



## Community-Based Services:

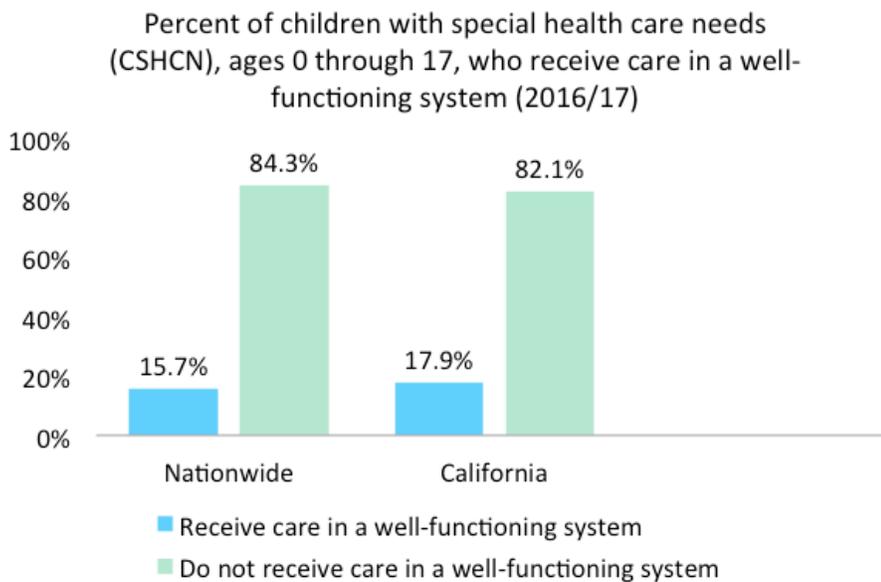
**MCHB Goal: Community-based services for children and youth with special health care needs are organized so families can use them easily.**

### Community-Based Services Definition:

“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 (AMCHP).”

### Data on Community-Based Services (NSCH):

#### **National Survey on Children’s Health Data, 2016/2017:**



### Findings and Data on Community-Based Services from the Title V Needs Assessment:

#### **Data from Family Survey (N = 3,419):**

*General family knowledge about systems of care for CYSHCN:*

- Over a quarter, **26.1%** of families said that they needed more information about CCS
- **23.5%** said they needed more information about Medi-Cal
- **41%** are aware of how to file a grievance or complaint about their child’s health care, **30.3 %** are not.



- Out of those that knew how to file a complaint, **38.9%** had and 18.1% had not filed a grievance or complaint
- **69.5%** of families know how to call in order to get answers about their child’s care or insurance, only 10% are not

*Care Coordination:*

- Over a quarter of families, **39.8%**, Always need interpretation services, 11.8% Usually, and 18.3% Sometimes.
  - Out of those that need interpretation services, **69.1%** Always find them available
- **53%** of families feel that their children’s services are always coordinated in a way that makes them easy to use, 29% said Usually, 14% said Sometimes, and 4% said Never.
- **49%** of families said it is Always easy to coordinate therapy (physical, therapy, occupational) for their child in a school setting, 21% said Usually, 10% said Sometimes, 7% said Never, and 12% said that they Did Not Know.
- Only **11.8%** of families felt that they Always needed extra help getting, setting up or coordinating their child’s care.

*Case Management & Care Planning:*

- **34.5%** of families said that nobody outside of the family helps to arrange or coordinate care for their child, **20.9%** said that a County CCS Case Manager helps.
- **32.8%** of families said that a health care provider or case manager had linked them to support and **30.5%** said they did not. The rest of survey participants did not know.

