

FAMILY ADVOCACY DAY 2024 STORYTELLING GUIDE

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Thank you for participating in Family Advocacy Day 2024! Below, you will find our main legislative priorities, as well as potential questions you could be asked by lawmakers, during filming sessions, etc.

Please remember that no one knows your story better than you! This document is a guide to help you share your experiences and advocate for your child.

YOUR DETAILS

- Child's name, current age, age of diagnosis, and medical condition?
- Facts about the condition and its rarity or prevalence?
- Name of primary children's hospital and distance from your home?
- Number of hospitals and providers you've visited?
- Number of tests, procedures, and/or surgeries your child has gone through?
- How is your child currently doing?
- Where do you live?

POLICY ISSUES

Pediatric Workforce Development

Key points

- Children need providers who are specially trained to meet their unique physical, developmental, and mental health needs, making federal funding for training programs critical and necessary.
- The Children's Hospitals Graduate Medical Education (CHGME) program, established in 1999, supports training in children's hospitals. This bipartisan program is the **ONLY** federal program devoted to training pediatricians and pediatric specialists.
- The CHGME program advances the quality of pediatric medical education, provides care for vulnerable and underserved children, and promotes community-based pediatric training.

Questions

- How many pediatric specialists does your child see regularly?
- Why is having a specialized pediatric workforce important to you and your family?
- Could you share a specific instance where you felt the specialized training of pediatric health care providers made a significant difference in your child's treatment or care?

Access to Health Care

Key points

- [Medicaid](#) is the single largest source of health care coverage for kids in the United States. About 35 million children rely on Medicaid for health care services, with children representing over 40% of all Medicaid enrollees.
- Medicaid plays a significant role in children growing up healthy.
- It is crucial we streamline administrative barriers for providers, particularly those who care for children from other states.
- The Accelerating Kids' Access to Care Act addresses these administrative issues and better supports timely, more accessible access to comprehensive and specialized care across state lines.

Questions

- What insurance does your family have?
- If you have private insurance and Medicaid, how do the plans work together to meet your child's specialized needs?
- How has having access to Medicaid and/or CHIP helped your child's quality of care/life?
- How do you think streamlining administrative barriers for providers could improve care for children with medical complexities like your child's?
- How many hours have you spent dealing with administrative hurdles to make sure your child gets the care they need?
- Can you share an experience where timely access to care was crucial for your child's health, and how Medicaid played a role?

Access to Comprehensive Mental Health Services

Key points

- The mental health challenges facing our children continue to grow. More needs to be done to address gaps in mental health care for kids, including prevention and early intervention services, developmentally appropriate treatment, and better community-based care systems.
- We also need to expand children's access to a full range of pediatric mental and behavioral health services and grow the pediatric mental and behavioral health workforce to deliver this essential care.
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Questions

- Does your child have a mental health condition they receive treatment for?
- How has your child's medical condition affected their mental health?
- How does your health insurance coverage impact your child's ability to get care?
- What mental health resources or treatments would help your child that aren't readily available?