



## INTRODUCTION

During the month of May 2014, a survey<sup>1</sup> was provided to local and district health departments (LHD) as well as Commission for Children with Special Health Care Needs (CCSHCN) clinics across the Commonwealth. The purpose of the 2014 Kentucky Consumer Survey was to find out the health care problems of women of childbearing age, babies, children, and adolescents in Kentucky as perceived by LHD patients and CCSHCN families. Further, the survey sought to learn additional information about children and youth with special health care needs (CYSHCN) including the prevalence of chronic health conditions, development disabilities, behavioral, and emotional problems as well as the co-occurrence of these conditions.

For those families who had a CYSHCN (whether or not they were currently enrolled in the CCSHCN), the survey also asked if they were aware of services provided by the CCSHCN and if they would use peer-support groups if available. Finally, for these children, researchers were interested in the age of diagnosis.

Another major section of the survey tool included questions about access/barriers to care. These questions ranged from problem with “*getting a Medical card*” (Medicaid) to “*learning about different places to find help in my community*” and “*wait times for medical/dental care*”.

The last portion of the survey examined co-sleeping for those who reported that they had an infant one year or younger in their household. Basic demographic information (race, ethnicity, age, marital status) was also collected.

This report summarizes our findings.

**Front Cover:** The *WordCloud* on the front cover was created with comments about resource and service needs provided by survey participants. To compile this information, we used written responses received for the request “*please list any community programs, services, or resources you would like to have for your family.*” The resulting WordCloud<sup>2</sup> summarizes these responses. The more times a specific word was mentioned by respondents, the larger it appears in the visual.

*The research team at the University of Kentucky College of Public Health would like to thank all those public health professionals across Kentucky who participated in this survey project in May of 2014. We would also like to thank the LDH patients and CCSHCN families who completed surveys for sharing their valuable opinions and ideas.*

*Special recognition also is due to those who participated through data analysis, report generation and data interpretation. These individuals included Radmila Choate, MPH; Caitlin Dunworth, MPH, CPH; and Hannah Palmer, University of Kentucky 2015 MPH Candidate.*

## METHODS

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<sup>1</sup> A copy of the survey tool is available upon request. Please contact Lorie Wayne Chesnut, DrPH, MPH, at 859-218-2226 for more information.

<sup>2</sup> Feinberg, J. Wordle – Beautiful Word Clouds. Accessed 06/26/2015 at <http://www.wordle.net/create>

In early May of 2014, the Kentucky Consumer Survey (Consumer Survey) was distributed to patients of LHDs for the period of one week. County and District Health Departments were asked to volunteer for survey distribution with each participating site<sup>3</sup> provided a survey template with a unique identifying code. During the course of that week period, all patients who came in for services were asked to voluntarily complete the two-page survey.

CCSHCN clinics<sup>4</sup> were involved as well but for families of CYSHCN, the survey distribution period was longer. Surveys were distributed during specialty clinics for the entire month of May and mailed to families who were not expected to attend a clinic during that period. From early to mid-May, an electronic link for the survey was posted on the CCSHCN Facebook site and also electronically distributed to select user lists.

Completed surveys from LHD and CCSHCN offices were returned to the Kentucky Department for Public Health (KDPH) and provided to the University of Kentucky (UK) research team for data input and analysis. This project was approved by both the Cabinet for Families and Children Institutional Review Board (CHFS-IRB-DPH-FY14-32) and the UK Institutional Review Board (Protocol 14-0393-P3H). The survey was available in both English and Spanish. Analysis was completed by the UK College of Public Health<sup>5</sup>.

At the end of May, a total of 3,361 surveys were returned. Of this total, 2,548 were from health department clients with 813 from CCSHCN families. Of the 813 CCSHCN surveys, 85 were returned electronically with an additional 240 returned through the mail.

The demographic profile of returned surveys was very similar to that of Kentucky as a whole (Table 1) however variations emerged when the data were stratified to compare LHD and CCSHCN results. The racial breakdown for the two groups did not vary although the number of individuals reporting Hispanic/Latina ethnicity was greater in the CCSHCN cohort (6.9%) as compared to LHDs (3.8%). Marital status was also substantially different with more CCSHCN respondents reporting that they were married (56.0%) as compared to LHD (39.1%) patients. Mean age also varied, with LHD patients averaging 30.56 years and CCSHCN respondents approximately eight years older (38.63 years).

