GRANT MAKERS IN HEALTH

Ensuring that Medicaid and CHIP Meet the Needs of Vulnerable Children

August 16, 2018 1:00 p.m. Eastern

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Ensuring Care for Children with Special Health Care Needs

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Grantmakers in Health Webinar

Agenda

- Overview: Children with Special Health Care Needs
- Examining Medicaid and CHIP's Role
- Ensuring Care for Children
  - Federal Issues
  - State Issues

Who are Children with Special Health Care Needs?

About 14.2 million children – nearly 1 in 5 of all children in the U.S. – have special health care needs

- **Children with Special Health Care Needs (CSHCN)** are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that usually expected for the child's age
- A subset of CSHCN are children with **complex medical needs**; these children may have a congenital disease, a severe neurologic condition with functional impairment and/or technology dependence of the activities of daily living

Sources: National Survey of Children's Health (NSCH), 2016, U.S. Census Bureau; Medicaid's Role for Children with Special Health Care Needs: A Look at Eligibility, Services, and Spending, 2018, Kaiser Family Foundation Analysis of the 2016 National Survey of Children's Health.

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Families Interact with Many Systems – and Often Many Care Managers

Services are often provided or authorized by different systems: physical health, mental health, public health, education, and social services

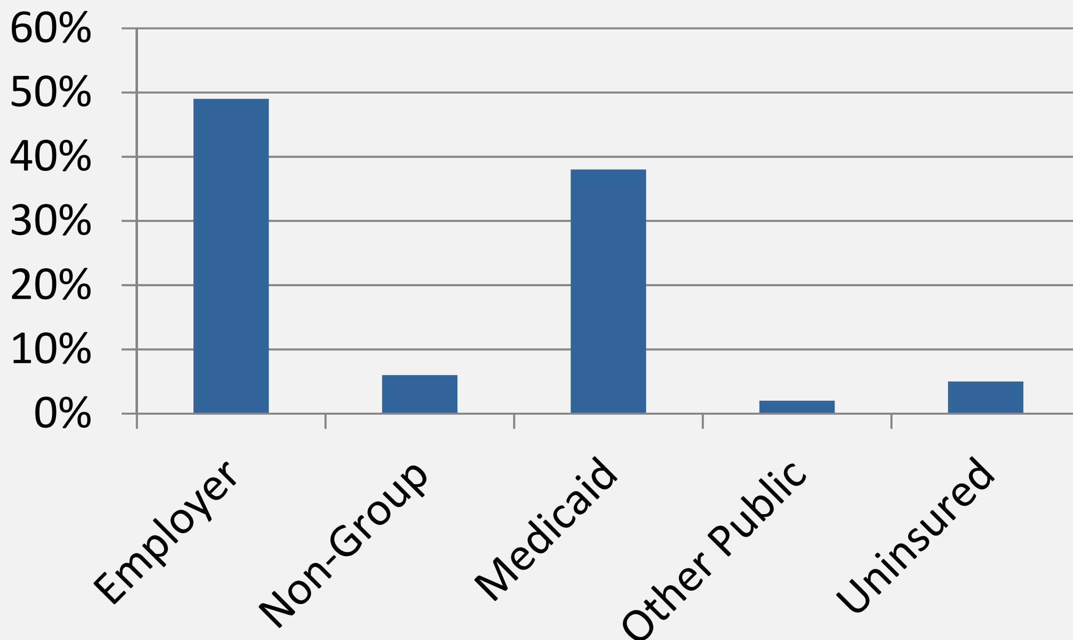
- Historically care has been **highly fragmented** and families have had the responsibility of navigating complex systems, resulting in unmet needs
- **19% of families** with a CSHCN reported at least one unmet need (e.g., preventive care, specialist care, prescription medicine, etc.)
- This number **jumps to 44%** when the child **was medically complex**

Sources: Children with Special Health Care Needs, 2018, HRSA Maternal & Child Health; Inequities in Health Care Needs for Children with Medical Complexity, 2014, Health Affairs.

Examining Medicaid and CHIP's Role

Understanding the basics: Medicaid and CHIP

Medicaid covers nearly 1 out of 4 children across the U.S.



- Over 35 million children are covered by Medicaid and CHIP
- Of those children, coverage for 9.4 million children is funded by CHIP

Source: Medicaid & CHIP Total Enrollment Chart – May 2018, 2018, Medicaid.gov; Current Population Survey (CPS), 2018, U.S. Census Bureau; Health Insurance Coverage of Children 0-18 Analysis, 2018, Kaiser Family Foundation; Children's Health Insurance Program (CHIP), 2018, Medicaid.gov.

