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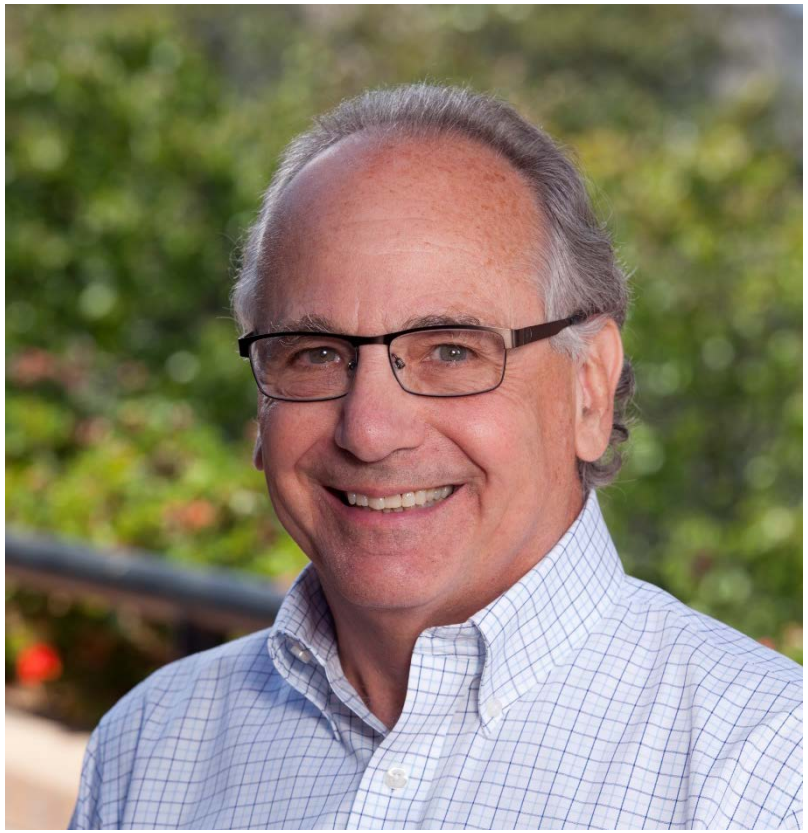
California Children with Special Health Care Needs and Their Families

Current Issues and Challenges Facing Our Most Vulnerable Population

Children with Special Health Care Needs Program Staff



Edward Schor, MD
Senior Vice President

Holly Henry, Ph.D.
Research Program Manager

Allison Gray, MA
Program Officer

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Our Focus Areas

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Objectives and Overview

Objective of Presentation

To provide an overview of topics which are a priority to the CYSHCN field

Objectives for Audience

To suggest issues that can be addressed by public agencies, and to identify resources to help guide new programs and policies

Main Points to be Covered

- Health care system standards and performance improvement opportunities
- Care coordination
- Family engagement and support

Improving the Systems of Care for CSHCN

- Grantmaking
- Advocacy
- Sharing Knowledge
  - Newsletters
  - Issue and Policy Briefs
  - Convenings and Webinars
- Community Engagement

Learn more: **lpfch.org/CSHCN**

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California's Quality of Health Care for CSHCN: National Comparison

National Ranking

- 50th in having at least one preventive care visit
- 46th for care coordination
- 50th in family-centered care
- 50th in proportion of parents with above average stress
- 45th in developmental screening
- 36th for transition to adult care
- 43rd in receiving needed mental health services

Source: 2009/10 National Survey of Children with Special Health Care Needs

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However, no "gold standard" exists for what constitutes a special health care need.

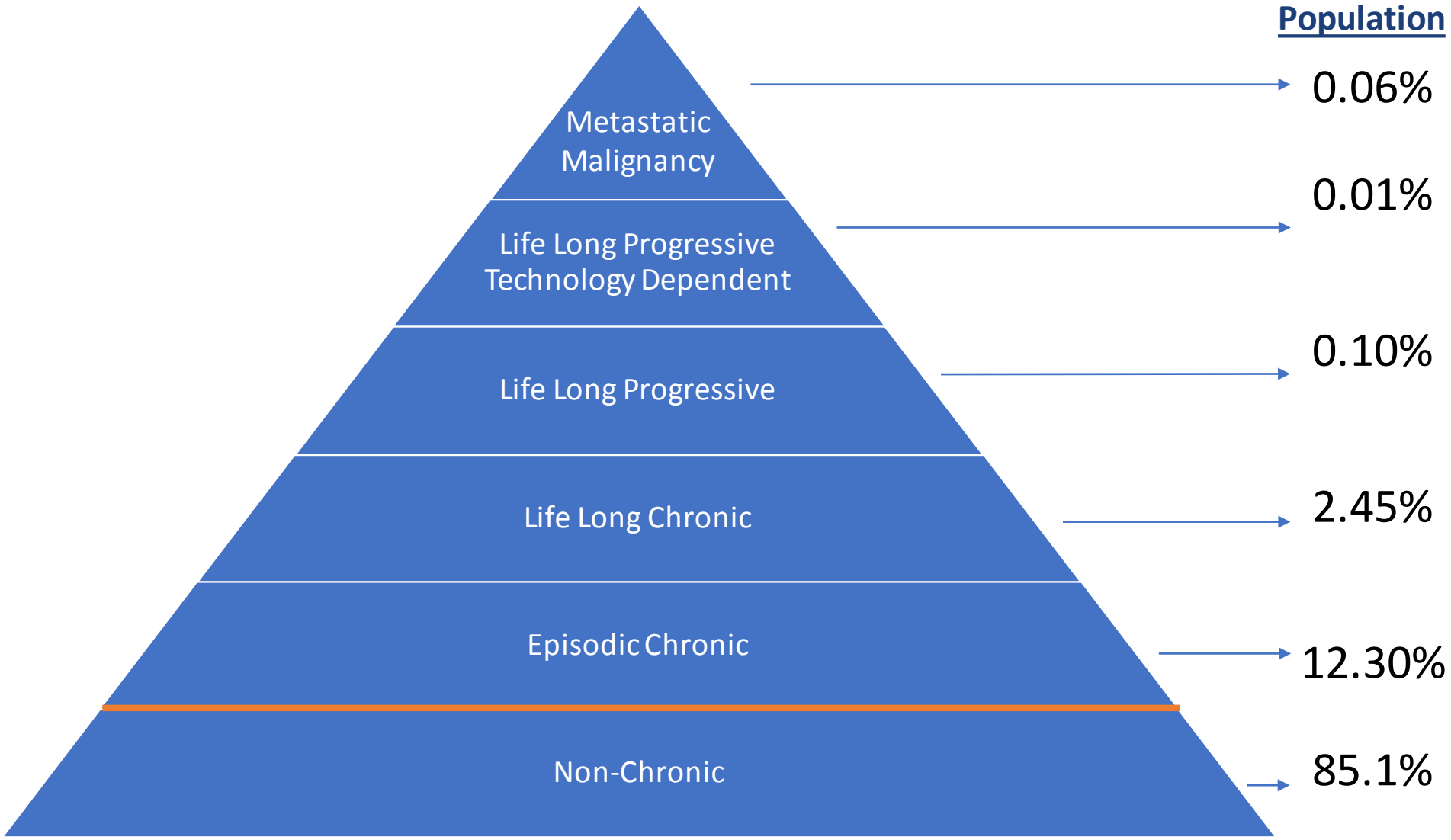
Definition:

Children with Special Health Care Needs

"Children with special health care needs are those who have or are at-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."

- Maternal and Child Health Bureau, July 1998

Distribution of Children By Chronic Illness Category



Source: JM Neff et al. Ambulatory Pediatrics, 2002;2(1):71-79

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Children with Medical Complexity

A Vulnerable Population

- Chronic, severe health condition and medically fragile
- Care provided by 2 or more pediatric subspecialists
- Technology dependent
- Multiple body organs affected
- Functional limitations

High Utilizer of Health Care

- <1% of general child population and ~1/3 of health care costs
- 10% of admissions and 41% of hospital charges
- ~5% of Medicaid children and >50% of costs
- 2 of 3 are enrolled in Medicaid

Who are the CCS-Enrolled Children?

Age—mean (SD): 7.3 (6.5) years	
	%
Sex—male	57.0
Race/Ethnicity	
White	16.6
Black	8.7
Hispanic	56.4
Insurance	
Medicaid Managed Care	47.6
Medicaid Fee for Service	19.6
CHIP	7.5
Mixed/Other	25.3
Medical Complexity	
Complex Chronic	51.4
Non-Complex Chronic	25.3
Non-Chronic	23.3

Courtesy of Center for Policy, Outcomes and Prevention

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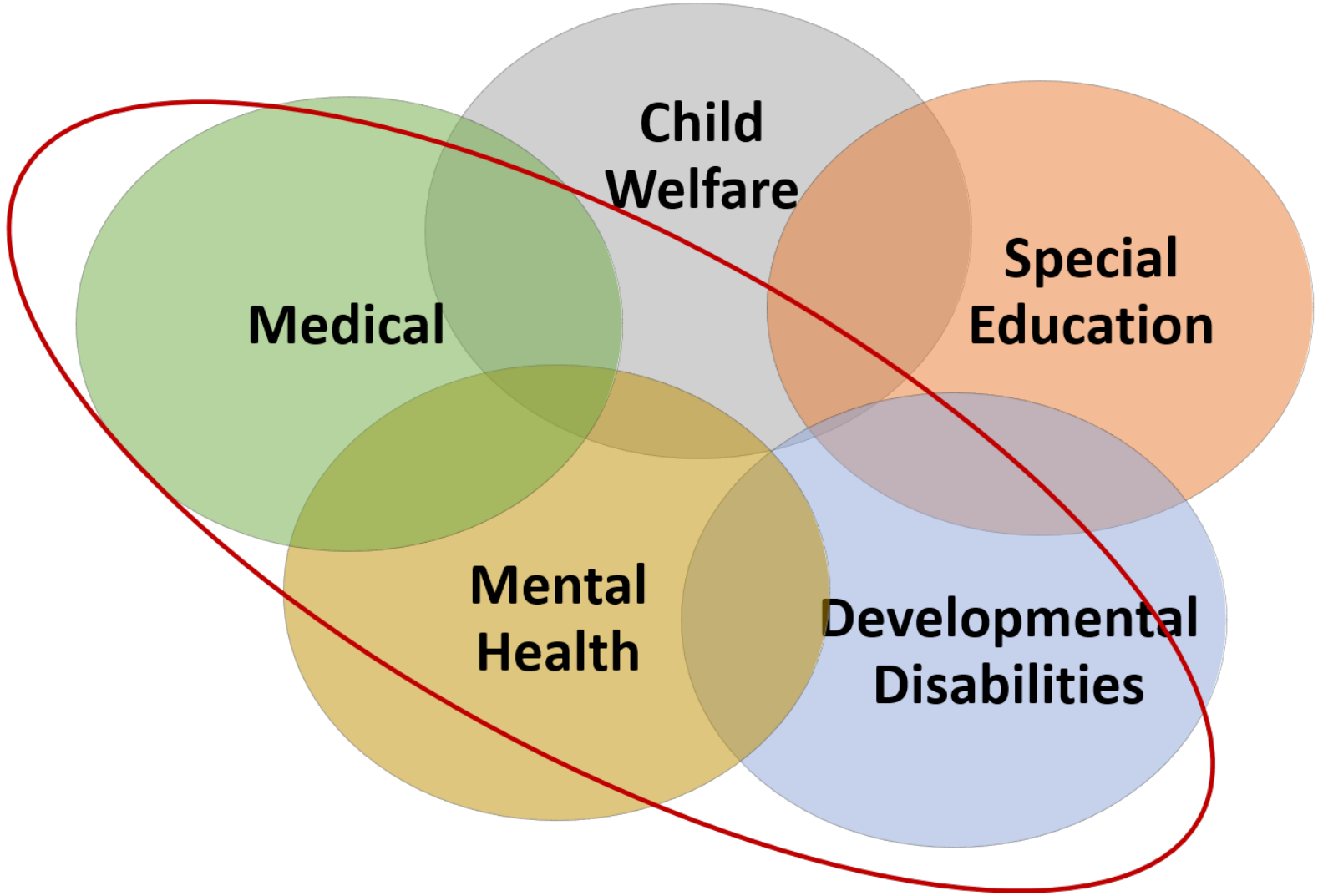
System for CSHCN is Overlapping Programs



