Title V Needs Assessment of CCS – Summary of Key Informant Interviews

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Key Informant Interviews - Background

- California Children's Services (CCS) – Title V Needs Assessment
  - Dept. of Health Care Services contracted w/ FHOP to conduct
  - Needs Assessment > 5-year action plan
  - Key Informant interview process to inform:
    - Focus Groups
    - Family and Provider Surveys
    - Final action plan – **How well are CYSHCN being served by CCS and non-CCS systems of care?**

Key Informant Interviews - Overview

- **16 interviews** w/ individuals from key organizations that serve Children & Youth with Special Health Care Needs (CYSHCN) or work w/ CCS, ex:
  - Health Plans
  - Pediatric Hospitals
  - Specialty Care Centers & Specialty Care MDs
  - Physical Therapy and Medical Therapy
- 90 minute phone interviews
- Questions were both about CCS *AND* non-CCS CYSHCN
- The following slides include the summarized **OPINIONS** and **THOUGHTS** of key informants and some direct quotes.

The Strengths of CCS

- Availability & proficiency of Specialists + Access to care
- State run program—better than private insurance and most other states
- Care Coordination/Case Management (even if it isn't perfect)
- Family & patient engagement/centeredness
- Administrative and systemic integrity

The Strengths of CCS - Quotes

- "That there are providers that are paneled and that provides some assurance on quality. [The]Result of CCS program is the Special Care Centers. I like that there are two parts of the system to ensure quality."

- "A primary strength is that it sets the standards statewide, whether in CCS or not – everyone can benefit from it."

- "Case management through the county-based system is essential to meeting the needs of kids…"

- "Helps parents get a lot of needs met in one place."

CCS Standards/Rules/Regulations are…

- Outdated & in need of updates that would benefit from provider input
- Some perceive as hard to understand and/or inconsistent (interpretation can be variable across counties)
- Valued and comprehensive—it is appreciated that providers have to be up to standards

CCS Standards - Quotes

- “Standards don't feel applicable to the health plans (provider only), guidance is too varied, numbered letters are hard to parse out and apply to programs, and there should be a Whole Child Model measure for each standard.”

- “Provider standards are stringent, but don’t keep them away, just make sure the providers are up to par. Lots of thought has gone into them. They keep adult providers from caring for these kids – because that would dilute the quality of the care.”

CCS Rules & Regulations - Quotes

- "Variability relies on medical directors, sometimes they lean towards different diagnoses that are more or less complex."
  - Meant that medical directors choose preferred DXs to focus on

- "I'm a little concerned that funding resources may affect whether or not counties are acting similarly. More wealthy counties, particularly those who have added money, may be more generous."

CCS Financial Eligibility is…

- Fair and considerate of State's financial capacity
- Unfair and does not adequately meet or consider the needs of low-income families in CA w/ CYSHCN
    - Needs to be re-evaluated

- "I wish that all kids had the same access as those that are financially eligible."
- "It is pathetic – it is an insult and so unrealistic, especially with inflation. It shocks me really. Especially hard in high cost counties."

CCS Medical Eligibility Criteria is…

- Complicated and confusing
- Does not cover everything it arguably should (only works for some dx populations)
- Too condition or DX driven
- "I would not make it **diagnosis driven** but instead based care coordination and case management needs, essentially taking care of whole child. When you go by a diagnosis only, you are not coordinating all things that the child needs."
- "The focus on medical and limit on behavioral conditions is very limiting to the program. Autism and developmental disorders should be included. **Doesn't include all high need children**."

Medi-Cal Reimbursement Rates

- Medi-Cal Reimbursement rates =
  - Too low
  - Not always in line w/ condition or dx
  - Sometimes complicate relationships with vendors
  - Further complicated by WCM

- "**Definitely low,** but the categories for reimbursement don't necessarily meet the conditions super well. Comprehensive visits at [specialty] centers (federally funded [CCS condition redacted] treatment centers), take several hours and they meet so many different members of their care team (physician, social worker, and therapist), and then are reimbursed at the same rate as a basic hospital visit. They are missing some of the categories that some patients need at specialty centers. There needs to be better reimbursement for comprehensive care models such as this, a billing item or billing category for comprehensive, multi-care giver visit."

