CYSHCN and Family Rights and Responsibilities for Telehealth

RIGHTS

You have the right to receive considerate, respectful and compassionate care through telehealth regardless of your age, gender, race, national origin, religion, sexual orientation, gender identity or disabilities.

You have the right to receive safe and high-quality care within the range of services that telehealth provides.

You have the right to ask your provider or the appropriate office staff any questions about logging on to, and needing assistance with, the telehealth platform.

You have the right to accommodations for vision, hearing and speech to be able to access your telehealth visit.

You have the right to access a telehealth visit in your primary language with effective and adequate interpretation services.

You have the right to have a family member, support person, or other individual present with you during your telehealth visit.

You have the right to share information and ask questions during a telehealth visit as you would during an in-person visit.

You have the right to receive the same type of information, such as test results or diagnosis, during telehealth as you would during an in-person visit.

You have the right to discuss and collaborate in making plans of care during a telehealth visit as you would during an in-person visit.

You have the right to disagree with any plans or ask for review or changes to the plan of care in a telehealth visit just as you would during an in-person visit.

You have the right to request an in-person visit if you feel that the telehealth visit will not meet your child or family's needs.

You have the right to stop a telehealth visit if you feel uncomfortable at any time.

You have the right to share a concern or grievance about your telehealth visit verbally or in writing with your provider and/or office staff.
You have the right to ask any trainees or support personnel observing or assisting in your telehealth visit to leave the room or discontinue viewing/listening to your visit.

You have the right to ask questions and receive information related to the confidentiality and privacy of your telehealth visit and the use of your medical information.

You have the right to access, either in writing or through an online portal, any plans of care, orders or action items from the telehealth visit.

You have the right to share in the planning of the next telehealth visit or follow-up actions.

RESPONSIBILITIES

■ Actively participate in the telehealth visit with information and updates about your child’s health, such as:
  - celebrations in your child’s life since last visit,
  - concerns, symptoms, treatments or hospitalizations since last visit,
  - medications,
  - updates from other providers, and
  - any other information you think your providers might need to know.

■ Offer your child or youth the same opportunity to actively participate in the telehealth visit. If your child or youth needs an accommodation to participate, such as for hearing, set it up ahead of the visit. Additionally, if your child or youth does want to participate, support their communication needs (such as with augmentative communication) or efforts ahead of the scheduled telehealth visit.

■ Prepare your child to participate in the telehealth visit, for example:
  - Schedule the appointment at a time of day that works for them
  - Discuss where to have the visit in your home so that is accessible and your child feels comfortable
  - Practice using the telehealth platform ahead of time so it is familiar
  - Discuss what to expect during the visit by using accessible language (“it is like when we face time with grandma but with Dr. Smith”), social stories, pictures or other communication tools
  - Encourage your child to bring something that gives them comfort to the visit, such as a stuffed animal or wear a favorite shirt

■ Assist with any physical examination of your child that may be needed during the telehealth visit.

■ Demonstrate in-home aspects of your child’s care, such as use the camera to show how equipment is used or how a medicine is dispensed.

■ Ask questions when you do not understand information or the plan of care.

■ Take notes of any questions or concerns you have, or of any orders, plans and action items discussed during the telehealth visit.

■ Treat your doctors, nurses and other health care team members participating in the telehealth visit with respect.