## RESULTS

<sup>3</sup> Twenty-three local health departments and eight district health departments participated in the survey. While this was a convenience sample (participation was voluntary), all areas of the state were adequately represented.

<sup>4</sup> Kentucky has twelve CCSHCN regions. All areas participated in this survey.

<sup>5</sup> The University of Kentucky College of Public Health Analytic Team was comprised of Lorie Wayne Chesnut, DrPH, MPH and Emily Ferrell, MPH, CPH. Also contributing to this project were Radmila Choate, MPH; Caitlin Dunworth, MPH, CPH; and Hannah Palmer, MPH (c). Analysis was completed using SPSS Software.

<b>Table 1. 2014 Kentucky Consumer Survey Demographics (n=3361)</b>	
<b>Race</b>	
White	83.5%
Black	8.3%
Asian/Pacific Islander	0.4%
Native American	0.6%
Other	1.1%
Missing	6.1%
<b>Ethnicity</b>	
Hispanic/Latina	4.2%
Non-Hispanic/Latina	87.6%
Missing	8.2%
<b>Marital Status</b>	
Married	40.6%
Single	36.5%
Single living with partner	11.6%
Other	5.2%
Missing	6.0%
<b>Average Age (years)</b>	34

Results from the data collection and analysis activities discussed in the previous section are presented in detail for each of the six required domains in the following order: Women/Maternal; Perinatal and Child Health; Adolescent; and CYSHCN. Cross-cutting issues, primarily access to care, will be discussed last due to the volume of content under this domain.

Each section will include a short introduction followed by priority issues as reported by survey respondents. Next, if comparable results exist from Kentucky’s 2010 Consumer Survey, these will be shared and discussed. Consumer Survey data was also analyzed regionally to observe whether responses varied across the state. If regional<sup>6</sup> differences have been identified, these will be noted as well. Finally, select patient comments will be shared throughout the document.

## Women/Maternal

Substance abuse in Kentucky, whether it involves smoking during pregnancy, prescription medications, methamphetamine, heroin or another illegal drug, was clearly the issue of greatest concern for women.

The statewide Consumer Survey identified the top issues for women as *overweight/obesity* (56.5%) followed by *drug or marijuana use* (34.3%) and *depression* (30.0%). *Women who smoke* (23.1%) was followed by *second-hand smoke* (22.6%), with other comments including *domestic violence, abuse, Hepatitis C* and *poverty*. This varies only slightly from Kentucky’s 2010 Consumer Survey where overweight and obesity was the top issue followed by concerns about depression and substance abuse ranked third.

*“Hopeless and don’t know  
what to do with a special  
needs child.”  
(Central Kentucky)*

Eastern Kentucky residents considered substance abuse among women a greater problem (46.9%) than those living in the Western portion of the state. However, concerns about depression, or feeling down and hopeless, were significantly higher in Western Kentucky (34.5%). Respondents from Western Kentucky also reported that health problems related to pregnancy were higher in their region as were sexually transmitted diseases. The comparisons (Table 2) illustrate statistically significant differences<sup>7</sup> across regions based upon survey responses.

<b>Topic</b>	<b>Eastern KY (n=939)</b>	<b>Central KY (n=1556)</b>	<b>Western KY (n=858)</b>
Drug or Marijuana Use***	<b>46.9%</b>	34.1%	22.9%
Feeling down or hopeless**	26.8%	30.5%	<b>34.5%</b>
Pregnancy & health problems related to pregnancy**	12.9%	16.0%	<b>18.4%</b>
Sexually Transmitted Disease***	9.3%	14.5%	<b>16.8%</b>

Pearson’s chi-square test for statistical significance: \*p≤0.05, \*\*p<0.01, \*\*\*p<0.001

## Perinatal and Child Health

<sup>6</sup> County data were stratified by Eastern, Central and Western regions of the state.

<sup>7</sup> Statistically significant differences mean that the differences researchers observed between regions are likely to be true and not the result of chance alone.

Consumer Survey respondents recognized the problem of second-hand smoke exposure (55.9%) and child abuse and neglect (53.2%) as the top two issues of infancy. Prematurity (20.5%) and use of car seats (20.2%) were also recognized as critical problems. The Kentucky 2010 Consumer Survey reflected similar results with second-hand smoke and child abuse the two top issues followed by car seat use and prematurity.

