



6 Things I've Learned

FROM CHILDREN AND FAMILIES
**LIVING WITH
AUTISM**

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On this particular day, I noticed that something was different about my four-year-old patient Jamie. In the past, she would be afraid, would cry and had great difficulty with her physical exam, especially when her ears were examined. Her mother and I were accustomed to her reaction. Jamie lives with autism, so we had always taken special care to make sure she wasn't kept in the waiting room too long, and that she was always seen in the exam room with the bird's nest décor, something she adores.

When Jamie arrived at her most recent appointment wearing a baseball cap and with earplugs, she was more cooperative. Her mother brought a small fan, which she turned on once they were in the exam room. Jamie's mother told me that she had taken her to an occupational therapist who diagnosed her with sensory processing disorder. She said that the cap, earplugs and fan helped Jamie navigate the bumps in her world.

I learned something that day, just as I do every day from my patients and families. While they come to me because I am an expert in child health, I learn from them because they are the experts in understanding their children.

Caring for children with special health-care needs is best done in a partnership with families, one that is built on curiosity, humility, celebrating small but important achievements, and brainstorming through challenges. Over my 32 years of pediatric practice, I have learned some important lessons from children and families. The following are just six things I've learned from those living with autism.

1

Families will seek and find resources that doctors may not have learned about.

I first learned about Sensory Integration Therapy, Parent-Child Interactive Therapy, Play Therapy, Floortime, and Social Skills Training from families who found that these approaches benefited their child. When it comes to making life better for children with autism and their families, we experts have a lot to offer, but we bring even more to the table when we learn from the wide range of experiences of families.

I urge parents to talk to other families to see what therapies have worked for them. Don't be afraid to suggest a therapy that is new to your pediatrician.

2

Families are creative as they incorporate solutions into everyday life.

I have learned that cooking, for example, is a great way to teach both math and reading skills, while also introducing new vegetables, spices, and textures to a child's palate. Be creative, and use your child's special interest to direct learning.

3

Professionals should act when families express concerns about their children's development.

Pediatricians are busy, and even the most observant ones have limited time with a child in the office. Families, on the other hand, are with their children around the clock. When they are concerned about their children's speech or behavior, professionals should act. As parents, speak up when you are concerned about your child. You know your child best.



4

Look to families for an honest review of local special education classes, preschools or therapists.

Pediatricians learn by asking about a child's day and note what occupies a child's time. Families tell us about the most effective programs over and over again. As a pediatrician, I've learned that I can pick up the phone and call the therapist or preschool program staff to learn more about what they do and why my families find these services helpful. When this happens, we are able to build a true partnership and establish communities that address the needs of our children.

Parents should encourage their child's teachers, therapists and pediatricians to communicate and build relationships with each other.

5

Family navigator programs are essential resources.

We don't need to reinvent the wheel when it comes to early intervention, school systems, specialists, therapists, insurance and systems of care. Families that are familiar with the system are an amazing resource for parents starting this journey. There are informal family navigators, such as the mother who always seems to have her child's services in order, and there are formal ones that form part of programs such as a [Family-to-Family Health Information Centers](#), started by [FamilyVoices](#). I encourage you to find a formal or informal family navigator program.

6

Families will trust us if we trust them.

Some families are reluctant to share their concerns about their child's development because they fear that they may have caused the child's problem and that no solutions are available. Pediatricians can overcome such hurdles by listening, prioritizing the family's goals, and finding a solution that works. This can help families gain enough trust in the pediatrician to allow for an evaluation of the child's specific disability.

Families are our greatest source of inspiration, celebration, new ideas, reasons to reflect, and continued advocacy. Our patients and families are the reason we come to work each day, explore new solutions, and make the calls needed to coordinate care.

As a family member, your insights and perspectives are valuable and important. Remember that your pediatrician is learning and growing along with you. We seek your wisdom, questions and guidance as we travel the road ahead with you and your child.

My final piece of advice is to be open with your pediatrician and share as much information as possible. That way, he or she can best direct your child's care.



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Through her work, Dr. Kraft's goals are to promote the optimal physical, developmental, and psychosocial health of all children, and to support those adults and professionals who care for all children.

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