Medi-Cal Managed Care & Whole Child Model (WCM)

- Pilot program → lots of struggle with transition to WCM & clarity
  - Especially with how it will function at the local level/future of local CCS staff
  - Medical Therapy Unit role unclear
  - Case management model of CCS does not integrate smoothly into Medi-Cal Managed Care (MCMC) WCM
- No initial evaluation = no baseline data to show it works or doesn't
- Communication is lacking between WCM Health Plans and local CCS and DHCS

Medi-Cal Managed Care (MCMC) & Whole Child Model Quotes

- "…people are really worried about case management transition from county to MCMC and concerned MCMC won't have experience, knowledge, relationships. Evaluation of how transition going might not be accurate, what is being considered is written grievances [as complaints/evaluation] and that is a barrier for families to do. Difference in philosophy with what CCS did for families and what MCMC will do. **MCMC will put burden of proof of necessity of care on families and when county CCS did –tried to help families get care. Insurance companies generally try to limit care**."

- "The State has been walking a tightrope in terms of contracting with Medi-Cal Managed Care and what the role of CCS will be. It has taken a different shape in different counties and left a lot to be worked out by MCMC and not a lot of direction from the state."

Challenges in Access to care for CCS and non-CCS CYSHCN

- Good quality **Medical Homes** & primary care
- Access to dental care
- Timely or costly DME &/or authorizations for care
- Keeping CYSHCN enrolled in CCS, especially when moving counties
- Non-CCS kids miss out on care coordination/quality

Challenges in Access to care for CCS and non-CCS CYSHCN

- Financial and medical eligibility criteria for CCS restricts access to program
- Cost of care can be burdensome, especially for non-CCS children
- Geography of where child with special health care needs lives impact access
- Amount of time needed for care coordination
- Scarcity of pediatric sub-specialists

Challenges in Access to care for CCS and non-CCS CYSHCN

- Access to behavioral and mental health care often limited by availability of providers, skill of provider, and insurance type
- Technology issues—CMS Net and electronic medical records
- Family-Centered care
- How all of these challenges are further complicated by WCM

Challenges in Access to care for CCS and non-CCS CYSHCN, quotes

- "[Some of the] biggest challenges [are] distance, time, and number of times have to go. Coordinating all of the appointments on to one day would be great. Some programs exist, but children have to have significant issues. Shortages of staff too, but that also leads to long wait times."

- "The extremely high cost of care for someone not insured/on private insurance. These families meet their deductible every single year, families have to pay deductibles every year and then end up unable to pay. If they know they aren't going to be able to pay the entire maximum deductible January 1st then they will skip out, which means they sometimes need to skip out on medications and they become temporarily non-compliant and end up in the ER for care."

Greatest Barriers to Accessing Care for CCS and Non-CCS CYSHCN

- Geography & transportation*
- Poor care coordination*
- Lack of appropriate language & cultural competency
- Lack of vendors &/or providers that will take Medi-Cal*
- Lack of family engagement/family-centeredness*

***mentioned as challenges also**

Greatest Barriers to Accessing Care for CCS and Non-CCS CYSHCN, quotes

- "Families understanding payer of last resort and how the program functions. Many families' members don't even realize how care is being paid for. Lack of education about the systems and how they work together – what is state, what is county, what is MCMC, what does fee for services mean? Parents are intimidated by the system, but they need to be a partner."

