



California Children's Services Program: Title V Needs Assessment 2018-2019

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Today's Objectives

- Summarize the Needs Assessment (NA) process, activities and key findings
- Review criteria for prioritizing problems/issues for program improvements
- Review, refine and prioritize problems/issues for ISCD to address in the next five years
- Discuss next steps and solicit volunteers for workgroups to develop Title V 2021-2025 Action Plan

Acronyms

- AAP = American Academy of Pediatrics
- CM = Case Managers
- CSHCN = Children with Special Health Care Needs
- CYSCHN = Children and Youth with Special Health Care Needs
- DHCS = Department of Health Care Services
- HHA = Home Health Agency
- ISCD = Integrated Systems of Care Division in the Department of Health Care Services
- MCHB = Maternal Child Health Bureau
- MCP = Medi-Cal Managed Care Plan
- PT = Physical Therapists
- OT = Occupational Therapists
- SARs = Services Authorization Request
- SDOH = Social Determinants of Health
- WCM = Whole Child Model

CSHCN Six Core Objectives

From MCHB-HRSA

1. **Families of CSHCN are partners** in decision-making at all levels, and are satisfied with the services they receive
2. CSHCN receive coordinated ongoing comprehensive care within a **medical home**
3. All CSHCN will be **adequately insured** for the services they need

CSHCN Six Core Objectives (cont.)

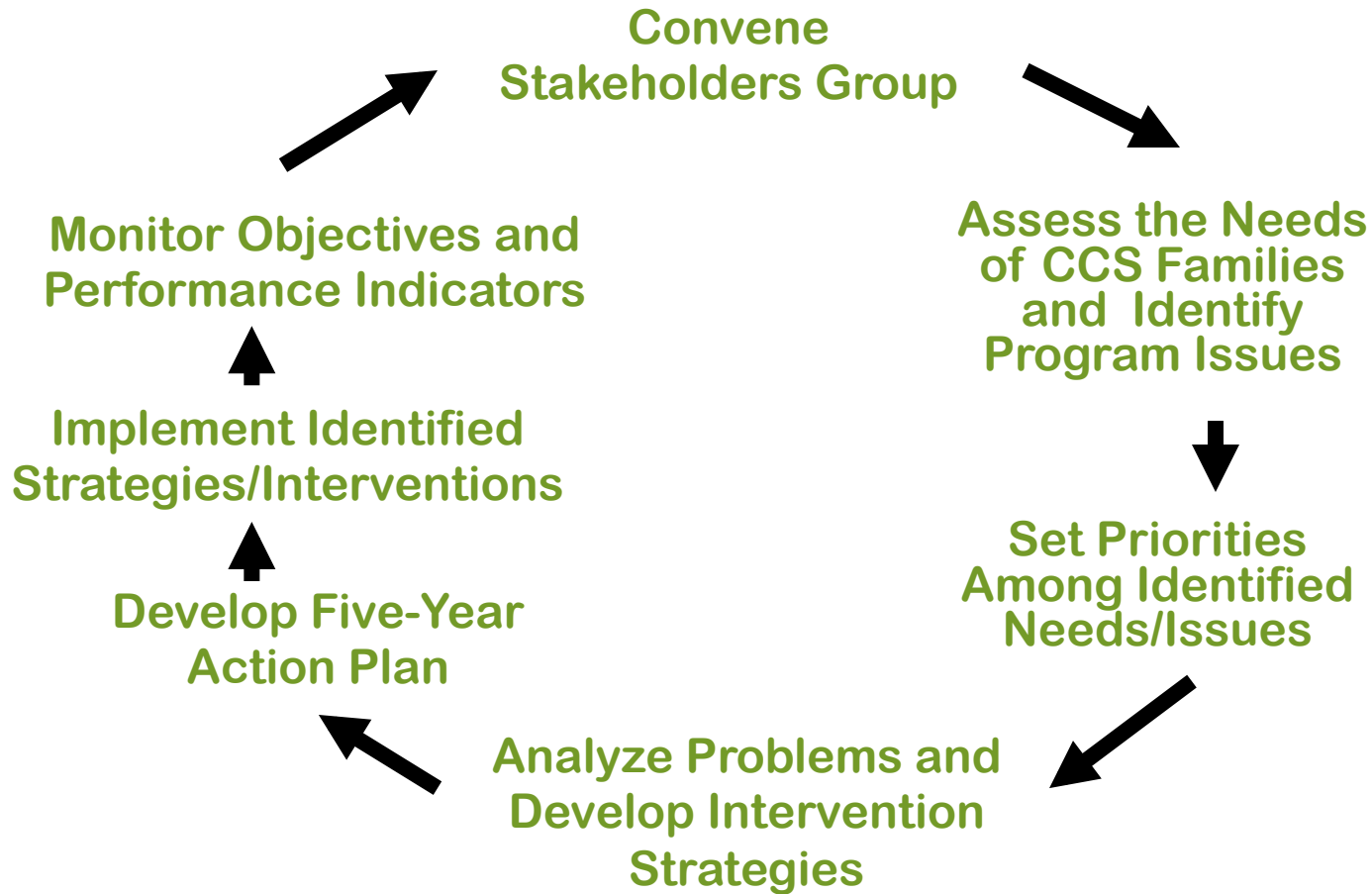
4. Children are **screened early and continuously** for special health care needs
5. **Services** for CSHCN will be **organized** so families can use them easily
6. All youth with special needs will receive services needed to support the **transition** to adulthood

Needs Assessment Process

CCS Needs Assessment and Action Plan Goals

- Within budget and legislative constraints, determine *Action* priorities to be addressed during FY 2021-2025
- Identify the most important and potentially effective changes CCS can make to improve services for CCS-eligible children and the systems that support CSHCN

Title V Assessment and Planning Cycle



Convene Stakeholders Group

Stakeholders representative of key interest groups:

- Families
- CCS County Programs
- Provider/Community/Advocacy Organizations
- Managed Care Plans
- Government/State Agencies
- Academia

Stakeholders provide input in all aspects of the needs assessment and will decide priorities

Assess the Needs of CCS Families and Identify Program Issues

- Worked with Stakeholders to identify key issues and existing data sources
- Collected additional data in an iterative process:
 - **Key Informant Interviews**
 - **Focus Groups**
 - **Online Surveys**
- Reviewed all data and findings with Stakeholders via webinars (4) and meetings and conference calls with Subcommittees (12+)

Key Informant Interviews

- With the key informant interview subcommittee
 - Developed interview guide and questions
 - Identified and recruited participants
- 16 Key Informant interviews with approx. 20 individuals conducted from October to December 2018
- Participants included MDs, CCS Program staff, reps. from children's hospitals, a WCM Health Plan, professional organizations, other DHCS department reps.

Focus Groups

- Worked with focus group subcommittee
 - Developed interview guide and questions
 - Identified types of groups and recruited participants
- 9 focus groups were conducted between November 2018 and February 2019
 - CCS families (26 participants)
 - 2 groups in Southern CA , 1 group in Northern CA
 - CCS providers (25-30 participants)
 - 2 groups in Southern CA, 1 group in Northern CA
 - CCS administrators (20-25 participants)
 - 1 group Northern CA, 1 group with CCS Administrators from WCM Counties
 - WCM Health Plans (8 participants)

Online Surveys

- ▶ Worked with survey subcommittee
 - Developed 3 surveys using information from stakeholders, key informants, and focus groups
 - Recruited respondents to complete the surveys
- ▶ CSHCN Family Survey - 3,419 responses from CCS families used in PRELIMINARY analyses, number of responses from non-CCS CSHCN to be determined
 - Administered in English and Spanish
- ▶ CCS Provider Survey - 188 responses
- ▶ CCS Administrator Survey - 44 responses representing 39 Counties

Family Survey: Region, Demographics, and Survey Method

Region	%	#
North Mountain	11.4	391
Bay Area	25.1	857
Sacramento	4.7	162
Central Coast	3.9	133
San Joaquin	4.4	152
Los Angeles	2.2	75
Orange	1.1	37
San Diego	4.5	154
Southeast	42.5	1,452
Missing	0.2	6

White	22.6
Black	5.0
Hispanic	55.4
Asian/PI	7.0
AIAN/Other/Multi	6.3
Missing	3.7

Who asked you to complete this survey?	%
County CCS	74.2
Health Plan	24.5
Local Family Resource Center	0.7
Family Voices	0.1
Children Now	0.0
My child's doctor	0.5
Missing	15.4

How did you complete this survey?	%
At CCS as part of annual paperwork	5.3
At my child's specialist	1.4
By phone (someone called me)	54.8
By computer (Survey Monkey)	11.0
By smartphone (Survey Monkey)	12.7
Interviewed over phone in English	8.0
Interviewed over phone in Spanish	6.3
Interviewed over phone other language	0.6
Missing	12.5

Family Survey: Demographics and Survey Method

Child's Age	%
Newborn-5	30.7
6-10	24.4
11-13	14.2
14-16	14.0
17-21	16.3
Missing	0.5

Income	%
Lt \$20,000	18.6
\$20,000-\$34,999	25.2
\$35,000-\$49,999	14.5
\$50,000-\$74,999	8.1
\$75,000-99,999	3.0
\$100,000 or over	5.3
Missing	25.4

Highest level of education completed by survey respondent	%
Middle school	6.4
Some high school	10.1
High school or GED	23.8
Some college	26.1
College bachelor degree	10.0
Graduate level or higher	5.1
Missing	18.5

Provider Survey Respondents (N = 188)

Included Pediatricians and Pediatric Subspecialists; Nurses and Nurse Practitioners; Physical, Occupational and Speech Therapists; Social Workers, and Others (Dietitians, Case Managers, Therapy Assistants)

50% are currently CCS-Paneled

Practice Setting	%
Tertiary Medical Center (Non-Kaiser)	9.2
Children's Hospital	21.3
Kaiser Tertiary Medical Center	10.9
Stand-alone specialty clinic	8.1
Primary care practice (private)	2.9
Primary care practice (public)	2.9
Federally Qualified Health Center (FQHC)	7.5
Other* (please specify)	53.5

% of Practice that are CCS Patients	%
0-25%	17.7%
26-50%	14.9%
51-75%	10.3%
76-100%	51.4%
Don't know/Not sure	5.7%

* Other setting is most frequently a Medical Therapy Unit (MTU)

CCS Administrator Survey Respondents

- 44 responses representing 39 Counties
- Current positions of respondents include CCS Administrators, Program managers, Public Health Nurses, Directors of Children's Medical Services, Directors of Nursing
- Years in current position range from 1 month to 20 years, about 25% have been in their current position for 10 years or more

Prioritization Criteria

Criteria for Prioritization of Issues/Problems

1. Review prioritization criteria developed by Workgroup
2. Vote on weights for criteria

Next Step: Develop Five-Year Action Plan

Timeline: October 2019 - February 2020

- Solicit stakeholders' input for action plans
- Work with CCS state and local staff to develop goals and SMART (Specific, Measurable, Achievable, Realistic, and Time-bound) objectives

Criteria Development Process

- Stakeholders provided input on selecting and defining criteria at initial stakeholder meeting
- Subsequent workgroup webinars selected manageable number of criteria, and further developed and refined selected criteria
- Current task – vote on weights for the criteria that will be used to prioritize problems/issues to be addressed in next five years

Prioritization Criterion 1

What is the impact on children's (CYSHCN) health of addressing the issue/problem?

Definition/Concept: The impacts of addressing the issue can range from no impact on family or the system, to moderate (e.g. reduction in delays in care), to large (e.g. preventing death or permanent disability, prolonging life or improving quality of life). Health impacts include physical and mental health as well as the overall quality of life for the child, their family, and their community.

Rating Scale:

- 0 = No impact
- 1 = Small impact, reduces hindrances that don't really have long-term, negative consequences
- 2 = Moderate impact, reduces difficulties (e.g. reduces delays in care) but only short-term, positive impact
- 3 = Severe/Large impact, reduces or mitigates long-term, negative impacts (e.g. prevents death or permanent disability)

Prioritization Criterion 2

Does addressing the issue reduce disparities in health care access and/or health outcomes?

Definition/Concept: One or more population subgroups of CYSHCN as defined by race/ethnicity, income, insurance status, gender, geography, or diagnosis have worse access and/or poorer health outcomes than the general group, and that addressing the problem would reduce disparity.

Rating Scale:

- 0 = Addressing the issue DOES NOT reduce disparities in health access/outcomes
- 1 = Addressing the issue DOES minimally reduce disparities in health access/outcomes
- 2 = Addressing the issue DOES moderately reduce disparities in health access/outcomes
- 3 = Addressing the issue DOES significantly reduce disparities in health access/outcomes

Prioritization Criterion 3

Do we have, or can we access, the financial resources to do what is needed to succeed?

Definition/Concept: Financial resources = funds from Federal, State, and Local government; foundation grants; partner contributions/investment; etc.

Rating Scale:

- 0 = No financial resources
- 1 = Some financial resources
- 2 = Available resources incomplete, e.g. we have the capacity but need to find the financial resources; we have the financial resources but need to build capacity
- 3 = Adequate financial resources

Prioritization Criterion 4

Do we have the capacity and will to do what is needed to succeed?

Definition/Concept: Capacity/will includes having all of the following factors: the resources (including infrastructure, personnel, and/or training capacity), political will, parental/family will, community will, potential to build on existing efforts, and the potential for partnerships.

Rating Scale:

- 0 = No capacity, no will
- 1 = Some capacity or some will, but not both
- 2 = Strong capacity or strong will, but not both
- 3 = Strong capacity AND strong will

Prioritization Criterion 5

Are there evidence-based or best practice strategies to address the issue?

Definition/Concept: Evidence-based means support in research/evaluation literature. Best practices have not been formally validated but are recommended by experts or by informal evaluations of local, state or national programs.

Rating Scale

- 0 = There are no best practices available
- 1 = There are best practice strategies available, but they are not yet evidence-based
- 2 = There are some evidence-based strategies that could be implemented
- 3 = There are evidence-based strategies that have a broad impact

Prioritization Criterion 6

Will addressing the issue ease the burden on families?

Definition/Concept: Burdens that families can face include: social, economic, emotional, psychological, physical, geographic/transportation, etc. Some examples of addressing issues that can decrease family burden include: in-home support, respite care, support groups, timely receipt of services and supplies.

Rating Scale:

- 0 = Not likely
- 1 = Somewhat likely to ease the burden
- 2 = Likely to ease burden
- 3 = Very likely

Voting on Criterion Weights

- The rating scales on the previous slides are designed to allow us to evaluate how well each identified problem meets each criterion
- Weights are used to compare the criteria with each other to determine which are the most important
- Weighting criteria allow you to give some criteria more weight than others in generating a score with which to determine which problems CCS should address. We use a scale of 0 to 4, with 4 being the most important
- Weighting criteria should result in larger distribution of ranking of priorities

To Vote on Criteria Weights Online:

- [https://www.surveymonkey.com/r/CCS CrWeight](https://www.surveymonkey.com/r/CCS_CrWeight)



Summary of Key Findings

Goal 1: Families Are Partners

- MCHB Outcome: Families of children and youth with special health care needs partner in decision-making at all levels, and are satisfied with the services they receive.

