

## Children with Special Health Care Needs Organization of Services

**MCHB Outcome #5: Community-based services for children and youth with special health care needs are organized so families can use them easily.**

**AMCHP System Outcome #5: Services for CYSHCN and their families will be organized in ways that families can use them easily and include access to patient and family-centered care coordination.**

*From the National Survey of CSHCN, 2009/2010<sup>1</sup>*

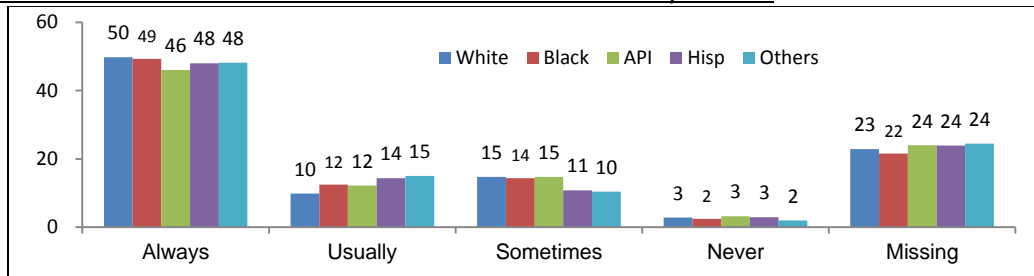
Outcome successfully achieved

California %:	64.8
Nationwide %:	65.1

### Organization of Services

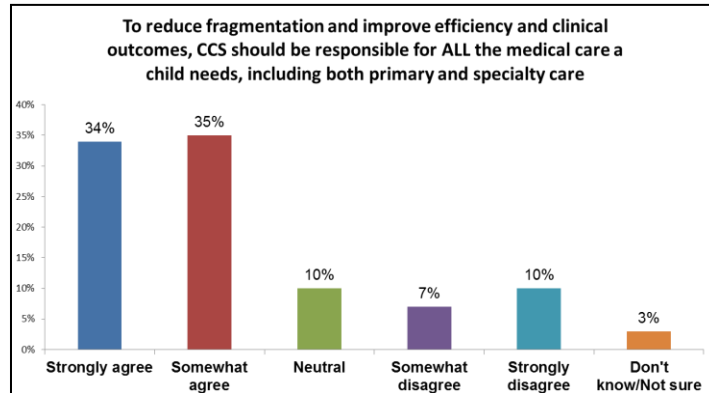
*From the FHOP Survey of CCS Families 2014*

How often child's services are coordinated that makes them easy to use?



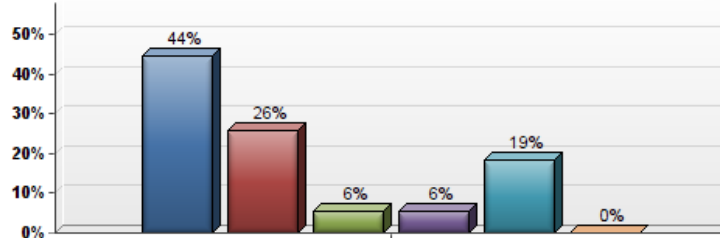
### Covering the Whole Child

*From the FHOP Survey of CCS Families 2014*



*From the FHOP Survey of CCS Administrators/Medical Consultants 2014*

■ Strongly agree   
 ■ Somewhat agree   
 ■ Neutral   
 ■ Somewhat disagree   
 ■ Strongly disagree   
 ■ Don't know/Not sure



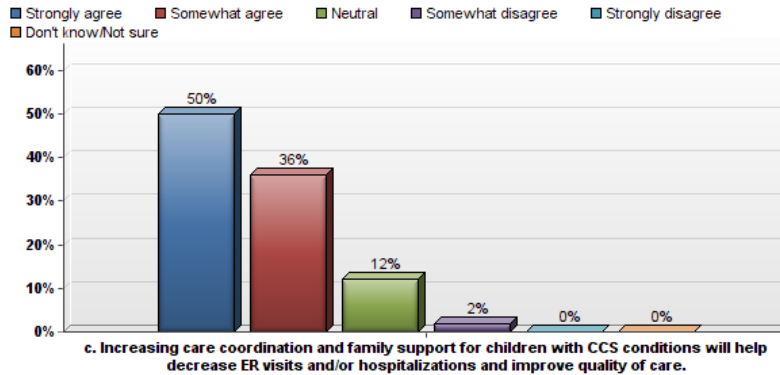
**a. To reduce fragmentation and improve efficiency and clinical outcomes, CCS should be responsible for ALL the medical care a child needs, including both primary and specialty care (versus the current CCS system which covers care ONLY related to the child's CCS-eligible medical condition).**