*Impact on Families:*

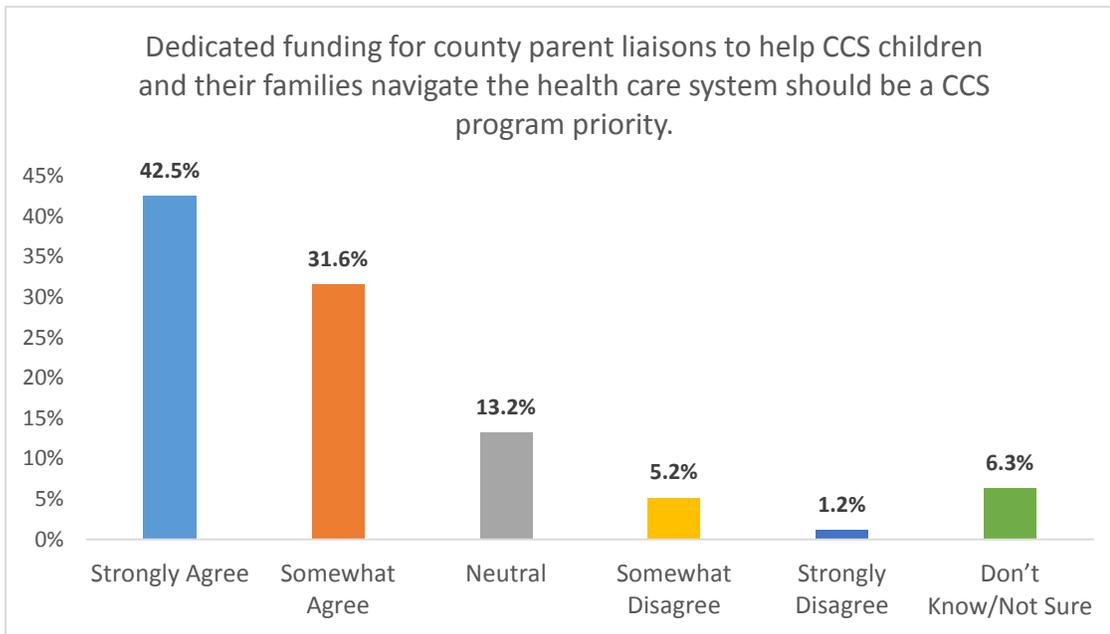
- **65%** of families spend between 0-5 hours a week arranging or coordinating care for their CYSHCN
- **14.1%** of families spend between 6-10 hours a week arranging or coordinating care for their CYSHCN
- **13.4 %** of families spend between 20+ hours a week arranging or coordinating care for their CYSHCN
- **50.8%** of families spend 0-10 hours a week providing care for their child’s medical condition at home, **10.4%** spend 10 to 20 hours, and **20% spend 70+ hours a week.**
- **54%** of families cut down on hours or had to leave their jobs because of their child’s health and **43.3%** did not

**Data from Provider Survey (N = 188):**

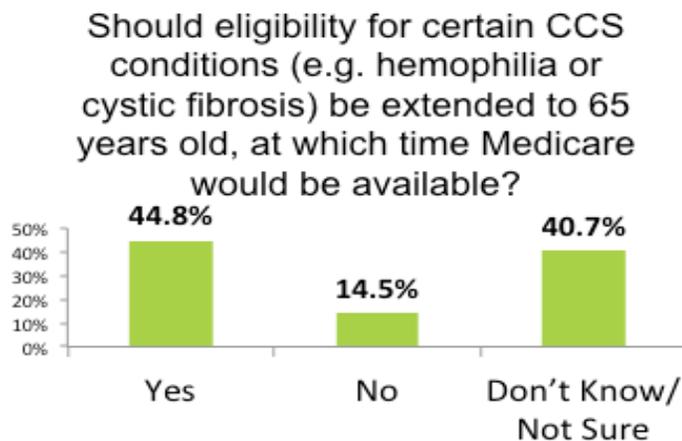
- Providers agree that care coordination is important, but a sizeable number of providers indicated that they don’t know who pays for it or no one pays for it:

How important is it for you (or your practice) to provide care coordination for CYSHCN? (N = 127)	%	Who Pays for coordination? (N = 125)	%
Very Important	70.1	CCS	29.6
Important	11.8	Medi-Cal Managed Care Health Plan	12.4
Somewhat Important	3.2	Private insurance	7.1
Not Important	3.9	Philanthropy	2.9
Don't Know/Not Sure	11.0	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

