CCS Title V Needs Assessment Key Informant Interview Guide
(For Interviewers)

[Introduction explaining the process and objective of the interview as well as confidentiality protocols]

Expected length of time: 60 to 90 minutes

Thank you very much for taking the time out of your day to contribute to our Needs Assessment process as a Key Informant. We will be asking you in-depth questions about programs that serve Children and Youth with Special Health Care Needs (CYSHCN) in California in order to inform our needs assessment. There are many questions in this interview guide, and some questions may not be applicable given your role/knowledge/experience. If a question doesn't seem applicable or you would prefer not to answer it, please feel free to say so and we will move on to the next question.

For the purposes of this interview, CYSHCN is defined by MCHB (maternal child health bureau) as "Children and youth with special health care needs (CSHCN or CYSHCN) have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally."

For interviewer: PROBES are optional and you may not have time to ask many, only use if needed. Definitions do not need to be read either – only read if needed.

CCS Program, Administration, and Funding

1. What do you believe are the strengths of the CCS program? Why?
   - *Probe 1:* In what areas does CCS meet the needs of the clients the best?
   - *Probe 2:* How is CCS meeting the needs of the clients?
   - *Probe 3:* Why do you think CCS is successful in these areas?
2. What is your opinion about the existing CCS standards? (note to person conducting the interview: this links you out to Provider Standards, there are different areas in CCS with different standards for different conditions)
   - *Probe 1:* What do the CCS standards accomplish?
   - *Probe 2:* How would you like to see the CCS standards done differently, if at all?

3. How well are CCS rules and regulations applied consistently across counties? [Note: some respondents may not have knowledge on this topic; if so, ok to move on to next question.]
   - *Probe 1:* What impact, if any, have you seen related to the inconsistent application of CCS rules and regulations across counties?
   - *Probe 2:* Please provide examples of any inconsistency of which you are aware regarding the application of CCS rules and regulations across counties by providers and/or administrators of CCS services. Please be specific, such as care coordination (different from client to client) vs. issues with administration.
4. What comments do you have regarding financial eligibility ($40K/year/family OR medical costs =

over 20% of family's yearly income) for CCS?

5. What comments do you have regarding medical eligibility for CCS (this link lists all eligible disorders)?
   Probe 1: What do you think about CCS covering the 'one-and-done' conditions (examples: some bone fractures, traumas, poisoning, neonatal care etc.)?
6. What is your opinion regarding Medi-Cal reimbursement rates for CCS authorized services – including clinical care, diagnostic tests, durable medical equipment, and pharmaceuticals? Do you think the rates are appropriately structured to support optimal care? Why or why not? How should they be changed, if at all?
   Probe 1: What impact of provider rates, if any, is there on access to care in CCS and Medi-Cal?
   Probe 2: Please describe any unintended consequences due, in part, to the way in which reimbursement rates are currently structured.
   Probe 3: What do you think about enhanced payment to primary care practices that serve CCS enrollees?
7. What has been *your* experience with collecting, accessing, and/or using data that is meaningful to you and relevant to CCS clients and CYSHCN?
   Probe 1: How important is having accessible and relevant data to serve CCS clients?
   Probe 2: What, if anything, needs to be done to address any possible gaps in data relevant to CCS clients?
   Probe 3: What additional data, if any, would be helpful or that should be available?
8. What data should be collected that would be meaningful to you concerning CCS children and/or CYSHCN?
9. What is your opinion regarding CCS's role as an approver of facilities as it currently stands? How, if at all, could the state improve upon how facilities are currently approved to provide CCS services?
   Probe 1: What other entity, if any, could/should be the approver of facilities that provide CCS services? Why?
10. Are there any new special care center designations that you would recommend and why?

Access to and Quality Care

Definition of *quality of care*: Care that is…1) **Safe**: avoiding injuries to patients from the care that is intended to help them; 2) **Effective**: providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit; 3) **Patient & family-centered**: providing care that is respectful of and responsive to individual and family preferences, needs and values and ensuring that patient values guide all clinical decisions; 4) **Timely**: reducing waits and sometimes harmful delays for both those who receive and those who give care; 5) **Efficient**: avoiding waste, including waste of equipment, supplies, ideas and energy; and 6) **Equitable**: providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status (National Committee for Quality Assurance-NCQA; MCHB/HRSA, http://mchb.hrsa.gov/research/strategic_definitions.asp).

