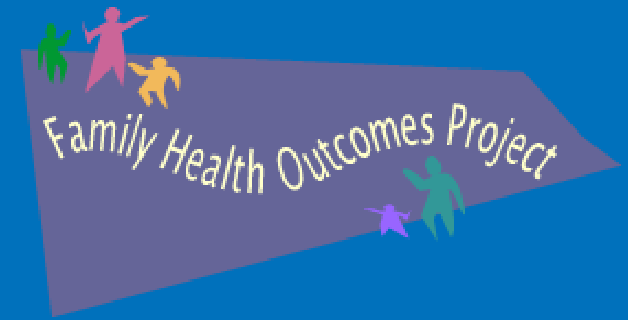


CYSHCN and Needs Assessment: Key Questions

Dec. 2018

Family Health Outcomes Project, UCSF

Jennifer Rienks, PhD, Linda Remy, PhD and Adrienne Shatara, MPH

Objectives

- Review the MCHB Goals for CYSHCN
- Provide suggestions for key questions for assessing the needs of CYSHCN and their families

MCHB Goals for CYSHCN

- **Community-Based Services** - ensure community services are organized for easy use by families
- **Early Continuous Screening** - Ensure children are screened early and continuously for special health care needs
- **Access to Medical Home*** - increase the number of CYSHCN who have a medical home that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective
  - Access to primary and specialty care, mental/behavioral health and durable medical equipment/supplies/home health services

MCHB Goals for CYSHCN (cont.)

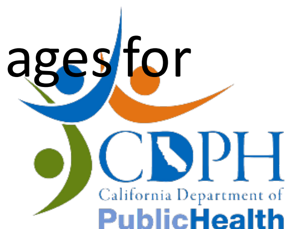
- **Transition to Adulthood*** - increase the % of adolescents with special health care needs who have received the services necessary to transition to all aspects of adult life, including adult health care, work, and independence
- **Adequate Insurance** - increase number of children who are adequately insured
- **Families as Partners** - Ensure families are partners in decision making
- ***Note: These are National performance measures**

Community Based Services - Family Support Services

- Are families connected to a parent mentor/parent advisor to help them when a child is diagnosed with a special health care need?
- Are families with a baby in the NICU connected to family support services?
- Are there local family support services available? (e.g. Family Resources Centers,
  - Are they culturally and linguistically appropriate for the population in LHJ?
  - Do they serve and meet the needs of families with children with different diagnoses?
- Are families of CYSHCN routinely offered family support services?

Community Based Services - Family Centeredness of Services

- Are services designed to make them easy to access for families (e.g. not too far away, after hours appointments for working families, materials available in multiple languages)?
- If needed services are not available locally, is there a clear process/structured handoff for accessing services in a different county/service area?
- Is there information on how to access various services (CCS – including Medical Therapy Program, Regional Center, Special Care Centers, Special Education Service, Home Health Care, Mental Health Services)?
  - Is the information easy to read and understand?
  - Is the information available in the appropriate languages for the population in your county?



Early Continuous Screening

- Are children receiving developmental screening per AAP Periodicity Schedule?
- Are children receiving Social/Emotional screening in addition to developmental screening?
- Are children who need developmental or social/emotional services being referred for those services?
- Is there a feedback loop in place so providers know if child gets services they were referred to?

Access to Primary and Specialty care and Medical Homes

- Is the access timely?
- Is there someone to contact after hours to provide medical advice/triage (24-7 access)?
- Same day or next day access to primary care available when needed for illness?
- Do local primary care providers have the skills and comfort to care for CYSHCN? Do they accept Medi-Cal?
- Are CYSHCN receiving yearly well-child visits and needed immunizations?

Access to Primary and Specialty care and Medical Homes (cont.)

- Are CYSHCN receiving care within a Medical Home (per AAP definition of a Medical Home)?
  - is there even data available that would enable you to know whether CYSHCN have a true medical home?
- Are CCS and other CYSHCN receiving timely and appropriate referrals to Special Care Centers (SCC)?
- Are there delays/long wait times/long distances to travel for specialty care, and if so, for which specialties?
- Are their locally available pediatric specialists that accept Medi-Cal?

Access to Mental Health Services

Infant-Family mental Health Services:

- Does your Department of Mental Health provide Infant-Family Mental Health Services?
- What evidence-based therapies and collateral support are provided for infant-family mental health services?
- In what languages are services provided?
- Does the County Mental Health Department have an MOU with the Early Start programs at the Regional Center?
- Do home visitor providers know how to screen and refer and what is required for the medical necessity that makes Medi-Cal infants and toddlers eligible?

