



All Under One Roof

Caring for Children with Medical Complexity Across Settings

Session #4: Psychosocial Supports

April 28, 2021

Telehealth ROCKS

Rural Outreach for the Children of Kansas



All Under One Roof: Caring for Children with Medical Complexity Across Settings

Session #1

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- ▶ **Completion certificates** will be emailed after all sessions are complete. Make sure your first and last name are visible.
 - ▶ Use the “rename” feature in the menu to change.
- ▶ Please introduce yourself by name and role in the chat
- ▶ Chat will be moderated and materials will be sent after the session

Agenda

- ▶ Introduction & disclosures
- ▶ Didactic presentation
- ▶ Case Presentation
- ▶ Group discussion

Faculty

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Project Disclosure Statement

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- ▶ We do not intend to discuss an unapproved/investigative use of a commercial product/device in our presentation.

Mitigating Potential Bias

- ▶ The information and recommendations involving clinical medicine are based on evidence that is currently accepted within the profession and are not medical advice.

Assessment

- ▶ Surveys: please complete any survey assessments emailed to you related this ECHO series. We appreciate your feedback!
- ▶ Presentation materials: the slides and chat log will be emailed to you.

Caring for Children with Medical Complexity Across Settings

Session #4: Psychosocial Supports

Emily Goodwin MD, Ryan Smith MD, Dana Bakula PhD

April 28, 2021

Objectives

1. List Types of Home Care Supports
2. Describe basic financial supports
3. List supports for children and their families for coping with chronic illness
4. Become familiar with psychosocial stresses for CMC families and means to family empowerment

Impact on Caregivers

- ▶ Home care & Financial Supports
- ▶ Coping & Mental Health Supports
- ▶ Family Empowerment

Katie Beckett

Home Care for Children

| | | | |
|---------------|--|-----------------------------------|------------------------|
| Nursing | Physical, Occupational, & Speech Language therapists | Respiratory Therapists | Medical Social workers |
| Psychologists | Dieticians | Home health or personal care aids | Private duty nursing |

Source Simpson, E., Hudak, M.L., 2017. Financing of Pediatric Home Health Care. Pediatrics 139, e20164202.. doi:10.1542/peds.2016-4202

Home Care & Financial Supports Overview



- ▶ Medicaid
 - ▶ Waivers
 - ▶ EPSDT Early and Periodic Screening Diagnostic Treatment
 - ▶ Early Intervention Services
- ▶ Financial supports
 - ▶ Children & Youth with Special Health Care Needs Programs
 - ▶ Supplemental Security Income (SSI)
 - ▶ ABLE accounts & Special Needs Trust
- ▶ Home Health Services
 - ▶ Private Duty Nursing
 - ▶ Consumer Directed Personal Assistance Programs

Family should contact service support coordinator or insurance case manager to discuss options

Medicaid

- ▶ Private Insurance Benefits lack coverage for extended home health services, including nursing, rehabilitation/habilitation, durable medical equipment (DME), and respite care.
- ▶ These services may be provided under Medicaid (even as secondary insurance)
 - ▶ Public insurance benefit—many paths to qualify for Medicaid
- ▶ Problem:
 - ▶ Medicaid permits each state to define “medical necessity” for evaluation and treatment and allows latitude in establishing the duration and /scope of medically necessary treatment
 - ▶ Durable Medical Equipment -DME coverage often inadequate
- ▶ The result: Inconsistent provision of home services across states

How to Get Health Insurance for Your Child: Kansas



Medicaid Waivers

1915(c) Waiver aka Home and Community-based Services (HCBS) waiver

- ▶ Medicaid waiver that allows states to provide Medicaid and additional support services that make it possible for individuals who otherwise require an institutional level of care to live at home and participate in community life. HCBS/1915 (c) waiver availability and eligibility vary by state
 - ▶ States can offer individuals with disabilities extra benefits other Medicaid recipients do not receive (respite, home or vehicle modification, training, special medical equipment, personal support, behavioral services).
 - ▶ Unfortunately, not entitlements which = LONG wait lists (years)
- ▶ [Missouri Wavier Factsheet](#)
 - ▶ Children with DD (Sarah Lopez), DD Comprehensive, Partnership for Hope, Autism
 - ▶ Families should contact their regional office to apply; typically wait list
- ▶ [Kansas Waiver Factsheet](#)
 - ▶ Autism, Technology Assisted (TA), I/DD, Severe Emotional Disturbance (SED)
 - ▶ Different entry points; some do NOT have wait list; must know what to apply for

Other Waivers (1915c and 1115 Demonstration waivers)

Examples of Kansas Waivers

A 3 year old female is diagnosed with ASD. Family applies for the waiver through the Autism Waiver Program Manager and is placed on a waitlist.

