



What Parents Wish Providers Knew...

Parents of children with special health care needs share what they feel medical professionals don't know, but should.

Listen to me. Don't just hear. My non-verbal cues matter as much as the words coming out of my mouth. I am worried about my child and may not know what to ask. Take time to make me feel comfortable. Make sure that there is someone available for me to follow-up with in case other questions arise. Respect the expertise I bring to the team.

Speak to me in plain language. Medical lingo and jargon gets lost in translation. Remember that I may be operating on little sleep. Even if I am not sleep-deprived, I am juggling many balls. Help me manage them by telling me what I need to know in a language that we both understand.

Explain the diagnostic criteria to me in more than one way. The way you say it may not be how I perceive it or the way I would describe it to you. The signs, symptoms and behaviors I note in my child outside of the appointment are important. Help me understand what I am looking for, share with me how to best communicate it to you, and ask questions until you are sure you understand.

Consider that I may know what I'm talking about. Sure, my child may not fit the diagnostic criteria during a particular office visit, but I may be onto something that should be considered.

If you don't know, admit it. I appreciate honesty. When you mask your insecurity behind detached interactions, our relationship suffers. I understand being unsure, confused, and even fearful and if that is how you are feeling too, I will respect you for telling me. Then we can work on it together.

If you are thinking I am imagining things, be very careful. Are you sure? Is it possible that what I am saying is true? Is it possible you just don't know? Telling me I am imagining things, or making me feel dismissed, is going to immediately amplify all the worry and stress I currently feel. It will make it difficult for me to keep my focus where it needs to be. There is a child in the middle of this. You must be sure.

If you are giving my child a diagnosis, understand that you are about to change my whole world. The words you say will resonate with me forever. Please try to understand and respond to the emotional impact, whether it is tears, anger or numbness. I may need to digest and collect my thoughts before I can ask any questions--that doesn't mean I am in denial. Have someone available to me when the time for questions comes along.

Understand that the best support comes from other parents who are raising children with special needs. They will understand my emotions and answer questions that you probably can't. Have information available on how to connect with those parents.

Provide me information about evidence-based research regarding my child's diagnosis. Don't assume that I can find it on my own or afford to print it.

Let me know that I haven't done anything wrong. There will be those who will judge me without knowing the facts. I need your assurance that my child's condition is not my fault. You have no idea how important this is. I may need to hear it more than once.

Find a way to get information to my child's other parent. Always ask about the other parent. They may not be able to accompany me to the appointment, but that does not mean they don't want to be a part of the care team. I am stressed and may not be the most reliable source to give them important information. A written plan of care and summary of the office visit is very helpful.

Don't assume anything about my child because of a diagnosis. Regardless of the diagnosis, my child is an individual and far more than their diagnosis. Please treat him/her as such.

If you have questions about my adolescent child, direct your attention to him/her. My child needs to be informed to the best of their understanding so that they can advocate for themselves both in and out of the medical office setting. If I don't understand why this is important, help me understand while respecting my fears. If it is a sensitive topic that may upset my child, find a way to talk to me without my child present.

Making decisions that impact my child is scary for me. I want to be involved, but that does not necessarily mean I want to be in charge. I need your expertise to help guide me to the best care and decisions for my child. I may not have enough information, so I rely on you to share information and suggestions based on your experience. Ask questions about the level of involvement I am comfortable with, and support me when there is a decision only I can make.

Communicate with my child's other providers. Help me build a care team with specialists we are both comfortable with and once we do, communicate with them. I may not realize what information is critical to pass along or I may simply forget. Work with me to create a family-centered medical home.

Don't act like the surgery that you are about to perform on my child is no big deal. You may have done it a hundred times, but to a parent any kind of surgery is terrifying. Best rule of thumb, it's all a big deal.

Follow up. After a test, I want to hear if the results were good, bad or indifferent. If there is complex news to share, invite me and my child's other parent into your office to discuss the results. Have information on supports and services available to us.

Remember, I'm busy too. I am raising this child and managing the complexity of life that goes along with that. I may have a job, a spouse and/or other children or aging parents to care for. In the limited time we have together, please don't make me feel rushed.

Ask me how I am doing. You may be surprised at what you learn from my experience. You may see that I need supports and services for myself. Always ask how your proposed treatment plan is going to impact the existing routines of the family. Can it be tweaked to make it more manageable?

I am not a super-parent. You see a parent who is knowledgeable, a strong advocate and organized. I have my breakdown moment, too. This is tough and unpredictable. Don't think that I have it all together all the time. Consider that I may need your permission to talk about what is not going well.