# TITLE V CCS NEEDS ASSESSMENT: PROVIDER SURVEY AND PROVIDER FOCUS GROUP SUMMARY REPORT

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# PRESENTATION OBJECTIVES

- Describe the work being done for the Title V CCS NA
- Summarize CCS Provider focus groups through several topic areas
- Summarize CCS Provider Survey through several topic areas

# TITLE V CCS NEEDS ASSESSMENT

- DHCS/ISCD contracted FHOP to conduct a 5-years Needs Assessment
  - Title V Block Grant
  - Components of the Needs Assessment: Key Informant Interviews; Focus Groups with Families, Providers, CCS Administrators, and Health Plans; Survey of Providers, Administrators, and Families; analyses of administrative data; review of other relevant data and research
- Today's presentation will cover two components:
  - Survey of CCS Providers (188 responses)
  - CCS Provider Focus Groups (3 in total, w/ 25-30 participants total)
    - Included Primary Care MDs, Specialists, and Nurse Case Managers
    - 2 Groups in Southern CA, one group in Bay Area
- *Note: "CCS Provider" can also mean a provider of care to non-CCS CYSHCN*

# CCS PROVIDER FOCUS GROUPS SUMMARY

# PARTNERSHIPS IN SERVING CYSHCN

*Working with Medi-Cal Managed Care (MCMC) Health Plans (HP)*

Benefits:

- Specialists serving low-income (accept Medi-Cal)
- Specialized care, better than other states
- Control of care

"[Their providers] have relatively good control of care from the authorization perspective, because MCMC has fewer barriers to getting authorizations than other insurers. In my experiences, commercial insurance with CCS-like services has a lot of trouble with this."

# PARTNERSHIPS IN SERVING CYSHCN

*Working with Medi-Cal Managed Care (MCMC) Health Plans (HP)*

## Challenges:

- Vendor delays
- Proper identification of CCS patients
- Difficulties w/ labs & bloodwork

"Sometimes there are issues down the road when CCS denies and then MCMC doesn't pay [either]."

"It is difficult to get labs and bloodwork done outside of the hospital because the patient has MCMC, and they likely are having their labs done by a specific contractor. Additionally, these lab results are also not sent electronically—whoever the contractors are, they will only fax it to us or we have to go to them and get a hard copy of the file (if they will even share results at all)."

- This experience was shared by many providers

# PARTNERSHIPS IN SERVING CYSHCN

*Working with Medi-Cal Managed Care (MCMC) Health Plans (HP)*

Challenges continued:

- Some feel CYSHCN that don't qualify for CCS are worse off
- Little communication between CCS & MCMC
- MCMC plans are sometimes unfamiliar w/ diseases of pt population

"We've had difficulties with [health plan] because they don't know anything about the disease. We've had two patients die because they weren't able to get the care that they needed, [health plan] wouldn't allow it. We made multiple phone calls and [sent] letters, notified the state. In California the lifespan for sickle cell disease is lowering, because there is increased mortality when they age out. GHPP* and MCMC, that is what the deaths were associated with, not Whole Child Model specifically. We collaborate across the state on hemophilia and sickle cell grants, the stories we hear from patients and providers are horrifying, especially in LA, there is no access, it is frightening."

"We're dealing with people that have no background in the diagnosis and they are the gatekeeper."

*Genetically Handicapped Person's Program, a DHCS program for children over 21 w/ certain genetic diseases

# PARTNERSHIPS IN SERVING CYSHCN

*Working with Medi-Cal Managed Care (MCMC) Health Plans (HP)*

Challenges continued:

- Uncertainty of what will be authorized under WCM

"I'm interested in what would be authorized under Whole Child Model, they were so vague about what they were going to authorize, and they *never* answered the question."

# DURABLE MEDICAL EQUIPMENT (DME)

Providers create workarounds for pts (sometimes w/ internal $):

"In the inpatient side, we have set up workarounds for when a patient could go home but [they] are just waiting for equipment, we use internal funds to get the patient out of the hospital. This is because we see delays in DME. Medications and SARs can take days to get authorized, delays there as well. Historically we did have patients that had to stay for longer, then we set up this fund to try to help with the issue, but they are never reimbursed for this expedited service."

# DME

- Some providers had never heard of any issues w/ DME vendors, others experienced the following issues that lead to delays in care:
  - Opportunistic vendors
  - Vendors withholding DME until paid

"Some vendors seem to be adding lots of things, [a] 'laundry list' that seems to just be adding a lot to bill more when it isn't something that a PT needs."

"[There was a] patient that has [health insurer] and needed a safety bed and the vendor was trying to get three pieces of equipment and then held the bed hostage because [health insurer] didn't pay for it. Then the mom went on social media, and then [health insurer] paid for it, and the child got the bed."

# DME

- Another common issue is CYSHCH living in remote areas have less access to DME:

"We also don't have a lot, but 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."

# MOST DIFFICULT DME TO GET:

- Lyrica, most commonly used to treat fibromyalgia
- Formula
- G-Tube supplies
  - **Please note that all of the above actually fall under the category of supplies or medications, but these were the answers of focus group participants.**
  - **Also, these individuals mentioned that non-DME supplies were actually most difficult to get for them—they regularly had trouble getting them added to the formulary.**
- Home Health Care, which is also not necessarily DME, but the provider expressed that there are large delays in their area.

# MEDICAL HOME

- Inconsistent Medical Homes for CYSHCN
- Specialty care centers can be Medical Homes
- Providers who are Medical Homes worry about transition to adult care:

> "If we do find one [an adult, primary care provider for a CYSHCN], we become a huge resource for that primary care MD because they don't understand the patient as well as we do."

# MEDICAL HOME

- Funding limitations prevent Medical Home capacity of some providers

"They [primary care providers] are coming to us for all of the things that they need because they have a money barrier, they [CYSHCN patients] have to come to us anyway, and when we give them PCP things such as flu shots then they don't have any reason to go to them."

- Some providers are unsure how to treat complex medical issues

"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…"

# WHAT DO PROVIDERS NEED TO PROVIDE MEDICAL HOMES?

"We would need **case managers** that are skilled and know how to navigate through all of the systems that serve children with special health care needs."

"Some concern about **burnout of nurse case managers** because they see so many patients and have to be in three places at once. Sometimes their jobs are also thankless and the "glory" goes to MDs for helping children."

"**Clinical nurse case managers** are necessary; we need someone to be very responsive like that."

# TRANSITION TO ADULT CARE

- NOT ENOUGH ADULT PROVIDERS for SHCN:

"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."

"Children are living for longer with complex diseases; when they show up at adult hospitals, they don't know how to treat them because these kids have historically been treated only at children's hospitals."

- Cost of living prevents patients from being near children's hospitals that do good transition work:

"The cost of living in big cities is prohibitive so these complex patients are moving farther and farther from adequate children's hospitals—so even if we could provide transition help, they aren't close enough to help them."

# TRANSITION TO ADULT CARE

*Providers also noted that lack of adequate transition could contributing to…*

- Fatalities:

"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."

- Disruption in continuity of care:

"[We] did a study in 2008 of children in [redacted county name] that aged out, had access to their records. Almost all of them continued in Medi-Cal, but almost half of them lost continuity of their specialists and maintained their CCS eligible conditions."

# SUGGESTIONS TO IMPROVE TRANSITION CARE

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."

# CARE COORDINATION

Capacity (time + resources) need by providers/practices to provide care coordination…

- Time
- Care coordination built into EHR
- Dedicated reimbursement & funding to implement
- Systems need to be allowed to share info
- Better communication/coordination between providers
- Covered transportation costs (for families)
- Family engagement (esp. low-income families)

"If it was reimbursed that would be helpful, we could dedicate entire appointments to it."

"Who would be driving it? We are all doing that on an individual basis and there are pieces of this that are happening, but they don't exist in one document—it is all largely fragmented. And we're already doing that outside of our clinical time."

# MENTAL & BEHAVIORAL HEALTH

Mental & Behavioral health needs are a huge priority for providers, and they speak about it with them often:

"All of the time. Every day. For both of these things and there are so many barriers. Access is one of the primary issues. We have a place they can go within our hospital, but there is a wait list and sometimes they have to wait 5-6 months and we don't have many other places to send them."

<u>Main Barriers:</u>

- CCS does not cover MH or BH care for other family members (esp. undocumented)
- Most MH & BH services are inundated and inaccessible
- Provider capacity (time + resources)
- Providers have to use workarounds to get family support:

"If we felt there was something glaring, we could refer to the family support program here under the kid's name, but they would know it was because of the parents. They give the parents a couple of calls, if they don't call back that is the end, or if they do call back then they get phone numbers to call and that is as far as it would go."

# MENTAL & BEHAVIORAL HEALTH

The primary suggestion to improve access to MH & BH is for CCS to bolster these services:

"In theory, CCS is supposed to cover all of the mental and behavioral health issues associated with their CCS condition. Does this happen? It is unclear."

"This would be a good area of expansion for CCS, a cadre of CCS psychologists would make a huge difference. It wouldn't be helpful to link it to the disease, they would just have to qualify based on being in CCS."

# FAMILY CAPACITY

In order to address family capacity, it is important to consider the following:

- Provider capacity is effected by families unmet needs
- Social needs screening can be helpful (if referral resources exist)
- Billing for services to address social needs is complicated
- Social workers have a key role/potential for partnership

"[Family capacity is addressed] when you have a family actively involved in child's care, which is so much easier to help the child. It is so much easier. When you have one that misses every apt and it take 4-5 calls to get them there, your time and effort is expended on that."

"There has been very little institutional education on how to bill for social needs, and then on top of that there is turnover in departments. Also financially, don't know how we would fund this work."