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### Care Coordination

From the FHOP Survey of CCS Families 2014

Please indicate how much you agree or disagree with the following statements:

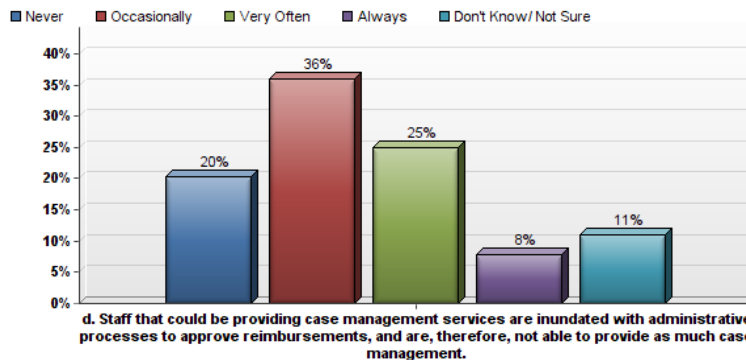


### Case Management and Case Loads

From the FHOP Survey of CCS Administrators/Medical Consultants 2014

Case Load	% of Independent County responses (N = 42)
50 - 300	14%
301 - 400	26%
401-500	24%
501-600	24%
601-800	10%
801-1100	2%

Case Load	% of Dependent County responses (N = 19)
50 or less	16%
51 - 100	26%
101 - 200	21%
201-300	16%
301 to 440	21%



### Tiering of Case Management Services

From the FHOP Survey of CCS Administrators/Medical Consultants 2014

Does county tier case management services based on:

	Yes	No	Don't Know/ Not Sure	Total N
Medical conditions	30%	62%	8%	63
The families capacity to meet the child's needs	27%	61%	13%	64
Social barriers the family encounters (poverty, low education level, lack of transportation, non-English speaking, etc.)?	28%	61%	11%	64

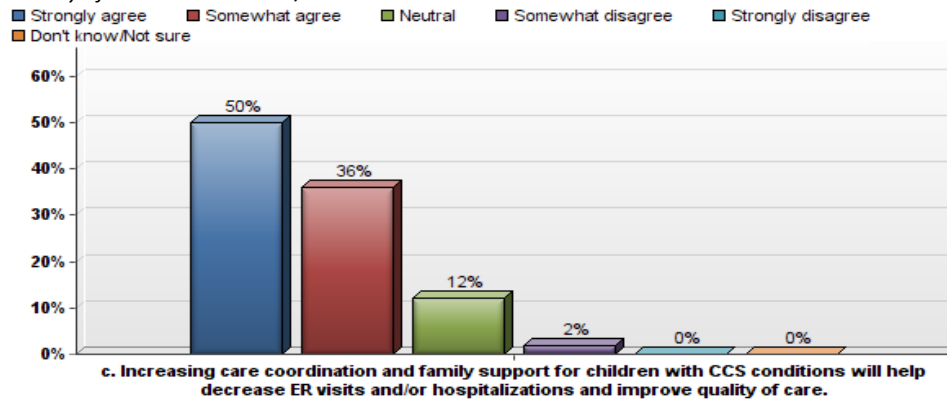
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Should case management services be tiered?

	Strongly agree	Somewhat agree	Neutral	Somewhat disagree	Strongly disagree	Don't know/Not sure	Total N
The provision of case management and care coordination services should be tiered based on the child's medical condition, the family's capacity to meet the child's needs and the social barriers they encounter (poverty, low education level, lack of transportation, non-English speaking, etc.).	41%	28%	13%	6%	6%	7%	54
The provision of case management and care coordination services should be based ONLY on the child's medical condition.	16%	5%	11%	32%	29%	7%	56

