COVID-19 Behavioral Health Policies Affecting CYSHCN: What to Keep, Modify, or Discard?

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Moderator

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Principal, Health Management Associates
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Today’s Speakers

Margaret (Meg) Comeau, MHA
Senior Project Director, Center for Innovation in Social Work & Health at Boston University

Debra Manners, MSW, LCSW
President & CEO, Sycamores

Nicole Pratt
Senior Parent Professional Trainer, Empowering Women Project Director, and Leadership Family Professional Partnership TA Facilitator, SPAN Parent Advocacy Network
Ask Questions!
We look forward to a lively discussion with our audience. Submit your questions through the Q&A.
COVID-19 EFFECTS AND RESPONSES: The Context

• The wide-ranging impact of SARS-CoV-2 (COVID-19) is undeniable

• Disproportionate effects on vulnerable populations including Children and Youth with Special Health Care Needs (CYSHCN)*
  o Cessation of, or reduction in, clinical, in-home, and school-based therapies and services

• Federal and state responses to pandemic
  o Temporary policy flexibilities through legislative, regulatory, and administrative mechanisms
  o Tied to federal or state Public Health Emergency (PHE) periods

* CYSHCN are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions. They also require health and related services of a type or amount beyond that required by children generally (McPherson, 1998)
COVID-19 EFFECTS AND RESPONSES: Research Questions and Methodology

Research Questions

- Which temporary policy flexibilities affected CYSHCN, their families, and their providers?
- Which policies should be continued after the Public Health Emergency ends?

Methodology

- Federal and state policy review
- Interviews with frontline clinicians, legal and family advocates, researchers, program leaders, and other public and private stakeholders

Report

COVID-19 Policy Flexibilities Affecting Children and Youth with Special Health care Needs: What to Keep, Modify or Discard?
Finding #1
Policies that expanded the use of telehealth have significantly impacted and been largely advantageous to CYSHCN and their families.

Finding #2
Other temporary flexibilities have also been beneficial to CYSHCN:

- Federal Medicaid funding
- Medicaid eligibility and enrollment (providers and beneficiaries)
- Prior authorization requirements
- Scope-of-practice
- Expanded ability to pay family caregivers

Finding #3
School closures, unemployment, isolation, & social drivers of health put tremendous strains on CYSHCN and their caregivers, affecting behavioral health.
BEHAVIORAL HEALTH: Pandemic Realities

- Sudden school closures
- Cessation of in-person therapy, clinical, and home-care visits
- Underemployment and lack of respite, childcare, and in-home care
- Dearth of flexibilities focused on behavioral health (apart from telehealth)
- Lack of preparedness or anticipation of behavioral health toll on children and families
Disruption, isolation, significant stresses that took a HUGE behavioral health toll on CYSHCN

- Routine behavioral health screening is “overlooked” under the best of circumstances and has worsened during pandemic
- Policy intervention options were largely limited to telehealth

Demands and strain on family caregivers exacerbated by demands for 24/7 care
Recommendations to Support Behavioral Health for CYSHCN and Family Caregivers

<table>
<thead>
<tr>
<th>Federal / Centers for Medicare &amp; Medicaid Services</th>
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<tr>
<td>- Continue reimbursement for behavioral health services via telehealth including audio-only</td>
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<tr>
<td>- Encourage and allow incentives for routine behavioral health screening for all children, including CYSHCN</td>
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<td>- Allow reimbursement to pediatric providers to screen caregivers of CYSHCN for behavioral health concerns</td>
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<th>States and Medicaid Plans</th>
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<tr>
<td>- Continue reimbursement for behavioral health services via telehealth including audio-only</td>
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<td>- Mobilize leaders to identify creative mechanisms to incentivize routine behavioral health screening for all, especially CYSHCN</td>
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<td>- Increase training and confidence of primary care providers to deliver behavioral health services</td>
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<td>- Make permanent the flexibility to transfer Mental Health Services Act (MHSA) reserves to meet local behavioral health needs</td>
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# BEHAVIORAL HEALTH: State and National Emergency in Child and Adolescent Mental Health

## Advocacy and Recommendations

- Improve access to technology and telemedicine, and school-based mental health services
- Accelerate adoption of effective and financially sustainable models of integrated mental health care in primary care pediatrics, including clinical strategies and models for payment
- Address the ongoing challenge of the acute and inpatient mental health care needs of children and youth
- Fully fund comprehensive, community-based systems of care that connect children, youth, and families with evidence-based interventions in their home, community, or school
- Accelerate strategies to address longstanding workforce challenges in child mental health

## Rates of childhood suicide and emergency department visits for mental health emergencies rose steadily between 2010 and 2020

- Health professionals witnessed soaring rates of mental health challenges among children, youth, and families during the pandemic
- More than 140,000 children lost a primary/secondary caregiver during the pandemic
- California saw 104% increase in inpatient visits for suicide, suicidal ideation, and self-injury for children ages 1-17 years old, and 151% increase for ages 10-14
- Suicide became the 2nd leading cause of death for youth ages 10-24

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**American Academy of Pediatrics, American Academy of Child and Adolescent Psychiatry, Children’s Hospital Association**
COVID-19 Impacts on Families Raising Children and Youth with Special Health Care Needs

Meg Comeau, MHA
Senior Project Director

Boston University School of Social Work
Center for Innovation in Social Work & Health
Sources

- **Health Management Associates**
  - Report: COVID-19 Policy Flexibilities Affecting CYSHCN: What to Keep, Modify, or Discard?