- Parent liaisons to help families navigate the health care system



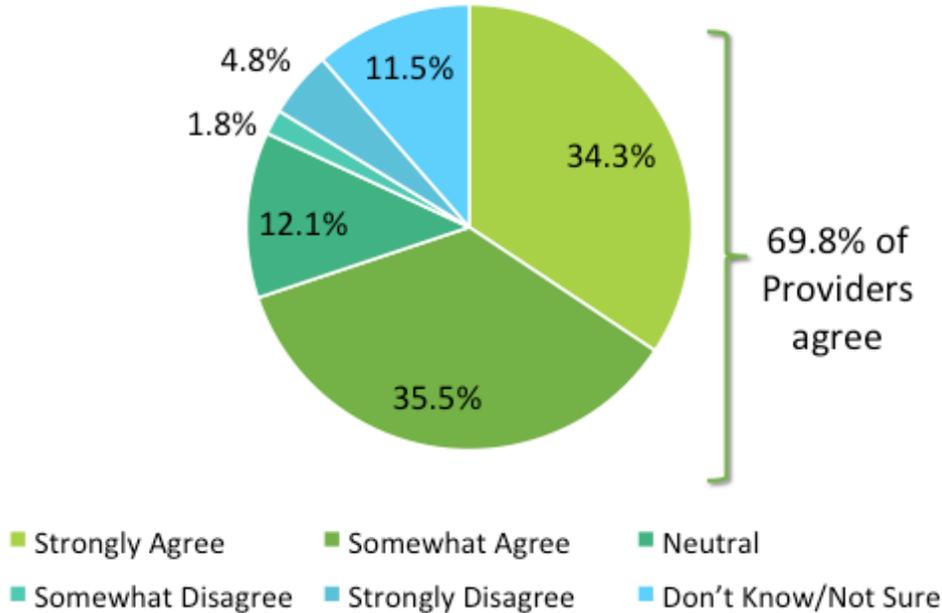
- Provider thoughts on extending coverage of CCS to 65 years of age:



**N = 145**

- Provider's responses on the availability and capacity of primary and specialty care providers:

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



**Family Engagement & Family-Centered Care, Comments from Key Informants:**

- **Strength of CCS: Care Coordination/Case Management:**
  - “Family centered case management and care coordination works well for the most part”
  - “Attempts at care coordination – even if it does not always work.”
  - “Case management is a strength, having a pivot point to help guide family through dynamic and complicated process.”
  - “Case management through the county-based system is essential to meeting the needs of kids, in [specialization center]—[providers] being able to communicate with multiple providers and have long-lasting relationships with our families.”
  - “Availability of coordination of care; point of contact with MD who can bill CCS.”
- **Challenges encountered or witnessed by key informants:**
  - Non-CCS children miss out on quality care and care coordination: “I know that our [redacted hospital name] nearby tries to get a lot of children [CCS] eligible. For our children, because we provide comprehensive case management, I don’t know of any other programs that would provide this for children that aren’t insured, I’m not sure how that works, that might be a challenge for children not [CCS] eligible and uninsured.”

**Case Management/Care Coordination in County CCS Programs:**

- **Major barriers: varies in quality and clarity on a county-by-county basis:**
  - “Varies enormously. **Huge case load differences across counties.** Some places it is probably done well and some done minimally. No standardized way to stratify CCS clients.”