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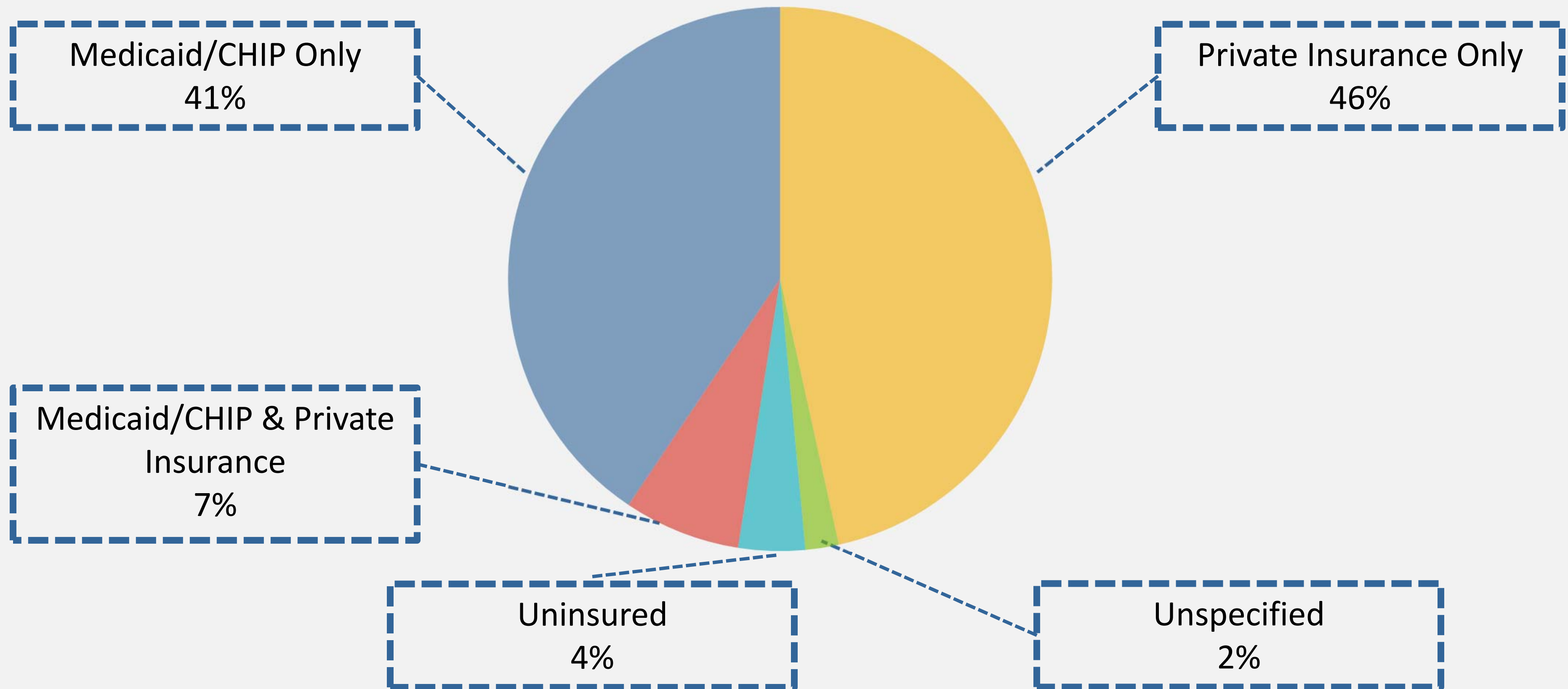
Medicaid and CHIP are Vital for CSHCN

Nearly half of all CSHCN are enrolled in Medicaid and CHIP



Sources: National Survey of Children's Health (NSCH), 2016, U.S. Census Bureau; Medicaid's Role for Children with Special Health Care Needs: A Look at Eligibility, Services, and Spending, 2018, Kaiser Family Foundation Analysis of the 2016 National Survey of Children's Health.

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Public Insurance Covers the Complex Needs of CSHCN

The children who receive care from Medicaid and CHIP have diverse needs

Common, but not exclusive, groups include:

- Children with physical impairments that impede movement and require mobile support
- Children with intellectual or developmental disabilities, and those with serious emotional disturbance
- Children who need long-term care services to help with daily living, such as private duty nursing, attendant care, or assistive technology

Sources: Children with Special Health Care Needs, 2018, Maternal and Child Health Bureau; Children with Medical Complexity: An Emerging Population for Clinical and Research Initiatives, 2011, Pediatrics.

Early and Periodic Screening, Diagnostic and Treatment

Early and Periodic Screening, Diagnostic and Treatment (EPSDT) is the Medicaid program's federally guaranteed benefit for all Medicaid enrollees under age 21

Early and Periodic Screenings

- Regularly scheduled comprehensive health and developmental screenings
- Comprehensive unclothed physical exam
- Appropriate vision and hearing testing
- Appropriate immunizations (according to age and history)
- Appropriate laboratory tests
- Dental screenings and referrals to a dentist (for children beginning at age 3)
- Health education

Diagnostic Services

- Medically necessary diagnostic services when a risk is identified, including follow-up testing, evaluation, and referrals

Treatment Services

- States must provide timely treatment services as determined by child health screenings
- Health care or treatment services include those that are medically necessary to correct or ameliorate defects and address physical and behavioral health conditions

Sources: Social Security Act § 1905(r); 42 CFR § 441.56.

Medicaid Covered Services Under EPSDT

Under EPSDT, states must cover all medically necessary services, including those that are "optional" for adults

Mandatory Services

- ✓ Family planning services and supplies
- ✓ Federally Qualified Health Clinics & Rural Health Clinics
- ✓ **Home health services**
- ✓ **Inpatient &outpatient hospital services**
- ✓ **Laboratory & X-Rays**
- ✓ Medical supplies and durable medical equipment
- ✓ **Non-emergency medical** transportation
- ✓ Nurse-midwife services
- ✓ Pediatric & family nurse practitioner services
- ✓ Physician services
- ✓ Pregnancy-related services
- ✓ Tobacco cessation counseling & pharmacotherapy for pregnant women

Optional Services

- ✓ Community supported living arrangements
- ✓ Chiropractic services
- ✓ Clinic services
- ✓ Critical access hospital services
- ✓ Dental services
- ✓ Dentures
- ✓ Emergency hospital services (in a hospital not meeting certain federal requirements)
- ✓ Eyeglasses
- ✓ **State Plan Home & Community Based Services**
- ✓ Inpatient psychiatric services for individuals under age 21
- ✓ **Intermediate care facility services for individuals with intellectual disabilities**
- ✓ Optometry services
- ✓ Other diagnostic, screening, preventive & rehabilitative services
- ✓ Other licensed practitioners' services
- ✓ Physical therapy services
- ✓ Prescribed drugs
- ✓ **Primary care case management services**
- ✓ Private duty nursing services
- ✓ Program of All-Inclusive Care for the Elderly (PACE) services
- ✓ **Prosthetic devices**
- ✓ **Respiratory care for ventilator dependent individuals**
- ✓ **Speech, hearing & language disorder services**
- ✓ **Targeted case management**
- ✓ Tuberculosis-related services

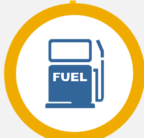
NOTE: Yellow services are particularly important for CSHCN
Source: Social Security Act § 1905.

