

# Facilitated Mini Training: Promoting Family Centered-Care for CYSHCN through Telehealth Training

## Speakers Notes

<p><b>Facilitated Mini Training – Promoting Family Centered-Care for CYSHCN through Telehealth</b></p> <p><small>This training was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$6,000,000 with no percentage financed with nongovernmental sources. The contents are those of the authors and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.</small></p> <p><small>The format for this training was inspired by the Spark trainings developed by the Adolescent Health Initiative at the University of Michigan. Their trainings can be found on their website at: <a href="http://bit.ly/AHL_Spark">http://bit.ly/AHL_Spark</a></small></p> <p><small>American Academy of Pediatrics DEDICATED TO THE HEALTH OF ALL CHILDREN</small></p>	<p>Slide 1&gt;&gt;</p> <p>Today we are going to do a facilitated mini training (mini training on Family Centered Care). The idea is to encourage discussion around this topic. In this training we will explore best techniques and strategies as it relates to Family Centered Care for CYSHCN through telehealth.</p> <p><b>As we get started, what words come to mind when you hear the phrase “family centered care”? Who can describe some of the components of family centered care?</b></p>
<p><b>LEARNING OBJECTIVES</b></p> <ul style="list-style-type: none"> <li>Understand telehealth needs for families/caregivers of CYSHCN.</li> <li>Describe strategies that clinicians and families can use to address family/caregiver telehealth needs.</li> <li>Describe 3 strategies to effectively <b>engage families/caregivers</b> of CYSHCN during telehealth visits</li> <li>Describe 3 strategies to effectively <b>build family/professional partnerships</b> via telehealth.</li> <li>Describe at least 3 strategies to facilitate <b>culturally competent</b> telehealth care for families/caregivers and patients.</li> </ul> <p><small>American Academy of Pediatrics DEDICATED TO THE HEALTH OF ALL CHILDREN</small></p>	<p>Slide 2&gt;&gt;</p> <p>The learning objectives for this session are to:</p> <ul style="list-style-type: none"> <li>Understand telehealth needs for families/caregivers of CYSHCN.</li> <li>Describe strategies that clinicians and families can use to address family/caregiver telehealth needs.</li> <li>Describe 3 strategies to effectively engage families/caregivers of CYSHCN during telehealth visits.</li> <li>Describe 3 strategies to effectively build family/professional partnerships via telehealth.</li> <li>Describe at least 3 strategies to facilitate culturally competent telehealth care for families/caregivers and patients.</li> </ul>
<p><b>WHAT IS FAMILY-CENTERED CARE?</b></p> <p>Family-centered care is:</p> <ul style="list-style-type: none"> <li>– A way of providing services that assures the health and well-being of children and their families through respectful family/professional partnerships;</li> <li>– It honors the strengths, cultures, traditions, and expertise that families and professionals bring to this relationship;</li> <li>– Improves the patient's and family's experience with health care, reduces stress, improves communication, reduces conflict (including lawsuits), and improves the health of children with chronic health conditions (1, 2)</li> </ul> <p><small>American Academy of Pediatrics DEDICATED TO THE HEALTH OF ALL CHILDREN</small></p>	<p>Slide 3&gt;&gt;</p> <p>In pediatrics in general, patient- and family-centered care is based on the understanding that the family is the child's primary source of strength and support. Further, this approach to care recognizes that the perspectives and information provided by families, children, and young adults are essential components of high-quality clinical decision-making, and that patients and family are integral partners with the health care team. Family centered care for CYSHCN is rooted in continuity of care. Telehealth can offer opportunities to connect that are more convenient for families while maintaining essential clinician-patient relationships.</p> <p>Therefore, some components that go into family-centered care are:</p> <ul style="list-style-type: none"> <li>Providing services through respectful family/professional partnerships.</li> <li>Honoring the strengths, cultures, traditions, and expertise that families and professionals bring to this relationship.</li> <li>Improving the patient's and family's experience with health care, reduces stress, improving communication, reduces conflict (including lawsuits), and improves the health of children with chronic health conditions.</li> </ul>

### 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.

American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN

#### Slide 4>>

So, what about family-centered care via telehealth? When it comes to telehealth visits, the same principles and components of family-centered care should apply. While the service may now be provided through a variety of digital platforms, the focus should remain on assuring the health and well-being of children and their families through respectful family/professional partnerships.