Access to Mental Health Services (cont.)

- Child/Youth Mental Health Services
  - Is there an adequate supply of mental health providers serving children and youth with Medi-Cal? With private insurance?
  - Do the available mental health providers work with CYSHCN? Have they had training to work with this population?
  - What are the wait times for appointments based on insurance type?
  - What are the travel distances for appointments based on insurance type?

Access to Mental Health Services (cont.)

- Mental Health Services for Families (parents and sibling of CYSHCN)
  - Are parents of NICU babies being screened for depression/anxiety and other mental health and substance use problems?
  - Are parent of CYSCHN being screened depression/anxiety and other mental health problems and substance use problems?
  - Are there mental health services available that are designed to meet the needs of families and siblings of a CYSCHN?

Access to Oral Health Services

- Are there locally-available providers of oral health services (dentists, hygienists) that accept Medi-Cal?
- Are there locally or regionally available pediatric dental specialists (e.g. Orthodontist, Endodontist, Oral and Maxillofacial Surgeon, Prosthodontist, Periodontist) that accept Medi-Cal?
- Do the available providers have experience treating CYSHCN? Is sedation available?

Access to Other Services for CYSHCN

- Regional Centers
  - Do families understand what services/resources are available at the Regional Centers and how to access them?
  - Are there challenges accessing these services (e.g. long wait times for appointments, travel distances)
- Lanterman Act – do families know what this is and how to use the law to get the services their child needs?
- Schools
  - Do families understand what services/resources are available through IDEA B and C (Early Start and Schools-IEP services, 504 accommodations)?
  - Are there challenges accessing these services?

Access to DME and Medical supplies, and Home Health Services

- Are there enough vendors to provide the different types of durable medical equipment (DME) needed by CYSHCN? (e.g. wheelchairs, hospital beds, oxygen equipment, hearing aids)
- Do children receive needed DME and medical supplies in a timely fashion?
- Are hospital discharges for infants/children delayed because of problems getting DME?
- Are home health services available and culturally and linguistically appropriate?
- Are families able to get other needed medical supplies to care for CYSHCN?

Case Management & Care Coordination

- Do families know what types of case management/care coordination services are available to them and how to access these services?
  - Are these services adequate and meeting families' needs?
- For families with case managers and/or care coordinators (e.g. from CCS, Regional Centers, Medi-Cal Managered Care Plans), are the case managers/care coordinators focused on condition-specific health services or are they referring more broadly to social services, mental health, etc. if needed?

Transition Services

- Are CYSHCN with ongoing chronic conditions receiving transition services, ideally starting by at age 12-14? (depending on condition and needs of child)
- Are CYSHCN 18 and older (21 and over for those in CCS) able to find adult providers to that will accept their insurance and care for them?
- Do the adult providers have the necessary skills and knowledge to care for CYSHCN ?
- What help is needed by CYSHCN to ensure a smooth transition from pediatric to adult providers?

Insurance Coverage

- Are CYSHCN adequately insured?
- Do parents understand the types of coverage they have for their child and what is and isn't covered? (e.g. what payer of last resort means)
- Do parents understand what they need to do to get insurance to pay for the care and services their CYSHCN need?
- **Regular and Continuous Screening**

Families as Partners

- Do families feel that they are partners in all decisions regarding the care of their child?
- Are family members involved in providing regular feedback on their child's care through individual consultations, group discussions, or surveys?
- Do you have family advisory committees in your region or county for CCS and families of other CYSHCN? If not, why?

Adverse Childhood Experiences (ACEs)

- Is the health care community in your LHJ, in general, aware of the link between ACEs and health outcomes?
  - Is there an understanding of resilience and the ability to improve health outcomes through interventions (e.g. positive parenting, mental health treatment, etc.)?
- Is there a county-level coalition working on ACEs, and is MCAH at the table?
- Is any ACEs screening happening in your county?
- Are there services available for children with 4+ ACEs? Any barriers to accessing these services?
- Are there services available to parents with 4+ ACEs? Barriers to accessing these services?

Questions?

Family Health Outcomes Project

CDPH
California Department of
PublicHealth

Contact Information

Family Health Outcomes Project

University of California, San Francisco

500 Parnassus Ave., Room MU-336

San Francisco, CA 94143-0900

Phone: 415-476-5283

Email: FHOP@ucsf.edu

Web site: http://fhop.ucsf.edu