Other Required Services that Support Access to Care

States must also offer services to promote access to preventive screening, diagnostic, and treatment services

Scheduling assistant for appointments

Necessary transportation to and from appointments



Related travel expenses

Language assistance services for individuals with limited English proficiency

Source: EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents, 2014, CMS.

Ensuring Care for Children: Federal Issues

Recent Threats to Medicaid and CHIP Coverage

2017 Congressional proposals put children's coverage at risk

- **2017 federal proposals would have cut Medicaid deeply and imposed caps on the federal funding available in the future**
  - **CSHCN were *not* protected from the impact of the cuts**

These proposals continue to be advanced (e.g., President's budget proposal)

- **CHIP suffered a four-month delay in renewal of funding but was funded for 10-years through 2027**

Source: Summary of House and Senate CHIP Legislation, 2017, Manatt Health and State Health & Value Strategies.

Ensuring Care for Children: State and Local Issues

Ensuring Care for Children: State Issues

Medicaid Managed Care

Medical Homes and Cross-System Partnerships

Social Determinants of Health

Medicaid Managed Care

CSHCN and Medicaid Managed Care

All states with Medicaid Managed Care enroll at least some CSHCN in standard managed care plans

- Many of these states have managed care contract provisions that explicitly address the needs of CSHCN
- These provisions vary in their focus and level of prescriptiveness

States are increasingly modifying their Medicaid Managed Care contracts to address the unique needs of CSHCN in the following key design areas:

- Supportive care management
- Access to providers
- Access to benefits
- Plan capacity and expertise

Sources: State Medicaid Managed Care Enrollment and Design for Children and Youth with Special Health Care Needs, 2017, NASHP; Access to Care for Children with Special Health Care Needs: The Role of Medicaid Managed Care Contracts, 2016, MACPAC.

Supportive Care Management in Managed Care

States are implementing federal minimum standards in different ways

Background on Federal Requirements:

- **For all populations:**
  - Ensure each enrollee has an on-going source of care appropriate to their needs
  - Coordinate between settings of care
  - Make best efforts to conduct an initial screening within 90 days of enrollment
- **For populations with special health care needs:**
  - Implement mechanisms for identification
  - Conduct a comprehensive assessment
  - Develop a person-centered treatment or service plan
- **Federal rules do not dictate how these coordination services are provided – e.g., at the plan or provider level**

New York

Managed care organizations (MCOs) must have a process in place to coordinate with school districts, preschool services, child protective services, early intervention officials, and developmental disability service organizations

Virginia

Case managers are required to assist CSHCN with scheduling appointments, providing referrals, identifying resources, contacting the member/family regularly and provide special transportation requirements, as necessary

Sources: 42 CFR 438.208; State Medicaid Managed Care Enrollment and Design for Children and Youth with Special Health Care Needs, 2017, NASHP; Access to Care for Children with Special Health Care Needs: The Role of Medicaid Managed Care Contracts, 2016, MACPAC; New York Medicaid Managed Care Model Contract, 2015, NYC DOH; MEDALLION 4.0 MANAGED CARE SERVICES AGREEMENT, 2018, Virginia Department of Medical Assistance.

Medical Homes and Cross-System Partnerships

Forming Cross-System Partnerships and Medical Homes

Medical homes and cross-system partnerships are integral to facilitating coordination and linkages between programs

Background:

- A medical home is a **team-based approach to primary care** that facilitates family-centered, continuous, comprehensive, and coordinated care
- Properly designed, medical homes can **reduce barriers to care and fragmentation of services** when state programs, providers & families work in concert
- **Goal is to create an accountable *system* of care** which may require:
  - Interagency agreements
  - Data sharing between agencies and systems
  - Cross-system workgroups or task forces
  - Supports that help children/families actively engage

Rhode Island

Developed five-year plan to ensure family centered, community-based, integrated systems of services through infrastructure building, training, and collaboration with consumers, and community agencies

Connecticut

Convened a work group to develop a state-wide model for efficient care coordination that avoids duplication of services

Sources: Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children With Special Health Care Needs, 2005, Pediatrics; State Strategies to Advance Medical Homes for Children and Youth with Special Health Care Needs, 2018, NASHP; Children & Youth with Special Health Care Needs and Connecticut's Medical Home Initiative, 2018, Connecticut Department of Public Health; Supporting Children and Youth with Special Health Needs, 2015, Rhode Island Office of Special Needs.

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Social Determinants of Health

The Importance of Social Determinants of Health

Interest in addressing social/economic needs of Medicaid enrollees is growing but children are not always the focus

Background:

- States, MCOs, and providers are increasingly focused on **addressing unmet social and economic needs** (e.g., lack of food, unstable housing) that contribute to poor health/high health care costs.
- These efforts could help CSHCN and their caregivers
- Requires concerted efforts and collaboration, with **families at the table**:
  - Identify social service assets and gaps
  - Develop assessment tools
  - Establish relationships with "non-traditional" partner organizations
  - Establish sustainable financing

Arizona

Requires coordination of community resources, such as housing and utility assistance, under its managed long-term services and supports (MLTSS) contract

North Carolina

Will require screening of Medicaid beneficiaries for access to food, stable housing, and transportation - and appropriate interventions - as state transitions to Medicaid managed care in 2019

Sources: Screening for Social Determinants of Health in Populations with Complex Needs: Implementation Considerations, 2017, Center for Health Care Strategies, Inc.; Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity, 2018, Kaiser Family Foundation; Arizona Revised Statutes (A.R.S.), Title 36, Chapter 29, 2016, Arizona Health Care Cost Containment System (AHCCCS), Request for Proposal for Medicaid Managed Care Prepaid Health Plan, 2018, NC DHHS.