Local health department and CSHCN families selected the following as the top five problems for Kentucky children: exposure to second-hand smoke (55.9%); child abuse or neglect (53.2%); babies born too early (prematurity) (20.5%); inadequate use of car or booster seats for infants and children (20.2%); and overweight/obesity (19.5%). Results of the 2010 Consumer Survey were similar, with an emphasis on second-hand smoke exposure and child abuse or neglect.

Regional variations (Table 3) identified a greater recognition of child abuse and neglect in Eastern Kentucky where nearly 60% of participants reported this as a concern. Safety in motor vehicles was also perceived as slightly more problematic in Eastern Kentucky<sup>8</sup> while breastfeeding issues were noted more often in Central Kentucky, although this topic was thought to be a lower priority overall. The comparisons presented below illustrate statistically significant differences across regions based upon survey respondent response.

Topic	Eastern KY (n=939)	Central KY (n=1556)	Western KY (n=858)
Child Abuse & Neglect**	<b>58.7%</b>	53.7%	50.7%
Breastfeeding problems***	4.2%	<b>8.4%</b>	6.4%

Pearson's chi-square test for statistical significance: \*p≤0.05, \*\*p<0.01, \*\*\*p<0.001

One striking feature about the responses for this section were the number of written comments specific to infants and children who were raised in a home where drugs were used or sold. While the survey included questions about drug or marijuana use when examining health issues for women and adolescents, no option to check “drug use in home” was available for the infant/child category. Lacking this option, nearly 100 respondents wrote in their comments, with examples provided below.

Co-sleeping was another topic addressed by the survey. Participants who had an infant that was one year or younger living in their home were asked to report on how often co-sleeping occurs<sup>9</sup>. One-thousand four-hundred and twenty (n=1,420) individuals responded to this question with just over half (53.7%) responding that co-sleeping *never* occurs. This total varied when data were examined by region of the state. Ever<sup>10</sup> co-sleeping was highest in Eastern Kentucky (57.3%), followed by Western Kentucky (52.2%) and lowest in Central Kentucky (48.8%).

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*““Child neglected from drug abuse in homes.” (Eastern Kentucky)*  
*“Mother’s substance abuse during and after pregnancy.” (Central Kentucky)*  
*“Mothers too young and no good resources available.” (Western Kentucky)*

<sup>8</sup> Although this difference was not statistically significant.

<sup>9</sup> Response options were: Always; Often; Sometimes; Rarely; Never

<sup>10</sup> Ever co-sleeping included always, often, sometimes or rarely.

Consumer Survey regarded drug or marijuana use (60%) as the top issue for the adolescent population with teen pregnancy following closely in second place (55.4%). Concerns for teen smoking (28.9%), exposure to sexually transmitted diseases (17.3%) and overweight/obesity (16.5%) followed. This rank order is very similar to 2010 results with the first four topics in the same order. The only difference in 2010 was that overweight/obesity was replaced by injuries or death associated with motor vehicle accidents.

On a regional level, concerns about drug use were higher in Eastern and Central Kentucky (Table 4). Consumer Survey response ranked motor vehicle accidents as higher in Eastern Kentucky while the risk of sexually transmitted disease and concerns about teens trying to harm themselves were considered more serious in the Western portion of the state. Comparisons noted are statistically significant.

<b>Topic</b>	<b>Eastern KY (n=939)</b>	<b>Central KY (n=1556)</b>	<b>Western KY (n=858)</b>
Drug or Marijuana Use***	<b>63.9%</b>	<b>63.2%</b>	51.3%
Motor vehicle, motorcycle or ATV accidents*	<b>18.6%</b>	14.2%	15.9%
Sexually Transmitted Diseases***	13.6%	17.5%	<b>22.3%</b>
Teens trying to harm themselves*	10.0%	11.5%	<b>13.7%</b>

Pearson's chi-square test for statistical significance: \*p≤0.05, \*\*p<0.01, \*\*\*p<0.001

As with other domains, the impact of substance abuse exposure and use in adolescents dominated discussions throughout the needs assessment process. This was coupled with concerns about mental health, stress associated with bullying and a lack of community-level resources for teens in some areas of the state. Patients talked about youth living with families that were addicted to drugs and the resulting depression and isolation that permeated their lives.