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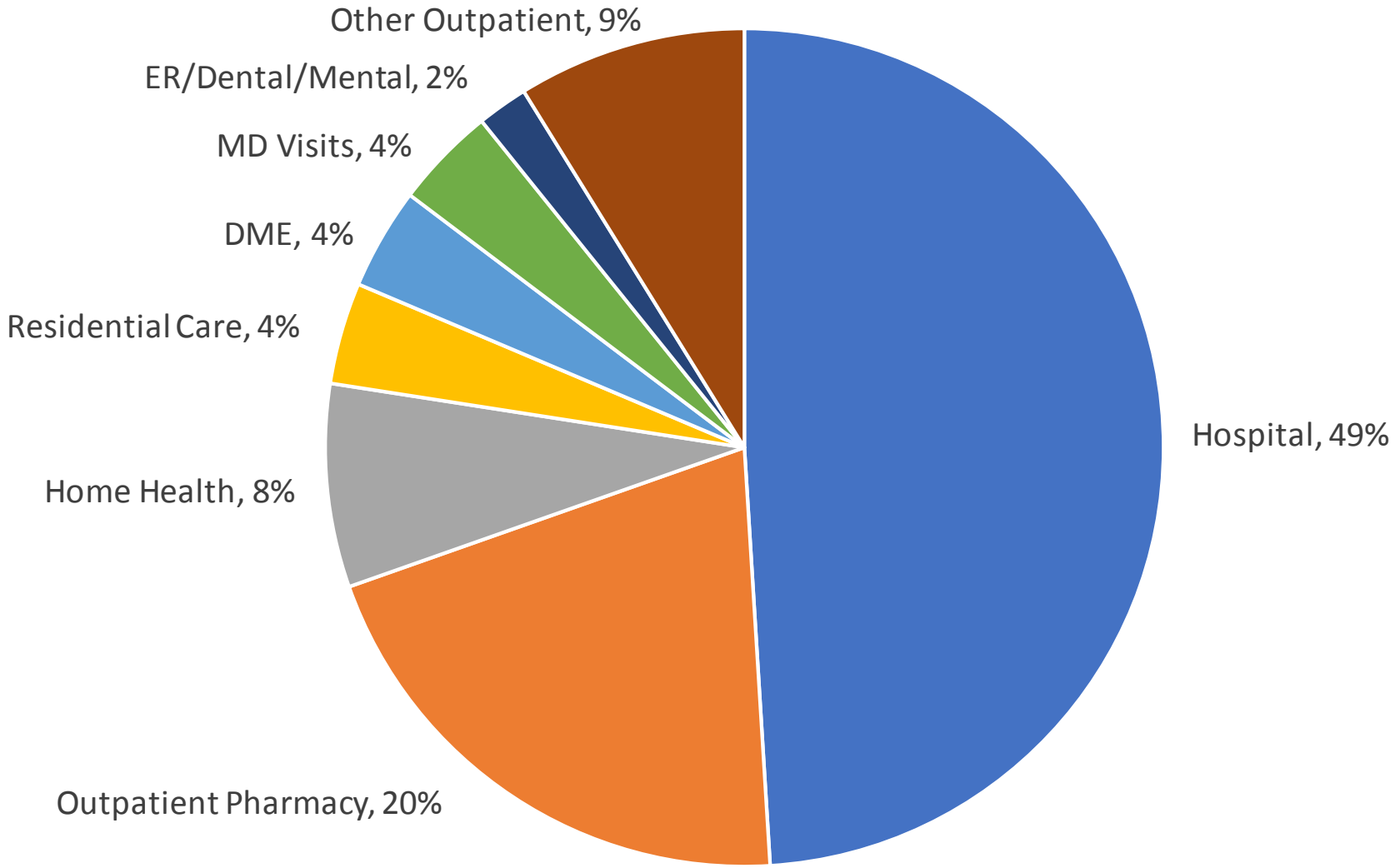
Key Components of a High Performance System for CSHCN

- Whole child, comprehensive coordinated services
- Integrated services plans and information sharing
- Meaningful family involvement
- Equity of access to good quality services
- Transparent monitoring to assure quality

CCS Program Spend by Health Service Category

2010-2012



Courtesy of Center for Policy, Outcomes and Prevention

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Comprehensive Care for Children with Medical Complexity

	Usual Care Rates are per 100 child-years, (N=96)	**Comprehensive Care** Rates are per 100 child-years, (N=105)
Medical costs	$26,781 per child year	$16,523 per child year
Outpatient costs	$1,722 per child year	$6,713 per child year
Hospitalizations	131	69
ED visits	90	190
Hospital visits	635	276
ICU admissions	44	9
IC days	178	52
Rate of serious illness	22	10

Source: Mosquera RA, Avritscher EBC, Samuels CL, Harris TS, et al. JAMA, 2014; (312(24):2640-2648

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Key But Missing Services for CSHCN

- Address Social Determinants of Health and Social Complexity
- Care Planning and Care Coordination
- Home Health Care
- Integrated Behavioral Health Care
- Integrated Funding
- Family Support
- Respite Care
- Transition Services
- Palliative Care
- Quality of Care Measures

California Children's Services (CCS) Program Transition

Past Program

Traditional Model
Fee-For Service for CCS Care

+

Medicaid Managed Care for
Non-CCS Conditions

Current Program

Traditional Model
Fee-for-Service for CCS Care
+
Medicaid Managed Care for
Non-CCS Conditions

Whole Child Model
Medicaid Managed Care for
CCS **&** Non-CCS Conditions

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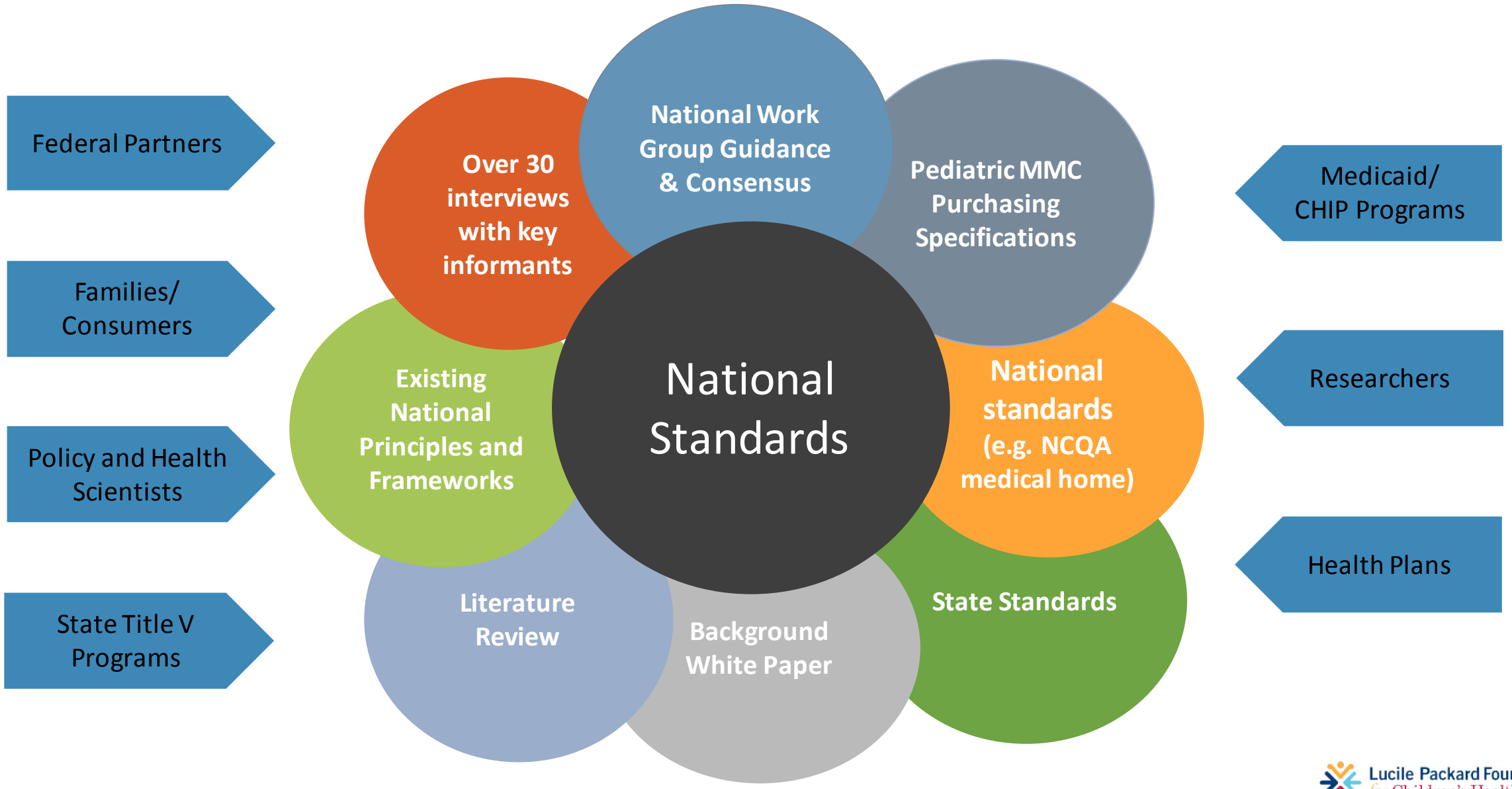
Parents Fear Managed Care

- Managing costs vs. managing care
- Limited benefits and barriers to care
- Limited access to pediatric subspecialists
- Loss of continuity
- Variable quality, including patient experience
- Fragmented care by undoing personal care systems

1990s: Mostly fee-for-service → 2017: 37 states mandated managed care enrollment of CSHCN

Developing the National System Standards



Association of Maternal & Child Health Programs, 2014

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National System Standards: Core Domains

- Screening, assessment & referral
- Eligibility and enrollment
- Access to care
- Medical home and care coordination
- Community-based services
- Family-professional partnerships
- Transition to adulthood
- Information technology
- Quality assurance & improvement
- Insurance & financing

Visit **NASHP.org** to access publication:
Standards for Systems of Care for Children and Youth with Special Health Care Needs Version 2.0, June 2017

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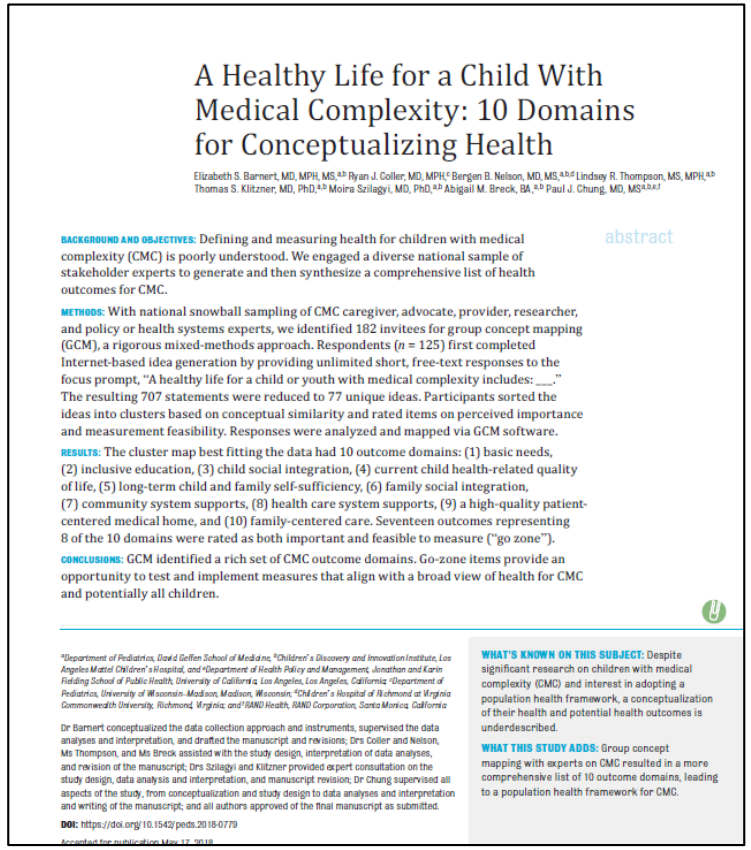
How States Are Using the Standards

1. Identify CYSHCN as a special population in managed care contracts
2. Determine performance improvement priorities
3. Guide strategic planning activities
4. Reference national system standards in managed care contracts
5. Create partnerships among Medicaid, MCOs, advocates and families to monitor access and quality
6. Guide local public health system development

Measuring the Health of CSHCN: Outcome Domains

- Basic needs
- Inclusive education services
- Child social integration
- Child health-related quality of life
- Long-term child and family self-sufficiency
- Community-based support systems
- Health care support systems
- Patient medical home
- Family-centered care



A Healthy Life for a Child With Medical Complexity: 10 Domains for Conceptualizing Health

Elizabeth S. Barnert, MD, MPH, MS,[a,b] Ryan J. Coller, MD, MPH,[c] Bergen B. Nelson, MD, MS,[a,b,d] Lindsey R. Thompson, MS, MPH,[a,b] Thomas S. Klitzner, MD, PhD,[a,b] Moira Szilagyi, MD, PhD,[a,b] Abigail M. Breck, BA,[a,b] Paul J. Chung, MD, MS[a,b,e,f]

abstract

BACKGROUND AND OBJECTIVES: Defining and measuring health for children with medical complexity (CMC) is poorly understood. We engaged a diverse national sample of stakeholder experts to generate and then synthesize a comprehensive list of health outcomes for CMC.

