Children with Special Health Care Needs: Collaborative Approaches to Address Their Needs

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Who Are CSHCN?

Federal MCHB Definition of CSHCN

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

McPherson et al., 1998

Who Are CSHCN in California?

- 15% of CA's Children < Age 18 – *~1.4 Million Children and Youth*-- Estimated to Have Special Health Care Needs by MCHB Definition
- Asthma, Allergies, ADD and Behavioral/Emotional Problems Most Common Health Conditions
- > Half of CA's CSHCN Have At Least 2 Health Conditions
- Worse Health Status and Suboptimal Health Care Experiences Are More Common in Low Income CSHCN, Publicly-Insured CSHCN, and CSHCN of Color

Why Attention to CSHCN Is Critical

- Impact on Families
  - 24% of Families of CA CSHCN Report Having to Stop Work or Cut Back Hours to Care for Children
  - Families of CSHCN Must Pay Out-of-Pocket for Uncovered Costs; e.g. 13% of Families of CSHCN Spent $500-$1000/Year and 11% Spent > $1000/Year
- Impact on Health Care System
  - CSHCN Have 3 Times Higher Health Care Expenditures than Children Without Special Health Care Needs
  - CSHCN (15% of Children) = > 42% of Total Medical Costs of Children

Why Attention to CSHCN Is Critical

- Impact on Children
  - Many Conditions among CSHCN Are Disabling or Potentially Disabling and Some Are Life-Threatening
  - All Require Access to "Right Care at the Right Place at the Right Time"
  - All Have Potential to Disrupt Children's Development, Behavioral and Mental Health, Education, and Social Interactions– and Keep Kids from "Just Being Kids"

CCS Children: California's Most Vulnerable CSHCN

- CCS Is Oldest Public Health Program in California
- Created in 1927-- 8 Years Before Federal Maternal and Child Health Program
- Originally Created to Address Polio Epidemic and Serve as Safety Net to Keep Families from Bankruptcy
- CCS Now CA's Official Title V Program for CSHCN
- Covers ~180,000 Children/Youth Aged 0-21 with Complex, Chronic, Potentially Disabling Conditions (e.g. Cancer, Congenital Heart Disease, Diabetes, Cystic Fibrosis, Sickle Cell Disease, Cerebral Palsy, Spina Bifida)

CCS Children: California's Most Vulnerable CSHCN

- Most CCS Children are Low-Income
  - 90% of CCS Children Have Full-Scope Medi-Cal
  - 10% Have No Insurance or Are Underinsured
- CCS Is Only Population-Based Program in California Specifically Designed for CSHCN and Sets Quality Standards for Pediatric Providers and Facilities in CA
- CCS Children Have Even More Extreme Expenditures than Other CSHCN
  - Some Children Very Expensive: 10% of CCS enrollees = 72% of CCS patient care expenditures^
- Program At Extreme Risk Because of State Proposal:
  - Shift Responsibility for Care Management from County CCS Programs to Medi-Cal Managed Care Programs

The Role of Multi-Disciplinary Collaboratives in Supporting CSHCN

Why Collaboratives?

- Alone We Can Do So Little; Together We Can Do So Much (Helen Keller)
- We Must All Hang Together, or Assuredly We Shall All Hang Separately (Ben Franklin)
- Gettin' Good Players Is Easy. Gettin' 'Em to Play Together Is the Hard Part (Casey Stengel)

Collaborative Case Example: CRISS

- Regional Collaborative Covering 27 Counties in Northern California
- Established in 1996 to Promote More Effective, Efficient and Family-Centered CCS Program
- Membership Is Classic 3-Legged Stool:
  - Families of CCS Children (Local Family Support Organizations and Family Voices of CA)
  - Providers (Pediatric Provider Organizations and Children's Hospitals)
  - CCS Program (County Programs)

CRISS Counties

- Alameda
- Butte
- Colusa
- Contra Costa
- El Dorado
- Fresno
- Glenn
- Humboldt
- Marin
- Mendocino
- Napa
- Placer
- Sacramento
- San Francisco
- San Joaquin
- San Mateo
- Santa Clara
- Santa Cruz
- Shasta
- Solano
- Sonoma
- Stanislaus
- Sutter
- Tehama
- Tulare
- Yolo
- Yuba

CRISS Goals

- Maintain Regional Vehicle for Coordination, Collaboration, and Pilot Testing of Innovative Models in CRISS Region
- Bring Together Stakeholders to Identify Problems and Generate Solutions
- Provide Forum for Regional Information-Sharing including Information on Best Practices and Quality Standards for CSHCN
- Promote Family-Centered Care for Children in the CCS Program

CRISS Highlights

- Only Multi-County, Multi-Disciplinary Collaborative in State Focused on CCS
- Expanded from Original 10 Counties to Current 27 Counties
- Recently Expanded to Valley Counties, Added CCS-Approved Kaiser Hospitals, and Increased Family Role in CRISS Leadership
- Developed Inter-County CCS Case Transfer Protocol Later Adopted by State
- Hold Conferences that Highlight CCS Policy Issues and Best Practices and Promote Parent-Professional Partnerships

CRISS Highlights

- Meet with State CMS to Discuss Concerns and Resolve Problems
- Meet Regularly with Medi-Cal Fiscal Intermediary to Identify and Resolve Claims Problems
- Reduce Inter-County Variation in Medical Eligibility in CRISS Region via CCS Medical Consultant Work Group
- Assisted in Building Statewide Group of CCS Medical Consultants to Standardize Medical Eligibility Approaches Statewide

CRISS Activities FY 2015-2016

- Continue to Promote Seamless Access to CCS Care in Region
- Address Critical Policy Areas for CCS
  - Continue To Participate in State CCS Advisory Group re: State CCS Redesign
  - Monitor CCS Pilot Projects
- Reduce Barriers to Timely Authorizations and Claims Payment
- Continue to Reduce Inter-County Variation in CCS Program Implementation
- Promote Medical Homes and Family-Centered Care
  - Family-Centered Transitions as Youth Age Out of CCS
  - "Best Practices", e.g. Intensive Case Management Based on Child/Family Needs, Better Coordination of Specialists and Primary Care Providers

How MCAH Programs Can Support CSHCN and Their Families

- Increase Knowledge of and Collaboration with County CCS Programs
- Involve Families in Planning and Decision-Making in MCAH Activities
- Stay Aware of State-Proposed Changes in CCS and Other Child Health Programs and Understand Impact on CSHCN

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