A 16 year old male with Trisomy 21 would like to work part time at a local sporting goods store and eventually live on his own. He will need assistance with job training, transportation to and from work, and help with independent living skills, like meal prep and paying bills.

A 6 month old male with cerebral palsy, epilepsy, and g-tube is being released from the hospital. His parents both work and it is difficult to find daycare providers who are willing to manage seizure medications and tube feeds.

A 13 year old female with mild intellectual disabilities has trouble with running away from home, is physically aggressive with siblings when she doesn't get her way, occasionally refuses to go to school, and last week, started a fire in a shed behind the family's home.

Examples of Kansas Waivers

A 3 year old female is diagnosed with ASD.

- After two years on the waitlist, she is granted the **autism waiver**. She now has daily in home ABA therapies from an autism specialist and communication therapies. Their current focus is learning her name and address as she is a flight risk and also learning to try different healthy foods despite sensory issues. The child has a few hours a week of personal care assistance for after school hours when parents are still working.

A 16 year old male with Trisomy 21

- **IDD Waiver** -Knowing that he may need assistance in the future, his family applied when he was 8 years old through their local CDDO. After 8 years on the waitlist, he now has a PCA through the waiver that has helped him apply for jobs and learn independent living skills like laundry and making his own meals.

A 6 month old male with cerebral palsy, epilepsy, and g-tube feeding

- The child qualifies for the **TA Waiver** and private duty nursing automatically. Although they are not able to fill the PDN hours, the family is currently able to be paid as caregivers during the pandemic, so father can reduce hours at work to care for his baby's needs.

A 13 year old female with mild intellectual disabilities, history of elopement and aggressive and destructive behavior

- Family contacts the local community mental health center and she is deemed eligible for the **SED Wavier**. Now the family has access to in home family therapy, behavioral intervention, and 24/hour crisis supports.

Financial Supports

Supplemental Security Income (SSI): Benefits for people with disabilities

- ▶ <https://www.ssa.gov/disability/>
- ▶ Children with disabilities may qualify
- ▶ Amount varies state by state
- ▶ Families should go to website to find out if qualify to apply and go to local SSA office to apply

Children & Youth With Special Needs Programs

- ▶ Missouri [The MO CYSHCN Program](#)
- ▶ Kansas [The Kansas Special Health Care Needs \(SHCN\) Program](#)

Additional Resources for Children with Complex Medical Needs in MO & KS

- ▶ <https://www.childrensmercy.org/in-the-community/resources-for-children-with-complex-medical-needs/>

ABLE account

Special Needs Trust

- ▶ Both allow saving without endangering qualification for public benefits (Medicaid, SNAP, SSI)
- ▶ Used to purchase items not paid for insurance or SSI related to needs of the individual with the disability
- ▶ Encourage Families to discuss with a Financial Planner

Private Duty Nursing

- ▶ Funded through Medicaid so qualification varies by state
- ▶ Qualification considerations
 - ▶ Usually minimum (often 4 hours) per shift
 - ▶ technology equipment needs (tracheostomy)
 - ▶ cognitive status, behavioral issues
 - ▶ Assistance needs for activities of daily living
- ▶ Number of approved hours varies
 - ▶ Often not filled-National shortage of PDN

Foster, Agrawal, Davis 2019 [Home Health Care For Children With Medical Complexity: Workforce Gaps, Policy, And Future Directions](#)

COVID19 Emergency

COVID-19

| APPROVED MEDICAID EMERGENCY AUTHORITIES | MO | KS | US |
|--|----|----|-----------------|
| Approved 1135 Waiver Provisions | | | |
| Permit payment for state plan personal care services rendered by family caregivers or legally responsible relatives or representatives | No | No | Yes = 13 States |

Source: Kaiser Family Foundation (2021)

Tip: Data accurate as of March 5, 2021. [1135 Waiver authorities](#) are available during any public health emergency (PHE). The provisions presented here were approved through authorities available during the COVID-19 PHE. Additional waiver authorities approved during the COVID-19 PHE can be seen [here](#). For more information on emergency waiver authorities during the COVID-19 PHE and their impact on CYSHCN, please see [these Catalyst Center fact sheets](#).

