MCHB Outcome & AMCHP System Outcome #1: Families of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive.

From the National Survey of CSHCN 2009/2010

Receives family centered care

<table>
<thead>
<tr>
<th></th>
<th>California %</th>
<th>Nationwide %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>61.2</td>
<td>64.6</td>
</tr>
</tbody>
</table>

Family centered care outcome successfully achieved, by insurance type

<table>
<thead>
<tr>
<th></th>
<th>Private insurance only</th>
<th>Public insurance only</th>
<th>Both public &amp; private insurance</th>
</tr>
</thead>
<tbody>
<tr>
<td>California</td>
<td>68.4</td>
<td>49.8^</td>
<td>55.0</td>
</tr>
<tr>
<td>Nationwide</td>
<td>72.5</td>
<td>55.7**</td>
<td>61.0</td>
</tr>
</tbody>
</table>

From National Survey of CSHCN 2009/2010

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

CSHCN whose families are partners in shared decision-making:

California ranks last (51st) in the nation

From FHOP Key Information Interviews 2014

Issued Raised Regarding Family-Centered Care:

- If families don’t understand the program, how can they participate?
- Need to get PCPs involved to provide family-centered care, can’t expect specialists to do it all and families need local care.

* 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
Children with Special Health
Family Centered Care

- Need a paradigm shift to more care coordination – meeting with families, doing home visits, etc...an increase of staff is needed to allow this to happen.
- Meaningful family representation on all of their committees, task force, etc. where decisions are made that affect the care of these children.
- Gap is getting the family to participate...[regional] centers could be more flexible with scheduling family time, better coordination of appointments.
- There is an unrealistic expectation about CCS can and cannot do [for families]. Need to try to help families to develop the skills to advocate for themselves.
- Families should be included in the discussion, sending something on paper doesn’t work [they need an orientation] when [a family] first gets authorized.

Parent Satisfaction with Services/Care
From the FHOP Survey of CCS Families 2014

![Parent Satisfaction with Services/Care Graph]

No Services n=359

CCS Case Management

<table>
<thead>
<tr>
<th>Does your child have a case manager?</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>2,658</td>
<td>65</td>
</tr>
<tr>
<td>No</td>
<td>526</td>
<td>13</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>698</td>
<td>17</td>
</tr>
<tr>
<td>Missing</td>
<td>183</td>
<td>5</td>
</tr>
</tbody>
</table>

From the FHOP CCS Family Survey 2014
Positive Comments
- Thank you for telling me I have a case manager.
- I appreciate the mail I get...I appreciate receiving paperwork from you.
- Everyone is always helpful and understanding. I always feel as though my concerns are heard and concerned.

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Title V CCS Needs Assessment 2015-2020 - 2 - Data Summary Sheet: Family Centered Care
Family Health Outcomes Project UCSF
Children with Special Health Family Centered Care

Challenges Raised by Families
- Many parents don’t know what this program is really about.
- Local case managers don’t really engage with parents other than for compliances and travel/med/supplies, which they do very well.
- I am unsure what to expect from CCS what services CCS provides...not sure how this program actually works.
- I would like to know more about the program. My child came to me through foster care and I did not receive info about CCS.

Specialty Care
From the FHOP CCS Family Survey 2014
Went to Special Care Center in the last 12 months?

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1956</td>
<td>49</td>
</tr>
<tr>
<td>No</td>
<td>1762</td>
<td>44</td>
</tr>
<tr>
<td>Do not know</td>
<td>295</td>
<td>7</td>
</tr>
<tr>
<td>Missing</td>
<td>52</td>
<td>1</td>
</tr>
</tbody>
</table>

Health Care Plans
From the FHOP CCS Family Survey 2014
 Been provided with a health care plan for child from doctor/nurse/clinic?

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1521</td>
<td>42</td>
</tr>
<tr>
<td>No</td>
<td>1462</td>
<td>41</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>611</td>
<td>17</td>
</tr>
</tbody>
</table>

Parent Liaisons
From the FHOP Survey of Physicians 2014

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

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Title V CCS Needs Assessment 2015-2020 - 3 -
Data Summary Sheet: Family Centered Care
Family Health Outcomes Project UCSF
Children with Special Health Family Centered Care

From the FHOP CCS Family Survey 2014

- Very little/poor communication
- Difficult getting appointments as needed due to a lack of communication (e.g., 1-lb premie had to wait 10 months for a pulmonology appointment)
- No knowledge of a CCS-sponsored case manager, who they are, how to connect, what they are for
- Little to no knowledge of services covered (or not) by CCS; lack of information in the community
- Unsure of service status
- Unsure of how CCS could help their child
- CCS staff at the same facility provide different answers to the same question from the same family about the same child
- Unsure of who to contact and how depending upon what the issue is (e.g., care provider, case manager, care coordinator, nurse, administrator); may not know who to contact for an issue and if they know who to contact, they don't know how to do so.
- Service lapse when families do not receive renewal notices

FHOP CCS Family Focus Groups & Survey

- Not enough phone contact for follow-up regarding administration.
- I would like to have a case coordinator. I would like to learn more about CCS. What programs do they offer that can help with my daughter's condition?
- There is a communication breakdown among providers...no one runs the system...there's no communication between specialists.
- How would you [parents, families] know what questions and how to ask the questions?

Overall Satisfaction with CCS Services

From the FHOP CCS Family Survey 2014

- 0 being not at all satisfied
- 10 being very satisfied

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