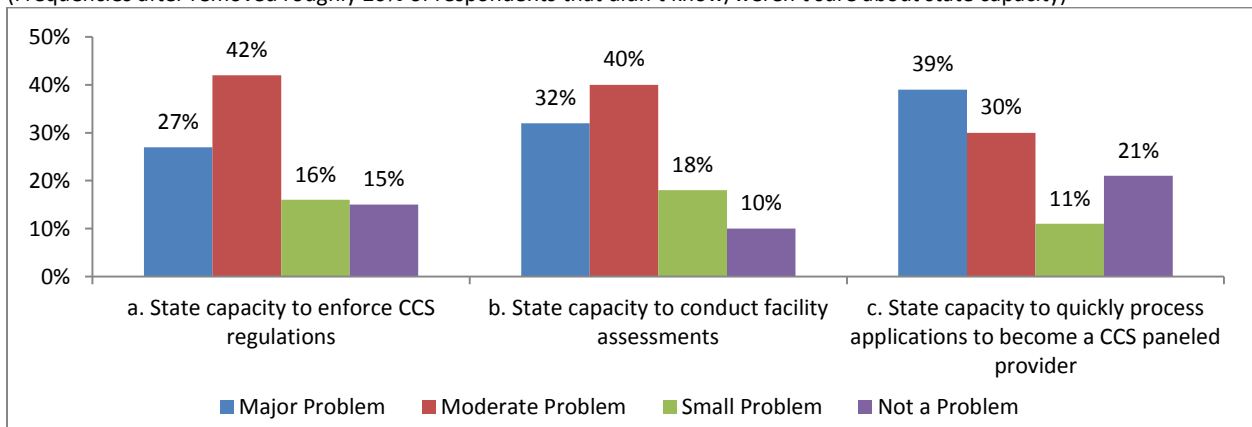
### Increasing care coordination

From the FHOP Survey of CCS Administrators/Medical Consultants 2014



### State capacity to ensure CSS children received high quality and well organized services

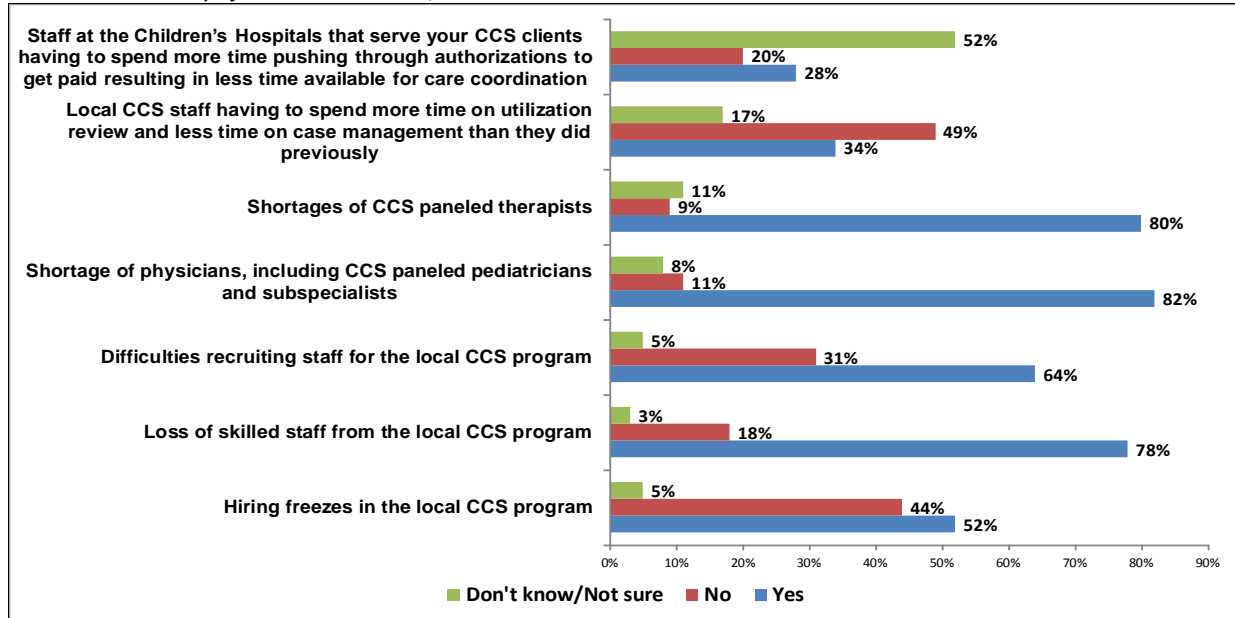
(Frequencies after removed roughly 20% of respondents that didn't know/weren't sure about state capacity)