"There is an underrepresentation of what I think social workers should be in pediatric clinics, limited by the CCS structure and how they can't bill for social needs. This could and should be a part of the comprehensive visits. This is not an easy thing to fix because the knowledge base is so low, they need to bring in the counties and build knowledge base and capacity for what we can do to improve."

# NAVIGATING CCS FOR FAMILIES

*How often do families utilize you as a provider to navigate CCS?*

"All of the time."

"All of the time. One hundred percent of the time. Some specialists have the messaging to go back to primary care provider."

"Often."

# BIGGEST ISSUES WITH CCS

"Why does it even end at 21? Or figure out how to make transition services smoother. It doesn't make sense to put 21 years into taking care of these children and then to just have them drop off the cliff at the end."

The age limit of 21

Provider inability to bill outside CCS range of treatments

"I would like to see CCS acknowledge us, other than the designation as a CCS provider—we are spending a lot of time and energy making sure that they are taken care of for things that are beyond their CCS condition and they make it impossible for us to get authorization to reimburse for treatments and equipment that aren't in the CCS condition, specifically."

"Pay the provider to do the home visit that may make it easier for the families."

# BIGGEST ISSUES WITH CCS

"Educating outside pharmacies on how to bill CCS for medications, they won't give to the family if they can't bill or will stick the family with a co-pay."

"Kaiser seems to maybe make it a requirement for employees to get their insurance, low income families get stuck between CCS and Kaiser—stuck with a huge bill, and scared to pay Kaiser."

Dysfunctional partnerships (esp. Kaiser)

"Fire Kaiser, there is a problem with the Medi-Cal managed care population for Kaiser. The Kaiser system provides substandard care according to patients."

"Denial of CCS patients that have Kaiser [NOT Kaiser Medi-Cal, Kaiser Medi-Cal will cover CCS], if you have Kaiser you are not eligible for CCS—but they don't provide that same kind of care. Kaiser kids can see us, but can't bill for CCS."

# BIGGEST ISSUES WITH CCS

"Other than not doing WCM, would like to see the letters updated"

"Reinstate CCS, stop the WCM pilot! It has not been good. There have been delays in medications, in labs; it is a bigger problem over time. Everyone at CCS agrees with me. Even in LA, it isn't easy down there. I would bet if they crunched the numbers, they aren't saving money."

"I'd want there to be a philosophy and actual, tangible experts that want us to succeed as a CCS center and to come out, not as police, but to support the work that we do and help to champion us. If they are really invested, the relationship should be mutual. A supportive champion that can help internally or externally."

"If there is a standard that we can reference, rather than a webinar that is lengthy. But if all else fails having a champion that I can ask about things I don't know."

# SUGGESTIONS TO IMPROVE CCS IN THE NEXT 5 YEARS

- Increase # of nurse case managers
- Re-consider services being lost to WCM
- Better coordination between CCS & Regional Centers
- Audit the quality of MTUs
- Build trainings into EPIC workflows across subspecialties
- Final comments…

"Overall, we do like CCS and don't want it to go away."

"CCS is great in its flexibility with contracting, this would not have been possible on Medi-Cal Managed Care."

# CCS PROVIDER SURVEY RESULTS SUMMARY

# PROVIDER SURVEY INFORMATION

- Developed with the assistance of the CCS Stakeholder Provide Survey Workgroup
- Informed by information collected from Key Informant Interviews and Provider focus groups
- Launched on June 19, 2019
- Available online via Survey Monkey
- Worked with Children's Specialty Care Coalitions, Children's Hospital Associations, CCS Stakeholders, County CCS Administrators and WCM Health Plans to distribute link and promote participation
- Total number of participants: 188
  - not all participants answered every question

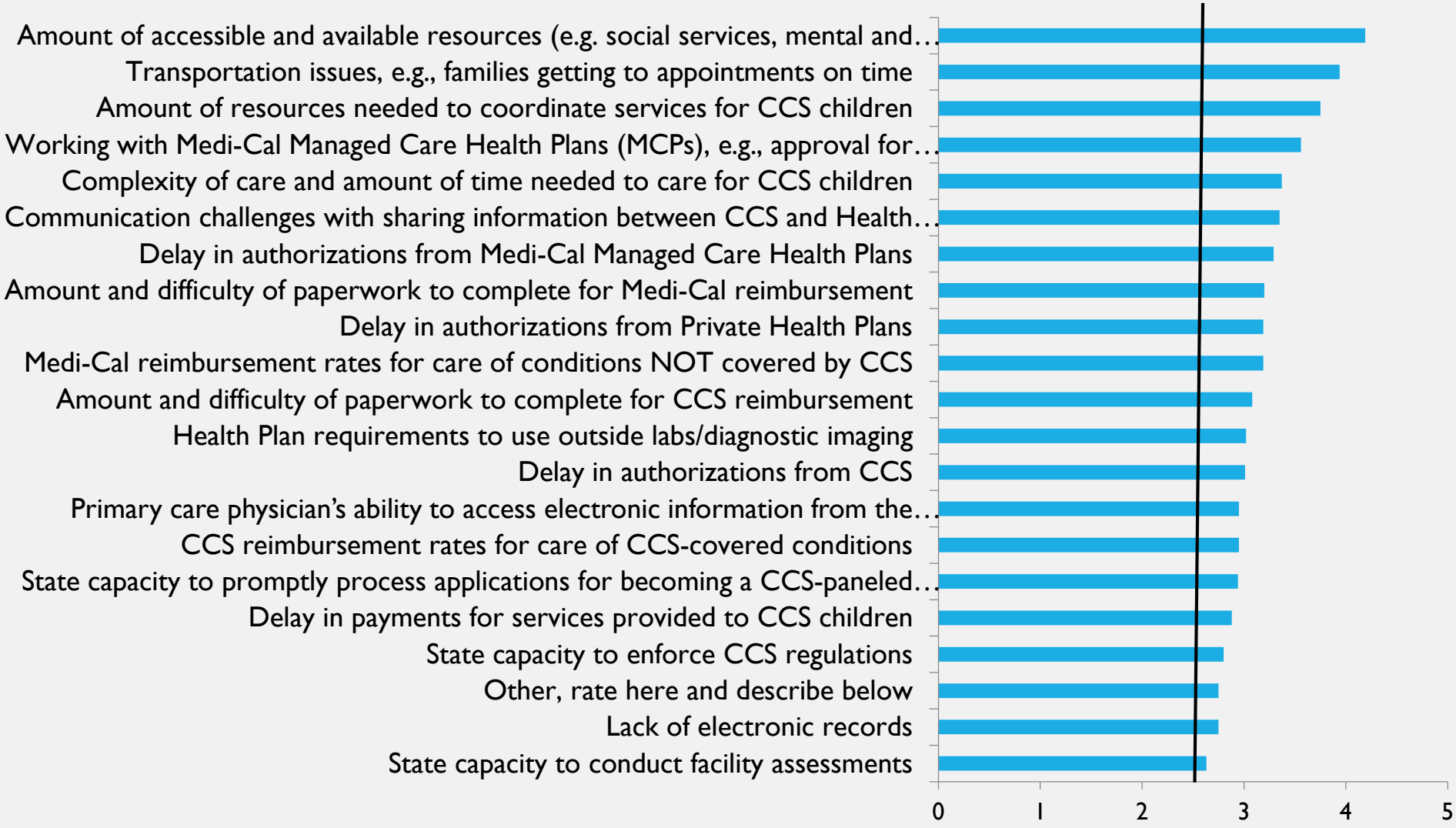
# PROVIDER SURVEY RESPONDENTS

- Includes Pediatricians and Pediatric Subspecialists; Nurses and Nurse Practitioners; Physical, Occupational and Speech Therapists; Social Workers, and Others (Dieticians, Case Managers, Therapy Assistants)
- 50% are currently CCS Paneled

| Practice Setting | |
|---|---|
| Tertiary Medical Center (Non-Kaiser) | 9.20% |
| Children's Hospital | 21.26% |
| Kaiser Tertiary Medical Center | 10.92% |
| Stand-alone specialty clinic | 8.05% |
| Primary care practice (private) | 2.87% |
| Primary care practice (public) | 2.87% |
| Federally Qualified Health Center (FQHC) | 7.47% |
| Other* (please specify) | 53.45% |

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

# BARRIERS TO PROVIDING HIGH QUALITY CARE TO CCS CLIENTS (0 = NOT A BARRIER,5 = SIGNIFICANT BARRIER)



# WHAT IS NEEDED FROM SYSTEM TO PROVIDE BEST QUALITY CARE TO CCS PATIENTS

Open-ended question with 139 responses. Key themes:

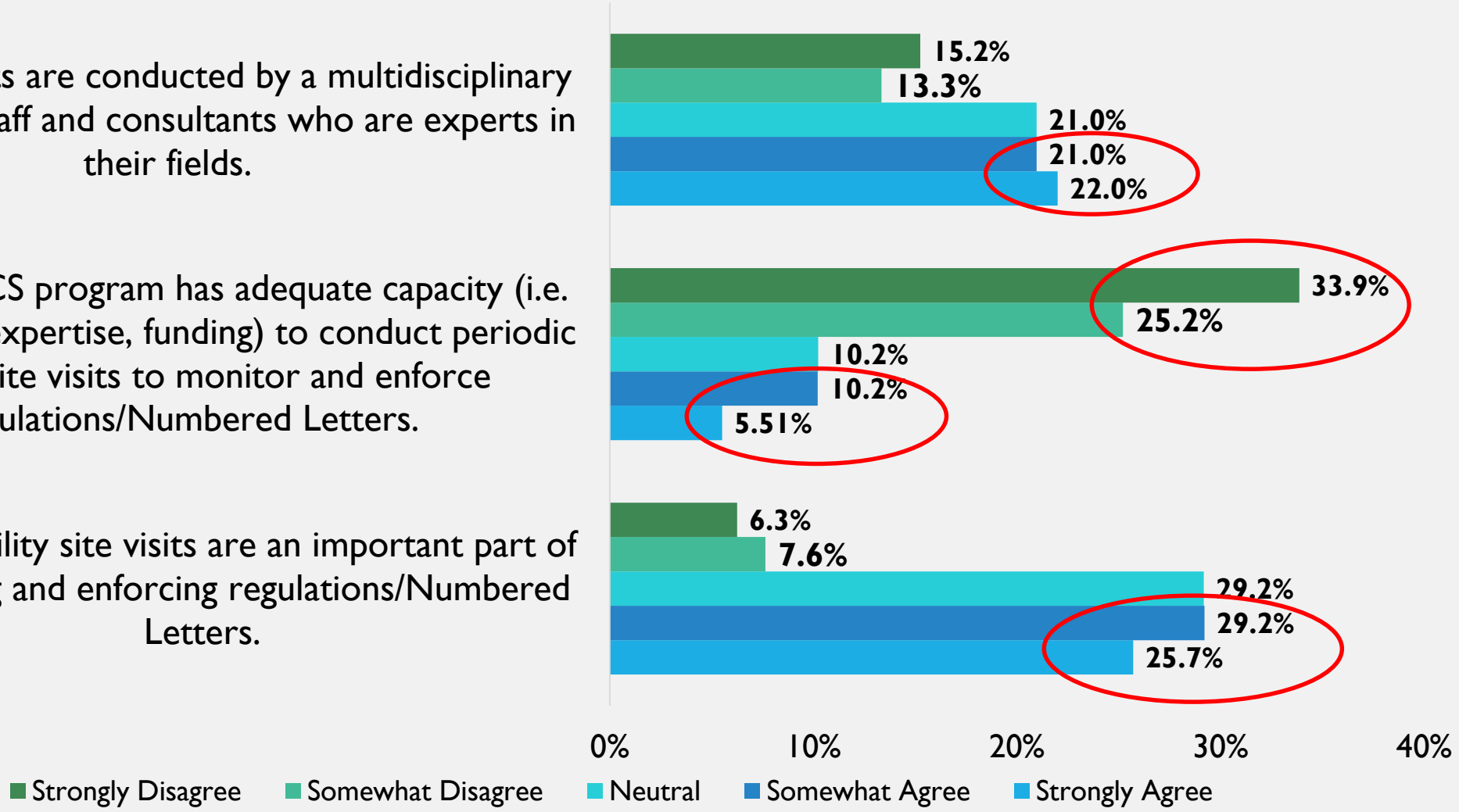
- **Better reimbursement** for providers, including DME providers
- **Increase number of providers**, including specialists and therapists
- **EMR system** for more efficiency between care providers, CCS **patient portal** for families
- **Better access** to behavioral health providers, social workers, and counseling
- **More support staff** to help with care coordination and case management and reimbursement for providing
- **Efficient and quick authorizations** for medications, procedures, & DME and transparent and consistent policies across counties
- Better **coordination between Medi-Cal and CCS** databases and authorizations
- **Recognize nurse practitioners** and **physician assistants** and allow them to prescribe and be reimbursed for time
- Easier ability to **communicate with Medi-Cal** representatives regarding coverage, authorizations, etc.
- Improve **transportations issues** for families to get to appointments

# CCS STANDARDS AND ENFORCEMENT

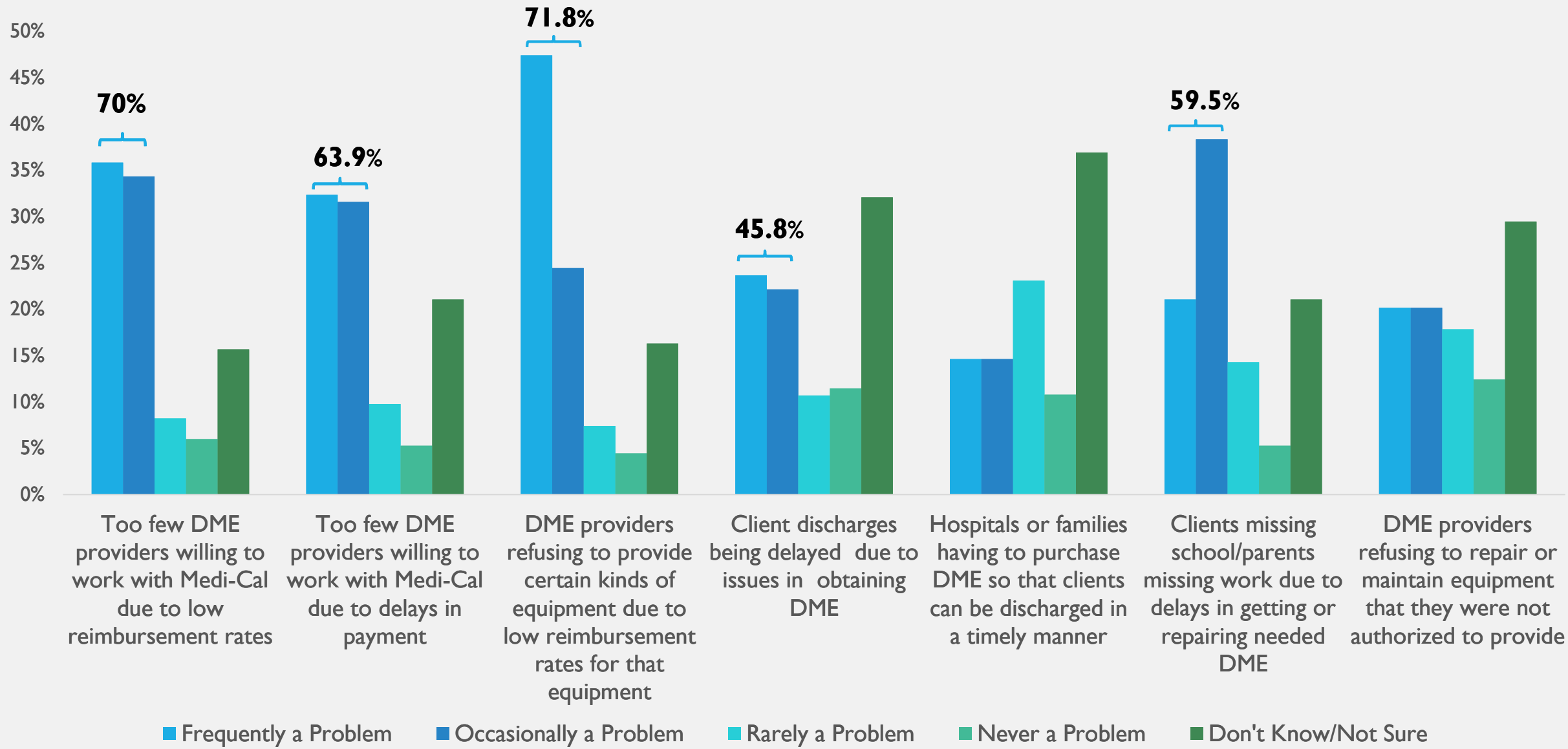
Facility site visits are conducted by a multidisciplinary team of state staff and consultants who are experts in their fields.

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.



# HOW OFTEN ISSUES RELATED TO DME PRESENT PROBLEMS FOR YOUR PATIENTS - SURVEY



# COMMENTS REGARDING DME FROM PROVIDER SURVEY

CCS DME has been terrible and getting worse. Getting Auths is an utter waste to time and the patients don't get what they need for their diabetes

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.

If the child has private health coverage and CCS, this usually causes extensive delays and the families often have to rely on assistance from payers of last resort such as regional centers

# MEDICAL HOME – SURVEY RESULTS*

- 48.8% Consider their practice to be a medical home for CYSHCN based on AAP definition of medical home
- 28% 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

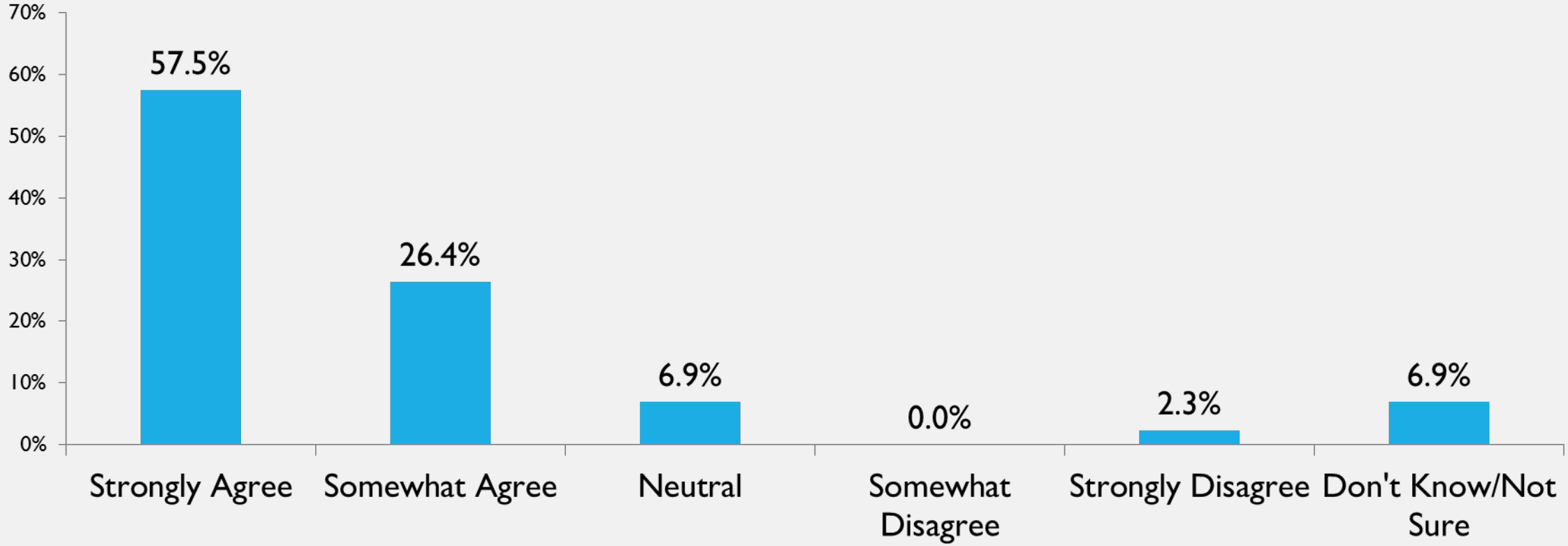
**Note: For medical home questions, survey results include only physicians and nurses*