METHODS: With national snowball sampling of CMC caregiver, advocate, provider, researcher, and policy or health systems experts, we identified 182 invitees for group concept mapping (GCM), a rigorous mixed-methods approach. Respondents (n = 125) first completed Internet-based idea generation by providing unlimited short, free-text responses to the focus prompt, "A healthy life for a child or youth with medical complexity includes: ___." The resulting 707 statements were reduced to 77 unique ideas. Participants sorted the ideas into clusters based on conceptual similarity and rated items on perceived importance and measurement feasibility. Responses were analyzed and mapped via GCM software.

RESULTS: The cluster map best fitting the data had 10 outcome domains: (1) basic needs, (2) inclusive education, (3) child social integration, (4) current child health-related quality of life, (5) long-term child and family self-sufficiency, (6) family social integration, (7) community system supports, (8) health care system supports, (9) a high-quality patient-centered medical home, and (10) family-centered care. Seventeen outcomes representing 8 of the 10 domains were rated as both important and feasible to measure ("go zone").

CONCLUSIONS: GCM identified a rich set of CMC outcome domains. Go-zone items provide an opportunity to test and implement measures that align with a broad view of health for CMC and potentially all children.

[a]Department of Pediatrics, David Geffen School of Medicine, [b]Children's Discovery and Innovation Institute, Los Angeles Mattel Children's Hospital, and [c]Department of Health Policy and Management, Jonathan and Karin Fielding School of Public Health, University of California, Los Angeles, Los Angeles, California [d]Department of Pediatrics, University of Wisconsin-Madison, Madison, Wisconsin; [e]Children's Hospital of Richmond at Virginia Commonwealth University, Richmond, Virginia; and [f]RAND Health, RAND Corporation, Santa Monica, California

Dr Barnert conceptualized the data collection approach and instruments, supervised the data analyses and interpretation, and drafted the manuscript and revisions; Drs Coller and Nelson, Ms Thompson, and Ms Breck assisted with the study design, interpretation of data analyses, and revision of the manuscript; Drs Szilagyi and Klitzner provided expert consultation on the study design, data analysis and interpretation, and manuscript revision; Dr Chung supervised all aspects of the study, from conceptualization and study design to data analyses and interpretation and writing of the manuscript; and all authors approved of the final manuscript as submitted.

DOI: https://doi.org/10.1542/peds.2018-0779

Accepted for publication May 17, 2018

WHAT'S KNOWN ON THIS SUBJECT: Despite significant research on children with medical complexity (CMC) and interest in adopting a population health framework, a conceptualization of their health and potential health outcomes is underdescribed.

WHAT THIS STUDY ADDS: Group concept mapping with experts on CMC resulted in a more comprehensive list of 10 outcome domains, leading to a population health framework for CMC.

Source: Barnert et al. Pediatrics. August 2017

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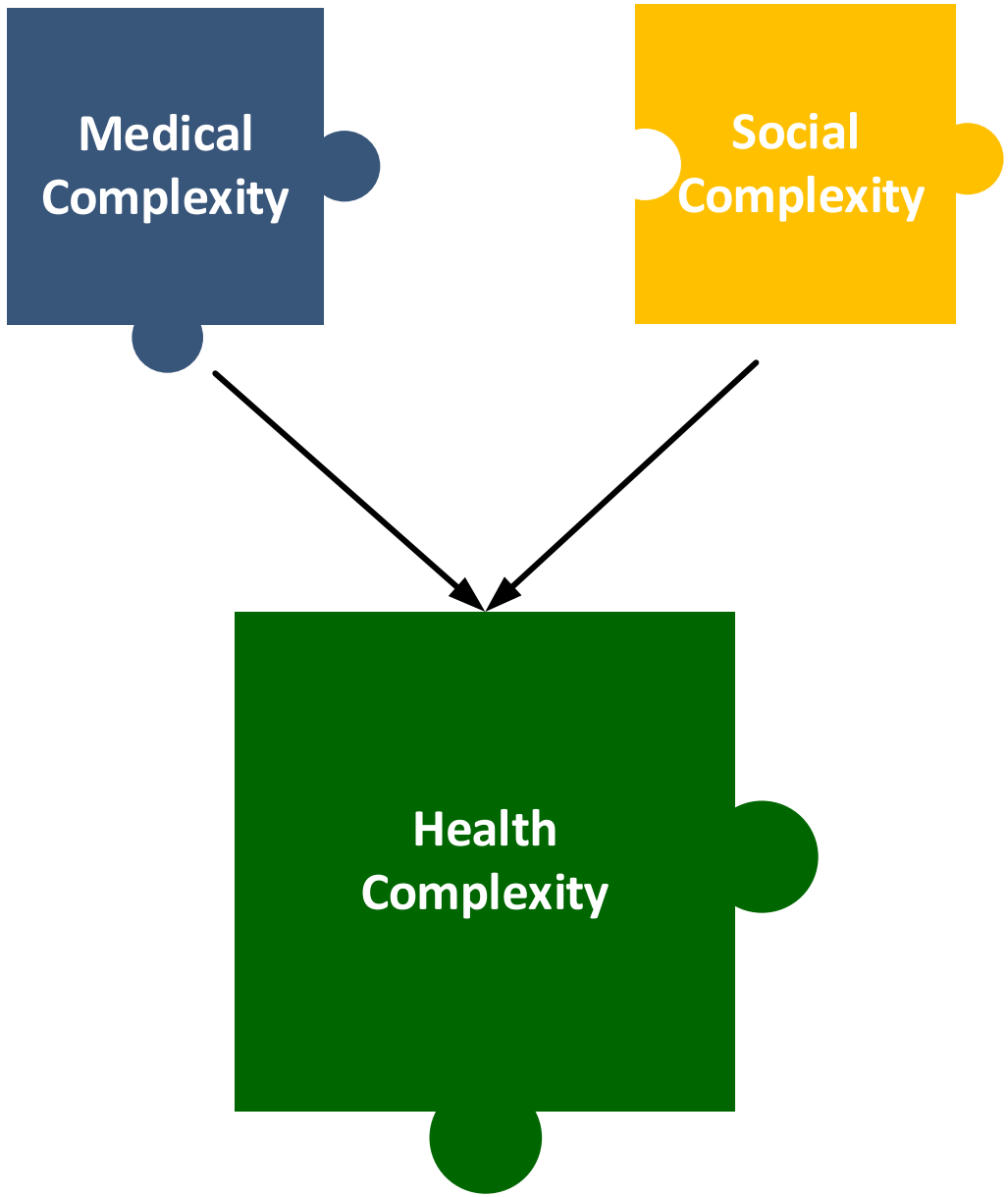
Biomedical and Social Determinants of Health



Social Complexity Indicators, 2018

Look Back Period: Presence of the risk factor in prenatal period (year before birth)-lifetime of the child.

INDICATOR	CHILD FACTOR	FAMILY FACTOR	TOTAL
Poverty –TANF (For Child and For Either/Both Parent)	X	X	X
Foster care – Child receiving foster care services DHS ORKids (since 2012)	X		X
Parent death – Death of parent/primary caregiver in OR		X	X
Parental incarceration – Parent incarcerated or supervised by the Dept. of Corrections in Oregon.		X	X
Mental Health: Child – Received mental health services through DHS/OHA	X		X
Mental Health: Parent – Received mental health services through DHS/OHA		X	X
Substance Abuse: Child – Substance abuse treatment through DHS/OHA	X		X
Substance Abuse: Parent – Substance abuse treatment through DHS/OHA		X	X
Child abuse/neglect: ICD-9, ICD-10 dx codes related to service	X		X
Limited English Proficiency: Language other than English listed in the primary language field		X	X
Parent Disability: OHA eligibility due to parent disability		X	X
Total Number of Individual Flags Included	**5**	**7**	**12**

Courtesy Oregon Health Authority, Oregon Department of Human Services and Oregon Pediatric Improvement Partnership

Oregon's Medicaid Enrollees' Health Complexity

MEDICAL COMPLEXITY (3 Categories)	SOCIAL COMPLEXITY (Total Factors Possible = 12)		
	3 or More Indicators	1-2 Indicators	No Indicators
HIGH Chronic, Complex	3%	2.4%	0.7%
MODERATE Chronic, Non-Complex	9.5%	7.2%	1.7%
LOW Non-Chronic	26.5%	32.6%	16.6%

Data Source: ICS Data Warehouse & Medicaid data sourced from Medicaid Management Information System (MMIS)
Courtesy Oregon Health Authority, Oregon Department of Human Services and Oregon Pediatric Improvement Partnership

More on System Standards and Quality

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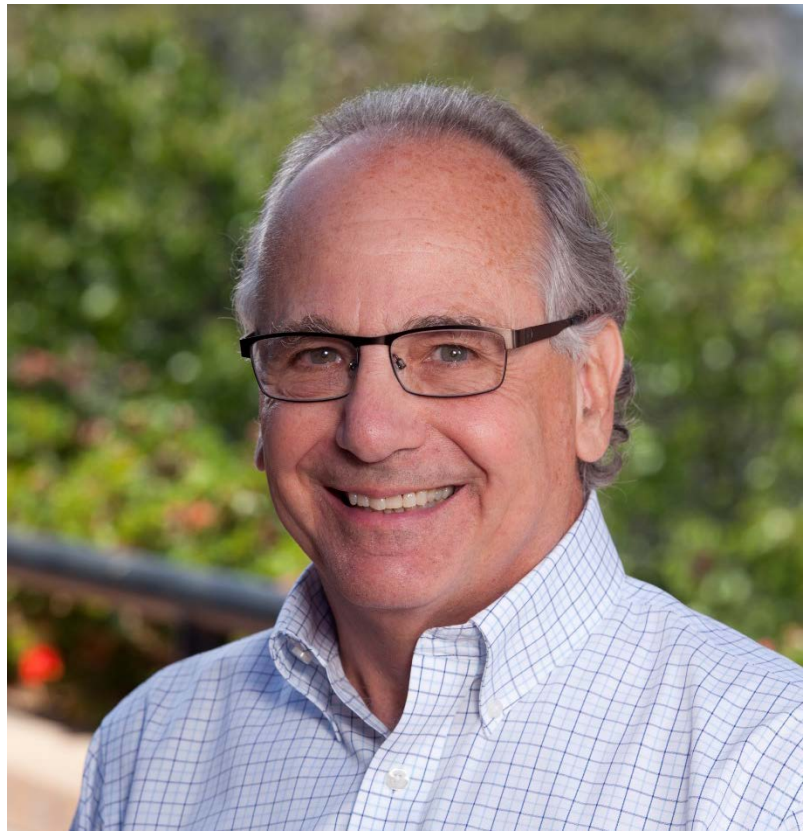
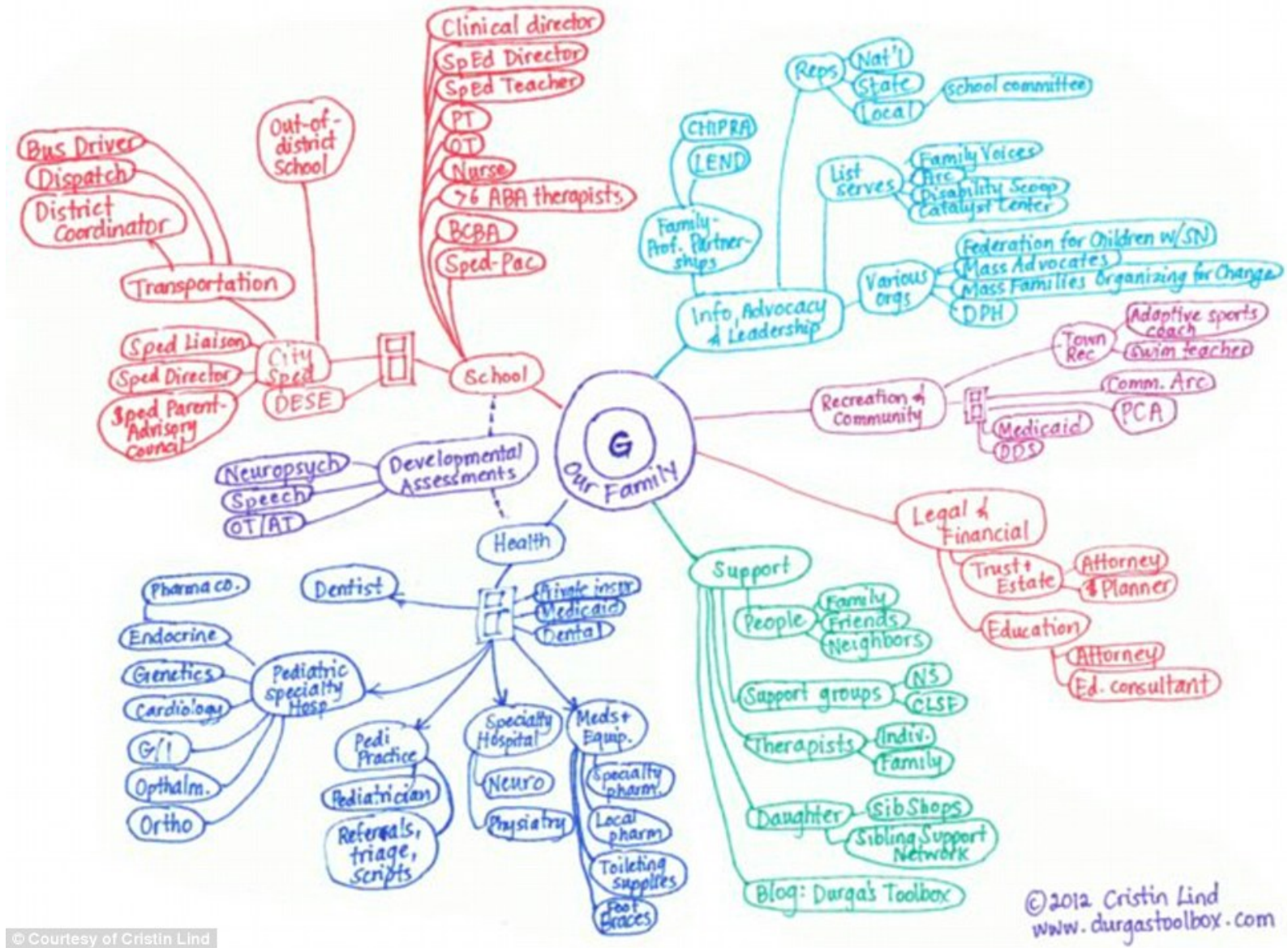


UPCOMING WEBINAR:
March 14, 2019, 10:30-11:30 am PST
Identifying and Serving Children with Health Complexity: Spotlight on Pediatric Care Together Webinar
Register: lpfch.org/cshcn

Care Coordination for CSHCN

Holly Henry, Ph.D.

