Telling your Child about Prosopagnosia

Many families shared their experiences regarding their decision to discuss, or not discuss, prosopagnosia with their child. Both positive and negative experiences were reported and we hope the reflections on these experiences are insightful for other families.

To tell? Or not to tell?

♦ “The kids WILL need to be told. It IS better to know than not. One day though. I admit I haven’t told my son.” – Adult & Parent w/ 7-year-old

Subtle conversation

♦ “We began to make some simple comments like “Oh you didn’t know it was her since you have a hard time telling people by their faces” comments as appropriate, over time. No big “sit down” talk. As more opportunities arose, we labeled it for her. We took opportunities to share challenges that others face and noted how this is one of her challenges. All very matter of fact. The explanation definitely evolves with her age.”- Parent w/ First Grader

♦ “When [my son] was little (say 5), I would point out if someone was not who he thought they were - 'I know this looks like Abbey, but it is another little girl' - he would be most indignant and declare it was, until I got the kid to tell him they were not. This was clearly necessary, but it did throw his confidence a bit. After a while he learnt to say 'I think that is.....' and look to me for reassurance.” - Parent w/ Secondary School Student

Reactions

Positive

♦ “We have explained it and told [our son] everything we know about it over a series of conversations. [He] was just glad to make sense of what was happening and given that his father has the same condition it was put as part of a family tradition... We talk about any problems openly and laugh often at the mix-ups.... I don't think our son is fully aware of the ways that prosopagnosia affects his life but he is happy with a wonderful set of friends at a school that nurtures and stretches him in all the right ways.” – Parent w/ Secondary School Student

♦ “[My son] was obviously aware that he was going through testing with the neuropsychologist and that we were all trying to get to the root of his anxiety, so he was as anxiously waiting for the testing results as we were. We told him that there was a section of his brain that was responsible for recognizing faces and that his didn't work as well as other people's did.... We also had him watch a short section of the 60 Minutes episode on prosopagnosia. That really caused the “light bulbs” to go off for him. He kept saying 'Oh my gosh! The same thing happens to me!! I'm not going crazy! I thought I was going crazy!'” -Parent w/ 10-year-old
“Knowing that others can recognize faces in a way that he does not has helped him understand what other people expect him to do and why. He was old enough when we did the online tests that he understood the process and what we were testing for. The relief that comes from understanding why certain things are more difficult for him seemed to balance the news that he could not perform as well at most people in this area. He excels in other areas and that seems to help him.” - Parent

“We have... told him about his diagnosis and it has given him a great sense of relief. He told us that he had thought he was going crazy and that he was so glad there was a reason why he was so anxious at times.” - Parent w/ 10-year-old

“He explained it to me as much as I did to him. The most difficult thing was explaining that most people actually CAN recognize other people by their faces!” - Parent w/ 18-year-old

**Negative**

“I tried [to explain] once when [my son] was younger (probably around age 7 or 8), and he got very upset. He still is bothered if he hears facial recognition difficulties described as a “disorder.” He has always been touchy about such things although we try to remind him that everyone has differences. He’s always been skittish about others with differences – autism, physical impairments – but that is improving. As he begins to accept others’ differences, I’m hopeful that he’ll also learn to be more tolerant of his own.” - Parent

“When [my son] was preparing for secondary school and I was concerned about him coping in a huge school after a tiny primary, I asked the Educational Psychologists for some help. I had to explain to him then why he was seeing her. He denied that he had any issues, and was clearly distressed and offended by the idea. So I dropped it. Since then we have realized that my husband is also affected, and so Face Blindness is talked about lightly and casually in our house, and though I have not addressed it formally with him, I think my son gets it, and accepts it on some level. I am sure we will need to have a conversation about it before he leaves home for [University], but at present he is coping fine.” - Parent w/ Secondary School Student

**The Child’s Preference for telling others**

“[My son] knows he has it; he is shy and doesn’t want people to know. He does not want to talk about it.... Friends know, but they have better things to talk about... And now in high school he is self-advocating, he told a teacher he did not know what character she wanted him to [analyze] in a movie.” - Parent w/ 14-year-old

“I think it’s been beneficial to have the diagnosis because, now that our suspicions have been made concrete, it’s clearer that we should talk about it with our son and help him accommodate. I don’t think there have been any harmful effects, but we haven’t shared the diagnosis with anyone outside of
Our family. Our son hasn’t wanted us to tell others.” - Parent

◆ “Our son has really owned this diagnosis from the beginning and hasn’t had trouble telling others about it.... He has a fairly small group of friends (interestingly, many of them are fairly distinctive looking) so I think that helps him manage. I think it helps that they know because they (and their parents) don’t get upset or offended if he calls them by the wrong name or doesn’t speak to them if we’re out in public and he doesn’t recognize them.” - Parent w/ 10-year-old

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