Early Continuous Screening

MCHB Goal: Children are screened early and continuously for Special Health Care Needs

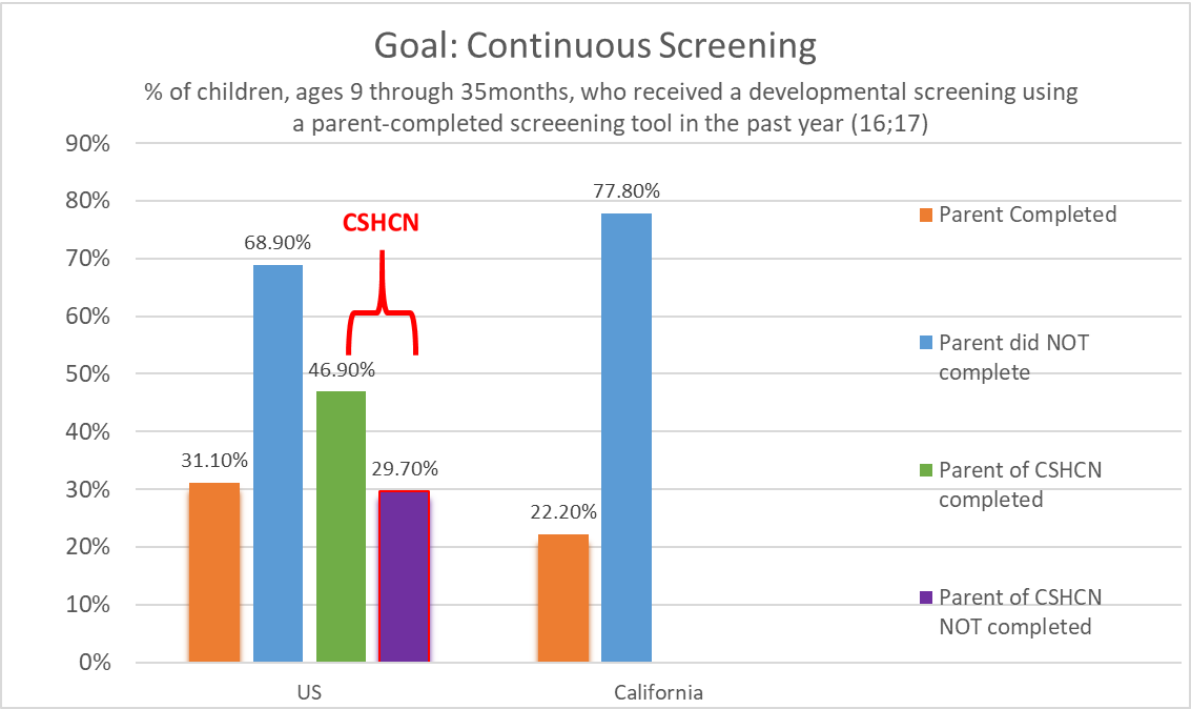
Early Continuous Screening Definition and Impact on Health Outcomes of CYSHCN:

"Early identification allows communities to provide children with earlier treatment or interventions that are more effective in improving delays and disabilities and less costly than special education services in later childhood. It is also an integral function of the primary care medical home, and improving the developmental screening rate is a national performance measure for the Title V MCH Block Grant program (AMCHP, 2019)."

Continuous Screening, Data from the California State Auditor's Report:

- "An annual average of 2.4 million children who were enrolled in Medi-cal over the past five years have not received all of the preventive health services that the State has committed to them"(Source: California State Audit Report 2019).
- Between 2013 and 2018, an average of 2.4 million children each year enrolled in Medi-Cal did not receive all required preventive services, according to the findings (Source: California Health Report).

Continuous Screening, Data from the National Survey on Children's Health:



Graph above - National Survey on Children's Health, 2016/2017:

- Out of all of the outcome and performance measures, this is one of the those where California is ranked the worst according to the NSCH; we are ranked 48th for % of parents completing developmental screening
- There was no data for California on parents of CSHCN completing developmental screening, but the national rate to not screen CSHCN is high as well.

Findings and Data from the High-Risk Infant Follow-Up Program (HRIF):

The High Risk Infant Follow-up (HRIF) Program Program, identifies infants who may develop a CCS-eligible medical conditions after discharge from a CCS-approved Neonatal Intensive Care Unit (NICU).

HRIF clinics provide follow-up care to l infants discharged from a CCS-approved NICU who were born before 32 weeks of gestation, or with a birth weight ≤ 1500 grams, as well as infants > 1500 grams and gestational age ≥ 32 weeks with specific medical eligibility criteria which put them at risk for suboptimal growth and development. risk factors.

HRIF is related the MCHB Goal of Early & Continuous Screening – because it is meant to provide early screening & detection of a special health care need to a high risk population.

- Tang et. al. (2018) surveyed high-risk infant follow-up programs in California, 56 (82%) responded to the survey
  - The first visit no-show rate between 10 and 30% was estimated by 44% of programs with higher no-show rates for subsequent visits.
  - Common strategies to remind families of appointments were phone calls and mailings.
  - Most programs (54%) did not have a strategy to help families who lived distant to the high-risk infant follow-up clinic.

