



Families as Partners

MCHB Goal: Families are partners in care.

Family engagement Definitions:

“Family-centered care is a process to ensure that the organization and delivery of services, including health care services, meet the emotional, social, and developmental needs of children; and that the strengths and priorities of their families are integrated into all aspects of the service system.”

-HRSA, MCHB 2013

Family Engagement Impact on Health Outcomes of CYSHCN & their Families:

On CYSHCN:

- The care coordination of the child is improved.
- It helps to reduce system fragmentation which removes barriers to health care for CYSHCN
- Overall improved health and quality of care for CYSHCN because families are the experts on their child’s condition and care, and their engagement in the systems that serve them is pivotal.

On Families of CYSHCN:

- By involving families at the systems level where policies and programs are created, not only do families get to raise their opinions and grievances, but also it has a better chance of the program/policy to succeed.
- It can mitigate economic and financial burdens on the families.
- The mental health and well being of the families is improved.
- There is increased satisfaction for the families with respect to care provided by doctors and medical professionals.
- Including families in decisions about their child’s care, and thoroughly explaining may help to reduce the frequency of emergency room visits.

Findings and Data on Family Engagement from the Title V CCS Needs Assessment:

Comments from families (from the family survey):

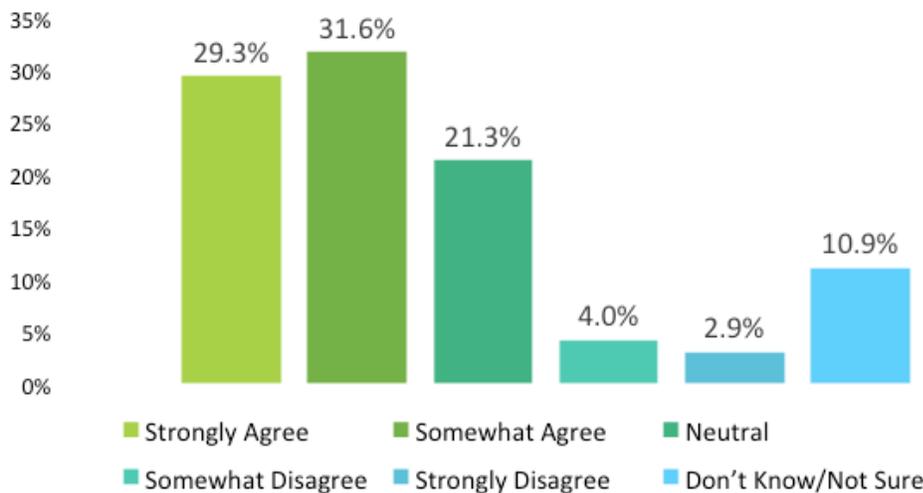
- Many parents are very grateful for CCS, and focus group participants were particularly thankful that the DHCS/ISCD had FHOP conduct focus groups as part of the needs assessment
- Parents are confident in CCS providers
- Parents who have lived the experience can help other parents navigate the systems, learn what to expect, and provide support
- More parent groups and parent support are needed
- There is no statutory language specifying that when a child qualifies for CCS services, the local Family Resource Center will be sent a referral to follow up with the family (this does happen when a child receives Regional Center services)

- There is some confusion about what services CCS covers and what Medi-Cal covers, more confusion for those with CCS and private insurance
- “CCS has been a big help, major surgery at [local children’s hospital] recently that went really well. The OTs and PTs are great and very knowledgeable about the MDs at [local children’s hospital]. No complaints about them. Only thing that is hard for me is that they don’t have after hours for therapy (OT), he has been missing school and getting depressed because he isn’t doing well in school.”

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

- **65%** of families felt that *they Always work together as partners with their doctors or providers to make health care decisions*, 20.9% said Usually, 9.2% said Sometimes, and 4% said Never.
- **66.8%** of families said that they *Always talk with their doctor or provider about the range of treatment and care choices for themselves and their child*, 20.3% said Usually, 9.5% said Sometimes, and 3.4% said Never.
- **64.6%** of families said that *their child’s doctor or other health care provider Always spends enough time with themselves and their child*, 25.7% said Usually, 8.2% said Sometimes, and 1.5% said Never.
- **59.7%** said that their provider *Always honors their requests for others to participate in the process that leads to decisions about care*, 20.1% said Usually, 7.8% said Sometimes, and 12.4% said Never.

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



- Only **46%** of families reported that they had been assigned a Case Manager while **20.6%** had not been assigned a Case Manager, and **22.9%** did not know.
- Out of families that were assigned a case manager, **71.4%** were Always satisfied with how their Case Manager helped them to connect their child with services in the past 12 months.



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

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

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

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

Comments from Key Informants on improving family centered care:

- Support staff for case management/care coordination
- Reimbursed time for longer visits
- Ability to make informal consults and contacts with subspecialty providers (email, phone consultation or telemedicine)
- Electronic medical record system that links with pediatric subspecialty providers.
- Support staff for case management/care coordination
- Readily available community level resources (e.g., Regional Center, Family Voices) for patients and their families to meet their social/home needs
- Reimbursed time for longer visits
- Readily available treatment guidelines for patients with specific diagnoses/conditions, e.g., autism, developmental delay.

Comments from Focus Groups (Family, Provider, and County Administrator):

- **CCS supports the involvement of families in program and policy development, but with some limitations and variation across counties (there is no standard or consistent example):**
 - “There are some counties that I heard will have family groups to hear needs of families, I don’t know how much that goes into program and policy development. I attended a Family Voices meeting last year and they were very into getting families involved in policy. We don’t here in [redacted county name] and don’t know what counties might be doing that.”

- **CCS does NOT support the involvement of families in program and policy development:**
 - “Not very. It depends on the source of care. I would give it a low grade and would give a low grade to DHCS and state CCS staff. Until legislation was passed that required advisory groups, it wouldn’t happen. In county CCS, family centeredness varies and lots of room for it [to improve].”

- In order to **engage families in a meaningful way in program and policy discussions**, CCS should:
 - **Forge trusting relationships with parent communities and community liaisons:**
 - “Supporting a parent liaison to speak for the other parents. Look in the communities where the parents are located and go to them.”
 - **Compensate families for their input and engagement at the county level (and create guidelines on doing so):**
 - “Having paid positions would really help. A guideline from the state about how to involve families at the local level...having paid parent position at state and local level.”
 - **Create standards and/or guidelines for how to facilitate family participation at the local level:**
 - “I don’t know myself as a [specialist] and a county employee, I don’t know how much I can even participate in policy, it is unclear to me so I don’t know how I would get families to participate if we don’t know ourselves.”
 - **Meet families where they are at:**
 - “Making it more accessible. We need more regional meetings or to let them be on the phone or skype – having them participate in that way because of distance and transportation [would help].”

- **CCS sometimes facilitates parent to parent support (mostly via special care centers), some other organizations do too:**
 - “There are in certain clinics and specialists [within CCS]. Pretty common to be offered.”
 - “I know don’t know, can’t even think of one time. We try to hook them up with **Family Voices (FV)**. Probably low. In [redacted county], there aren’t parent mentors that I know of, just the **FRC** and **FV**, which do have parent mentors.”
 - “Our infant program does, but that is part of the **county office of Education** so it doesn’t really fit. But a parent mentor is the first to go and start the process.”
 - “**Packard** does. They have a very formal parent mentoring program and they have asked for support to teach it to other children’s hospitals.”