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Thank you

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Ensuring that Medicaid and CHIP Meet the Needs of Vulnerable Children: Issues for Children in Immigrant Families

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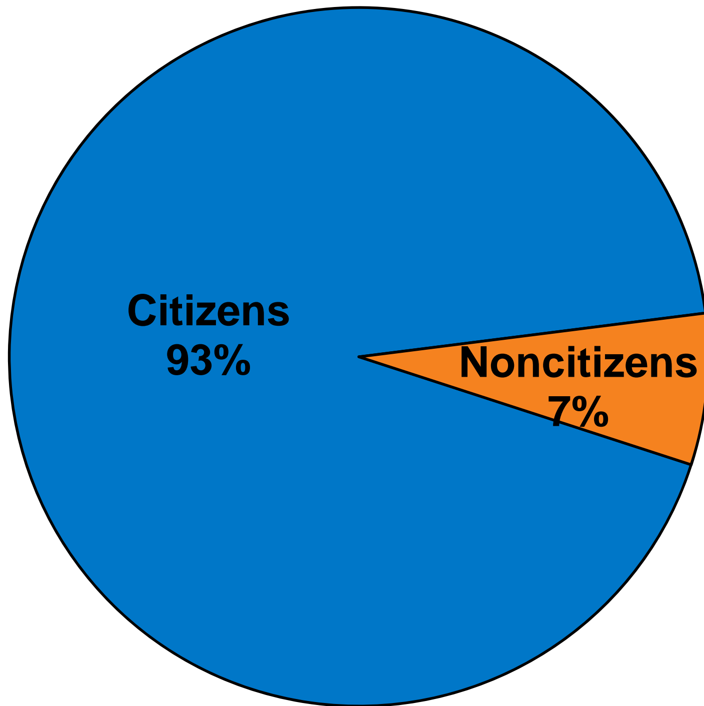
Kaiser Program on Medicaid and the Uninsured
The Kaiser Family Foundation

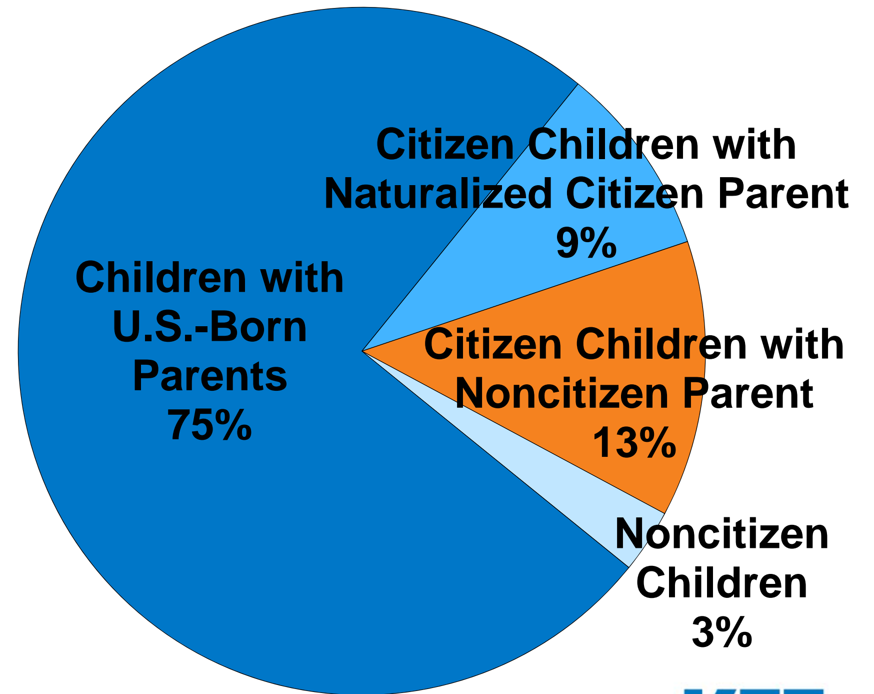
Presented: August 16, 2018
For Grantmakers in Health
Webinar

Filling the need for trusted information on national health issues.

Immigrants are a diverse group of individuals who came to the U.S. to seeking safety and improved opportunity; most children of immigrants are citizens



