MCHB Outcome #2: Children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home.

Medical Home

From the National CSHCN Survey 2009/2010[i]

The National Survey of CSHCN implements the America Academy of Pediatrics definition of a medical home – medical care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective and delivered or directed by a well-trained primary care or specialty physician who helps to manage and facilitate essentially all aspects of care for the child. The medical home variable is derived from responses to questions about having a usual source of care, having a personal doctor or nurse, having no problems receiving referrals when needed, and family centered care.

CSHCN who receive coordinated, ongoing, comprehensive care within a medical home:

Outcome **NOT** achieved:

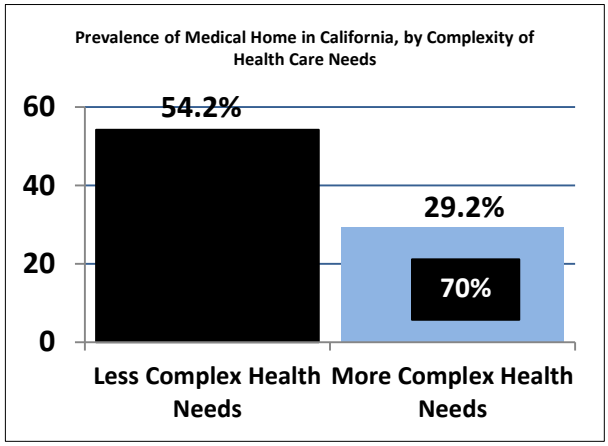
California %	61.7
Nationwide %	57.0

Outcome not achieved by race/ethnicity:

	CA	Nationwide
White, non-Hispanic %	54.7	51.2
Hispanic %	65.1^	66.8**
Black, non-Hispanic %	64.2^	66.5**
Other, non-Hispanic %	68.4^	60.9**

From "Children with Special Health Care Needs: A Profile of Key Issues in California" (Bethell, 2014)
Data Source: 2011/12 National Survey of Children's Health

California State Ranking on Medical Home Overall and Subcomponents	
Overall Medical Home	**44th**
Care Coordination	46th
Family-Centered Care	44th
Problems Accessing Needed Referrals	50th

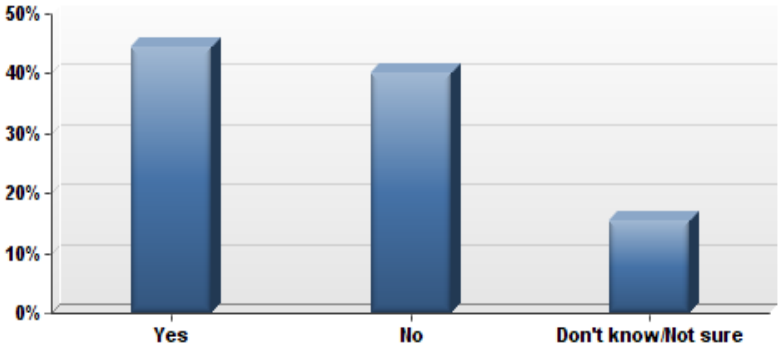


* Difference between CA and Nation significant at $p < .05$
** Differences within the Nation significant at $p < .05$
^ Difference within the State significant at $p < .05$

Who Provides a Medical Home

From the FHOP Survey of CCS Physicians 2014

Do you consider your practice a medical home for your CCS clients?



Medical Home by Practice Site	Yes %	No %	Don't know/Not sure %	Total N
Tertiary Medical Center (Non-Kaiser)	39	42	19	69
Kaiser Tertiary Medical Center	100	0	0	1
Stand alone specialty clinic	50	50	0	4
Primary care practice (private)	60	20	20	10
Primary care practice (public)	100	0	0	1
Federally Qualified Health Center (FQHC)	55	45	0	11
Other	0	100	0	1
Total	44	40	15	97

Role in CCS by do you consider your practice to be a medical home	Yes	No	Don't know/Not sure	Total
Neonatalogist	7	5	1	13
Neurologist	0	1	0	1
Otolaryngologist	0	1	0	1
Pediatrician	13	6	4	23
Pediatric Cardiologist	4	2	3	9
Pediatric Critical Care Physician	1	4	0	5
Pediatric Endocrinologist	0	1	1	2
Pediatric Gastroenterologist	1	2	0	3
Pediatric Hematologist	5	0	0	5
Pediatric Infectious Disease Physician	2	0	1	3
Pediatric Nephrologist	0	1	1	2
Pediatric Neurologist	1	5	1	7
Pediatric Oncologist	2	3	1	6
Pediatric Pulmonologist	2	1	1	4
Pediatric Surgeon	1	1	0	2
Psychiatrist	0	1	0	1
Other	4	5	1	10
Total	43	39	15	97

* Difference between CA and Nation significant at $p < .05$
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FHOP Key Informant Interviews 2014

