

## Children with Special Health Care Needs Transition to Adulthood

**MCHB Core Outcome & AMCHP Systems Outcome #6: Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.**

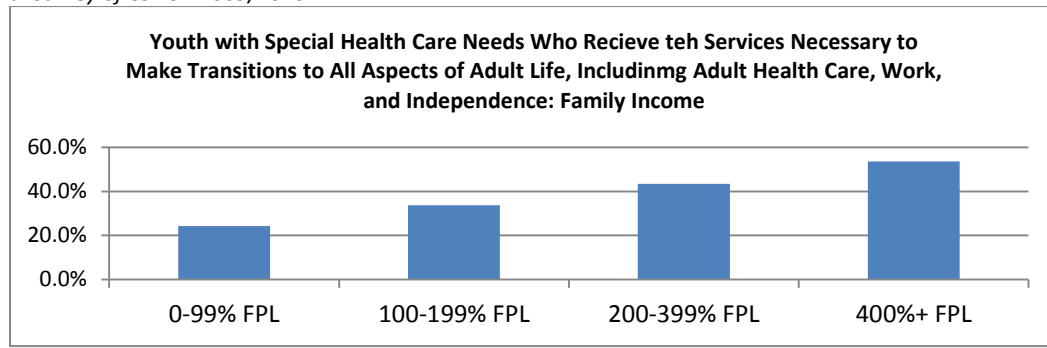
From National Survey of CSHCN 2009/2010

- 37.1% of youth in California and 41.2% of youth nationwide achieved this outcome (not a significant difference).

Youth who did not receive services necessary to make appropriate transitions to adult health care, work and independence (CSHCN 12-17 years only)

	Hispanic	White, non- Hispanic	Black, non-Hispanic	Other, non-Hispanic
California %	77.9 <sup>^</sup>	49.6	84.1 <sup>^</sup>	47.2
Nationwide %	74.7 <sup>**</sup>	54.3	71.9 <sup>**</sup>	59.8

From National Survey of CSHCN 2009/2010



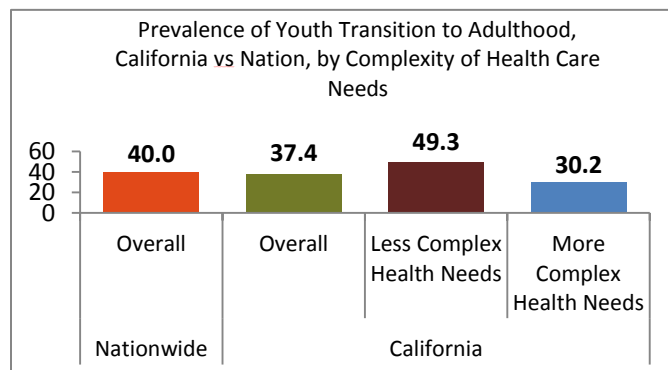
FPL = Federal Poverty Level. In 2005, the DHHS poverty guidelines defined 100% of poverty as \$19,350 for a family of four.

From "Children with Special Health Care Needs: A Profile of Key Issues in California" (Bethell, 2014)

DATA SOURCE: 2009/10 National Survey of Children with Special Health Care Needs

California ranks 45<sup>th</sup> in the nation for transition to adulthood

**Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work and independence -- CSHCN age 12-17 years only**



Components of Youth Transition in California:

**Anticipatory Guidance:** Over half of adolescents (58.4%) did not get all needed anticipatory guidance

- Discuss shift to adult health care providers
- Discuss changing health needs as youth becomes an adult
- Discuss health insurance as youth becomes an adult

**Self-Management Skills:** Almost ¾ of adolescents have doctors who encourage self-management skills (73.7%)

- Older youth are more likely to be encouraged (12-14: 65.4%; 15-17: 81.2%)

\* Difference between CA and Nation significant at  $p < .05$

\*\* Differences within the Nation significant at  $p < .05$  (w/ Hispanic as reference group)

<sup>^</sup> Difference within the State significant at  $p < .05$

### Transition from the Family Perspective

From the FHOP Survey of CCS Families 2014

- 34% of respondents had a child that is 14 years or older
- 28% of those with a child 14+ report providers talking to them about how their child's health care needs will be met when he/she turns 21
- 15% of those with a child 14+ report CCS helping to find an adult provider
  - Of those reporting CCS help finding an adult provider, 80% were successful
- 71% of those with a child 14+ would find more information on transition helpful

### Transition Comments

- Issue/Concern
  - Dissatisfaction with transition help or lack thereof
  - Scared as to what will happen when child "ages-out"
  - Lack of information
  - Discrimination felt from CCS staff by Spanish-speaking family members
- Suggestions
  - Continue to educate families on transition services
  - Help needed in finding appropriate adult service providers
- *It will be sad when [my son] is 21 and it will be gone...they make a big difference in my son's life.*
- *I pray when she gets to be an adult, she gets services equal to CCS.*