Families Are Partners: What We Heard

- Many parents very grateful for CCS, and focus group participants were particularly thankful that the DHCS/ISCD had FHOP conduct focus groups as part of the needs assessment
- Parents are confident in CCS providers
- Parents who have lived the experience can help other parents navigate the systems, learn what to expect, and provide support
- More parent groups and parent support are needed
- There is no statutory language specifying that when a child qualifies for CCS services, the local Family Resource Center will be sent a referral to follow up with the family (this does happen when a child receives Regional Center services)
- Some confusion about what services CCS covers and what Medi-Cal covers, more confusion for those with CCS and private insurance
- “CCS has been a big help, major surgery at [local children’s hospital] recently that went really well. The OTs and PTs are great and very knowledgeable about the MDs at [local children’s hospital]. No complaints about them. Only thing that is hard for me is that they don’t have after hours for therapy (OT), he has been missing school and getting depressed because he isn’t doing well in school.”

Families Are Partners: What We Heard

In Family Focus Groups:

- The majority of families emphasized the importance of their relationships w/ CMs
- For the most part, families feel they are the primary coordinators of care.
- When it isn't just them, therapists from MTUs or specialists were mentioned most as sometimes also coordinating care; when asked who coordinates care for their child, one parent said:

“We do! Parents coordinate care for their children. But beyond that, MTUs seem to have yearly care plans. Physicians have care plans for specific diagnoses, but not specific to the child. CCS never provides us with a care plan.”

Families as Partners: Family Survey

Do you and your doctor/provider work together as partners to make health care decisions?	%
Always	65.9
Usually	20.9
Sometimes	9.2
Never	4.0

How often did your child's doctor and/or other health care providers spend enough time with you and your child?	%
Always	64.6
Usually	25.7
Sometimes	8.2
Never	1.5

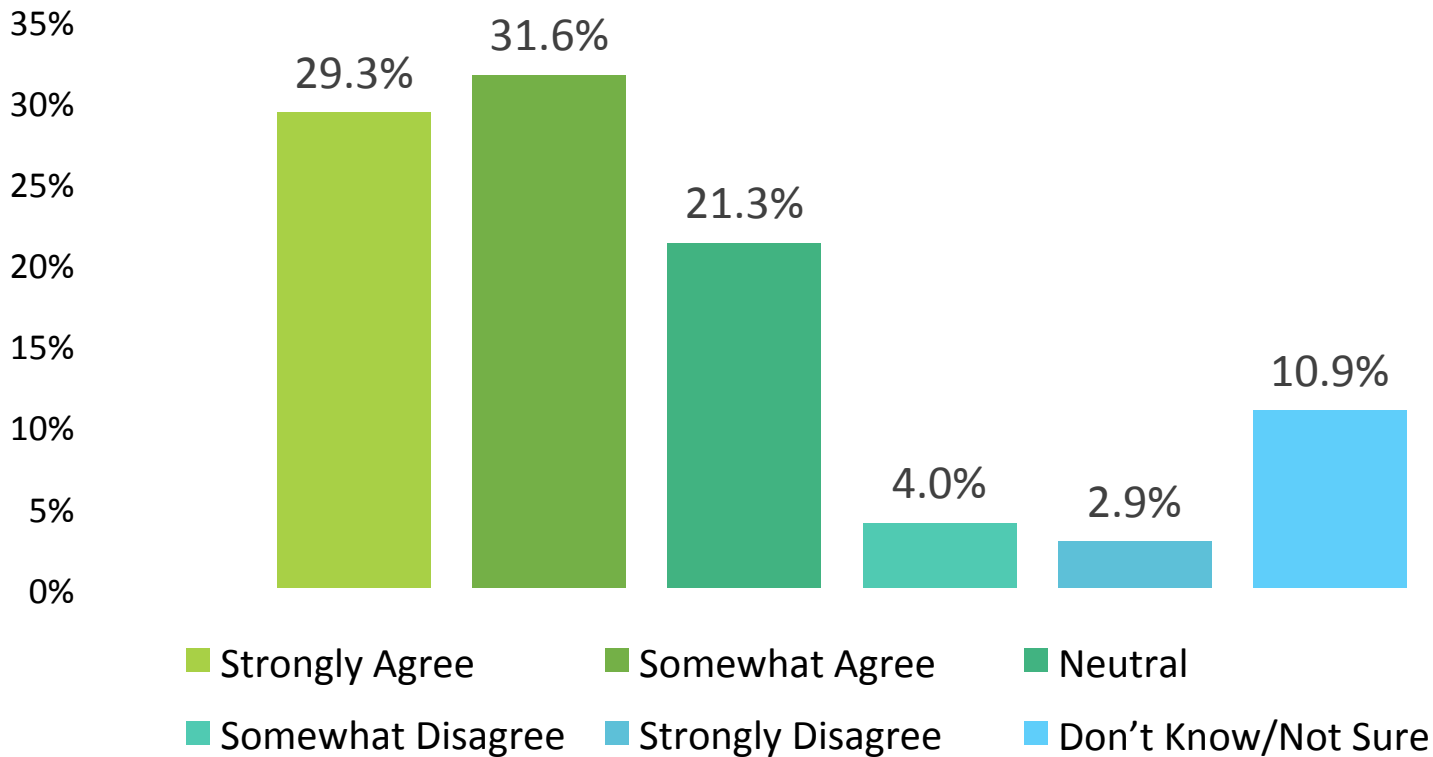
Have your child's doctors or other health care providers worked with you and this child to create a written plan to meet the child's health goals and needs?	%
Yes	66.6
No	21.3
Do not know	12.1

Does your provider honor your requests for others (extended family, community elders, faith leaders or traditional healers that are designated by the family) to participate in the process that leads to decisions about care?	%
Always	59.7
Usually	20.1
Sometimes	7.8
Never	12.4

Do you and your doctor/provider talk about the range of treatment and care choices for your child/youth?	%
Always	66.8
Usually	20.3
Sometimes	9.5
Never	3.4

Families Are Partners: Provider Survey

Families would benefit from County CCS programs being required to convene family advisory committees



Case Management: Family Survey

Has your child/family been assigned a case manager?	%
Yes	46.8
No	20.6
Do not know	22.9
Missing	9.7

If case manager assigned, what agency? Check all that apply.	%
County CCS	73.7
Health Plan	6.2
Regional Center	19.6
CCS Special Care Center	18.9
Other	6.9
Missing	1.9

If case manager assigned, how satisfied have you been in the past 12 months with how your case manager helps your child connect with services?	%
Always	71.4
Usually	21.7
Sometimes	5.9
Never	1.0

Satisfaction with CCS and Health Plan: Family Survey

Overall, how satisfied are you with the CCS program on a scale of 0 (not at all) to 10 (very)?	%
0 to 5	4.8
6 to 8	24.6
9	10.8
10	59.8

What is your overall satisfaction with the services that your Health Plan provides for your child?	%
0 to 5	6.5
6 to 8	24.7
9	12.6
10	56.2

Goal 2: Medical Home

Medical Home - a medical home can be a physician's office, a hospital outpatient clinic, a community health center or school-based clinic, as long as it provides the services that constitute comprehensive care – continuous access to medical care; referral to pediatric medical subspecialties and surgical specialists; and interaction with child care, early childhood education programs and schools to ensure that the special needs of the child and family are addressed (American Academy of Pediatrics)

https://mchb.hrsa.gov/research/strategic_definitions.asp

Medical Home: What We Heard

- Inconsistent Medical Homes for CYSHCN
- Specialty care centers can be Medical Homes in some cases
- Funding limitations prevent Medical Home capacity of some providers
- Local CCS Administrators know many doctors are trying, but not always successful
- Medical Home capacity varies by geography
- EMR & EHR are not always built to accommodate the Medical Home concept

Access Issues

- Lack of paneled primary care providers and specialists in rural areas
- Long drives to Special Care Centers for those in rural areas
- Some families experience a great deal of trouble and delays in getting appointments with specialists
- Lack of paneled mental health providers

Medical Home: What We Heard

Durable Medical Equipment

- Delays in getting DME and some equipment unavailable because cost to vendor less than reimbursement
- Lack of DME or timely DME leading to hospitals covering costs so child can be discharged or delays in discharge
- Vendors have a hard time getting reimbursed through CCS = delays & fewer willing vendors as a result

Communication between Providers

- Need for better communication between primary and specialty care providers and others who serve child

Workforce/Capacity Issues

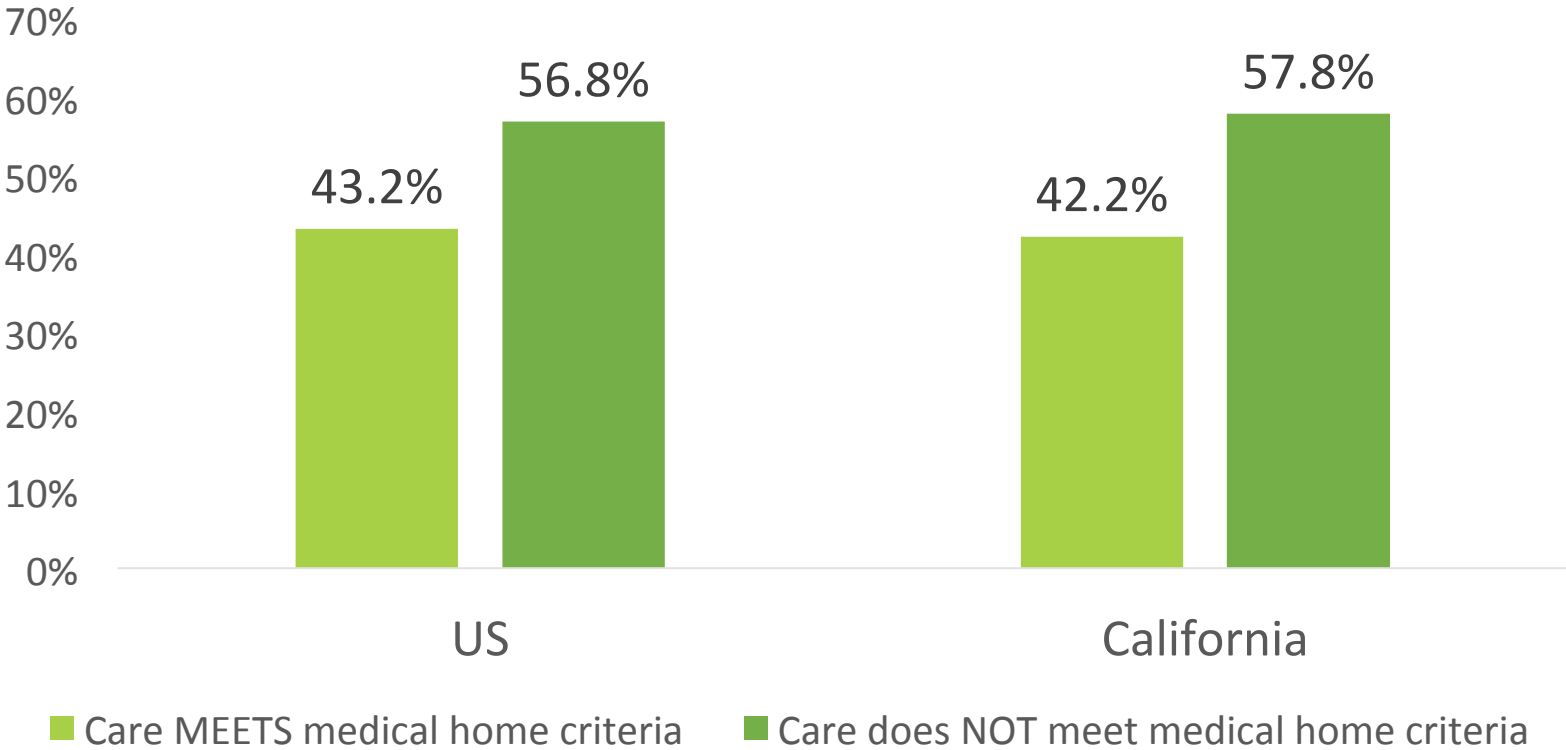
- Many barriers to physician participation in CCS – delays in payments, complex paper work, challenges dealing with Medi-Cal Managed care plans
- Reductions of staff at the state level to administer CCS and provide leadership, enforce standards, panel physicians
- Budget cuts and loss of trained staff at the local level

Medical Home: What We Heard

- “Difficulties with Medical Home is that some pediatricians are really afraid of our patients—if our patients are immunosuppressed that scares clinic pediatricians in the area. We don’t have a list of the ones that will take them and do well, and we don’t know which ones will work with our patients, and we also don’t know what insurance the good ones take. Patients in the farther flung communities have a harder time...” – *Provider Survey*
- “I think the answer varies with the geographic region you are talking about. We are a very pediatrician-rich community because of the hospitals that we have—have fed pediatricians into the community that have stayed. We are pretty lucky in that the pediatricians in our community are pretty good at providing care coordination, because our kids are low-income and the pay isn’t very good, and the private MDs can’t take too many kids with Medi-Cal so FQHCs cover the gaps because they are not scared of the low reimbursement rate.” – *Administrator Survey*

Medical Home: National Survey of Children's Health (NSCH)

% of CSHCN, ages 0 through 17, who have a medical home that meets the medical home criteria (2016 +2017)



Medical Home: Provider Survey*

- 48.8% Consider their practice to be a medical home for CYSHCN based on AAP definition of medical home
- 28.0% Do not
- 23.2% Don't know/not sure

What would your practice need to become a medical home for CCS clients?	%
Additional resources (e.g. financial reimbursements, more staff)	46.9
Nothing, I have everything I need to be a medical home for CCS clients	9.9
Nothing, there are other reasons for my not providing a medical home for CCS clients	6.2
Don't know/Not sure	29.6

Are you currently part of a Health Plan that is supporting your practice to become a medical home?

