

## What is Family-Centered Telehealth?

Family-centered telehealth is a way of providing services through a variety of digital platforms that assures the health and well-being of children and youth with special health care needs (CYSHCN) and their families through respectful family/professional partnerships. Although this way to deliver health care is not new, the use of telehealth platforms for providing health care and related services to CYSHCN is unprecedented. Therefore, it is necessary to ensure that telehealth is not simply reactive or a temporary substitute for in-person care, but actively uses the core concepts of family-centered care to enhance the delivery of healthcare services and meet the needs of CYSHCN and families. The core concepts of family-centered care, detailed below, relate to dignity and respect, information sharing, participation, and collaboration. Family-centered telehealth can help CYSHCN and families access health care, improve experience with healthcare, reduce stress, improve communication between all team members and across systems, and improve quality of life and well-being.

## Core Concepts of Family-Centered Telehealth

### Dignity and Respect

Ask for, listen to and integrate the strengths, cultures, traditions, and expertise that CYSHCN, families and professionals bring to the telehealth visit. Families define themselves and determine who and how they will participate in their children's care, decision-making and telehealth visits. Build on family strengths and acknowledge the family as the constant in the child's life. Support CYSHCN in learning about, self-managing and participating in his/her care and decision-making.

### Information Sharing

Communication goes in both directions, between CYSHCN and families and their health care teams, and is open and honest. All members of the health care team, including CYSHCN and their family, receive timely, complete and accurate information in order to foster shared decision-making and effectively participate in telehealth. Discussions are not limited to symptoms, concerns, needs and clinical information, but also celebrate successes and involve other aspects of child and family life.

## Participation

Ensure access to broadband or cellular signals, devices and platforms necessary for CYSHCN and families to engage with and support the use of technology for telehealth. Work together as partners to develop creative, flexible and responsive adjustments, modifications or accommodations to access and participate in telehealth. Encourage and support CYSHCN and families to participate in care, planning of care and shared decision-making during telehealth. Support youth to learn how to participate in telehealth.

## Collaboration

Acknowledge trust as fundamental to family-centered care and communication, and be willing to negotiate. Integrate CYSHCN and families into the care team; value celebrations, challenges and needs in the collaborative planning and decision-making processes. Encourage family-to-family and peer support to navigate telehealth and other systems of care (health, education, social, justice, etc.). Partner in meaningful and authentic ways with CYSHCN and families to improve, create and guide telehealth policy at the systems level.