From the FHOP CCS Family Focus Groups 2014

- Not enough education and information available to clients, families, and providers as to how to go about transitioning CCS clients to adult care; it's a complicated process
  - *Transitioning for me was personally hard. Thank god I had my mom that knew everything I needed to get done. So much paperwork that I wouldn't have known how to do. The state needs to make it easier for people without support to transition. If I didn't have my mom for support I wouldn't have had any idea how to transition to adult providers. We should stay on CCS until we get another type of coverage – on dad's private insurance until 26 but when he ages out he won't have anything else. The private insurance doesn't cover the same things that CCS covers.*
- Should extend care to cover until client is 26 years old (e.g., Diabetes) with some extend until they are 65 years old when Medicaid takes over (e.g., Sickle Cell Anemia)
  - *My...daughter is 23, she's transitioned out and she has nothing. She figured out yesterday that should could do needle exchange program for heroin addicts and exchange needles for diabetes...I would like to see CCS program expand and help kids get through school to help them function in society so they can finish school and get a job.*
- Should change language to be about meeting 'milestones' not transitions and have it be a celebratory process of moving from one phase to the next
  - *Should be at every age level, not just when aging out (e.g., early intervention, elementary school, etc.); better planning will make it easier for everyone.*
  - *Should have therapy ongoing because things change as they age.*
- Tremendous fear of losing services and care that families are completely dependent upon
  - *I am terrified of what's coming when my daughter turns 20...it's an extreme problem that no one is telling anyone how to do it.*
  - *I'm nervous because I'm afraid of all of the things I am going to lose. Just because they've aged, their medical needs haven't changed.*

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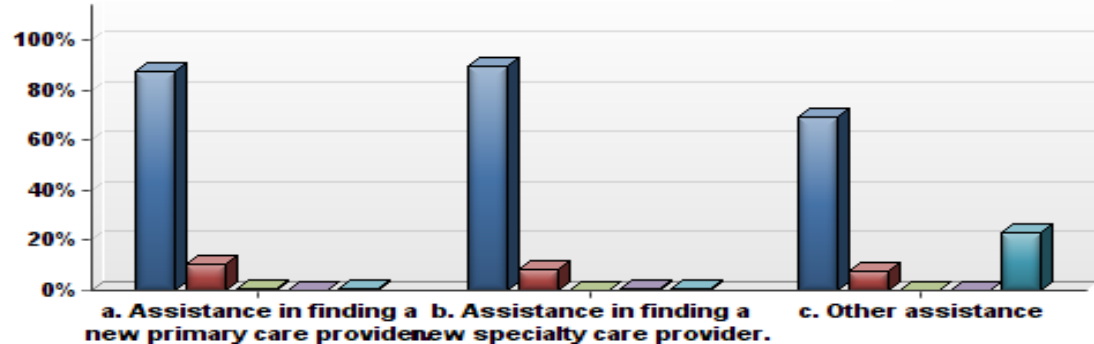
### Transition from the Provider/Program Perspective

From the FHOP Survey of CCS Physicians 2014

- 88% of respondents believe that the multidisciplinary team for transition age CCS clients should include both pediatrician(s) and an internist to help facilitate transition
- 58% of respondents believe that eligibility for certain CCS conditions should be extended to 65 years

Youth/young adults with Medi-Cal aging out of CCS would benefit from:

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



What is Needed:

- *Clearly defined transition programs...developing a much more systematic method for transition of care to adult...[including] feedback from young adults who have transitioned to adult care.*
- *Improving the transition from pediatric to adult care once the patient turns 21 years old. It is very difficult to find primary care providers for these patients. Some of the reasons are financial - the primary care doctor just doesn't receive enough reimbursement for the amount of time a patient may need, specialists either are not familiar with pediatric conditions that now can be survived into adulthood and/or unwilling to accept the low reimbursement.*

From the FHOP CCS Provider Focus Group 2014

- *Unmitigated disaster...there is a no transition, your services end on your birthday.*
- Greatest challenge is finding adult specialists willing to accept clients who have 'aged-out' of CCS
  - *There are no places that want to receive these kids.*
- MediCal Managed Care plans should take the lead and ensure there is a transition plan, train providers and patients appropriately, and take responsibility for kids CCS clients
  - *It's not CCS' fault...they are trying but there is a lack of financial and overall incentive to make sure the kids have a place to go.*
  - *There's no community that takes full responsibility for transitioning these kids.*
- CCS vs. GHPP Transitioning – should occur across the life span
  - *Why is the CCS transition not the same as GHPP [Genetically Handicapped Persons Program]? Why isn't CCS taking the time to align kids as GHPP does?*
- Positive and negative reactions to extending CCS past 21 years of age
  - Some conditions should qualify until 65 years of age when Medicare would take over (e.g., neurological conditions, Sickle Cell Anemia)
  - Keeping patients from 21-25 years of age would be a burden to handle as they continue to become even more complex
    - Pediatric nurses are not comfortable providing care to adults (18+ years)
    - Adults (18+ years) patients do not want to go to a pediatric facility

