Choosing to Work with the School: Benefits and Issues

Parents report a wide range of experiences related to the public school system. Some families have wonderful experiences in which the educators are eager to learn about prosopagnosia and are willing to adapt the learning environment to fit the child’s needs. In other cases, there is difficulty getting the school team “on-board” with a prosopagnosia diagnosis. The quotations below reflect a broad range of experiences and offer suggestions of how to best interact with the school system. Getting involved in the school system is often necessary, but not always easy. As most educational teams have never heard of prosopagnosia before, it can require a lot of work. Here, parents have outline benefits of getting involved and working with the school system and have also outlined a few issues they have run into in the process.

Benefits and Successes

♦ “Simply using the face blindness or prosopagnosia terms to identify the difficulties and make them aware, have been all we needed. I also volunteer where I can so that I know the children and adults my child is interacting with. They get a chance to know me, which helps when misunderstandings arise.” - Parent

♦ “His prosopagnosia has seemed a bigger problem than the other diagnoses. Staff/employers have been great at introducing themselves/wearing labels.” - Parent w/ 18-year-old

♦ “Teachers or administrators were more reluctant to believe his complaints because it was hard for them to understand how someone could not know or identify a person who was taunting, pushing etc. them. When I let them know that my child had trouble recognizing faces, they seemed to at least pause when deciding that my child was just making false accusations. This really didn’t happen very often. When I first used the term ‘face blindness’ with the middle school administrator, the idea finally got some traction and changed how they were handling situations. Although my child doesn’t have an official diagnosis of any visual impairment, once I gave a label to the condition, they could see it for themselves.” - Parent

♦ “We had suspected for years but without absolute certainty. As a teacher myself, I was able to translate the diagnosis into a practical action plan at a meeting with relevant staff. His school was very helpful. Our son is very upfront about it and informs staff and other pupils about any difficulties. The culture of the school is always positive. My husband attended a conference (as he too has prosopagnosia) and spoke to one of the speakers. The speaker was able to visit our home and diagnose our son. Only down side is that every pupil in the school knows our son by name and is curious about prosopagnosia.... The English teacher (after asking our son and ourselves) set a homework in which they had to write from the point of view of somebody with prosopagnosia. .... Our son made lots of friends and is very happy at his secondary school.” - Parent w/ Secondary School Student
“Everybody [in the school system] comes with different expertise and skills to offer.” - Parent w/ Secondary School Student

“The usage of other general strategies/suggestions varies. I think that my daughter compensates so well that actual strategies to assist are often faded out ‘I asked her to hand back papers and she did fine’ one teacher said. - Parent w/ First Grader

“All safety accommodations are complied with (e.g., adult contact in fire drill, assemblies, field trips; teacher eye contact with parent at drop off etc.).” - Parent w/ First Grader

Issues

“I have had teachers who were just hellish and teachers who are awesome... My son had a hard year with one teacher who thought he was being fresh [for sitting with the wrong student]. She made him sit by himself looking at a wall and would not let him participate with the project. I have had many conversations with his teachers and with the superintendent.” – Parent w/ 14-year-old

“[I] took out the papers to take [the school system] to court for not servicing my son the way I knew he deserved.... [They] said the only placement for him would be in a substantially separated class for autistic kids. (This was for middle school) I fought it, won, and now he is in honor classes in high school.” –Parent w/ 14-year-old

“They didn’t believe me until a year had passed and I was still talking about [his prosopagnosia].” – Parent w/ 7-year-old

“Teachers forget to follow through... They never take the IEP seriously. It might be a plan but there’s no clear strategy provided to me, no goals or plan of how to reach them. This term he didn’t even get an IEP.” – Parent w/ 7-year-old

“[S]ome of those teachers did mess with my head when they could not see it. It is hard to tell the Head of my son’s primary school that it was her that was mistaken not myself but I still did it.” - Parent w/ Secondary School Student

“We had him in weekly counseling for the anxiety and were trying to work with the school on ways to support him. The school, however, wanted to treat it purely as a behavioral issue. We knew that there was something else going on, but didn’t have any kind of diagnosis to back it up at the time. Therefore, we didn’t have a lot of ground to stand on with the school, especially since his grades weren’t really suffering.- Parent w/ 10-year-old

It would be nice if any one of our specialists here at home knew what the diagnosis was. We definitely have support, but constantly providing education has been exhausting.” - Parent w/ First Grader

“I have to remind every teacher each year and sometimes many times, that movies are hard for him to follow (High School watches and analyzes many movies).” – Parent w/ 14-year-old
School uniforms can make it very difficult to recognize people. – Multiple Parents

“Our son was unhappy at primary school and felt excluded.... Part of it was the not understanding why, and this developed into a school phobia. That has all changed now that he has moved up to secondary school and their inclusive attitude.” – Parent w/ Secondary School Student

Good Communication: A key to success

“A support worker (for all pupils) who can point pupils in the right direction if there is a crisis or question that needs answering. Available by email as well as in person and for parents as well as pupils. Problems are sorted fast before they get out of hand.” - Parent w/ Secondary School Student

“Staff training and special training for the teachers of our son at the start of the year. Our son is the first pupil diagnosed with the condition at his school.” - Parent w/ Secondary School Student

“Good communication with staff before our son started his current school. Problems are anticipated and often avoided.” - Parent w/ Secondary School Student

“Good communication with our son’s teachers via email, telephone or in person. Problems are sorted.” - Parent w/ Secondary School Student

Choosing to Homeschool

“[O]nce we learned about his prosopagnosia we decided to continue to homeschool him because we felt like it allowed us to provide the best learning environment for him. He participates in several enrichment classes and other activities with other kids, but the groups are smaller than a typical classroom setting and in a setting with less kids overall.” - Parent w/ 10-year-old

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.