*Before asking these questions, clearly state that the "care" we are asking about is specialty care, primary care, emergency care, oral health care, DME (Durable Medical Equipment), and therapies for

CYSHCN both within and outside of CCS and if they are referring to anything outside of these modes of care, it would be helpful to note that.*

11. What challenges, if any, have you encountered when dealing with access to care for CCS clients? And, what about access to care for other CYSHCN not enrolled in CCS?
    - *Probe 1:* What is your overall feeling about access to care for CCS clients?
    - *Probe 2:* What challenges, if any, have you encountered in regard to accessing flexible, reliable, and consistent services for CCS clients?
    - *Probe 3:* What areas are successful or need improvement in regard to accessing care for CCS clients? For CYSHCN? Why? How?
12. What do you see as the greatest barriers to accessing care for CCS clients and how might we overcome them? For non-CCS CYSHCN?
    - *Probe 1:* Why is [x], [y], and/or [z] the greatest barrier?
    - *Probe 2:* What would it look like if these barriers were overcome?
    - *Probe 3:* Who is responsible for addressing the barriers? Why?
    - *Probe 4:* Are the barriers different for non-CSHNCN? Why?
13. What do you think about the quality of specialty medical care provided to CCS clients? For non-CCS CYSHCN?
    - *Probe 1:* What is your overall feeling about access to quality of specialty medical care for CCS clients?
    - *Probe 2:* What barriers, if any, have you faced in regard to access to quality, flexible, reliable, and consistent services for CCS clients?
    - *Probe 3:* What areas are successful or need improvement in regard to accessing quality of specialty medical care for CCS clients? Why? How?
14. What do you think about the quality of preventative care, acute care, and/or primary care provided by CCS providers to CCS clients and their families? For non-CCS CYSHCN?
    - *Probe 1:* What role, if any, should CCS have in regard to training of primary care providers? What role, if any, should CCS have in maintaining a high quality of care provided by primary care providers to CCS clients?
    - *Probe 2:* What strategies could CCS undertake to address gaps and/or areas of weakness?
    - *Probe 3:* How could CCS sustain and bolster existing areas in which training and quality of care by primary care providers to CCS clients is seen as strong?
    - *Probe 4:* If it is not the role of CCS, who should be responsible for ensuring quality of care and necessary training of primary care providers for CCS clients when specialists are not available? Why?
15. What, if any, health disparities have you observed in access to quality care (including mental and oral health care)? Furthermore, have you noticed subsequent health outcomes based on race, ethnicity, creed, health literacy, geography, income, insurance type, etc.?
    - *Probe 1:* Have you observed or do you know about disparities in access to mental health care for the families of CYSHCN and CCS children?
    - *Probe 2:* Do you have any recommendations or can you think of times when you've seen disparities addressed successfully?
16. What challenges, if any, are there in recruiting and maintaining healthcare providers [Note: specify

the type or provider, as needed dependent upon the audience, during the interview (e.g. medical and/or therapeutic providers).]? What obstacles could prevent the recruitment and retention of qualified healthcare providers for CCS children? Why?

Probe 1: Why is [x], [y], and/or [z] a barrier?
Probe 2: How can the barrier(s) be overcome?
Probe 3: Who is responsible for recruiting and maintaining healthcare providers? Why? How?
Probe 4: How might this be the same/different when referring to other types of providers (e.g., pharmaceutical, oral, vision, audiology, DME providers, etc.)?

17. How well are CCS clients able to access medically necessary durable medical equipment, medical supplies, and other services?

Probe 1: How well are clients able to access equipment in a timely fashion?
Probe 2: What barriers, if any, are there to accessing DME?
Probe 3: What ideas do you have for addressing those barriers?
Probe 4: What problems have you observed in accessing DME?

Care Coordination/Wrap-Around Services/Holistic Approach

[Note of clarification, if needed: 1) medical case management is LESS inclusive than care coordination and 2) care coordination is MORE than just case management.] I will define both case management and care coordination first thing, they are often difficult to differentiate between so please let me know if you would like me to reference the definitions again as we go through the questions.

Definition of a *case manager*: Case managers are advocates who help patients understand their current health status, what they can do about it and why those treatments are important. In this way, case managers are catalysts by guiding patients and providing cohesion to other professionals in the health care delivery team, enabling their clients to achieve goals more effectively and efficiently (e.g., treatment plan, service authorization, monitoring care for CCS- eligible condition). (Case Management Society of America, CMSA; http://www.cmsa.org/;)

CCS Case management services: Services include referrals to medical specialists and centers, help to coordinate care with schools, public health/school nurses, social workers, and other agencies, transferring medical records, locating new facilities and services when needed, and assisting families to cope with a child's condition. During the last CCS Needs Assessment, it was determined that many parents were unaware that they had access to a case manager.