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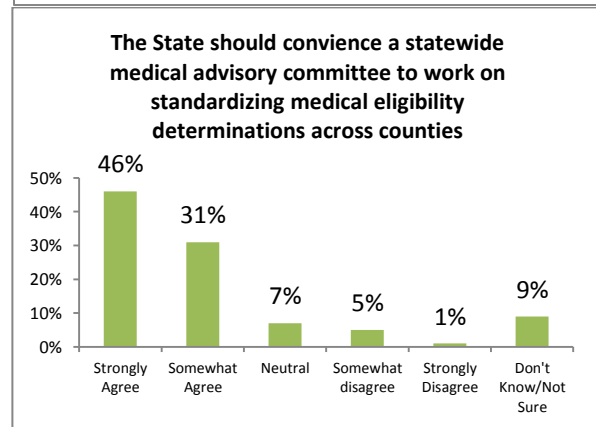
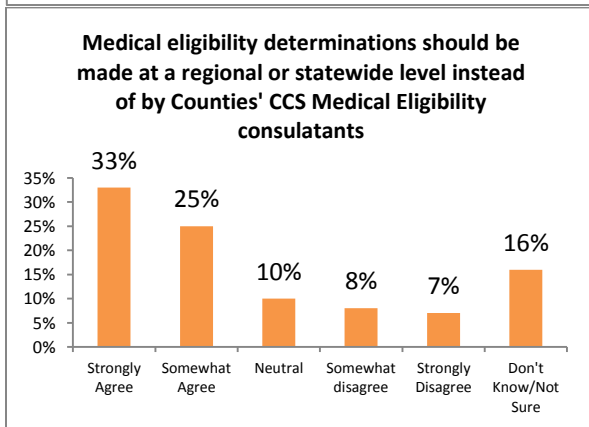
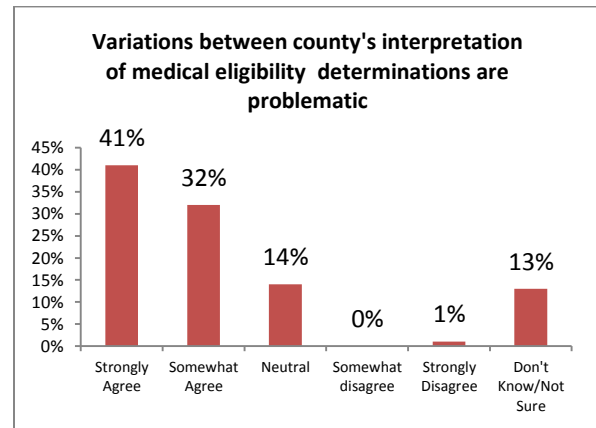
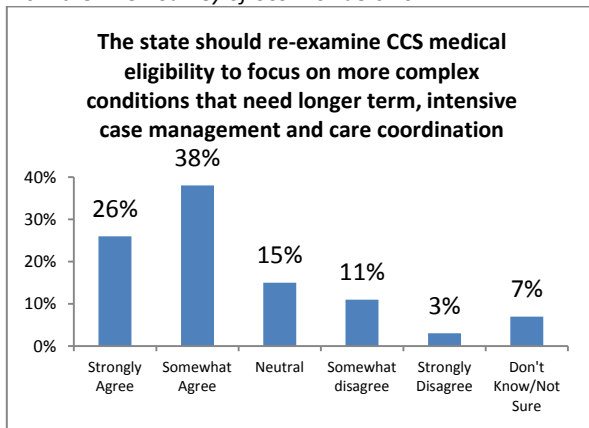
### Potential issues impacting local capacity to ensure CSS children received high quality and well organized services

From the FHOP Survey of CCS Administrators/Medical Consultants 2014



### Medical Eligibility and Consistency Across Counties

From the FHOP Survey of CCS Providers 2014



## Children with Special Health Care Needs Organization of Services

From the FHOP CCS Key Informant Interviews 2014

### Issues/Concerns

- *Language confusion can lead to inconsistent application of standards (e.g., medical home – what does that mean? For families? For providers?)*
- *Some counties have an implicit look at their balance sheet and others are just doing [what is needed].*
- *Biggest area [of discrepancy] has to do with medical eligibility because of ambiguity in regulations...seems to be more variation between Northern and Southern California [regarding] practice differences. Some things are considered eligible in the North but not in the South...culture difference.*
- *Different counties will interpret the number letters differently. Physicians within the same county do not always agree on interpretation...[they] don't always understand medical eligibility.*
  - *Example: child in one county will receive a wheelchair while in another county the same child would not receive a wheelchair for the same condition.*
- *Families find themselves in the middle of trying to figure out how to get care for their child instead of caring for their child. They end up in the middle of disagreements between agencies with no ability to resolve the issue.*