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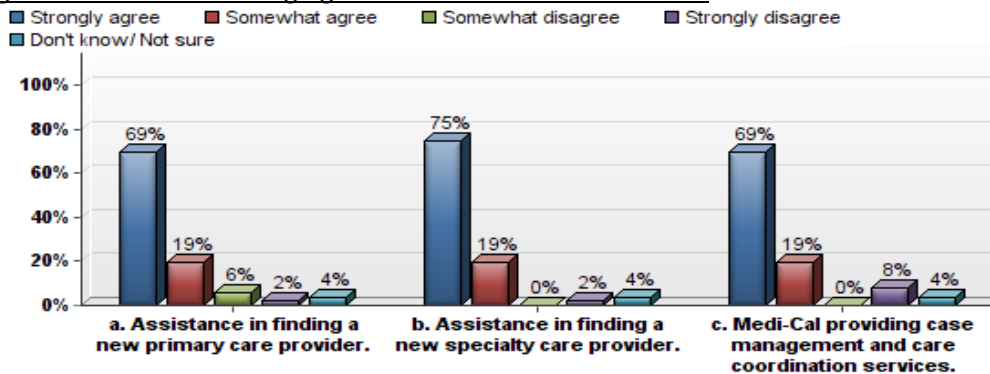
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## Children with Special Health Care Needs Transition to Adulthood

From the FHOP CCS Administrators/Medical Consultants Survey 2014

- 65% of respondents believe multidisciplinary team for transition age CCS clients should include both pediatrician(s) and an internist to help facilitate transition, and 29% don't know or aren't sure.

Youth/young adults with Medi-Cal aging out of CCS would benefit from:



What Works:

- We've augmented our annual transition fair to a transition conference, which entails transitioning into and out of CCS.
- We have a parent liaison that works closely with our families and helps them with any problems they may experience in finding community resources. She also attempts to contact each young adult who is transitioning out of CCS to assist them with any transitioning problems or questions they may have.

Assistance Needed:

- A complete Resource List outlining the different agencies and programs available to transitioning clients with special needs.
- Clients transitioning...should have a care coordination team and a transitional period in both programs in order to ensure clients do not experience a gap in services.
- Hospital or tertiary care center for emergencies or procedures and for young adults with Oncology diagnosis who will need lifetime surveillance.
- Special Care Centers...need to actively transition clients and if adult providers are untrained to accept them, train them in the SCC...till we have [enough] trained adult providers.

Comments:

- Clients transitioning in to other programs such as GHPP should have a care coordination team and a transitional period in both programs in order to ensure clients do not experience a gap in services. When the CCS Program closes all authorizations are cancelled. Currently, the GHPP program requires the CCS case be closed before their program will accept a referral. CCS closes the day before their 21st birthday and a client only receives authorizations for medications and services until that day. Therefore the client transfers to a new program without any medications and no transitional plan to ensure expedited authorization or services are available. Clients go months without medications being authorized due to program regulations between managed care and GHPP

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

- Needs to be much more support for families as they transition both in AND out of CCS
  - There are multiple times during the life of a CCS client where the client 'transitions'; considering renaming these transitions as 'milestones'
    - Encourage families to come and celebrate the milestones of their child's life and then use it as an opportunity to learn about the next phase/step.

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## Children with Special Health Care Needs Transition to Adulthood

- 18-21 year olds fall into a gap – still 'kids', but want to be adults
  - Changing the age of CCS coverage
    - Stop CCS at 18 years of age so that clients can transition to adult providers at 18
    - Continue CCS until 25-26 years of age to maintain coverage similar to ACA
    - Maintain some conditions under CCS until age 65 when MediCare takes over
  - Additional challenges
    - Difficult to find appropriate providers; once found patients are constant no-shows
    - Pregnant and parenting CCS clients – who will see them and for what?
    - Involvement with the criminal justice system

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1. 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 [12/31/2014] from [www.childhealthdata.org](http://www.childhealthdata.org).

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Title V CCS Needs Assessment 2014 - 5 -  
Data Summary Sheet: Transition

Family Health Outcomes Project UCSF