- “If ‘case management’ falls under the umbrella of ‘care coordination’, then we are doing case management for eligible conditions.”
- “Mostly observational, patients coming from dependent to a large county with more services and resources.”
- “I would have at one time said that we do a great job, but we don’t. Within our county we’ve never been proactive in case management, **it is almost crisis driven** which does not meet the definition of case management.”
- “In my experience, I think we do a fantastic job of providing comprehensive case management for our clients.”
- **Major barriers: large and unmanageable caseloads, and the introduction to WCM (losing Case Managers):**
  - “We currently have **one nurse case manager for 900 cases**, they do their best they can. We have two Social workers. They work very hard but hard to get to everyone. It is hard to do case management the way they want to. We had a case manager leave and it is hard to replace them because of Whole Child Model and job ending. State gives limited money for case management. I have heard that Partnership has 80 cases per case manager. **Decreasing the case load would be good.**”
  - “The definition of case manager and what they do (the activities listed) are not aligned. They are the catalyst and the advocate, they are only supposed to have a few dozen cases, but CCS staff has hundreds of cases, as a result some get managed really well and others don’t. **The term case management doesn’t make sense when the case load is so large.**”
- **Both a barrier and a success of case management and care coordination: family engagement and participation:**
  - “Parents do and are helped by others. There are good outcomes because of a strong parent at the head of the table. But, should parents have to do that? Some parents wouldn’t give up leadership no matter how competent other people at the table are. But, this could help to lift the burden on families.”
  - “It varies. If you have a strong, decisive leadership from parents and other professionals around the table, you can have well-coordinated care, but there are other things that can get in the way, for example, [parents will have] problems getting DME.”
  - When asked who coordinates care for CCS clients: **“I would be surprised if the answer was anything other than the parents. There isn’t a single care coordinator that I’ve ever seen for our children.”**
- Suggestions for improvement are **communicating and working with community partners:**
  - “Get to know community partners and partner. Don’t be a closed system.”
  - “Too big a job for CCS to do with current capacity and coordination. What [redacted hospital] recommended to [redacted county name] CCS was build relationships with their community partners, counties don’t typically do that, it is a very isolated and closed system. They started to get results when they started helping [redacted specialty center] get to know the community partners. If they don’t know who is in the community, they can’t tell the family.”
  - “Part of the problem is that it involves lots of different agencies and hard to make it convenient for families. Incentives just aren’t there to be an active partner. To make it work, everyone needs to feel invested in getting best outcomes but no incentives other than meeting system needs. We need to prioritize family needs. How do we set better incentives for the right outcomes?”
- Suggestions for improvement are **clarity around roles in case management and coordination:**
  - “Sorting out who should be doing what. For CCS kids, CCS should take the lead in sorting it out.”
- Suggestions for improvement are to **increase knowledgeable staff to conduct case management and/or care coordination:**
  - “We need more and better trained, delegate tasks that don’t requiring nursing expertise”



- “More case managers, making the Primary Care Physician the pivotal point. The PCP could see the client in a different way.”
- Suggestion for improvement is **additional state funding to bolster case management and care coordination staff and efforts:**
  - “Reducing caseloads. More training in case management funded by state.”
  - “Getting there, but resources are allocated disproportionately.”
- Suggestion for improvement is to **do care coordination and case management with the specialists:**
  - “Looking at different model and actually doing care navigation and integration with specialist. We have done some of this in the past when in the program and working with hospital. It needs to be more holistic. We wanted the provider to take care of whole child, and not the health plan.”
- Also important to note, **some key informants thought that Whole Child Model will or already is improving these services:**
  - “What they are trying to do with pilot [of whole child model]. Focus, redirection and resources.”
  - “If we were not in our pilot [for WCM], care coordination in anemic and not happening.”
- Suggestions to **change (if they would change) care coordination, case management, and continuity of care for both CCS and non-CCS CYSHCN to make it more family-centered:**
  - “**Medical homes, regionalization of care to center of excellence.** Look at the data and use to improve outcomes.”
  - “Needs to be **legislative advocacy at a really high level and family centeredness.** Until systems are integrated and talking to each other – has to happen at top level, like making shared plan of care required by law.”
  - “**Training for staff** might help. Coming up with **good behavioral questions** to ask families to get a good assessment of what is going on. We have so many clients that can’t do it. **When thinking of the child, think of whole families because it affects them too. When families are in the know, it is easier and better for the child.**”
  - “Getting **more involvement of families in advisory council.** Also need to engage families differently to be more family centered – engaging a family”
  - “...do care planning, make sure every CCS client has a **real care plan.** What are family’s goals and priorities and what role do they want to play. If they **required care plans,** that would at least get the information. Needs to **be standardized and comprehensive care planning.** For both CCS and non, this would educate families to expect family centered care”

### Comments from Family Focus Groups:

- “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 under diagnosed 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.