Lucile Packard Foundation for Children's Health




DANIEL'S
HOMEWORK
FOLDER

Care Coordination

Individualized care that is:

- Family-centered
- Assessment-driven
- Team-based
- Guided by care plan

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Benefits of Care Coordination

Enhanced caregiving that meets the needs of each patient and their families

Patient & Families

- Improved health outcomes
- Reduced burden on families
- Increased family functioning

Clinicians

- Increased quality of care
- Increased patient and family satisfaction

Healthcare Organizations

- Reduction in health care costs
- Reduction in health care utilization

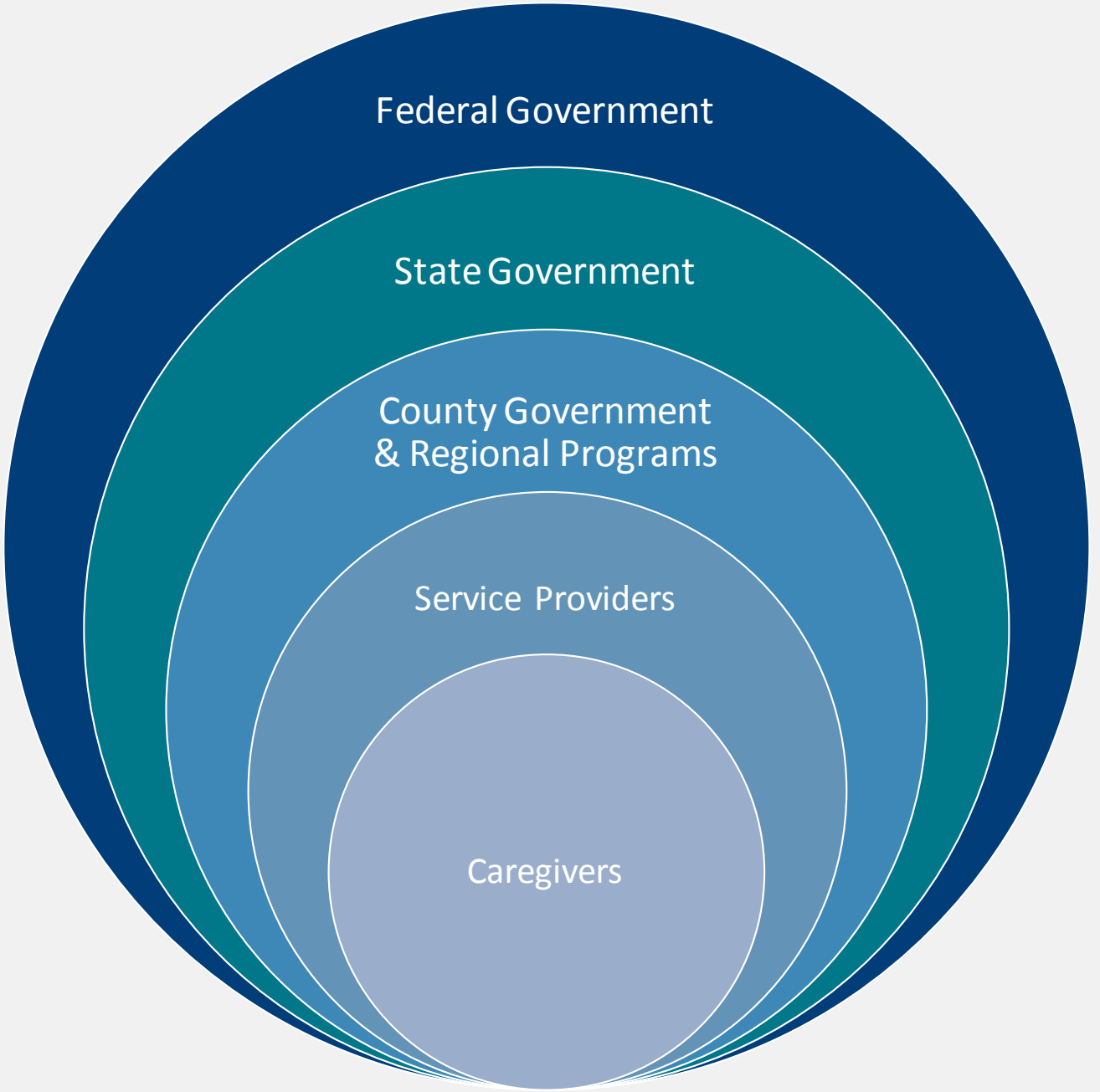
Barriers to Care Coordination

Our fragmented system of care

- Time intensive process
- No reimbursement
- No designated leader
- Lack of knowledge about available services
- Lack of staff trained to coordinate care
- Lack of standards

48% of parents of children with special health care needs in California report not receiving effective care coordination

Care Coordination Responsibility Across Our Health Care System



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Our Approach:

Care Coordination

Help create and assure access to effective care coordination systems that **connect** children to services, **facilitate** service provider communications, and **support** families as primary caregivers.

Pediatric Integrated Care Survey

Family Experience with the Integration of Health and Related Services

Validation of a Parent-Reported Experience Measure of Integrated Care

Sonya I. Zinel, PhD, MA[a,b,c,d] Hannah N. Rosenberg, MSc[e] Ashley M. Bach, BA[f] Sara J. Singer, MBA, PhD[b,c,g] Richard C. Antonelli, MD, MPH[c,e]

abstract

OBJECTIVES: The objectives of this study were to design and validate a survey measuring the parents' and caregivers' experiences of integration of their child's care across providers.

METHODS: After review of the literature on care coordination and integration, we solicited input regarding care experiences from focus groups of families with children with chronic conditions. These data informed a 95-item pilot survey that included elements from a care integration measure designed for adult care experiences. The survey was then administered to parents of children who had had at least 1 primary care appointment and 2 specialty care appointments in the previous 12 months. Psychometric analyses were used to establish scales through exploratory factor analysis, internal consistency using Cronbach's α, test-retest reliability using Spearman's rank correlation coefficient, and known-group validity according to χ^2 tests. All research activities were institutional review board approved.

RESULTS: The pilot survey was completed as either a Web or mail survey by 255 participants. After excluding nonrating or screening questions and items not applicable to a large percentage of participants, 26 experience items were included in the exploratory factor analysis. The final survey contained 19 experience items in 5 scales: access, communication, family impact, care goal creation, and team functioning. Psychometric analyses supported these 5 scales.

CONCLUSIONS: This project developed and validated a survey with 19 experience items, plus additional demographic and health needs and usage items. The Pediatric Integrated Care Survey can be used in quality improvement efforts to measure family-reported experience of pediatric care integration.

Care delivery for children and youth with special health care needs (CYSHCN) is often experienced by families as being fragmented, resulting in outcomes not meeting their needs.[1,2] The implementation of standardized activities of care coordination (CC) is often cited as a solution. CC addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes.[3] It is unknown if broadly implemented CC activities influence the outcome of family experience of care integration across providers, nor how measures of CC relate to measures of family experience of integrated care. Singer et al[3] have proposed a definition of integrated patient care, describing it as "care that is coordinated across professionals, facilities and support systems; continuous over time and between visits; tailored to the patients' needs and preferences; and based on shared

DOI: 10.1542/peds.2016-0878

Accepted for publication Sep 27, 2016

To cite: Zinel SI, Rosenberg HN, Bach AM, et al. Validation of a Parent-Reported Experience Measure of Integrated Care. Pediatrics. 2018; 138(6):e20160878

Downloaded from www.aappublications.org/news by guest on February 15, 2019

PEDIATRICS Volume 138, number 6, December 2016:e20160878

SPECIAL ARTICLE

- Available in English and Spanish
- 5 Core Modules
  - Access to Care
  - Communication with Care Team Members
  - Family Impact
  - Care Goal Creation and Planning
  - Team Functioning and Quality
- County programs serving CSHCN could use this tool to assess how well care is being coordinated

To access the instruments, contact: Richard.Antonelli@childrens.harvard.edu

Validation of a Parent-Reported Experience Measure of Integrated Care

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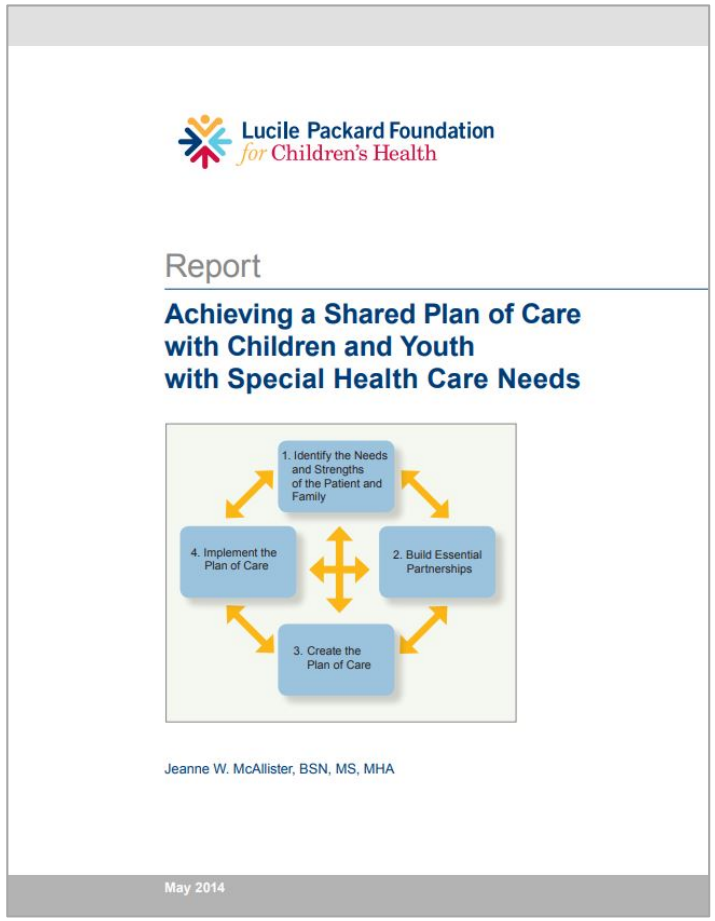
Achieving a Shared Plan of Care

A Step-By-Step Approach to Developing a Comprehensive, Family-Centered and Integrated Plan



- Identify the needs and strengths of the patient and family
- Build essential partnerships
- Create the plan of care
- Implement the plan of care

Visit **lpfch.org/CSHCN** to access publication:
Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs

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Pyramid of Complexity Tiering for CSHCN

Aligning Services with Needs

- Share data across health care entities
- Information about social determinants of health should be included
- Rationale for tiering should be made transparent
- Tiering systems should include periodic reassessment

Visit **lpfch.org/CSHCN** to access publication:
Aligning Services with Needs: Characterizing the Pyramid of Complexity Tiering for Children with Chronic and Complex Conditions