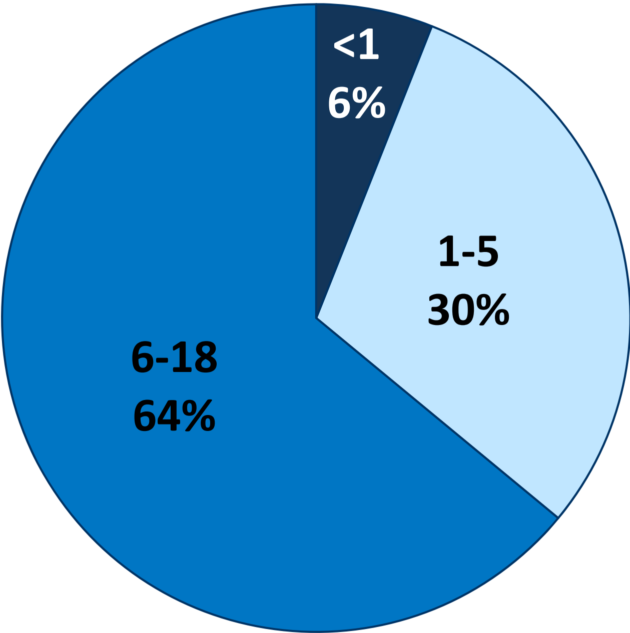
Total U.S. Population: 320.4 Million

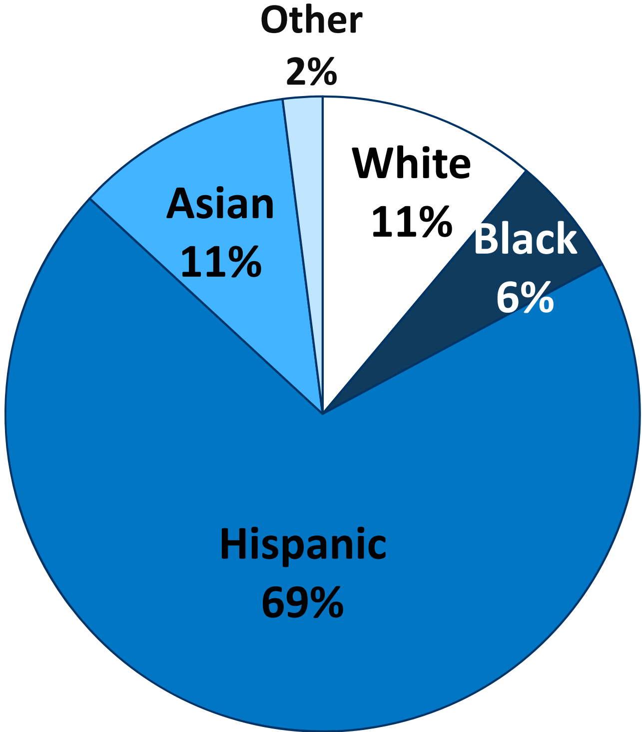


Total Children (Ages 0-18): 78.2 million

SOURCE: Kaiser Family Foundation analysis of March 2017 Current Population Survey, Annual Social and Economic Supplement