- *State should provide training, county should have accountability measures, PCP should have responsibility, families don't know what a medical home is, what qualifies it and what a good one looks like and they should be provided this information to have this be a success.*
- *Would be nice if CCS program could define who can be a medical home for CCS kids (e.g., board certified pediatrician as opposed to general practitioner). Anything more complex would be hard.*
- *Role falls to special care centers, but not ideal; not a role that centers want to take on.*

FHOP CCS Administrators Focus Groups 2014

- *FQHC can be a medical home for undocumented, MediCal, Children's, private insurance and…the Kaiser model is built on the idea of a medical home. Challenges lie when collaborating with other agencies outside of the health providers*

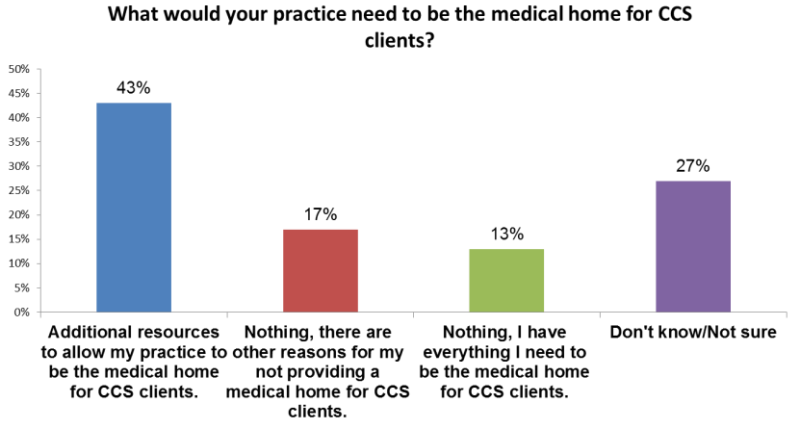
Who should provide a medical home to CCS clients

From the FHOP CCS Administrators/Medical Consultants Survey 2014

Answer – check all that apply	For clients w/ chronic complex conditions	For clients w/ conditions of limited complexity or duration
Pediatric Primary Care Provider	87%	91%
Family Medicine PCP	35%	58%
Federally Qualified Health Centers (FQHCs)	44%	60%
Pediatric Sub-Specialist	43%	25%
Special Care Center	46%	15%
Other	11%	6%
A Community Clinic that is not an FQHC	17%	38%

Barriers to Providing a Medical Home

From the FHOP Survey of CCS Physicians 2014



FHOP Key Informant Interviews 2014

- *Generally speaking, no true adherence to the medical home concept. We are never going to control cost and guarantee quality until we understand the need to do this.*
- *Without it, quality of care erodes.*
- *It is an enormous failing of the current system.*

* Difference between CA and Nation significant at $p < .05$
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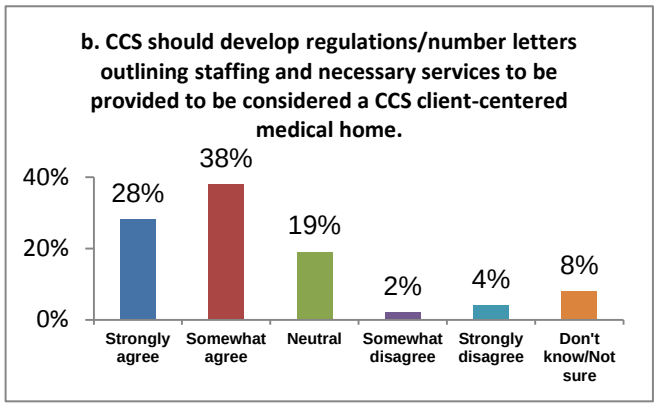
- *If* [we] *try to do this for CCS kids, CCS will be out of business in two years. The idea is unrealistic given the current financing and program structure. Everyone wants to do it, but no one can do the financing.*
- *What CCS-related conditions are appropriate to have their medical home be a general pediatrician?*

FHOP CCS Administrators Focus Groups 2014

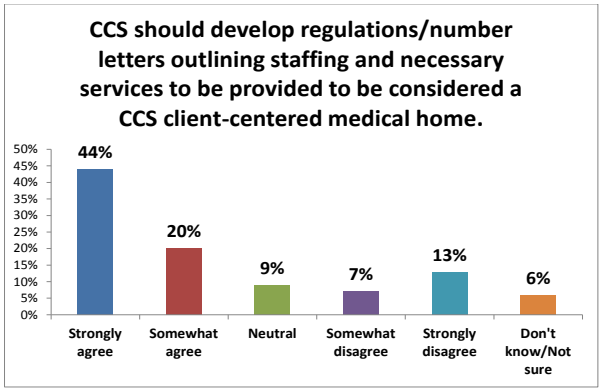
- *Regulations for medical homes requires caring for the whole child.*
- *All CCS clients have a medical home (aka PCP), but probably 90% are not acting as a medical home…but they do what they can to help.*
- *How can you ask a MediCal provider, being paid $20/visit, to manage all of the care? Some do it on their own time. It would require caring for the whole child [and be]…incentivized.*

Medical Home Standards

From the FHOP Survey of CCS Physicians



From the FHOP CCS Administrators/Medical Consultants Survey 2014



Having a Usual Source of Care and Personal Provider

From CMS Net[ii]

In CMS Net, having a medical home is defined as having a primary care provider. California counties vary widely in 2014 in their percentages of CCS children with a medical home, and the pattern is the same as it was in 2010.