Lessons from Medicare

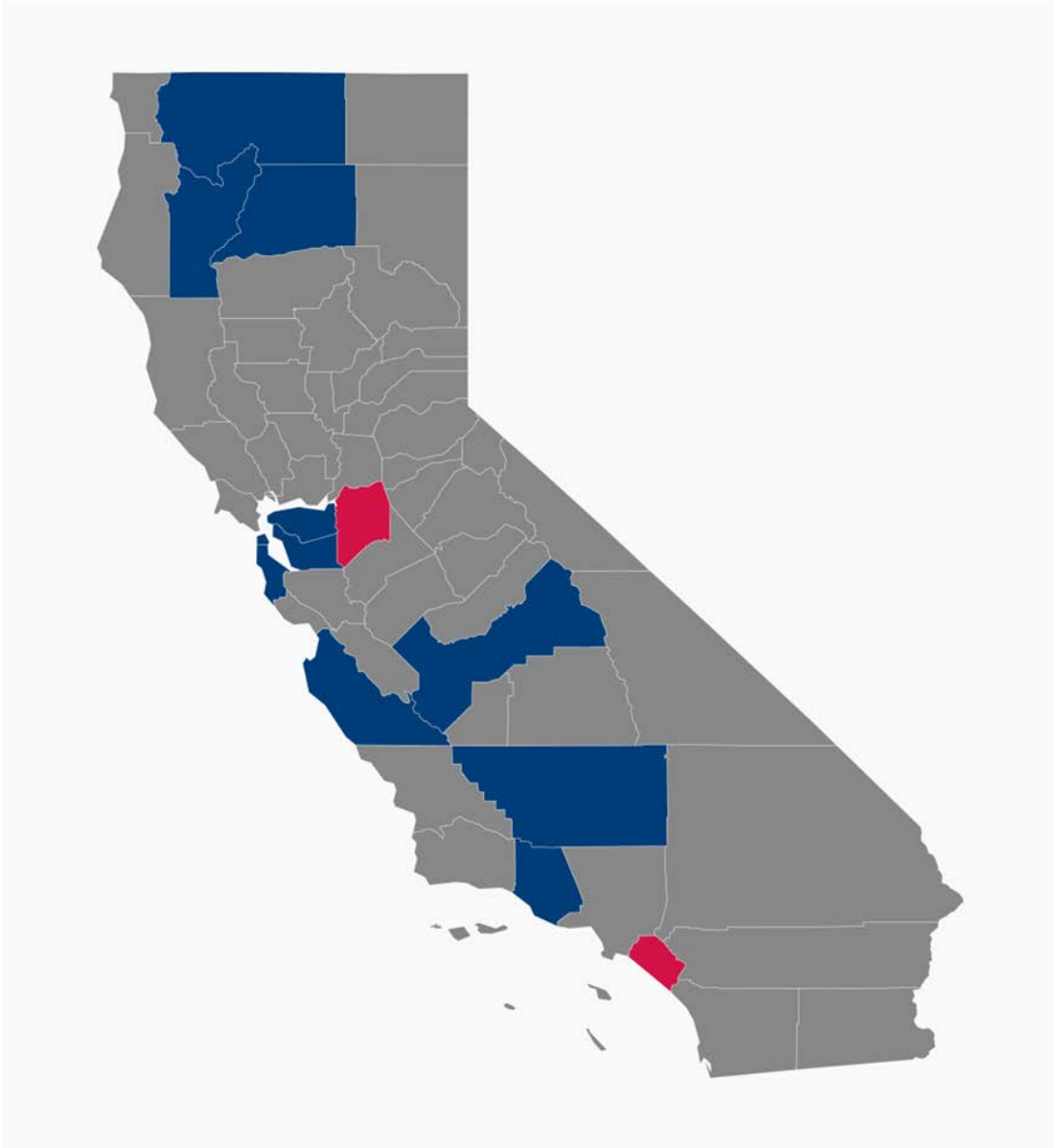
Coordinating Care for CSHCN

- Identify and target specific subgroups
- Set clear goals for outcomes that are feasible in the time period
- Encourage engagement between care coordinators and primary care providers
- Require in-person contact between care coordinators and patients/families
- Facilitate information sharing
- Supplement care coordinators capabilities with those of clinical experts

Visit **ajmc.com** to access publication:
Care Coordination for Children With Special Needs in Medicaid: Lessons from Medicare, April 2018

National Care Coordination System Standards

- Project in initial stages
- Key informant interviews and development of a National Work Group
- Will provide clear guidance on staffing ratios, sharing of information across systems, job training and risk assessments



California Community Care Coordination Collaborative (5Cs)

Promoting inter-agency collaboration to improve **local systems** of care coordination

County Coalition Members include:

- California Children's Services
- Family Representatives
- MCAH Directors
- Medi-Cal Managed Care Organizations
- Mental Health
- Pediatric Providers
- Regional Center
- Public Health Nursing
- Special Education

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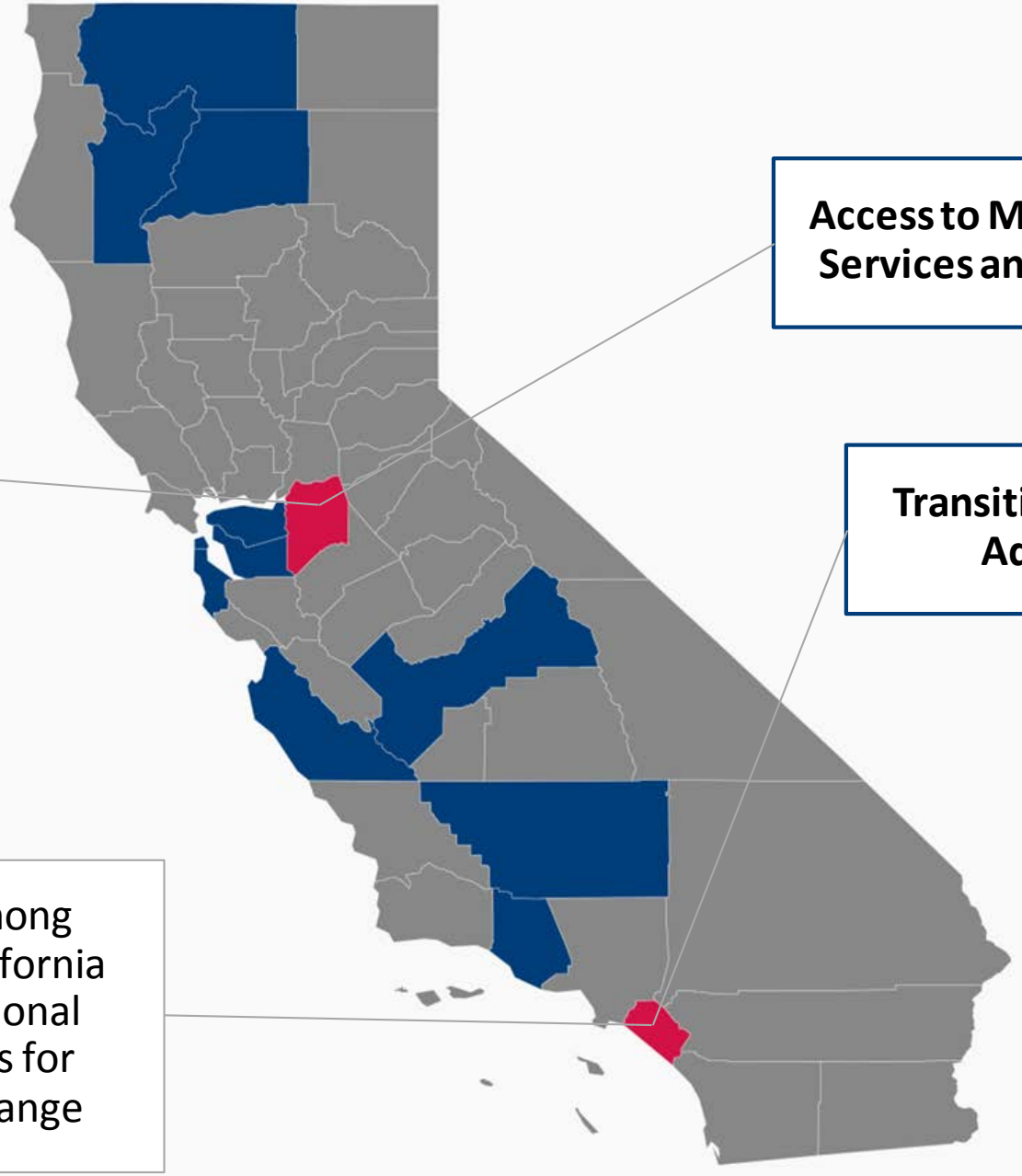
5Cs System Work



Access to Mental Health Services and Resources

Improving access to out-of-county Non-Emergency Medical Transportation in San Joaquin County

Transition from Pediatric to Adult Health Care

Increasing coordination among Medi-Cal Managed Care, California Children's Services and Regional Center to reduce wait times for incontinence supplies in Orange

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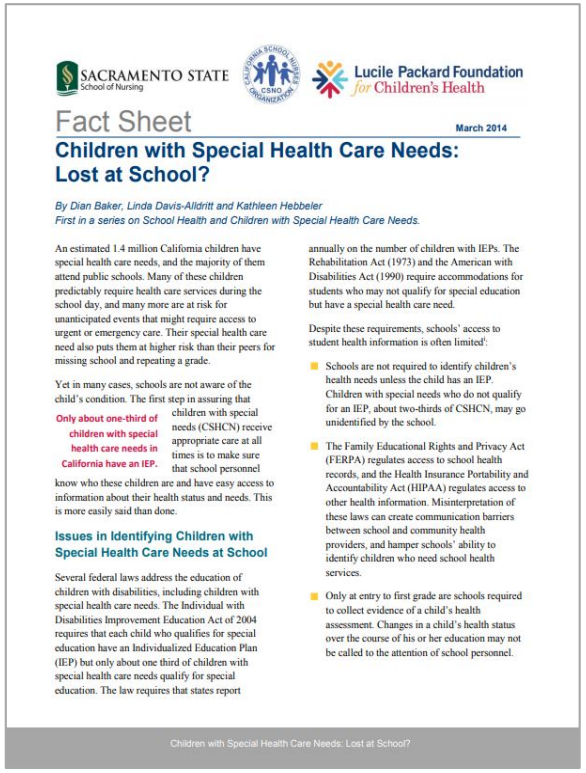
Hidden Health Care System in California Schools

As of 2014, California did not use any of its Title V funds to support school health services



SACRAMENTO STATE School of Nursing

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Fact Sheet

March 2014

Children with Special Health Care Needs: Lost at School?

By Dian Baker, Linda Davis-Alldritt and Kathleen Hebbeler
First in a series on School Health and Children with Special Health Care Needs.

An estimated 1.4 million California children have special health care needs, and the majority of them attend public schools. Many of these children predictably require health care services during the school day, and many more are at risk for unanticipated events that might require access to urgent or emergency care. Their special health care need also puts them at higher risk than their peers for missing school and repeating a grade.

Yet in many cases, schools are not aware of the child's condition. The first step in assuring that children with special needs (CSHCN) receive appropriate care at all times is to make sure that school personnel know who these children are and have easy access to information about their health status and needs. This is more easily said than done.

Only about one-third of children with special health care needs in California have an IEP.

Issues in Identifying Children with Special Health Care Needs at School

Several federal laws address the education of children with disabilities, including children with special health care needs. The Individual with Disabilities Improvement Education Act of 2004 requires that each child who qualifies for special education have an Individualized Education Plan (IEP) but only about one third of children with special health care needs qualify for special education. The law requires that states report annually on the number of children with IEPs. The Rehabilitation Act (1973) and the American with Disabilities Act (1990) require accommodations for students who may not qualify for special education but have a special health care need.

Despite these requirements, schools' access to student health information is often limited[1]:

- Schools are not required to identify children's health needs unless the child has an IEP. Children with special needs who do not qualify for an IEP, about two-thirds of CSHCN, may go unidentified by the school.
- The Family Educational Rights and Privacy Act (FERPA) regulates access to school health records, and the Health Insurance Portability and Accountability Act (HIPAA) regulates access to other health information. Misinterpretation of these laws can create communication barriers between school and community health providers, and hamper schools' ability to identify children who need school health services.
- Only at entry to first grade are schools required to collect evidence of a child's health assessment. Changes in a child's health status over the course of his or her education may not be called to the attention of school personnel.

Children with Special Health Care Needs: Lost at School?

- Only about one-third of CSHCN have an Individualized Education Plan, the other two-thirds may go unidentified in school
- Only 56% of school nurses reported they knew how many CSHCN were in the schools they served
- Only at entry to first grade are schools required to collect evidence of a child's health assessment – changes in status may not be reported or known by school
- County public health agencies may contract to assist with health care required during school hours

Visit **lpfch.org/CSHCN** to access publication:
The 'Hidden Health Care System' in California Schools and Children with Special Health Care Needs

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Access to Durable Medical Equipment

"Parents of children with special health needs do not have spare time like other parents do. Not to mention that calling everyone is extremely frustrating and complicated. The job of resolving interagency billing disputes should not fall in our laps."

– Parent of CCS Child

"Most families with a child who has a disability would give anything to not need the requested equipment. It's like adding insult to injury to make it so difficult to obtain any equipment."