- 21.3% Yes
- 32.0% No
- 46.7% Not sure/Don't know

**Note: For medical home questions, survey results include only physicians and nurses*

Medical Home: Provider Survey

Rating of importance of the following resources that could enable your practice to be a primary medical home for CCS clients	5 - Very Important
Electronic medical record system that links primary care with pediatric subspecialty providers	57.8%
Ability to make informal consults and contacts with subspecialty providers (email, phone consultation, and/or telemedicine)	56.3%
Reimbursement for longer office visits	61.9%
Support staff for case management/care coordination	70.3%
Adequate reimbursement for care coordination and case management services	64.1%
Readily available treatment guidelines for patients with specific diagnoses/conditions (e.g., neurofibromatosis, seizure disorders)	40.6%
Readily available community level resources (e.g., Regional Center, Family Voices) for my patients and their families to meet their social, psychosocial, and home health needs	50.8%
Availability of subspecialty pediatric providers in my network	66.7%
Direct mechanism for communication and interacting with the child's school	31.3%

Accessing Health Care: Family Survey

Is there a place that this child USUALLY goes when they are sick and you or another caregiver needs advice about his or her health?	%
Yes	66.9
No	18.8
Do not know	5.5
Missing	8.9

During the past 12 months, how many times did your child visit a hospital emergency room?	%
0	49.2
1	19.1
2	9.7
3	5.3
4+	7.0
Missing	9.8

During the past 12 months, how many times did your child see a doctor, nurse, or other health care professional for sick-child care, well-child check-ups, physical exams, hospitalizations or other kind(s) of medical care?	%
0	2.9
1	9.1
2 - 3	32.6
5 - 7	17.2
8+	28.5
Missing	9.7

Diagnoses

Has a doctor or other health care provider ever told you that your child had or has any of the conditions in the list below? If yes, does the child currently have the condition, and is/was that condition mild, moderate, or severe? (check all that apply)

Number of Conditions	% Any
1	31.7
2	17.3
3	11.9
4	9.5
5	7.6
6-7	10.5
8+	11.7

Diagnoses	Total	Mild	Mod	Sev
Attention deficit disorder or attention deficit hyperactive disorder (ADD or ADHD)	10.2	35.0	43.4	21.7
Allergies	25.2	46.8	36.9	16.3
Anxiety problems	15.0	39.3	43.2	17.4
Arthritis or joint problems	11.1	27.5	45.3	27.1
Asthma	15.0	51.2	34.3	14.5
Autism, Asperger's disorder, pervasive developmental disorder (PDD), or autism spectrum disorder (ASD)	8.3	35.3	32.1	32.6
Behavioral or conduct problems	13.1	33.0	45.4	21.6
Blindness or impaired vision	23.1	41.7	34.7	23.6
Blood problems other than hemophilia or sickle cell anemia	4.2	39.4	25.5	35.1
Broken bones	6.9	46.1	27.9	26.0
Cancer, tumors	5.3	27.4	30.8	41.9
Cerebral palsy	18.8	31.3	38.7	30.0

Diagnoses (cont.)

Has a doctor or other health care provider ever told you that your child had or has any of the conditions in the list below? If yes, does the child currently have the condition, and is/was that condition mild, moderate, or severe? (check all that apply)

Diagnoses	Total	Mild	Mod	Sev
Cleft lip/cleft palate	3.6	38.8	38.8	22.5
Congenital heart disease	9.8	39.6	30.4	30.0
Cystic fibrosis	1.1	44.0	28.0	28.0
Diabetes	8.2	21.5	48.6	29.8
Depression	7.3	49.1	37.3	13.7
Dental problems	15.3	42.2	40.7	17.1
Developmental delay	29.5	31.9	32.1	36.0
Down syndrome	2.6	34.5	29.3	36.2
Epilepsy or seizure disorder	13.9	33.4	36.4	30.2
Genetic disorder	11.8	19.1	30.5	50.4
Head injury, concussion, or traumatic brain injury	7.5	27.1	31.9	41.0
Hearing loss	16.4	25.1	42.4	32.5
Heart problems	13.2	43.2	31.2	25.7
Hemophilia	0.8	55.6	16.7	27.8
HIV or AIDS	0.4	75.0	12.5	12.5
Infectious disease	1.7	47.4	28.9	23.7

Diagnoses (cont.)

Has a doctor or other health care provider ever told you that your child had or has any of the conditions in the list below? If yes, does the child currently have the condition, and is/was that condition mild, moderate, or severe? (check all that apply)

Diagnoses	Total	Mild	Mod	Sev
Intellectual disability	17.4	28.2	31.8	40.1
Intestinal or gastrointestinal problem	17.3	27.3	44.5	28.1
Kidney disease or other kidney problems	7.4	29.7	41.8	28.5
Liver problems	2.3	40.0	36.0	24.0
Lung disease	5.7	29.1	37.8	33.1
Mental health problem (Other than depression)	5.0	31.3	39.3	29.5
Migraine or frequent headaches	9.1	43.1	40.1	16.8
Muscular dystrophy	3.0	20.9	31.3	47.8
Sickle cell anemia (trait or disease)	0.9	40.0	25.0	35.0
Spinal bifida	2.8	24.6	34.4	41.0
Spinal cord injury	1.6	41.7	22.2	36.1

Access to Specialty Care: Family Survey

Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who focus on one area of health care. How many different specialist doctors has your child seen in the last 12 months?	%
0	10.9
1	35.9
2	26.5
3	15.5
4+	11.2

In the last 12 months, how often was your child able to see a specialist when needed?	%
Always	74.2
Usually	19.2
Sometimes	5.5
Never	1.1

How many times did your child see a specialist(s) in the last year?	%
0	7.6
1	18.9
2	20.2
3	12.3
4	10.6
5+	30.4

In the last 12 months, how often was your child able to see a specialist in a quick and timely manner?	%
Always	59.8
Usually	26.2
Sometimes	11.2
Never	2.8

Access to Specialty Care: Family Survey

- What type(s) of specialist(s) were you NOT able to see in a quick and timely manner table
- 19.2% of families report not being able to see at least one type of specialist in a quick and timely manner

Specialist	%
Allergy/Immunology	4.6
Cardiology	9.3
Dermatology	5.5
Developmental Medicine	5.0
Endocrinology	9.5
Gastroenterology	14.8
General Surgery	3.0
Genetics	7.5
Gynecology	1.1
Hematology	2.4
Nephrology	3.5
Neurology	23.0
Neurosurgery	10.5
Newborn Medicine	1.2
Nutrition	4.0
Ophthalmology	16.3
Otolaryngology	10.5
Plastic Surgery	2.4
Psychiatry	5.0
Pulmonology	8.4
Rheumatology	1.4
Sports Med/Orthopedics	10.4
Urology	4.7

Access Issues: Data from the California Specialty Care Collaborative (CSCC)

Average patient wait time for the following specialties that exceeded 15 business days for the 3rd next available initial appointment

Specialty	Days
Orthopedics	16
Hematology/Oncology	16
Infectious Disease	16
Gastroenterology	20
Urology	22
Endocrinology	23
Plastic Surgery	23
Otolaryngology	25
Rehabilitation Medicine	26
Psychiatry	31
Pulmonary	31
Palliative Care	30
Rheumatology	32
Pain Services	33
Nephrology	44
Neurology	41
Ophthalmology	45
Metabolic	54
Medical Genetics	73

Average length of time CSCC members have been recruiting for certain subspecialties that exceed one year

Subspecialty	Months
General Surgery	14
Medical Genetics	14
Allergy	14
Behavioral/Developmental	14
Otolaryngology	15
Rehabilitation	15
Palliative Care	16
Pulmonary Medicine	18
Neurology	18
Orthopedic Surgery	21
Metabolic	23
Ophthalmology	22
Cardiothoracic Surgery	24
Dermatology	24

Service Needs and Care Received

Any Services Needed	%
1	16.7
2	15.8
3	14.7
4	14.1
5-6	19.4
7+	19.4

During the past 12 months was there any time when your child needed the following services:	% Received care (%)			
	Total	All	Some	None
Communication aids or devices	5.1	80.6	8.6	10.8
Dental checkup/teeth cleaning	19.3	88.0	7.6	4.4
Durable medical equipment	13.3	85.9	7.7	6.4
Eyeglasses or vision care	13.8	87.0	8.5	4.5
Hearing aids or hearing care	4.8	83.3	9.8	6.8
Home health care	5.4	82.4	8.1	9.5
Hospitalization (in-patient stay)	10.5	90.6	6.6	2.8
Mental/behavioral health care	6.2	84.1	7.6	8.2
Medications	19.3	89.0	7.2	3.8
Other dental care	3.7	77.5	9.8	12.7
Pain management	14.2	86.1	9.5	4.4
Physical/occupational therapy	11.3	33.4	36.4	30.2
Specialty care	12.6	87.8	9.0	3.2
Speech therapy	10.1	85.8	9.8	4.4
Substance abuse treatment/ counsel	0.1	50.0	0.0	50.0
Well-child check-up	18.3	90.6	7.0	2.4
X-rays	12.6	91.0	6.4	2.6

Access to Care: Challenges in Rural Counties

- “Difficulty accessing local services - with the rural nature of our county, our children and families must travel anywhere from 4-6 hours to access specialty medical services. Because of this, our attendance to appointments is difficult and it can be hard to maintain services without regular appointments. Our families know the importance of attending regular appointments, but simply cannot make them due to distance, weather, inability to take time off work, and having multiple other children with some also having special medical needs” – *CCS Administrators’ Survey*
- Providers, CCS Administrators, and Medi-Cal Managed Care Health plans **all recognized geography as a barrier in getting access to care**. During a focus group question about DME, one provider stated:

“...we do pick up a lot of kids that have chronic infections in remote counties, we don’t send [those] kids home sometimes because they won’t be able to get what they need out there—we can’t find anyone out there that can do the dressing changes or get home care.”

Access to Care: Administrative Issues

From CCS Administrators Survey:

- Vast inequality between independent and dependent counties in regard to timeliness of authorizations and opening cases
- Improved processing time needed for cases requiring ISCD review
- “Better communication from ISCD regarding eligibility, annual renewals, and eligibility for new referrals. We are not receiving returned emails.”
- “Expiring annual renewals without a contact person to talk to. We have had three recently that expired without contact from the state though we submitted documents three months ahead of time.”

Access to Care: Workforce Issues

- “The current supply of pediatric subspecialists is inadequate to meet the current and future health needs of children in California” – California Specialty Care Coalition
- 70% of Providers agree that the Medi-Cal provider network presents challenges in terms of the availability and capacity of primary and specialty care providers - Provider Survey
- Of the 44 respondents to the CCS Administrators survey, 100% stated that there are challenges in their program’s capacity to perform, including:
 - Difficulty hiring and retaining staff (physical and occupational therapists, nurse case managers, public health nurses, clerical staff)
 - State capacity to approve SARs in a timely fashion for dependent counties
 - Uncertainty if allocation to County CCS programs for WCM counties will be adequate to cover minimum staffing standards
 - Unanticipated and unfunded workload in WCM County CCS programs

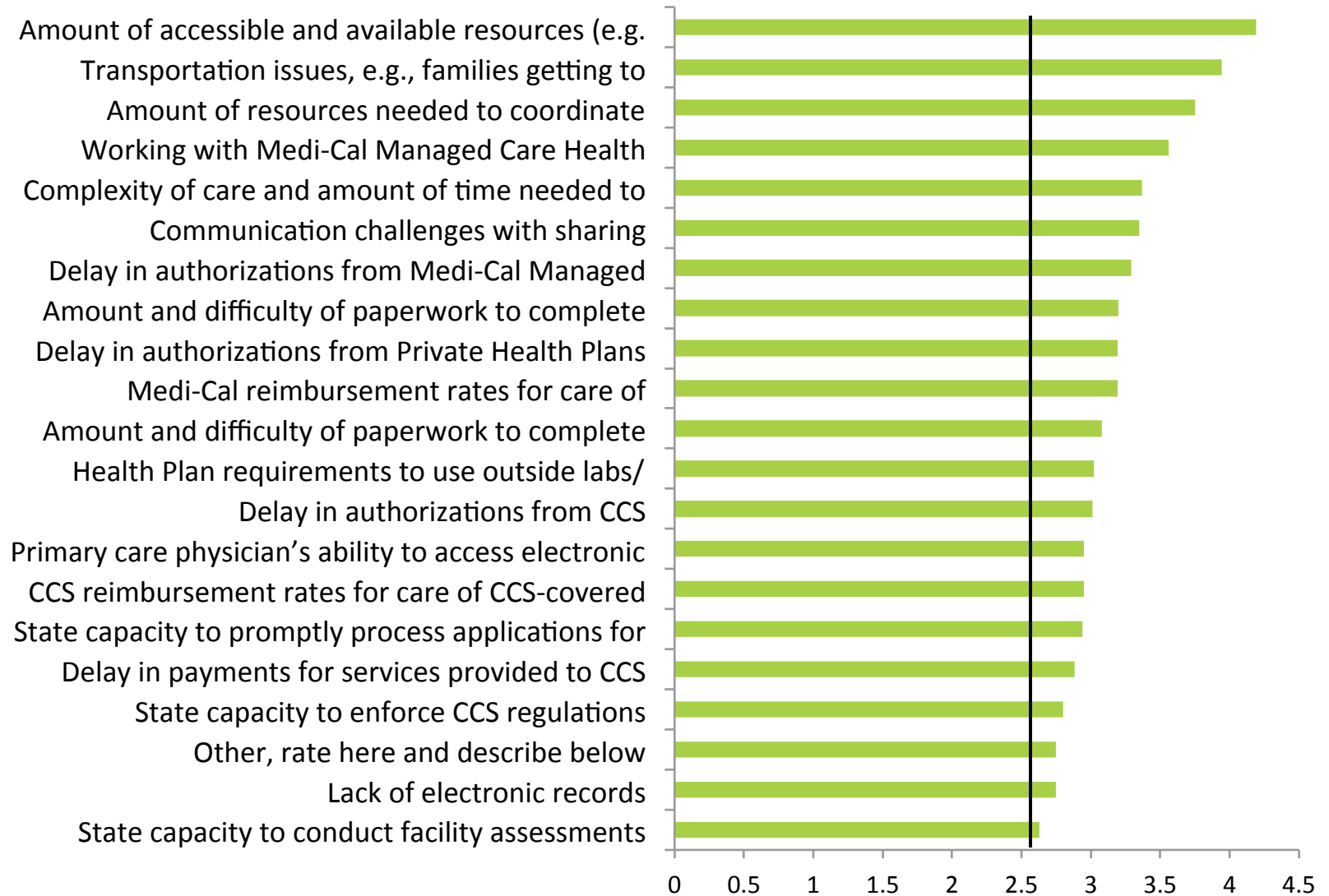
Access to Care: Workforce Issues (cont.)

“There is unanticipated/unfunded workload remaining at the counties that was not planned as part of WCM, such as AMRs [annual medical reviews] taking much longer than the State-allocated 12 minutes, since the Health Plans are not able to provide medical records needed for AMR. Counties are also chasing the Medi-Cal churn as clients fall on and off of Medi-Cal. Inter-county Transfers are significantly more complex, with difficulty obtaining records from the Health Plan. Complexities of straddling communication with the Health Plans, use of SFTP for constant PHI data transfer, weekly, monthly, quarterly meetings with the Health Plans to troubleshoot and problem solve implementation and transition issues.”

