



Transition to Adult Care

MCHB Goal: Families and providers plan for transition to adult care and services.

Transition Definitions:

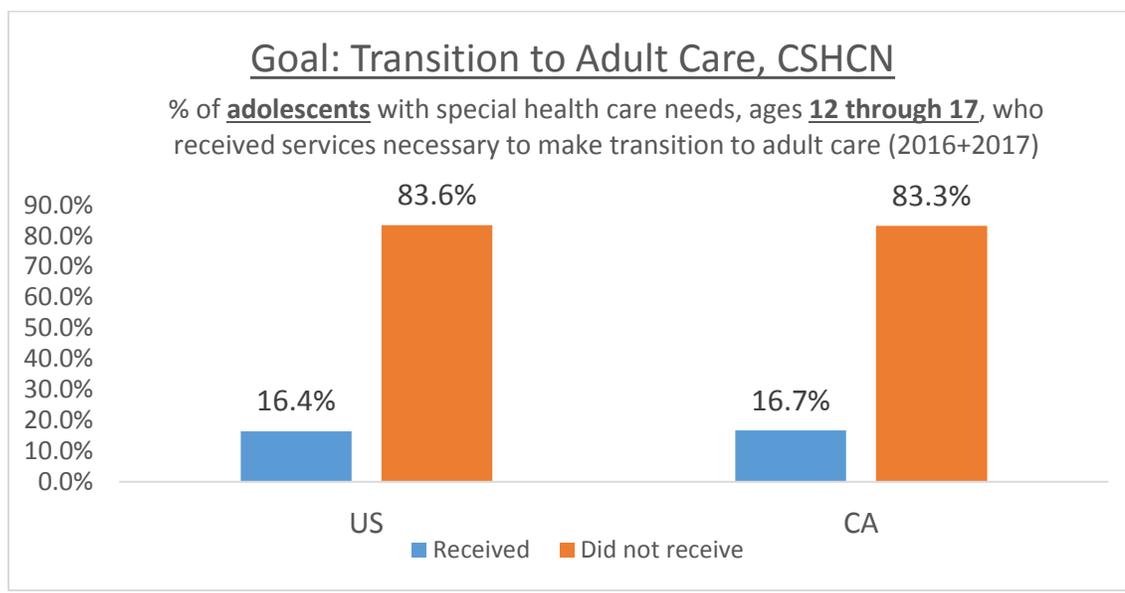
Children and Youth with Special Health Care Needs (CYSHCN) are only eligible for CCS services until they are 21 years old. CCS mandates that CYSHCN and their families are adequately prepared for transition to adult care once CYSHCN age out.

Data on Transition (NSCH):

Data from the National Survey on Children's Health, 2016/2017):

National Survey of Children's Health 2016 & 2017 (Source: Child and Adolescent Health Measurement Initiative)

The percentage of adolescents with SHCN who have received the services necessary to transition to all aspects of adult life, including adult health care, work, and independence.



- Definition of this measure: In order to meet the criteria for this measure, youth with special health care needs 12-17 years old must meet three components: 1) doctor spoke with child privately without an adult in the room during last preventive check-up; 2) if a discussion about transitioning to adult care was needed it must have happened; and 3) doctors actively worked with child to gain skills and understand changes in their health care. If a child has at least one valid positive response to any of these components and the remainder of the components were missing or legitimately skipped, these children were categorized as receiving adequate transition to adult health care in the 2017 scoring of this measure



- Similar to the medical home data, both of California’s rates have wide confidence intervals so you’ll need to proceed with caution when looking at this data, HOWEVER CIs do overlap with the US, so the rates are probably similar, which is represented here in this slide.
- In consideration of that, the rate for adolescents with special health care needs that are not receiving necessary transition services is notably high and concerning.
- California is ranked 19th for this performance measure (19th at providing necessary transition criteria)

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

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

Is your child 14 years or older?	%
Yes	27.1
No	62.5
Missing	10.4

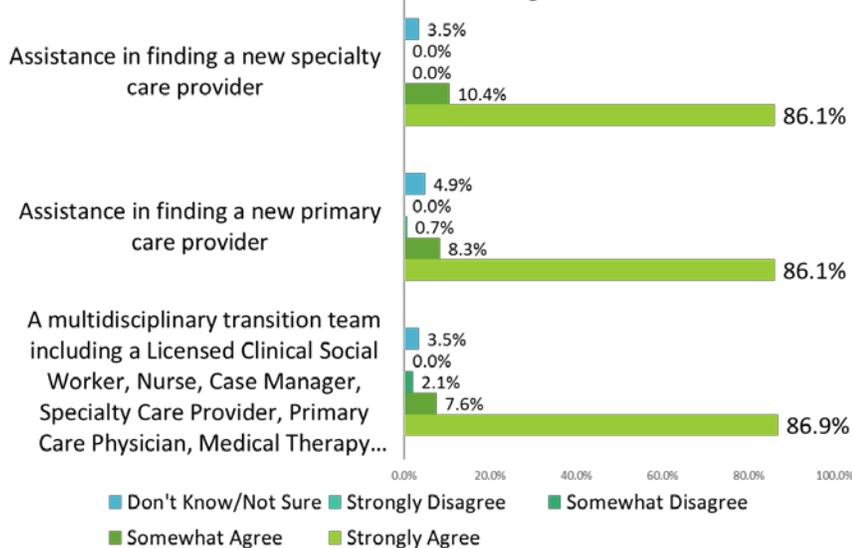
Have doctors or other health care providers talked with your child about how their health care needs will be met when your child turns 21?	%
Yes	36.7
No	48.5
Do not know	11.5
Missing	3.2