Definition of *care coordination*: Care coordination is a family-centered, team-based, interdisciplinary activity guided by an individualized care plan designed to meet the needs of children and youth while supporting and enhancing the care-giving capabilities of families. Care coordination are those services that promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families (Lucile Packard Foundation for Children's Health, http://lpfch-cshcn.org/glossary/care-coordination/ and MCHB/HRSA, http://mchb.hrsa.gov/research/strategic_definitions.asp)

18. In your experience, how well do County CCS Programs do case management for CCS clients?
19. What do you see as the main barriers to better case management for CCS clients?
20. How should case management be improved, if at all?
21. Have you observed or experienced variability in the amount and quality of case management in different counties? If so, how has it varied and how should it be addressed, if at all?

Questions on *care coordination*:

22. In your experience, who coordinates care for CCS clients? Does that care coordination meet the needs of the patient population and their families?
23. In your experience, how well coordinated is the care for CCS clients?
24. What do you see as the main barriers to better care coordination for CCS clients and how could care coordination be improved?

Definition of *medical home*: A medical home is a model for organizing health care so it is continuous comprehensive, coordinated and family-centered care in the child's community…[it is a] collaboration among health care professionals and other agencies and service providers assisting these families. [A medical home] provides the services that constitute comprehensive care – continuous access to medical care; referral to pediatric medical subspecialties and surgical specialists; and interaction with child care, early childhood education programs and schools to ensure that the special needs of the child and family are addressed (Lucile Packard Foundation for Children's Health, http://lpfch-cshcn.org/glossary/medical-home/ and The American Academy of Pediatrics; MCHB/HRSA, http://mchb.hrsa.gov/research/strategic_definitions.asp, accessed June 18, 2014)

25. From your perspective, how many CCS clients and non-CCS, CYSHCN have a *medical home*?
    Probe 1: What is the goal of a medical home for CCS clients or non-CCS CYSHCN? What would a good medical home look like?
    Probe 2: Who is responsible for providing a medical home for these populations?
    Probe 3: What would you like seen done differently, if anything? Why? How?
    Probe 4: Should primary care practices or special care centers serving as medical homes be required to meet certification standards for medical home status? Should CCS/Medicaid offer enhanced payment for medical home certified practices?

Definition of *family-centered care*: Family-centered care is a standard of practice in which families are respected as equal partners by health professionals. Families and providers work together to create a care plan and families' needs are incorporated into the delivery of health care services. Families also receive timely, complete and accurate information in order to participate in shared decision-making. Family-centered care is based on the understanding that the family is at the center of the child's health and well-being and emphasizes the strengths, cultures, traditions, and expertise that each individual brings to the relationship. (Lucile Packard Foundation for Children's Health, http://lpfch-cshcn.org/glossary/family-centered-care/, accessed June 18, 2014)

26. How family-centered is the care for CCS clients?
    Probe 1: As you understand it, what is the goal of family-centered care for CCS clients? What does appropriate family-centered care look like for CCS clients?
    Probe 2: How can we improve the family centeredness of care for CCS clients?
    Probe 3: This question as it applies to non-CCS CYSHCN
    Probe 4: Can you provide some examples of family-centered care that you have experienced or participated in at the local level.
27. How is family capacity (capacity = resources and circumstances) considered when meeting the needs of the CCS or non-CCS CYSHCN client?
28. How do you feel about the way in which CCS services meet (or doesn't meet) the emotional, social, and developmental needs of CCS clients?
    Probe 1: What should be the goal of CCS in meeting these needs of the CCS clients?
29. How well, within the State, do you feel that the emotional, social, and developmental needs of CYSHCN are being met?
30. How well, within the State, do you feel that the emotional, social, and developmental needs of the families of CYSHCN being met?
31. How would you change, if at all, the continuity and coordination of care and services for CCS clients to make them more family centered?
32. How would you change, if at all, the continuity and coordination of care and services to make them more family centered for non-CCS, CYSHCN?
    Probe 1: do you see a difference in either CCS or non-CCS CYSHCN continuity and coordination of care and services in private vs. public insurance?
33. How well does CCS support the participation of families in program and policy development and implementation? What does CCS do to bring families to the table?
34. What could CCS do to increase the participation of families in program and policy discussions?
35. Do you know how often parents of newly diagnosed children are referred or connected to a parent mentor?
36. Do you know if any of Children's hospitals, NICUs or pediatric practices have policies or protocols in place to refer or connect parents of newly diagnosed children to a parent mentor?