Impacts of access issues

- 81% of Providers agree that increasing access to specialty care (81%) and primary care (73.3%) for children with CCS conditions will help decrease ER visits and hospitalization

Barriers to providing high quality care to CCS clients (0 = Not a barrier, 5 = significant barrier): Provider Survey



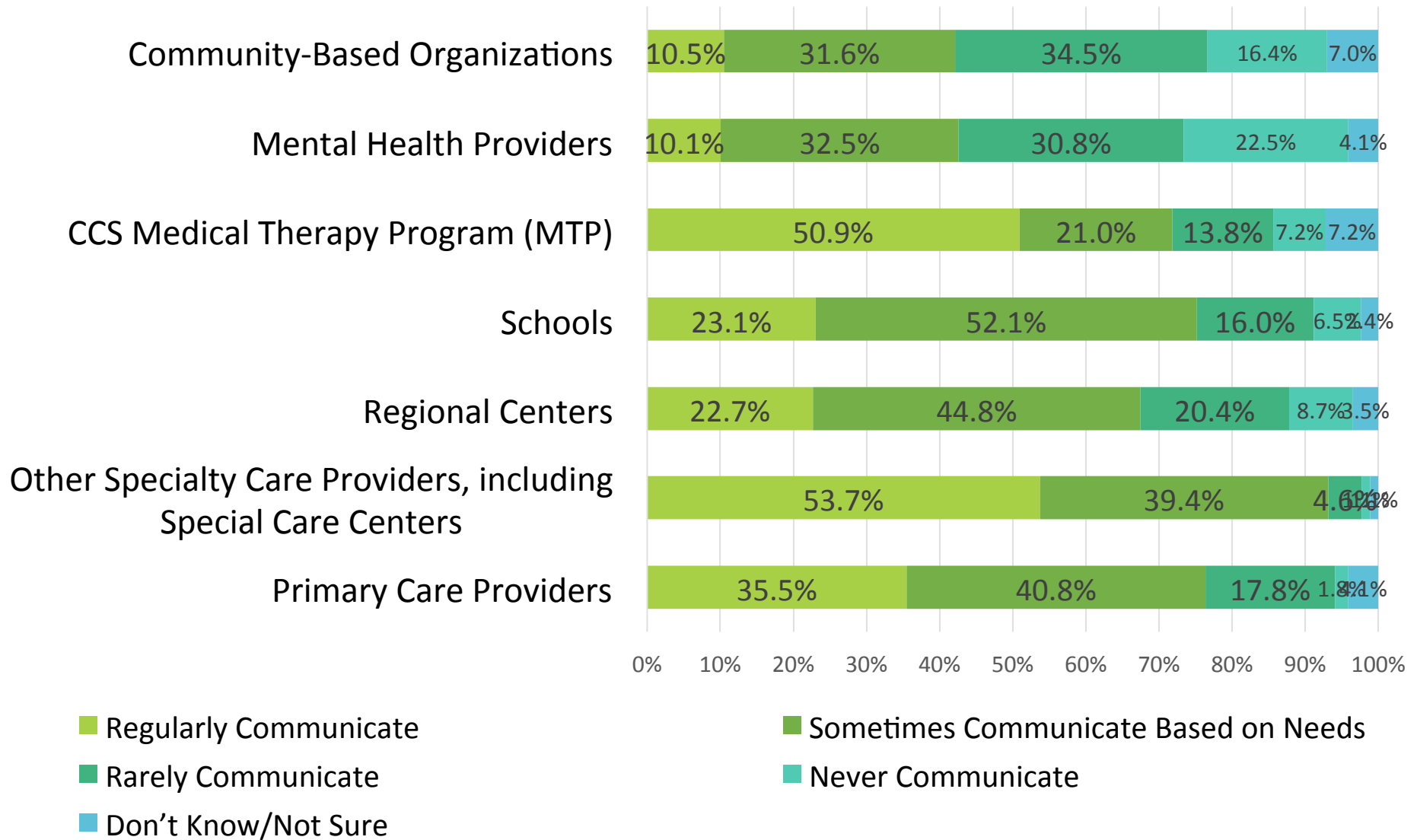
Communication between Providers: What We Heard

- “I think we need much better communication—really great if the kid is in clinic—not in clinic communication is spotty. We’ve had issues where pulmonology is concerned about scoliosis but not talking to the ortho doc and the kid is scheduled for surgery and the pulmo doc isn’t signing off on it. There are other examples where we don’t know how to intervene. Communication needs to be improved” – *Provider Focus Group*

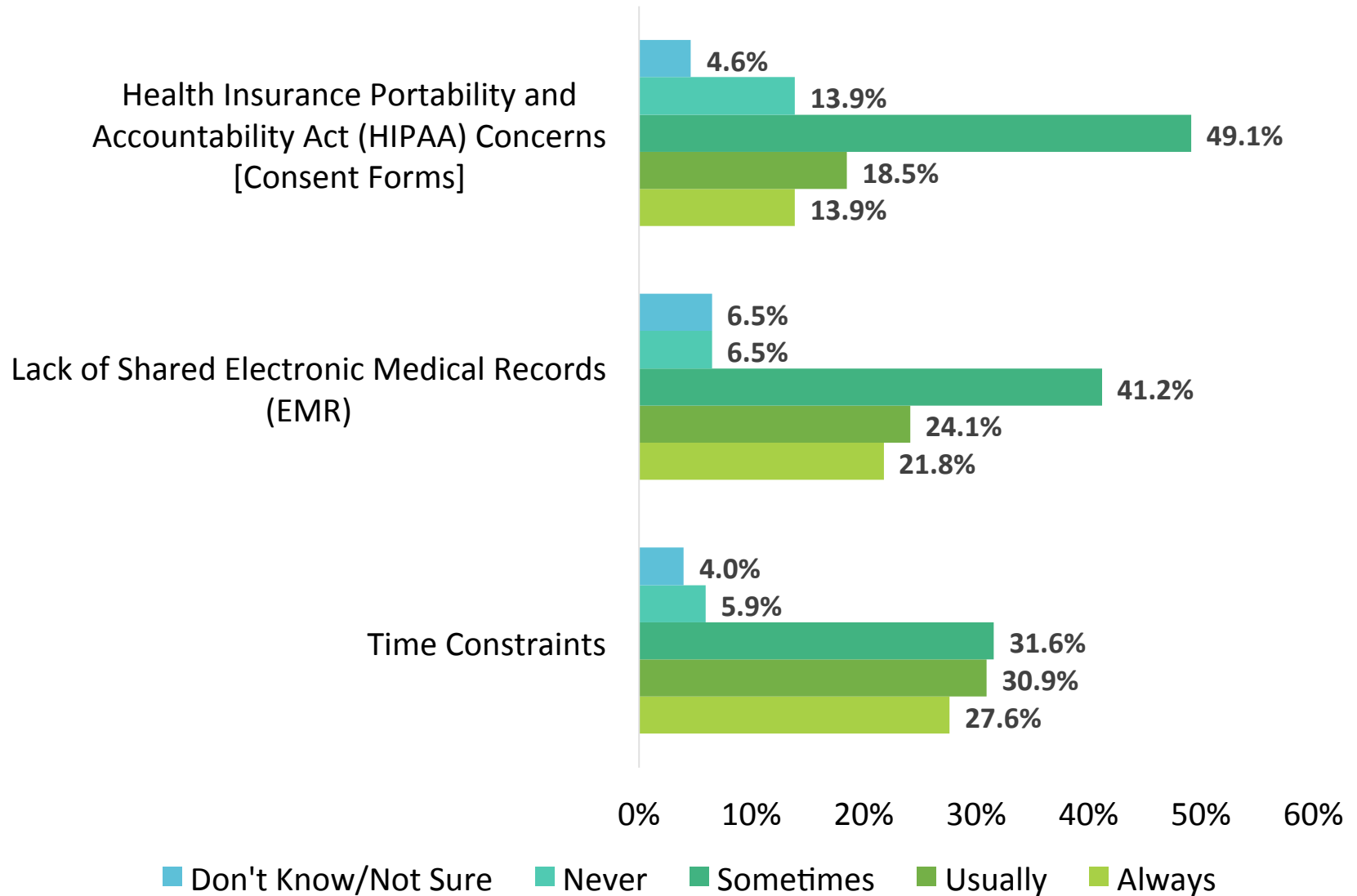
Family Focus Groups:

- Families feel that providers are limited in their ability to communicate with each other and this leaves parents as the go-between.
- Theme of parents being afraid to share info with providers (e.g., getting private therapy services) since services may be taken away

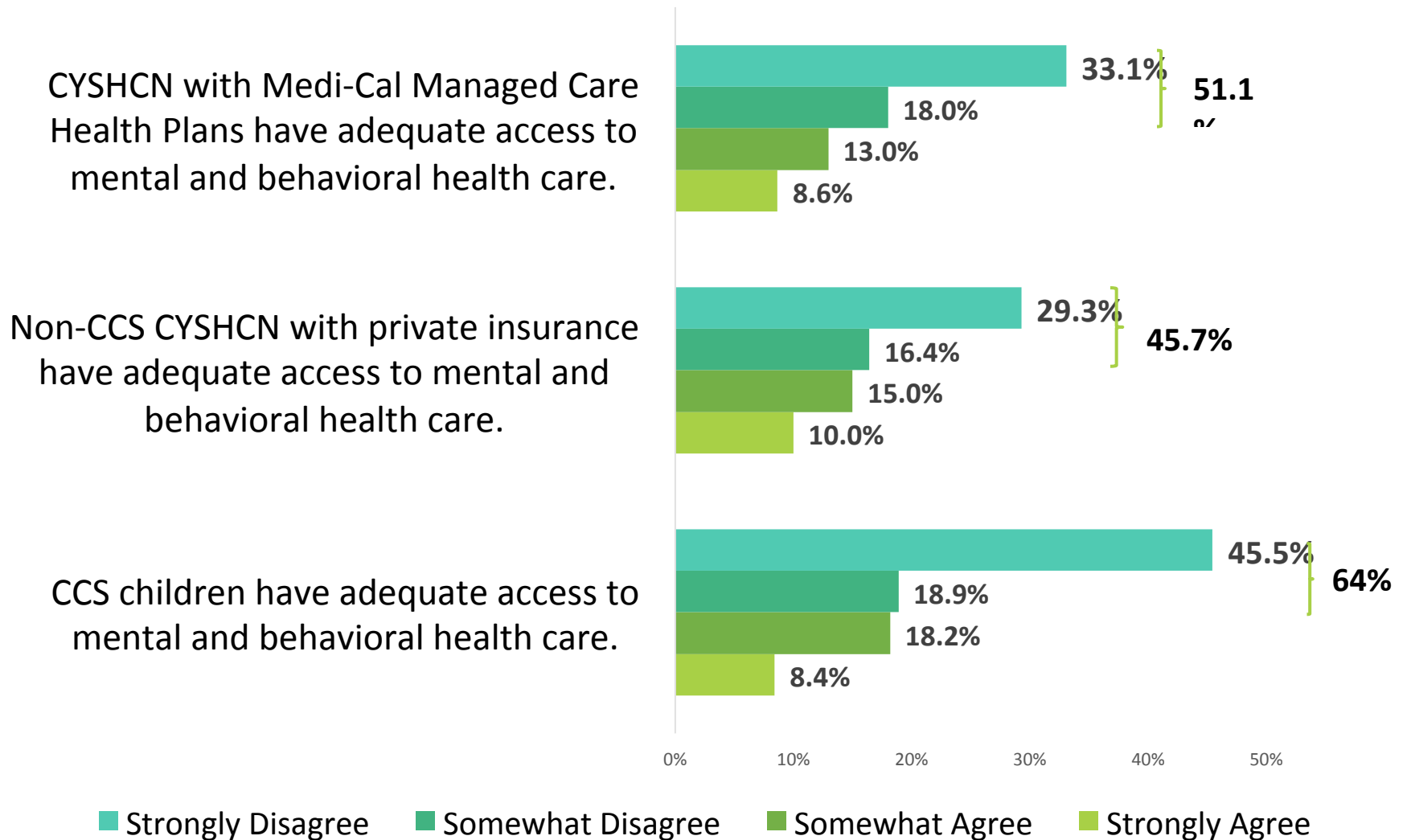
Communication with Others Serving CCS Population: Provider Survey



Barriers to Provider Communication: Provider Survey



Access to Mental and Behavioral Health Care: Provider Survey



Mental Health and Social Determinants of Health (SDOH) Screening: Provider Survey

Use a screening tool to identify needs related to mental and behavioral health for your non-CCS CYSHCN patients?



Use a screening tool to identify needs related to SDOH for your non-CCS CYSHCN patients?



Use a screening tool to identify needs related to mental and behavioral health for your CCS patients?



Use a screening tool to identify needs related to the SDOH for your CCS patients?