Therefore, the goal of this presentation is to explore those useful and practical considerations for assuring family-centered care for children and youth with special health care needs (CYSHCN) and their families **that are applicable to telehealth care.**

### WHAT IS FAMILY-CENTERED TELEHEALTH?

- Dignity and Respect
- Information Sharing
- Participation
- Collaboration

American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN

#### Slide 5>>

What are some main concepts of family-centered telehealth?

- **Dignity and Respect**
  - Everyone brings different perspectives- honor them.
  - Who, what and how participation will look for telehealth is defined by the family?
  - The family is the constant in the child's life.
  - Do not forget the child, empower them as the main participant in their own care.
- **Information Sharing**
  - Open and honest communication in both directions is crucial.
  - Timely, complete, and accurate information is required to foster shared decision-making.
  - By celebrating family successes, discussions are not limited to just symptoms and clinical information.
  - Share web-based resources easily and review together
- **Participation**
  - Access for all to broadband signals, devices and platforms are paramount.
  - Creativity, flexibility and adjustments, modifications or accommodations may be needed for family participation.
  - Encourage participation in care, planning of care and shared decision making by family.
  - Youth may need extra support to participate in telehealth.
- **Collaboration**
  - Trust is fundamental to family-centered care.
  - Integrate Families into the care team.
  - Value celebrations, challenges and needs in the planning and decision-making processes.
  - Encourage family-to-family and peer support to navigate telehealth.
  - Include family centered perspectives to create and guide telehealth policy.

### TELEHEALTH OPPORTUNITIES AND CHALLENGES

#### Opportunities

- Reduced burden of travel on families
- Increased access to health care for families of "rural" or underserved or rural communities
- Reduced wait time to receive medical services
- Ability to demonstrate challenges in the natural environment
- Opportunity for collaboration with other providers, community partners, and extended family members
- Opportunity to share web-based resources and review in real time
- Opportunity for family to step out of the "room" and share confidential concerns in less obtrusive way
- Increased personalization of visits by seeing, getting, trying, assessing, more
- Time off work/school

#### Challenges

- Access to internet or broadband
- Access to tele-ready devices
- Challenges with technology literacy
- Finding a quiet space, private space to hold appointments
- Concerns regarding confidentiality and security
- Lack of personalization due to virtual nature of visit can lead to reduced partnership
- Inability to perform physical exam and validity of observations
- Reduced accessibility if disability accommodations are not available

American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN

#### Slide 6>>

**What are some opportunities that Telehealth presents for Family Centered Care in the populations that you serve?**

**<wait for responses/discuss responses>**

**What are some challenges?**

**<wait for responses/discuss responses>**

- There are several Opportunities and Challenges that Telehealth poses for providing family-centered care.
- For example, travel to visits contributes to family burden. Some families are unable to take paid time off or leave from their employment to get their child to appointments. This is magnified when a child has special health care needs. Telehealth allows families to determine what location is best for them to participate in their health care. It may be their home, their school or they may choose to attend an in-person doctor's appointment. This helps CYSHCNs and their families develop self-determination skills and advance shared decision making between the care team and the family.
- There is added cost to the family when each visit must be in person. Gas, time off work, missed school and other opportunity costs. There are also added facilities expenses on hospital and clinic infrastructure when all appointments are in person. Telehealth options can help reduce this burden for both the family and the medical organization.
- Access to more efficient care through telehealth can support a family's access to more frequent visits and follow-ups. Compliance with treatment may be improved.
- Some CYSHCNs experience significant behavior challenges in transit from one location to another. Telehealth offers an alternative to accessing needed care while keeping the child and caregivers safe and comfortable.
- There are many benefits to telehealth that enhance family centered care for CYSHCNs. Reducing burden associated with travel, costs, time away from work and school that is often associated with SHCNs is a major benefit.
- There are also opportunities for improvement. Access to devices and available broadband internet in urban and rural locations can be a significant barrier to telehealth access. Limitations in physiologic monitoring like vital signs and other measurements can be a barrier to supporting CYSHCN via telehealth.
- Payment parity will also be essential to supporting the availability of telehealth services for all people.