Age and Race/Ethnicity of Citizen Children with a Noncitizen Parent, 2016

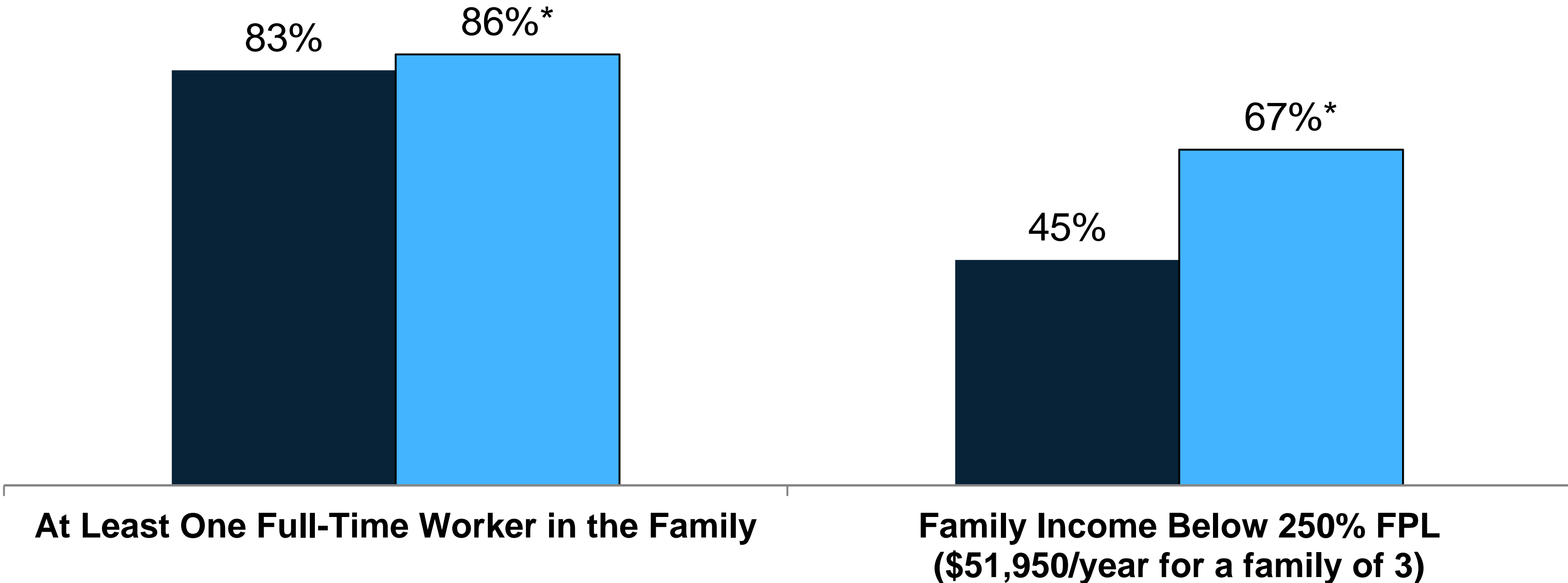




Total = 10.4 Million Citizen Children with a Noncitizen Parent

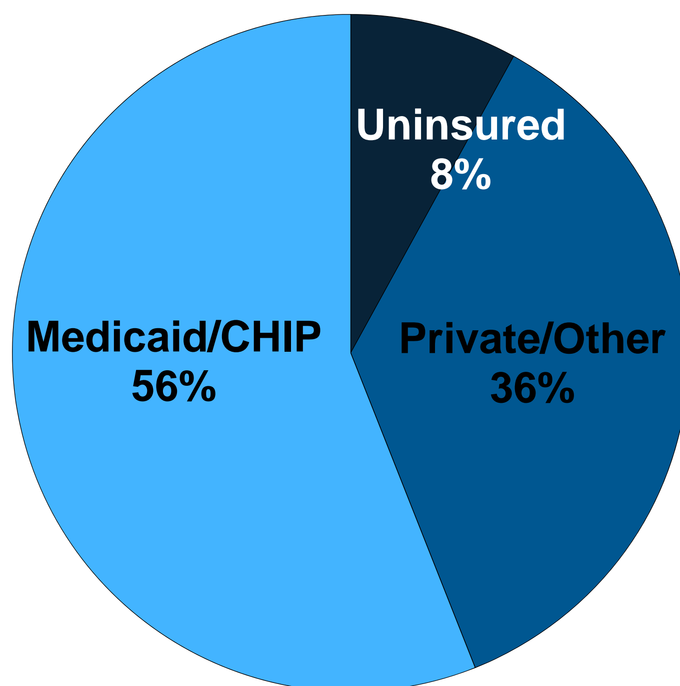
NOTES: Children ages 0-18. Data may not total 100% due to rounding. Persons of Hispanic origin may be of any race; all other race/ethnicity groups are non-Hispanic.
SOURCE: Kaiser Family Foundation analysis of the March 2017 Current Population Survey, Annual Social and Economic Supplement.

Family Employment and Income among Children by Parental Citizenship Status, 2016



NOTES: *Indicates statistically significant difference from citizens at p<0.05 level. Income based on 2016 Census Bureau federal poverty level for a family of three (with one child).
SOURCE: Kaiser Family Foundation analysis of March 2017 Current Population Survey, Annual Social and Economic Supplement

Health Coverage of Citizen Children with a Noncitizen Parent, 2016



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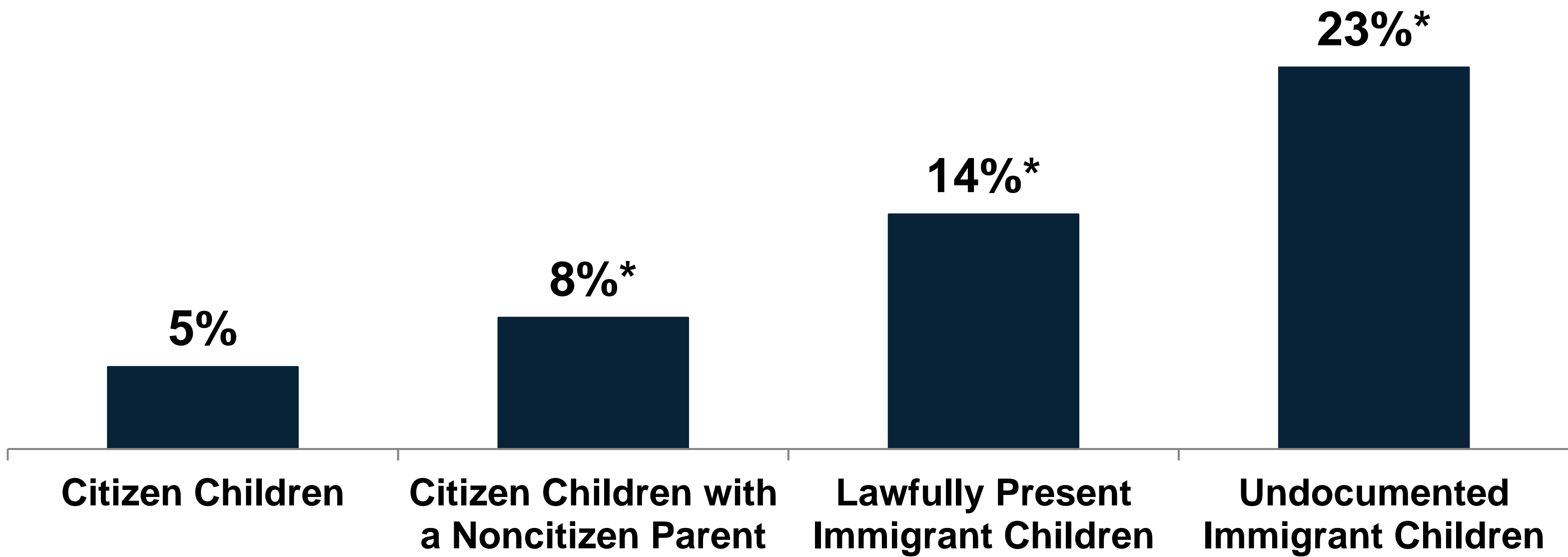

*Indicates statistically significant difference from citizens at $p<0.05$ level.

SOURCE: Kaiser Family Foundation analysis of March 2017 Current Population Survey, Annual Social and Economic Supplement