Transitioning Adolescents

Definition of *transitioning adolescents*: Transition in health care for young adults with special health care needs is a dynamic, lifelong process that seeks to meet their individual needs as they move from childhood to adulthood. The goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. It is patient centered, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination.

Physicians are of special importance in this process because of the frequent contact with many of these

young people and the close relationships that often develop with them and their families.
A well-timed transition from child-oriented to adult-oriented health care allows young people to optimize their ability to assume adult roles and functioning. For many young people with special health care needs, this will mean a transfer from a child to an adult health care professional; for many others, it will involve an ongoing relationship with the same provider but with a reorientation of clinical interactions to mirror the young person's increasing maturity and emerging adulthood.

A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs from American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine
(http://pediatrics.aappublications.org/content/110/Supplement_3/1304.full)

37. What is your experience and/or knowledge about how well CCS clients are prepared to transition from pediatric to adult care? What about for non-CCS CYSHCN?
38. How could transition services for CCS clients be improved?
39. In your experience, are there gaps in health care services for the CCS clients aging out of CCS? For non-CCS CYSHCN transitioning from pediatric to adult care?
    Probe 1: How can these gaps be addressed?
    Probe 2: Who should be responsible for addressing the gaps?
    Probe 3: What are the barriers to addressing the gaps in health care services? Why?

CCS Partnerships

[Examples of partners: foundations, professional organizations, other State departments, schools, and other agencies serving children with special health care needs (e.g., regional centers and advocacy organizations such as Family Voices).]

40. What is your impression regarding how well local CCS programs currently partner with different local entities such as= families, providers, health plans, Regional Centers, schools, and advocacy organizations?
41. What is your impression regarding how well the State CCS program currently partners with different State entities, such as Title V MCAH, Medi-Cal Managed Care, DDS, DDE?
    Probe 1: What are the gaps in CCS partnerships? Why?
    Probe 2: What are the strengths with CCS partnerships? What makes them successful?
    Probe 3: How can successful partnerships with orgs that serve CYSHCN be replicated? And with what other partners?
    Probe 4: How can CCS strengthen existing partnerships?
42. Who should CCS partner with? Why? How?
    Probe 1: Are there partnerships that have not been successful? Why?
43. **ASK FOR CCS ADMINISTRATORS/MEDICAL CONSULTANTS ONLY:** What do you feel is the role of your Local Health Jurisdiction or other county health organization in relation to DHCS?
44. **ASK FOR CCS ADMINISTRATORS/MEDICAL CONSULTANTS ONLY:** Can you suggest operational changes that might benefit the relationship between DHCS and county-level organizations?

Medi-Cal Managed Care/Whole Child Model

45. What have been your observations and/or anticipations with the coordination of CCS and managed care within Whole Child Model Counties?
    Probe 1: What are the benefits/challenges of this arrangement?
    Probe 2: What is your experience regarding communication between the Medi-Cal managed care plan and CCS?
    Probe 3: How could this arrangement be improved, if at all?
46. With the shift from MediCal fee for service to MediCal managed care, what impact, if any, is this having on…
    a. On Medical homes?
    b. On accessing primary and specialty care for conditions not covered by CCS?
    c. On provider networks?
    d. On Care coordination?
    e. On Transition? Is CCS working with managed care plan on transition issues?
    f. Transportation issues?
47. On the impact of capacity: Have you seen any changes in the CCS services or the speed of CCS services since implementation of WCM?
48. Has the WCM impacted the capacity of local CCS programs, including services provided and/or staffing?
49. Have you seen any changes in morale among CCS staff as a result of WCM?
50. What are your greatest needs in regards to the implementation WCM?

Other Issues

51. From your perspective, what is the biggest unmet need for CCS clients, and what should the program be focusing on in the next 5 years?
52. From your perspective, what is the biggest unmet need for children and youth with special health care needs?
53. From your perspective, what is the greatest success of CCS?
54. Please share positive and/or negative feedback on how CCS clients or non-CCS CYSHCN and families are managing within the current structure.
55. Please share any experiences, thoughts, comments, suggestions, etc. you have regarding CCS that was not yet discussed during the interview.