# MEDICAL HOME – SURVEY FINDINGS

| **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% |

# MEDICAL HOME – SURVEY RESULTS

It would be helpful if Medi-Cal Managed Care Health Plans funded pediatric practices that care for CYSHCN to become certified medical homes, and provided additional reimbursements to cover the costs of the additional staff and services required to be a medical home.



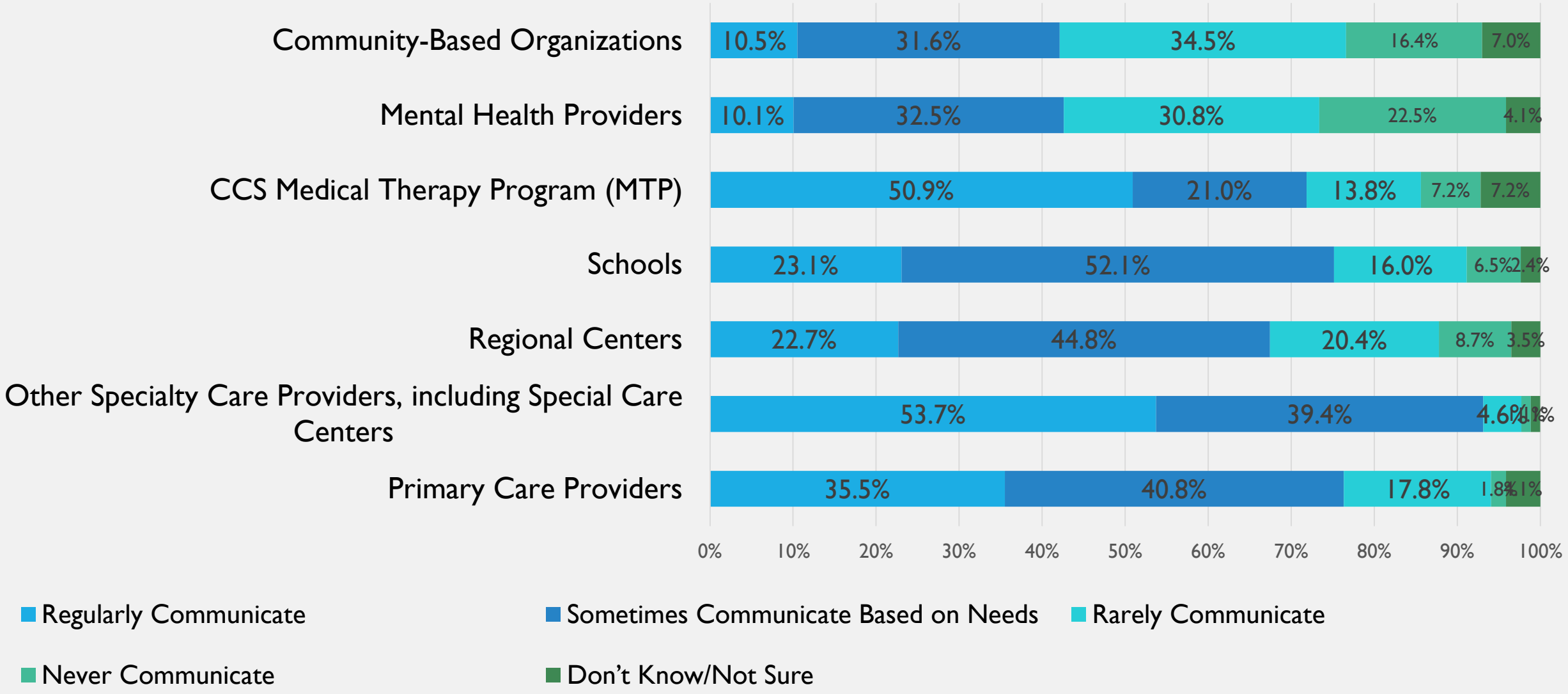
# MEDICAL HOME COMMENTS – SURVEY RESULTS

1/3 if my practice is complex CCS eligible patients the **current reimbursement model penalizes me for longer appointments** which are necessary for appropriate quality care. There **is no reimbursement for the extra time spent with these patients for case management and coordination of care**. Some patients see 4-8 specialists and frequently each of those specialists are assigning tasks to be completed at the primary care level so reports need to be carefully read and execute the request. My care allows many of these dailies to remain in the community and also out of the hospital as much as possible. There should be a productivity model that provides some reimbursement for the complexity of the care.

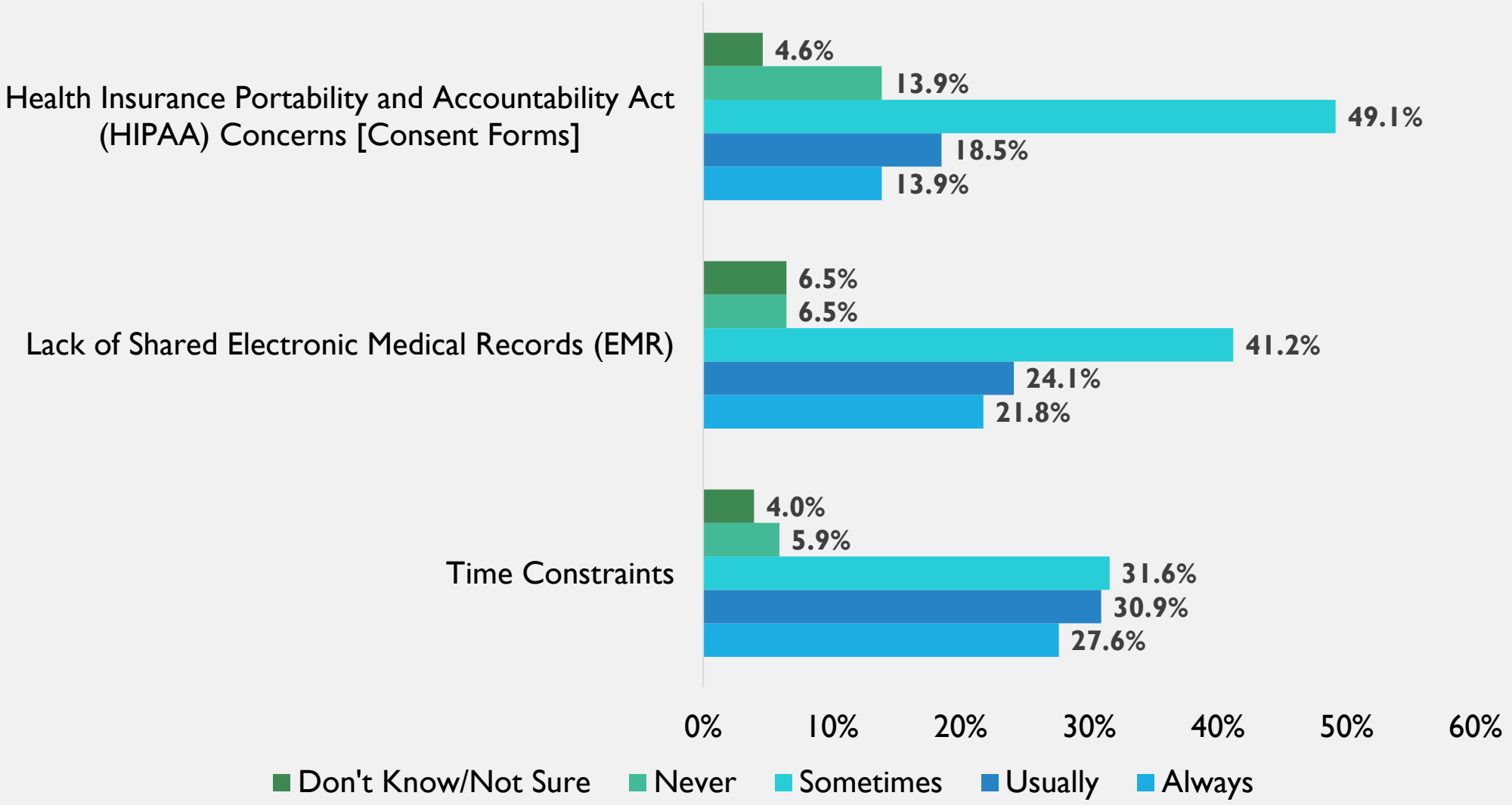
*~Nurse Practitioner*

Kaiser a whole if you are referring to both primary care and specialty is quite integrated and if in combination with pediatrician and our pediatric specialty group then we can meet the definition of a medical home.