- In 33% of counties, 80% or more of their CCS children have medical homes
- In 47% of counties, between 60 to 79% of their CCS children have medical homes
- In 14% of counties, between 40 to 59% of their CCS children have medical homes
- In 5% of counties, between 20 and 39% of their CCS children have medical homes
- In 0% of counties, fewer than 30% of their CCS children have medical homes.

Unmet Needs

Unmet need is a direct measure of access to health care services. Unmet service needs may affect severity of the disease, lead to more urgent care contacts and greater emergency department utilization, and ultimately reduce children's physical and mental well-being.

From the National Survey of CSHCN 2009/2010[i]

CSHCN with no unmet needs for health care services[i]

	2001	2005/2006	2009/2010
California %	76.9	82.5	74.1
Nationwide %	82.3	83.9**	76.4

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CSHCN with no unmet medical needs by race/ethnicity[i]

	White	Black	Hisp	Other
California %	78.1	73.2	69.9	77.0
Nationwide %	79.4	71.5	71.6	73.9

CSHCN with no unmet medical needs, by insurance status[i]

	With Insurance	Without Insurance
California %	75.2	39.1
Nationwide %	77.5	44.3

Percent of CSHCN in California with no unmet medical needs, by medical home[i]

With a medical home	88.9
Without a medical home	64.6

CSHCN whose families have any unmet need for support services[i]

	2009/2010
California %	10.3
Nationwide %	7.2

Provider-to-Provider Communication

From the FHOP Survey of CCS Physicians 2014

Frequency of you/your clinic/practice communicating with other providers who are also serving your CCS Clients

	Regularly	Sometimes based on needs	Rarely	Never	Don't know/Not sure
Primary care providers	56%	36%	5%	1%	2%
Other specialty care provider, including special care centers	56%	37%	4%	0%	3%
Regional centers	23%	37%	29%	7%	4%
Schools	17%	37%	29%	12%	4%
CCS Medical Therapy Program (MTP)	19%	33%	23%	13%	11%
Mental Health Providers	8%	30%	32%	17%	13%
Community-based Organizations	9%	27%	36%	18%	10%

Barriers to providing quality care

From the FHOP Survey of CCS Physicians 2014

Answer (Rate from 0-5, with 5 being a very significant barrier)	Ave.	Std. Dev.	N
f. Amount of resources needed to coordinate services for CCS children	3.6	1.5	94
g. Amount of accessible and available resources (e.g. social services, mental health, respite care) for CCS children and families	3.4	1.5	96
e. Complexity of care needed by CCS children and amount of time needed to care for them	3.4	1.7	93
i. Working with managed care plans (e.g., Approval for services/special tests or procedures, reimbursement process)	3.4	1.5	94
a. Medi-Cal outpatient reimbursement rates for care of conditions NOT covered by CCS	3	1.7	95
d. Amount and difficulty of paper work to complete for reimbursement	2.8	1.6	91
b. CCS reimbursement rates for the care of CCS-covered conditions	2.6	1.6	86
c. Delay in payments for services provided to CCS children	2.5	1.7	89
l. State capacity to quickly process applications to become a CCS paneled providers	2.3	1.6	82
h. Primary care physician's ability to access electronic information from the specialty care providers that are also serving the same CCS children	2.3	1.5	87
m. Anything different from the list above that decreases your ability and willingness to participate in the CCS program (please describe):	2.1	2.1	42
j. State capacity to enforce CCS regulations	2.1	1.6	83
k. State capacity to conduct facility assessments	1.9	1.4	77

* Difference between CA and Nation significant at $p < .05$
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What you need from the system to provide best quality medical care for CCS patients?