- Hintz et. al (2019) did a study to determine how to prevent Loss to Follow-Up (LTFU), which can be detrimental to families and children, especially very low birth weight (VLBW) infants. They have determined that:
  - Out of the 80% of VLBW infants referred to HRIF in 2010-2011, 74% had at least 1 HRIF visit w/in 12 months
  - Identified reasons for loss to follow-up included: Parent refused (6%), family moved (5%), insurance authorization denied (3%), unable to contact (14%), other high risk follow-up (3%), other reason (8%)
  - BUT the majority (48%) of the reasons for LTFU were unknown
  - More likely to attend the first HRIF visit was associated with:
    - Older maternal age, lower birth weight, private insurance, a history of severe intracranial hemorrhage, 2 parents as primary caregivers, HRIF program volume, and lower birth rates
  - Less likely to attend the first HRIF visit with associated with:
    - Maternal race of African American or Black or living a greater distance from the HRIF program

HRIF Needs and ongoing efforts:

Needs based on research findings:

- Identify family challenges in access and resource risk factors during infant hospitalization in the neonatal intensive care unit
- Provide families enhanced education about the benefits of HRIF
- Create comprehensive neonatal intensive care unit-to-home transition approaches

HRIF program is working to:

- Better characterize family & caregiver barriers to HRIF visits
- Better understand what program-level resources are needed & what process challenges there are
- Identify opportunities for intervention & strategies that need to be tailored to HRIF programs and regional needs

Findings and Data on Early Continuous Screening from the Title V CCS Needs Assessment:

Data from Provider Survey (N = 188)

Over 95% of providers feel that the annual well-child visit for CYSCHN is very important (N = 66)

Are CYSHCN receiving well-child visits? (N = 70)

- **50%** said: Yes, most appear to be having these visits
- **24.2%** said: Yes, but only some appear to be having these visits
- **9.1%** said: No, it appears that most are not having these visits
- **16.7%** said: I don't know whether they are having these visits

Who is providing these visits: (open-ended)

- Almost all reported Primary Care Providers

Data from Family Survey (N = 3,419):

During the past 12 months, how many times did your child receive a well-child check-up, which is a general check-up, when they were NOT sick or injured?	%
0	8.8
1	16.8
2	15.8
3+	15.0
Missing	10.2

Comments from Key Informants:

Some Stakeholders stressed the importance of the social, economic, and educational background of families in relation to what children are screened and when:

- "Real disparity in the success of the program depending on the social and economic status of the family they are from. There is a wide variety within in CCS. Ability to navigate the system to some degree relates to privilege and education level, which extends to getting kids screened early, doesn't happen if children don't have a 'strong advocate'."

They also feel that screening needs are not being met:

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

Comments from Focus Groups:

- "…there is always a huge waitlist in getting kids into any kind of behavioral program. We're not equipped to help families through this, that's not our training. I see this as a real need." (CCS County Administrators Focus Group)
- "Mental and behavioral health of the child—it is lacking and has never been well addressed." (CCS County Administrators Focus Group)
- "My daughter has multiple conditions that began with ADHD—it took six years to get proper machines for breathing at night—we've had issues with specialists saying that my child's needs are not medical, just behavioral. They have told me all my children's lives that if they didn't have physical indicators of disability that they are not a priority—many of my children have attempted suicide—many employers won't hire them with their disabilities. [Health insurance] has been one of the better places to bring them for mental and behavioral health issues where this is covered by Medi-Cal." (Family Focus Group)
- "Not for my CCS child. CCS has said that it is not up to us to decide issues in mental health. CCS does not cover autism. " (Family Focus Group)
- "Children with schizophrenia and bi-polar disorder are not being served by CCS and they are having a hard time." (Family Focus Group)
- "…It is a transition pilot, but I don't think we serve our patients well at all because they don't know how to interact with primary care. Especially if they have ACEs and need mental health care, even if peds have a lot of time, it isn't realistic that they can cover all of their needs. We aren't even able to do appropriate developmental screenings. The child is going to have to be the ambassador to train the new, adult provider." (Provider Focus Group)
- "Oftentimes that no-show is a 'solution' to things that aren't being managed: income, food, shelter, security, trauma—pediatric handholding, when you don't have a family that is able to engage we have providers that can address these underlying basic needs. We need to do social screening and we need Ped MDs that can address these social issues." (Provider Focus Group)
- "At least for our patients, the PCP ends up being their urgent care—we have one sided information where we tell them what they need to do, but they don't talk to us. They rarely get them for well-child visits. Sometimes they see them for flu shots…" (Provider Focus Group)

Recommendations from others:

From the California State Audit Report 2019:

To help improve the access to preventive health services these are a few recommendations:

- Increase funding to help programs that implement a pay-for-performance program that motivates plans to provide more consistent preventive services to children in Medi-Cal.
- Assess travel distance and time for Medi-Cal beneficiaries and help obtain health services outside the plan.
- DHCS can help by tracking and reporting utilization rates on performance measures, increasing providers where they are needed the most, conducting annual medical audits for the procedures, validating the accuracy of the directories, and identifying effective incentive programs at the plan level and sharing these results.