

## Family Focus Group Guide

### Introduction

Notes for introductory section/discussion:

- Thank you for participation including background on the focus group and why it is being conducted
  - 60-90 minute discussion about experiences with the California Children's Services (CCS) program
- Review of consent and confidentiality
- FHOP contact information for post focus group questions/comments/concerns

**Key Definitions:** There will be definitions throughout the guide as you go along, but first here are some initial key definitions and acronyms we will use regularly:

**California Children's Services (CCS):** a state program for children with certain diseases or health problems. Through this program, children up to 21 years old can get the health care and services they need. CCS will connect you with doctors and trained health care people who know how to care for your child with special health care needs.

**Children and Youth with Special Health Care Needs (CYSHCN):** Have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and also require health and related services of a type or amount beyond that required by children generally.

### Questions:

1. Please tell us your name and how old your child is, and if your child is currently or has ever been covered by CCS.
  - *Probe 1:* Which CCS County serves you and your child?
2. How familiar are you with the CCS program, what it does, and what it covers?
  - *Probe 1:* How has CCS communicated information about your child's care and eligibility over the years?
  - *Probe 2:* If your child was dropped from CCS, how was that information communicated to you?
  - *Probe 3:* If this has been appropriately communicated to you in the past, how might CCS continue to communicate this information?
3. If you feel comfortable answering this question: What medical problem or problems does your child have? Do you know which of these conditions are covered by CCS?
4. How well are you/your child's needs being met by the CCS program and other programs that serve children and youth with special health care needs (CYSHCN)?
  - *Probe 1:* What do you like/not like about the CCS program or other CYSHCN programs?

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- *Probe 2:* What needs does you/your child/your family have that are not being met by CCS or other CYSHCN programs?
5. What has been your experience getting care for your child from a specialist when it was needed?
- *Probe 1:* Have you had delays in accessing specialists? What kind of specialists did you experience a delay in accessing?
  - *Probe 2:* Please share your experience with delay(s) in getting care for your child from a specialist and why you think it occurred.
  - *Probe 3:* What has been your experience accessing **Telehealth/Telemedicine with a CCS specialist**? And has it been helpful?
    - **Definition of Telehealth/Telemedicine:** the provision of healthcare remotely by means of telecommunications technology or any other form of technology (i.e. video conferencing).
6. What has been your experience with your child's CCS case manager?
- *Probe 1:* When did you learn about your child's CCS case manager? Under what circumstances?
  - *Probe 2:* What does your child's case manager do for your child? For you? For your family?
  - *Probe 3:* How do you think a CCS case manager can help you/your child/your family?
7. Please explain who coordinates care for your child. Does your child have a care plan specific to your child? If yes, who developed the care plan?
- *Probe 1:* Is your child's care coordinated in a way that makes things easier for you, your child, and your family? Why or why not?
  - *Probe 2:* What parts of a child's care do families need help coordinating?
  - *Probe 3:* How could care coordination be improved?

**Key Definition – Shared Plan of Care (SPoC):** This is a new and emergent model that can be a tool used to support care coordination and is developed and implemented with input from members of the team caring for a child, including community partners, educational specialists, primary care providers, dental providers, medical and surgical subspecialists, and the family and patient themselves.

8. Has anyone that provides care and/or a care service for your child ever mentioned or suggested developing a Shared Plan of Care (SPoC) model?
- *Probe 1:* How well do your child's different providers communicate and share information with each other? For example, does your child's specialist communicate with your child's medical therapy program or school, when needed?

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**Key definition – Culturally Sensitive Services:** When providers approach families without judgment or ideas about what their cultural beliefs are without knowing the family. The family will feel valued and comfortable when accessing services.

9. What has been your experience with culturally sensitive services?

- *Probe 1:* Please share positive and/or negative experiences regarding availability/accessibility of culturally sensitive services.
- *Probe 2:* Please share any other comments/feedback you have regarding culturally sensitive services?
- If you have used interpretation services, what has been your experience with them? **[NOTE: Ask set of questions below only if interpretation services have been utilized by those present and not hearsay.]**
  - *Probe 1:* Are materials translated into the language you need before they are sent to you?
  - *Probe 2:* Who needed the interpretation/translation services (e.g., you, your child, other family member or caregiver)?
  - *Probe 3:* In what language(s) was the interpretation service needed?
  - *Probe 4:* Please share an experience you had when an interpreter was not available. What happened? How could this have been improved?
  - *Probe 5:* Besides helping with translating another language, is there any other time that you would find an interpreter helpful, for example, having someone to help you understand the medical language being used?

10. What have been your experiences with getting medical equipment that your child needs (e.g., walker, wheelchair, nebulizer, feeding tubes, or oxygen equipment) and/or medications (e.g., prescribed and over-the-counter) in the last 24 months?

- *Probe 1:* Please share your experiences in getting equipment and/or medication for your child. How much time does it take? How many trips/stops does it take?
- *Probe 2:* What has been your experience in locating a provider? How far did you have to travel for services?
- *Probe 3:* What issues, if any, have you experienced in regard to the billing/reimbursement process for medical equipment and medications prescribed by your child's provider?

11. Children covered by CCS eventually need to transition from pediatric to adult care. What do you know about transitioning for your child and your family? **[NOTE: Ask this question only in groups with parents of transition age children.]**

- *Probe 1:* If you have a child near to transitioning (14 years of age and older), how have you, your child, and your family been helped in preparing for the transition?
- *Probe 2:* What information would be useful for you, your child, and your family as you prepare for transitioning care?
- *Probe 3:* What types of support would be helpful for you, your child, and your family as you prepare for transitioning care?

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- *Probe 4: Was your child able to find a physician who would assume his care after transitioning from CCS? What were the barriers to finding such a physician?*

The next question is about your child's mental health and your mental health, we understand that this may be too personal to share. Please let us know if you would like to skip this question.

12. What has been your experience with accessing mental or behavioral health services for your child? Has anyone recommended or suggested mental health services for your child?

- *Probe 2: What challenges or difficulties have you encountered with mental health services?*
- *Probe 1: Has anyone that is within the system of care for your child asked about your mental or behavioral health or wellbeing at any point during your child's care? Or have you been given the opportunity to give information about your mental health?*

13. Have you and your family been receiving the support that you need?

- *Probe 1: If not, can you describe what support you would like to have?*

14. What would you like CCS to know about you, your child's, and your family's experience with the CCS program? What has been positive? What needs improvement? How would you like to see things done in the future, if differently?

- *Probe #1: How would you like to see patients, parents/caregivers, and/or families more involved, if at all?*
  - Increasing opportunities to participate in decision making about the way CCS is run?
  - Creation of a parent/caregiver and/or transitioned adult advisory committee?
- *Probe 2: How do you see CCS changing in the next 5 years? What should be the top 3 priorities for CCS for the next 5 years?*
- *Probe 3: Please share any other experience and feedback you think relevant to our discussion today.*

**THANK YOU!**