Acknowledgements

- Collaboration with the Association of Maternal and Child Health Programs (AMCHP)

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About NCSL

- National bi-partisan membership organization
  - 7,383 legislators and all legislative staff
  - Offices in Denver and Washington, D.C.

- NCSL is committed to the success of all legislators and staff. Our mission is to:
  - Improve the quality and effectiveness of state legislatures.
  - Promote policy innovation and communication among state legislatures.
  - Ensure state legislatures a strong, cohesive voice in the federal system.

Overview

- **Welcome and Introductions**
  - Tahra Johnson, Program Manager, National Conference of State Legislatures

- **Challenges to Accessing Care**
  - Michelle Jarvis, Specialist for Family Engagement and Leadership Development, Association of Maternal and Child Health Programs (AMCHP)

- **Telehealth for Autism Spectrum Disorder (ASD)**
  - Shawna Wright, Assistant Director of Behavioral Health at the University of Kansas’ Center for Telemedicine and Telehealth

- **Policy Options Related to Access to Coverage and Care**
  - Thomas Holmes, State Representative, South Dakota
  - Susan Lontine, State Representative, Colorado

- **Audience Questions and Answers**
Who are children and youth with special health care needs (CYSHCN)?

They are "those who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

-The Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB).
Michelle Jarvis  
Specialist, Family Engagement and Leadership Development  
mjarvis@amchp.org

“We have recognized the critical role of families in their children’s lives, and have learned to see ourselves as service and support personnel. The paradigm shift requires new ways of working between families and the many agencies, professionals, and others who interact with and influence their lives.”

~Merle McPherson
OHANA means family.
Family means nobody gets left behind or forgotten.
The benefits!

Barriers
Thank you!
With admiration and appreciation to our participating families and their communities, our partner sites, our team, and our funders

University of Kansas Center for Telemedicine & Telehealth (KUCTT)

- Kansas is an ideal state for telemedicine
- Approximately 8,000 video encounters/year across 60 providers and educators
- Behavioral consults are the most common outpatient consultation across psychiatry, psychology, and developmental medicine
- Most clinics utilize a traditional telemedicine model in supervised settings, with telemedicine presenters
- As an academic health center, have focused efforts on team-based services with trainee participation
Benefits of Telemedicine

- Improve health care access
- Reduce unnecessary patient transport
- Addresses health care provider shortage
- Reduce provider travel time/cost to outreach sites
- Reduce patient travel time and cost (Outpatient)
- Retain patients locally in their home communities
- Reduces family stress

Poverty: Telehealth ROCKS focuses on the poorest region of the state, with 30% of children living in poverty, many at risk for behavioral and developmental difficulties.

Health outcomes: KIDS COUNT (2014) data reflects that Kansas Southeast counties have some of the worst health outcomes (mortality, immunizations, mental health), education indicators (Early Head Start, Head Start), and economic indicators (poverty, free & reduced lunch) in the state.

Established telemedicine infrastructure: The proposed project will pair the extensive history of the University of Kansas Center for Telemedicine and Telehealth (KUCTT) with rural primary care practices serving children in poverty in Southeast Kansas.

Partnership with community health and healthcare leaders, Community Health Center of Southeast Kansas, Tallgrass Clinic in Sedan, Lifespan Institute in Parsons, and other leaders.
Telehealth ROCKS Goals

Screening & Assessment

Treatment

Engagement

Maintenance & Support

Education & Mentoring

Telehealth ROCKS GOALS

Telehealth ROCKS Schools GOALS

Assessment & Treatment

Workforce Development

Engagement & Family Support

Education & Mentoring

Prevention

Rural Outreach for the Children of Kansas
Telehealth ROCKS & Telehealth ROCKS Schools Services

Family/Behavioral Therapy
• Modified Parent-Child Interaction Therapy
• Psychological strategies for behavioral concerns, trauma, and chronic conditions
• Behavioral strategies for autism/comorbid concerns

Medication Management & Consultation
• Behavioral medication management
• Medication consultation related to developmental concerns

Parenting/Prevention
• OASIS intensive parent/guardian training (Online and Applied System for Intervention Skills)

Assessment
• Autism assessment
• Functional behavioral assessment

Feeding & Weight Issues
• Feeding difficulties
• Pediatric obesity

Toileting Concerns
• Toileting

Implementation and lessons learned

Implementation
Community Engagement
Telemedicine Rooms and Equipment
Telemedicine Personnel
Quality improvement

Barriers
Lack of telemedicine policy
Need for in-person visit for select services
Limited space in originating/community sites
Paperwork
Project ECHO

Moving knowledge, not patients

Project ECHO in action

- Collaborative virtual learning – built on existing technology
- Proven method for enhancing primary care workforce capacity
- Promotes best practices
Project ECHO Outcomes

- Patients – right care, right place, right time
- Providers – new knowledge, treat rather than refer
- Community – reduce disparities, keep patients local
- System – access, quality, cost

Janine Gracy, Project Director
A HRSA-Funded Telehealth Resource Center Grant Program
Providing Technical Assistance

- Assist health care organizations, networks and providers to implement cost-effective telehealth programs
- Advance the effective use of telehealth technologies
  - Equipment
  - Practice Guidelines
  - Program Design
  - Reimbursement
  - Business Models
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Policy Options
Related to Access to Coverage and Care

Thomas R. Holmes,
State Representative,
South Dakota
South Dakota

Bill signing in Governor Daugaard's office
Policy Options Related to Access to Coverage and Care

Susan Lontine, State Representative, Colorado
The Colorado Experience
Access to Care for Children With Autism Spectrum Disorders

Representative Susan Lontine, Colorado House District 1
July 26, 2017

Colorado’s Progress

SB15 -015 Mental Health Parity for Autism Spectrum Disorders

HB15-1186 Services for Children with Autism

HB13-1266 Aligned state health insurance laws with the requirements under the ACA and the Health Care and Education Reconciliation Act

SB12-159 Evaluation of Home and Community-Based Services for children with Autism under the Medicaid Waiver Program

SB10-129 Care Coordination Services for Children with Autism
Continuing Barriers

- Providers reluctant to conduct initial screenings for very young children
- Screenings for minority children have a high rate of false positives
- Tremendous amount of bureaucracy for providers to wade through
- Wait lists for diagnoses and treatment can be very long

And More

- Families struggling with no insurance or can’t qualify for Medicaid
- For families with children covered by Child Health Plan Plus, services are limited to occupational therapy (OT), physical therapy (PT) and Speech Therapy. CHP+ doesn’t cover Applied Behavioral Analysis (ABA).
- Navigating a complicated system
- Cultural norms sometimes make it difficult for parents to accept a diagnoses of ASD.
How do we address continuing barriers?

- Reduce bureaucracy for pediatricians as well as look at other models that allow for alternative providers and maybe even parents to do initial screening.
- Further study of cultural differences to understand the prevalence of false positive screenings for minority communities as well as parents ability to accept a final diagnoses.
- Research alternative methods of delivery of services that address critical workforce shortages. This is especially important for rural communities.
- Explore opportunities to bring together parents and providers to address the disconnect.
- How can we streamline our systems so that navigating is easier for families?

Audience Q&A

☐ Please enter your questions in the chat box on the bottom left-hand side of the screen
Questions?

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