– from a Parent Interview

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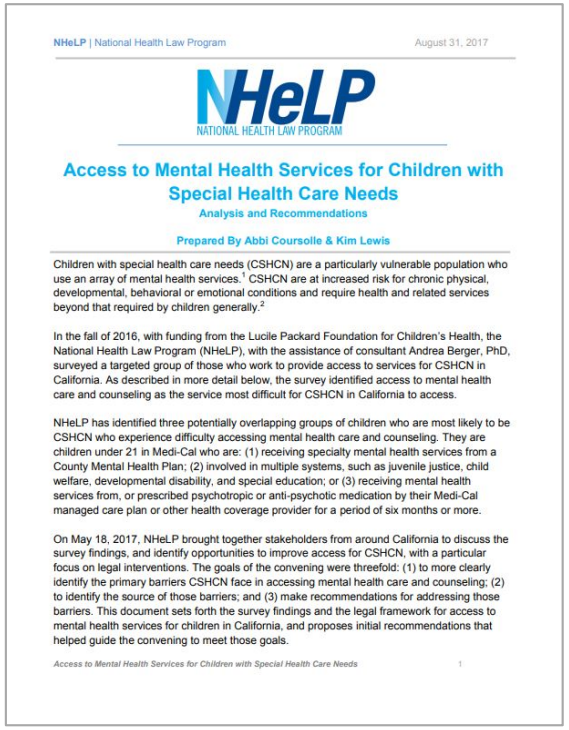
Which service is most difficult to obtain for California CSHCN and their families?

Service	Number of Respondents
Mental Health Care or Counseling	**15**
Behavioral Health Therapy Services	10
Private Duty Nursing	6
Neurology	5
Respite Care	4
Personal Care Services	3
Orthodontic Care	3

Access to Mental Health Services

Over one-third of California children who need mental health treatment fail to receive it



NHeLP | National Health Law Program August 31, 2017

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NATIONAL HEALTH LAW PROGRAM

Access to Mental Health Services for Children with Special Health Care Needs

Analysis and Recommendations

Prepared By Abbi Coursolle & Kim Lewis

Children with special health care needs (CSHCN) are a particularly vulnerable population who use an array of mental health services.[1] CSHCN are at increased risk for chronic physical, developmental, behavioral or emotional conditions and require health and related services beyond that required by children generally.[2]

In the fall of 2016, with funding from the Lucile Packard Foundation for Children's Health, the National Health Law Program (NHeLP), with the assistance of consultant Andrea Berger, PhD, surveyed a targeted group of those who work to provide access to services for CSHCN in California. As described in more detail below, the survey identified access to mental health care and counseling as the service most difficult for CSHCN in California to access.

NHeLP has identified three potentially overlapping groups of children who are most likely to be CSHCN who experience difficulty accessing mental health care and counseling. They are children under 21 in Medi-Cal who are: (1) receiving specialty mental health services from a County Mental Health Plan; (2) involved in multiple systems, such as juvenile justice, child welfare, developmental disability, and special education; or (3) receiving mental health services from, or prescribed psychotropic or anti-psychotic medication by their Medi-Cal managed care plan or other health coverage provider for a period of six months or more.

On May 18, 2017, NHeLP brought together stakeholders from around California to discuss the survey findings, and identify opportunities to improve access for CSHCN, with a particular focus on legal interventions. The goals of the convening were threefold: (1) to more clearly identify the primary barriers CSHCN face in accessing mental health care and counseling; (2) to identify the source of those barriers; and (3) make recommendations for addressing those barriers. This document sets forth the survey findings and the legal framework for access to mental health services for children in California, and proposes initial recommendations that helped guide the convening to meet those goals.

Access to Mental Health Services for Children with Special Health Care Needs 1

- CSHCN may receive mental health services from Medi-Cal Health Plans, County Mental Health Plans, Schools and/or Regional Centers
- Need for one centralized entity for initial screening and referrals for mental health concerns

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Access to Mental Health Services for Children with Special Health Care Needs in California

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More on Care Coordination

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SUBSCRIBE TO CSHCN NEWSLETTER:
Stay informed on news, policy, research, events, and advocacy opportunities by subscribing to the newsletter from the California Advocacy Network for Children with Special Health Care Needs.

Sign up: lpfch.org/cshcn/join-us

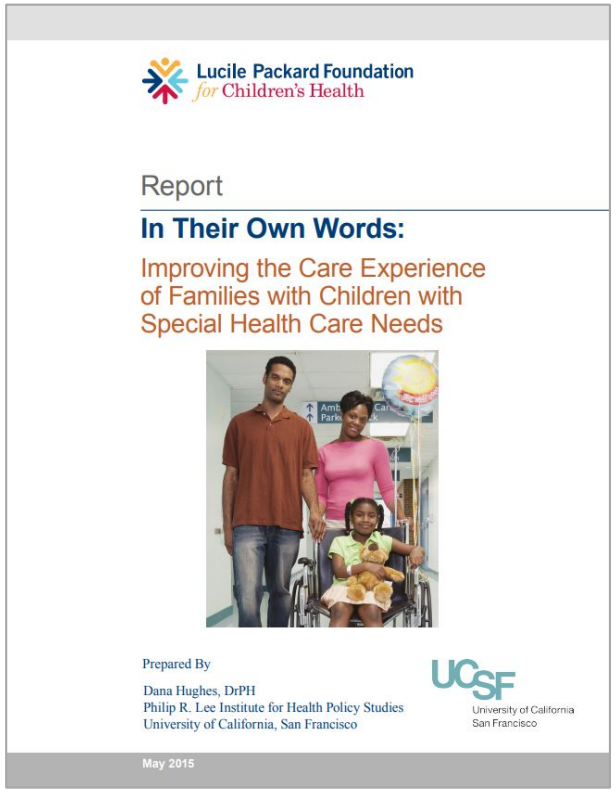
Family Engagement

Allison Gray, MA

Lucile Packard Foundation for Children's Health

In Their Own Words:

Improving the Care Experience of Families with Children with Special Health Care Needs



- What are your children's special needs and how do these affect their health, well-being, functioning and development? How do they affect the rest of the family?
- How well are your children's needs being met? What about the system of care is working well for children and families? What is not working well?
- What specific recommendations do you have about how the system of care can better meet your children's needs?

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In Their Own Words: Improving the Care Experience of Families with Children with Special Health Care Needs

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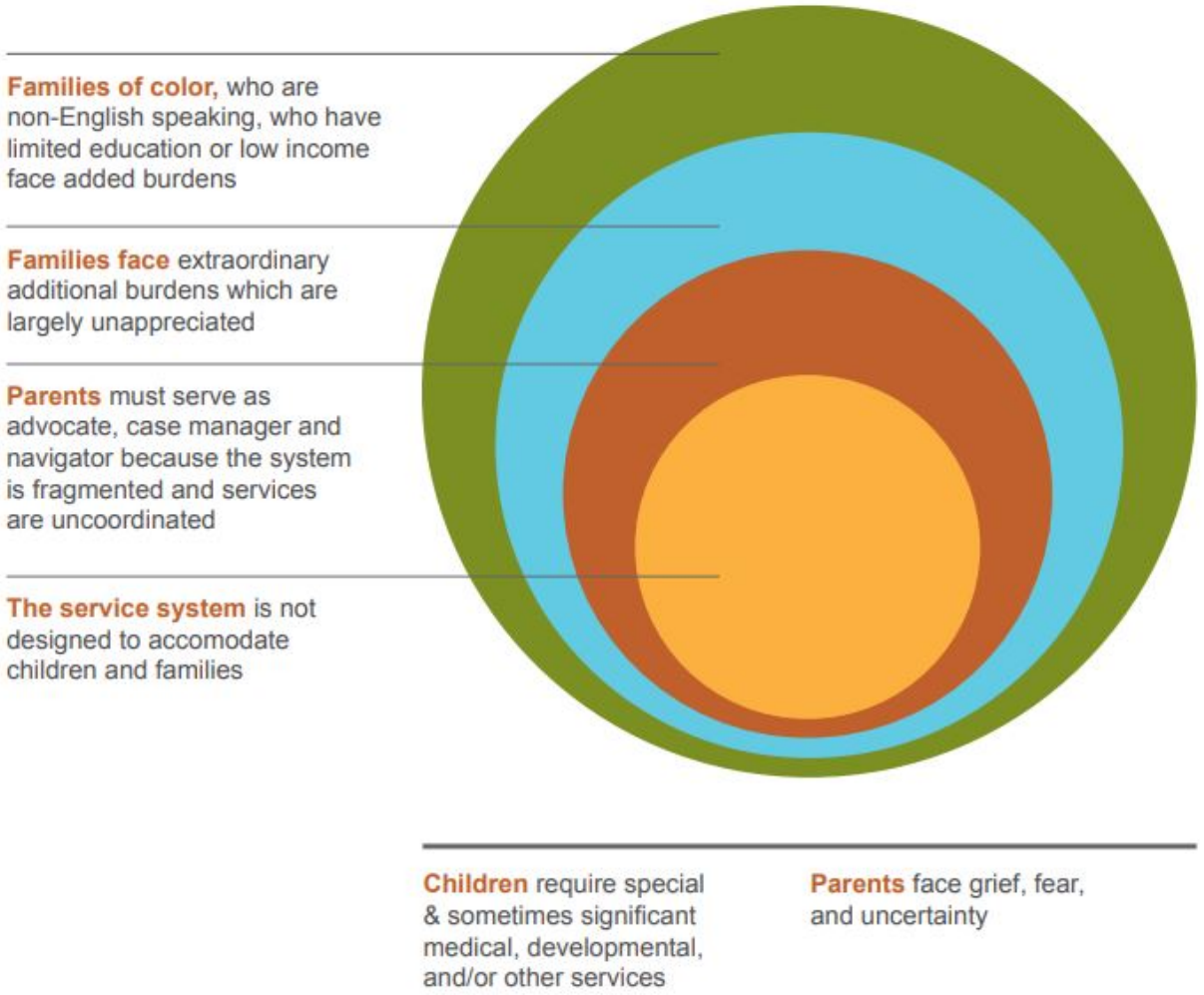
Family Experiences: Core Themes



Source: Hughes, D. In Their Own Words: Improving the Care Experience of Families with Children with Special Health Care Needs Lucile Packard Foundation for Children's Health; June 2015

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Family Provided Health Care

- 5.6 million children with special health care needs in the U.S. receive **1.5 billion hours** of unpaid family-provided health care annually
- Parents providing this unpaid care lose out on an estimated $17.6 billion in missed earnings annually

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Source: Romley, J.A., Shah, A.K., Chung, P.J., Elliott, M.N., Vestal, K.D. & Schuster, M.A. (2017). Family-Provided health care for children with special health care needs. Pediatrics, 139(1):e20161287.

Burden on Families of CSHCN in CA

- **30%** cut back or stopped working to care for their child
- **24%** report their children's conditions cause family financial problems
- **16%** spend 11 hours or more per week coordinating care

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Source: National Survey of Children with Special Health Care Needs (2009-2010). From Kidsdata.org.

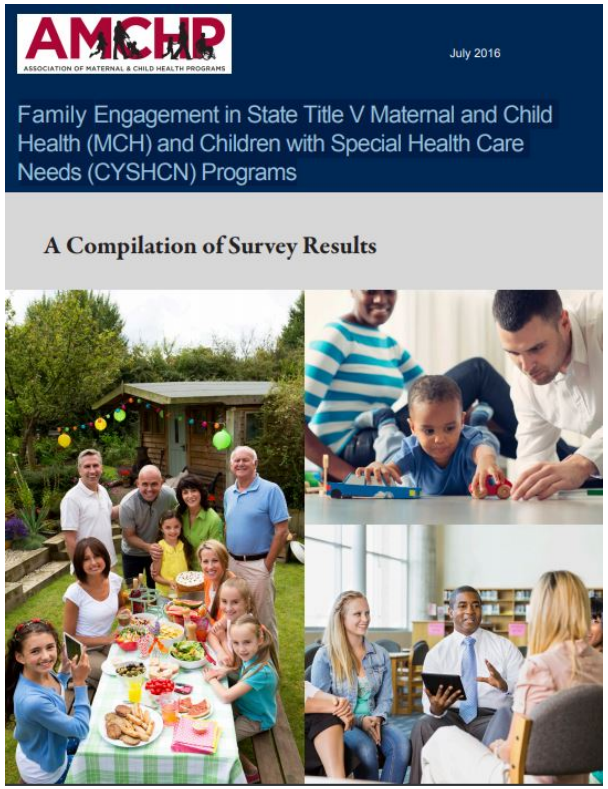
Family Recommendations

- Simplify eligibility and enrollment
- Broaden benefits
- Improve linkages between services
- Increase availability of respite care
- Improve access to mental health supports
- Assure family-centered care
- Improve care coordination, navigation and advocacy
- Reorganize service delivery
- Educate healthcare providers

"Fundamentally, parents feel that they don't have a voice."