#### COMPONENTS OF FAMILY CENTERED-CARE FOR CYSHCN THROUGH TELEHEALTH

- 1 Addressing needs for families/caregivers of CYSHCN
- 2 Engaging families/caregivers of CYSHCN during telehealth visits
- 3 Building effective family/professional partnerships via telehealth.
- 4 Facilitate culturally competent telehealth care for families/caregivers and patients.

American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN

#### Slide 7>>

There are 4 main Components of Family Centered-Care for CYSHCN through Telehealth. In this presentation we will go over examples of each one in more detail...

#### ADDRESSING FAMILY/CAREGIVER TELEHEALTH NEEDS



American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN

#### Slide 8>>

Here are some examples of strategies that clinicians and families can use to address family/caregiver telehealth needs: these can include options for personal or virtual visits, setting clear expectations, discuss accommodations, be clear about expectations, understand technology needs, prepare visuals.

**What are some strategies that you have used and found particularly effective or challenging in addressing family/caregiver telehealth needs?**

**<wait for responses/discuss responses>**

Slide 9>>

#### ADDRESSING FAMILY/CAREGIVER TELEHEALTH NEEDS

- Creating the Space to Connect
  - Co-Parents; Extended Family
  - Team Members
  - Virtual Case Conferences
  - Caregiver to pediatrician in private
  - Patient to pediatrician in private
  - Teaching trainees

American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN

- Some additional ways to address family/caregiver telehealth needs can be:
- Co-parents and extended family can attend from any location, allowing for more communication across family members.
- Multiple team members like therapists, aides, case-managers can attend from their respective locations to foster additional modes of information sharing.
- Professional case conferences can be facilitated through telehealth and engage all care members – medical, therapy, school, and home care can be more easily engaged through increased access as compared to an in-person care conference (team members do not have to travel)
- Parents/caregivers can step into a more private room to have a conversation about specific topics that may be sensitive. Similarly, children and youth can take the telehealth device to a private spot and connect with their pediatric care provider in much the same way. This offers more opportunities for dignity and respect to be maintained while continuing to foster continuity of care.
- Telehealth also offers opportunities to continue teaching medical students, residents, and others about how to deliver family-centered care to CYSHCNs. They are able to continue learning alongside their preceptor in the same way they would in person.

Slide 10>>

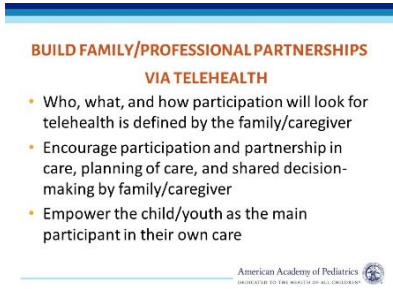

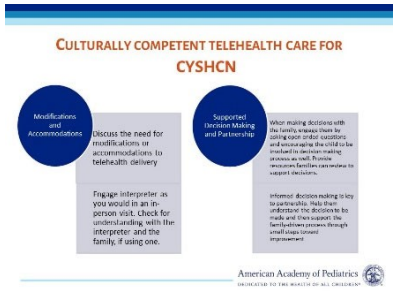
#### ENGAGING FAMILIES/CAREGIVERS OF CYSHCN DURING TELEHEALTH VISITS

- Value celebrations, challenges, and needs in the planning and decision-making process
- Observe/Show and Tell
  - Look at their interests
  - Meet sibling, pets, see their room/collections
  - Virtual Background fun, videos, toolkits
- Encourage family/patient to share one great thing they did this week
- Provide timely, complete, and accurate information and feedback
- Have open and honest conversations