Reimbursement/Financial - Provider

- General displeasure with the rates of reimbursement, which has led to challenges in making referrals, for patients to see specialists, and to recruit and retain providers:
- *Better reimbursement for specialists so they will want to take CCS patients and I can make referrals more easily*
- *Because the payments don't match the salaries and benefits of trained, experienced staff, we CONSTANTLY have to look to other sources of funding to keep our staffing*
- *Inadequate reimbursement for physicians which limits access to health care for some patients, and reimbursement for hospital visits and necessary procedures that puts Children's Hospital's at risk financially.*

Reimbursement/Financial - Family

- General desire to see an increase in financial assistance to families seeking care and treatment:
- *Provide transportation to clinics for families with transportation problems.*
- *We subsidize the cost of local apartments to keep the cost to families less than $10/day [when their child is hospitalized] but even that is often beyond the means of some of the families. This can lead to longer hospital stays to be sure the patient is stable enough to go back to home.*

Support and/or Additional Staff/Providers

- *More mental health. More mental health. More mental health.*
- *Support for care navigators...access to social work and psychological services...physician extenders (e.g., nurse practitioners and other advanced practice nurses to perform follow up for complex patients).*
- *Nutritionists*
- *Dentists and orthopedic surgeons*

Patient as the Priority

Providers pushing for the focus to remain on the patient and a faster, more streamlined approval process:

- *[There needs to be a] willingness to put patient care as the first priority.*
- *The systems need to be actually concerned about patient welfare, patient needs, and look beyond stifling regulations.*
- *Less paperwork and faster approval...easier approval for requested services...easier and quicker access to authorizations for tests, etc.*

Coordination

- *CCS and Medi-Cal need to work together to provide comprehensive care for children with complex diagnoses and special needs. There is a lack of coordination and the result is that children are not well served.*
- *Clear guidelines and staff to deal with all the paperwork and coordination.*

Education and Knowledge

- There seems to be a level of confusion and lack of information about the CCS system, regulations, criteria, etc.:
- *It would be helpful to have a simple flowchart explaining the other (non-clinical care) aspects of CCS including the relationship between CCS and the State and CCS and MediCal and who the key personnel are.*

* Difference between CA and Nation significant at $p < .05$
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- *Clearer understanding of CCS regulations, eligibility criteria, covered conditions, medication, and treatments.*
- *Need easily available information about what is covered for CCS patients.*

Eligibility

- Increase/broaden covered diagnosis:
- *Accept more patients with chronic, complex diseases, including genetic disorders not yet specified.*
- *More access to CCS...wider diagnosis covered.*
- *CCS is a "Swiss cheese" program with so many holes in it that many children who need services are deemed "not eligible" and Medi-Cal which is mostly managed care just denies care as a way to keep costs down.*

Transition

- *I would love to see CCS services provide navigation for the first year of patients transferring to adult subspecialty providers. This would go a long way toward preventing drop out and unnecessary morbidity.*
- *Patient support for maintaining insurance into adulthood*

Communication

- *Easier access to the decision makers in each county. often the problem is solved in a simple 2 minute conversation that makes clear the sticking point (either to approve or deny, it's better to be DONE) while getting to that person in power can take weeks of ferreting out the proper phone number*
- *Assistance with the navigation of the CCS provider structure, more time meeting with the key players on a formal and informal basis, perhaps an email listserv type system where providers can problem solve together.*

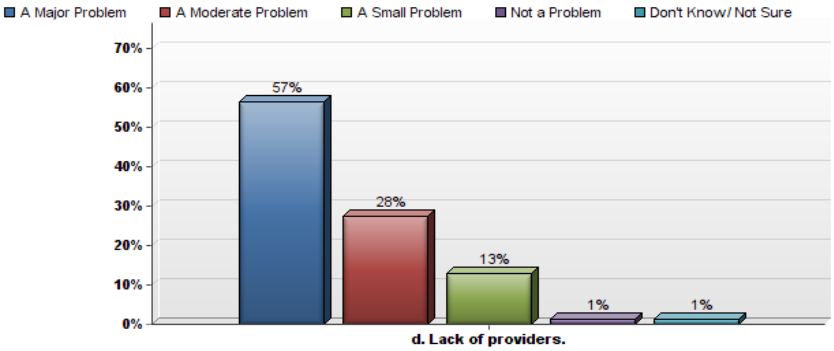
Other Needs

- *Less obstruction by uninformed Medical directors. More assistance with complicated social problems. More cordial interactions.*
- *CCS is very helpful for our patients but there are still barriers to care for complex patients with medical conditions*
- *Less talk, more action.*
- *Managed Medi-Cal programs have imposed huge barriers on access to specialty care.*

Access to Care

From the FHOP CCS Administrators/Medical Consultants Survey 2014

Barriers families may experience in seeking care for their child – Lack of providers