CCS Family Engagement Survey

Initial survey of all state Title V MCH and CSHCN programs by Association of Maternal & Child Health Programs (AMCHP)



- Survey based on previous surveys by the National Parent Resource Center (1992) and Family Voices (2002)
- Nationally, CSHCN programs had higher levels of family engagement than MCH programs
- Decentralization of CCS → separate county-level survey in California

Visit **lpfch.org/CSHCN** to access publication:
Family Engagement in State Title V Maternal and Child Health (MCH) and Children with Special Health Care Needs (CYSHCN) Programs

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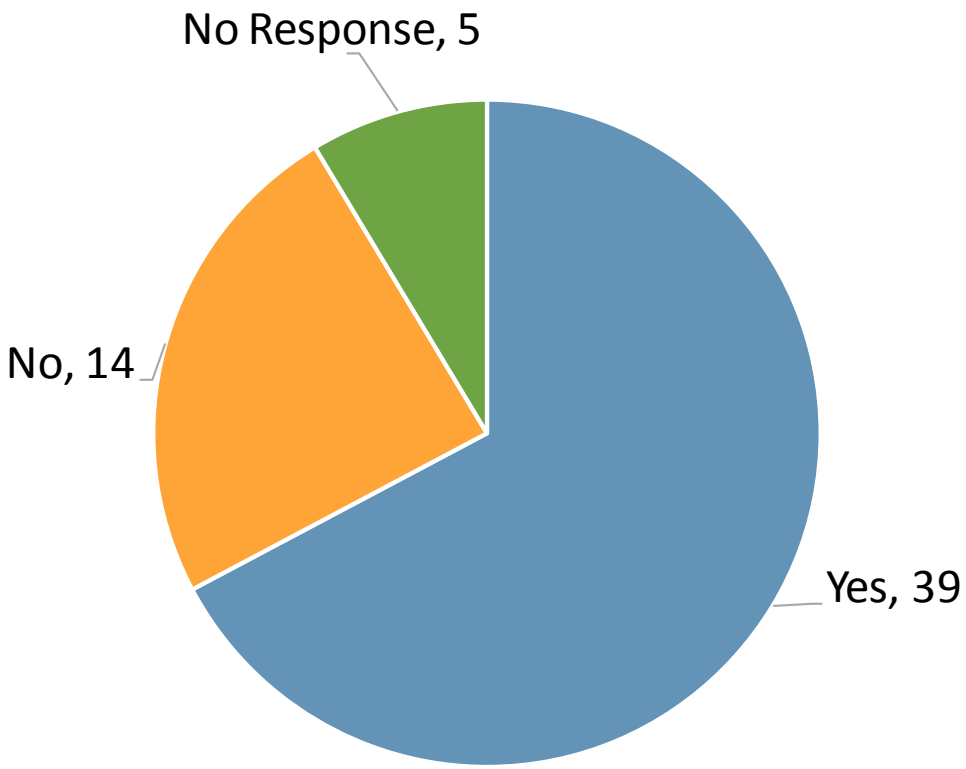
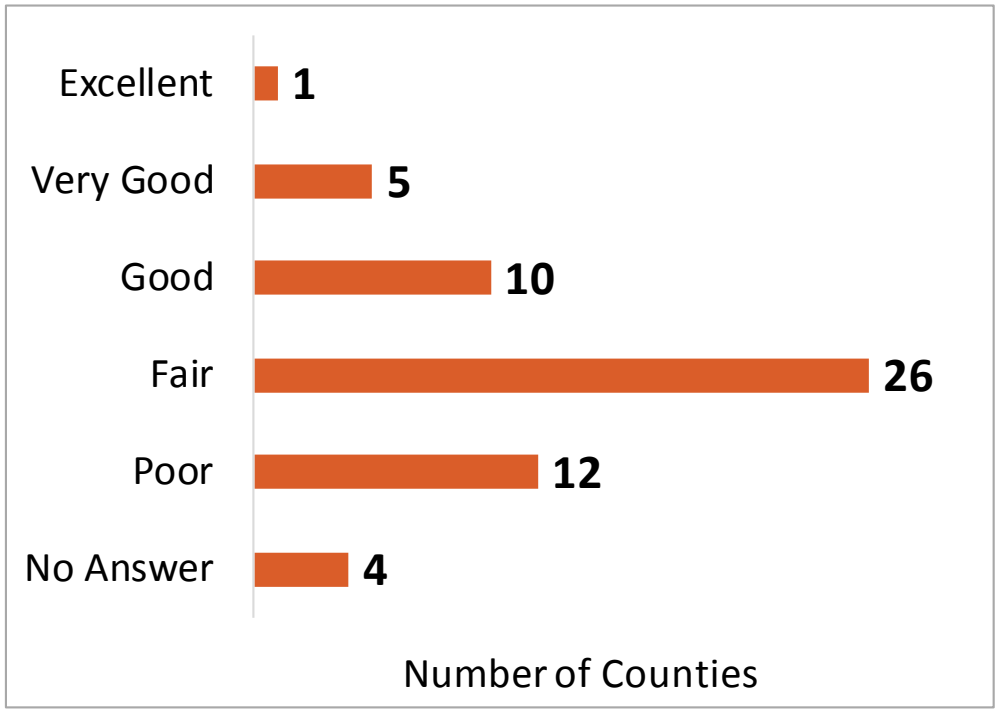
High Level Survey Results by County

Program Encourages or Seeks Family Input



Self-Reported Effectiveness of Family Engagement Activities



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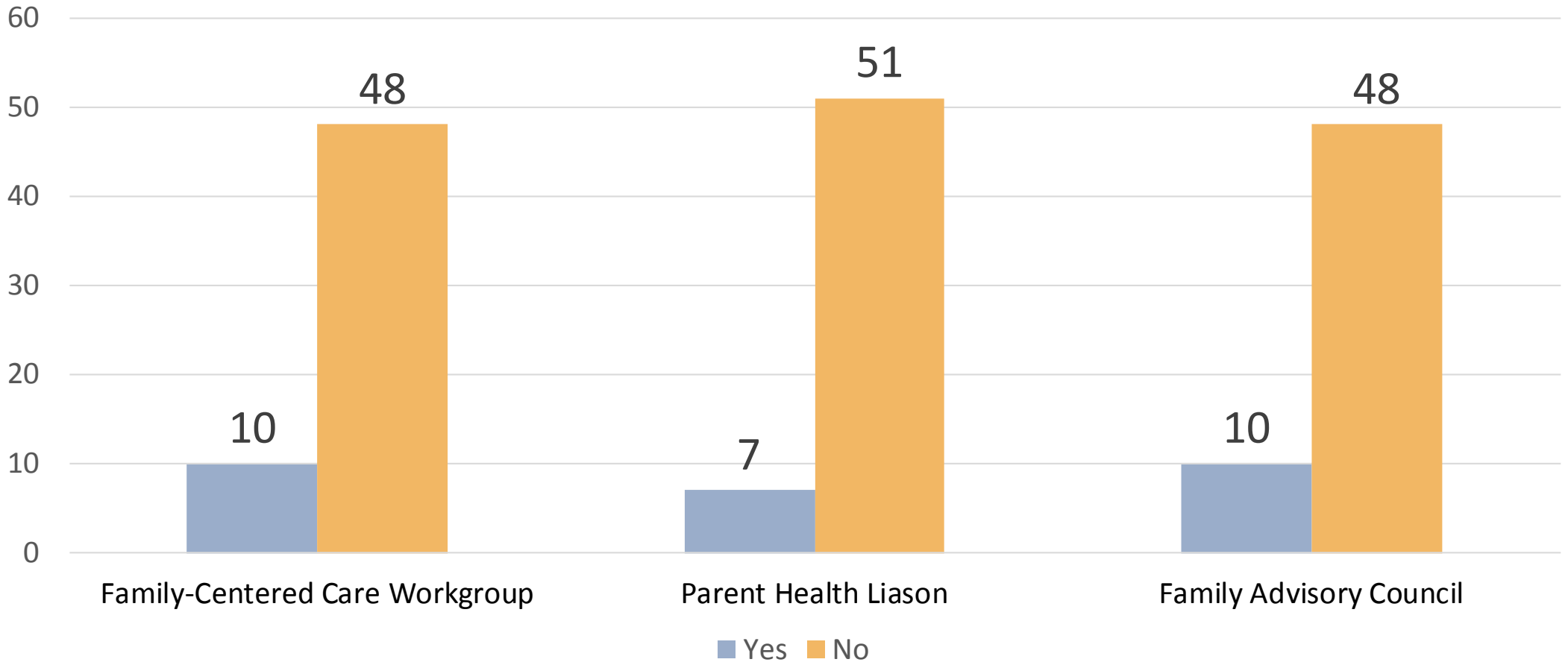
Opportunities for Family Engagement in 58 Counties



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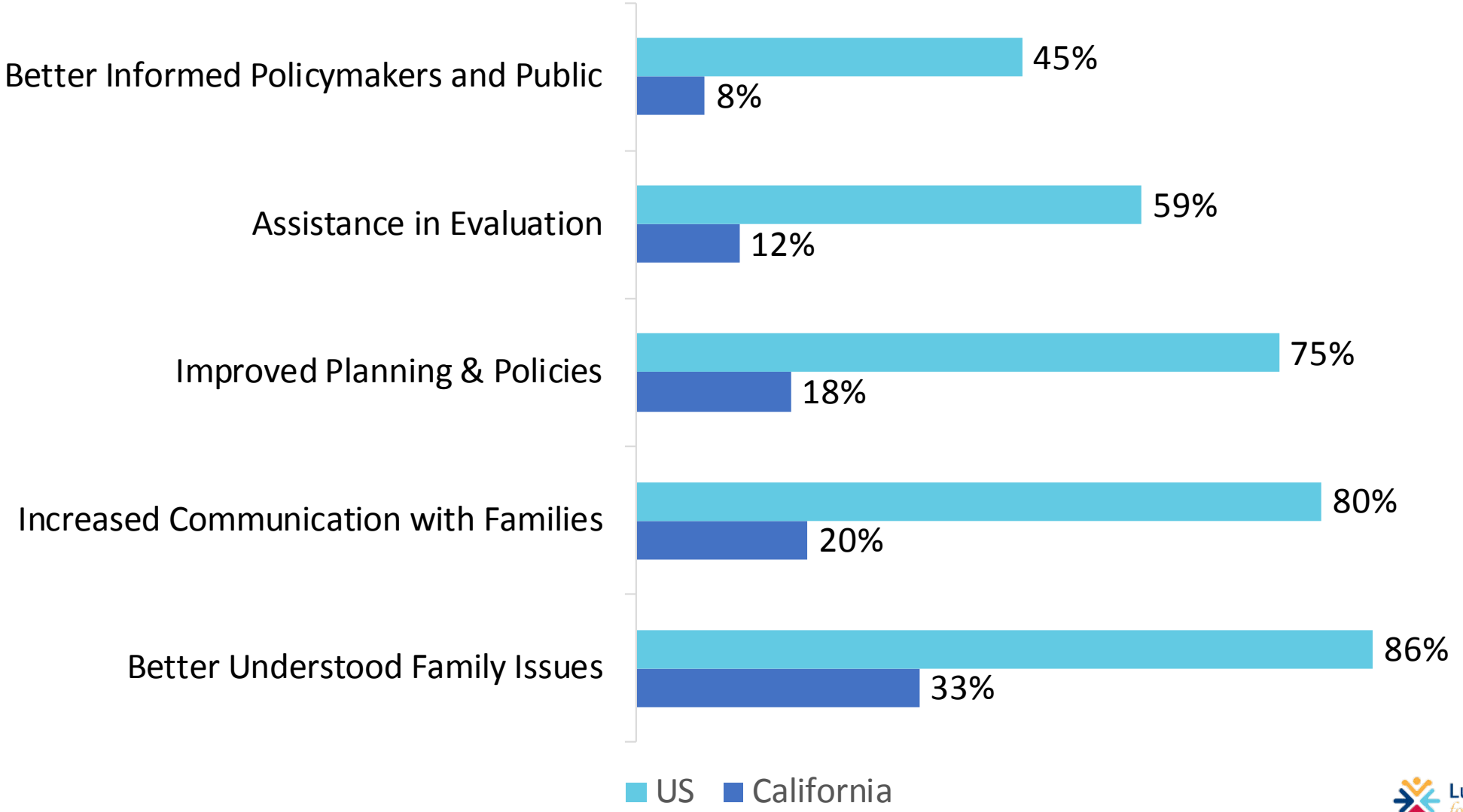
Reported Benefits Resulting from Family Engagement