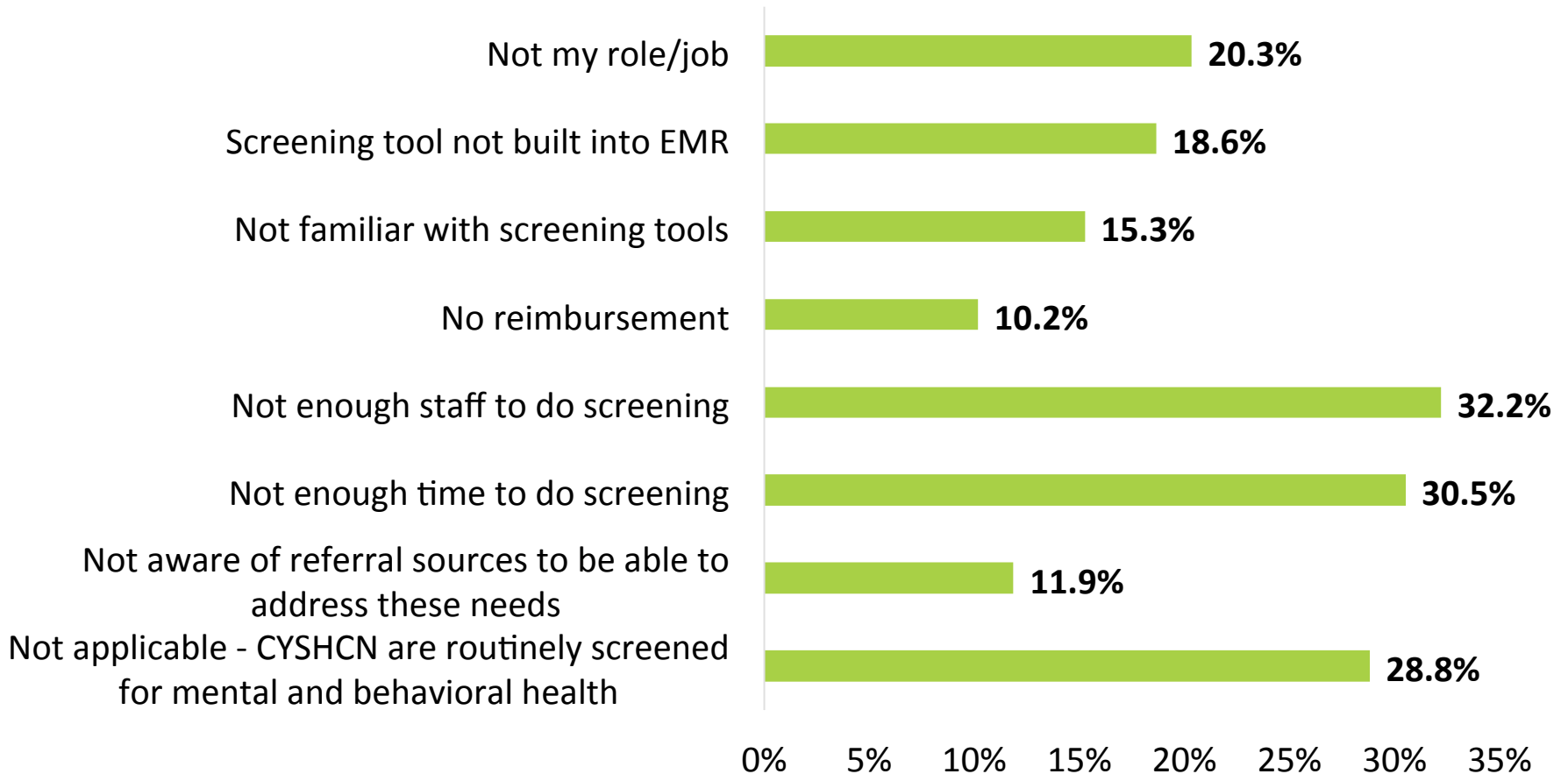


0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

■ Always
 ■ Usually
 ■ Sometimes
 ■ Never
 ■ Don't Know/Not Sure

**Note: Survey results only include nurses and physicians*

Reasons for Not Screening for Mental Health or SDOH



**Note: Survey results only include nurses and physicians*

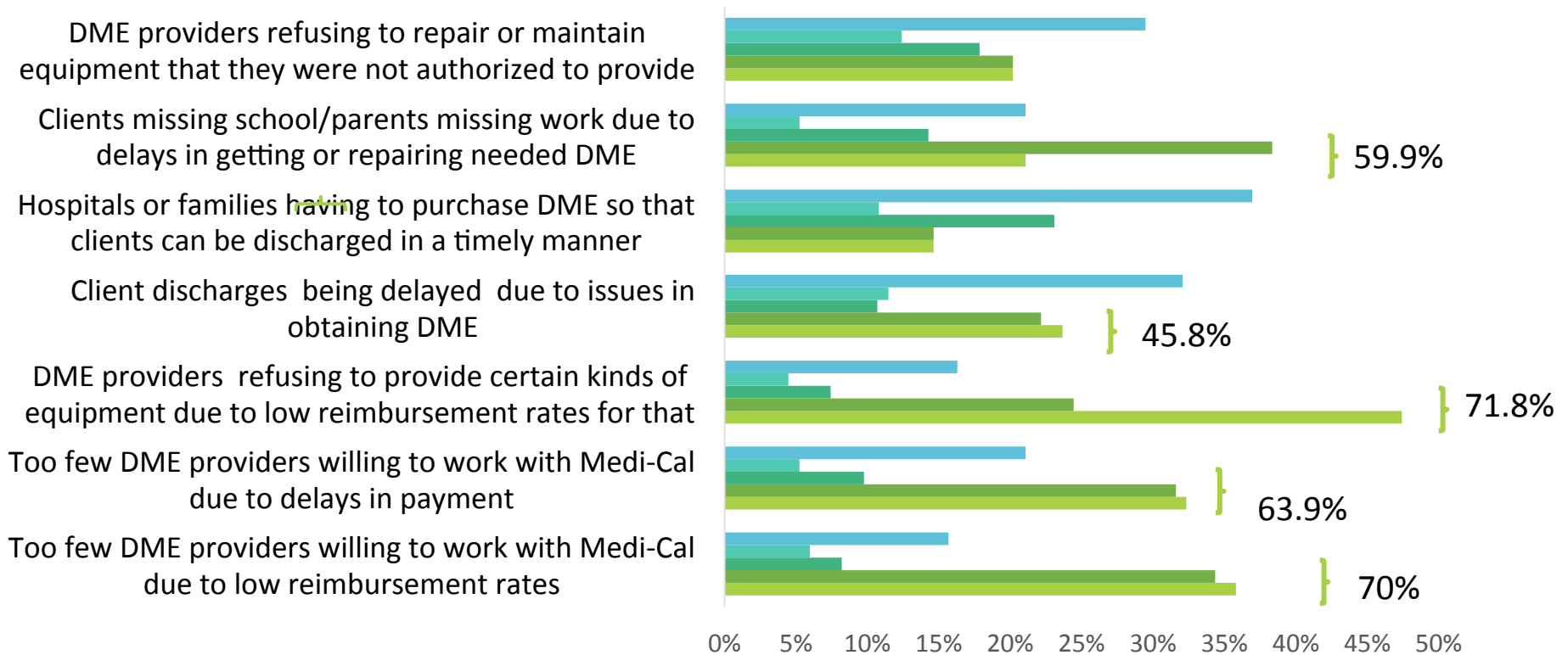
Access to DME and Medical Supplies: What We Heard

- “Some of the rates are good and some are bad, can’t get a vendor to pay for certain things unless we pair them all together. For example, a helmet is hard to get from a vendor unless the child is getting a wheelchair, and a walker, then they’ll throw the helmet in—they don’t want to do all that paperwork for just a helmet.” – *Provider focus group*
- “There are an increasing number of DME items that we can no longer obtain due to the fact that the Medi-Cal reimbursement for the item is less than the vendors cost. Also a problem is the fact that large companies are buying out the smaller DME companies. These larger companies have increased the turnaround for obtaining DME dramatically. This is a great frustration for staff and CCS MTU families.” - *Provider focus group*

Access to DME and Medical Supplies: What We Heard

- “Most of the programs seem to be working well. The guidelines are constantly changing for CCS, and they don’t inform you. I went to college, but even for me it is confusing. The biggest issue that I had is that a lot of the treatments are not consistent—there was a period of time when my daughter did not get any therapy (5 years old, cerebral palsy) and I was given all of the excuses in the book. One thing is that they only allow you to get one necessary medical equipment and then are only granted one when the child is actively able to use it, for example a gait trainer. I had to get the regional center involved asking for medical equipment that CCS would not grant us (a light gate trainer). In therapy—they give her all kinds of equipment to use and then they tell the parents to duplicate it at home, but CCS won’t give them more than one piece of equipment—how are parents supposed to duplicate therapy at home so that she doesn’t lose what she has gained. Single mother, has nobody else to help. Other children w/ private insurance are surpassing my daughter and we lost a year because of CCS. A lot of the “prescriptions” they grant have to be signed off by an MD and there are always delays due to this. Long wait between prescription and administration, MDs sometimes don’t return authorizations don’t carry over, have to go back to the new MD for a new authorization.”

ACCESS to DME- How often issues related to DME present problems for your patients: Provider Survey



■ Don't Know/Not Sure
 ■ Never a Problem
 ■ Rarely a Problem
■ Occasionally a Problem
 ■ Frequently a Problem

Medical Home

Administrative Processing Times

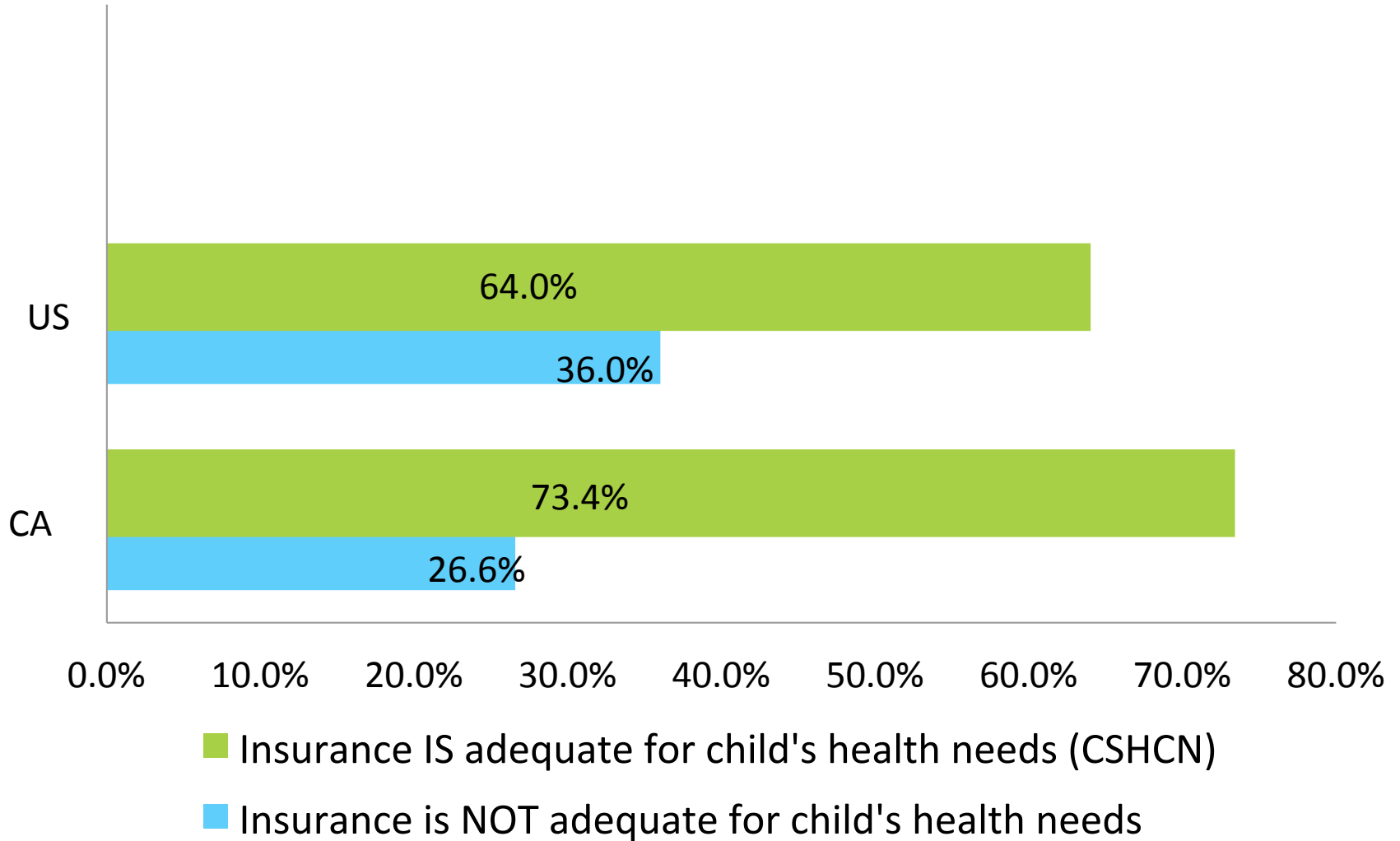
		2 Days or Less	3 days to 1 wk	Within 1 week	Within 2 weeks
Referral until first SAR auth.	2014	8.6% (4071)	30% (13999)	39%	65%
	2018	5.9% (15406)	11.7% (30492)	17.6%	28.8%
SAR request to first auth.	2014	40.2% (185816)	25%(117038)	65%	79%
	2018	16.9% (18889)	17.6%(19590)	34.5%	51.5%
HHA SAR to Auth.	2014	40.6% (1205)	33% (983)	74%	86%
	2018	25.1% (1198)	29.3% (1397)	54.4%	68.5%
Wheelchair SAR to auth.	2014	37.6% (1074)	21% (604)	58%	73%
	2018	25.9% (970)	18.9% (604)	44.8%	58.7%

Source: CMSNet 2014 & 2018

MCHB Outcome #3: Insurance Coverage

Families of CSHCN have adequate private and/or public insurance to pay for the services they need.

Adequacy of Insurance: NSCH 2016/17



Insurance Coverage: Administrator Survey

- “Create an aid code that pends the Medi-Cal for CCS eligible clients rather than dropping the Medi-Cal if pended so that folks do not experience a lapse in care”
- “Stop the CHURN [children falling on and off Medi-Cal and CCS]. This leads to poor case management and fragmented services”
- “Improve the Medi-Cal Churn, consider extending the CCS eligibility to 6 months, not monthly”
- “Require [Medi-Cal Managed Care Plan] to keep their children for 30-60 days when they fall off of [Medi-Cal Managed Care Plan] but still have fee for service Medi-Cal.”
- “Difficulty with the managed care covering health care needs while waiting for CCS eligibility”

Insurance Coverage: Family Survey

Child covered by any of the following types of insurance (check all that apply)	%
Medi-Cal	90.9
Private	13.5
Do not know	0.2
Uninsured	0.1

Does your child's health insurance allow your child to see the health care providers that your child needs?	%
Always	74.5
Usually	18.6
Sometimes	4.2
Never	0.6
Not applicable	1.2
Missing	0.7

Insurance Coverage: Family Survey

- During the last 12 months, did your child need any services that their insurance did not cover? Please check all that apply:
 - 17.8% (609) checked at least one service

Service	%
Communication aids or devices	7.2
Dental checkup/teeth cleaning	14.3
Durable medical equipment	20.0
Eyeglasses or vision care	17.9
Hearing aids or hearing care	5.4
Home health care	3.6
Hospitalization (in-patient stay)	4.1
Mental/behavioral health care	5.1
Medications	26.8
Other dental care	12.3
Pain management	2.0
Physical/occupational therapy	11.7
Specialty care	8.7
Speech therapy	10.8
Substance abuse treatment/counsel	0.2
Well-child check-up	4.6
X-rays	2.6

MCHB Outcome #4: Screening and Prevalence

Children are screened early and continuously for special health care needs

High-Risk Infant Follow-Up Program (HRIF)

California's High Risk Infant Follow-up (HRIF) Program, run by CCS, oversees outpatient follow-up of infants requiring additional developmental care after discharge from the NICU through local HRIF clinics.

HRIF clinics provide follow-up care to all infants born before 32 weeks of gestation, or with a birth weight less than or equal to 1500 grams, as well infants with a range of neurologic and/or cardiovascular risk factors.

- Infants who have spent time in the NICU are often at higher risk for behavioral, neurological, developmental, or growth challenges later in childhood.
- HRIF clinics ensure that these infants grow as expected after discharge and meet developmental milestones.
- HRIF clinics provide three or more assessment visits with CCS-paneled providers who follow the infant over the first three years of life and identify existing and new issues as they arise.