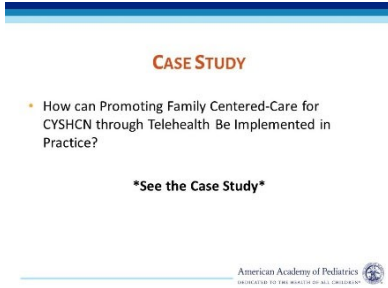

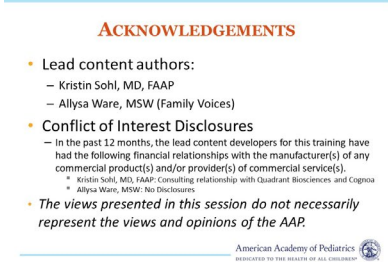



American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN

- Next, we have some strategies for engaging families/caregivers of CYSHCN during telehealth visits:
- Telehealth allows you to connect with patients and their families in new ways. Helps to **celebrate** their successes and identify areas for growth and focus by allowing more personal glimpses into the families lived experience.
- Telehealth offers opportunities to more fully appreciate the context of the CYSHCN at home/community. For example, to **observe** how they maneuver equipment around their home, how they interact with siblings or pets and what their interests are. It also offers opportunities to guide parents during real-time situations that may be more representative of day-to-day life than what can be seen in a clinic setting (thinking behavior). You can also engage with families through show and tell as a way for the CYSHCNs to demonstrate their own interests and ideas about their health and future.
- Telehealth also offers unique opportunities to engage patients that traditional in-person does not through novel virtual backgrounds in the child's interest or through other unique virtual experiences that can strengthen the doctor-patient relationship. Telehealth visits are also great for sharing other visual tools, such as videos, handouts, and web toolkits.
- Encourage family/patient to share one great thing they did this week as well as provide timely, complete, and accurate information and feedback.
- It is also very important to maintain the focus on having open and honest conversations with the families, value celebrations, challenges, and needs in the planning and decision-making process. This helps to lay the foundation for trust and relationship with the patient as they get to be actively engaged in the visit and may have more opportunity to feel comfortable as they are in their environment. This can lead to better self-determination skills and self-advocacy skills over time.