- "Not being able to get vendors to provide supplies or timely access to behavioral health depending on who will and won't take Medi-Cal. For the broader group [non-CCS CYSHCN], same kind of challenge, if they don't quality for CCS and just have Medi-Cal, it is very limited about what can be provided to them. Access issues because of Medi-Cal reimbursement. This is the group that falls through the cracks but none of their issues qualify them for CCS. But county programs and Regional Centers can't do it all."

Quality of Specialty Medical Care

- Excellent if at CCS facility or with CCS paneled providers
- Lacking in quality measures
- Great & valuable to parents
  - "SCCs are phenomenal. I get to read all of the notes and I'm amazed at things they think of and the abilities they have. I love the fact that providers have good communication and care coordinators and know parameters."
- Lacking or variable for non-CCS CYSHCN if not seen at a special care center
- For Kaiser, usually not a team and social worker not regularly included

Quality of Preventative Care, Acute Care, &/or Primary Care

- Inconsistent, especially for non-CCS CYSHCN
  - "Highly dependent and variable, some [providers] are very comfortable with complex needs of their patient population, and some not. PCPs outside of CCS don't have the skills to take on complex kids."
- Sometimes under-utilized, especially preventative care
- Not good at transition care or caring for aged out CYSHCN
- Difficult to maintain primary care providers
- Needs more preventative/primary care practices
- Limited referral sources for non-CCS CYSHCN

Observed Health Disparities in Access to Quality Care

- Large disparities in social, economic, and educational background of family
- Mental and behavioral health access
- Dental health access
- Geographic & cultural disparities
- Disparities in access for Black and African American families
- Disparities based on insurance provider (for mental or dental care specifically)

Observed Health Disparities in Access to Quality Care

- "Huge disparities in **mental health** and **oral health**, **geographic** *and* **financial**, can be urban and rural but some urban areas are not served well either."

- "In CCS they have to go to the dentist they are assigned and most dentists don't know how to say that they don't know how to provide specialty dental services. Families don't know where to go and we don't know where to refer them. In my opinion I feel like the mental health care is out there, I think it is more an issue of people admitting they have a mental health need in order to access the health care services."

CCS Healthcare Providers

- Difficulty recruiting/maintaining
- Geography—difficult to recruit in remote areas, not enough $ to stay in big cities
- Rare disorders = small patient populations don't support large, thriving practice
- Not enough diversity among providers
  - "…**Providers don't reflect the community**. Makes it harder for parents to connect with the provider and trust the provider..."
- Not enough sub-specialists

Access to Durable Medical Equipment (DME)

- Inconsistent (access only good for some counties and conditions)
- Low rates for DME vendors means fewer vendors, especially in rural areas
- Vendors have a hard time reimbursing through CCS = delays & fewer willing vendors as a result
- CCS + other insurance = vendor complications

Care Coordination & Case Management

- Varies by county (CCS)
- Frequently large & unmanageable caseloads in CCS
  - "They are the catalyst and the advocate, only supposed to have a few dozen cases, but CCS staff has hundreds of cases, as a result some get managed really well and others don't; The term case management doesn't make sense when the case load is so large."
- Transition to Whole Child Model creates complications (limited role for case managers in CCS compared to the past)
- No best practices in family engagement, varies in success

Care Coordination (CC) & Case Management (CM) – Suggestions for Improvement

- Community partnerships
- Clarity around roles of CM & CC
- ↑ knowledgeable staff & reduce caseloads
- ↑ State funding to bolster CC & CM
- Some feel Whole Child Model *is* improving these things

Medical Home

- Unclear how many children (CCS and non-CCS) actually have them based on AAP definition
- Challenge is who is going to pay for additional services needed to be a medical home – (e.g. care coordination)
- Kaiser and FQHCs are viewed by some as medical homes

"With this definition, very few, maybe 20% and I'm being generous. We have pieces, we might have access to medical care, but might not be able to access early childhood education because of some health issue, or because the family doesn't feel comfortable. Then who supports family around that issue?"