| Approved Section 1915c Waiver Appendix K Provisions | | | |
|---|-----|-----|-----------------|
| Add home-delivered meals | Yes | Yes | Yes = 15 States |
| Add medical supplies, equipment, and appliances | No | Yes | Yes = 14 States |
| Add assistive technology | No | Yes | Yes = 7 States |
| Temporarily permit payment for services rendered by family caregivers or legally responsible relatives (if not already permitted in waiver) | Yes | Yes | Yes = 39 States |

Source: Kaiser Family Foundation (2021)

Tip: Data accurate as of March 5, 2021. [Section 1915c Appendix K Waiver](#) authorities are available during any public health emergency (PHE). The provisions presented here were approved through authorities available during the COVID-19 PHE. Additional waiver authorities approved during the COVID-19 PHE, can be seen [here](#). For more information on emergency waiver authorities during the COVID-19 PHE and their impact on CYSHCN, please see [these Catalyst Center fact sheets](#).

Behavioral Health

- ▶ What is “Behavioral Health”?
 - ▶ A blanket term (includes mental health)
 - ▶ How behaviors impact someone’s health – physical and mental
 - ▶ May include...
 - ▶ Coping with adversity
 - ▶ Mental health
 - ▶ Behavioral difficulties
 - ▶ Trauma responses

Child Behavioral Health

- ▶ Many children are quite resilient
- ▶ However...
 - ▶ Children with medical complexity are more likely than other children to have...