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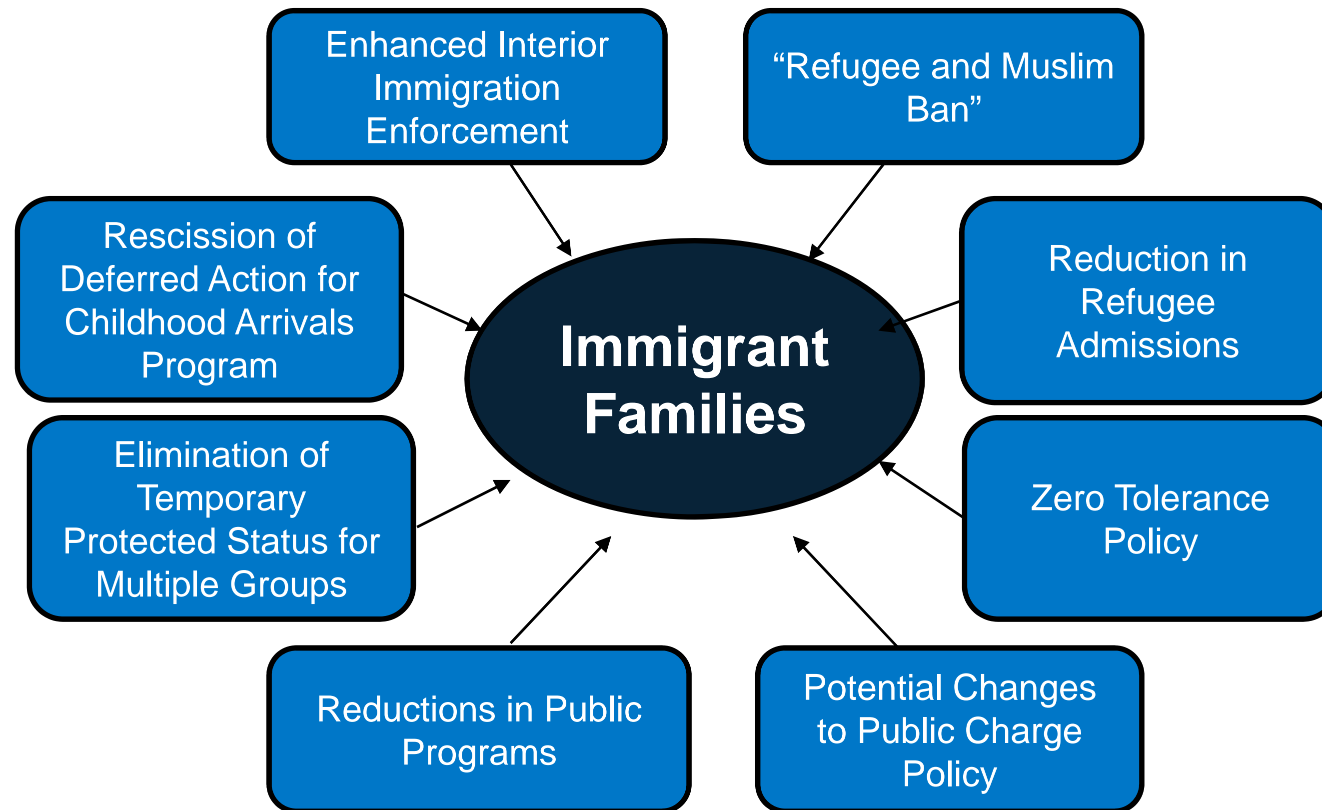
Immigrants face a range of barriers to health coverage.

- **More limited access to private coverage**
- **Eligibility restrictions for Medicaid and CHIP**
  - Five-year waiting period for many lawfully present immigrants
  - State option to eliminate five-year waiting period for pregnant women and children
  - Undocumented immigrants ineligible to enroll in Medicaid and CHIP or ACA Marketplaces
- **Enrollment barriers for eligible individuals**
  - Lack of information/confusion
  - Difficulty completing application/meeting paperwork requirements
  - Language barriers
  - Fear and uncertainty

A wide range of policies are affecting immigrant families today.



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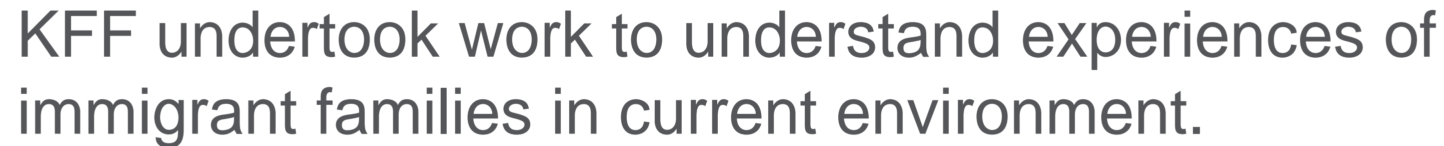
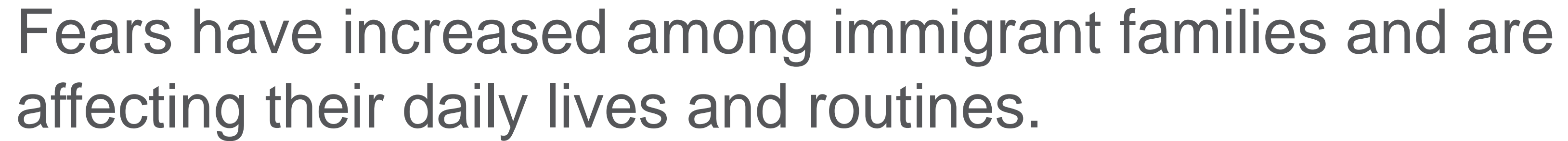


- **In Fall 2017, conducted focus groups in 5 languages with 100 parents from 15 countries**
    - Spanish, Portuguese, Korean, Farsi, Arabic
    - Varied immigration statuses
    - 8 cities in four states (IL, CA, MA, MD)
    - Blue Shield of California Foundation supported work in CA
- **13 telephone interviews with pediatricians**
    - Serving immigrants from around the world
    - Practicing in 9 states (AR, CA, DC, IL, MN, NC, PA, TX, VT)
- **Currently in the field with follow-up project focused on families that have recently been separated from a family member due to detention or deportation**



Fears have increased among immigrant families and are affecting their daily lives and routines.

- Fears and feelings of uncertainty extend to those with lawful status
- Some families are limiting time outside the home to essential activities
- Increased difficulties finding employment
- Concerns about interacting with police/authorities
- Decreased school attendance after election and immediately following raids in a community

"…we wake up every day with the fear of being deported, of the separation of our families, to have to leave the kids." --Latino Parent, Boston, MA

"We feel that in any moment a new rule could be issued leading to expelling us and sending us back." --Arabic-speaking Parent, Anaheim, CA

"Before, there were many kids in the parks… but now… the kids spend more time inside these days, because we are afraid of being deported." --Latino Parent, Boston, MA

Increased fears are negatively affecting the health and well-being of children.