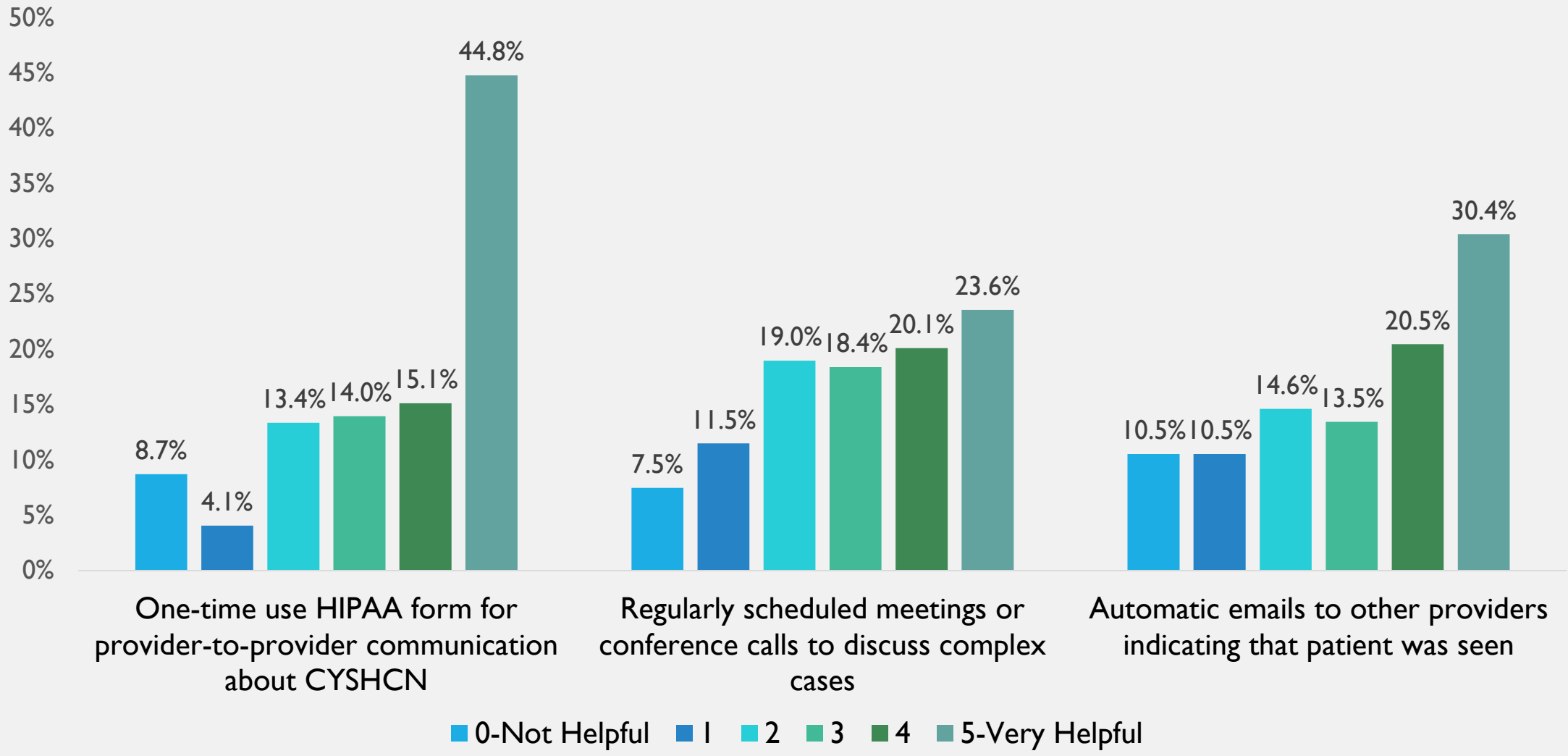
# COMMUNICATION WITH OTHERS SERVING CCS POPULATION – SURVEY RESULTS



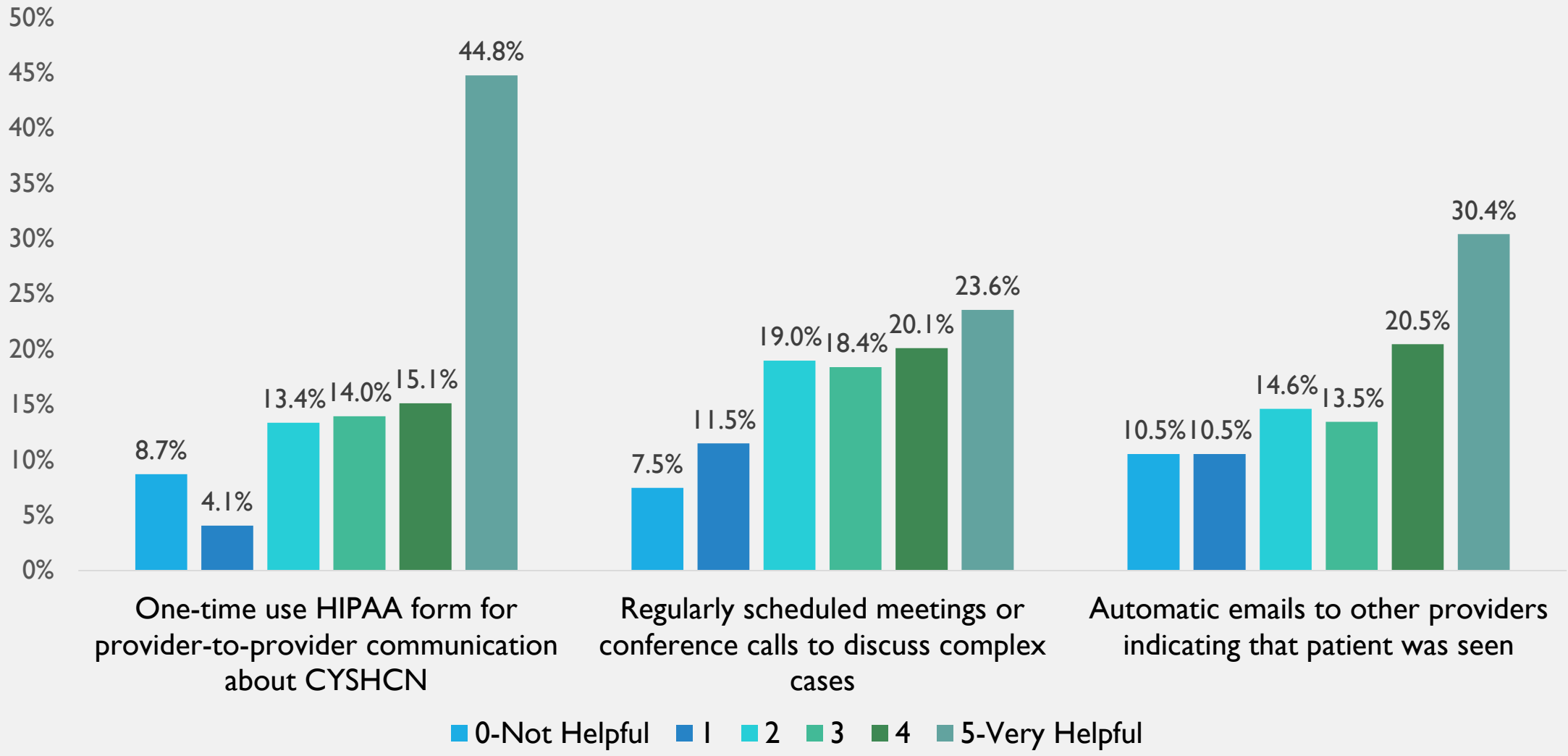
# BARRIERS TO COMMUNICATION – SURVEY RESULTS



# STRATEGIES TO IMPROVE COMMUNICATION – SURVEY RESULTS



# STRATEGIES TO IMPROVE COMMUNICATION – SURVEY RESULTS



# CARE COORDINATION – SURVEY RESULTS

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

Key themes & 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."