HRIF is related the MCHB Goal of Early & Continuous Screening because it is meant to provide early screening and detection of a special health care need to a high risk population.

HRIF: Data on Loss to Follow-Up

- Tang et. al. (2018) surveyed high-risk infant follow-up programs in California, 56 (82%) responded to the survey
 - The first visit no-show rate between 10 and 30% was estimated by 44% of programs with higher no-show rates for subsequent visits.
 - Common strategies to remind families of appointments were phone calls and mailings.
 - Most programs (54%) did not have a strategy to help families who lived distant to the high-risk infant follow-up clinic.
- Hintz et. al (2019) did a study to determine how to prevent Loss to Follow-Up (LTFU), which can be detrimental to families and children, especially very low birth weight (VLBW) infants. They have determined that:
 - Out of the 80% of VLBW infants referred to HRIF in 2010-2011, 74% had at least 1 HRIF visit w/in 12 months
 - Identified reasons for loss to follow-up included: Parent refused (6%), family moved (5%), insurance authorization denied (3%), unable to contact (14%), other high risk follow-up (3%), other reason (8%)
 - BUT the majority (48%) of the reasons for LTFU were unknown

HRIF: Data on Loss to Follow-Up (cont.)

Hintz et al. (2019) also found:

- Higher odds (more likely to attend) for first HRIF visit attendance was associated with:
 - older maternal age
 - Lower birth weight
 - private insurance
 - history of severe intracranial hemorrhage
 - 2 parents as primary caregivers
 - HRIF program volume
 - Lower birth rates
- Lower odds (less likely to attend) for first HRIF visit attendance was associated with:
 - maternal race African American or black
 - greater distance to HRIF program

HRIF: Needs and Ongoing Efforts

Needs based on research findings:

- Identify family challenges in access and resource risk factors during infant hospitalization in the NICU
- Provide families enhanced education about benefits of HRIF
- Create comprehensive NICU-to-home transition approaches

HRIF program is working to:

- Better characterize family & caregiver barriers to HRIF visits
- Better understand what program-level resources are needed and what the process challenges are
- Identify opportunities for intervention and strategies that need to be tailored to HRIF programs and regional needs

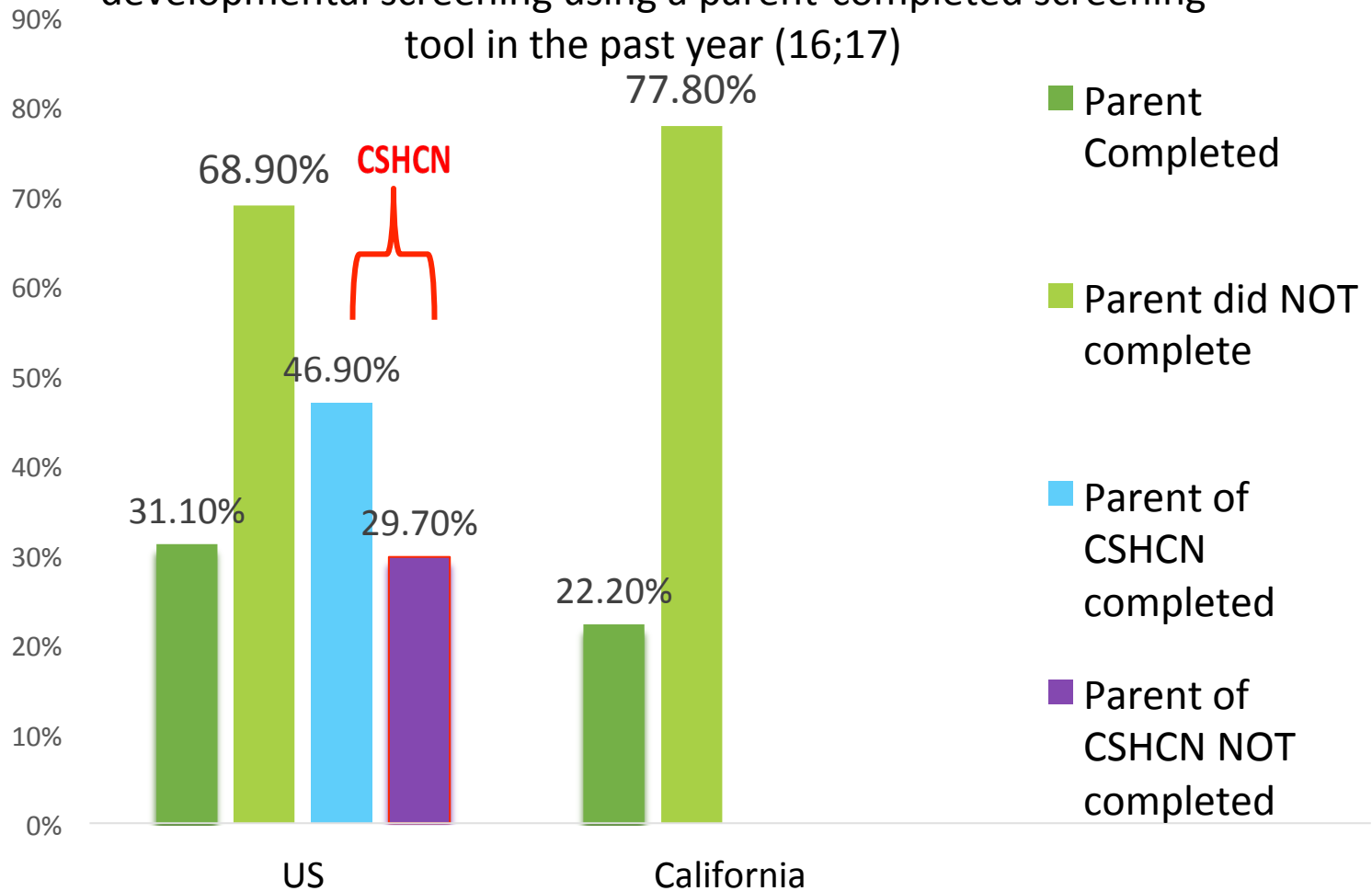
Screening of Medi-Cal Children

- Preventive services include Early Continuous or Developmental Screening
- “An annual average of 2.4 million children who were enrolled in Medi-cal over the past five years have not received all of the preventive health services that the State has committed to them.” - *Source: California State Audit Report 2019*
- Between 2013 and 2018, an average of 2.4 million children each year enrolled in Medi-Cal did not receive all required preventive services, according to the findings - *Source: California State Audit Report 2019*

Developmental Screening: NSCH

Goal: Continuous Screening

% of children, ages 9 through 35 months, who received a developmental screening using a parent-completed screening tool in the past year (16;17)



Well-Child Visits

Provider Survey:

Over 95% of providers feel that the annual well-child visit for CYSCHN is very important (N = 66)

Are CYSCHN receiving well-child visits? (N = 70)

- Yes, most appear to be having these visits 50.0%
- Yes, but only some appear to be having these visits 24.2%
- No, it appears that most are not having these visits 9.1%
- I don't know whether they are having these visits 16.7%

Who is providing these visits: (open-ended)

- Almost all reported Primary Care Providers

Family Survey:

During the past 12 months, how many times did your child receive a well-child check-up, which is a general check-up, when they were NOT sick or injured?	%
0	8.8
1	16.8
2	15.8
3+	15.0
Missing	10.2

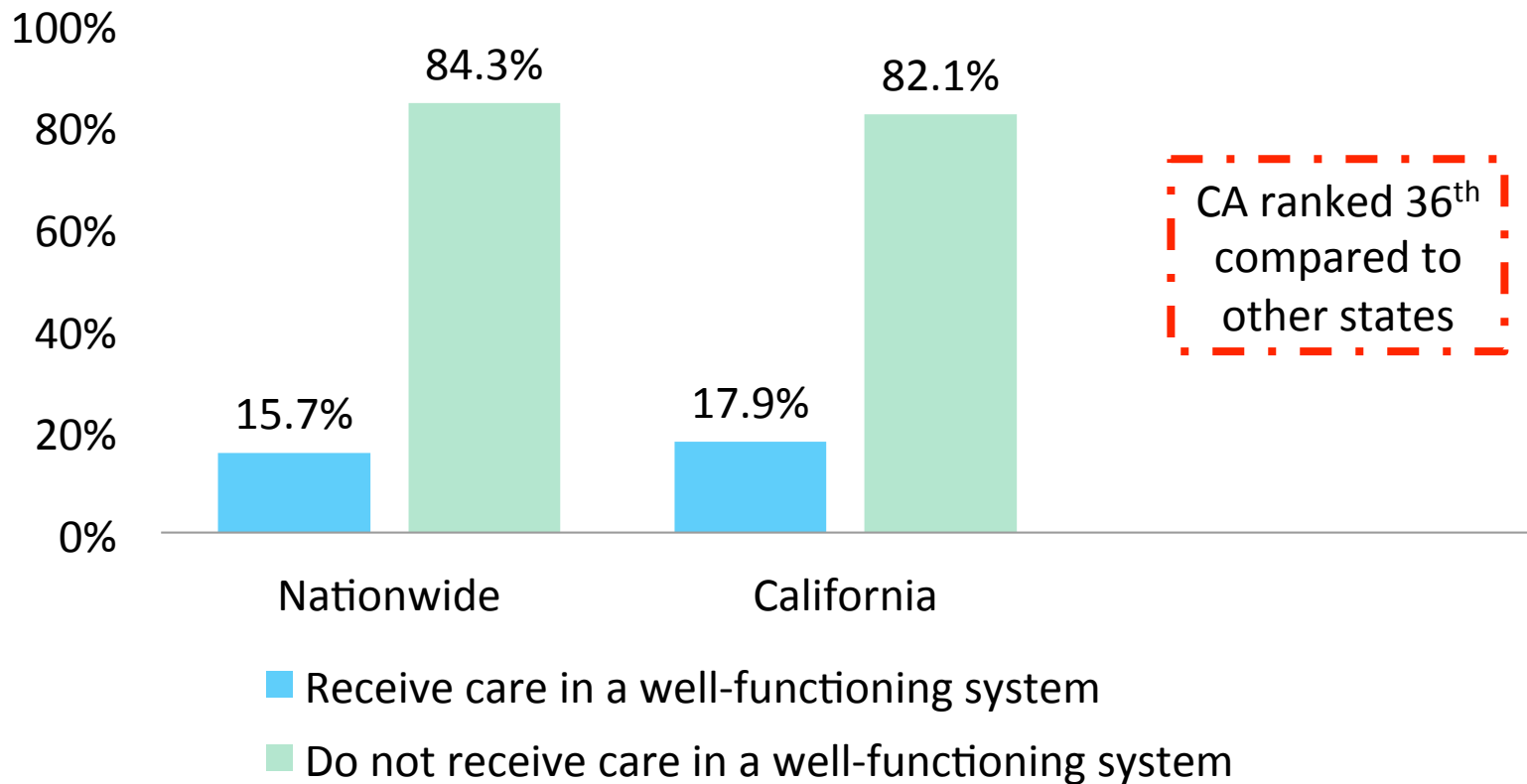
**Note – reporting data only for physicians and nurses*

MCHB Outcomes #5: Organization of Services

Community-based services for children and youth with special health care needs are organized so families can use them easily.

MCHB Outcomes #5: Organization of Services

Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system (2016/17)



Organization of Services: What We Heard

- “About half of the CCS patients are extremely socioeconomically challenged with parents that struggle either with finances, language, or comprehension of the condition. Simple things such as go to lab and get blood drawn, making appointments, following medication instructions are challenging for them. Many do not have transportation to come to clinic. We're lucky that our institution provides case managers that helps us with paperwork related to coverage, but they can't help the post discharge execution by the families. Having someone from the health plan that knows the care plan and help the family adhere to it would be extremely helpful. The possibility of transport assistance is also extremely helpful.” – *CCS Provider Survey*
- “We need to know what services and medications are covered by CCS clearly and by county as the formularies are different. We need to know which diabetes supplies are covered and which brands are covered. We need this information easily accessible to providers and pharmacists so the correct medication can be provided. Families have delays in getting prescriptions or glucose test strips and our staff spends significant amounts of time sorting this out. Counties change what they will cover and and it seems providers are the last to know. We would appreciate a list from each county sent to providers or up on the CCS website listing what is covered and changes to coverage.” – *CCS Provider Survey*

Organization of Services: What We Heard

- “My 18 year old grandchild (I am his guardian/conservator for 15+ years and have cared for him since birth) has been receiving CCS benefits since he was an infant. I honestly can say I don't know what I would have done back then without them. He has a twin with the same muscle disease and is also a CCS client. Their particular disease is known as one of the most underdiagnosed diseases due to the complexity of symptoms. It is genetic with each generation presenting more severe until finally a baby with the most severe form is diagnosed. We are so grateful to have our CCS manager who understands my grandsons' needs and helps us keep our team of doctors that care for them. And now with the new dx of leukemia, it is even more important than ever that we keep receiving our authorizations in a timely manner. It means so much to have a specialized group at CCS that truly understands complex diseases and knows the importance of keeping on top of the kids needs. We have never had a delay in a call back or authorization ever, and when you have a seriously ill child, that means a lot. We are also grateful to the Lucile Packard Children's Hospital and Medical doctors that accept Medi-Cal/CCS.” – *CCS Family Survey*

Organization of Services: What we heard

- “My nurse case manager always reaches out to me and to my wife what we needed to do. For example, who to call, and what stuff we needed so that CCS can authorize services. My nurse case manager also kept us updated of what is going on so we know what to expect.” – *CCS Family Survey*
- “A lot of it is better communication. Even sending out, what rights are in CCS , understanding of how program works. I didn't even know how my child qualified. It was a traumatic time when I signed the paperwork and I must've signed it not realizing. I'm sure someone told me because I was caught up in life.” – *CCS Family Survey*

Organization of Services - WCM: What We Heard

- “Our Health Plan also subcontracts transportation, pharmacy, and radiology, and there is a lot of fragmentation because the family needs to call these different companies in order to access the services. We hear from families that they need to make multiple phone calls—whereas in the past we could make sure that they get what they need. Not all families are equipped to do this.” – *CCS Administrator Focus group*
- “The providers that knew it before, knew about authorization. In Medi-Cal Managed Care it is actually fragmented and they want a separate authorization—providers feel like they have to ask for everything. When we do authorizations, these authorizations tend to encompass that diagnosis—so it is a broader authorization off of a specific diagnosis. Now, with Whole Child Model they are adding additional steps and complications.” - *CCS Administrator Focus group*
- “There is nobody doing oversight, we’ve actually been told when we ask case management questions, we are told ‘well, that’s not your business.’ Clients don’t know who to call at the Health Plan—they have to tell their story to four different people in four different departments.” - *CCS Administrator Focus group*