- Children manifesting fears in many ways
  - Behavioral changes
  - Psychosomatic symptoms
  - Mental health issues
  - School performance
- Pediatricians uniformly concerned about long-term health consequences
  - Toxic stress
  - Growth and development
  - Social and economic factors influencing health
- Most parents were continuing to access care for their children and maintain Medicaid/CHIP coverage, but some reported changes in care and enrollment

> "When you're worried every day that your parents are going to be taken away or that your family will be split up, that really is a form of toxic stress. …we know that it's going to have long-term implications for heart disease, for health outcomes for these children in adulthood."
>
> Pediatrician, MN

> "What I do have more and more families doing is not taking food stamps, not taking WIC, not wanting to take federal services because they're afraid…"
>
> Pediatrician, VT

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- **Individuals who are determined to be a “public charge” can be denied lawful permanent residence or entry into the U.S.**
- **Currently, public charge determinations do NOT consider:**
  - Use of non-cash benefits, like health and nutrition programs
  - Use of benefits by children or other family members
- **Under draft proposed changes, public charge determinations WOULD consider:**
  - Previously excluded health, nutrition, and other non-cash programs
  - Use of programs by children and other family members
- **Expected to decrease participation in Medicaid, CHIP, and other programs among legal immigrant families, including their citizen children, even though they would remain eligible**

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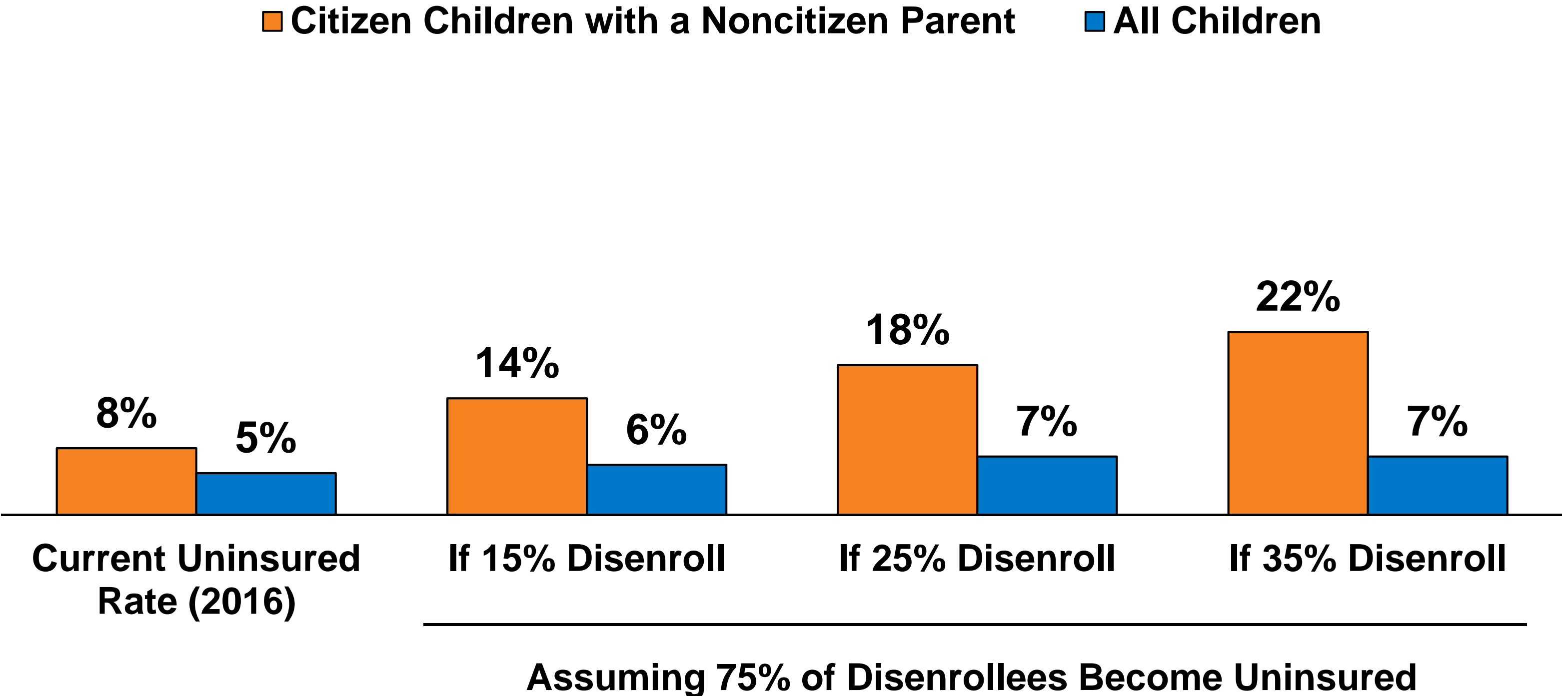
Public charge changes would lead to coverage losses for children



Source: Kaiser Family Foundation analysis of March 2017 Current Population Survey, Annual Social and Economic Supplement.

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Conclusion

- Immigrants come to the U.S. seeking safety and refuge from war and violence and better opportunities for themselves and their children
- Medicaid and CHIP play a key role in covering children in immigrant families, but they still remain more likely to be uninsured
- The current environment is increasing fear and leading to toxic stress among children in immigrant families, which will have short- and long-term consequences for their health and well-being
- Support for parents and families is key for helping to buffer effects on children
- Evolving immigration policy may amplify effects among families and lead to decreased participation in health other programs that would negatively affect health

Thank you.

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Questions?

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- More webinars on this topic?
- New topics you want to tackle or learn more about?
- Innovative work that you want to share?
- A question you want to pose to your colleagues?

Contact us at childrenandfamilies@gih.org