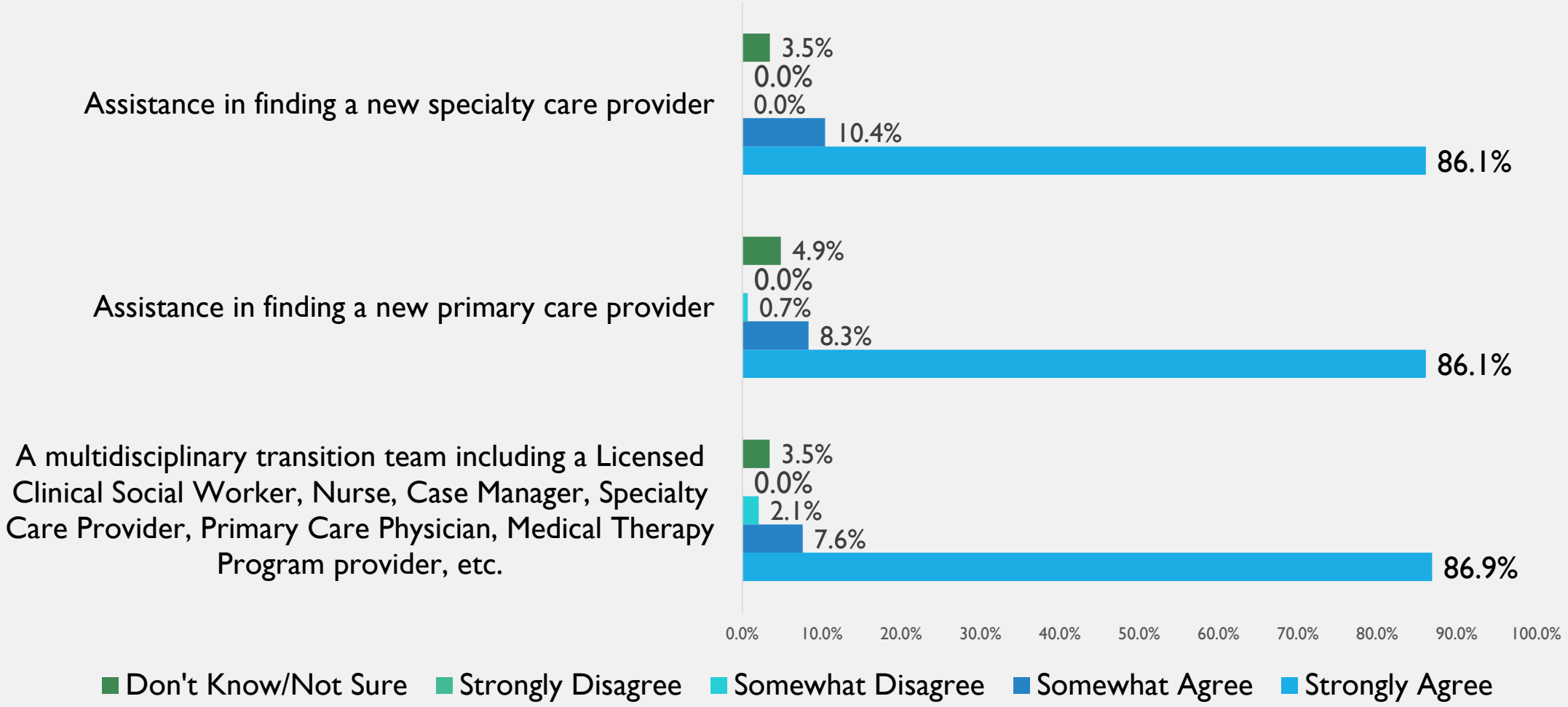
# CARE COORDINATION – SURVEY RESULTS

| 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% |

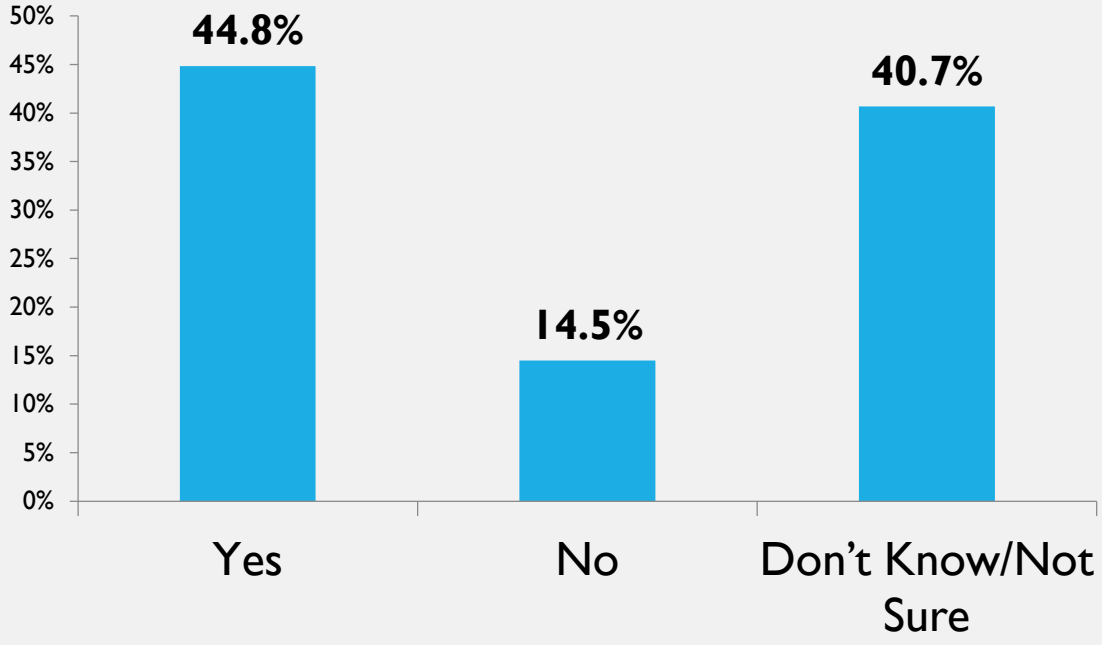
# STRATEGIES TO IMPROVE TRANSITION – SURVEY RESULTS

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



# EXTENDING CCS ELIGIBILITY – SURVEY RESULTS

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?



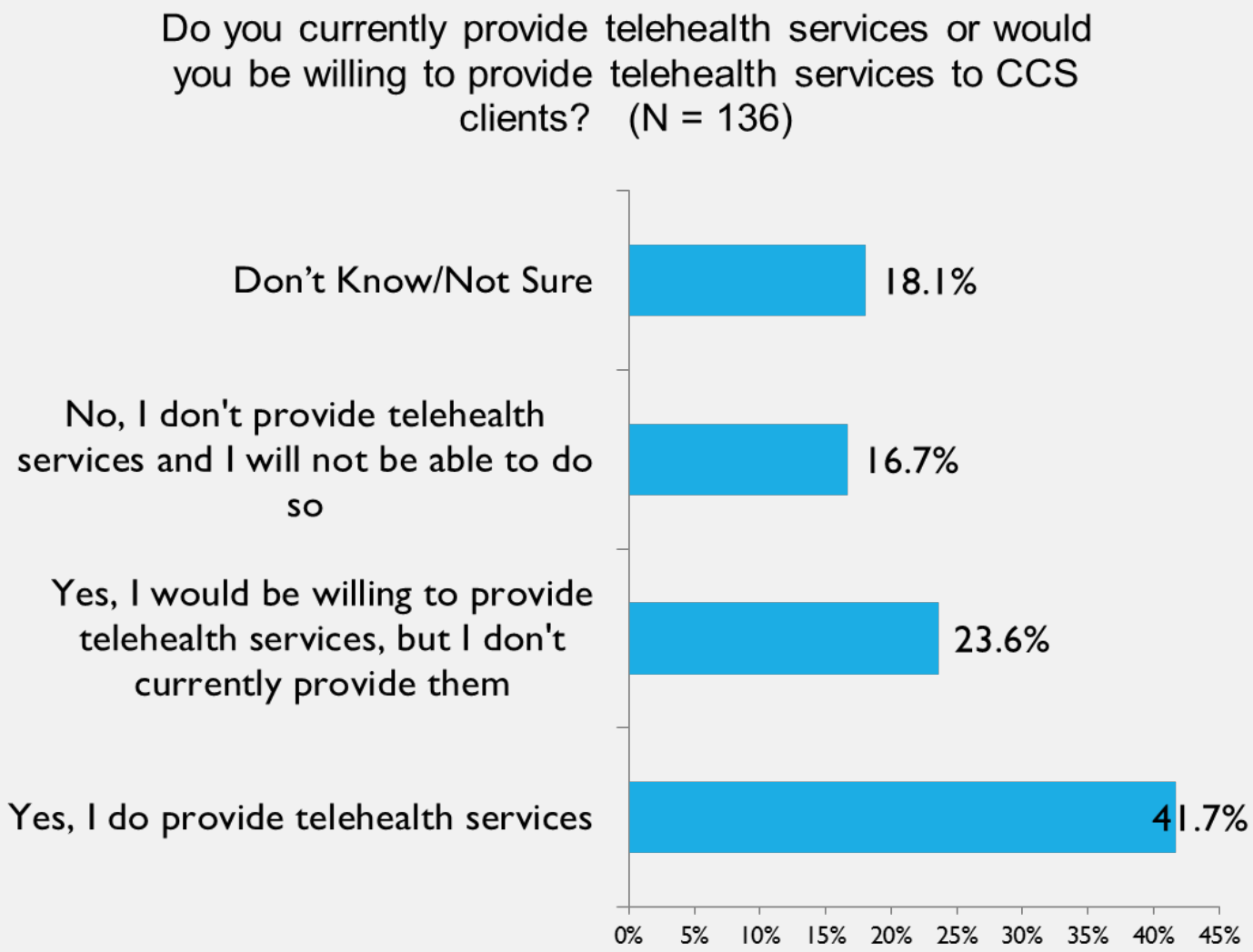

N = 145

Which CCS conditions should be extended to 65 years old? (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."

