

Results: 2016-2020 Children and Youth with Special Health Care Needs Five-Year Assessment: Kentucky

Commission for Children with Special Health Care Needs

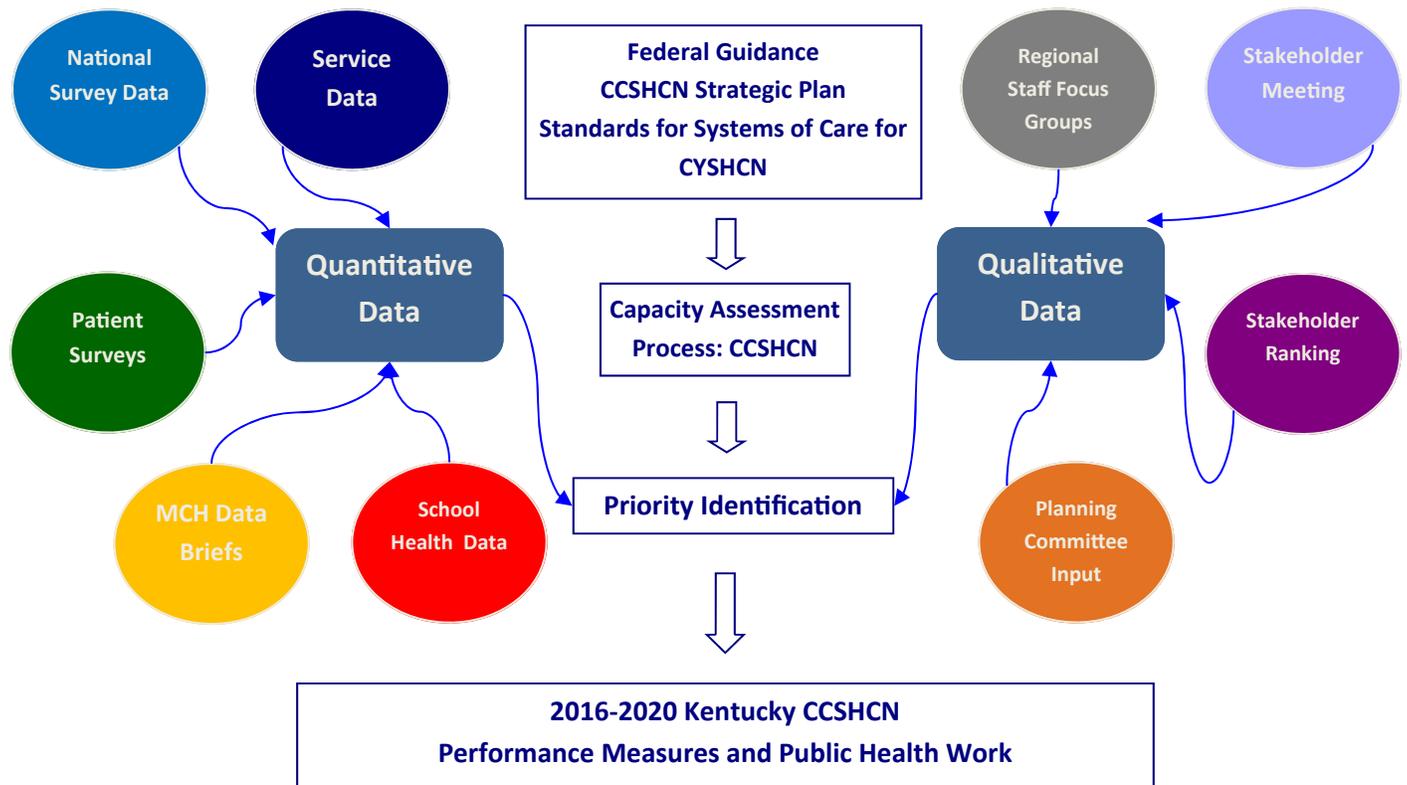


Overview

Every five years, states are required to submit a Needs Assessment for their Maternal and Child Health Services Title V Block Grant federal funding. The Kentucky Department for Public Health (DPH) is the Kentucky grantee; as a sub-recipient, guidance requires that at least 30% of Title V funding be allocated for services for Children and Youth with Special Health Care Needs (CYSHCN).

