California Children with Special Health Care Needs and Their Families

Current Issues and Challenges Facing Our Most Vulnerable Population
Our Focus Areas

- Care Coordination
- System Standards and Quality
- Family Engagement
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
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
However, no “gold standard” exists for what constitutes a special health care need.

“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

- **Non-Chronic**: 85.1%
- **Episodic Chronic**: 12.30%
- **Life Long Chronic**: 2.45%
- **Life Long Progressive**: 0.10%
- **Life Long Progressive Technology Dependent**: 0.01%
- **Metastatic Malignancy**: 0.06%

# 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?

<table>
<thead>
<tr>
<th>Age—mean (SD): 7.3 (6.5) years</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
</tr>
<tr>
<td>Sex—male</td>
</tr>
<tr>
<td>57.0</td>
</tr>
</tbody>
</table>

### Race/Ethnicity

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>16.6</td>
</tr>
<tr>
<td>Black</td>
<td>8.7</td>
</tr>
<tr>
<td>Hispanic</td>
<td>56.4</td>
</tr>
</tbody>
</table>

### Insurance

<table>
<thead>
<tr>
<th>Insurance</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicaid Managed Care</td>
<td>47.6</td>
</tr>
<tr>
<td>Medicaid Fee for Service</td>
<td>19.6</td>
</tr>
<tr>
<td>CHIP</td>
<td>7.5</td>
</tr>
<tr>
<td>Mixed/Other</td>
<td>25.3</td>
</tr>
</tbody>
</table>

### Medical Complexity

<table>
<thead>
<tr>
<th>Medical Complexity</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complex Chronic</td>
<td>51.4</td>
</tr>
<tr>
<td>Non-Complex Chronic</td>
<td>25.3</td>
</tr>
<tr>
<td>Non-Chronic</td>
<td>23.3</td>
</tr>
</tbody>
</table>

Courtesy of Center for Policy, Outcomes and Prevention
System for CSHCN is Overlapping Programs

- Medical
- Child Welfare
- Special Education
- Mental Health
- Developmental Disabilities
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

Hospital, 49%
Outpatient Pharmacy, 20%
Home Health, 8%
Residential Care, 4%
DME, 4%
MD Visits, 4%
ER/Dental/Mental, 2%
Other Outpatient, 9%

Courtesy of Center for Policy, Outcomes and Prevention
## Comprehensive Care for Children with Medical Complexity

<table>
<thead>
<tr>
<th></th>
<th>Usual Care</th>
<th>Comprehensive Care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical costs</strong></td>
<td>$26,781 per child year</td>
<td>$16,523 per child year</td>
</tr>
<tr>
<td><strong>Outpatient costs</strong></td>
<td>$1,722 per child year</td>
<td>$6,713 per child year</td>
</tr>
<tr>
<td><strong>Hospitalizations</strong></td>
<td>131</td>
<td>69</td>
</tr>
<tr>
<td><strong>ED visits</strong></td>
<td>90</td>
<td>190</td>
</tr>
<tr>
<td><strong>Hospital visits</strong></td>
<td>635</td>
<td>276</td>
</tr>
<tr>
<td><strong>ICU admissions</strong></td>
<td>44</td>
<td>9</td>
</tr>
<tr>
<td><strong>IC days</strong></td>
<td>178</td>
<td>52</td>
</tr>
<tr>
<td><strong>Rate of serious illness</strong></td>
<td>22</td>
<td>10</td>
</tr>
</tbody>
</table>

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
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

- Federal Partners
- Families/Consumers
- Policy and Health Scientists
- State Title V Programs
- Medicaid/CHIP Programs
- Researchers
- Health Plans

National Standards

- Over 30 interviews with key informants
- National Work Group Guidance & Consensus
- Pediatric MMC Purchasing Specifications
- Existing National Principles and Frameworks
- Literature Review
- Background White Paper
- National standards (e.g. NCQA medical home)
- Federal Partners
- Families/Consumers
- Policy and Health Scientists
- State Title V Programs
- Medicaid/CHIP Programs
- Researchers
- Health Plans

Association of Maternal & Child Health Programs, 2014
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](http://NASHP.org) to access publication:
*Standards for Systems of Care for Children and Youth with Special Health Care Needs Version 2.0, June 2017*
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

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.