**The Collaborative Improvement and Innovation Network to Advance Care for Children with Medical Complexity Project (CMC CoIIN)**

- 23 family focus groups (14 during the pandemic time period)
- Family and provider surveys
- COVID-19 and CMC ECHO medical education project with the American Academy of Pediatrics
- Recordings of all ECHO sessions: [https://ciswh.org/covid-19-webinars/](https://ciswh.org/covid-19-webinars/)
CYSHCN and their families did not experience many new stressors during the COVID-19 pandemic but it significantly exacerbated existing ones

- Mental health strain for the whole family, including on typically healthy siblings who were often forgotten
- School with distance learning – Individualized Education Program “out the window”
- Complete isolation – even small pleasures were lost
- Hard to find home health care nurses willing to work in home settings – hospitals paying more
- Competition for scarce “everyday” resources (gloves, masks, vent supplies, etc.)
- The risk of hospitalization from either pre-existing health needs or COVID was very scary for many families

“We have complex mental health issues for some of the kids in our house and COVID’s made it worse – we have no respite, we have no nursing. We can’t go anywhere and it’s been a burden on me, I’m managing everything for everybody and trying not cause a problem for anyone. A break when the kids went to school is gone (now).”

--Parent, Family Focus Group June 2020
All children who lived through the pandemic are at risk for behavioral health challenges, but the resources to address challenges for CYSHCN must be customized to fit their unique needs

• All children, including CYSHCN, should be screened for mental/behavioral health needs

• Providers may need to be creative in working with CYSHCN; for example, non-verbal children, or those with ID/DD, and interdisciplinary team-based care is optimal

• Therapists should be matched to family need and care should be trauma-informed

• Need to adapt what was working for children’s behavioral health needs before the pandemic

• Many states and regions have resources for physician support in psychiatry and shared-decision making
Better integration of physical and behavioral health is necessary to improve overall health as well as quality of life and well-being for CYSHCN and their families

- Fragmentation of care is a significant problem for CYSHCN and their families
- Families view their children holistically, and everyone benefits when care is provided in a holistic way
- Few incentives for integrating physical and behavioral health currently exist

“I just feel like I’m constantly running to this specialist, or that one, and no one sees the big picture. It’s on me to try to make sure she has everything she needs and deserves. It’s a heavy load to carry.”

--Parent, Family Focus Group, August 2020
Service Delivery in the COVID-19 Pandemic
In the months leading up to the COVID-19 pandemic (Jul ’19 – Feb ’20), there was an average of 16 suicidal ideation incidences reported per month.

During the pandemic (April ’20 – Sep ’21), there have been an average of 23 incidences reported per month (44% increase).

Sycamores Data as of: 10/21/2021
In the months leading up to the COVID-19 pandemic, there was an average of 2 suicidal attempts reported per month.

During the pandemic, there have been an average of 4 suicidal attempts reported per month (100% increase).

Sycamores Data as of: 10/21/2021
There was a 47% increase in psychiatric hospitalization during the pandemic (avg.=24) compared to the months leading up to it (avg.=17).

Sycamores Data as of: 10/21/2021
Services at Sycamores have consistently been provided in person despite the COVID-19 pandemic.

In the first 3 months of the COVID-19 pandemic, 20% of all services were delivered in-person.

Over the past 3 months, 40% of all services were delivered in-person.
Overall, mental health services increased by 32% from FY 19-20 to FY 20-21.
Service Engagement

During the pandemic we surveyed:

Caregivers
96% were satisfied with the services their child received and felt staff helping their child stuck with them no matter what

Sycamores Staff
89% of Sycamores staff felt they were able to successfully fulfill their role in meeting consumer needs

Community Partners
90% of community partners are likely to refer to Sycamores again
### My Family

<table>
<thead>
<tr>
<th>Access to mental health services for my daughter</th>
<th>Access to mental health services for my son</th>
<th>Affects of stress on my family—needing mental supports for self</th>
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Nicole Pratt, SPAN Parent Advocacy Network
Senior Parent Professional Trainer, Empowering Women Project Director Leadership Family Professional Partnership TA Facilitator
Audience Q&A

Please submit your questions through the Q&A
We pursue a system that works for children with special health care needs.

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