### Suggestions

- *Provide dedicated funding for county level and/or regional family liaisons to train families on how to navigate system and get what they need.*
- *Partner with families at all levels – including discussions about standards, quality of care and systems, medical homes, transitions, organization of services, and screening.*
- *Need to have ability to apply standards in a way that makes sense...different places have different conditions...can't be rigid...need some flexibility. It is important to permit variation because California is a big state and important that counties have the flexibility to respond to local needs.*
- *What is missing is any analytic capacity to see what is useful variation versus variation based on inefficiency and bad practices.*
- *It would be great if the State could provide a more detailed guide as to how the regulations are to be interpreted.*

From the FHOP CCS Family Focus Groups 2014

- *Why can't all...counties get treated equally?...would like to see all the counties equal...[there] needs to be more unity across the board in the counties...[should be the] same for all the counties.*

From the FHOP Provider Survey 2014

- *Consistency for eligibility at the State...consistent statewide approach to eligibility and care...inter-county consistency in eligibility determination [is needed].*

From the FHOP CCS Administrator, Hospitals, and Health Plans Focus Group 2014

- *Vast differences among local counties, for example, a local HMO currently works with 7+ counties and keeps a list of which county will authorize services for which conditions.*
- *Gray area of diagnosis...depends upon the county and the medical consultant.*
- *[Authorization] discussion goes back and forth between CCS, MediCal, [private insurance], etc., while the patient waits to receive services, and some providers will not accept a patient without the CCS authorization.*
- *[Case management is]...a county-by-county issue heavily influenced by the amount of staff...less staff [means] less ability to meet the client's need.*

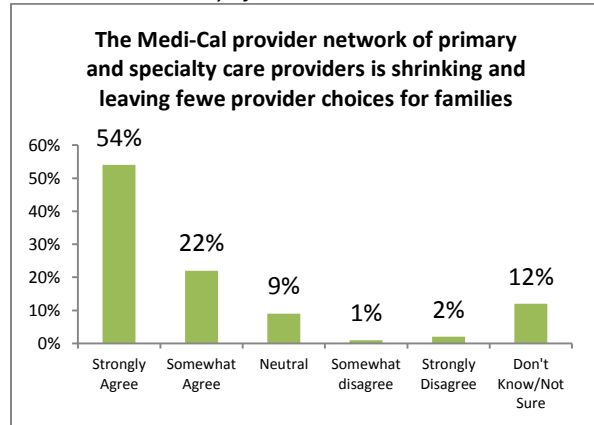
## Children with Special Health Care Needs Organization of Services

FHOP CCS Administrators/Medical Consultants Survey

- Even though there is a policy at the state level, my county follows their own reimbursement policy with only some guidance from the state policy.

### Working with MediCal Managed Care Plans

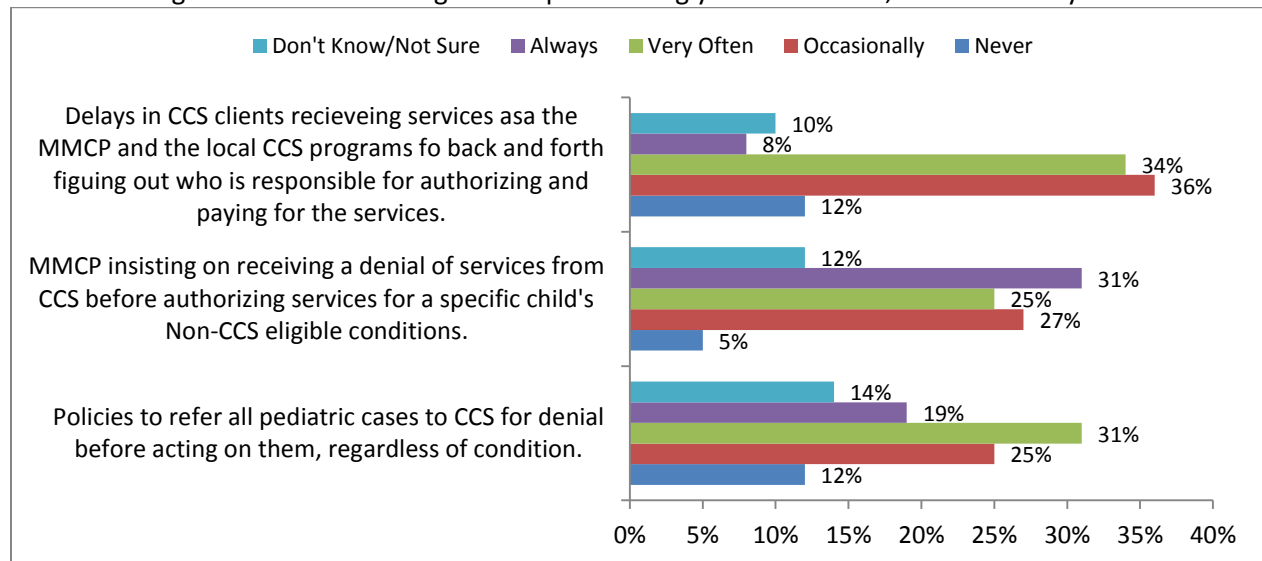
From the FHOP Survey of CCS Providers 2014