	<p><b>Which of these engagement strategies do you think might be most effective during the telehealth visits with the families/caregivers that you serve? What fun ways do you connect with patients in your office? What could you try in the virtual space that would be fun there, too?</b></p> <p><b>&lt;wait for responses/discuss responses&gt;</b></p>
 <p><b>BUILD FAMILY/PROFESSIONAL PARTNERSHIPS VIA TELEHEALTH</b></p> <ul style="list-style-type: none"> <li>Who, what, and how participation will look for telehealth is defined by the family/caregiver</li> <li>Encourage participation and partnership in care, planning of care, and shared decision-making by family/caregiver</li> <li>Empower the child/youth as the main participant in their own care</li> </ul> <p>American Academy of Pediatrics DEDICATED TO THE HEALTH OF ALL CHILDREN</p>	<p>Slide 11&gt;&gt;</p> <ul style="list-style-type: none"> <li>Building strong family/professional partnerships should continue to be a priority via telehealth.</li> <li>It is important to stay focused on family/caregivers role in the decision-making process of their care plan. Therefore, family/caregiver should continue to define who, what and how participation will look for telehealth.</li> <li>You should encourage this participation and partnership in care, planning of care, and shared decision-making by family/caregiver, as well as empower the child/youth as the main participant in their own care.</li> </ul>
 <p><b>BUILD FAMILY/PROFESSIONAL PARTNERSHIPS VIA TELEHEALTH</b></p> <ul style="list-style-type: none"> <li>Shared Learning <ul style="list-style-type: none"> <li>Family/caregiver check-in. <i>How are you doing?</i></li> <li>Share one great thing your child did this week</li> <li>Review of IEP/school supports</li> <li>Review of clinic based supports – SLP, OT, PT</li> <li>Discuss family/caregiver's perception of progress</li> </ul> </li> <li>Community Resources <ul style="list-style-type: none"> <li>Regional office, parent support group, respite, behavior therapy</li> <li>Toolkits to support current issues</li> </ul> </li> </ul> <p>American Academy of Pediatrics DEDICATED TO THE HEALTH OF ALL CHILDREN</p>	<p>Slide 12&gt;&gt;</p> <ul style="list-style-type: none"> <li>There are also many opportunities for shared learning in the care of CYSHCNs. Telehealth care supports this.</li> <li>You can start out with starting with the child's strengths that week and how the family is doing before jumping into more procedural things.</li> <li>Some platforms offer secure file transfer allowing real time transfer of documents like IEPs that the family/caregiver has that need to get to the EMR. All telehealth systems allow for visual sharing of information like showing a document to the camera or possibly sharing the screen.</li> <li>Patients and caregivers can more easily share their information with the care team (share screen, show and tell) and pediatricians can share real time plain language resources through screen share or link sharing directly through a link in the chat feature of most platforms.</li> </ul> <p><b>Which of these strategies for building family/professional partnerships via telehealth do you think might be most effective with the families/caregivers that you serve?</b></p> <p><b>&lt;wait for responses/discuss responses&gt;</b></p>
 <p><b>CULTURALLY COMPETENT TELEHEALTH CARE FOR CYSHCN</b></p> <p><b>Modifications and Accommodations</b> Discuss the need for modifications or accommodations to telehealth delivery</p> <p><b>Engage interpreter as you would in an in-person visit. Check for understanding with the interpreter and the family, if using one.</b></p> <p><b>Supported Decision-Making and Partnership</b> When making decisions with the family engage them by asking open ended questions and encouraging child to be involved in decision making process as well. Provide resources family can review to support decisions. (Decision Aides)</p> <p><b>Informed decision making is key to partnership. Help them understand the decision to be made and then support the family-driven process through small steps toward improvement.</b></p> <p>American Academy of Pediatrics DEDICATED TO THE HEALTH OF ALL CHILDREN</p>	<p>Slide 13&gt;&gt;</p> <ul style="list-style-type: none"> <li>In order to offer culturally competent telehealth for CYSHCN, it is important to provide necessary <b><u>modifications and accommodations</u></b> for the families/caregivers as well as to <b><u>support shared decision-making and partnership</u></b>.</li> <li>Discuss the need for modifications or accommodations to telehealth delivery prior to the visit. Engage interpreter as you would in an in-person visit. Check for understanding with the interpreter and the family, if using one.</li> <li>When making a decision with family, engage them by asking open ended questions and encouraging child to be involved in decision making process as well. Provide resources family can review to support decisions. (Decision Aides)</li> <li>Informed Decision making is key to partnership. Help them understand the decision to be made and then support the family-driven process through small steps toward improvement.</li> </ul> <p><b>Which of these strategies for culturally competent telehealth do you think you might be most effective within the community that you serve?</b></p> <p><b>&lt;wait for responses/discuss responses&gt;</b></p>



	<p>Slide 14&gt;&gt;</p> <p><b>[Go over the case study]</b></p> <p><b>&lt;How can Promoting Family Centered-Care for CYSHCN through Telehealth Be Implemented in Practice? Do you anticipate any changes to processes or workflow? What are some barriers you might encounter, and how could those barriers be mitigated?&gt;</b></p>
	<p>Slide 15&gt;&gt;</p> <p>Here are some additional resources related to telehealth and family-centered care.</p>
	<p>Slide 16&gt;&gt;</p> <p>Here are the course author acknowledgements.</p>
	<p>Slide 17&gt;&gt;</p> <p>To keep this conversation going over the next month, I will share small posters that relate to this topic. I will share these around the office in places that you all can easily see them. Thank you for your time and participation today!</p>

*This course was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$6,000,000 with no percentage financed with nongovernmental sources. The contents are those of the authors and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.*