Depressive,
anxious, and
posttraumatic
stress symptoms

Behavior problems

Low self-esteem

- ▶ Learning difficulties also contribute to these concerns

Child Behavioral Health

Bronfenbrenner's Ecological Systems Theory

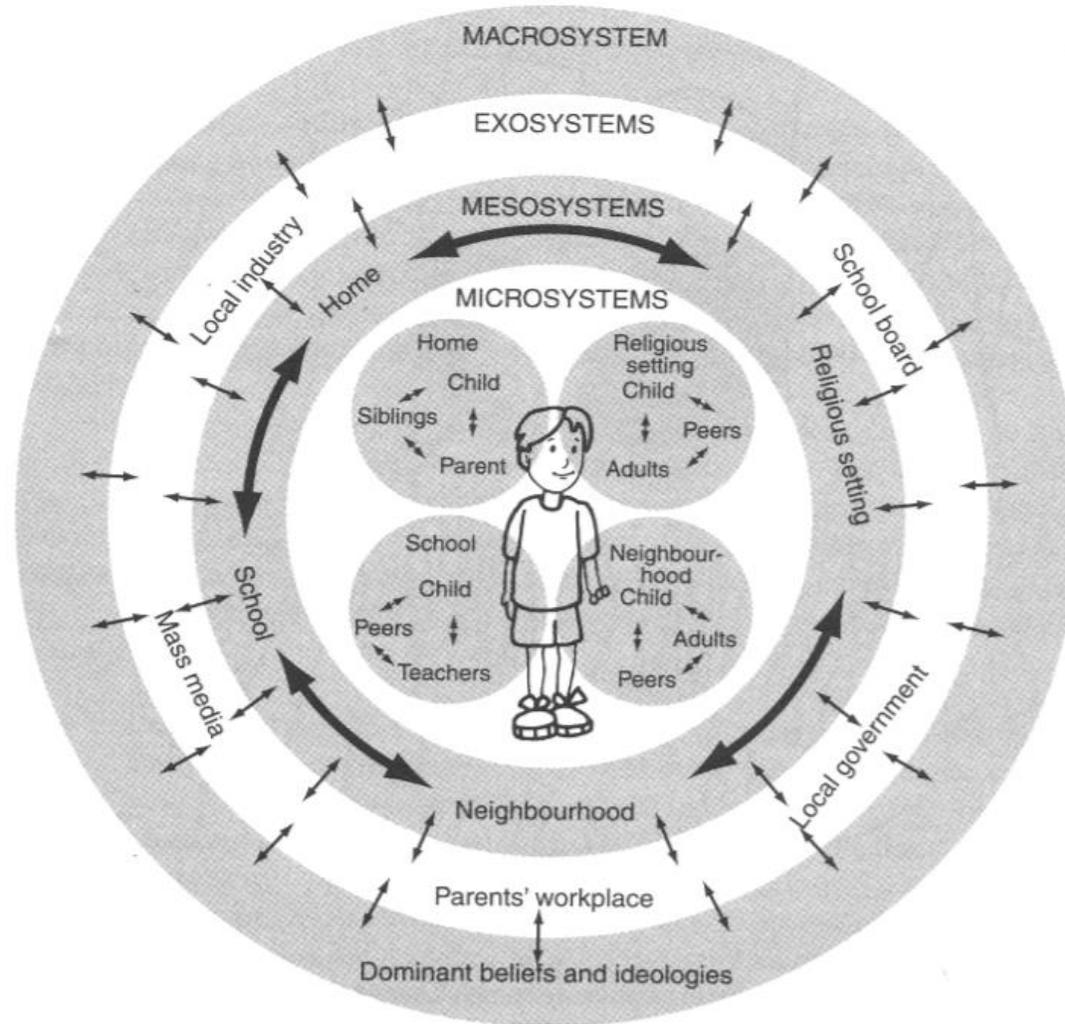


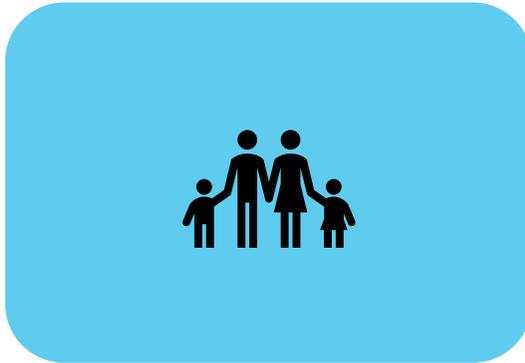
Figure 1. The ecological approach, which hypothesizes the layers of influence on a young child's development. (Picture scanned from Penn, H. 2005. Understanding early childhood education, Issues and controversies).

Family Behavioral Health

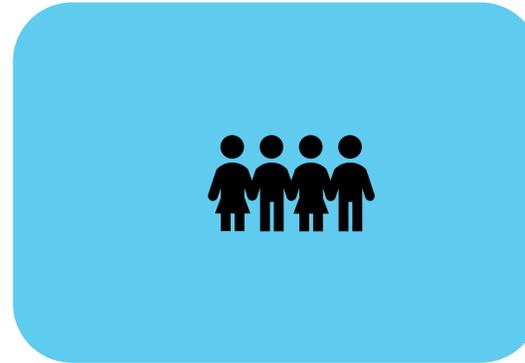
- ▶ Many parents and families are quite resilient
- ▶ However...



Parents are at higher risk for parenting stress & depressive, anxious, and posttraumatic stress symptoms



Families are at risk for poorer family functioning



Siblings can experience mental/behavioral health difficulties

Behavioral Health - Why Do We Care?

- ▶ Child behavioral health concerns can impact
 - ▶ learning and school engagement
 - ▶ Health
- ▶ Parent and family behavioral health can impact
 - ▶ child behavioral health
 - ▶ parent ability to complete important tasks
 - ▶ downstream effects on child health and learning
 - ▶ Access to basic needs: safety, housing, supervision of children, food/formula for feeds, transportation and ability to work for an income

Ways to Support Child Behavioral Health



Meet children's medical and educational needs



Patience



Use coping strategies to manage your own distress



Notice distress



Communicate with the family



Collaborate with/coordinate and communicate with PCP/care teams



Give hope and plan for follow up

- There are people who can help (psychologists, counselors, ABA therapists)

Ways to Support Family Behavioral Health



Recognize the inherent challenges as well as strengths of the child and family



Listen and Validate



Normalize



Ask permission to problem solve

- Consider options such as respite care, social support, talking with child's medical team, talking with parent's own PCP

How Behavioral Health Professionals Can Help

Behavioral Therapy/Parent Training

- Parent-Child Dyadic or Family Visits

Adaptive Child Therapies

- Adaptive Cognitive Behavioral Therapy
- Adaptive Trauma Informed CBT

Parent Therapy

- MBSR (link in resource slide)
- Problem Solving Training

Psychological evaluations with adaptive testing as appropriate

Advocacy and family support

Poll Everywhere: What words come to mind when thinking about what its like to be a parent of a CMC?

