Self-Advocacy Tips

Self-advocacy is an important skill to have in gaining communication access in all environments including telehealth and it begins with your understanding of your vision and hearing loss, the barriers you are facing and knowing what you need to communicate.

1. Know your rights:
   - The U.S. Department of Health & Human Services and the U.S. Department of Justice have provided Guidance on Nondiscrimination in Telehealth and are “committed to ensuring that healthcare providers who use telehealth, including telehealth that is available 24/7, do so, in a nondiscriminatory manner”.
   - The Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act require that healthcare providers provide individuals with disabilities full and equal access to their healthcare services. Effective Communication is essential to the patient being able to access health services that are provided at the same level of care as the general population.
   - The ADA applies to public and private hospitals, clinics, and healthcare providers. Section 504 of the Rehabilitation Act applies to recipients of federal financial assistance such as Medicaid and federally funded programs. Section 1557 of the Affordable Care Act protects against discrimination in the delivery of or receipt of covered health programs or activities.
   - The 21st Century Communications and Video Accessibility Act requires access to video communications such as those used for telehealth.
   - It is your right to have communication access and it is the responsibility of the healthcare provider to provide it.

2. Know what to expect:
   - Ask questions that will help you prepare
     - What platform will be used?
     - Do you login to the patient portal to access the appointment?
     - Who will you meet with first, the healthcare provider or someone else?

3. Know the accommodations you will need:
   - An accommodation is a change in the usual way of communicating to provide communication access to the patient and/or companion.
   - Before you contact your provider to schedule an appointment, be aware of the accommodation(s) you will need. If you need help learning about possible accommodations, contact the NC DSDHH DeafBlind Services Specialist for a consultation.
4. **Request accommodations:**
   - Request accommodations when scheduling the appointment
     - Note the name, job title, phone number and/or email of the person who will handle the accommodation request.
     - You will need to ask for your accommodations with each provider for every appointment.
   - Follow up with the contact person a week before the appointment to confirm everything is all set. If you have requested an interpreter, ask for the interpreter’s name.
   - Remind your provider before the appointment of the [Communication Guidelines Checklist for Healthcare Providers Working with DeafBlind Patients](#) document.

5. **Additional tips:**
   - Ask the person who schedules the appointment to provide you with a direct contact phone line for the provider that will meet with you. This will be useful if you become disconnected during the telehealth call and need to reconnect easily without having to navigate a complex phone system.
   - Some healthcare providers are willing to text with patients, while others have policies against it. Ask your provider if they are willing to text with you if you prefer texting.
   - Consider using the patient portal for communicating with your provider and getting information about your appointment. See the [Tips for Navigating the Patient Portal for DeafBlind Patients](#) document to learn more about this option.

*To learn more about your rights during telehealth appointments, and how to advocate for your communication access, please contact the [NC DSDHH Regional Center](#) near you.*

*This document is not legal advice and is intended as informational guidance only.*