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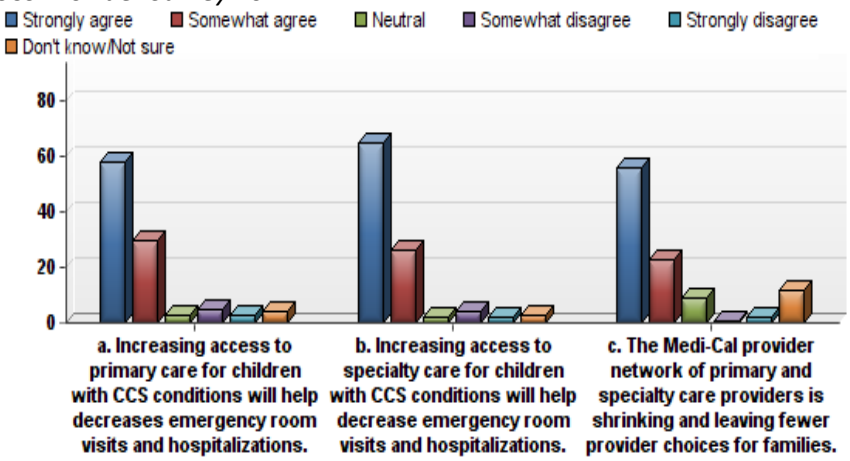
How often are the following types of providers lacking?

	Never	Occasionally	Very Often	Always	Total N	Mean
CCS Paneled Audiologists	5%	28%	24%	43%	58	36
CCS Paneled Physical Therapists	14%	24%	32%	31%	59	36
CCS Paneled Occupational Therapists	14%	24%	31%	32%	59	36
CCS Paneled Primary Care Providers	21%	35%	30%	14%	57	35
CCS Paneled Registered Dietitians	19%	25%	15%	42%	53	36
CCS Paneled Respiratory Therapists	32%	16%	12%	40%	50	36
CCS Paneled Social Workers	29%	15%	8%	48%	52	36
CCS Paneled Orthodontists	17%	21%	17%	45%	53	36
CCS Paneled Otolaryngologists	29%	23%	17%	31%	52	36
CCS Paneled Pediatric Neurologists	9%	35%	30%	26%	54	36
CCS Paneled Endocrinologists	15%	23%	23%	40%	53	36
CCS Paneled Plastic Surgeons	16%	33%	22%	29%	51	36
CCS Paneled Pediatric Cardiologists	28%	40%	12%	20%	50	35
Other CCS Paneled Provider (please specify)	22%	15%	26%	37%	27	36

From the FHOP CCS Provider Survey 2014



From the FHOP CCS Administrators/Medical Consultants Survey 2014

- 74% Strongly or somewhat agree that increasing access to primary care will help decrease ER visits and hospitalization
- 88% Strongly or somewhat agree that increasing access to specialty care will help decrease ER visits and hospitalization

Strategies to increase CCS paneled providers

From the FHOP CCS Administrators/Medical Consultants Survey 2014

Question	Very Helpful	Helpful	Only a little helpful	Not helpful	Don't Know/ Not Sure	Total N
b. Expanding telehealth options for CCS children, particularly in rural areas	42%	17%	10%	8%	23%	60
d. Consider strategies to recruit/graduate more pediatric sub-specialists in California	60%	22%	2%	2%	15%	60
c. Raise Medi-Cal/CCS rates to encourage higher participation in the program	75%	10%	2%	2%	12%	60

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Referrals

From the National Survey of CSHCN 2009/2010[i]

CSHCN needing a referral for specialty care and having difficulty getting it[i]

California %	33.9
Nationwide %	23.4

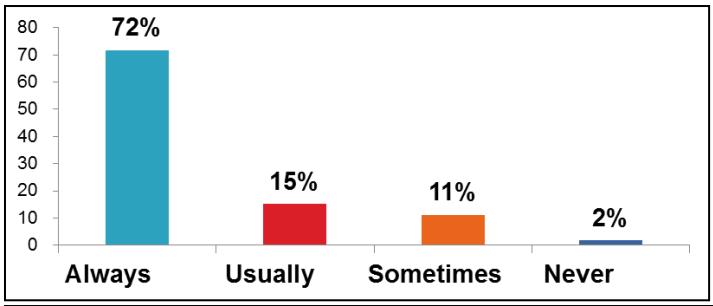
CSHCN needing a referral for specialty care and having difficulty getting, by race/ethnicity[i]

	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Other, Non-Hispanic
California %	22.0	36.8	43.8	32.6
Nationwide %	20.7	20.8	32.8	25.6

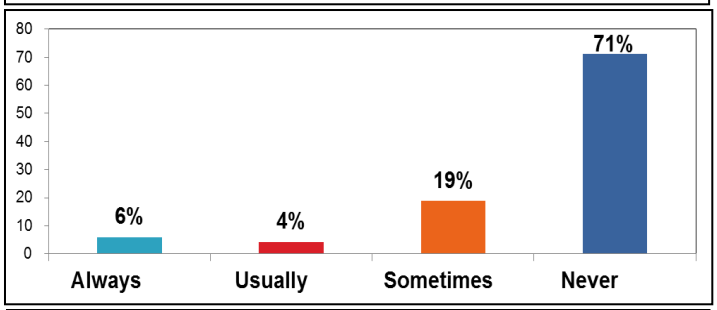
From the FHOP Survey of CCS Families 2014