- “My nurse case manager always reached 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.”
- “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.
- Whole Child Model County, family comment: “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?”**

**Many families feel that CCS has been supportive and helpful since their child was diagnosed (with the addendum that most feel that Whole Child Model and health plans have changed this).**

Comments from families in Whole Child Model, Medi-Cal Managed Care health plan counties:

- “It was wonderful, before the change. I liked CCS. They did the AFOs, they did the tubes, the diapers, they did PT, they were awesome. They were always there.”
- “In the beginning, when you have a child with a life-changing, lifelong diagnosis, there are so many agencies coming at you. In CCS, my daughter had the same case manager the entire time, maybe two in all of her years, she had CCS until she turned 21. If I had a question, I could call Patty [case manager], if I had a “share of income letter,” that scared me, I could call Patty. Supplies were covered very constantly. They even helped with transition.” Note: this person’s child aged out of CCS prior to WCM.
- “All the people you dealt with had such great expertise.”
- “They’ve met all of her needs. The diapers too, they give you and extra money for two different types of diapers. As of right now, [health plan] is not covering it right now because of my grades. They were putting \$30 onto my mom’s EBT. I asked and they didn’t do anything, but sometimes I don’t feel like asking again and again.” *Note: we believe that this participant received misinformation because this particular health plan would never restrict access based on someone’s grades. The parent in this case was a teenager.*

**In particular, they feel that health plans do not familiarize themselves at all with individual cases and that is problematic for the care of medically complex children:**

- “I complained to [health plan] and I asked them why they were doing this, they aren’t becoming more familiar with my daughter—CCS used to be like my family away from family because I didn’t have to justify with them. They knew my child’s history; if they had questions, they’d call me and/or get back to me.
- “One of the problems that [health plan] is having is that they hired people that don’t know what CCS does and they don’t provide direct care. If this is the same care, why do we have to work so much harder for it? The [health plan’s] complaint department only keeps complaints for 24 hours.”
- **“The diff between CCS and [health plan] is, that CCS errs on the side of the child and [health plan] is cost-saving.”**

**Sometimes CCS (both with and without the WCM changes) isn't really modeled to make the most sense or in consideration of things outside of the child's medical condition for CYSHCN and their families:**

- “My son had a neurologist in [city over 100 miles from where we live], and he knew my son and his issues really well—but in order to see this same specialist, he has to go to his PCP for authorization first.”
- “CCS has been a big help...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.”
- “After hours therapy would have been helpful so that A) kids don't get pulled out of school, and B) parents are able to be there to learn what they need to duplicate at home.”
  - Several other parents expressed that their children were being pulled out of class, and sometimes they didn't have any idea of what CCS was doing in these sessions. *Note: it is unclear whether or not this is an issue with CCS or the school district.*
  - Other parents also mentioned children missing school for OT/PT, and being held back and missing classes for medical appointments.
- “It is very hard to make appointments or schedule regular appointments. The employees are switched a lot. It doesn't make sense why I can't have a regular appointment (ex. Regular apt at 8 on Tuesdays).”
- “They don't cover vitamins and it gets very costly outside of CCS.”

Comments from families that are **not** in Whole Child Model counties:

- “Just started OT and PT through CCS, on campus where she goes to preschool. Have two 30 minute sessions each week—it has actually been going really well so far. There has been an issue with covering visits with specialists, but I feel good about that being covered.”
- “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.”

One common theme in our family focus groups: **families worried that CCS services would be taken away if they found out families were utilizing private insurance services:**

- “CCS would not allow us to do private therapy as well as CCS—we found out that she would be kicked out of CCS if they found out that we were accessing private insurance too. Why couldn't we take her to get extra therapy without keeping it ‘hush-hush’?”