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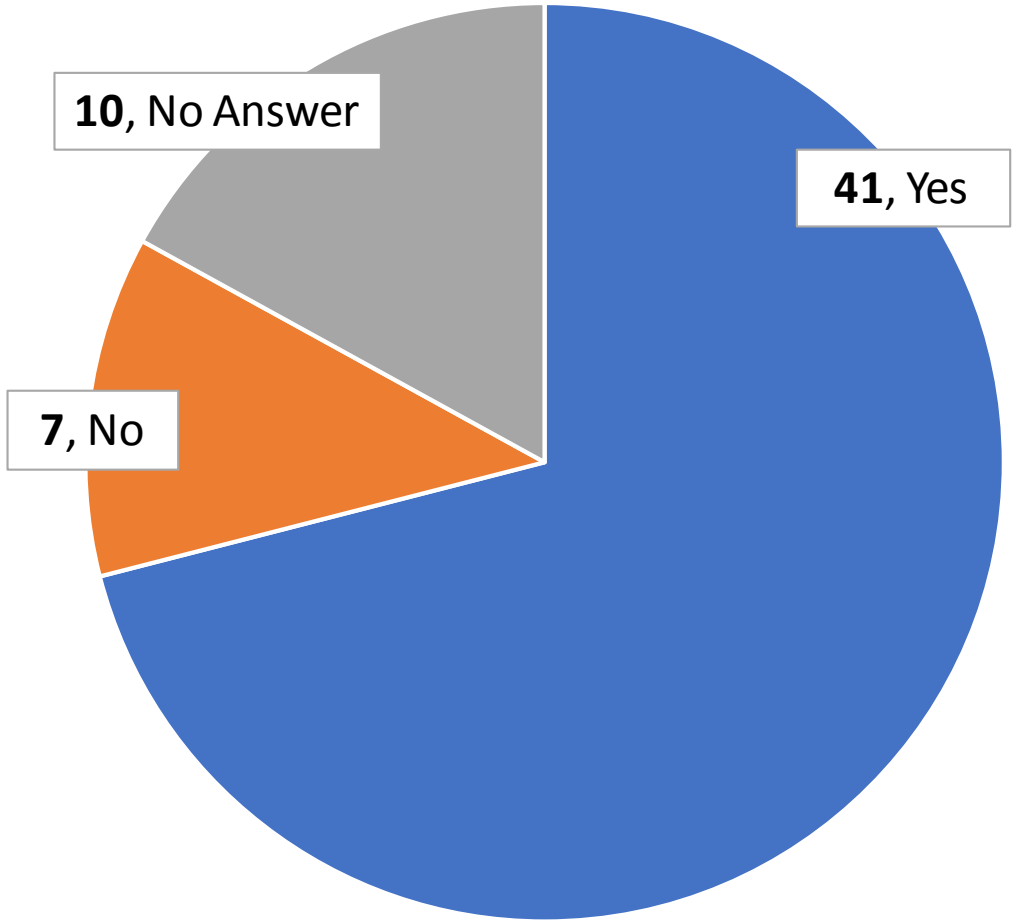
Willingness to Learn More About Family Engagement



41 counties are interested in receiving training or information about increasing family engagement.

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Vision for

Family Engagement

All public and private programs and agencies serving children and youth shall demonstrate meaningful family engagement.

Family Engagement

The intentional practice of working with families **at all levels** – individual, community, and policy – to achieve optimal outcomes in all aspects of health and well-being through the life course.

Assures parents and caregivers are engaged as **full-partners** in the planning and implementation of health care policies, programs, and individual service plans.

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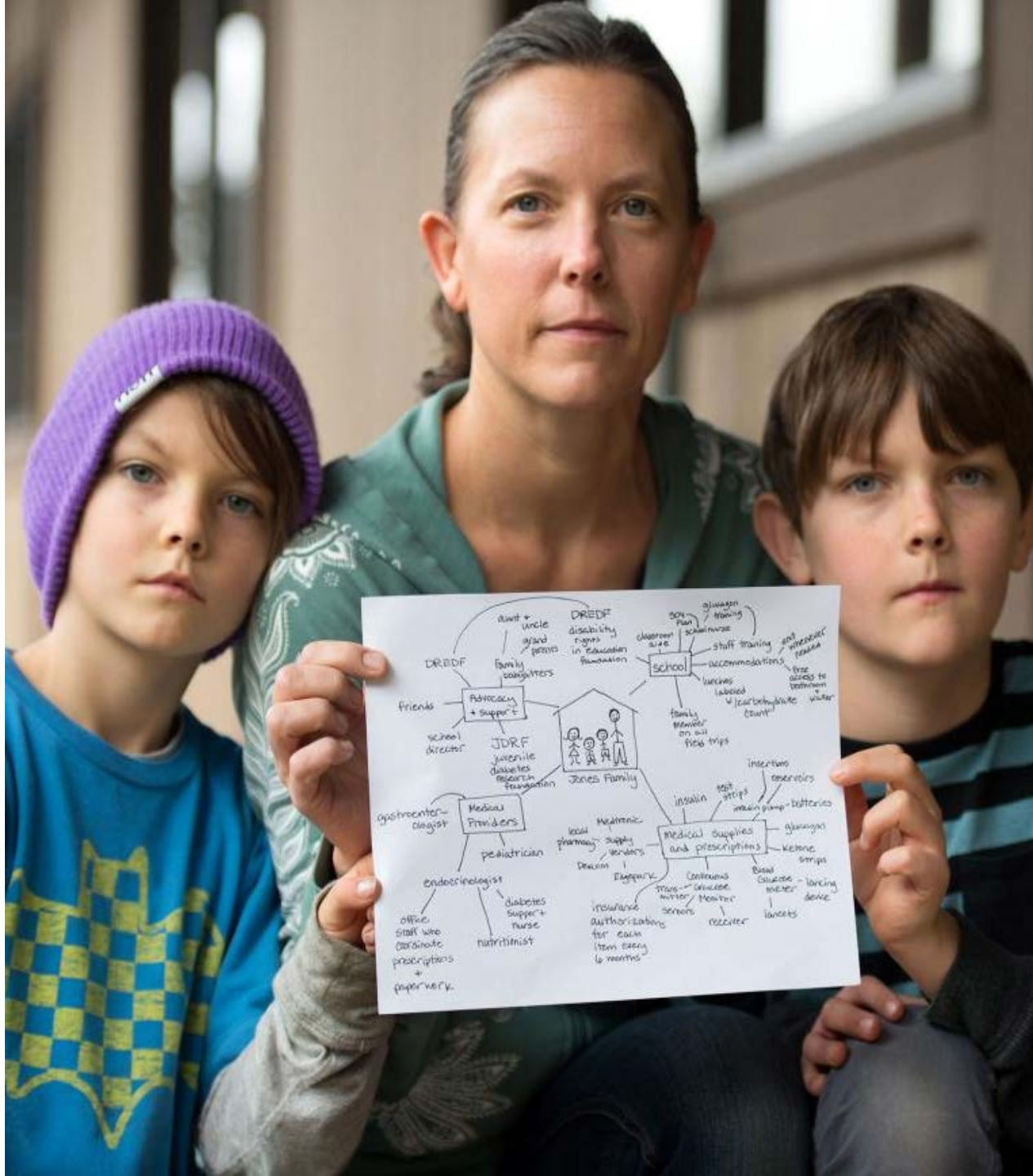
Barriers

- **Lack of orientation**, mentoring and ongoing support to enable families to participate meaningfully
- **Lack of consideration** for families' schedules when setting meeting times and locations
- **Lack of compensation** for families' contributions and incurred costs
- **Lack of guidance and protocols** for engaging families
- **Lack of opportunities for families** to participate in program and policy planning
- Changes required in **organizational culture** and behaviors to engage with families



Family Voices of California

Project Leadership

- Improved confidence in leadership skills
- Empowered to access more services for children
- Better prepared to advocate for their children and for systems change

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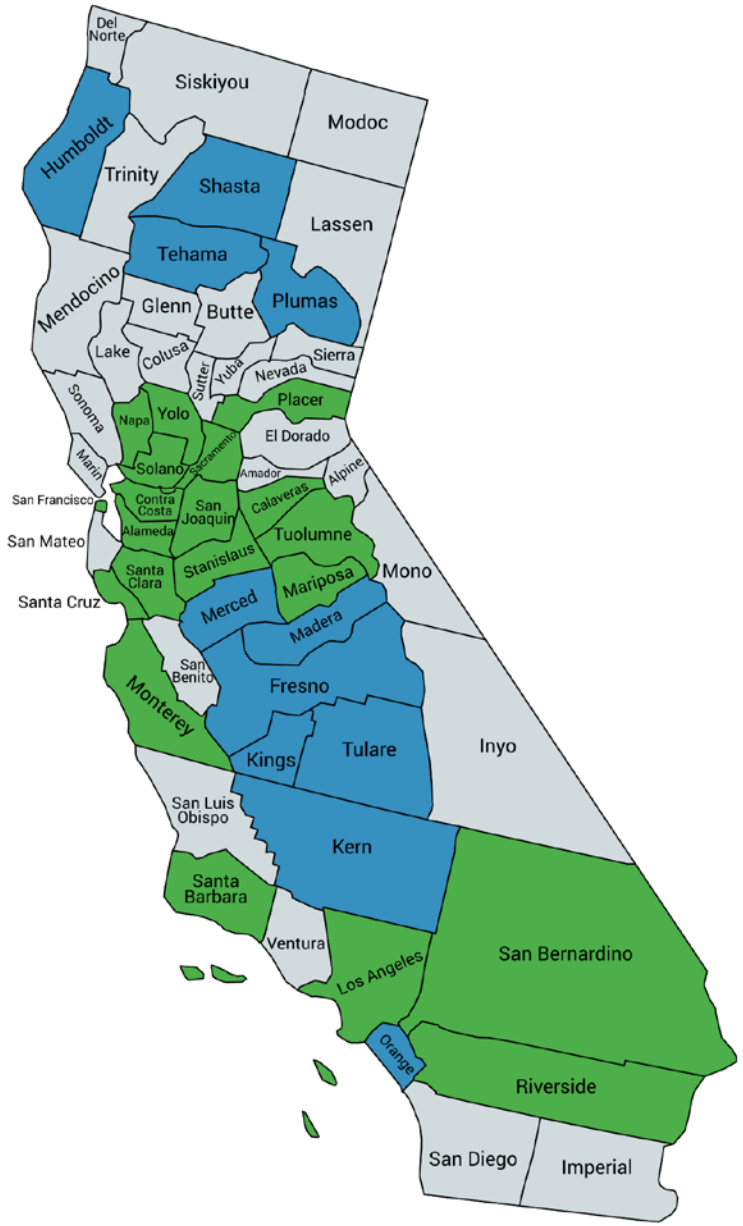
Source: Evaluation Report: Project Leadership, Leslie S. Linton, Terry Conway, Christine Edwards, Health Policy Consulting Group, May 2014

Current Participants
Expansion Counties



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Project Leadership Trainings

280 Graduates

88 Facilitators

49 Agencies

4 States

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Graduate Activities

Serve on Groups

74%

Contact Legislators

63%

Provide Testimony

42%

Interact with Media

19%

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Build Partnerships

Family Resource Centers Network of California: frcnca.org

Family Voices of California: familyvoicesofca.org

Lucile Packard Children's Hospital Stanford Children's Health

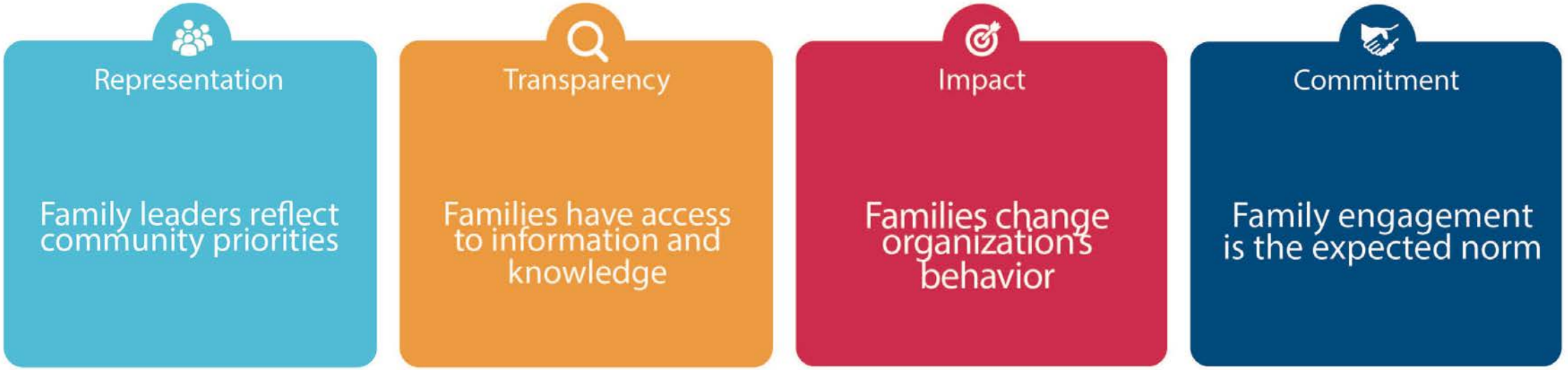
- California Patient and Family Centered Care Network of Pediatric Hospitals
- State-Wide Learning Collaborative to Promote Parent Mentor Programs
- Establishing New Role for Parent Mentors as Members of Health Care Team

Family Voices National

- Framework for Assessing Family Engagement
- Systems Assessment Tool (FESAT) and Tool Kit
- *Upcoming:* Implementation/ Technical Assistance for FESAT Tool

A Framework for Assessing Family Engagement

Four Domains for Promoting Meaningful Family Engagement in the Health Care System



Visit **lpfch.org/CSHCN** to access publication:
A Framework for Assessing Family Engagement in Systems Change

More on Family Engagement

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LOOK FOR US AT AMCHP 2019 ANNUAL CONFERENCE

March 9-12 in San Antonio, TX

Introducing the FESAT: A Tool to Enhance Family Engagement in our Health Care System

Register: eventscribe.com/2019/AMCHP

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