Specialists

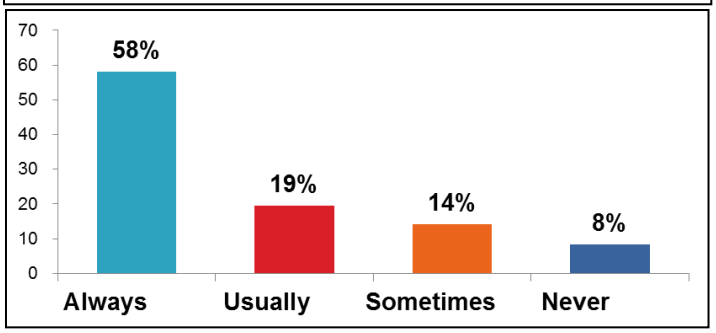
In the last 12 months, saw specialist when needed?



Delays or problems getting referrals to CCS Specialists?



In the last 12 months, how often felt specialist and PCP were working together to provide care for child?



Reoccurring Themes Regarding Access to Specialists

FHOP CCS Family Focus Groups 2014 – Northern and Southern California

Experiences shared by families regarding communication and access (e.g., obtaining an appointment as needed) have been mixed

- Some families have had wonderful, seamless experiences whereas others have had an obstacle at every step of the way
- Some families without Private insurance report regular obstacles in accessing specialists

* Difference between CA and Nation significant at $p < .05$
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- *Why should a CCS child on MediCal have to wait 6 months see a specialist whereas if you have private insurance or cash [out of pocket], you can be seen right away? A lot of people then go to the ER because they cannot wait for an appointment. This clogs the ER, doctors there aren't trained to care for CCS kids, so they are usually admitted and the cost of admission and treatment is so much more than preventing the child from going to the ER in the first place.*

Waiting times from referral to first authorization for CCS services *from CMS Net*

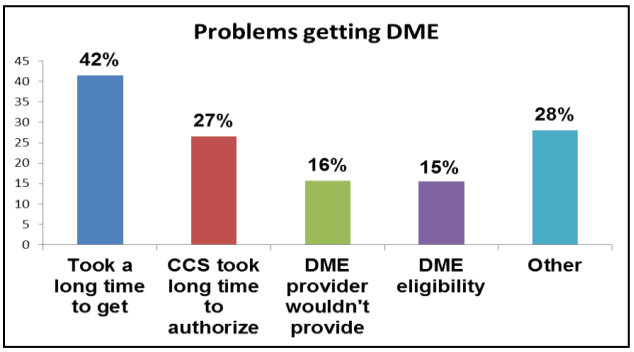
- In 54 CA counties in 2005, average waiting times for referral to authorization varied from 55 to 227 days, with an average of 127 days.
- In CA counties in 2010 (all except LA), wait times range from 0 to 364 days, with an average of 32.5 days, a mode of 0 and a median of 17 days; in LA, wait times ranged from 0 to 381 days with an average of 12 days
- In CA counties in 2014, wait times range from 0 to 490 with an average of 21 days; in LA, wait times ranged between 0 to 391 days with an average of 17 days.
- Relative risk statistics were computed comparing dependent counties with independent counties. For CCS children in the dependent counties, they are 1.9 times (down from 6.2 times in 2010) more likely to have to wait longer than a month from referral to first authorization than are CCS children in independent counties (CI 1.8 – 1.9))

Durable Medical Equipment

From the FHOP Survey of CCS Families 2014

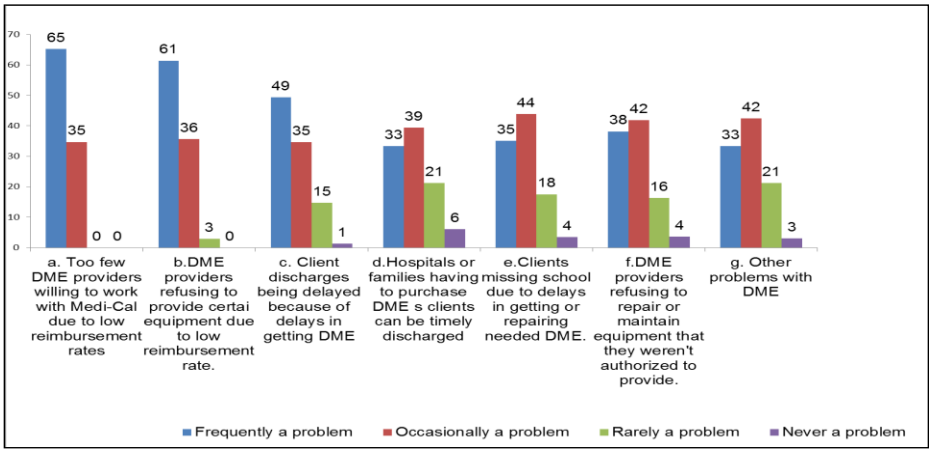
In the last 24 months, had problems getting medical equipment?