Family-Centered Care

- Uncertainty if family-centered care is a requirement or expectation of CCS and there are not standards
- Varies by county – "larger and better funded counties doing better on this"
- Considered a top priority to work on—when addressed, everyone benefits
- There are available resources to address family capacity, but capacity not always assessed
- **Families need to be brought to the table for program and policy development—and they need to be 'met where they are at'**

Mental & Behavioral Health & Developmental Services

"Given that we don't have comprehensive care coordination, mental health or developmental screening…not doing well."

- Access to mental and behavioral health care noted as a **challenge** & **observed health disparity**
- Disparities based on insurance provider

"This is a real area of opportunity for improvement because there is not currently a consistent way that these needs are being met."

Mental & Behavioral Health & Developmental Services

- Emotional, Social, and Developmental needs being met?
  - Most said no (both CCS and non-CCS CYSHCN)
  - Special care centers and specialists are the largest supporters
  - Sometimes these needs are met, but often not until it is an emergency

"I think our therapists are doing a fantastic job, so much of it is the whole family and I think our therapists really try and see where the parents are at and what are their well-being and social needs. We do a good job of asking. And the education we provide helps with developmental needs."

Transitioning Adolescents

- Always complicated—most CYSHCN experience gaps when they age out of CCS (similar for non-CCS)

- Difficult to find adult providers for CYSHCN
  - "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."
- Training on transition needed for staff, providers, and child
- Sometimes specialty centers or health plans create 'safety net' programs or protocols for transition (but this is uncommon)

Whole Child Model & Medi-Cal Managed Care Health Plans

"**We have just divided the state into two systems of care** (WCM and classic CCS), and families are going to be in and out of MCMC and families won't be able to get access..."

Whole Child Model & Medi-Cal Managed Care Health Plans

- Most are struggling with pilot programs, varies in counties
  - Transportation has been an issue
- Role of local/county CCS unclear & inconsistent
  - Especially case management & medical therapy programs
- No baseline evaluation, won't be able to measure success (need meaningful data!)
- Better communication needed across all orgs

Greatest Needs to Implement WCM

- Care coordination
- 'Virtual Medical Home'
- Provider orientation
- Shared EMR (with risk assessment scores)
- Educate Health Plans on how to care for CYSHCN & family
- Education/communication for families on how to navigate new system
- Reduce rather than increase delays in care
- If it does not work, go back to the old model instead of pushing forward

Biggest Unmet Needs + the Next 5 Years

- Non-clinical, non-medical needs to be considered as part of caring for the whole CYSHCN and their family, specifically **mental and behavioral health**, and school-based services
- **Care coordination and case management** services must be improved
- Special care centers and specialists must stay and be supported by programs like CCS, additionally they should bolster adult provider networks to care for those aging out CCS
    - Also, greater education and preparation for transition
- **Communication** with and **education** of CYSHCN, families, and providers needs to be improved for systems to more successfully address needs
- We need to find ways to support CYSHCN living in **rural** and remote areas

Biggest Unmet Needs + the Next 5 Years

- **Timely care** —delays are a consistent concern (esp. under WCM)
- Technology can be used to work on many issues such as delays in care and care coordination/case management, but there needs to be EMR that is specific to CYSHCN within CCS and Health Plans.
- **Eligibility**, both medical and financial needs to be re-evaluated more regularly than it currently is
- Valuable data needs to be collected, including **data on outcomes** (not just claims data)
- MTP services for CYSHCN need to be **consisten**t statewide, especially within CCS
- **WCM** needs rigorous **evaluation,** including outcomes data

Biggest Needs + the Next 5 Years

- **Mental** and **Behavioral health**, and School-Based Services
- **Care coordination** and **case management** services must be improved
- Maintaining comprehensive **access** to Special Care Centers and specialists
- Preparation for **transition** must be improved, need for **training** and **standards**
- **Communication** with and **education** of CYSHCN, families, and providers
- Better support of CYSHCN living in **rural** and remote areas

Questions?

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