*“Feeling alone, no one to talk to.” (Central Kentucky)*

*“Depression from family issues from drugs.” (Central Kentucky)*

*“Not motivated toward anything but welfare.” (Eastern Kentucky)*

*“Not having proper parenting –someone who makes them do good (sic).” (Western Kentucky)*

**Children and Youth with Special Health Care Needs**

When asked about needs for CYSHCN, Kentucky’s LHD Consumer Survey respondents said that their greatest concerns were the ability of families to receive services; their ability to find insurance to pay for care; and the availability of developmental, social, and emotional screening services. Training and support for children with behavioral issues and finding doctors who can provide care were the last two priorities.

However, when this same category was examined using only data from *families* of CYSHCN enrolled in CSHCN clinical programs, priorities varied, if only 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 Consumer Survey responses were examined by Kentucky region, some interesting and statistically significant variations occurred (Table 5). 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 and nearly one quarter of respondents from Eastern Kentucky said that early identification of CYSHCN was a high priority need in their region. Finally, the need for transition services was thought to be slightly greater in Eastern Kentucky.

<b>Table 5. Regional Variations in Consumer Survey Response: Problems for CYSHCN</b>			
<b>Topic</b>	<b>Eastern KY (n=939)</b>	<b>Central KY (n=1556)</b>	<b>Western KY (n=858)</b>
Finding doctors who can provide care***	25.5%	19.1%	<b>27.8%</b>
Finding insurance to pay for needed services**	23.3%	<b>29.0%</b>	27.7%
Early identification of special health care needs*	<b>24.5%</b>	20.0%	20.3%
Receiving services necessary to move into adult life*	<b>16.4%</b>	13.4%	12.1%

Pearson’s chi-square test for statistical significance: \*p≤0.05, \*\*p<0.01, \*\*\*p<0.001

A number of written comments addressed issues involving education including the need for teacher and parent training, concerns about “mistreatment” in the school system, and bullying. Several respondents wrote in about children who needed opportunities to socialize with others and how, in their community, few opportunities existed for special needs children.

*“Educational services not provided to meet individual needs” (Eastern Kentucky)*

*“All parents need training along with school employees” (Eastern Kentucky)*

*“Lack of funding for adaptive and transportation (sic) equipment” (Central Kentucky)*

*“Respite for parents with children who are special needs” (Western Kentucky)*

The 2014 Consumer Survey included a series of questions that allowed respondents to identify whether they had a child (birth to 21 years) in their family with chronic health conditions<sup>11</sup>, developmental disabilities<sup>12</sup>, behavioral,<sup>13</sup> or emotional<sup>14</sup> problems. While it was assumed that all CCSHCN clients would complete this portion of the survey, some LHD patients also indicated that they had a child that met the criteria. Analyzing this data gives Kentucky's CCSHCN an understanding of how many more children need their services and where they might be in the state.

Results were enlightening. In addition to those responding who were current CCSHCN clients (n=813), an additional 806 individuals from LHD clinics indicated that they had a child living in their home who met these qualifications. The total sample for this data set was 1619 individuals.

One thousand three hundred seventy-five (1375)<sup>15</sup> out of 1619 respondents (85%) reported<sup>16</sup> that a child (or children) in their family had one or more of the following health care needs: Behavioral Problems (51.3%); Chronic Health Conditions (48.3%); Emotional Problems (39.3%); and Developmental Disabilities (34.4%). Just over half of families (53.2%) reported a child with a single condition while about one quarter (27.1%) reported a child with conditions in two categories. An additional 19.8% reported a child with health issues in three or more categories. Of those reporting above, 41% (569 individuals) were currently enrolled in the CCSHCN while 59% (806 individuals) were LHD patients from the areas served by CCSHCN regional offices.

When asked at what age their child was diagnosed, about one third (36.5%) said that the child had been diagnosed<sup>17</sup> by or before the age of two years. Of those who reported early diagnosis, the majority (60%) were CCSHCN enrollees. Twenty-two percent (21.8%) were diagnosed between the ages of 2 and 4 with the remainder (41.7%) diagnosed after the age of 4 years. Interestingly, while the majority of children diagnosed early in life were already enrolled in the CCSHCN program, exactly half (50%) of those children diagnosed between the ages of 2 and 4 years were currently enrolled. Those children who were diagnosed later were primarily children of or living with LHD patients.

