Appendix 14
Physician Focus Group Summary

CCS Title V 2015-2020 Needs Assessment

Physician Focus Group Summary

A provider focus group lasting approximately 60 minutes was conducted in-person in November 2014 in Southern California. The CCS Title V Stakeholder Physician Survey and Focus Group Subcommittee provided input on the focus group guide and Stakeholders from Southern California assisted in recruiting participants. The provider focus group was conducted with 6 participants all of whom are medical doctors and specialists providing care to CCS-enrolled children.

Qs. #1: Care Coordination Barriers and Impact on Quality of Care

- CCS should include care coordination in the medical primary care setting and cover the whole child to remove barriers to care coordination
  - Eligibilities are ‘slicing and dicing’ instead of taking care of whole kid...they qualify you on some things but not on overall condition. CCS doesn’t think that they’re charge to provide care for whole child, [even though the] capacity is there, the challenge is to get resources and billing is difficult and burdensome.
- Communication with CCS is limited to providers and not with families
  - Families get denial letters and they are difficult to understand.
  - CCS is more passive...they wait until the ‘squeaky wheel’ keeps squeaking, but not so much of an active process.
- Providers have the capacity to bill for care coordination, but it’s a complicated process
  - Billing is many steps and its complicated...this is burdensome.
  - It seems like there are resource available for care coordination, but all the hoops you have to jump through make it challenging to access.
  - In the High Risk Infant Follow-up (HRIF) program, linking across systems takes management and if not a priority for CCS, [we would] have to bill individual clients to make it happen.

Qs. #2: Experience with MediCal Managed Care Plans

- Unnecessarily challenging; very difficult to determine who is responsible for what
  - The dilemma is the way the inclusion criteria are set up.
  - Irony that seems like dollars start at the top at the same place and trickle-down to the same client, but [monies] have to be fought over in the middle [by the families].
- It ends up being a lot more work than necessary and delays care for patients
  - We do a good job of taking care of whoever is in front of us, but spend a lot of time going in circles to figure out who is paying for it.
  - Case managers have appointments with families to just help them understand the program, which delays care.
- Longest delays occur with DME and delay hospital discharges and allowing for children to attend school
  - Prosthetic example: DME shop will make prosthetic but won’t release it until they get paid by MediCal or CCS, and by the time they decide who pays for it the kid has outgrown the prosthetic
Wheelchair example: process of obtaining a wheelchair took months and it prevented the child from attending school

Qs. #3-4: Access to a Medical Home and Resources Needed to Provide a Medical Home
- In theory, they’re supposed to have a medical home under MediCal Managed Care, but in practice their ability to provide care is limited
  - Most patients have primary care providers, but patients don’t have confidence in using them so they come to the SCC anyway.
  - [In practice,] we’re the medical home but communication with the primary care provider is lacking.
- Education for providers, access to care coordination and co-care models, and increased access to funding are resources needed to provide medical home in the community

Qs. #5: Experience and/or Knowledge regarding CCS Clients Transitioning to Adult Care
- 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 isn’t 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 kids from 21-25 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

Qs. #6: Communication among Providers
- [Within the] four walls of CHLA, it’s easy to get/stay in touch with providers and...it works well until the age of 18.
- MTU is biggest challenge
It’s a magic black box where great things happen, but there is a lack of understanding of what actually gets done there.

Qs. #7: Communication with Decision Makers
- Very responsive to providers while patient access is limited
  - Families don’t know what to do with denial letters, so they bring them to physicians [and nurses] because providers are rarely rejected.
- Eligibility criteria/paperwork hinders process; can be onerous

Qs. #8: Priorities for CCS Program Improvement for next 5 Years
- Data demonstrating outcomes for kids in the program to show value of a program that’s largely underappreciated working in conjunction with and/or duplicating proven methods
  - CCS keeps amazingly low profile, too low of a profile to inform the general State population. If they blew their own horn a little bit more, the general population would gain more acceptability and...maybe they would have more solidified funding and more constituents supporting them.
- Transition including places for connecting pediatric and adult providers easily
  - If you want in on the CCS program, you have to provide transition care.

OTHER: Biggest Challenge for the CCS Program
- Eligibility needs to be an updated, simpler process
  - There’s not a lot of support form the State side...State doesn’t seem to know what to do with CCS.
  - We’ve carved it down too far...eligibility requirements need to be revisited and updated.