Have any of the following people or organizations helped your child find an adult medical provider? Check all that apply:	%
CCS	22.2
Health Plan	13.8
Our Pediatrician	13.5
None of the above	47.2

If yes, were you able to find an adult doctor or provider?	%
Yes	20.7
No	4.2
Do not know	9.3
Missing	1.9

Data from Provider Survey (N = 188):

Youth who have aged out of CCS and have Medi-Cal would benefit from having:



Strategies to improve transition:

- Pediatric providers/specialists see CYSHCN into adulthood
- Telehealth
- More family engagement from CCS
- More collaboration & partnership between pediatric & adult providers
- Providers need to start discussing transition at age 14
- Outside funding for specialized transition programs (which some have already)



Provider Focus Group Comments:

Focus group themes:

- Very hard to find a provider to see CCS clients as they age out, especially with Medi-Cal insurance
- Lack of transition planning
- Lack of adult specialists with expertise in conditions originating in childhood

Focus Group Comments:

- “For pediatric and adult world it is day and night. We noticed when they transition it is hard to find a provider that understands the complexities of their disease, we have a lot of kids bouncing back and asking to be seen by us after transition. Need a smoother transition.”
- “We are trying to partner with providers in outlying counties that may only see one HIV transition special health care needs kid, and they may only call them once and if they don’t show up, they say that is ‘too bad’ because they are adults and they can take care of themselves. We’ve had several patients die in the last ten years because of this, because they have had 10-12 regimens in their lifetime and the MDs don’t have the capacity or the support groups to deal with the ‘born with HIV’ population, they don’t fit into the behavioral health support groups for this.”
- “The cost of living in big cities is prohibitive so these complex patients are moving farther and farther from adequate children’s hospitals—so even if we could provide transition help, they aren’t close enough to help them.”

CCS County Administrators and Health Plans Focus Group Comments:

- “The other issue that we faced is that PCPs in the community were afraid to take on complex kids as adults.”
- Unsure of how transition will be affected by WCM, but some HPs have plans in place: “Our plan has a three-year follow-up period. So at a minimum they have to check in once a year.”

Key Informant Interview Comments:

Summary of comments on how well families and adolescents are prepared for transition both in and out of CCS:

- Transition is **always complicated**—it is **consistently hard to find adult providers for individuals with special health care needs**, but *sometimes* specialty centers or specialty programs create a ‘safety net’ for transition, but they take years to establish and are only for very small portions of the special health care needs population, and *sometimes* these programs are doing it under CCS direction, but that isn’t common or consistent:
 - “In specialty centers, we have a process to transition to adult specialty care but not so much with primary care. We have a good process and start early and document well...I’m not sure what CCS does with those transitioning. In pilot [WCM pilot], they should be working on both primary and specialty care get transition services.”
 - “Very difficult. There have been some efforts, but it is a systems issues and people have to be on the same page. If CCS is trying to get hospitals to play with them around transition and the hospital doesn’t want to do it, it is a big loss to kids. **Not a requirement.** Lots of work for CCS to do to change the system.” **(Please Note: it is, in fact, a requirement.)**



- “So many working on it but not sure it gets done. There are three challenges: first, make sure kid is adequately engaged in providing their own self-care. Two, adequate adult providers to take care of kids – especially ones that take Medi-Cal, and three – couldn’t we all have a shared consolidated plan? Each entity could take a part e.g. health plan, SSC, etc.”
- “I am unaware of any. But a good idea.”
- **The majority of CYSHCN and adults with SHCN experience gaps when they age out of CCS, and it seems to be similar for non-CCS populations as well:**
 - “Yes, gaps in every disease state. Not enough providers. If they had a **common transition database** that all could work with and the various agencies that work with child.”
 - **“There is no system for kids aging out.”**
 - “On the private insurance side, there is such a lack of understanding about how this works, especially with SHCN, they are not prepared for what it takes to navigate and make this transition.”
- **Suggestions to improve transition services for CCS clients:**
 - **Keep patients into adulthood, forget about age requirements:**
 - “In my practice, **I treat the condition not the ages**. Patients don’t want to leave and we never ask them to. The majority of them over are 18, and I do take Medi-cal.”
 - **Have dedicated staff whose only job is transition:**
 - “[Redacted county] has someone dedicated to this.”
 - **Create a training for all staff and providers within CCS or guidelines, and standards/guidelines within CCS:**
 - “There needs to be a curriculum for training staff and providers. Needs to start early, it always sneaks up on people.”
 - “Needs to be a definition of what are appropriate and best practice activities for transition. Statewide policies and guidelines.”
 - **Teach families and teenagers how to advocate for themselves before transition age hits, because nobody else is there to help with transition:**
 - “Building advocacy skills for child and family...But they are teenagers so there are challenges with self-care. Not a lot of follow-up to make sure that they are getting adult services and getting access – no accountability.”
 - **Each county having a directory of providers that are comfortable with adult SHCN:**
 - “Nice if each county could have a resources manual or list of PCPs comfortable taking care of aging out CYSCHN. For example, GYN is hard since most providers don’t feel comfortable seeing [special needs individuals for that]. **Building out network of adults providers.**”
 - “...There isn’t a warm hand off. It would be excellent if they all knew who each other was.”
 - **Get Medi-Cal to pay more for transition services:**
 - “Not sure how to address the issue of finding adult providers – real dilemma. CCS could do training programs or **get Medicaid to provide enhanced payment**. Planning and educating would be easier. Also, other human services are paid for by the state think about transitioning.”