



# All Under One Roof

All Under One Roof: Caring for Children with Medical Complexity Across Settings  
Resources from all sessions

## **Session 1: Preparedness & Medical Emergencies on January 27, 2021**

Telehealth Rocks Schools: <https://www.telehealthrocks.org/>

### **Children with Medical Complexity or Chronic Conditions:**

- Key article: Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives. Pediatrics Mar 2011, 127 (3) 529-538; DOI: 10.1542/peds.2010-0910
- CDC Healthy Schools Managing Chronic Conditions: <https://www.cdc.gov/healthyschools/chronicconditions.htm>

### **Medical Home:**

- National resource center for patient/family-centered Medical home: <https://medicalhomeinfo.aap.org/Pages/default.aspx>
- Article: Mosquera RA, Avritscher EB, Samuels CL, Harris TS, Pedroza C, Evans P, Navarro F, Wootton SH, Pacheco S, Clifton G, Moody S, Franzini L, Zupancic J, Tyson JE. Effect of an enhanced medical home on serious illness and cost of care among high-risk children with chronic illness: a randomized clinical trial. JAMA. 2014 Dec 24-31;312(24):2640-8. doi: 10.1001/jama.2014.16419. PMID: 25536255.

### **Local Medical Home Programs and Resources for Children with Medical Complexity:**

- Beacon Program at Children's Mercy Kansas City: <https://www.childrensmercy.org/departments-and-clinics/beacon-program-and-clinic/>
- Pillars at KUMC <https://www.kansashealthsystem.com/care/conditions/pediatric-medical-complexity>

### **Support for CMC during the pandemic:**

- AAP guidance on Caring for Children and Youth with Special Health Care Needs during the pandemic: <https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/caring-for-children-and-youth-with-special-health-care-needs-during-the-covid-19-pandemic/>
- Children's Mercy COVID-19 Resources: <https://www.clechildrensmercy.org/health-and-safety-resources/information-about-covid-19-novel-coronavirus/returning-to-community-activities/>
- Telehealth Rocks COVID-19 Resources: <https://www.telehealthrocks.org/covid-19>
- CDC Making Decisions about Children Attending In-person School During the COVID-19 Pandemic: Information for Parents, Guardians, and Caregivers <https://www.cdc.gov/coronavirus/2019-ncov/community/schools-childcare/decision-tool.html>

### **Emergency Planning:**

- American Academy of Pediatrics: <https://www.aap.org/en-us/advocacy-and-policy/aap-healthinitiatives/Children-and-Disasters/Pages/CYWSN.aspx>
- Beacon Program Website <https://www.childrensmercy.org/in-the-community/resources-for-children-with-complex-medical-needs/>
- Video on Emergency Planning <https://youtu.be/24y3hUCJW1g>
- CDC: <https://emergency.cdc.gov> and <https://www.cdc.gov/ncbddd/disabilityandhealth/emergencypreparedness.html> and checklist: <https://www.cdc.gov/childrenindisasters/checklists/special-healthcare-needs.html>
- Children's Mercy Emergency preparedness website: <https://www.childrensmercy.org/health-and-safety-resources/emergency-preparedness/>
- Emergency Information Forms: AAP and ACEP <https://www.acep.org/Clinical---Practice-Management/Emergency-Information-Form-for-Children-With-Special-Health-Care-Needs/#sm.0000e1jynd13vzd5hrfwgkcofzwo4>
- Emergency Information Forms and Emergency Preparedness for Children With Special Health Care Needs. American Academy of Pediatrics, Committee on Pediatric Emergency Medicine and Council on Clinical Information Technology, American College of Emergency Physicians, Pediatric Emergency Medicine Committee. Pediatrics Apr 2010, 125 (4) 829-837; DOI: 10.1542/peds.2010-0186. <http://pediatrics.aappublications.org/content/pediatrics/125/4/829.full.pdf>
- The Whole Person Emergency Preparedness: <http://thewholeperson.org/resources/general-resource-library/emergencypreparedness.html>
- United Way 211: <https://www.unitedway.org/our-impact/featured-programs/2-1-1>

## **Session 2: Assistive Technology on February 24, 2021**

- Medical Home Portal- <https://www.medicalhomeportal.org/living-with-child/assistive-technology>
- Gastrostomy tube video by Children's Mercy Surgery- <https://www.youtube.com/watch?v=uUWLsa5surA&feature=youtu.be>
- Feeding Tube Awareness- <https://www.feedingtubeawareness.org/>
- Oley Foundation Troubleshooting a feeding tube- <https://www.feedingtubeawareness.org/>
- Toronto Sick Kids tracheostomy education- <https://www.aboutkidshealth.ca/article?contentid=3264&language=english>
- Parent decision guide for tracheostomy -<https://courageousparentsnetwork.org/guides/child-tracheostomy-decision-guide>