Seventy-six percent (76%) of CCSHCN families and 55% of LHD patients across the Commonwealth said that they knew about the services<sup>18</sup> offered by the CCSHCN. When asked if they would use peer<sup>19</sup> support groups if available, 63% of LHD patients and 74% of CCSHCN families said that they would use these services.

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<sup>11</sup> The chronic health conditions category included examples such as asthma, spina bifida, and cerebral palsy.

<sup>12</sup> The development disabilities category included examples such as autism, Down Syndrome, and intellectual disabilities.

<sup>13</sup> The behavioral problems category included examples such as substance abuse, bullying, and ADHA.

<sup>14</sup> The emotional problems category included examples such as depression, bipolar disorder, and anxiety.

<sup>15</sup> Nearly 250 CCSHCN enrollees who completed the survey did not respond to this set of questions.

<sup>16</sup> Respondents could pick one or more categories and may be reporting about one child or multiple children in their response.

<sup>17</sup> Respondents could pick one or more categories for this question and may be reporting about one diagnosis or multiple diagnoses in their response (n=1279).

<sup>18</sup> A total of one thousand three hundred thirty-eight (n=1338) individuals completed this question (services)

<sup>19</sup> A total of one thousand eighty-nine (n=1089) individuals completed this question (peer support groups).

## Cross-cutting Issues – Access to Care

Despite an ever increasing number of Kentuckians who are insured under the Affordable Care Act and Medicaid expansion, obtaining a Medical card (Medicaid) was ranked as the number one problem by patients, with enrollment in the Kentucky Health Benefits Exchange (KYNECT) program ranked in third place (Table 6).

For Kentuckians, being insured does not necessarily assure access to care. Provider shortages continue to plague many regions of the state forcing families to travel long distances for care or sacrifice care completely. Wait times for medical or dental care was identified as a problem experienced by one quarter of respondents, with the need to see a doctor or dentist close to home ranked in fourth place. Western Kentucky residents ranked this as their top issue, with 29.1% of participants reporting challenges for this measure.

When data were stratified by LHD and CSHCN affiliation<sup>20</sup>, differences emerged. Respondents who had a CSHCN reported that they had a harder time getting a yearly check-up like a mammogram or pap smear (CSHCN 15.8%; LHD 10.9%); seeing a medical specialist (CSHCN 28.4%; LHD 18.2%); and noted that long wait times were a problem (CSHCN 32.0%; LHD 23.1%). They also needed more help navigating the system of care and getting to care. They reported more problems finding help in their community (CSHCN 32.7%; LHD 19.2%); finding people to help them move through the health system (CSHCN 27.0%; LHD 15.4%) and getting to care (transportation) (CSHCN 21.4%; LHD 15.9%). Finally, about twice as many CSHCN respondents reported that they felt that they were treated differently because of their race as compared to LHD patients (CSHCN 10.8%; LHD 4.7%) although overall, this question fell low in the ranking of problem areas. This issue will be explored in the future.

A positive result of the needs assessment process was learning what was going well. Few reported problems obtaining family planning services, getting “baby-shots” for children or WIC vouchers. Seeing a doctor for care during pregnancy or for yearly checkup was ranked as *least likely* to be a problem by LHD and CSHCN patients and families.

<b>Table 6. Kentucky 2015 Consumer Survey Respondents Reporting Challenges in Access to Care</b>	
<i>Did you face a problem in:</i>	
Getting a Medical Card (Medicaid)	27.7%
Wait times for medical or dental care	25.3%
Getting insurance through Kentucky Health Benefits Exchange (KYNECT)	23.7%
Being able to see a dentist or doctor close to my home	23.5%
Learning different places to get help in my community	22.6%
Being able to see a medical specialist for a specific health problem	20.8%
<small>Respondents could select “yes”, “no” or “not applicable” to each question. Only “yes” or “no” responses are included. Total response to individual questions varied with an average of 2,613 responding to each question.</small>	

<sup>20</sup> Respondents could select “yes”, “no”, or “not applicable” to each question. Only “yes” or “no” responds are included in the results. Total responses to individual questions varied. This comparison examined LHD patient responses (n=2548) as compared to CSHCN responses (n=813) with no overlap between the two groups.