tested for intelligence really assumes you can control your body. But I’m not able to think and move at the same time. Let’s assume I’m asked to determine geometric equations. I haven’t got the motor control to easily write, so I would appear to not get the problem. If someone allowed me to spell it out, I could demonstrate my knowledge. Motor skills are an unreliable measure of a person’s intelligence.

Paul says it was nearly “unbearable” to be assumed to have cognitive impairment, and he offers advice for professionals: “Always acknowledge a person’s intelligence and they will be more receptive. Often we can be perceived as being unintelligent and it can diminish the relationship between teachers and students. Structure and forceful instruction are important to help initiate activity.”

Paul recounts that inherent in forceful instruction is the need for repetition of the motor aspects of the task due to motor planning difficulties, but with an ongoing acknowledgment of intelligence:

Always make hard motor tasks like handwriting assignments possible to do without fine motor ability. That helps to acknowledge that the person is capable with the content but must repeatedly do it for the motor skill proficiency. Routines help me focus by being familiar. I need explicit instruction to help fight impulsivity. Teachers that understand strengths and limitations on students are best suited to find approaches that help unconventional individuals.

In addition to the need to be perceived as competent by teachers and therapists, Paul outlines his need for autonomy or

independence and relatedness, all critical for growth and living a self-determined life.⁵

INDEPENDENCE

Paul identifies the importance of occupational therapy’s collaborative role in fostering independence. Motor planning has always been a challenge for Paul, and he speaks to the need for therapists to break down basic and instrumental activities of daily living skills in order to lay the foundation for independent living, to the extent possible:

I have a thorough and now voracious need to live independently, and I need good instruction to achieve my goals. I’m capable of much but very dependent and that has to change more easily. This is very hard. Occupational therapy helps build the mental clarity I need to take on more responsibility. I can slowly be in more control and a better frame of mind if I am regulated. For example, sensory input before typing helps clarify my thinking noticeably.

RELATEDNESS

Paul, who wants to become more and more independent and live on his own with friends, says that he can certainly feel empathy toward others, something that individuals with an ASD are often perceived as having difficulty with, or of not having at all. Paul says:

I can feel those things but have trouble demonstrating them, although it is slowly getting better. I can show it through my words, [but that is] very inadequate when I readily want to hug the person and be physical. I am capable of hugging but become very disorganized in a fiercely emotional situation. Occupational therapists [should] act interested in more personal ways. Like caring if [clients are] not calm



Paul at his GED graduation ceremony.

and assuring them that you are going to help them connect their mind and emotions to their bodies.

DIRECT BENEFIT OF OCCUPATIONAL THERAPY

Paul has received direct benefits of occupational therapy, especially in the areas of self-regulation. As an adult, he is learning to become an advocate for his needs.

I find that occupational therapy greatly helps by teaching me about regulating my body. When really stressed, I need full body pressure. I do like the squeeze machine as it allows me to control the level and length of pressure. Self-advocating meant getting more of the sensory levels appropriate for me at any given moment. Communicating what worked best for me meant creating more effective plans. Occupational therapists [have] helped me by talking with me about different sensory diets depending on my level of anxiety.

“I [never dreamed] I’d reach the level I have. I thought I was trapped forever without a voice. It is so mind blowing to face having my autism as a part of me but not defining me. Very liberating.”

FOR MORE INFORMATION

ThAutcast: A Blogazine for the Autism and Asperger Community
<http://thautcast.com>

AOTA Autism Resources
www.aota.org/autism

Autistic Self Advocacy Network (ASAN)
www.autisticadvocacy.org

Thinking Person's Guide to Autism
<http://thinkingautismguide.com>

Paul, however, is beginning to interpret these characteristics as strengths:

Things can be difficult for me and so I'm ready to sympathize with the struggles of others. I believe others can benefit from my experiences. I want to tell others what I needed to hear as I was learning: [You] have the potential to live a normal life, that [you can] become independent and achieve intellectually.

SHIFTING TO A STRENGTHS-BASED APPROACH

In my work with Paul, I asked him to identify the strengths in having autism—what is he able to do because he processes information the way he does that is different versus dysfunctional? He struggled to define the process as a “strength,” but says the gains he's made have been personally rewarding: “I [never dreamed] I'd reach the level I have. I thought I was trapped forever without a voice. It is so mind blowing to face having my autism as a part of me but not defining me. Very liberating.”

Paul identifies how an occupational therapy practitioner can foster this idea of strength early by not focusing primarily on remediating deficits:

Younger children very much need to hear that they can accomplish more than some people believe is possible. Specifically, it is very helpful to measure progress, making note of not only needs, but also talking about strengths and how those strengths overcome areas of need. Allow for success often and interpret success as the result of a person's strengths.

CONCLUSION

Paul emphasizes the need to always trust in a person's intelligence:

I still carry many needy thoughts about myself; however, very slowly, I am appreciating my accomplishments. I feel the answer lies in my acceptance of having autism as a positive thing. Don't dwell on autism as an injury. Listen and observe and go with talents. If strengths are used to stake goals on, the autistic person each day earns respect for himself.

So the challenge to occupational therapy practitioners is to partner with adolescents and adults with ASDs to foster a sense of competence by using strengths, relatedness by presuming intellect, and autonomy by assisting and encouraging the development of self-advocacy capabilities. Occupational therapy practitioners have always had a unique view of the sensory and motor challenges that individuals with an ASD encounter on a daily basis. In our work with adolescents and adults, and arguably with children as well, it is time to shift to the opportunities and strengths that are unique to those we serve. ■

References

1. Koenig, K. P., & Kinnealey, M. (2010). Adults with autism spectrum disorders. In H. Kuhanek & R. Watling, *Autism: A comprehensive occupational therapy approach* (3rd ed.). Bethesda, MD: AOTA Press.
2. Mukhopadhyay, S. (2008). *Understanding autism through Rapid Prompting Method*. Parker, CO: Outskirts Press.
3. Dawson, M., Soulières, I., Gernsbacher, M. A., & Mottron, L. (2007). The level and nature of autistic intelligence. *Psychological Science, 18*, 657–662.
4. Estes, A., Rivera, V., Bryan, M., Cali, P., & Dawson, G. (2010). Discrepancies between academic achievement and intellectual ability in higher-functioning school-aged children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 41*, 1044–1052.
5. Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development and well-being. *American Psychologist, 55*(1), 68–78.

Paul David Kotler attended TALK Institute and School in Newtown Square, Pennsylvania, from 2002 to 2011. TALK is a full-day, intensive speech-and-language school that is an integrated therapeutic and academic program. Kotler still attends TALK for speech and occupational therapy as part of his program. He currently is a student at a local community college and is interested in studying neuroscience.

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In today's society, approximately 1 in 100 children is diagnosed with an autism spectrum disorder (ASD). Children with an ASD experience a range of occupational challenges that make providing therapeutic services to them both exciting and challenging.

This CEonCD is the first of a three-part series that builds on content from the 2010 3rd edition of *Autism: A Comprehensive Occupational Therapy Approach* and offers occupational therapy practitioners the opportunity to expand their understanding and practice with children on the autism spectrum through building the intentional relationship, using occupational therapy evaluation strategies, addressing sensory integration challenges, and planning intervention for praxis. Highlights also include video clips and strategies that will enhance the provision of evaluation and intervention services.

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