Organization of Services - WCM: What We Heard

- “I never had a problem with the diapers before, they would come all of the time and on time and then we started to notice that they weren’t showing up. When June came, I called to find out and they said that she needed to get a prescription from the vendor. When I called the vendor they said that due to the changes they were not contracted with [health plan], and then I called CCS and they said that the vendor should be contracted and expected me to call and figure out who they are contracted with. Then finally, I got a list for three places in [county name], and they all said was “we don’t know why they keep referring you here, we don’t offer those services.” Then I finally called shield and they were explaining she didn’t qualify for drugs. I had to go back to the original vendor to get the list of what they sent her in the past, had to go to the MD to get an authorization. **Why do I have to keep asking for something that they know my daughter has a lifetime need for?” – CCS/ CYSHCN Family Focus Group**

Organization of Services -WCM: What We Heard

- “It was very good about that [telling us what conditions were eligible], but it isn’t anymore. The whole child model —people are struggling because they are CCS eligible, but not allowed to use CCS fee-for-service. Half of them haven’t even read it at [redacted name of health plan] and cannot interpret it. Pretty much didn’t tell us anything until it happened. It is difficult now because we are really CCS clients, but we can’t use it. [Health plan] is still figuring out how to fit it into their system.” – CCS/CYSCHN Focus Group

Health Plans: Family Survey

Do you need more information about:	%
CCS	26.1
Medi-Cal	23.5
Private Insurance	2.0
Do not know	2.3
My child is not insured	0.1
I do not need more information	55.0

Do you know how to file a grievance or complaint about your child's health care?	%
Yes	41.9
No	30.3
Not sure	14.5
Not applicable	3.2
Missing	10.0

Do you know whom to call to get answers about your child's care or insurance (for example if services are denied and you want to ask why)?	%
Yes	69.5
No	10.5
Not sure	9.2
Not applicable	1.2
Missing	9.6

If yes to Q28, have you ever filed a complaint?	%
Yes	38.9
No	18.1
Not sure	10.0
Not applicable	2.1
Missing	0.5

Interpretation Services: Family Survey

Is English the primary language spoken in your home?	%
Yes	70.0
No	29.5

How often do you need an interpreter to help you speak with doctors and nurses?	%
Always	39.8
Usually	11.8
Sometimes	18.3
Never	8.7

How often are interpretation services available? (for those who always, usually or sometimes need an interpreter)	%
Always	69.1
Usually	17.3
Sometimes	11.3
Never	0.8

Coordination of Services: Family Survey

How often are your child's services coordinated in a way that makes them easy to use?	%
Always	53%
Usually	29%
Sometimes	14%
Never	4%

How often is it easy to coordinate therapy (physical therapy, occupational therapy) for your child in the school setting?	%
Always	49%
Usually	21%
Sometimes	10%
Never	7%
Do not know	12%

Impact on Families: Family Survey

How many hours per week do you or other family members spend arranging or coordinating care?	%
0 to 5	65.0
6 to 10	14.1
11 to 15	5.1
16 to 20	2.4
20 +	13.4

Have you or other family members ever cut down on hours or had to leave a job because of your child's health?	%
Yes	54.0
No	43.3
Do not know	2.6

How many hours per week do you or other family members spend providing care for your child's medical condition at home for your child?	%
0 to 10	50.8
10 to 20	10.4
20 to 30	6.8
30 to 40	4.1
40 to 50	3.6
50 to 60	2.2
60 to 70	2.1
70 +	20.0

Case Management/Care Planning: Family Survey

In addition to yourself and your family, who helps to arrange or coordinate care for your child? (check all that apply)	%
Nurse Case Manager	12.3
Health Plan	8.6
Regional Center	15.3
Special Care Clinic/Center	14.1
County CCS Case Manager	20.9
Childs school	4.6
Nobody helps	34.5
Dont Know/Not Sure	7.9

Has a health care provider or case manager help linked you with support (e.g. family support groups, parent mentors, online support groups, etc.)?	%
Yes	32.8
No	30.5
Do not know	26.1

During the past 12 months, have you felt that you could have used extra help getting, setting up or coordinating your child's care among the different health care providers or services?	%
Always	11.8
Usually	7.0
Sometimes	17.8
Never	43.1
Not applicable	7.3
Missing	13.4

If you feel that more social and/or emotional support would help you or your family cope, what kind of social and/or emotional support would you like for you or your family? Please check all that apply:	%
Online or telephone support group	18.2
In person support group	22.8
Parent mentor or parent partner	11.2
Not Applicable – no additional support needed	42.1

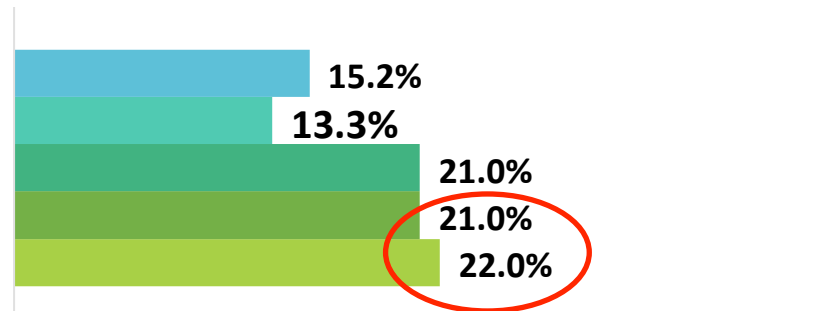
Family Need for other Services – Family survey

- 10.8% of families needed at least one of the services below.

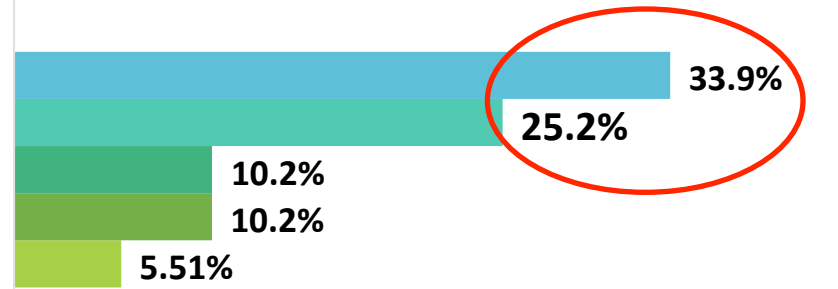
During the past 12 months was there any time when you or other family members needed the following services and did not receive them?:	Of those with any need, % needing service	Received care (%)			
		Always	Usually	Some	Never
Respite Care	36.2	31.3	14.1	21.7	32.8
Genetic Counseling	16.3	51.7	5.6	14.6	28.1
Mental Health Care, Emotional Support or Counseling	37.5	37.6	12.7	24.9	24.9
Legal Issues	10.6	27.6	10.3	24.1	37.9
Housing Issues	12.6	27.5	13.0	20.3	39.1
Accessing Food Assistance and Other Gove	17.4	56.8	8.4	21.1	13.7
Other	4.0	40.9	18.2	27.3	13.6

Organization of Services: CCS Standards and Enforcement

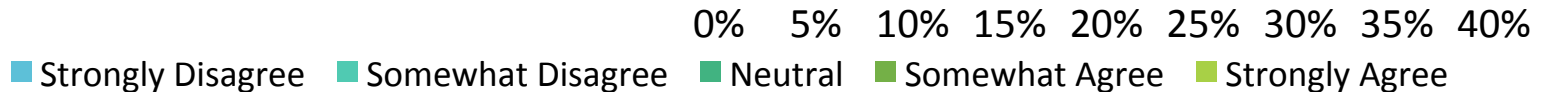
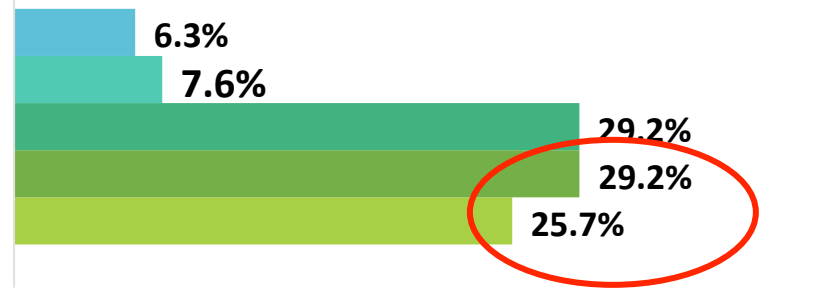
Facility site visits are conducted by a multidisciplinary team of state staff and consultants who are experts in their fields.



The state CCS program has adequate capacity (i.e. staff, clinical expertise, funding) to conduct periodic facility site visits to monitor and enforce regulations/Numbered Letters.



Regular facility site visits are an important part of monitoring and enforcing regulations/Numbered Letters.



Organization of Services: Standards and Enforcement

CCS Administrator Survey:

Comprehensive care coordination and oversight from State of care coordination [for WCM Health Plans]

Fully define and implement Case Management by the Health Plans

Define, create, and implement standards for Medical Homes. All CCS clients to have an appropriate medical home.

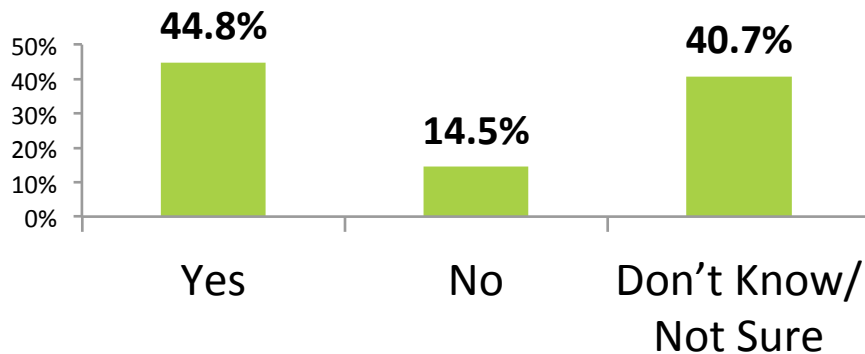
Finalize the Inter-County Transfer Numbered letter

Improving the transfer process between counties - creating a standard protocol for all counties to be on the same page

Provide PDN (private duty nurse) Policy or Numbered letter

Extending CCS Eligibility: Provider Survey

Should eligibility for certain CCS conditions (e.g. hemophilia or cystic fibrosis) be extended to 65 years old, at which time Medicare would be available?



N = 145

Which CCS conditions should be extended to 65 years old? (Provider Survey, open-ended, N = 68)

Themes and quotes:

- Congenitally acquired conditions that are chronic and will last into adulthood, e.g., cerebral palsy, muscular dystrophy, spina bifida
- “All congenital diseases. Too difficult finding adult providers who are familiar with childhood conditions. Adult providers do not have the infrastructure to coordinate care”
- “Metabolic/genetic conditions such as PKU, Fatty acid oxidation defects, urea cycle defect, etc... There are no adult physicians trained in metabolic/genetic disorders.”

Care Coordination: Survey Results

What differences, if any, are there in the coordination of health care for CCS versus non-CCS CYSHCN? (Provider Survey, open-ended question)

Key themes and quotes:

- CCS patients have greater need and complexity of medical, therapy, financial, and mental health issues.
- “Coordination of care is better for CCS patients, and support services for non-CCS patients are provided by my team but are NOT reimbursed by anyone! It becomes essentially FREE care (RN, Soc Wkr, e.g.), which is not sustainable for large numbers of patients.”
- “CCS patients require an extra layer of paperwork and coordination that commercial patients don't have.”
- CCS CYSHCN receive more specialized case management.
- “CCS provides some care coordination centrally which is helpful. Fragmented responsibility (CCS and health plan) leads to additional work in seeking authorizations, denials, etc.”

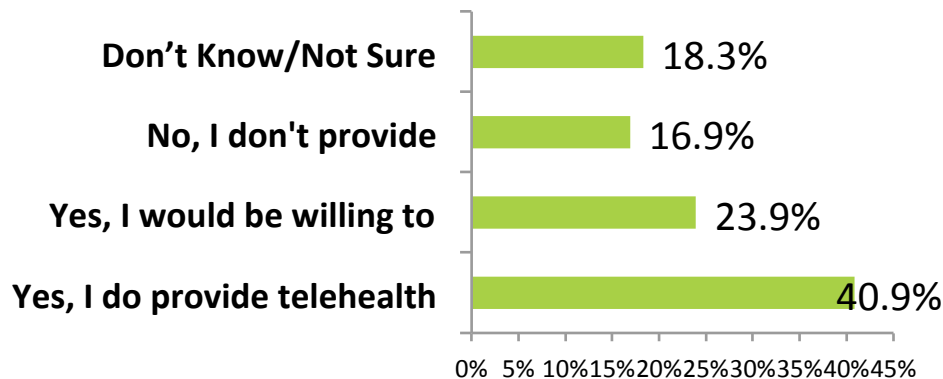
Care Coordination: Provider survey

How important is it for you (or your practice) to provide care coordination for CYSHCN? (N = 127)	%
Very Important	70.1
Important	11.8
Somewhat Important	3.2
Not Important	3.9
Don't Know/Not Sure	11.0

Who Pays for coordination? (N = 125)	%
CCS	29.6
Medi-Cal Managed Care Health Plan	12.4
Private insurance	7.1
Philanthropy	2.9
No one pays for it, we just do it because it is needed	13.6
Don't know/Not Sure	30.2
Other (please specify)	4.1

Telehealth Survey Results

Do you currently provide telehealth services or would you be willing to provide telehealth services to CCS clients?



