Autism Resource Center | *Tip sheet*

Perfectly John

By John Langlow, MD, MBA, Lucet Medical Director

My son, John, is sitting across from me at his favorite restaurant, Dairy Queen. He's 34 and has autism spectrum disorder (ASD). He is mostly non-verbal. On the way here, he used his iPod Touch, with an app called Proloquo2go, to let me know what he wants to do today. "Dairy Queen, chicken fingers, fries, Fanta, Oreo Blizzard, Walmart." A sly smile crosses his face as he waits for his favorite meal. I treasure those occasional smiles!

I remember the early years after John first received a diagnosis of ASD. John had a regressive form of autism. He started developing normally, but around age 2, he started to lose words. We were in denial until a friend told us to get him evaluated. I'm not sure how we dealt with it as well as we did, but we got to work trying to find him, and us, some help. I learned that the worst feeling for a parent is the feeling that they cannot help their child. In those days there weren't the resources that are available now. Now there are more educated teachers, behavioral analysts, assistive and augmentative communication providers, and others. We learned about the importance of early intervention, and he had a wonderful pre-school teacher. We started networking with other parents, and shared pain and triumphs.

Everyone needs hope for the future. And with a child with ASD, you never know when you might make progress. When John was four, I learned about something called the Picture Exchange Communication System (PECS). We worked on it for days, and suddenly it clicked for John. He could use pictures to communicate! I was so proud of him!

Later, as I say it, John "found his finger." This means that he learned that if he pointed at something, it meant something to us! I was in the car when he was about five and he started pointing to where he wanted the car to go. I got so excited that I went where he pointed, and of course we ended up at McDonald's! This taught me that children with ASD can indeed grow and develop, just perhaps not at the same pace as others. This and other small victories gave us hope.

Families with a child with disabilities can be helped by anyone in the community. They need practical help. They need someone to cook them dinner. They need a respite sometimes. They need to know that other families accept their child. They need providers that can give them hope. They need friends that will help them vigorously advocate for their child, often in a way they never had before. They need good advice about treatments that may or may not be a wise idea. They need hope that their family will get better.

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When he graduated from high school, we started to think about where John would live as an adult. Every single day, parents think of what will happen to their child with challenges after they are gone. John went to the Learning Tree to live for a year. It was such a wonderful experience for him. They showed compassion in their expectations for John to improve, and he did! Then he went to Glenwood where he lives now. Glenwood believes in continuous quality improvement. They really care. They are superb and they keep getting better! Glenwood, and providers like them, are such a blessing.

Our food comes and John looks at me to see if it is okay to start eating, something he learned at Glenwood. I say, "go ahead," and he starts eating. Another smile! I no longer focus on autism as a disease or a set of deficits so much anymore. John is perfect. He's perfectly John!

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