Obtaining a Diagnosis of Prosopagnosia in Childhood

Some families have obtained a diagnosis for their child, where as others have not. Although some have had success, a diagnosis of childhood prosopagnosia is often difficult to come by. Here is what families had to say about obtaining a diagnosis of prosopagnosia . . .

Benefits of a diagnosis

♦ “[I am] able to express why I don’t notice my best friend or sister after she gets a haircut. I now have no problem explaining it.” – Parent & Adult

♦ “Knowing about our son’s prosopagnosia has empowered us in so many ways. It has explained so many things about his behavior and anxiety in certain situations and has helped us to know when to really push him (when he’s really just acting out and trying to get out of something) and when we need to provide him extra support. I feel it has also enabled us to speak more confidently on his behalf and speak more confidently to his needs.” - Parent w/ 10-year-old

Pediatric Neuropsychologist

♦ “When he was in 2nd grade and started showing a lot of anxiety around school (and other large social gatherings) we did some testing with an educational psychologist. She told us that she believed that there was more going on than what she had been able to discover through testing and suggested that we obtain a neuropsychological evaluation. The pediatric neuropsychologist that we ended up working with took our son through a series of tests over several months, one of which was a facial recognition test that was a part of an overall memory test battery. Our son did very, very poorly on the test and was diagnosed through that. The neuropsychologist said that our son was the first child he had diagnosed with prosopagnosia in his 34 years of practice. We have only seen a benefit to having this diagnosis thus far.” – Parent, aged 10

No Official Diagnosis

♦ “I asked doctors, 2 pediatricians, a patricide occupational therapist, teachers and educational psychologists, and without exception I knew much more about [face blindness] than them. This was not helpful, and on occasion humiliating.” - Parent w/ Secondary School Student

♦ “My son does not have a diagnosis. I found one neuropsychologist who felt qualified to evaluate [him], but gave me an estimate of $2300 to $3300 to do so. Since there is no known therapy or cure, and I only need this so that school administrators can be aware of my child’s difficulties, I could not justify spending the money. I was also wary of paying someone who didn’t really know anything about prosopagnosia but was willing to learn on my dime.” - Parent
“My daughter participated in research which helped, but could not technically diagnose her due to her age.” - Parent w/ First Grader

“[Our] biggest challenge has been the lack of understanding and information out there, although that’s clearly changing. I took my son to a vision therapist when he was in Kindergarten to seek help, and they told me he had Asperger's Syndrome and just wasn’t attending to faces.... We also had lots of different diagnoses when he was young and none of the experts agreed. He was diagnosed with autism, dyspraxia, pragmatic language disorder and possibly a few others. We were told he was developmentally delayed... [or] gifted. It was frustrating.... We’ve ignored [the] diagnoses. However, the biggest changes came when I determined facial recognition to be a challenge and worked on that with him and when we asked our occupational therapist to work with him in his preschool classroom. She helped him make meaningful connections with other kids and as he saw the benefit of such relationships he began to seek them on his own.” - Parent

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