	N	%
Yes	407	16
No	2157	84
N/A	1436	



DME Issues that present problems for patients:

From the FHOP Survey of CCS Providers 2014



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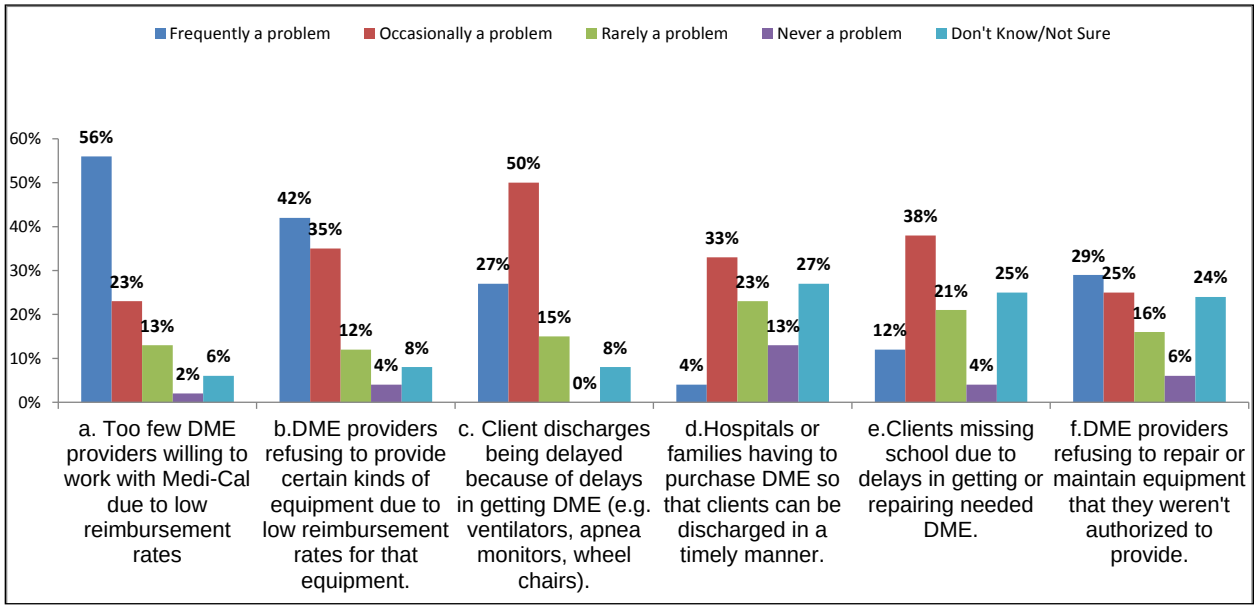
Comments on DME:

- Hospital discharge delays are a VERY frequent problem due to delays in obtaining DME. Nothing happens (no progress) on even simple DME such as home 02 occurs after Wednesday until the next week
- We have ONLY one provider of DME for Santa Clara County
- Teaching families the use of DME has been a problem for two reasons: scheduling has not been family friendly. Teaching is not offered in family's language.
- Apnea monitors are being rationed in San Bernardino County
- main problem is Pulmo-Aides
- patient after 21 years of age who are on home ventilator have no support, low reimbursement to adult providers impair the care.
- The skill of DME providers is variable as well. One issue is the need for some DME that isn't being provided. For example, if someone has a home suction machine and needs a portable suction machine so that they can take their child into the community. Another issue that myself and several of my colleagues think would be a good direction to move in would be a 5 or $10 co-pay for all durable medical equipment. This provides some ownership of the equipment by the family providing even a monetary amount of the overall price.
- CCS not approving certain DME
- Many DME vendors not wanting to serve remote family homes esp since care for these children is difficult and often lapse in DME function could be lethal for some patients.

From the FHOP Survey of CCS Administrators/Medical Consultants 2014



	Never	Occasionally	Very Often	Always	Don't Know/ Not Sure	Total N
CCS clients experience delays in getting medical supplies because a CCS paneled physician isn't accessible to order them.	14%	55%	20%	3%	8%	65
Hospital discharges are delayed for CCS clients because of delays in coordinating care/obtaining equipment that will be needed once discharged.	9%	57%	18%	0%	15%	65

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Comments on DME

- *Again, in our rural community, suppliers are few, re-imbursement is an issue as the provider cannot provide equipment for a loss. They buy in smaller quantities, ie their cost is higher and need to be reimbursed at a higher rate.*
- *DME providers are not reimbursed adequately by MediCal. The reimbursement has not kept up with the cost of current technology, eg, hearing aids resulting is a refusal by local audiologist to provide care. Prosthetics are also not being adequately reimbursed. Some DME providers have changed their business model and have declined to take MediCal altogether, resulting in providers who are no closer that 150 miles and families having to pick up and deliver the DME, eg wheelchairs.*
- *The criteria for DME in CCS is specifically for the CCS dx and criteria. Many managed health care plans assume that developmental delay, as a co-morbidity with a CCS dx, for example, seizures, automatically is an eligible criteria for DME from CCS. The state/CCS has a fiduciary obligation to provide the DME necessary for the child's needs. Convenience as encouraged by DME vendors is not part of the stewardship practice granted to CCS by State guidelines. Families are authorized DME which sometimes they fail to use.*