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

Courtesy Oregon Health Authority, Oregon Department of Human Services and Oregon Pediatric Improvement Partnership
Oregon’s Medicaid Enrollees’ Health Complexity

<table>
<thead>
<tr>
<th>MEDICAL COMPLEXITY (3 Categories)</th>
<th>SOCIAL COMPLEXITY (Total Factors Possible = 12)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3 or More Indicators</td>
</tr>
<tr>
<td>HIGH Chronic, Complex</td>
<td>3%</td>
</tr>
<tr>
<td>MODERATE Chronic, Non-Complex</td>
<td>9.5%</td>
</tr>
<tr>
<td>LOW Non-Chronic</td>
<td>26.5%</td>
</tr>
</tbody>
</table>

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

Edward Schor, MD
Email: edward.schor @lpfch.org
Phone: (650) 736-2663

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.
Care Coordination

Individualized care that is:

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

• 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
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
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
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
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

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

<table>
<thead>
<tr>
<th>Service</th>
<th>Number of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health Care or Counseling</td>
<td>15</td>
</tr>
<tr>
<td>Behavioral Health Therapy Services</td>
<td>10</td>
</tr>
<tr>
<td>Private Duty Nursing</td>
<td>6</td>
</tr>
<tr>
<td>Neurology</td>
<td>5</td>
</tr>
<tr>
<td>Respite Care</td>
<td>4</td>
</tr>
<tr>
<td>Personal Care Services</td>
<td>3</td>
</tr>
<tr>
<td>Orthodontic Care</td>
<td>3</td>
</tr>
</tbody>
</table>
Access to Mental Health Services

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

- 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

Visit lpfch.org/CSHCN to access publication:
Access to Mental Health Services for Children with Special Health Care Needs in California
More on Care Coordination

Holly Henry, Ph.D.
Email: holly.henry@lpfch.org
Phone: (650) 736-0677

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
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?

Visit lpfch.org/CSHCN to access publication:
In Their Own Words: Improving the Care Experience of Families with Children with Special Health Care Needs
Family Experiences: Core Themes

- **Families of color**, who are non-English speaking, who have limited education or low income face added burdens
- **Families face** extraordinary additional burdens which are largely unappreciated
- **Parents** must serve as advocate, case manager and navigator because the system is fragmented and services are uncoordinated
- **The service system** is not designed to accommodate children and families

**Children** require special & sometimes significant medical, developmental, and/or other services

**Parents** face grief, fear, and uncertainty

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
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

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

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
High Level Survey Results by County

Program Encourages or Seeks Family Input
- Yes, 39
- No, 14
- No Response, 5

Self-Reported Effectiveness of Family Engagement Activities

<table>
<thead>
<tr>
<th>Effectiveness</th>
<th>Number of Counties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>1</td>
</tr>
<tr>
<td>Very Good</td>
<td>5</td>
</tr>
<tr>
<td>Good</td>
<td>10</td>
</tr>
<tr>
<td>Fair</td>
<td>26</td>
</tr>
<tr>
<td>Poor</td>
<td>12</td>
</tr>
<tr>
<td>No Answer</td>
<td>4</td>
</tr>
</tbody>
</table>

Number of Counties
Opportunities for Family Engagement in 58 Counties

- Family-Centered Care Workgroup: 48 Yes, 10 No
- Parent Health Liaison: 51 Yes, 7 No
- Family Advisory Council: 48 Yes, 10 No
Reported Benefits Resulting from Family Engagement

- Better Informed Policymakers and Public: 8% (US), 45% (California)
- Assistance in Evaluation: 12% (US), 59% (California)
- Improved Planning & Policies: 18% (US), 75% (California)
- Increased Communication with Families: 20% (US), 80% (California)
- Better Understood Family Issues: 33% (US), 86% (California)
Willingness to Learn More About Family Engagement

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

- 41, Yes
- 10, No Answer
- 7, No
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.
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

Project Leadership Trainings

280 Graduates
88 Facilitators
49 Agencies
4 States
Graduate Activities

Serve on Groups 74%
Contact Legislators 63%
Provide Testimony 42%
Interact with Media 19%
Build Partnerships

Family Resource Centers Network of California: frcnca.org

Family Voices of California: familyvoicesofca.org
- 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

- **Representation**: Family leaders reflect community priorities
- **Transparency**: Families have access to information and knowledge
- **Impact**: Families change organization's behavior
- **Commitment**: Family engagement is the expected norm

Visit [lpfch.org/CSHCN](http://lpfch.org/CSHCN) to access publication:

*A Framework for Assessing Family Engagement in Systems Change*
More on Family Engagement

Allison Gray, MA
Email: allison.gray@lpfch.org
Phone: (650) 497-3506

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
Take Action

Subscribe to our twice-monthly newsletter

Explore our resources to access publications and tools

Follow us on Facebook @LucilePackardFoundation

Visit lpfch.org/CSHCN