

The Role of Healthcare Providers in Bridging Medical Communication Gaps Among Autistic Patients: An Important Message to Autistic Adults about The Responsibility of Healthcare Providers

Dear Autistic Adult,

I have been through many different medical experiences with various types of providers and have used the strategies shared throughout this website to maximize my success.

Sometimes, despite my best efforts, I still leave appointments feeling unheard, misunderstood and frustrated with healthcare. I used to blame myself and wonder what I was doing wrong.

Then I came to the realization there are some providers who may not ever be a good fit for me and my needs. Some providers lack knowledge and experience treating autistic patients and others just lack a desire to understand or accommodate me. If this has been your experience and no one has told you, let me say it now: It's not your fault.

Throughout the years, I've learned that it is okay to question and/or disagree with my providers and to share with them why I felt appointments did not go well.

I've also discovered that it is my right to find a different provider when necessary. In the pages that follow, I want to share with you some helpful suggestions to try when an appointment does not go well.

Kim Clairy, OT Autistic Adult December 2020

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Although it can be helpful for you to use strategies to help healthcare appointments go smoothly, it is also the responsibility of the medical provider to contribute to the success of your appointment. Sometimes an appointment may not go well because the medical provider lacks knowledge regarding autism. They also may not fully understand what you need from them to be successful during healthcare visits.

Many providers are interested in learning how to better support autistic patients. However, you may encounter a provider that is not cooperative with your strategies and needs during a visit. In this case, here are a few suggestions:

- Talk to a trusted person about your concerns. Share with them the strategies you tried during your healthcare appointment and the response(s) of the provider. Sometimes it can help to get the input of a trusted person and they can help you determine next steps you should take.
- 2. Share feedback with your provider via email or healthcare portal. After an appointment, send a short message to your provider about what they did that was helpful as well as a few things you would like to be done differently during the next appointment. Your provider may not realize what you need to be successful.

- 3. Explain why you are requesting certain accommodations. When making requests for the provider to implement during the next appointment, it can be helpful to state the request and then explain how that will promote your success (e.g., please turn off any overhead fluorescent lights because they are so overwhelming that it reduces my ability to focus on what you are saying).
- 4. **Seek a more supportive provider**. If your insurance allows, seek out a different provider that may be more supportive during your visit. Many people find a new provider if they are not satisfied with the care they are receiving.
- 5. Question your providers' recommendations or assessments when you disagree or need more information. Explain why you think differently in a polite manner in order to promote a mutually respectful relationship. Sometimes the provider may give you more information that justifies their recommendations, but if you continue to disagree with their opinion, seek out a second opinion from a different provider.
- 6. Start out with a provider that is knowledgeable in autism. To reduce the chance of being misunderstood or unsupported by a provider, before making an appointment, inquire about their knowledge of autism and experience with other autistic patients. Finding providers that have advanced understanding in supporting autistic patients can be a challenge at times, but they do exist. You can even try contacting pediatricians or pediatric specialists (e.g., pediatric Occupational Therapists) who tend to have more autism training than adult providers and ask them to consider accepting you as a patient/client (it can be helpful to explain to them why!).

For more information: www.autismstaysafe.org