Wait time between request for in-home support services and authorization

From CMS Net

- In 2005, wait time between request for and authorization for in-home support services ranges from 0 to 1469 days in 2005, with average being 24 days, the mode (most frequent value) being 0 days and the median (middle value) being 5 days.
- In 2009, wait time for request until authorization of in-home support improved with a range of 0 to 303 days and an average of 18.2 days and a mode of 0 days.
- In 2014, wait time for request until authorization of in-home support improved with a range of 0 to 1039 days, and a mean of 10 days, a mode of 0 days, and a median of 4 days.

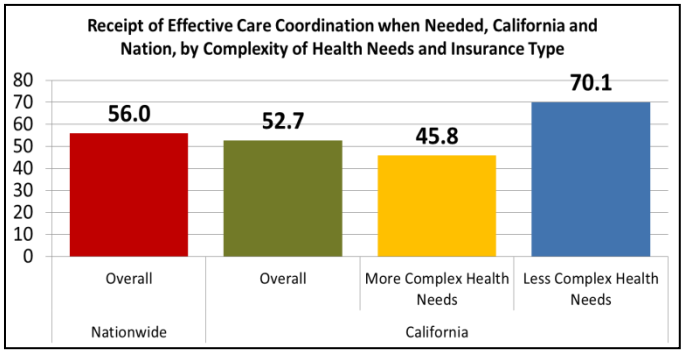
Wait time between request for equipment (wheelchairs) and authorization

From CMS Net

- In 2005, the wait time between request for and authorization of equipment ranged from 0 to 1838 days, with average being 29 days, the mode (most frequent value) being 0 days and the median (middle value) being 12 days.
- In 2009, the wait time showed improvement with a ranged between 0 and 321 days, and an average of 22.2 days and a mode of 0 days.
- In 2014, the wait time showed continued improvement with a range between 0 and 2,857 days and an average of 14 days, and a mode of 0 days, and a median of 5 day.

Coordination of Services

From "Children with Special Health Care Needs: A Profile of Key Issues in California" (Bethell, 2014)
Data Source: 2011/12 National Survey of Children's Health



* Difference between CA and Nation significant at $p < .05$
** Differences within the Nation significant at $p < .05$
^ Difference within the State significant at $p < .05$

CSHCN Receiving Care Coordination	More Complex CSHCN	Less Complex CSHCN
% CSHCN 2+ services (qualify for CC items)	83.7%	59.5%
% 2+ getting any CC help	22.2%	19.5%
% very satisfied with doctor-doctor communication	44.8%	33.1%
% very satisfied with doctor-school communication	52.8%	21.8%
Summary Measure: % who received effective care coordination, when needed	45.8%	70.1%

Telehealth

From the FHOP Survey of CCS Providers 2014

- 61% of providers would be willing to participate in providing telehealth services
- Identified barriers to providing telehealth include:
  - Inadequate infrastructure including technological, personnel, lack of appropriate compensation for services.
  - Lack of uniform information / data platforms; concerns regarding liability and confidentiality
  - Telemedicine Equipment
  - Not sure about the legal and insurance issues
  - Equipment and training
  - HIPPA regulations. Hospital firewalls
  - We don't have the materials, scheduling, documentation, or reimbursement workflows set up.
- Suggested strategies for reducing telehealth barriers include:
  - Support for technological upgrades, hiring of nursing staff, fair compensation
  - Uniform data / imaging platforms; defined physician protection regarding liability and privacy
  - Provide training and equiptment and support services if needed.
  - More rural access to Telehealth equipment at dedicated sites.
  - Rates need to be increased and need to be able to charge for visits.
  - Better interpreter services integration; getting devices and bandwitdth into homes-- some families don't have electricity at home.
  - Involve the department and IT.
  - State mandated data communication standard.
  - Improving quality of telehealth infrastructure so that examinations would be of appropriate quality for diagnosis.
  - 1. Having sufficient volume to allow time to be dedicated to project. 2. Collaborate on provision of technology to facilitate adoption. 3. Simplify the reimbursement process for telehealth visits.
  - Have codes to allow for billing telehealth services.

FHOP Survey of CCS Administrators/Medical Consultants 2014

- 65% of respondents weren't sure if CCS paneled physicians in their county were willing to provide telehealth services, and 33% of respondents indicated that the physicians would

[i] National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 12/30/14 from www.childhealthdata.org.

[ii] CMS Net

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