Planning Committee

A team representing staff of both DPH and CCSHCN (as well as faculty from the University of Kentucky College of Public Health) is responsible for guiding the development of the needs assessment process and priorities. The process involved the analysis of six population health domains (of which CYSHCN was one) using quantitative and qualitative data as illustrated below. The goal was to examine the data that will drive Maternal and Child Health work for the next five years, with the overall aim of measurable improvement in the health of the population.



National Survey Data

	2009-2010 NS-CSHCN	2011 NSCH
National Average Rate	15.1%	19.8%
Region IV Average Rate	16.5%	21.1%
Kentucky Rate	19.5%	26.4%
Kentucky Ranking (of 50)	49	50
Kentucky Population Estimate	197,916	268,795

National Survey Trends

Overall, Kentucky fared well as compared to HRSA Region IV and the nation. Two measures were targeted for improvement:

- Access to community-based services; and
- Transition services

When condition prevalence was examined for these same areas, Kentucky had more children living with:

- Asthma;
- Arthritis;
- ADD or ADHD;
- Behavioral or conduct problems;
- Epilepsy/seizure disorders;
- Heart problems; and
- Cerebral Palsy.

9400 Served by CCSHCN—FY 2014

- ◇ Clinic visits (in-person & via Telemedicine)
- ◇ Audiology visits (and Early Hearing program)
- ◇ OT/PT/SLP services
- ◇ Foster home visits
- ◇ Indirect & non face-to-face services provided through partnerships

*Additionally, Family to Family Health Information Centers served 1587 families, undupli-

Kentucky fared better than either Region IV or the nation in autism prevalence and blood problems.

CCSHCN Service Data

CCSHCN reported population improvement in six of eight performance measures (six national, two state-level) examined between the period of 2009 and 2014. The number of infants screened for hearing before hospital discharge revealed a slight decline within this timeframe, due in part to better tracking and an increase in home births. Another measure – tracking childhood BMI – rose slightly in 2013 and 2014, though no discernible trend is evident over the five year period.

Kentucky Department of Education: School Health Data

To better estimate the prevalence of common chronic conditions (Asthma, Diabetes, and Epilepsy) within the Commonwealth and CCSHCN Regions, staff reviewed school health data. CCSHCN staff was able to estimate the proportion of children affected by county for each condition of interest. The proportion was then applied to the total population of all children (aged 5 – 19 years) residing in each county and estimates about the true prevalence of each condition were extrapolated. These estimates were compared with CCSHCN CUP patient data, allowing CCSHCN leadership to identify gaps, if they existed, at both the state and CCSHCN regional office level. Regional variation data currently under examination.

Patient Survey Data

Surveys were distributed in health departments as well as CSHCN clinics. CSHCN also placed the survey on the agency Facebook page to encourage input. Surveys were also mailed to CSHCN families whose children were not expected in clinic during survey administration.

3,361 surveys were returned; 813 from CSHCN families. Statewide and regional CYSHCN reports were generated.

Families said that their greatest concerns for CYSHCN were:

- Making sure families have the ability to receive services;
- Ability to find insurance to pay for care;
- Availability of developmental, social, and emotional screening services;
- Training and support for children with behavioral issues; and
- Finding doctors who can provide care

Priorities of families enrolled in CSHCN clinical programs varied slightly:

- The need to find insurance moved off the list completely and was replaced by concerns about finding doctors to provide care as the second priority issue.
- Training and support for children with behavioral issues moved to the third priority and the need for early identification of special health care needs was added to the list.

