Concerns Parents have Reported

In the surveys, several parents reported differing concerns directly related to prosopagnosia. These ranged from safety concerns to concerns about the child's social development.

Drawing the line between parenting and allowing your child to explore

◆ “I think we need to really be diligent about her safety and have done more to prepare her for possible problems (losing us in a crowd, how to handle ‘strangers’ etc.). Also just managing her socially, trying to help her navigate social situations while at the same time teaching her ways to cope and handle these situations without us. As with any child with social deficits, we also have to deal with other parents who don’t know her diagnosis and only see her behaviors.” - Parent w/ First Grader

Your child walking away with someone else

◆ “That was my biggest fear. My son was not a wonderer, so that ended up not being too much of a concern. I had to learn to remember not to walk off without him. Example: at a store if he was looking at something I could not walk even a few steps away. Now, if he is trying on clothes at the store I cannot move far from the door. [When you] say “I will be right here”... you need to mean it.” - Parent w/ 14-year-old

◆ “[W]e have had to make sure that any adult who is going to be responsible for our son in a group setting or public place knows what's going on. Especially in crowded public places, we make sure that they know our son likely won’t be able to find them in the crowd if he gets separated from them. Most have been really great about wearing an easily spotted color or hat. We’ve also made sure that he carries a copy of their cell phone number in case he were to get separated. We even do this as his parents if we’re going to be somewhere crowded.” - Parent w/10-year-old

Doubt

◆ “As he gets older, his coping mechanisms improve....In fact, for some periods I thought he had out grown it, and then another weird thing would happen to remind me it is still there. The last time he thought someone was me - his mother - who was sitting in a car 5 paces away from him - since then I don’t question it any more!” - Parent w/ Secondary School Student

◆ “Once it was recognized, he was reassessed for ASD as he already had a diagnoses of Asperger’s, Tourette’s syndrome, ADHD and Sensory Integration Dysfunction, but the presence of Prosopagnosia made everyone question the ASD in case what we were seeing was Prosopagnosia and the Non-obscene-socially-inappropriate-behaviours of the Tourette’s looking like ASD, rather than actual ASD.” - Parent w/ 18-year-old
“Occasionally he’ll recognize someone out of their regular context and I can’t understand [how] he did. Or, he’ll say something like, “Of course I know that’s [blank]... He’s my best friend.” Times and comments like those confuse me because it’s not obvious to me what he’s using to recognize the person.” - Parent

“For the most part, when I have doubts, I try to talk to my son. I think he should be in charge in deciding how much his difficulties are discussed and when and if they're disclosed.” - Parent

“As someone who doesn't have facial recognition difficulties, it has been hard at times for me to really “get it.” There are also days that our son’s recognition seems to be better than other days and I have to admit that I have thought “Is this for real?” But then something will happen that shows me that it is very real for him.... It’s in moments like that that I’m reminded how real his prosopagnosia is and that, as his parents, we have to constantly look at the world through that lens in order to best support him.” – Parent w/ 10-year-old

**Difficulty making friends**

“Yes, I think that his social skills have suffered. He doesn’t recognize emotions very well by looking at someone’s face. He tends to avoid situations with a lot of people.” -Parent

“My son is a friendly and kind kid. He has a good circle of about four close friends. However, there are other kids he should be better friends with, but I think he [isn’t] because he can’t find them in large-group situations such as on the playground. I no longer worry that he won’t make friends, but I am still concerned that he’ll miss out on potential relationships because of his difficulties with facial recognition.” - Parent

“[It] seemed hard for him to really connect with other kids. He was very friendly and enjoyed being around other kids, and other kids seemed to enjoy being around him. His friendships never seemed to go below the surface level though and he never seemed able to tell us much about his friends.” - Parent w/ 10-year-old

“As a researcher, I find that there are widely varying reports of the degree to which prosopagnosia leads to social difficulties. Some kids experience a lot of social anxiety and others seem to go the other direction, being socially friendly with everyone!” - Researcher

**DISCLAIMER:** There is no research to confirm or deny any benefits to you or your child that may result from the information included in Project ProsoFamily. The University of Minnesota does not endorse anything on this page. It is simply words of wisdom from individuals and parents based on their personal experiences for you to adapt as you see fit.