## **Session 3: Educational & Medical Supports on March 31, 2021**

### **Key Resources:**

- CDC Resources on Developmental Disabilities: <https://www.cdc.gov/ncbddd/developmentaldisabilities/freematerials.html>
- Wrights Law (Special education law and advocacy center) <https://www.wrightslaw.com/>
- Understood (Non-profit informational resource) <https://www.understood.org/about>

- Got Transition <https://gottransition.org/>
- Kansas State Department of Education (Special Education Resources) <https://www.ksde.org/Agency/Division-of-Learning-Services/Special-Education-and-Title-Services/Special-Education>
- Don't Wait and See: A Neuropsychologist's Guide to Helping Children Who are Developing Differently (Book), By: Emily Papazoglou, PhD, ABPP-CN
- Families Together (advocacy) <https://famielstogetherinc.org/contact-us/>
- Glossary of Developmental Disability Terms <https://ddrcco.com/resources/terms-and-definitions>

**Wichita Medically Complex Clinic:** <https://wichita.kumc.edu/pediatrics/pediatric-divisions/ambulatory-pediatrics/about-us/specialty-clinics/cerebral-palsy-clinic.html>

### **COVID-19 Specific:**

#### **Individualized Education plan (IEP) and 504 plan Advocacy:**

- Questions and Answers on Providing Services to Children with Disabilities During the Coronavirus Disease 2019 Outbreak. U.S. Department of Education. March 2020. <https://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/qa-covid-19-03-12-2020.pdf>

#### **Children's Mercy:**

- Protecting Children with Special Needs or Chronic Conditions: <https://www.childrensmercy.org/health-and-safety-resources/information-about-covid-19-novel-coronavirus/protecting-children-with-special-needs-or-chronic-conditions-during-covid-19/>
- Return to School and Community Safely: <https://www.childrensmercy.org/health-and-safety-resources/information-about-covid-19-novel-coronavirus/returning-to-community-activities/> which includes guidebook and consultation for schools
- CHILDREN'S MERCY COVID-19 HOTLINE (816) 302-8800 The hotline provides options for parents to ask questions regarding their child's health not answered on the website

#### **American Academy of Pediatrics (AAP):**

- American Academy of Pediatrics (AAP) HealthyChildren.org: <https://www.healthychildren.org/English/health-issues/conditions/chest-lungs/Pages/COVID-19-Information-for-Families-of-Children-and-Youth-with-Special-Health-Care-Needs.aspx>
- AAP Guidance for school re-entry: <https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/covid-19-planning-considerations-return-to-in-person-education-in-schools/>
- AAP Caring for Children and Youth with Special Health Care Needs During COVID-19 Pandemic: <https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/caring-for-children-and-youth-with-special-health-care-needs-during-the-covid-19-pandemic/>

#### **Centers for Disease Control (CDC):**

- Those who need extra precautions: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/index.html>
- Schools and Daycare: <https://www.cdc.gov/coronavirus/2019-ncov/community/schools-childcare/index.html>

## **Session 4: Psychosocial Supports on April 28, 2021**

### **Siblings support:**

- <https://www.siblingsupport.org>
- <http://siblingleadership.org>

### **Resource for families:**

- [Respite Care Notebook](#) from Child Neurology Foundation
- <https://insighttimer.com/BeaconMindfulness>
- <https://insighttimer.com/beaconmindfulness/guided-meditations/grounding-meditation-31>
- Kids Health Resources for Parents <https://kidshealth.org/en/parents/emotions/?WT.ac=p-nav-emotions#catfeelings>

### **Waivers:**

- MO Waiver Factsheet <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/Waiver-Descript-Factsheet/MO#4185>
- KS waiver fact sheet <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/Waiver-Descript-Factsheet/KS#4165>

### **Financial Supports:**

- Benefits for people with disabilities: <https://www.ssa.gov/disability/>
- Children & Youth With Special Needs Programs – MISSOURI: <https://health.mo.gov/living/families/shcn/cyshcn.php>
- Children & Youth with Special Needs Programs – KANSAS: <https://www.kdheks.gov/shcn/>

### **ABLE Account:**

- Video about Special needs trust and able accounts: <https://youtu.be/Zkiydp7VCXk>

### **Immigrant and Refugee support:**

- Communities Concerned for Immigrants and Refugees has printed translated materials and recorded webinars: <http://ccirkc.com/>
- Translated dental health materials: <http://www.kansasaap.org/wordpress/immigrant-oral-health-handouts/>
- <https://www.bethelcenter.org/>

### **Other:**

- Home health care for CMC: <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2018.05531>
- Beacon program <https://www.childrensmarcy.org/in-the-community/resources-for-children-with-complex-medical-needs/>

- Pillars: <https://www.kansashealthsystem.com/care/conditions/pediatric-medical-complexity>
- Bags of Fun: <https://bagsoffun.org/>
- Hope Kids: <https://www.hopekids.org/>
- Telehealth ROCKS website: <https://www.telehealthrocks.org>