# TELEHEALTH – SURVEY RESULTS




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"

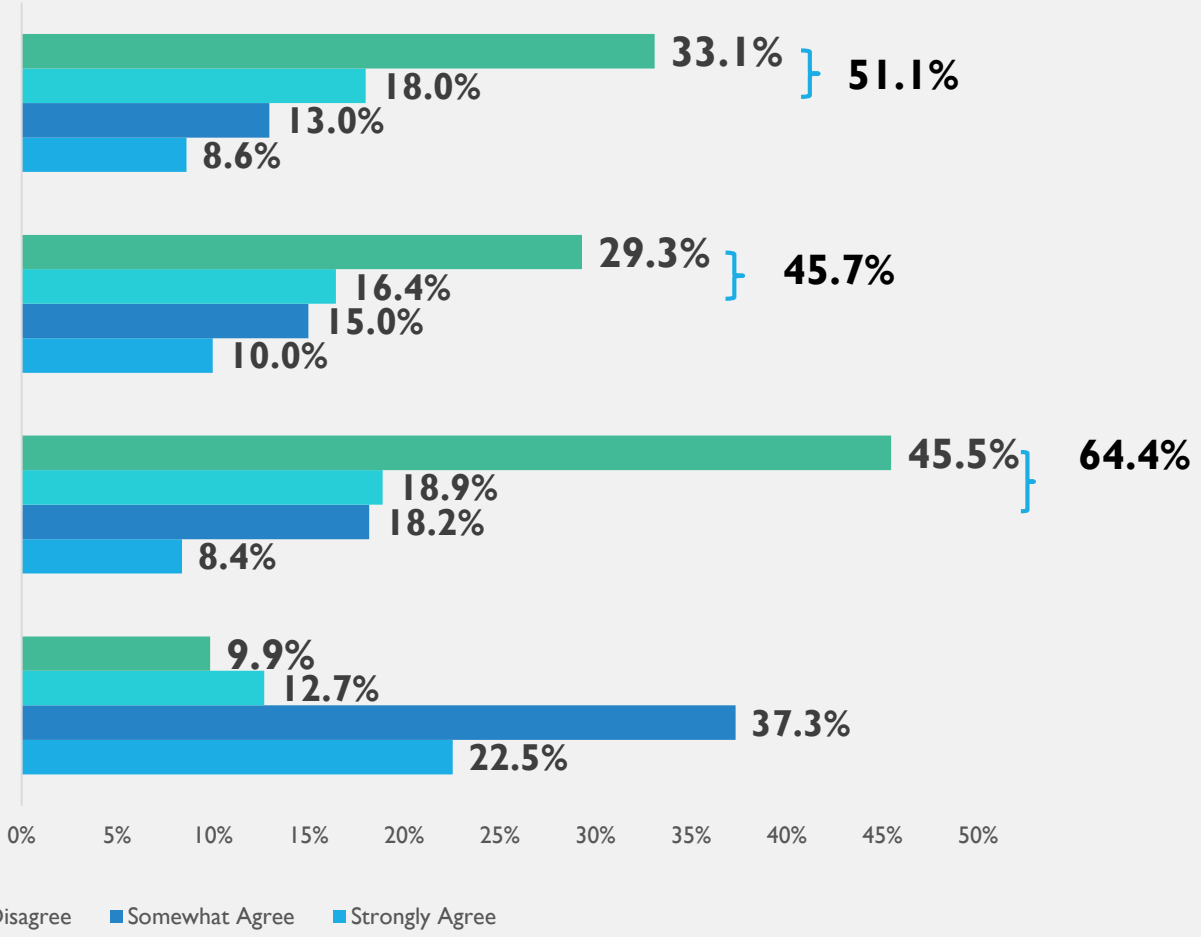
# ACCESS TO MENTAL HEALTH AND TRANSPORTATION

CYSHCN with Medi-Cal Managed Care Health Plans have adequate access to mental and behavioral health care.

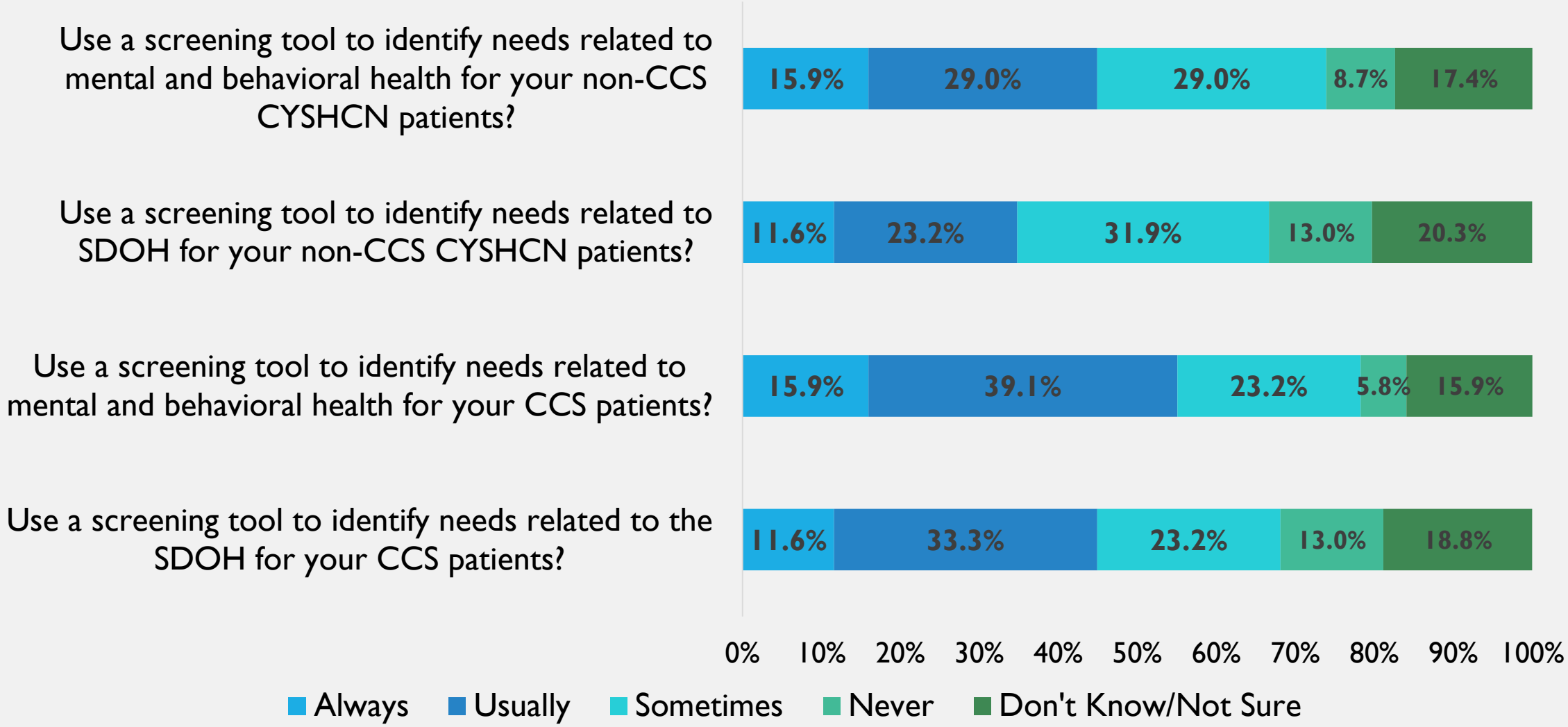
Non-CCS CYSHCN with private insurance have adequate access to mental and behavioral health care.

CCS children have adequate access to mental and behavioral health care.

Medi-Cal will cover the cost of transportation to and from appointments for your CCS and Medi-Cal patients.