- Using a scale of 0-5 with 0 being not a barrier and 5 being a very significant barrier, physicians gave “Working with managed care plans (e.g., Approval for services/special tests or procedures, reimbursement process)” a score of 3.35. This was seen as a bigger barrier than MediCal rates.

From the FHOP Survey of CCS Administrators/Medical Consultants 2014

When working with Medi-Cal Managed Care plan serving your CCS clients, how often do you encounter:



### Regionalized Specialty Care

From “Regionalized Specialty Care for California’s Children” (Stanford Center for Primary Care and Outcomes Research, 2014)

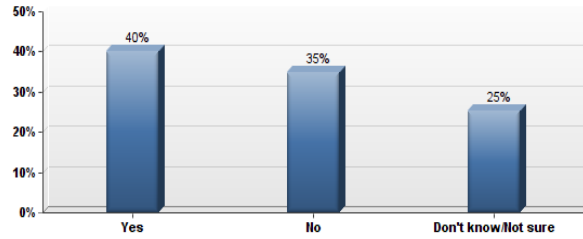
- **In recent years, the number of hospitalizations at pediatric specialty care hospitals has increased.**
- The portion of all pediatric discharges and pediatric bed days from specialty care hospitals that are insured by public programs (e.g., California Children’s Services, Medicaid, State Children’s Health Insurance Program) has increased.
  - **Publicly insured children** are now more likely to be hospitalized at specialty care centers than at nonspecialty centers.
  - **Privately insured children** are less likely to receive care in a specialty care center than their publicly insured counterparts.

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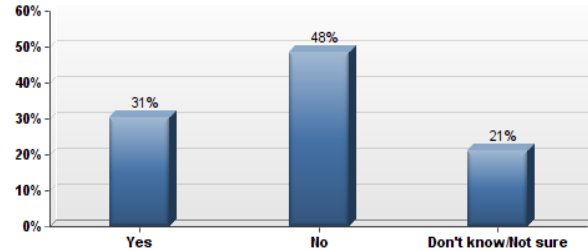
### Palliative Care

From the FHOP Survey of CCS Providers 2014

#### CCS clients that got palliative care services in the CCS palliative care program

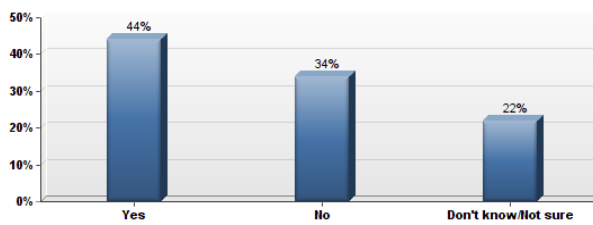


#### % of physicians that have CCS clients that would benefit from but are not receiving palliative care

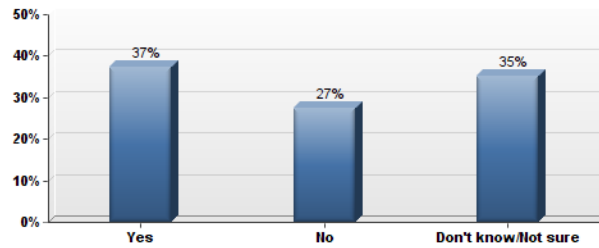


From the FHOP Survey of CCS Administrators 2014

#### CCS clients that got palliative care services in the CCS palliative care program



#### % of physicians that have CCS clients that would benefit from but are not receiving palliative care



<sup>1</sup> 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](http://www.childhealthdata.org).