Barriers to providing telehealth:
(open-ended, N = 95)

Themes and quotes:

- Reimbursement for staff and resources needed
- Lack of patient access to needed technology
- Up to date and secure (HIPPA Compliant) programs, portals, and electronic devices
- “Very time consuming when using an interpreter”
- “You can't do a physical exam”

**Note: Survey results only include nurses and physicians*

Telehealth Survey Results

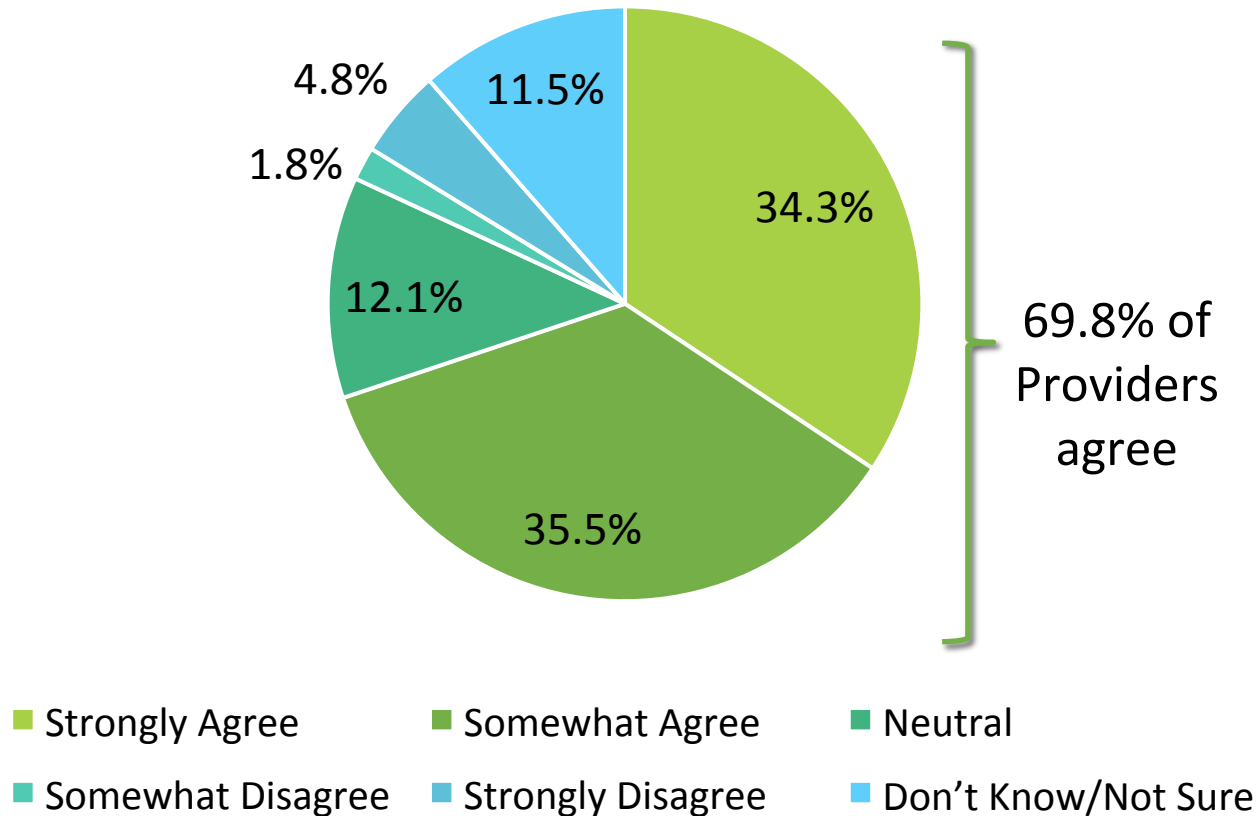
What steps should be taken to reduce barriers to providing telehealth services? (open-ended, N = 72)

Themes and quotes:

- Improving reimbursement
- Funding for secure technology needed to provide telehealth
- “Eliminating the requirement that the telehealth services be provided at a health care center. Wouldn't it be great to conduct telehealth visits using a patient's home???”
- “Having a city or county based location a patient could go for a telehealth visit if they do not have access to the appropriate equipment or reliable internet connection”
- “Encouraging ALL families to sign up for MyChart at the time of all new appointments and at the next available appointment when they haven't signed up yet.”
- “Get up to date phone numbers at every encounter”

Medi-Cal Provider Network: Provider Survey

The Medi-Cal provider network presents challenges in terms of the availability and capacity of primary and specialty care providers.



MCHB Core Outcome #6: Transition to Adulthood

Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Transition to Adulthood: What We Heard

Provider Focus Groups:

- Very hard to find a provider to see CCS clients as they age out, especially with Medi-Cal insurance
- Lack of transition planning
- Lack of adult specialists with expertise in conditions originating in childhood

Family Focus Groups:

- Many families in focus groups did not have children that were at the age of transition yet; if they were above 14, most hadn't been spoken to about it, but many were concerned what it would mean for their CYSHCN
- Some parents just handled the transition themselves, some with the help of county case managers

Transition to Adulthood: What We Heard

- “The other issue that we faced is that PCPs in the community were afraid to take on complex kids as adults.” – CCS Administrators focus group
- “We are trying to partner with providers in outlying counties that may only see one HIV transition special health care needs kid, and they may only call them once and if they don’t show up, they say that is ‘too bad’ because they are adults and they can take care of themselves. We’ve had several patients die in the last ten years because of this, because they have had 10-12 regimens in their lifetime and the MDs don’t have the capacity or the support groups to deal with the ‘born with HIV’ population, they don’t fit into the behavioral health support groups for this.” – CCS Provider Focus Group
- “For pediatric and adult world it is day and night. We noticed when they transition it is hard to find a provider that understands the complexities of their disease, we have a lot of kids bouncing back and asking to be seen by us after transition. Need a smoother transition.”

Transition to Adulthood: What We Heard

Family Focus Group Parent:

“For us, it went smooth. We were not able to find an adult provider though; I pick up where Medi-Cal leaves off. I found the PCP for her, the pediatrician gave three recommendations and none of them would take her because of her need. The equipment that they gave us after transition was good quality enough and we haven’t had a need for DME. This was before Whole Child Model, our case manager made sure that we had every bit of equipment we needed when she aged out.”

Transition to Adulthood: What We Heard

Providers suggested...

- Pediatric providers/specialists see CYSHCN into adulthood
- Telehealth
- More family engagement from CCS
- More collaboration & partnership between pediatric & adult providers
- Providers need to start discussing transition at age 14
- Outside funding for specialized transition programs (which some have already)

“We have sickle cell [transition] boot camps with donated money. We start kids at 13. These exist all over the country; I don’t know how successful they are.”

Transition to Adulthood: Family Survey

Is your child 14 years or older?	%
Yes	27.1
No	62.5
Missing	10.4

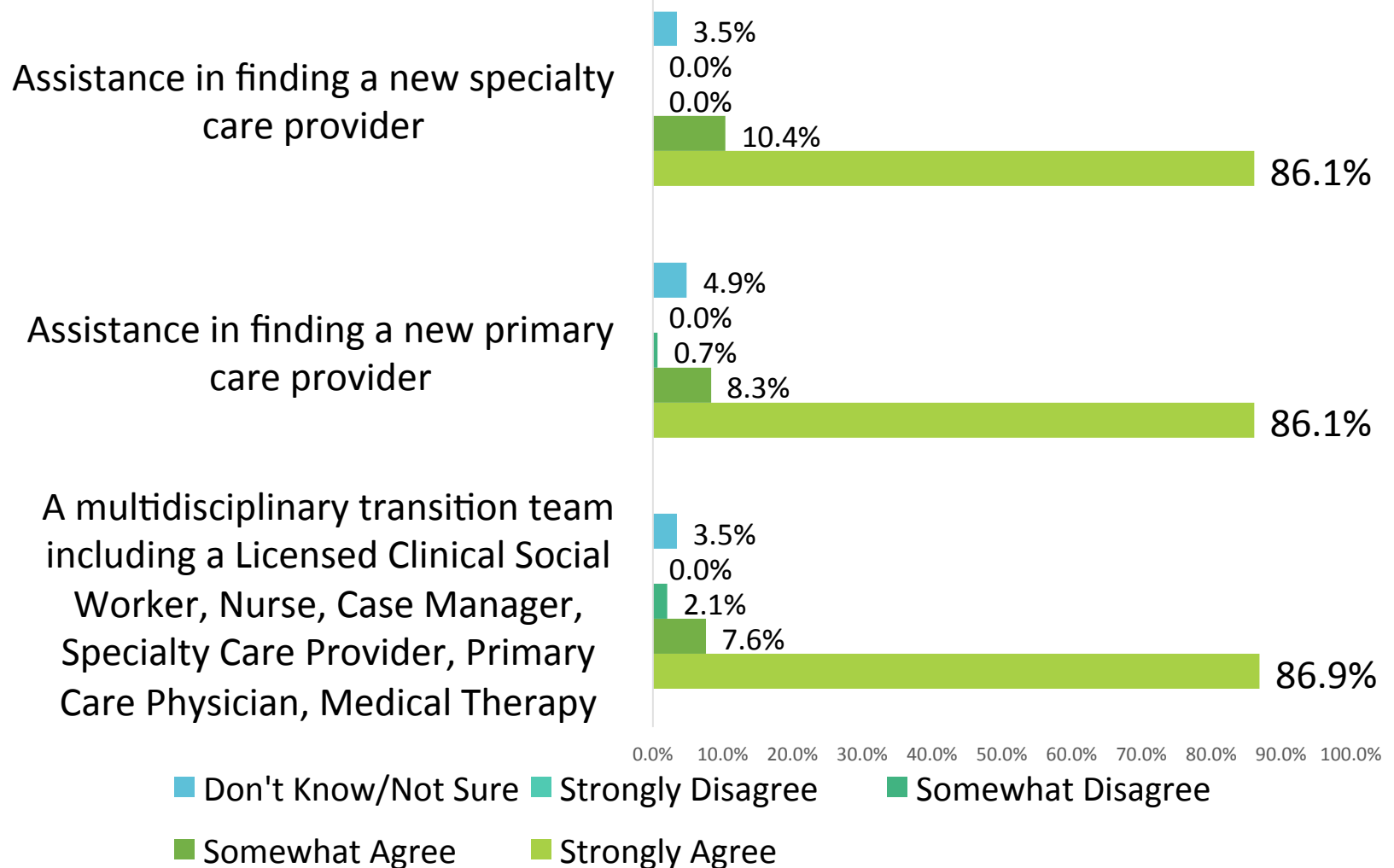
Have doctors or other health care providers talked with your child about how their health care needs will be met when your child turns 21?	%
Yes	36.7
No	48.5
Do not know	11.5
Missing	3.2

Have any of the following people or organizations helped your child find an adult medical provider? Check all that apply:	%
CCS	22.2
Health Plan	13.8
Our Pediatrician	13.5
None of the above	47.2

If yes, were you able to find an adult doctor or provider?	%
Yes	59.4
No	12.1
Do not know	26.6
Missing	1.9

Strategies to improve Transition: Provider Survey

Youth who have aged out of CCS and have Medi-Cal would benefit from having:



Potential Priorities

Families are Partners: Potential Priorities

- Care needs to be more patient-centered, driven by patient experiences
- Increase staff that are responsible for care coordination
- Increase case management staff
- Create protocols or regulations mandating that families are involved in decision making about their child
- Create more opportunities for families to receive communication and education from Medi-Cal Managed Care
- Create new materials to educate and communicate the CCS system to families in language that will make sense to them, with input from families and CYSHCN
- Increase CCS social worker staff to address the social needs of families
- Improve website to be easier for families to navigate
- Get rid of “milestones” as a measure of a child’s development, it isn’t inclusive of all DXs

Medical Home: Possible Priorities

- Increase support (funding) for primary care for CYSHCN, specifically for Medical Home programs
- Develop Medical Home criteria and standards to promote clarity and understanding across organizations
- Provide additional provider education on how to work with CYSHCN
- Increase number of CCS providers AND mental health providers that can serve CYSHCN by providing additional funding and incentives (i.e. loan forgiveness)
- Integrate mental and behavioral health programs to CCS services available to CYSHCN AND their families, if they already exist, increase them via funding
- Clarify the role of MTUs both for traditional CCS and Whole Child Model counties
- Allow WCM families to still see CCS-Paneled providers from outside of the Health Plans
- Ensure that families in WCM counties are being referred to MTUs

Medical Home: Possible Priorities (cont.)

- Develop protocols to ensure that families are able to duplicate PT at home
- Re-evaluate the process for DME authorization so that vendors stop favoring privately insured individuals
- Incorporate protocols or regulations that address the social determinants of health and adverse childhood experience into the CCS program
- Return case management to the way that it was under traditional CCS (even if Health Plans are implementing it)
- Financially incentivize institutions and practices to have social services
- Develop protocols or regulations for screening CYSHCN AND their families for mental and behavioral health issues
- Determine if WCM children are receiving the same level of benefits as traditional CCS children, and if not, find a way to provide the same level of care

Medical Home: Possible Priorities (con.t)

- Develop regulations for telehealth so that it can start to be more available to CYSHCN and their families
- Streamline process so providers can see if medication or supply is covered by CCS (similar to what is done for private insurance plans)
- Improve technological resources like eSARS, Patient Portal and Provider Portal, Update MTU online Program and make web based and hosted by state so all documentation for CCS MTP clients can be universal allowing smother transfer or cases between counties
- Develop a process for improved electronic record sharing among CCS providers

Early and Continuous Screening: Potential Priorities

- Mandate that all CYSHCN and families will be screened and appropriately referred to mental health services
- Reduce loss to follow-up for infants/children referred to the High Risk Infant Follow-up Program (HRIF)
- Ensure CCS children are receiving yearly well-child visits and developmental screening
- Improve proactive identification of cases for MTU services
- Improve CCS referrals particularly in Whole Child Model counties

Insurance Coverage: Possible Priorities

- Extend CCS coverage past age 21
- Expand medical criteria or change it to be more inclusive of more CYSHCN conditions (does not address emergent conditions that don't qualify)
- Increase reimbursement rates for Medi-Cal providers
- Increase reimbursement rates for vendors that provide DME to CCS CYSHCN
- Ensure that Medi-Cal covers care until CCS eligibility is determined
- Medi-Cal Managed Care Health Plans need to allow secondary diagnoses in order to mitigate delays in care
- Financial criteria is too low, it needs to be increased, ideally with consideration of location and family size.
- Increase funding for addressing social needs

Transition to Adulthood: Potential Priorities

- Bolster and improve transition resources
- Increase CCS social worker staff to address transition to adult care
- Develop a plan to find adult providers that work with SHCN patients so that they can be used a resource during transition
- Extend CCS beyond 21
- Transition preparation with other CYSHCN should be built into specialty care

Organization of Services: Potential Priorities

- Mandate that all CYSHCN and families will be screened and appropriately referred to mental health services
- Reduce loss to follow-up for infants/children referred to the High Risk Infant Follow-up Program (HRIF)
- Ensure CCS children are receiving yearly well-child visits
- Improve proactive identification of cases for MTU services
- Improve CCS referrals particularly in Whole Child Model counties

Breakout Group: Assign Task Instructions

- Select recorder to enter info into the laptop
- Select recorder to write on poster paper
- Select presenter to report back for the group

Breakout Groups: Mission

- Review draft list of problems/issues and
 - Add problems/issues if missing
 - Delete problems/issues if redundant, or not needed
 - Reword listed problems/issues into priorities/goals

GOAL: Manageable list of priorities for stakeholders to rank

Next Steps: Ranking/Scoring Priorities

- List of priorities will be entered into online survey or Stakeholders will be emailed Prioritization spreadsheet to complete
- Stakeholders will rate each priority using the 6 prioritization criteria developed with Stakeholder workgroup
- Criterion weights will be applied, using the weight the most Stakeholders selected for each criteria
- Final scores for list of priorities will be shared with Stakeholders
- DHCS/ISCD will make the final determination of the priorities to be addressed

Next Steps: Developing Action Plans

- Additional analyses of data for top priority areas
- Inclusion and sharing of additional relevant data
- Continued involvement of stakeholders and state and local CCS staff in the development of action plans
- Establish performance measures to evaluate implementation of action plans

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Thank You