- ▶ Click the link in the chat
 - ▶ You can skip entering your name
 - ▶ Multiple words must be typed without a space
 - ▶ Example: Type “wordcloud” instead of “word cloud”

Family Empowerment: Moving forward together

- ▶ Family
- ▶ Service System
- ▶ Community



Barriers to
Care



Care
Coordination



Interactions
with providers

Respite Care

Psychosocial stresses

- Parents
- Families
- Friends

Including

- Strain on relationships
- Finances

Addressing stress of caregivers is critical

- Peer to peer supports

Finding Meaning and Joy

- ▶ Growing opportunities
 - ▶ Hope Kids
 - ▶ Flight to the North Pole
 - ▶ Camps
- ▶ Spend time with parents, siblings, and self
- ▶ Build/ identify/ grow relationships

Palliative Care

Discipline in health care that prioritizes quality of life and limiting discomfort

Patient- and family- focused

Not strictly hospice care

Key Takeaways

- ▶ Connect families to financial and social services and insurance supports
- ▶ It is important to both recognize and communicate about behavioral health concerns so that the family can be supported.
- ▶ Work to empower patients and recognize resources available in cases of family and child stress

Key Resources

Siblings support:

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

Resource for families:

- ▶ [Respite Care Notebook](#) from Child Neurology Foundation
- ▶ <https://insighttimer.com/beaconmindfulness/guided-meditations/grounding-meditation-31>
- ▶ <https://insighttimer.com/BeaconMindfulness>
- ▶ 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>

Key Resources

- ▶ Beacon program <https://www.childrensmercy.org/in-the-community/resources-for-children-with-complex-medical-needs/>
 - ▶ Includes info on waivers, financial supports, respite, sibling and caregiver supports and community supports
- ▶ Pillars <https://www.kansashealthsystem.com/care/conditions/pediatric-medical-complexity>
- ▶ Telehealth ROCKS website: <https://www.telehealthrocks.org>

Case Presentation Discussion

Guest Experts:

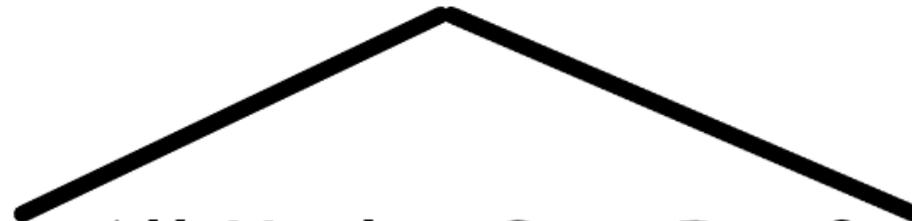
Leslee Belzer PhD



Patti Pepple LSCSW, LCSW



Kelly Kreisler, MD, MPH, FAAP



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Case Presentation

Presented by Michelle Bonebrake

4th grade boy

- ▶ **Diagnoses:** Complex past medical history including Spastic diplegic Cerebral Palsy, Malnutrition, Global Developmental Delay, Scoliosis, Failure to Thrive, Dysphagia, Slow transit constipation, Neurogenic Bladder, Craniosynostosis, Dental Caries, Cortical Visual Impairment.
- ▶ **School Supports:** IEP and therapies including adaptive equipment to aid in social skills, self-help skills and instruction.
- ▶ **Equipment:** Wheelchair, feeding tube, suction machine
- ▶ **Additional info:**
 - ▶ Previously, accessing formula was a big issue. Family would feed him by mouth if out of formula. He is supposed to be NPO for swallowing safety. The school was helping order formula and tried to teach the process to the family by including his high school brother and making a social story pictorial.
 - ▶ Language and Cultural barriers. Family are refugees and Non-English speaking. Difficult to secure interpreters for correct dialect. Mother kept him alive in a refugee camp with limited medical intervention.
 - ▶ Child has chronic dental problems-leading to fever, facial swelling, and behaviors that communicate discomfort and pain.
 - ▶ Constant communication with the KU PCP medical team made things a bit more stable. There is still a different understanding between school/family/medical team on his NPO status.
- ▶ **Goal:** School would most like guidance on how to help family understand when to contact the medical team or seek help.

Case presentation

Next steps:

- ▶ Clarifying questions
- ▶ Recommendations
- ▶ Summary

Participants: Please type any questions and recommendations you have in the chat

Questions?



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Thank you for participating!

Slides and materials will be sent to your email.

Please don't forget to complete survey assessments related to this ECHO series.

We value your feedback!