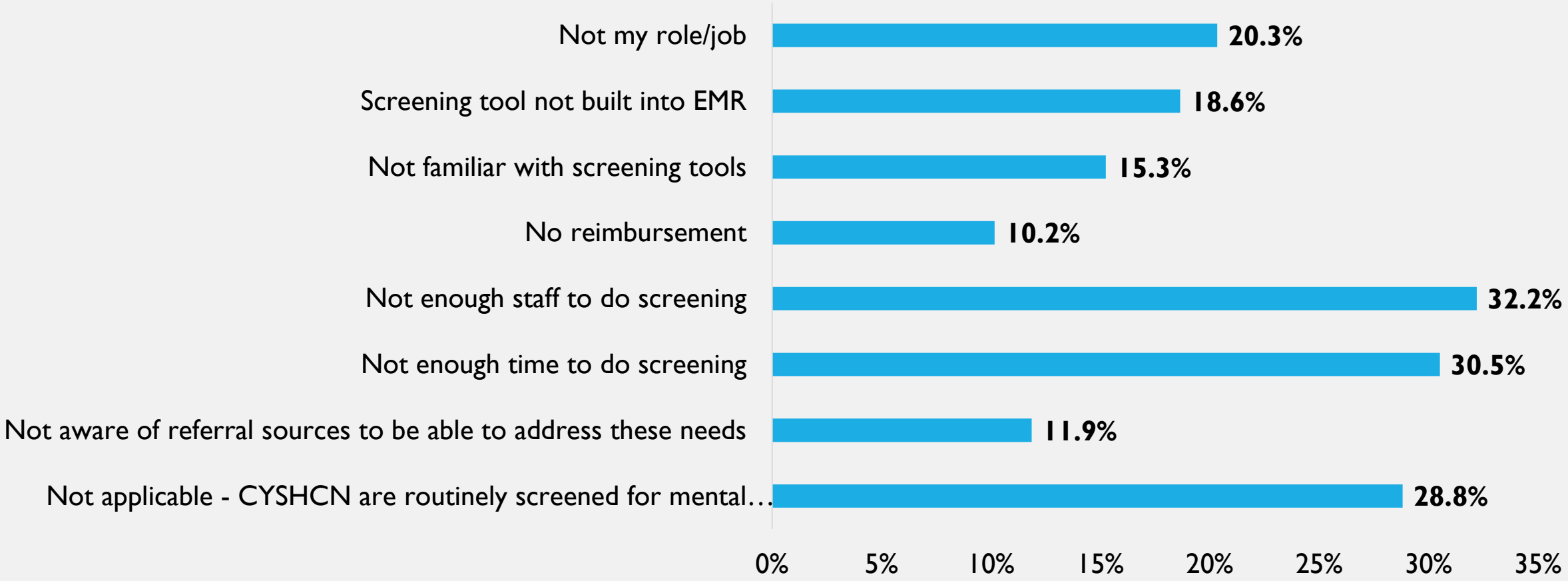


# MENTAL HEALTH AND SOCIAL DETERMINANTS OF HEALTH (SDOH) SCREENING – SURVEY RESULTS



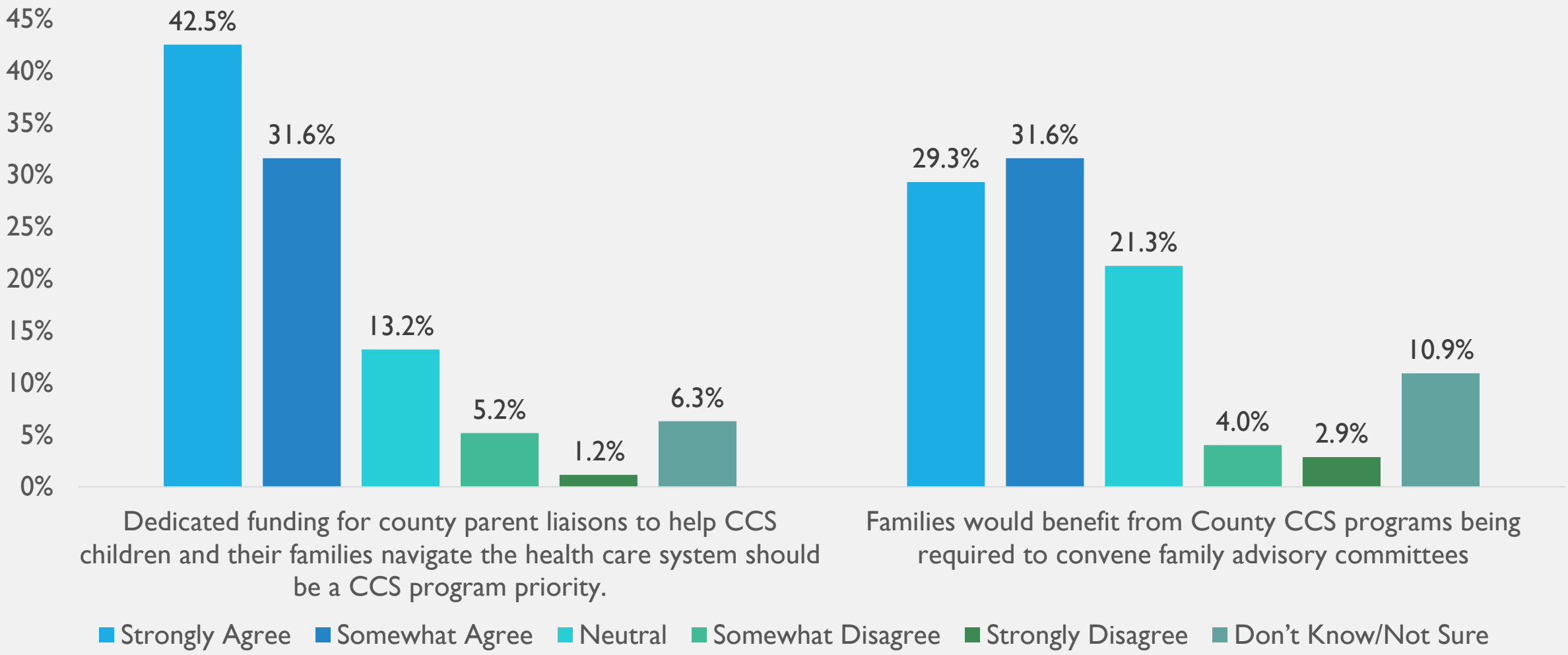

**Note: Survey results only include nurses and physicians*

# REASONS FOR NOT SCREENING FOR MENTAL HEALTH OR SDOH




*Note: Survey results only include nurses and physicians

# FAMILY NAVIGATION AND FAMILY ADVISORY COMMITTEES – SURVEY RESULTS



# WELL CHILD VISITS*

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

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

# CCS PRIORITIES FOR NEXT 5 YEARS – SURVEY RESULTS

Providers were asked to list their top 3 priorities for CCS for next 5 year (open-ended) (N = 97)

**Increase reimbursements/funding**

- Increase reimbursement rates for providers
- Increase reimbursement for home/DME/community services
- Increase DME vendors, improve access to DME
- Increase reimbursement for PCP visits
- Adequate funding to provide best care, closest to home for all

**DME**

- Improve access to DME
- Increase reimbursement for DME
- increase DME vendors

**Address social needs**

- Increase funding for social needs
- Increase staffing of social workers to meet outside resources needs
- Financially incentivize institutions and practices to have social services

**Mental Health**

- Improve access to mental health services
- Integrate behavioral and mental health services
- Incorporate research on social determinants of health & adverse childhood experiences into proactive program
- financially incentivize child mental health providers

**Authorizations**

- Improve timeliness of authorizations
- Enough staff to be able timely process authorizations

**Patient centered Care and Family engagement**

- Improve patient centered care
- Improve and increase care coordination
- Support home visits for MTU services for medically fragile children
- Involve families in decision making and incorporate family support networks
- Encourage more family engagement
- Help families navigate Medi-Cal/CCS and pharmacies
- Make the system less confusing to families

# CCS PRIORITIES FOR NEXT 5 YEARS – SURVEY RESULTS (CONT.)

**Patient centered Care and Family engagement (cont.)**

- Help families navigate Medi-Cal/CCS and pharmacies
- Make the system less confusing to families

**Communication and Technology**

- Improve communication between provider and agents for CCS and WCM Health Plans
- Improve communication between state and county CCS offices
- Improve ability of MTUs to communicate with specialists regarding clients' needs
- Electronic record sharing
- Improve electronic communication – 'Get rid of paper'
- Increase access to telehealth and tele-monitoring (e-consult and Project ECHO)
- Streamline process so pharmacy can see if medication/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 = smother transfer of cases between counties
- Better database and organizational tools

**Whole Child Model**

- Evaluating WCM
- ensuring that Managed Care Plans Provide adequate services similar to fee for service
- maintain and expand CCS services and standards in WCM counties
- return of case management to county CCS programs

**Eligibility**

- Extend CCS coverage past age 21
- Extend CCS to cover more conditions
- Adapt income eligibility to current economic reality

**Improve Access to Services**

- Increase number of CCS providers
- Expanded specialty networks

# CCS PRIORITIES FOR NEXT 5 YEARS – SURVEY RESULTS (CONT.)

**Medical Home**

- Increase support for primary care driven complex care programs (medical homes for children with medical complexity)
- Develop medical home model

**Standards, Quality Improvement & outcomes**

- Update standards
- Quality improvements
- common outcome measures
- Align program guidelines with current practice regulations
- incorporate current evidence-based best practices
- some 'futile' treatments that have not outcome benefits are being made CCS benefits
- Enforcement of CCS paneling requirements by state and Medi-cal Managed Care Plans
- Track services and outcomes in the current system before changing it

**Workforce/Staffing**

- Increase staffing of therapists at MTU
- Improve/increase care coordination (increase number of NPs providing CCS case management in primary and tertiary care clinics)
- Increase staffing at state and county levels
- Have county based care coordinators and case managers)
- Better support at state (physician leadership)
- Increase number of CCS providers
- Expanded specialty networks
- Educate pediatrician on caring for CYSHCN
- Recognize nurse practitioners as CCS providers
- Use a team based approach for specialty care

**Transition**

- Improve transition, resources for transiting youth
- Improve transition from NICU to home

# PROVIDER COMMENTS REGARDING PRIORITIES

- The transportation services have been unreliable creating major obstacles for our CCS patients to receive care. Arranging transportation is not an efficient use of our nurses time
- In our county we are pleased Managed Medi-Cal has taken over case management from local CCS office as it seems thus far much more patient centered.
- The State needs to decide who is going to administer the program, the state/counties or managed care plans. Having both is causing confusion, delays and decreased client/family satisfaction. If it was confusing for families in the past, having certain medical conditions carved out of their managed care plans or Medi-CAL, then its even more confusing to have certain medical conditions carved out and split responsibilities of who is making the determinations and who is providing authorizations, etc and then for the procedures to be different from county to county from managed care plan to managed care plan without consistency. This is a big disservice to children and families that are already disadvantaged, dealing with more stressors, trying to navigate through the health care industry. How does it make sense with providing continuity of care when there is not a shared system such as CMSNet throughout the State? Or when provider access has barriers because qualified approved providers don't have working contracts with individual managed care plans? A State-wide program should be run state-wide. A child can be managed in a Whole Child model well in either arena, CCS vs MCP but not split between the two. CCS is where the specialists are; the specialty providers, the Medical Therapist, the Nurse Case Managers with a minimum of a Bachelors Nursing degree and Public Health Certification. Who would you want your child seen by?

# PROVIDER COMMENTS REGARDING PRIORITIES

- CCS needs to expand the whole child model, as well as expect that model to continue after age 21; and Medi-Cal needs to fund this coordination of care past 21 for these kids with complex needs because the conditions don't generally go away.
- Many families are being forced to take high-deductible plans if they are not eligible for MediCal - Some of these plans are HMOs which disqualify the family from CCS services making it financial impossible to pay for medications, labs, etc.
- The budgetary cuts to the county CCS programs were not well thought out and caused a severe "brain drain" to this complex program statewide. I have doubts about the justification and rationale behind the WCM Redesign.
- The CCS program has an excellent model for providing medical services for our clients. Improved funding across the state, especially to help oversee statewide documentation (MTU online) seems appropriate and necessary as the current system is outdated and much unnecessary time is spent on documentation due to glitches in the system (information is frequently lost, causing need for repetitive documentation of the same material). Online documentation is a basic necessity in the current healthcare market and it should be a basic standard part of the CCS program (not vary in different Counties throughout the state).
- The CCS program is the best program for infants, children, adolescents, and young adults with complex, lifelong medical condition in the U.S. This is why families from other states and country move to California. We must do everything that we can to ensure the viability of this program that impacts the quality of life for so many children.

# QUESTIONS?

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