When patient survey responses were examined by Kentucky region, some interesting and statistically significant variations occurred:

- Finding doctors who can provide care was of greater concern in Western Kentucky than in Eastern Kentucky, though the latter is known for its provider shortages;
- Finding insurance to pay for care was more of an issue in Central Kentucky;
- Nearly one quarter of respondents from Eastern Kentucky said that early identification of CYSHCN was a high priority need in their region; and
- The need for transition services was thought to be greater in Eastern Kentucky.

Regional Focus Groups

At ten focus groups (plus 1 pilot) held throughout Kentucky during 2014, MCH professionals (and parent representatives) discussed issues pertaining to CYSHCN and their families. Access to resources and services was the primary topic of discussion but the impact of substance abuse on families and communities, as well as the increased risk for child abuse, were also highlighted.



MCH Stakeholder Meeting

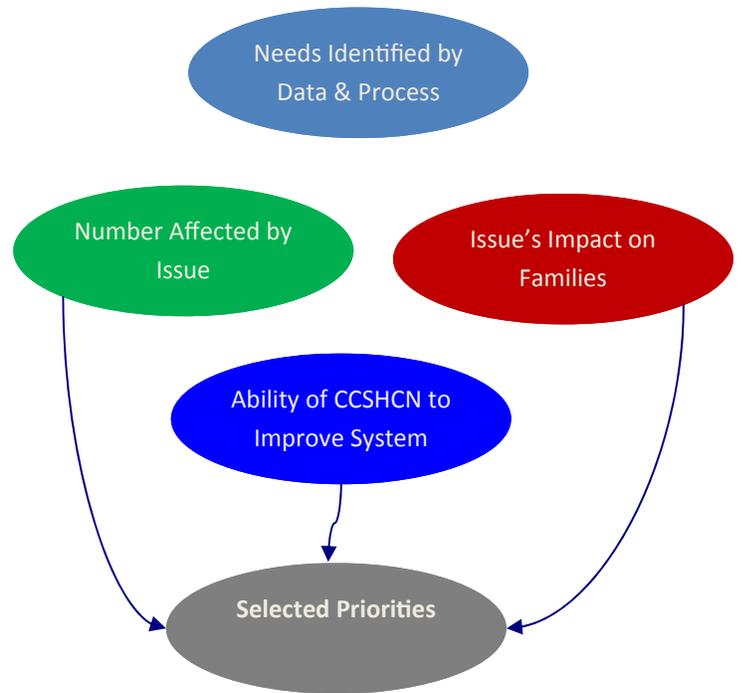
At a November meeting in Frankfort, nearly one hundred partners convened to discuss MCH improvement. Two tables were selected for in-depth exploration and discussion of CYSHCN issues. Tables addressed gaps associated with access to care, provider capacity and supports/resources for families. Stakeholders identified possible solutions and promising practices to these complex issues.

Alignment with CYSHCN Outcomes

A well-functioning system of services for CYSHCN includes the following, which CCSHCN bears in mind in selecting priorities:

- Family Partnership & Satisfaction
- Medical Home
- Transitions Preparation
- Insurance Adequacy
- Early Screening
- Ease of Use of Community Based Services

Prioritization Process



Final Selected Priorities

Easy access to care and services – including:

- (1) Access to medical and specialty care,
- (2) Assuring the availability of provider networks to reach CYSHCN; and
- (3) Developing and promoting an easy to access system of supports and resources for CYSHCN and their families.

Improvement of transitions services

Adequate insurance to pay for needed services

Improvement of data capacity

Next Steps

In partnership with DPH and other stakeholders, and in accordance with national best practice standards and the agency strategic plan, CCSHCN will be developing Evidence-Based and/or Evidence-Informed Measures will to assist in achieving success in each of these priority areas. Progress or lack of progress will be measured through an annual scoring of Kentucky's specific implementation plans.

For More Information:

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Learn more about CCSHCN programs and services by calling (800) 232-1160, or visiting the website: <http://www.chfs.ky.gov/ccshcn>